20 years

British Columbia
Persons With AIDS Society

Dedication

To all members, past and present,
who have contributed extraordinary amounts of time and energy
in the struggle to improve the lives of all persons with HIV/AIDS.
This documented history is in honour of your immense contributions.

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Acronyms

ACAP	AIDS Community Action Program
ACT	Access to Careers and Training Centre
ARC	AIDS Related Complex
ASO	AIDS Service Organization
AV	AIDS Vancouver
BCCfE	British Columbia Centre for Excellence in HIV/AIDS
BCCPD	British Columbia Coalition of People with Disabilities
BCPWA	British Columbia Persons With AIDS Society
BIA	Bioelectric Impedance Analysis
CAAN	Canadian Aboriginal AIDS Network
CAM	Complementary and Alternative Medicines
CAS	Canadian AIDS Society
CHALN	Canadian HIV/AIDS Legal Network
CHF	Complementary Health Fund
CHRC	Canadian Human Rights Commission
CPP	Canadian Pension Plan
CTAC	Canadian Treatment Advocates Council (re-named: Canadian Treatment Action Council)
CUPE	Canadian Union of Public Employees
CWGHR	Canadian Working Group on HIV and Rehabilitation
DEYAS	Downtown Eastside Youth Activities Society
DTES	Downtown Eastside
EDRP	Emergency Drug Release Program
HAART	Highly Active Antiretroviral Therapy (also ART: Antiretroviral Therapy)
HIV	Human Immunodeficiency Virus
HPB	Health Protection Branch
IDUs	Injection Drug Users
MLA	Member of the Legislative Assembly
MNSB	Monthly Nutritional Supplement Benefit
MP	Member of Parliament
NAC	St. Paul's Hospital Neighbourhood Advisory Committee
NAS	National AIDS Strategy
NAS II	National AIDS Strategy, Phase II
NDP	New Democratic Party
PAN	Pacific AIDS Network
PARC	Pacific AIDS Resource Centre
PMPRB	Patent Medicines Prices Review Board
PIs	Protease Inhibitors
POP	Prison Outreach Program
PSAs	Public Service Announcements
PWA	Persons with AIDS
PWN	Positive Women's Network
SAP	Special Access Program
TIP	Treatment Information Program
UBC	University of British Columbia
UI	Unemployment Insurance (re-named: Employment Insurance (EI))

History of BCPWA

"First and foremost, the concept that has shaped the PWA Coalition is empowerment taking charge of your life. If you see yourself as a victim, that's a short-cut to death."
Kevin Brown

In 1982, rumours of a *gay plague* in New York, San Francisco, and Los Angeles were emerging and, by the following year, evidence of this new disease was starting to appear in Vancouver. As members of the community became ill, there was an urgent need to gather and distribute information on this new disease.

In the fall of 1983, AIDS Vancouver (AV) was formed and provided initial support services to persons with AIDS (PWAs) in Vancouver. It became one of the first community-based AIDS organizations in Canada. Under the auspices of AIDS Vancouver, self-help groups for PWAs were formed. Many of these early meetings took place informally in people's homes. Eventually, the meetings were moved to St. Paul's Hospital where they became more structured and formalized.

Late in 1985, a local doctor applied to the Federal Health Protection Branch for the release of experimental AIDS drugs on compassionate grounds. His application was denied on the basis that there was no viral testing lab in British Columbia. In response to this rejected application, the first Canadian demonstration by AIDS activists was organized in Victoria in March of 1986. PWAs picketed the British Columbia Legislature in Victoria to demand a viral testing laboratory in Vancouver. This became the first of many political actions led by local PWAs and established an organizational history firmly rooted in both collective and individual advocacy.

With increasing demands for its services, AIDS Vancouver inevitably grew and received federal funding. As a condition of this funding, however, the organization was obliged to adhere to an agreement with the federal government to refrain from any form of political action and/or the promotion of alternative medicines. This agreement included prohibitions against providing treatment information and lobbying to demand access to experimental drugs. In essence, the agreement between AIDS Vancouver and the federal government restricted forms of action that were necessary to advance the needs and rights of PWAs. It became apparent that if PWAs were to have the freedom to take actions they deemed necessary, there would need to be an alternate AIDS organization run by PWAs, for PWAs. As Michael Welch, former AIDS Vancouver counselor said, "The truth of the matter is that between 1982 and 1986, AIDS grew to be such an incredibly vast social issue that one group couldn't handle all the issues and problems and support needs of PWAs."[1]

It was in April 1986 that the differences with AIDS Vancouver's policies, objectives, and tactics became irresolvable and the groundwork was laid for the formation of a new organization. The emerging organization's first acts of business involved opening a separate bank account and installing a telephone line. A volunteer office manager joined the organization to coordinate correspondence and contributions; this quickly became a paid position when funds became available. The Vancouver Persons With AIDS Coalition was the chosen name for the new organization.

The initial goal of the Vancouver PWA Coalition was to provide a forum for PWAs to advocate for their rights and their health issues. "Take back the power" was one of the key rallying cries. As more people joined and became involved, the Coalition increasingly moved towards promoting positive attitudes, encouraging the will to live, and working towards casting off the *victim role*, which appeared so pervasive in the media and medical establishment.

The first business meeting of the Vancouver PWA Coalition was held in May 1986. At this meeting, and during the weekly meetings that followed, the organization's 15 founding members engaged in the day-to-day business of the organization. The most well known founding members were Kevin Brown, Taavi Nurmela, and Warren Jensen; in those early years, they came to symbolize and represent the human face of AIDS and the process of self-empowerment. However, of this group, Kevin Brown quickly became the recognized leader. When speaking about Kevin Brown, Pei Lim, a former Chair of the Board, stated:

> *Kevin was gifted with leadership qualities. He was the pioneer, leading us where we had not dared to go before. He never hesitated to speak up for PWAs, yet he was always very warm and considerate of others. He realized that different people make different decisions as to which treatments they use, and he was supportive even when he might not agree with them. Kevin Brown taught us what the Coalition is all about supporting each other, even when we do not see eye to eye. Compromising with one another, in order that we might achieve the best results for all of us.*[2]

The Vancouver PWA Coalition became the first self-help, self-care organization in Canada, entirely run for and by PWAs. In the beginning, the fight for medical care, housing, research for treatments, and funding for community-based organizations were the focus for the Coalition. Another challenge was the homophobic provincial government led by Bill Vander Zalm of the ultra-conservative Social Credit Party. These social attitudes were paralleled within the US under the similarly homophobic, conservative, Reagan administration.

On June 15th 1986, the first Vancouver PWA Coalition WALK-a-thon was held around the Stanley Park seawall and raised $7,900. This event was the beginning of an annual tradition of AIDS WALKs that eventually spread from Vancouver to numerous small and large cities across the country.

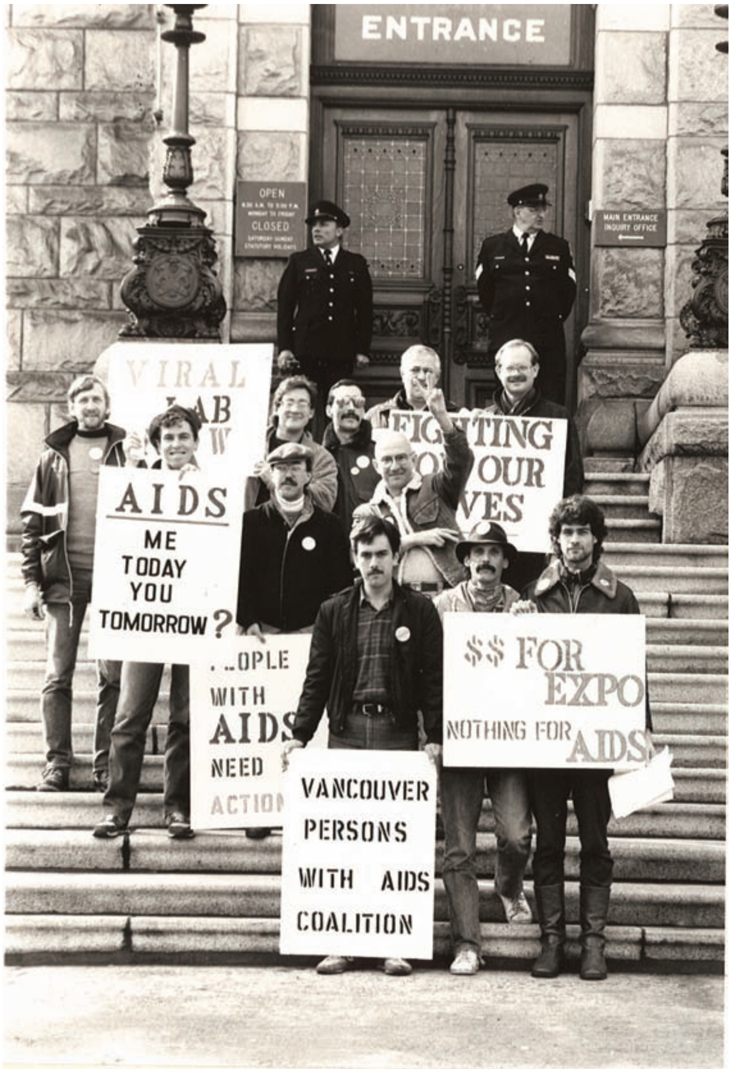
The fight to obtain access to experimental drugs proved to be a strong, uniting force for the new Coalition. Members started a petition that was sent to the Federal Health Protection Branch, requesting that local AIDS doctors be given permission to write their own protocols for experimental drug testing, determine appropriate end points for studies and, in consequence, run their own drug trials independent of the Branch. Members collected 3,000 signatures in three weeks and contacted over 150 gay and lesbian groups across Canada to request their assistance and support.

1986

Another landmark moment occurred in June of 1986 when Kevin Brown and Warren Jensen met with Federal Health Minister Jake Epp, making them the first PWAs to meet with a Canadian Federal Minister. The purpose of the meeting was to advocate for the availability of experimental drugs on compassionate grounds for all 317 Canadian PWAs who might wish to try them. During this meeting the petition of signatures was presented to the Minister.

Kevin Brown took advantage of his trip to Ottawa by stopping in Windsor, Ontario to meet with eight Ontario community AIDS organizations. Representatives from Thunder Bay, Toronto, Ottawa, Kingston, Cambridge-Kitchener-Waterloo, Windsor, and London attended this meeting. A key outcome of this meeting was an agreement on the necessity of a unified strategy for the prevention of AIDS and the provision of support and education for concerned groups and individuals. In addition, a lack of funding was highlighted as a pressing issue for all.

On August 17th 1986, the first victory for the Coalition was won. Jake Epp, the Federal Health Minister, and Jim Nielson, the Provincial Minister of Health, announced that a viral testing lab would be constructed in Vancouver. Now, for the first time in western Canada, blood could be tested for the Human Immunodeficiency Virus (HIV). The lab also allowed doctors to effectively monitor the impact of



March on Victoria 3/26/86

experimental drugs among the patients taking them, and their effectiveness in killing the virus.

Also in August of 1986, the Vancouver PWA Coalition found their first home at 1170 Bute Street. With a permanent location, the organization was able to provide its members with a lounge, library, and office space. The Gala Opening for the new office was held on November 2nd 1986.

In October 1986, the first issue of the *Vancouver PWA Coalition Newsletter* was published. The newsletter announced that the Coalition would grant members with AIDS or AIDS Related Complex (ARC) up to $200 per month to purchase therapies, courses, or training through the Holistic Health Fund. Subsequently re-named the Complementary Health Fund (CHF), the CHF was the first program of its kind established in Canada, and was solely funded through the support of local businesses, individuals, and charity events (particularly through revenue from the annual AIDS WALK for LIFE event).

The issue of access to experimental drugs continued to be a rallying point and a central concern for members of the Vancouver PWA Coalition. On October 17th 1986, Greg Smith, Coordinator of the AIDS Centre for Disease Control in Ottawa, announced that AZT would not be made available to Canadian PWAs, even on compassionate grounds, until after the completion of a study by the Centre of Disease Control in Atlanta, Georgia that was scheduled to start in January 1987.

In response to the October 17th announcement, Kevin Brown stated that the Vancouver PWA Coalition would investigate the possibility of sending Canadian PWAs to the Harbour Medical Centre in Seattle, Washington for AZT treatment. If this treatment could be arranged, there was a potential need to create a secret shuttle down to Seattle given that US border guards had been instructed to deny entry to persons with AIDS.

In November of 1986, the Coalition began a letter-writing campaign to Members of Parliament (MPs) to demand that AZT be released on compassionate grounds for PWAs likely to die before the drug would otherwise become available. Due in part to these efforts, Kevin Brown became the first person in Canada to legally obtain AZT in December of 1987.

During this period, the organization continued to grow and change and the administrative needs became more complex. Past Board member Greig Layne recalled:

> ***In 1986, every Monday morning, we would hold our weekly business meeting. Anywhere from 10 to 20 of us would sit cramped in a very small office and go through the entire week's business: all the correspondence, donations, all the outside meetings anyone was attending, political issues, and all our own programs and services. Everything was discussed, and decisions were arrived at by consensus. It was an amazing example of self-empowerment. After our Board activated itself to comply with the Society Act of BC, our first 50-odd motions were passed unanimously. For a time, whoever showed up for Monday morning in essence became the Board for that week. From that developed the Board and committee system that we have today.***[3]

1987

The beginning of 1987 saw the establishment of a more formal structure for the Vancouver PWA Coalition. At the beginning of January, the Health Promotion Directorate of Health and Welfare Canada approved a $27,000 grant to the Coalition, which made it the first federally funded PWA organization. This grant coincided with the Coalition's first Annual General Meeting, which took place on January 16th 1987. At this meeting, the Coalition adopted a new structure of four Standing Committees:

1. **The Personnel Committee:** to work on administrative aspects of the organization
2. **The Finance Committee:** to undertake most of the fundraising work
3. **The Program Committee:** to develop and implement support services for PWAs, including support groups, workshops, peer counseling, out-of-town retreats, a healing circle, a library, and funding for alternative and holistic therapies
4. **The Advocacy Committee:** to examine political strategies to carry out the Coalition's mission of improving quality of life for PWAs. This committee was to develop a public image, deal with the media, publish a newsletter, maintain a speakers bureau, facilitate drug studies and treatment investigations, do community relations and networking with other AIDS organizations, help members sort out problems with Unemployment Insurance (UI), welfare, etc…, and lobby governments.

The Coalition was formally incorporated as the Vancouver Persons With AIDS Society on March 9th 1987. The Constitution of the Society was adopted at this time and stated that the purposes of the Vancouver Persons With AIDS Society were (and continue to this day) to be:

1. To create a positive attitude and engender a feeling of hope in persons with AIDS/ARC
2. To provide support activities and facilities to members for the purpose of self-help and self-care
3. To maintain an organizational structure to act in an advocacy role for members relating to government and the community
4. To provide support services for members and non-members
5. To assist in creating a positive image of persons with AIDS/ARC in the community
6. To operate as a charitable institution (without profit to its members) to acquire, construct, provide, maintain, lease, own, and manage real estate or any interest therein, including one or more low-rental housing projects for persons with HIV/AIDS
7. To raise funds for these purposes

A number of important activities were undertaken by the Vancouver PWA Society in 1987. In April, a program was approved that allowed the Society to conduct weekly presentations at St. Paul's Hospital. The objective of this program was to get AIDS patients out of their hospital beds and to encourage them to explore alternative ways to promote improved health and positive attitudes. On May 25th, the Vancouver PWA Society and AIDS Vancouver organized the first AIDS Candlelight Vigil that was attended by approximately 300 people. In addition, June 15th was the date of the second annual 10 kilometre WALK-a-thon, which raised $15,000.

Also in 1987, Kevin Brown attended the IIIrd annual International Conference on AIDS in June in Washington, DC. This marked the first time that a person with AIDS had actively participated in an international AIDS conference. When speaking about the conference Kevin said: "We put a face to this disease for most researchers who now realize that we are human beings and not statistics. We reached over a thousand respected people at this conference and put out a positive message— PWAs being responsible for their lives, in control, no longer victims, demanding to be involved".[4]

By September of 1987, Society members increasingly took steps toward assuming control of their lives. When they became frustrated with the lack of government support for AIDS research, they decided to spend proceeds from fundraising events to conduct a pilot study on an AIDS therapy called AL721. This study became the first patient-run research project in Canada.

Part of assuming greater control of their lives included fighting for the protection of their rights. On September 26th, in opposition to the proposed provincial law that would allow the government to quarantine those infected with HIV, the Society organized a march through the streets of downtown Vancouver and a rally of more than 200 people on the Vancouver Art Gallery steps. In addition, a detailed letter that expressed the views of PWAs on the proposed amendments was sent to every Member of the Legislative Assembly (MLA) in BC.

December 8th 1987 saw changes in the Society's membership policy. The Board of Directors adopted a new three-tiered membership policy that distinguished between members, associate members, and group members. Membership was opened to people without AIDS or ARC; however only those persons with AIDS or ARC retained voting privileges and had access to financial assistance for health-related activities not covered by government or private agencies.

Obtaining experimental drugs continued to be an issue of concern for the organization and its

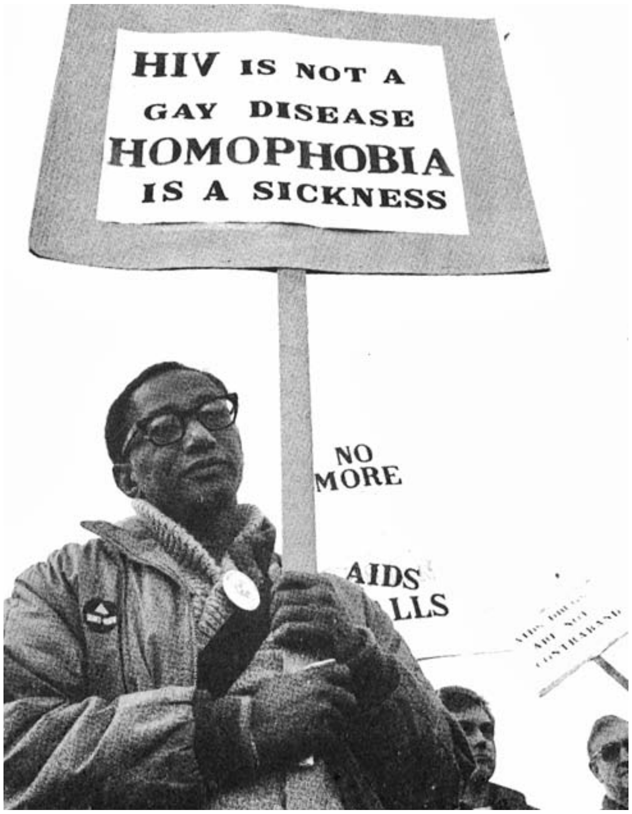
members. After much lobbying by HIV/AIDS organizations across Canada, federal health officials agreed that doctors of AIDS patients could utilize the provisions of the Emergency Drug Release Program (EDRP) to obtain experimental AIDS drugs. EDRP restrictions were later relaxed to provide easier access. However, obtaining AZT in British Columbia was still a challenge. While all other provinces covered the exorbitant cost of AZT (approximately $8,000 a year), the BC government only covered 80% of the cost under Pharmacare. This policy left PWAs responsible for paying up to $2,000 per year in additional drug costs.

The Society initially tried to change this policy through a media campaign and extensive lobbying. When this strategy proved unsuccessful, they chose an unprecedented tactic. On December 13th 1987, Kevin Brown, who was living with AIDS, an unnamed man with ARC, and the Vancouver PWA Society filed a court challenge claiming that the government billing policy discriminated against people with AIDS, a disease primarily affecting gay men. They alleged that this discrimination had caused them to suffer financial and emotional insecurity, and high stress levels that threatened their health. On this issue, Kevin Brown expressed:

> ***It's a sad state of affairs when people with this disease have to take the BC government to court to fight for something that is only fair and just. But we seem to be dealing with a government that has no concept of the meaning of compassion and caring or any kind of human dignity. This court case seems to be the only way that we can attempt to bring about some justice and fair play in this province.***[5]

Although the Society received a commitment of support from the BC Civil Liberties Association and the NDP Health Critic, Margaret Mitchell, the case dragged on for some time, finally coming to trial in late September 1989. At last, on January 25th 1990, the BC Supreme Court made its ruling: it criticized the provincial government for its HIV/AIDS policies and actions but ruled against PWA et al on the AZT funding case.

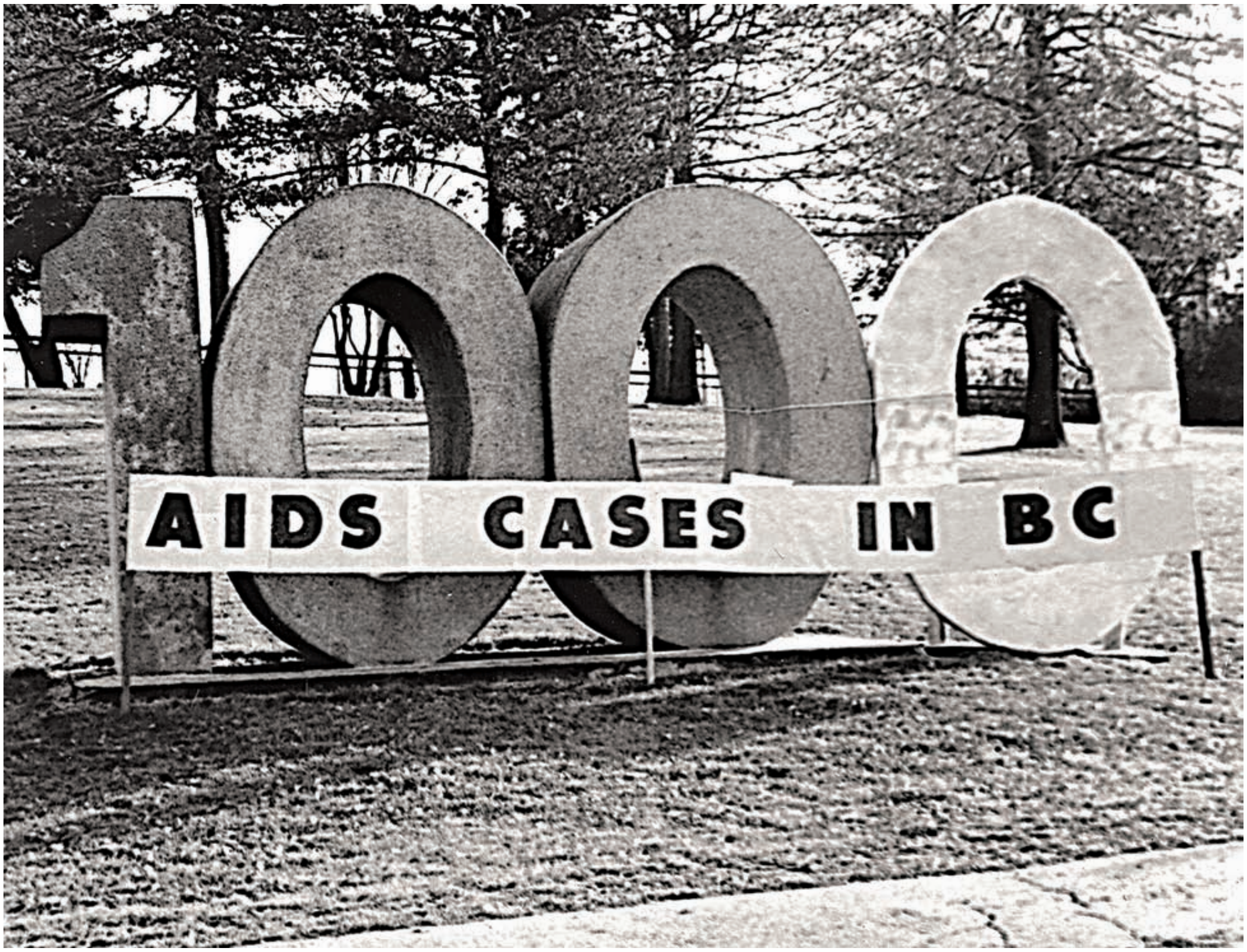
As a tool to ensure the active promotion of the needs and concerns of persons with HIV/AIDS, the organization made a commitment to work in partnership with other HIV/AIDS organizations in Canada and internationally. The Society had been an active member of the Canadian AIDS Society (CAS), the National Advisory Committee on AIDS (responsible for advising the Federal Minister of Health on HIV/AIDS issues), and the Steering Committee of the International PWA Network. It had also been instrumental in the formation of the BC AIDS Network and the National Network of Persons Living with HIV. In addition, members had spoken at various International AIDS Conferences.



1988

The second Annual General Meeting of the organization was held on January 16th 1988. At this meeting, Kevin Brown explained the functions of the new structure of the Society. This was followed by the election of the Board of Directors. The Board of Directors' goals for the term were to ensure that the proper legalities were followed in the formation of the Society, and to establish a framework that would meet the expanding needs of the organization. At this time, there was a call for members to assume greater involvement within the organization by working on one or more Standing Committees. Both members and associate members were encouraged to join.

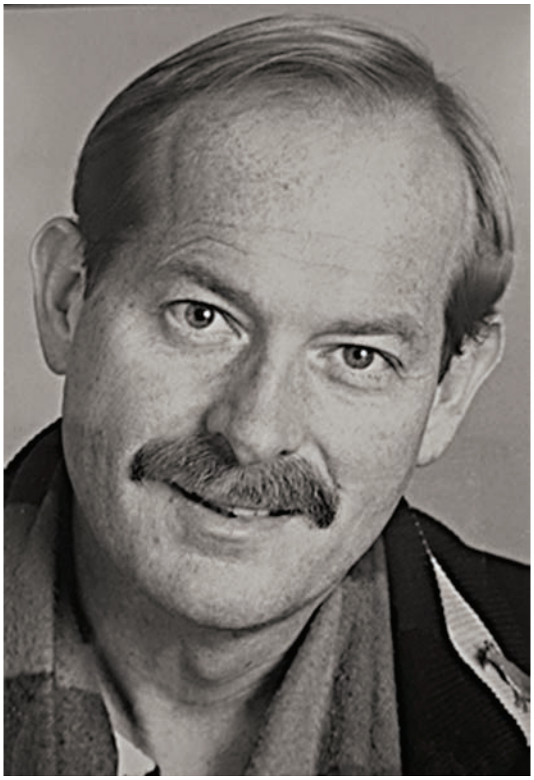
By 1988, fundraising for the organization began to diversify. The annual Vancouver PWA Society WALK-a-thon involved 107 WALKers (and one roller-skating mama) raising $15,000. Federal funding increased to $50,000. And, after a battle with Vancouver City Hall over a denied request for $23,000, City Council approved $11,750 for core funding for the Society in October. This municipal funding was used to hire a second staff person and to install an improved phone system to help the organization respond to an increasing demand for information and programs.



1989

The Vancouver PWA Society experienced some changes in the beginning of 1989. Chris Sabean was hired as the General Manager to help improve and expand the programs of the PWA Society and to advance program delivery and services. At the Annual General Meeting in April, Alex Kowalski was elected as the new Chairperson of the Society and Kevin Brown was elected Chair Emeritus (retired).

In June 1989, the Vancouver Persons With AIDS Society sent five representatives to the Vth International AIDS Conference held in Montreal. However, Kevin Brown was not to join them. As Jackie Haywood, Director of Support Services, explained: "Kevin was asked to be the opening speaker. He was very ill, and some people were worried he would not make it. So they pre-recorded his speech on video. Unfortunately, Kevin passed away before the conference, but the video was viewed and his message went across."[6]



Kevin Brown

Kevin's pre-recorded opening ceremony message criticized the government for its inaction in the AIDS epidemic. The credibility of the Vancouver PWA Society was firmly established at this conference, also due to the final remarks at the closing ceremony by Don deGagne, a member of the Society who worked hard to have a strong, visible PWA presence. When speaking about the conference, he stated: "I was chosen to represent PWAs at the 1989 International AIDS Conference in Montreal … My role in Montreal, as the first person with AIDS officially working on an international meeting this kind, was to bring PWAs and networks of PWAs as speakers and to raise their visibility. It was the first conference to tackle the psycho-social sides and the human side of AIDS."[7]

The Vth International Conference on AIDS held in Montreal provided the momentum for the development of the National AIDS Strategy, with a commitment from the Federal Minister of Health and Welfare, Perrin Beatty. At this conference, the Minister recognized community-based and non-governmental organizations as key partners in the efforts to fight and reduce harm caused by HIV/AIDS. During the conference, Don deGagne spoke to the Minister personally about specific PWA issues (i.e., international travel and visibility of PWAs on advisory boards). On September 18th 1989, Don was appointed by the Minister to the National Advisory Committee on AIDS (NAC-AIDS), a committee mandated to advise the Minister on activities leading to the implementation of medical care, research, and other strategies for the diagnosis, treatment, control, and prevention of AIDS in Canada.

After a year-long consultation process with groups across Canada—community-based groups, health care providers, researchers, provincial governments, municipal governments and others—the Department of National Health and Welfare presented the first formally written official attempt at a comprehensive federal policy on AIDS in June of 1990: *HIV and AIDS: Canada's Blueprint and Building an Effective Partnership: The Federal Government's Commitment to Fighting AIDS*, which comprised the first National AIDS Strategy (NAS), in 1990.

Since the creation of the organization, the membership has endured many losses. Taavi Nurmela was the first of the three founding members to die on September 23rd 1987. Kevin Brown died on June 5th 1989, and Warren Jensen passed away on September 16th 1989. The loss of these three founding members illustrates the heartbreaking challenges that this organization experiences daily. As an acknowledgement of the compassion and commitment of those who have died, their names remain on the membership roll of the Society.

In July 1989 the Society decided to change its membership policies to provide full membership to anyone with confirmed HIV-positive antibody status rather than solely to people with AIDS or ARC. This decision resulted in a large increase in membership.

On July 7th 1989, Dr. Tom Perry, MLA, made a private member's statement in the British Columbian Legislature that outlined the NDP's strategy for dealing with AIDS in the province. This statement was made in solidarity with and in support of PWAs to the ultra-conservative and prejudiced Social Credit government. The provincial NDP's proposals included issues such as: ongoing coordinated education programs; increased funding for prevention programs (especially those targeting prisoners, street youth, and injection drug users (IDUs)); funding for AZT and other treatments; increased funding for research, hospice care, anonymous seroprevalence testing, and human rights legislation to protect persons with AIDS. Evaluations of all AIDS education, prevention, and treatment programs were also recommended.

In September of 1989, Vancouver PWA Society members rallied at Fantasy Gardens in protest against homophobic comments made by the BC Forestry Minister, Dave Parker, and the BC Minister of Health, Peter Dueck. More than 400 supporters took part in the rally. A signature sheet was distributed and messages from the participants were collected and presented to Premier Vander Zalm. The event raised $722 in donations and also garnered support from the Carnegie Centre and AIDS Vancouver Island.

Organized opposition to the Social Credit government continued. On October 27th 1989 at the Social Credit Convention, members of the Vancouver PWA Society greeted delegates outside of the convention with leaflets. The leaflets asked for an immediate response to the need for full funding of AZT and other promising AIDS treatment drugs; it demanded an end to government policies based on discrimination and punitive attitudes; and insisted that delegates consider other issues important to members, such as education, housing, needle exchange programs, and AIDS protection for prisoners. Over 200 leaflets were distributed and this low-key presentation was well received by most of the delegates who were approached.

The Vancouver Persons With AIDS Society received a financial boost in December 1989 when $125,000 in funding was issued by the Honourable Perrin Beatty, Federal Minister of Health and Welfare, under the AIDS Community Action Program (ACAP). This money was in recognition of the valuable services provided by the Vancouver Persons With AIDS Society and it was a credit to the organization's effectiveness as a self-help group. A similar recognition was reflected through increased funding, to $46,000, from the Vancouver City Health Department.

1990

The following year, 1990, was a time of reflection and evaluation for the Society as it became more responsive to the needs of its membership. The Health Promotion Branch of Health and Welfare Canada provided the Society with a $50,000 grant to undertake an evaluation of its programs, services, and operations. The organization's current mission statement came from this original strategic plan. The mission statement reads:

> ***The British Columbia Persons With AIDS Society exists to enable persons living with AIDS and HIV disease to empower themselves through mutual support and collective action. From our personal struggles and challenges come our courage and strength.***

Arn Schilder, former Chair of the Board, stated, "that mission statement is one of the soundest most useful mission statements ever. This is because it is still relevant and poetic as time goes by."

Building on the visionary nature of that year, a Housing Needs Project was created. This project worked to identify the housing needs of PWAs and then started to work toward the provision of more affordable housing that would meet identified needs. A Steering Committee was established in partnership with other community groups including AIDS Vancouver and the YWCA Housing Registry.

Housing concerns persisted as PWAs consistently identified the overwhelming need for clean, comfortable, and affordable housing. Hoping to draw attention to this critical issue, Vancouver PWA Society members attended several rallies. The Society teamed up with the British Columbia Coalition of the Disabled (subsequently re-named the British Columbia Coalition of People with Disabilities (BCCPD)) and other groups to demonstrate these concerns to Vancouver City Council. In addition, the Society took part in a march from Denman Street to Robson Square where a rally was held over adequate and affordable housing. In December 1990, after a long and persistent lobby, the British Columbia Housing Commission, at the request of the Ministry of Health, awarded the Vancouver PWA Society an allocation of 25 portable housing subsidies for persons living with HIV/AIDS. These subsidies ensured that rent for those participating would be no more than 30% of their monthly income.

In January of 1990, the Society continued to demonstrate its leadership in activism when a resolution was passed not to attend the VIth International Conference on AIDS in San Francisco in an official capacity. This decision was made in protest against the discriminatory US legislation which required persons with HIV/AIDS to declare their HIV status in a waiver application when entering the country. The following statement was made in solidarity with persons with HIV/AIDS from the developing world who could have faced serious repercussions if their status were declared. Don deGagne, in a letter to the Federal Minister of Health and Welfare, stated:

> ***We recommended that you support the removal of discriminatory travel and immigration policies affecting people with HIV and in particular, request that members of the Canadian AIDS community refuse to participate in the VIth International Conference on AIDS because of US policy in this area.***
>
> ***During the course of the discussion on this resolution, I realized how this issue brings all of us involved with HIV/AIDS to consider fundamental questions. Do we truly believe that people with HIV are equal partners in the fight against AIDS and that we are not part of the problem but part of the solution? … I cannot legally travel to the United***

> ***States without facing discrimination … all of my distinguished colleagues may legally go to San Francisco and I may not. The only difference is that I am a person with AIDS and the borders are closed to me.***[8]

The first meeting of a national network of persons living with HIV took place in Vancouver from March 2nd – 4th 1990. The National Network of Persons with HIV was created to act as a unifying structure, to strengthen the voices of HIV-positive people, and to address the needs of persons living with HIV. The meeting began with a welcoming reception hosted by the Vancouver PWA Society.

In April 1990, the Society's logo first appeared on the cover of Issue 35 of the organization's newsletter. The logo of the Vancouver Persons With AIDS Society was a pair of outstretched wings on a gradient background above the Society name and a single feather below. Former Society Chair, Pei Lim, designed the logo. He described the symbols as follows:

> ***Wings symbolize the freedom we find in our empowerment, the support we find in caring, the strength we find in our abilities. The spread of the wings suggests power, motion through time and space, bearing news, awareness and hope everywhere. The sky shaded from dark to light represents a new dawn, hope and spirituality. The fallen feather is to honour those who have passed away. It courageously acknowledges death, loss, and grief.***

In May 1990 the Vancouver Persons With AIDS Society moved into larger quarters at 1447 Hornby Street. A special open house party was held on May 4th.

In June 1990, the Board of Directors of the Vancouver PWA Society called for a boycott of businesses operated by White Spot Restaurants Limited, including the Kentucky Fried Chicken chain in British Columbia (excluding Prince George), after a complaint that the company had terminated an employee living with AIDS, a member of the Society, solely on the basis of his disability. This situation was settled in favour of the Vancouver PWA Society's member later that year. The Society would not tolerate human rights violations such as capable people being fired from work and paying customers being refused service. Further North American boycotts at that time included the following businesses that had discriminated against persons with AIDS: Marlboro cigarettes, Philip Morris Company, Coors beer, Shell gasoline, and Bristol-Myers products.

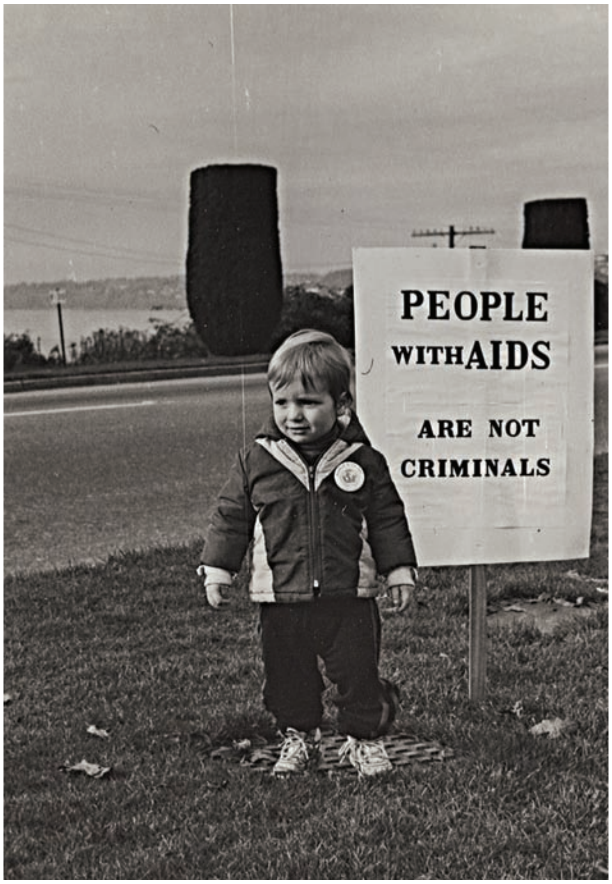
The first phase of the National AIDS Strategy (NAS) was released on June 28th 1990. Community AIDS groups and activists expressed little optimism regarding its efficacy. The Society felt that the NAS did not provide a reasonable timeframe for the supply of adequate resources to the HIV/AIDS movement. It was felt that many people would die before the government made sufficient commitments. It was also felt that the NAS was missing the elements of: effective action adding sexual

1990

orientation as a protection under the Canadian Human Rights Act; the elimination of unreasonable travel restrictions for PWAs; AIDS prevention programs for incarcerated populations; and, above all, increased funding for community groups to ensure their viability in delivering care and service at required levels.

Also in June, a very influential book was published by John Dixon, the President of the BC Civil Liberties Association, entitled *Catastrophic Rights*. Kevin Brown and Greig Layne had been part of the author's inspiration for this book. Catastrophic illness is defined as a condition that is untreatable and generally fatal. When speaking of catastrophic rights, the Canadian AIDS Society (CAS) stated, "the reality is that when people discover they are infected with HIV, they are faced with many decisions involving their health care. These decisions, which can be life or death decisions, are being made in a situation which does not provide a full range of treatment possibilities. Treatments which show promise, or have been proven successful in other countries, are still being denied to many infected persons."[9] Based on this reality, Dixon stated that when considering PWAs, "their special circumstances give them a greater than ordinary right to obtain and use experimental drugs."[10]

The fight for low-cost or free AIDS drugs continued in 1990. Late in 1990, the Vancouver PWA Society once again lobbied the BC Ministry of Health to provide AZT and other AIDS drugs at low or zero cost as a preventive measure to safeguard public health. Access to these drugs would give asymptomatic HIV-positive persons the option of continuing work, thus avoiding the higher costs of treating advanced AIDS conditions for both productive persons and the Ministry.



Vancouver PWA Coalition boycotts VIth International AIDS Conference (San Francisco) opposing discriminatory US legislation requiring HIV disclosure.

The next year, 1991, was a year of anniversaries. The Society itself reached its five year mark, growing from a small coalition of roughly 20 people to an organization with over 1,000 full members. Likewise, the Society's budget grew from a handful of coins to over one million dollars in 1991. This year also marked the ten-year anniversary of the first diagnosed case of AIDS. Although there had been many strides in the area of treatment, there was still a long way to go to meet the diverse support, advocacy, and treatment needs of people with HIV and AIDS. Testament to this observation was the death of Alex Kowalski, on Monday, March 25th 1991. As the former Chairperson of the organization, he had moved the Society forward during the previous two years, and his vision of a one-stop-shop for PWAs subsequently became the model for the Pacific AIDS Resource Centre (PARC).

Early in 1991, as in previous years, some medical professionals expressed concern regarding treatment coverage in the *Vancouver PWA Newsletter*. As one doctor stated, "...[the newsletter] causes confusion in my patients' minds [because] your information is sometimes inaccurate or incomplete [and] now patients waste my time with questions."[11] However, the Society felt that it was obliged to report on controversial matters in a fair and responsible way so that readers could understand treatment-related developments and how they might affect Society members. The Society position was that informed patients were better equipped to be full partners in their own health care and that understanding increased compliance with new treatment regimens.

In the spring of 1991, Victoria members of the Society were invited, through an advertisement in the *Vancouver PWA Society newsletter*, to discuss their interest in forming a local support group. Approximately seven members attended this first meeting and acknowledged that local resources in Victoria were not meeting their needs. They approached the Board of Directors with a request to sponsor a Vancouver Island Outreach project. The Board accepted this proposal and provided the group with a small budget for basic start-up costs including a post office box, telephone line, postage, and travel expenses to attend meetings in Vancouver.[12] By midsummer of 1991, this small budget planted the seed that later grew into the Victoria Persons with AIDS Society (subsequently re-named the Vancouver Island Persons With AIDS Society).

The 5th International Conference for People with HIV/AIDS, held in the fall of 1991, examined the important issue of HIV and human rights. This event was planned, organized, presented, and attended only by PWAs from around the world. The conference identified mechanisms for acknowledging violations of human rights and made a strong statement that people with HIV/AIDS have the right to intervene, interfere, and step forward in the face of these violations. Access to treatment and research was identified as a fundamental human right. The acknowledgment of these human rights, in combination with the definition of health promotion put forth by the *Ottawa Charter*, enabled the organization to move forward and have legal grounds on which to advocate for quality of life and health for people with HIV/AIDS. The *Ottawa Charter for Health Promotion*[13] was presented with support from the World Health Organization at the First International Conference on Health Promotion, Ottawa, November 21st 1986. The Charter defines health promotion as:

> ***... the process of enabling people to increase control over, and to improve, their health. To reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change***

1991

or cope with the environment. Health is, therefore, seen as a resource for everyday life, not the objective of living. Health is a positive concept emphasizing social and personal resources, as well as physical capacities. Therefore, health promotion is not just the responsibility of the health sector, but goes beyond healthy life-styles to well-being.[14]

In 1991, the Society was awarded an additional 19 housing subsidies for PWAs; with the 25 subsidies previously granted to the organization, this placed the total number of housing subsidies at 44.

In 1991, the Support Services Committee identified and created 30 different programs to meet the needs of the organization's diverse membership. These programs included: free donated clothing, support programs for heterosexuals and inmates in correctional facilities, and Alcoholics Anonymous/ Narcotics Anonymous for HIV-positive members.

In 1991, the organization grew to over 1,000 full members with the total annual Society revenues exceeding one million dollars. Fundraising represented the largest single portion of income. The annual WALK-a-thon had grown to 4,000 registered WALKers, 45,000 pledged donors, 325 volunteers, and raised over $280,000.


Polli and Esther's Closet.

The following year, 1992, was a year of significant collaboration between the Vancouver PWA Society and other organizations in the community. Perhaps the most significant change was the formation of the Pacific AIDS Resource Centre (PARC) at 1107 Seymour Street. This space was shared by the Vancouver PWA Society, AIDS Vancouver, and subsequently, the Positive Women's Network. The formation of PARC was a step in the direction of the one-stop shop for people requiring information or support related to AIDS and HIV infection first proposed by Alex Kowalski, and it provided more opportunities for collaboration and cost-sharing between the organizations. Some of the joint ventures fostered by this move included: the PARC Training Project, which provided AIDS sensitivity training to personnel from the Ministry of Social Services; the Peer Counseling Training Project; the provision of weekly testing for TB; and the development of the Health Promotion Project.

Another initiative that required a great deal of collaboration for the Society was the formation of the AIDS Secretariat. The AIDS Secretariat brought together many partners of the British Columbia AIDS Network and provided advice to the Provincial Minister of Health on all AIDS-related issues.

The British Columbia Centre for Excellence in HIV/AIDS (BCCfE) began operations in May/June 1992, occupying an area on the 6th floor of the Burrard Building at St. Paul's Hospital. The Centre's major activities focused on: the drug treatment program; epidemiology and impact assessment; laboratory research; clinical activities; and education.[15] The next year, 1993, marked the beginning of a long and mutually productive relationship between the British Columbia Centre for Excellence in HIV/AIDS and the Vancouver PWA Society.

In 1992, the Society launched its Prison Liaison Support Program, which later grew into the Prison Outreach Program (POP). The program was initiated when an HIV-positive prisoner contacted the organization to ask for assistance and to express frustration with the lack of resources available to him in prison. With this first point of contact, the Society started to provide support, counseling, and educational materials to federally and provincially incarcerated inmates living with HIV and AIDS. That prisoner, Michael Linhart, later became the Society's first full-time Prison Outreach Program Coordinator and, in 2002, received the Canadian AIDS Society's prestigious Leadership Award.

Also in 1992, the staff of the Vancouver PWA Society unionized by joining the Canadian Union of Public Employees (CUPE) Local 3495. The union was formed to ensure fairness and equality among employees, while establishing a personnel structure that would guarantee benefits, stability, and a system of seniority.

In 1992, the British Columbia Health Minister announced that the provincial government would allocate $2.5 million to AIDS initiatives. Finally, the provincial government was playing a significant role in the financing of the Society, providing 14% of total revenues for 1992.

The Vancouver PWA Society was one of the organizers for the 2nd National AIDS Awareness Week, which took place October 5th – 11th 1992. Events were held in Robson Square and politicians in Ottawa were urged to increase federal funding for AIDS research, treatment, community-based education, prevention, and support programs. Together with other organizations from across Canada, the Society circulated a petition calling for the federal government to increase funding for AIDS groups.

On November 29th 1992, the Society held an Extraordinary General Meeting to consider the issue of confidence in the Board. At this meeting, confidence in the Board of Directors was re-affirmed.

1993

The year 1993 began with the Society's endorsement of the Denver Principle, a declaration written by PWAs in the United States. The Denver Principle stated: "We condemn attempts to label us as *victims*, a term which implies defeat, and we are only occasionally *patients*, a term which implies passivity, helplessness, and dependence upon the care of others. We are *people with AIDS*."[16] For more information about the Denver Principle, please see Appendix B.

On March 5th 1993, the largest medical forum in the history of the Vancouver PWA Society was held. Close to 100 people packed a downtown centre to hear Dr. Bernard Bihari speak. Dr. Bihari was a board-certified neurologist, psychiatrist, and Director of the Community Research Institute. This Institute was one of the first grassroots research centres devoted primarily to exploring drugs that had potential as AIDS therapies but were not being investigated because of lack of a potential profit.

In recognition of the problems of inadequate funding for community-based AIDS organizations in Canada, the federal government approved the National AIDS Strategy, Phase II (NAS II) in March 1993. To continue the efforts to stop the spread of HIV/AIDS and provide services for those infected, Cabinet approved $203.5 million, comprising $40.7 million each year for five years, beginning in April 1993.

In 1993, the Vancouver PWA Society conducted several Membership Surveys. The first survey was mailed out with the newsletter and approximately 20% (roughly 200) of the membership responded. The survey asked the membership questions on controversial issues that were critical for the Society during that time and provided a vehicle through which to express opinions and concerns on such issues as: membership, confidentiality rights, and the principal role of the Society. One question posed was whether or not the Society should accept money from pharmaceutical companies; the consensus was that such monies could be accepted as long as there were no conditions attached to the funding. Members also indicated their interest in receiving treatment information from both the medical establishment and alternative practitioners to create a comprehensive approach to health care.

Another survey distributed to the Vancouver PWA Society membership was *The Care Survey*. This survey was undertaken in partnership with the British Columbia Centre for Excellence in HIV/AIDS and was used to help the Society plan and lobby for future HIV/AIDS support, treatment, and improvements for members.

Lastly, a *Migration Survey* was conducted, also in partnership with the British Columbia Centre for Excellence in HIV/AIDS. The objective of this study was to understand how the need for social support, treatment, and care affected where HIV-positive people decided to live. Survey results showed that migration appeared to occur soon after diagnosis and was linked to the dramatic and sudden decline in gross annual income after infection. Ultimately, this study found that migratory patterns significantly impacted health care delivery, especially in large urban centres such as Vancouver and Victoria, and had an effect on socio-economic policy affecting the lives of PWAs in British Columbia. This study provided hard data, which placed the organization in a stronger position to challenge the system and to lobby for persons with HIV/AIDS.

Although by 1993 the AIDS epidemic was into its 12th year, there had not yet been created a baseline standard for care. This inconsistency of standards led to a stalemate between HIV care partners, with an inability to calculate related costs or to determine the cost/benefit relationship of various models of care. This lack of information did not allow for the proper planning of programs or the allocation of appropriate resources. The *Care Survey* and the

Migration Survey were both attempts to break through this impasse. The efforts of the organization to secure accurate and quantifiable data encouraged Health Canada to establish standards of care that were made available in late 1993. These standards of care were to be utilized by general practitioners within a community context.

The 1993 AGM held on April 18th resulted in some changes for the Society. The members voted to change the name of the Vancouver Persons With AIDS Society to the Persons with AIDS Society of British Columbia, which became the BC Persons With AIDS Society (BCPWA) for everyday use. This change was officially implemented at the beginning of the following year. Other resolutions passed at the AGM enabled the Society to accept monies from pharmaceutical companies with provisions that protected the integrity of the organization, and that full membership in the Society required proof of an applicant's HIV-positive status.

The Society had a strong contingent at the IXth International AIDS Conference in Berlin, Germany from June 6th – 11th 1993. At the conference, members became more acutely aware of the legitimacy that the organization had gained globally among PWAs, international agencies, and governments around the world.

The year 1993 proved to be turbulent for the Society; there were many reasons for this unrest. A rapid increase in membership and its diversity caused members to face competing and diverging needs. In addition, the stress inherent within the organization—where members frequently experienced illness, suffering, and death of their peers, friends, and partners—proved fertile ground for tension and controversy. Against these odds, the Society found a sense of compromise and resolution and used these experiences to grow and become a stronger, more focused organization.

During the same year, the Society became concerned with the emerging issues around dual diagnoses (i.e., psychiatric disability and chemical dependency) and multiple diagnoses (i.e. psychiatric disability, chemical dependency, and HIV/AIDS). These concerns were submitted to the Canadian AIDS Society (CAS) and the Canadian HIV Therapies Committee. The Society identified the need to coordinate education programs, activities, housing, and advocacy strategies to ensure that the distinct and complex needs of PWAs with dual or multiple diagnoses would be met.

By 1993, there were increased reports that a number of Canadians had contracted HIV from transfusions of blood collected and distributed within the national blood system of Canada. Increasing public outrage led to an announcement in the fall of 1993 by the Judicial Committee of the Privy Council, on the recommendation of the Prime Minister, that a Commission led by the Hon. Horace Krever would be established to review and report on the mandate, organization, management, operations, financing, and regulation of all associated with the blood system in Canada. This investigation included events surrounding the contamination of the blood system in Canada in the early 1980s.[17] The report would be known as the *Krever Inquiry* and representatives of the Society were active in speaking and providing information at this Inquiry.

Along with a growing professionalism, there were further expansions in the programs of the Society. In 1993, the Peer Counseling Project expanded, conducting an additional counselor training in October. The same year, the organization doubled the number of portable housing subsidies for PWAs. Along with the increase in housing subsidies came the rising need for human resources to administer the program. By 1994, the business of and demand for BCPWA's Housing Program had exceeded the resources of the Society's Board of Directors. The

1993

Board determined that the best interests of the Society and member housing needs would be served by establishing an independent organization to manage this program. That year, the Wings Housing Society was established to continue the work of the Society's original Housing Project and to administer what would eventually grow to 111 subsidies funded by the British Columbia Housing Management Corporation to individuals and families living with HIV/AIDS throughout BC. Today, the BCPWA Society still maintains representation on the Wings Housing Society Board of Directors to address the housing concerns of PWAs.

Pacific AIDS Resource Centre Float at Gay Pride.

The AIDS Memorial Quilt.

In 1994, the PARC Library was created and quickly gained popularity and credibility. Prior to this, both the BCPWA Society and AIDS Vancouver operated separate libraries. Each organization continued to contribute to the library; however, AIDS Vancouver committed to cover the cost of employing the librarian. In its first year, over 3,000 people accessed the PARC Library. The initial collection of combined AIDS-related materials included over 2,500 books, hundreds of journals, newsletters, videos, and audiotapes—a commendable collection that continues to grow.

Also in 1994, volunteers assisted with renovations to the PARC building on Seymour Street. These renovations were undertaken, in part, to create a new space for the Positive Women's Network, which moved from the second floor of the building to the ground floor and had a separate entrance off Helmcken Street.[18]

With an increase in membership to nearly 2,300 people in 1994, the Board of Directors decided that it needed to research and produce a current and comprehensive strategic plan. The Board identified priorities in the area of governance, advocacy, support, human resources, education and communications, finance, and administration in order to fulfill the changing needs of the organization and its members. This became the foundation for work on the strategic plan to carry the organization from 1995 – 2000.

By 1994 there had been a period of rapid growth in individual advocacy needs and the development of expertise in response to injustices that many of the Society's members faced. In order to respond to this situation, volunteer advocates were trained. A new training manual was developed for volunteers to equip themselves with the skills needed for peer advocacy. Following training, the volunteer advocates handled 243 case files related to issues of discrimination, human rights, housing, income security, and health issues—an increase in caseload of 1,060%.

Also in 1994, representatives from BCPWA were invited to sit on St. Paul's Hospital Neighbourhood Advisory Committee (NAC). The purpose of NAC was to provide a forum for hospital/community dialogue and collaboration in an effort to better understand and respond to the needs of the local community served by the hospital.

The British Columbia Persons With AIDS Society received national news coverage in the *Globe and Mail* in June of 1994. An article entitled "Budget Rebellion Hits AIDS Conference" explained the Society's influential boycott of the forthcoming 1996 International AIDS Conference that was scheduled to take place in Vancouver. The article states, "In an unprecedented revolt, the Persons With AIDS Society of BC—the umbrella organization marshalling the boycott—has sent out more than 15,000 letters to individuals, government agencies, and medical research firms to dissuade them from attending the conference."[19] The letter-writing campaign included letters written directly to Premier Mike Harcourt expressing outrage over provincial funding cuts; the New Democratic Party's (NDP) provincial budget included severe cutbacks to the city's AIDS prevention programs at a time when the impact of AIDS on the population was growing. The community felt that, in the context of the current political climate, to showcase British Columbia at an international conference as an example to the world would be hypocritical. Conference organizers took the boycott seriously given that a previous boycott in 1992 had caused the International AIDS Conference to be moved from Boston to Amsterdam.

On May 10th 1994 the British Columbia Persons With AIDS Society once again took a controversial stand when it adopted a position paper on euthanasia entitled: *Choices: A Position Statement on Euthanasia*.

1994

The importance of the Society's role is summarized in the in the first paragraph of the preamble: "The British Columbia Persons With AIDS Society is mandated to empower our members by providing information about all available health care options and advocating for safe access to all health services. Where services do not exist, or are unavailable, the Society works on behalf of its membership to ensure that each individual has real choices."[20] This advocacy role extended to the rights of Society members to die with dignity, adopting the position that "The British Columbia Persons With AIDS Society is mandated to empower our members by respecting each individual's choice regarding euthanasia and advocating for safe access to health services."[21]

In 1994 the Prison Outreach Program (POP) became more established within the organization. A Prison Outreach Committee was created to support the work of program volunteers. The committee had 12 members with a mandate to provide support and advocacy for HIV-positive persons incarcerated in British Columbia. During this year, the Complementary Health Fund (CHF) was made available to prisoners. In addition, Society volunteers made hospital visits to inmates, provided citizen escorts to inmates, and coordinated awareness events on Prisoners' Justice Day.

In 1994, the Canadian Human Rights Commission (CHRC) issued a policy statement on AIDS, revising its original 1988 policy statement that declared:

> ***The Canadian Human Rights Act prohibits discrimination on the basis of disability. Individuals with HIV/AIDS may therefore seek protection under the Canadian Human Rights Act. People who are not HIV positive may also be subject to discrimination by virtue of their real or perceived membership in a risk group or their association with a person or people with HIV/AIDS. These individuals may also seek protection under the Canadian Human Rights Act on the basis of perceived disability.***[22]

This statement set a national precedent in which HIV/AIDS became officially defined as a disability. People diagnosed with HIV/AIDS could apply for disability income under BC Benefits. This policy was also the impetus for the nomination of BCPWA to the Board of British Columbia Coalition of People with Disabilities (BCCPD). Prior to that nomination, a strong working relationship had been established with the BCCPD during 1990. In 1993, a joint venture was undertaken between the two organizations to plan a national AIDS and Disability Conference. Thereafter, the two organizations undertook many joint initiatives to ensure the rights of people living with disabilities in British Columbia.

As BCPWA membership grew, so did the number of volunteers. In 1994, 120 volunteers were recruited and over 500 people volunteered for the AIDS WALK. Two volunteer recognition lunch events were held during the year and over 4,600 lunch vouchers were distributed to members who provided volunteer time. The Lunch Voucher Program began early in the organization's history as a way for members, who were volunteering many hours for the organization and who often lived on a fixed income, to receive adequate nutrition during their hours of work.

In late 1994, as the federal government made moves to reform the social security net, Arn Schilder, past Chair of BCPWA, made a presentation to the Standing Committee on Human Resources Development. In this presentation, Arn outlined the realities for people living with HIV and AIDS and what they would face if the social support system were to be cut back. In many ways this presentation highlighted the research done by the Society and stressed the importance of action on the part of the federal government rather than the redundancy of further study. He stated:

> ***What we need are not cutbacks, but more effective ways of helping those in need live and die in dignity. It is simply not possible to live a healthy life if you have a chronic medical condition and are forced to survive only on welfare. People are already dying faster than necessary because of previous cutbacks. What we need is for the federal government to take action*** *now* ***and set up a national catastrophic disability program. Such a program will save taxpayers money and help people with HIV and other catastrophic illnesses live longer, healthier lives.***
>
> ***Ladies and gentlemen, what we don't need is to wait for a study to prove what most of us already know. Cutting transfer payments that support the safety net means condemning people to a dog-food diet and an early death. Let's not wait five years for a study to prove it.***[23]

Researching at the PARC library.

1995

In response to the proposal to re-vamp the social security system and in an attempt to influence change, the British Columbia Persons With AIDS Society and the British Columbia Centre for Excellence in HIV/AIDS undertook a groundbreaking survey in 1995. This survey explored quality of life issues for people living with HIV disease and AIDS and was called the *Taking Care of Ourselves Survey*. The data was used to inform decision-makers about the realities and challenges that persons living with HIV and AIDS face daily. This was an extensive survey that was distributed to the full membership of BCPWA, resulting in 583 responses. The survey examined differences in demographics: gender, age, ethnicity, and geographic location. It also looked at the health and quality of life among respondents and posed questions about housing. Some of the results suggested that there was not enough affordable, accessible, acceptable housing in the Lower Mainland for PWAs and that there was a greater need for a continuum of care.[24]

In 1995, one year had passed since the provincial government had cut over $624,000 from established HIV/AIDS organizations, a claw-back of over 22%. Furthermore, the reduced monies had been allocated to an additional 23 new groups that had been established throughout the province, spreading funding even thinner. However, the provincial government was caught off guard by the strong negative response to this policy put forth by the BCPWA Society, in conjunction with over 35 other AIDS organizations. In an act of damage control, the government initiated a province-wide consultation to put in place a comprehensive Provincial AIDS Strategy. BCPWA had a voice in the discussions around this Strategy. The result of these efforts was *The Bridging Year*, a document that outlined phase one of a strategic plan that coordinated a response to address HIV/AIDS in BC to the year 1999.

Meanwhile, the Society was completing its own strategic plan. Following the initiative started the previous year, the Board of Directors, with input from the membership, key volunteers, and staff, completed the strategic plan entitled: *Towards 2000: BCPWA Strategic Plan, 1995 – 2000.* Through this process, BCPWA produced and published its core values and beliefs:

- ***Our mission statement is our guide to everything that we do;***
- ***We are inspired by our unique history and honour the contributions of our founding members;***
- ***We respect confidentiality and privacy;***
- ***Persons living with HIV/AIDS are the soul of the Society and control and direct its goals and objectives in partnership with affected persons;***
- ***We believe that the abilities of those with HIV disease are of value to the Society and that we have a duty to promote this;***
- ***The diverse life experiences, knowledge and beliefs of persons living with HIV/AIDS informs the Society;***
- ***Our culture promotes healthy behaviour, respectful and honest interaction and safe supportive environments for all people;***
- ***We have a duty to foster, encourage, and enable all of our members;***
- ***We view HIV/AIDS as a challenge rather than a defeat and honour courage, bravery, and humour in the face of catastrophic tragedy;***
- ***People have the right to make choices with respect to the quality of their own lives;***

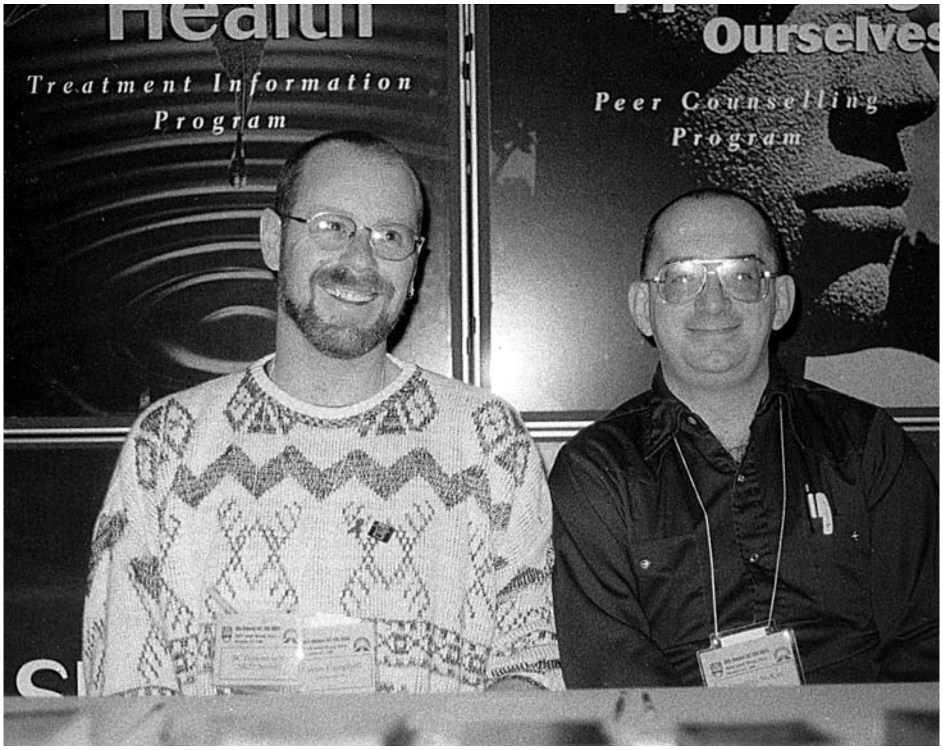
- ***People have the right to death with dignity;***
- ***We encourage a healthy relationship with the community;***
- ***We strive to uphold the credibility of the Society.***[25]

In response to the collapse of the BC AIDS Network, a new provincial organization—the Pacific AIDS Network (PAN)—was formed in 1995. BCPWA, AIDS Vancouver, and AIDS Vancouver Island spearheaded the formation of this organization. BCPWA played the role of the Society of Record for PAN during its early years and gave funding to PAN to support its work. BCPWA continues to be a participant in PAN's initiatives.

Among the highlights in 1995 in the Support Services Department were: art therapy; continued interest in Body Positive, a weekly drop-in and peer facilitated support group; the distribution of 1,000 complimentary theatre/entertainment tickets to members; and an average of 50-60 people visiting the Members' Lounge each day.

The Advocacy Department also had many accomplishments in 1995. The department collaborated with the British Columbia Coalition for People with Disabilities and worked strategically on such issues as income, assisted suicide, and adult guardianship. BCPWA also worked together with the School of Nursing and the Faculty of Medicine at the University of British Columbia to design a new curriculum that gave students the opportunity to learn how to better care for PWAs.

In December, the Society was involved in drafting recommendations for the 8th Report of the Standing Committee on Health that examined how to establish an understanding of the epidemic. A total of 23 recommendations were made with a demand to the federal cabinet to work towards improving the health of affected communities.



Volunteers representing BCPWA at the BC AIDS conference.

1996

In 1996, BCPWA worked alongside partners at PARC to establish the PARC Diversity Working Group. The Working Group consisted of staff and volunteers and was formed to address issues of diversity and representation within PARC and the environment of the PARC building. Part of the vision statement for this Working Group stated:

> ***We, the membership, volunteers and staff at PARC endeavour to reflect the diversity of all communities affected by HIV and AIDS. This includes individuals of any age, race, religion and belief, culture, ability, economic level, and health status. We are men, women, and transgendered. We are different sexual orientations. We value that diversity. We are dedicated to creating respectful, supportive environments and expect that all who come to PARC will extend the same to all those they meet here. Therefore, we at PARC act to promote the inclusion of all.***[26]

The period leading up to the provincial election on May 28th 1996 was a time of concern for the BCPWA Society. This was due in part to the crucial strategic role that electoral politics plays in HIV/AIDS organizations and in the lives of PWAs. The New Democratic Party (NDP), in power at the time, had been working in consultation with community-based organizations to draft a *Provincial Strategy on AIDS*, which guided provincial planning and funding of AIDS initiatives and issues. However, a change in government had the potential to change the commitment in the fight against AIDS. BCPWA wanted all parties running in the election to make a commitment to the statement, "AIDS is a catastrophic terminal illness not a chronic manageable condition."[27] With the Positive Women's Network (PWN) and AIDS Vancouver, BCPWA submitted a list of questions to all parties running in the provincial election. The responses, from those parties who answered, were assembled into a document entitled Fighting HIV and AIDS in British Columbia: Questions for the Political Parties in the BC Provincial Elections, May 28th 1996; and this document was made available to individuals upon request.

The XIth International Conference on AIDS held in Vancouver from July 7th – 12th 1996 marked an important time for BCPWA because of the international recognition the Society received. This conference was significant because, for the first time, the community sector was included on the agenda of what was still largely a scientific conference. The organizers recognized the need to listen to the voices of those people living with the disease, as well as learn from the expertise of frontline AIDS workers. The conference was a great opportunity for BCPWA and the other agencies of PARC to showcase innovative local approaches developed to meet the needs of people living with HIV disease in British Columbia to a global audience.

One of the Society's major contributions to the conference was its pre-conference work raising awareness on Canada's crumbling National AIDS Strategy. Prior to the conference, it became known that the former Minister of Health, Dianne Marlow, had signed the bill that eliminated the option to bring forward a new National AIDS Strategy. Without a new or renewed NAS, federal funding for AIDS would have dropped from $42 million to $10 million, a 75% cut. This decision was coupled with the decision of Prime Minister Chrétien not to open the conference. "One [decision] with real consequences, the other symbolic—ha[d] infuriated AIDS researchers, community groups and people with the disease … they sa[id] the decision not to renew funding for the … National AIDS Strategy will hamper research efforts and … [affect] community groups that educate the public about AIDS and help those who have been infected with HIV."[28]

On July 7th 1996, the opening day of the conference, the Society organized a community-based march to draw attention to the important issue of funding. The march started at the Vancouver Public Library and ended at General Motors Place where delegates of the XIth International Conference on AIDS could then attend the Opening Ceremony. This demonstration received world-wide media coverage.

Members of the Society who were invited to speak at the conference prepared poster presentations, staffed an exhibit table, and worked closely with organizers to ensure that PWAs played a significant role. In addition, performance art created by members of BCPWA's troupe, Theatre Positive, was presented at the Vancouver Playhouse as part of the cultural programming during the XIth International Conference.

In hindsight, the most significant outcome of the conference was the introduction of protease inhibitors (PIs), which lead to the new definition of HIV/AIDS as a *chronic manageable illness*. Researchers claimed that when taken in combination with existing drugs, protease inhibitors would halt a critical step in the reproductive cycle of the virus. These drugs were hailed as a powerful new weapon against AIDS and were proven to increase the quality and lengthen the lives of people living with HIV. This new definition of AIDS as a chronic manageable illness hindered the struggle of PWAs because it reduced public concern by inadvertently positioning the new drugs as a cure rather than a treatment. However, protease inhibitors would quickly prove not to be a cure for HIV/AIDS; the drugs created new problems, and as they were very expensive, proved unaffordable and unattainable to 90% of the HIV infected population in the developing world as well as to lower-income people in the developed world. In addition, it became harder to raise funds for HIV/AIDS organizations, BCPWA included, once the public perceived that the threat of HIV/AIDS was over.

BCPWA was instrumental in the formation of the Canadian Treatment Advocates Council (subsequently re-named the Canadian Treatment Action Council (CTAC)) in 1996. CTAC was created to respond to the complex issues arising from the introduction of combination antiretroviral therapies. The Council was also designed to provide an ongoing structured relationship related to treatment and access issues, directed at both pharmaceutical companies and consumers, in order to share information regarding access to HIV drugs.[29] When speaking about BCPWA's past Chair Tom McAulay's involvement with CTAC, Patricia Rowe, Manager, HIV/AIDS Relations at GlaxoWellcome stated:

> ***Without Tom's vision and creative insight, we would not have a single unifying Canadian pharmaceutical advisory board, and people living with HIV/AIDS across Canada might not have a council of their peers, working closely with community groups, physicians, companies, and governments to ensure that the best and latest treatments and treatment information are made available to them as soon as possible.***[30]

Past BCPWA chair Tom McAulay

1996

In 1996, the Prison Outreach Program (POP) phone line was created. This service was provided so that inmates could call for support and information. The line operated from 4pm – 10pm, Wednesdays through Sundays. That year, volunteers on the POP line fielded roughly 10 – 15 calls a week. In addition, POP volunteers made visits to the Vancouver pre-trial and other area correctional institutions, and served as liaison between inmates and the Society, which included assisting them in accessing the Complementary Health Fund (CHF) and other BCPWA services.

In 1996 the Society was successful in stabilizing long-term funding from the provincial and federal governments. It received close to $1 million from the provincial government and over $150,000 from the federal government. Stable funding allowed BCPWA to undertake more long-term planning to develop and enhance existing services; this included hiring additional staff. Also, the AIDS WALK continued to grow and had become a successful event for BCPWA, taking place in two locations in 1996: the Vancouver route remained along the Stanley Park seawall and the Fraser Valley WALK took place at the South Surrey Youth Centre. WALK pledges accounted for 80% of the funds required by the CHF.

There were big changes on the communications front in 1996. The Society's newsletter, *BCPWA NEWS*, underwent a readability re-design and assumed a much more professional look. One of the most significant changes to the newsletter included a major revision of the Positively Happening section, a listing of resources available to PWAs, updated to meet the membership needs of that time.

Staff from the Treatment Information Program (TIP) and the Prison Outreach Program (POP) in 1999.

1997

On February 27th 1997 an Extraordinary General Meeting (EGM) was held. Non-partisan procedures developed by a contracted elections consultant allowed the meeting to run more effectively. Resolutions were proposed with respect to elections of the Board of Directors, and there was also a discussion about Board members' staggered terms. Other decisions made at that meeting included establishing a formalized process to call an EGM, when required, and implementing protocol to safeguard the privacy of membership information. Finally, the fundamental quality of the Society as a consumer-based, member-driven organization was strengthened and affirmed.

In March 1997 the Treatment Information Program's (TIP) first *TIP NEWS* was published and was received with great enthusiasm. *TIP NEWS* arose out of the increased demand for current and unbiased treatment information. The bi-monthly *BCPWA NEWS* publication could not keep up with rapid developments in medicine and alternative therapies, so the Treatment Information Program undertook the publication of *TIP NEWS*, a bi-monthly supplement (printing in alternate months) to *BCPWA NEWS*.

Also in 1997, the Treatment Information Program wrote, produced, and published a series of seven basic information pamphlets entitled: Alternative Complementary Therapies; Antiretrovirals; Fraud; Interpreting Your Lab Results: CD4, CD8 and Viral Load; Nutrition; Traditional Chinese Medicine; and Vitamins and Minerals.

The introduction of protease inhibitors (PIs) and combination therapies into HIV/AIDS drug regimes gave new hope for many PWAs returning to the workforce. In 1997, the British Columbia Centre for Excellence in HIV/AIDS demonstrated that the triple drug therapies, first received with great optimism at the International AIDS Conference in Vancouver, had decreased the AIDS death rate at St. Paul's Hospital from 30 patients a month to an astonishing nine patients a month. The Re-entry into the Workforce Project was initiated in 1997 with the intent of supporting persons with AIDS in achieving their job, career, self-employment, or educational goals. The presentation of this program at the Third International Conference on Community Care for Persons Living with HIV/AIDS in Amsterdam, May 21st – 24th 1997, acknowledged this as an emerging issue on the world stage.

In July 1997, after a nation-wide search, the Society appointed a new Executive Director, Ross Harvey. He was hired to work with the Board of Directors to plan, lead, and support the activities of the staff and volunteers as the organization moved forward.

August 9th 1997 was the annual Prisoners' Justice Rally Day. A BCPWA Advocacy volunteer gave a speech at the rally demanding that the government reduce HIV transmission in Canadian prisons by developing education and prevention programs, including medical, psychiatric, and peer support services. He also demanded that correctional institutions make safe consensual sex a non-offense for inmate populations.

Throughout 1997 the Society continued to exert political pressure to try and stop the government from deducting the Canadian Pension Plan (CPP) dollar-for-dollar from income assistance/welfare payments. In response to the CPP crisis, the Society began the Schedule F/Schedule C initiative. BCPWA advocates used a loophole in existing legislation to apply for a monthly health allowance for members. Some members received upwards of $350 per month to purchase nutritional and health care goods and services. For more information on the Schedule C fight, please see Appendix B.

The Advocacy Department experienced many accomplishments in 1997. It assisted nearly 700 members with advocacy advice, CPP Disability

1997

applications and appeals, and debt forgiveness (it filed one-third of the Schedule F/C appeals to the BC Benefits Appeal Board that year). In addition, the department created the Advocacy Update column in *BCPWA NEWS* and established the Advocacy Information Line telephone service. Moreover, apart from all of the frontline advocacy work carried out, the Advocacy Department also published articles in outside journals such as the Legal Services Society's *Community Law Matters* and the BC Coalition of People with Disabilities' Transitions. These publications gave additional exposure to the experiences of, and issues encountered by PWAs.

The Support Services Department also saw a number of highlights during 1997. The growth in the extremely successful peer counseling outreach program allowed peer counselors to provide on-site services at the Gastown Medical Clinic. Theatre Positive had a successful year as it played a major role in the 1997 Pride Parade, staging two performances of one of its most powerful one-act plays that first premiered at the International AIDS Conference. The Wednesday Evening Support Group (a drop-in group predominately for men who had sex with men) continued to be the longest running AIDS support group in Vancouver. And the Monday Night Support for HIV-positive male survivors of sexual abuse was established in partnership with the UBC Department of Counseling Psychology.

For the first time, BCPWA partnered with Friends for Life, the Dr. Peter Centre, and AIDS Vancouver to host the annual Christmas event known as Yuletown. Yuletown took place in the BCPWA Members' Lounge and was a two-day family event. Music, refreshments, and craft materials for making gifts were available. Along with Yuletown, BCPWA hosted its annual members' Christmas dinner and provided over 300 sit-down dinners, 500 Santa sacks, and entertainment for guests.

Even with the creation of the National AIDS Strategy, Phase II (NAS II) in 1993, the problem of inadequate funding continued to exist, especially with the federal government's declining interest in renewing the Strategy, which was due to expire in March 1998. In an attempt to bring the issue of funding back on the political agenda, BCPWA submitted a petition to Ottawa, urging Prime Minister Jean Chrétien to renew the NAS II. On October 17th 1997, the Society produced a briefing paper on the National AIDS Strategy Phase III, recommending that outstanding issues needed to be addressed in NAS III and demanding total commitment from the government in making the fight against HIV/AIDS a priority. Outstanding issues included: problems related to access to treatments, the lack of research priorities, and the needs for optimal care for people living with HIV/AIDS.

Seeing the urgency to secure negotiations for a renewed National AIDS Strategy (NAS), BCPWA became a strong leader in the formation of the alliance called WAKE UP CANADA — The Network of Canadian AIDS Activists. This group was formed because the alliance members felt the Canadian AIDS Society's AGM had seriously compromised the political agenda of PWAs. Those involved felt that it would be beneficial for members of the WAKE UP CANADA alliance to connect with each other electronically so that activism efforts could be coordinated and strategies shared across the country.

On December 1st 1997, after much lobbying and advocacy by BCPWA, both independently and in collaboration with groups such as the Canadian AIDS Society (CAS), Minister of Health Allan Rock introduced the third phase of the National AIDS Strategy. Re-named the Canadian HIV/AIDS Strategy, Rock committed $42.2 million per year, restoring the budget to original levels promised during Phase II.

By the end of 1997 the hope that had been placed in the AIDS cocktail therapies, and especially in protease inhibitors, was beginning to wane. Studies concluded that the drug cocktail was failing in 35% of people with HIV. Stories were emerging of a series of bizarre side effects associated with the drugs, including the growth of breasts and bellies as well as the presence of peri-anal abscesses. There was a fear among PWAs that the pharmaceutical hype would lull the public into believing that AIDS was a chronic manageable disease and that this would result in diminished levels of support for PWAs.[31]

In 1997, BCPWA embraced the information superhighway by creating the Society's first web site, *www.bcpwa.org*. The site provided access to information about the Society, current events, and contained links to over 100 AIDS-related web sites around the world. The web site was produced with technical and design support from students at the Vancouver Film School along with financial support from the pharmaceutical company Glaxo Wellcome. The popularity of the web site substantially exceeded expectations with over 54,000 hits during its first year. The calibre of the information on the web site was recognized in 1997 when it won the *HealthyWay Best of the Web* award from Sympatico.

The 1997/1998 fiscal year was a time of transition for fundraising at the BCPWA. Effective independent fundraising became a priority as government funding had declined. The Fund Development Department was created to help position the organization to achieve longer-term financial security. Previously, fundraising for the organization was undertaken by outside contractors. By bringing fund development activities in-house, the department's responsibilities now included: AIDS WALK, maintaining collection boxes, donor recognition, and creating other fundraising initiatives.

BCPWA's Annual Christmas Dinner.

1998

By 1998, BCPWA was Western Canada's largest AIDS organization with a membership of over 3,400 individuals. Epidemiological findings also showed that British Columbia had one of the highest incidences of HIV infection in the developed world.

The fight for drug access was not over by 1998. As a result of cutbacks, HIV drugs had not been awarded priority review status. No new AIDS drugs had been approved in Canada since 1996 and this was unacceptable to BCPWA. The Society turned up the heat on the Health Protection Branch (HPB) on February 20th 1998, when six representatives met with Greg Smith, Western Regional Director of HPB. At this meeting, BCPWA's reprepresentatives emphasized the government's responsibility to continue to recognize and respond to the AIDS epidemic.

On March 5th 1998, a local treatment activist and a BCPWA official interrupted a meeting being held with the Honourable Allan Rock, Federal Minister of Health, at St. Paul's Hospital, to demand access to HIV/AIDS drugs. At the same time, a protest rally organized by BCPWA and others attracted more than 100 people outside the hospital. Protesters carried placards that read *New AIDS Drugs Now* and *Time Wasted = Lives Lost*. Red heart-shaped balloons were released to signify PWAs lives lost while waiting for new medications.

In the fall of 1998, after 10 years of calls from AIDS groups for a Provincial AIDS Strategy, BC's Health Minister, Penny Priddy, released the widely praised *Framework for Action on HIV/AIDS*. This document identified HIV-specific priorities for government, health authorities, and other key partners in improving services and care for PWAs in the province. A representative from BCPWA contributed to this document.

Also in the fall of 1998, the Supreme Court of Canada made a ruling in the case of *R vs. Cuerrier*. This case involved a British Columbian man charged with two counts of aggravated assault for having consensual sex with two women without telling them he was HIV-positive. Neither woman contracted HIV as a result. This case was eventually heard by the Supreme Court of Canada, and the Canadian AIDS Society (CAS), the Canadian HIV/AIDS Legal Network (CHALN), and BCPWA jointly intervened to argue against such a decision. However, the Supreme Court ultimately ruled that it was a criminal offense for an HIV-positive person to engage in consensual sex without disclosing his/her HIV status.[32] In response to this ruling BCPWA, the Positive Women's Network (PWN), and AIDS Vancouver called on the federal and provincial governments to fund a two-pronged national public education campaign, as most public health experts agreed that the issue of HIV transmission was best addressed through public education initiatives rather than criminal prosecution. The first part of the campaign would be a message to the public on how to protect oneself from contracting the virus. The second part would be directed towards HIV-positive people, to inform them about the situations in which they were required to disclose their HIV status.

In 1998, BCPWA's Vocational Rehabilitation Project grew. Collaboration was undertaken with the Access to Careers and Training Centre (ACT) in order to carry out a *living research* pilot project, involving 10 BCPWA members and ACT's vocational counselors.

BCPWA's Vocational Rehabilitation Project.

The project explored the implications of returning to work for persons with HIV and determined the need for, and design of, an ongoing program. BCPWA also collaborated with IAM Cares, an agency specializing in job placements for people with disabilities. By the fall of the same year, BCPWA had established an Information and Referral Program to provide information on health and financial security issues, as well as vocational rehabilitation and training opportunities. Starting on July 1st 1999, an employment service was initiated twice weekly for PWAs interested in returning to work.

Disturbing allegations that new AIDS drugs were being denied to HIV-positive injection drug users (IDUs) prompted a community forum to be held in November 1998, which was attended by both doctors and community groups. Emerging issues included the conflict between an individual's right to effective treatments versus public health concerns raised by the appearance of new drug-resistant strains of the virus caused by improper adherence to drug regimens. Glen Hillson, from the BCPWA Board of Directors, raised concerns about the lack of access to treatment for women, IDUs, and children with HIV. He called for further research in the Downtown Eastside, in order to identify more manageable therapies, such as once-daily treatments.

During this time, BCPWA's Treatment Information Program (TIP) continued to expand. Outreach projects targeted specifically at the Downtown Eastside were undertaken, including weekly treatment information peer counseling at the Blood Alley Clinic, meditation classes and treatment information counseling at the Carnegie Community Centre, and weekly facilitated group discussions at the Vancouver Native Health Society. TIP also participated in community-based research and developed five research protocols involving various complementary therapies: utility of bioelectric impedance analysis (BIA) testing diagnostically and prognostically; the effects of lauric acid (coconut fat) on viral load and CD4s; vitamin B6 and acupuncture for peripheral neuropathy; comparative trial of milk thistle, NAC, alpha lipoic acid and B12 injections into acupuncture points for effects on liver function; and the liver supportive effect of milk thistle vs. placebo in people on highly active antiretroviral therapy. Unfortunately these proposals were never funded.

Since the early 1990s, University of British Columbia Law School students had been offering free legal advice to members on such topics as wills, powers of attorney, landlord-tenant issues, and other concerns. In 1998, the program expanded by offering the services of five (rather than the usual three) students, one evening every two weeks.

In 1998, the Support Services Department saw some changes as well as some new programs added. The waiting list for the Complementary Health Fund was eliminated; this was accomplished by reducing the monthly amount allocated to $35/month per member. And, during this year, over a quarter of a million dollars was provided for health services not covered by the government. In a collaborative initiative between BCPWA, AIDS Vancouver, YouthCO AIDS Society, and the Asian Society for the Intervention of AIDS (ASIA), social events were organized. These events were intended to break down barriers and build community between HIV-positive and HIV-negative gay men. Two retreats were organized and 75 members attended the three- and four-day getaways. Also, in an effort to support male youth involved in the sex trade, BCPWA participated in the creation of *Boys R Us* gatherings; several evenings per week, roughly 35 at-risk youth attended informal drop-in sessions located in the Downtown South, close to the area then known as *boystown*.

1999

In the February/March 1999 issue of BCPWA NEWS, former Board Chair Glen Hillson called on the Canadian Government to finance the clinical testing of medical marijuana. And at a Board of Directors meeting late in August of 1999 a motion was passed, and was supported by the membership at the AGM, to approve in principle the legalization of marijuana for medical use. Less than a month after Hillson's appeal, Federal Minister of Health, Allan Rock, announced that he had directed his department to prepare for clinical trials to determine the medical benefits of marijuana.

Since its initial launch in April 1997, BCPWA's web site activity grew exponentially. In 1998 the Society's flagship publication, *BCPWA NEWS* was uploaded to the site and recorded over 50,000 hits during the 1997/98 fiscal year. By 1999, *www.bcpwa.org* was Western Canada's most popular AIDS site, housing the Society's position papers, treatment and advocacy information, and an in-depth resource guide including links to other relevant organizations. The same year, on March 26th 1999, the second edition of the *Positive Living Manual*—a practical guide to living with HIV—was published simultaneously in print and online.

Throughout the late 1990s, one of the biggest problems associated with antiretroviral drugs was their high cost. High prices limited access to these life-saving medicines to all except the small percentage of the HIV-positive population in the world who could afford them. Even in developed countries, high prices excluded access to treatment for some individuals. As new drugs entered the market, drug companies increased their prices up to $5,000 per year for a single drug in a cocktail therapy, making accessibility to drugs an even more critical issue. After a series of communications with DuPont Pharma on this issue, AIDS activists went public with their anger, staging a protest at the Canadian HIV/AIDS Research Conference held in Victoria in early June 1999. This event was organized by the Canadian Treatment Advocates Council (subsequently re-named Canadian Treatment Action Council (CTAC)) and included a press conference. Glen Hillson, past Chair of BCPWA's Board, was one of the speakers who stressed the importance of keeping drug prices accessible. As a result of its history of poor judgment and lack of transparency and accountability, another target for activists was Canada's Patent Medicines Prices Review Board (PMPRB), a group with the power to review and regulate prices of patent medicines throughout Canada.

In response to the pressures exerted by activists and because of statements from the BC Centre for Excellence in HIV/AIDS, the PMPRB reversed its earlier decision on the price of SUSTIVA (efavirانz). SUSTIVA, a drug produced by DuPont Pharma, was the first antiretroviral approved for once daily dosing and had a price tag of $5,000/year. The PMPRB's commitment to lowering the price of SUSTIVA was a crucial step in slowing the upward spiral of prices for new AIDS drugs and improving accessibility to these life-saving medicines.

The first edition of *living*⊕ magazine was published in July/August 1999. *living*⊕ represented an amalgamation of *BCPWA NEWS* and *TIP NEWS* into a 40-plus page magazine of information and insights on a broad range of AIDS-specific and related topics, including 20 pages per issue of current treatment news. The magazine also allowed for a limited amount of paid advertising space in each issue as well as paid subscriptions for non-members, organizations, groups, and businesses.

Another publication released in 1999 was entitled *Positive Change*. Produced by BCPWA, with the financial support of the Law Foundation of British Columbia, *Positive Change* was a resource manual of legal information on issues of concern to HIV-positive British Columbians. It was intended to be used as a resource for community advocates (but not as a substitute for legal advice).

In September 1999, Theatre Positive, a BCPWA Support Services Department initiative for the past four years, brought its newest original play *S.E.X.* (Synergistic Energy Xchange) to the Vancouver Fringe Festival. Theatre Positive was also invited to participate in the 10th Annual One Act AIDS Play Festival in San Francisco.

Also in September, the Treatment Information Program in partnership with the BC Centre for Excellence in HIV/AIDS took its nationally recognized workshop—Treatment ABCs—on the road, traveling to various communities around British Columbia. This customized workshop had been designed for people living with HIV/AIDS, frontline workers, and caregivers, and covered a number of major topics that enabled people to make informed decisions about their health.

After more than a year of advocacy efforts by BCPWA representatives, the committee at the BC Centre for Excellence in HIV/AIDS that writes and publishes therapeutic guidelines for HIV doctors developed a set of guidelines for nutrition management. The development of these guidelines represented an important step forward in health management and promotion because it heightened awareness, particularly among medical doctors, of the importance of assessing and monitoring the nutritional status of all persons infected with HIV.

In 1999, 669 HIV-positive British Columbians responded to a province-wide survey entitled *Tell Us Your Side of the Story*. This survey examined from whom, where, and when people access treatment information. The top five sources of treatment information for HIV-positive people across BC were: Doctor, 83.9%; *BCPWA NEWS*, 63.2%; *TIP NEWS*, 48%; HIV-positive friends, 47.3%; and BCPWA Treatment Information Project, 46.4%. These results demonstrated the critical importance of BCPWA as the number one information resource for HIV-positive British Columbians, after their doctor.

Around this same period, BCPWA's Fund Development Standing Committee was successful in increasing community collaboration through partnerships for AIDS WALK and other fundraising events in 1999. The goal of community collaboration was to build relationships with individuals who would support BCPWA in both the short- and long-term. *Care to Dance* (1999 and 2000), the Society's second annual pledged fundraising event, consisted of a five-hour dance party, and was co-produced with the Shooting Stars Foundation; proceeds were shared between BCPWA and YouthCO AIDS Society. *Hairdo!* (1999), an event where participating hair salons donated 25% of one day's hairstyling revenue to PWAs, was a first year event coordinated in partnership with Friends for Life. AIDS WALK 1998 included 11 other community partner HIV/AIDS organizations in the Lower Mainland. By the following year, AIDS WALK, based on attendance and revenue, became Western Canada's largest AIDS fundraiser. Finally, support from the Society's *Be an Angel* direct mail campaign enabled BCPWA to finance its annual Christmas dinner for members. Fundraising became increasingly important to the Society during this time, especially since BCPWA's membership had nearly doubled in the previous four years, from 2,300 in 1995 to over 4,000 in 1999; during this same period, the total amount of government funding had fallen by $75,000.

In 1999, after eight years of operating a Prison Outreach Program (POP) without any provincial or federal funding, BCPWA took the unprecedented step of creating a paid staff position to support volunteers working in area prisons. Health Canada had refused to fund this BCPWA project, despite the fact that it was recommended for funding by an independent review committee and was an identified priority of the National AIDS Strategy.

The Treatment Information Program hosted a series of five community forums in 1999 entitled: *Are HIV Drugs for Me?, HIV Drugs: What's Happening to Me?, Antiretroviral Update, Food and Supplements for HIV/AIDS,* and *Managing Side Effects: Conventional*

1999

and Complementary Approaches. In addition, the Treatment Information Program undertook a new project. With funding from Health Canada, the position of Complementary and Alternative Medicines (CAM) Coordinator was created. The project involved the creation of workshops aimed at under-serviced communities. In 1999 the CAM Coordinator undertook a research study with the following objectives:

- ***To assess PWA and conventional health care provider perceptions of the risks and benefits of CAM;***
- ***To describe communication between PWAs and conventional health care providers about CAM, and elucidate associated legal and ethical issues;***
- ***To identify recommendations for improved communication about CAM and the integration of complementary, alternative, and conventional medicine in the context of HIV/AIDS treatment, care, and support.***[33]

The study, entitled *Optimal Environments for Integrated Care: Complementary and Alternative Medicine in HIV Management in British Columbia*, concluded that "CAM use is common among HIV-positive individuals. PWAs and healthcare providers conceive of a significant beneficial role for CAM in the management of HIV/AIDS. Cost, lack of information, and poor communication pose risks. Open communication with knowledgeable and supportive conventional health care providers can reduce the risks and optimize the benefits associated with CAM use."[34]

Also by 1999, the Advocacy Department was routinely successful in securing health care goods, food, vitamins, water, and nutrients for individual members under Schedule C of the BC Benefits Program. Furthermore, the Society's advocates defeated 100% of appeals at the Appeal Board by the Ministry. These efforts were instrumental in the Society's groundbreaking efforts to acquire Schedule C support for all qualifying PWAs. Three BCPWA representatives—the Board Chair during that period, Glen Hillson, Advocacy Department Director Tarel Quandt, and Executive Director Ross Harvey—initiated a protracted lobbying effort that finally, in 2001, resulted in the Monthly Nutritional Supplement Benefit (MNSB). For further information on the Schedule C fight, see Appendix B.

During this same year, the Communications and Education Department, in collaboration with the Vancouver Film School, National Public Relations, and the BC Ministry of Health created a series of three Public Service Announcements (PSAs) geared to three distinct demographic groups. The purpose of these PSAs, which were broadcast on December 1st World AIDS Day, was to raise awareness about HIV/AIDS and decrease prejudice and discrimination against PWAs.

By 1999, the membership of BCPWA had grown to over 4,000 HIV-positive individuals and represented almost one-third of all HIV-positive British Columbians. However, 1999 also marked a milestone of great sadness for the Society: the number of deceased members reached and surpassed the 1,000 mark.

In 1999, BCPWA began work on Y2K compliance, ensuring that the Society's technology systems would function properly after the start of the new millennium. This event was the catalyst for the organization's subsequent plan to streamline data collection for the improvement of services. As a result, in April 2000, BCPWA initiated Project Talk, an integration of its information databases. Project Talk increased organizational efficiency, helped to identify program usage and appropriate programming, and produced meaningful statistics used to apply for and obtain funding. Due to the implementation of this new project, all individuals receiving services through the organization were required to provide an identifying number.

In January 2000, the Complementary Health Fund that had been reduced from $100/month per member down to $35/month per member in 1998, was increased once again, to $55/month per member. This increase allowed members additional benefits and accommodated all members who wished to draw from the fund.

In February 2000, a new project called HepHIVe was created under the auspices of the Treatment Information Program and in partnership with Vancouver Native Health Society. This project involved educating individuals about HIV and Hepatitis C co-infection and received preliminary funding of $250,000, over three years, from Health Canada. A staff person was hired and an outreach office was opened in April 2000 to serve co-infected members in the Downtown Eastside.

The Provincial AIDS Strategy that had acted as the framework for the response to HIV/AIDS in BC came under threat in 2000. The provincial government intended to regionalize the HIV/AIDS division, effectively destroying the Provincial AIDS Strategy and leaving British Columbia with a collection of conflicting and competing regional AIDS strategies. BCPWA's Collective Advocacy Committee quickly initiated a campaign to stop regionalization in order to ensure that PWAs in British Columbia could continue to select the programs and services they wanted, independent of where they lived in the province.

By 2000, the readership of *living* ⊕ Magazine had reached over 10,500. A survey entitled *Now it's Your Turn to be the Editor of living* ⊕ *Magazine* was distributed to readers; 84% of survey respondents indicated that the magazine had improved their knowledge of treatments. Based on feedback from the survey, several improvements to the magazine were implemented, including more original content and an increased focus on rural issues.

In 2000, the Treatment Information Program set up a monthly program for members interested in checking their bioelectric impedance analysis (BIA). BIA technology had been used to measure body composition in HIV disease for several years and had been accepted by HIV nutrition experts as a valuable method of interpreting what is happening in the body.

In June 2000, the HIV/AIDS community of British Columbia received a community consultation document from the Medical Health Council of BC. The document recommended that HIV infection be added to a list of reportable diseases. Reportability meant that every time a person was tested for HIV, they would have to supply their name. If the test result was positive and confirmed with a second test, their name would go into a master provincial databank which listed HIV-positive British Columbians. The BCPWA Society opposed this recommendation and considered it a dangerous strategy that would exacerbate stigma and function as a barrier to effective public health interventions.

During the XIIIth International AIDS Conference in Durban, South Africa held in July 2000, BCPWA in collaboration with the BC Centre for Excellence in HIV/AIDS, presented four research papers. These papers were based on the results of the 1999 BCPWA survey of HIV-positive women who had experienced sexual violence, as well as on data obtained from the 1998/1999 Drug Treatment Program.

On August 10th 2000 national and community AIDS organizations across Canada joined forces on Prisoners' Justice Day to denounce the treatment of people living with HIV/AIDS in Canada's correctional system. HIV/AIDS infection rates in prisons were many times higher than those in the population at large, and access to effective treatments, doctors, and harm reduction initiatives remained major problems in Canadian prisons.

2000

At the Annual General Meeting held on October 21st 2000, several major proposed changes were put forward by the organization's Board of Directors. With the intention of better serving HIV-positive British Columbians and enhancing the voice of all of its members, it was proposed that BCPWA establish organizational branches throughout the province. Province-wide referendums were also proposed to allow members to vote at local meetings or by means of a mailed ballot. To ensure that HIV-positive people living outside of the Lower Mainland had real decision-making power at the governance level of BCPWA, it was proposed that the Society establish six provincial electoral areas in addition to changes in the number and composition of the Board of Directors. Later, the Registrar of Companies rescinded the resolution to vote by mail retroactively. Of the three governance resolutions proposed, two were defeated: one to allow for the creation of BCPWA branches in other areas of BC, and the other to create regional electoral areas to provide for representation on the Board from across the province. Other resolutions voted on included the Complementary Health Fund and AIDS WALK. It was decided that money raised by the WALK could be used for nothing but the CHF unless and until the CHF could be sustained at $100/month per eligible member (with no wait list). Under no circumstances was AIDS WALK money to be used for staff salaries.

In 2000, BCPWA, with financial support from Health Canada, conducted a research study with PWAs and conventional healthcare providers to examine the risks and benefits of complementary therapies. The first phase of the research was conducted among HIV-positive women and healthcare providers at the Oak Tree Clinic, a multidisciplinary HIV clinic in Vancouver.

Also in 2000, BCPWA's Standing Committee structure was fully operationalized. This system ensured that a Standing Committee chaired by a Board member governed every BCPWA department. The committees included designated staff members, department volunteers, and other interested members. Paid staff had voice but no vote. This structure ensured that BCPWA members continued to exercise active and decisive control over the work and operations of the Society.

Glen Hillson, past Chair of BCPWA, and Melissa Davis, past Director of Fund Development at the 2000 AIDS Walk.

In 2001, after more than two years of community advocacy efforts led by BCPWA, BC's Health Minister finally announced that regionalization would not be forced upon AIDS organizations that did not want it. However, that year's provincial general election resulted in victory for the Liberal party, which subsequently implemented a system of regionalization with respect to HIV/AIDS funding.

Also in 2001, BCPWA participated in the development of a resource manual, *Module 7: Rehabilitation Services*, for Health Canada and created a position paper on workplace issues from the perspectives of the Society's members, staff, and volunteers. In addition, the Society continued its active involvement with the Canadian Working Group on HIV and Rehabilitation (CWGHR), established in 1998.

The Buddy Program, a hugely successful initiative of BCPWA's Advocacy Department that launched in June 2000, underwent expansion in 2001. This program, which trained members to assist their peers in advocating for Schedule C benefits, broadened its training so that members could help each other on a wider range of advocacy issues. The Advocacy Department offices were physically enlarged to make room for the increased activity in the department. In addition, the department began to develop self-advocacy *Action Kits*, plain English information sheets that addressed current advocacy problems faced by persons living with HIV/AIDS. These step-by-step *Action Kits* were made possible with funding from the Law Foundation of British Columbia.

After a four-year fight by BCPWA with regard to Schedule C applications and tribunals, the BC Liberal government, in October 2001, finally announced the creation of a long awaited program to provide monthly nutritional allowances for qualifying recipients of disability benefits. Under the new program, eligible people with HIV/AIDS and other diseases and disabilities would receive the Monthly Nutritional Supplement Benefit (MNSB)—an additional $225/month for nutritional supplements, vitamins, and purified drinking water. While this amount fell short of the previously negotiated sum of $300/month promised by the NDP, and the average amount awarded in tribunals of $430, it eliminated the more than two year waiting list, along with the anguish many people suffered while awaiting a decision on their appeal. As a consequence of the implementation of the MNSB, by 2002, the cumulative total benefits that the Advocacy Department had secured for BCPWA members included $175,000 in monthly health nutritional supplements, $118,700 in debt relief, and $60,000 in other benefits.

In December 2001, BCPWA's Communications and Education Department re-designed the organization's web site to include more interactive features, such as a chat room and bulletin board on which to post questions. These provisions allowed members, particularly those in remote and rural locations, to be more connected with the Society. Also, access to the Internet for members was facilitated by the introduction of the Internet Café in the fall of 2001, which received an impressive 552 visits in January through March.

Staff and volunteers working at the reception for the BCPWA AGM in 2001

2002

During the 2001/2002 fiscal year, BCPWA's Fund Development Department created its second signature fundraising event, *AccolAIDS*. This awards banquet was developed to honor achievements in the BC AIDS movement and to raise additional funds for the Society. The first event, held in April 2002, was a tremendous success, recognizing 32 dedicated nominees—individuals, organizations, groups and businesses—and raising over $42,000. In addition, in September 2002, strengthened support from corporate sponsors, teams, and individual participants, resulted in the Vancouver AIDS WALK's most successful year in its history, grossing almost $479,000. As a follow-up to that event, a donor acquisition telemarketing campaign was undertaken by an energetic group of volunteers from Starbucks Coffee Canada, asking AIDS WALK donors to join BCPWA's monthly giving program. The campaign resulted in an impressive 18.5% response rate.

The year 2002 was a time of change in the structure and internal operations of BCPWA. AIDS Vancouver decided to relocate its administrative offices outside of the 1107 Seymour Street building, dissolving the 10 year old Pacific AIDS Resource Centre partnership. Internally, BCPWA consolidated its Advocacy, Treatment Information, and Prison Outreach programs into one department which was re-named the Treatment Information and Advocacy Department (TIAD). This reorganization streamlined responsibilities and allocated more staff time to provide front-line services.

Throughout 2002, BCPWA was actively engaged in planning the first Positive Gathering conference, an event developed for and by British Columbians living with HIV/AIDS, to increase awareness, support, and knowledge. The conference was held over three days in October and attracted roughly 200 participants. The event included a series of workshops on a range of treatment and community-related issues, as well as a gala dinner for participants.

In 2002 a new initiative, Positive Prevention, was added to the projects under BCPWA's Communications and Education Department. The program was intended to target information and support initiatives to HIV-positive individuals, with the objective being health protection and promotion for PWAs and HIV prevention more generally. The first awareness initiative consisted of a series of four posters and postcards, reflecting an HIV-positive person's perspective, and directed at men who have sex with men (MSM).

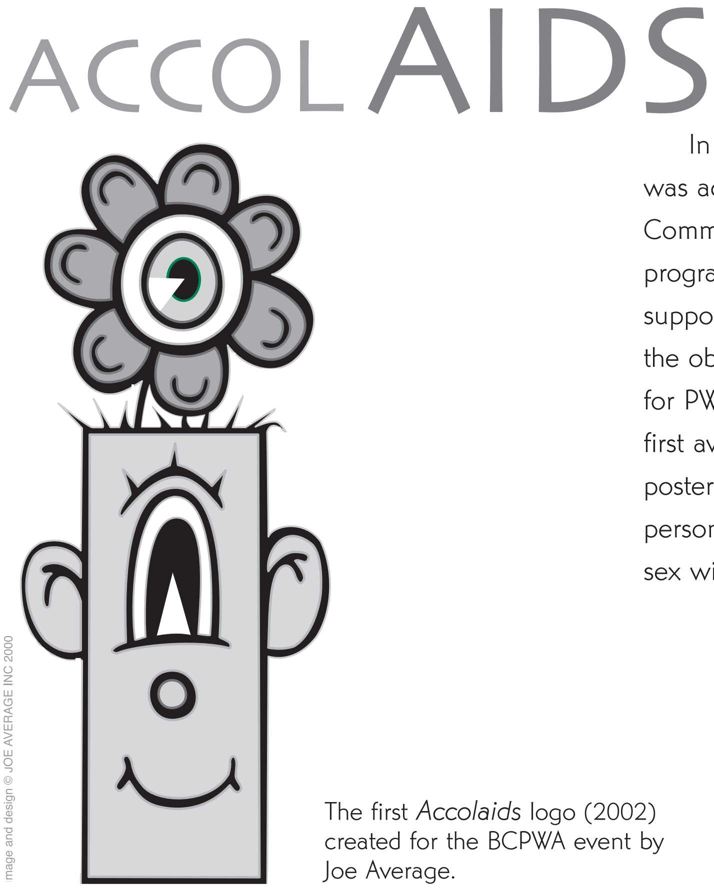


image and design © JOE AVERAGE INC 2000

The first *Accolaids* logo (2002) created for the BCPWA event by Joe Average.

2003

Overall, the year 2003 was one of consolidation and preparation for renewed growth and new development at BCPWA. The exception was the untimely death of past Chair Glen Hillson on June 12th, after a lengthy fight with AIDS and Hepatitis C. Glen was a brilliant, enthusiastic, and high profile AIDS activist for the last seven years of his life and Chair of the BCPWA Society for the last four. Glen was a tireless activist who remained involved in all aspects of the Society's business and advocacy efforts, including the campaign around PWA eligibility for liver transplantation. His enormous contribution to BCPWA and to people living with HIV/AIDS was honored the following year, at the 2004 AccolAIDS event, when he was posthumously awarded the *BCPWA Kevin Brown PWA Hero Award*.

Recognizing the important role that prevention plays in individual and societal health, BCPWA established Positive Prevention as its own department in October 2003. The department collaborated with other NGOs and ASOs to ensure effective outreach to PWAs and to prevent duplication of services.

In October 2003, following a day-long brainstorming session involving all staff, the Board of Directors and selected senior staff participated in a three-day retreat to discuss BCPWA's future. The outcome of this process ultimately formed much of the content for BCPWA's Strategic Plan 2005 – 2010. The focus of the forthcoming five-year period was for BCPWA to further enhance and develop its services to members, increase levels of member engagement, provide increased volunteer training, and to extend its collective advocacy efforts on behalf of membership.

In an attempt to create valuable resources and address important issues that had not previously received attention, BCPWA recorded two information videos in 2003: one on mental health and HIV, and the other on treatment side effects and HIV. The videos were well received by the broader AIDS community, made available for distribution, and placed on the Society web site.

Fusion inhibitors (FIs), a new class of drugs that prevent HIV from entering CD4 cells, were introduced in 2003. Fusion inhibitors were unique because they worked prior to cell infection, whereas traditional protease inhibitors (PIs) took effect *after* HIV had entered the cell. The introduction of these drugs provided hope for HIV-positive individuals who had become resistant to other medications.

During 2003, the Treatment Information and Advocacy Department resolved all issues related to accessing monthly benefits for members without once having to resort to an administrative appeal system. No tribunals meant that members endured less stress and that BCPWA was recognized and respected as an authoritative advocacy force. By the end of the year, the cumulative total benefits that advocates had helped members to secure had soared to $207,225 in monthly nutritional payments, $461,776 in debt forgiveness, $370,267 in other benefits, and $2,235,237 in ongoing Schedule C allowances.

The Collective Advocacy Standing Committee had a busy year in 2003. It opened up forums on an extensive number of issues including medical marijuana access regulations, prisoner human rights issues, access to pharmaceuticals, fair drug pricing, legalities of HIV disclosure before sex, and many others.

2004

In January 2004, the Treatment Information and Advocacy Department hosted a community forum on HIV and Hepatitis C co-infection. The event resulted in the formation of an *ad hoc* group of interested parties, including BCPWA, liver doctors from Vancouver General Hospital, representatives from the BC Centre for Disease Control, the BC Centre for Excellence in HIV/AIDS, the provincial Health Ministry, and several Hepatitis C consumer organizations active in the province. Although there were no public statements, policies, or documents issued from this group, its goal to provide Hepatitis C treatment and prevention services throughout BC spurred the Health Ministry to release a pre-emptive strategy subsequently, in the winter of 2005/2006.

Another community forum presented in Abbotsford, in March 2004, led to the formation of a group of community agencies and activities which, by late 2006/early 2007, had succeeded in opening a part-time HIV/HCV clinic and a part-time HIV-positive persons' drop-in Lounge in three locations throughout the Fraser Valley: Abbotsford, Surrey, and New Westminster. Future plans for a full-service AIDS service organization in the region are also in progress.

In September 2004, BCPWA's Communications and Education Department distributed surveys to the membership to determine whether or not *living* ⊕ Magazine and the web site were meeting the needs and expectations of HIV-positive British Columbians. After evaluating the feedback, BCPWA found that 94% of *living* ⊕ Magazine readers thought the magazine's articles were easy or very easy to read, and 82% of readers had either significantly or very significantly increased their understanding of HIV/AIDS as a result.

Through a grant from the Vancouver Foundation, BCPWA's Communications and Education Department released its third edition of the *Positive Living Manual* on World AIDS Day, December 1st 2004. The third edition was attractive, easy to read, and included a range of information for people newly diagnosed with HIV. Content explored the entire continuum of living with HIV/AIDS, from disclosure issues and lifestyle choices, to treatment information, health care, advocacy, community resources, and even end of life planning. By early 2006, over 3,000 copies of the manual had been distributed throughout the province.

In 2004, BCPWA received over $55,800 worth of computer software, including 55 licenses for Microsoft Office 2003 and XP Pro, Systematic Anti-Virus and SQL Server database from the Tech Soup I CAN software donation program. This generous donation greatly enriched the Information Technologies division of the Society.

Positive Prevention undertook a number of initiatives in 2004/2005. The department launched a condom and lubricant distribution program (previously managed by the Society's Support Services Department), during which time 6,237 condoms and 3,432 packages of water-based lubricant were distributed to members. In addition, the *Vancouver Sex Positive Guide* was published for HIV-positive gay men and distributed to ASOs, STD clinics, mental health teams, and community-based organizations, both provincially and nationally. Workshops, resource development, and presentations at provincial and national conferences were also integral parts of the department in 2004 and 2005, making it a leader in prevention education.

2005

In 2005, BCPWA introduced an innovative retreat to meet the emerging needs of its diverse membership. The SeroSupportive workshop was developed for HIV-positive members and their HIV-negative partners to strengthen, affirm, and enhance their relationships.

The 2005/2006 fiscal year was an extremely challenging period for BCPWA. The Society endured a net decrease of $127,000 in funding and a dramatic increase in operational costs, including a 20% increase in insurance premiums, and an 11% increase in property taxes. The Society's adverse financial situation affected the Positive Prevention Program drastically. The full-time Director was, along with two other staff members, laid off, and the program's innovative activities were suspended. However, the program remained in high esteem, as indicated by an invitation to participate on a special panel dealing with positive prevention issues at the 2006 XVIth International AIDS Conference.

In an effort to provide educational resources through new media in 2005, the Treatment Information Program partnered with the Positive Women's Network (PWN) and launched *Retro Woman*, a CD-ROM focusing on treatment information for women, including a lecture series, easy-to-read fact sheets, and resources for HIV-positive women.

Due to decreasing AIDS WALK revenue and attendance in 2003 and 2004, BCPWA realized that its signature event would require fundamental structural changes to reach in order to reach its full potential. In a strategic move to strengthen the WALK, the Society joined the national WALK for LIFE campaign and adopted a new look in September 2005. The partnership with the National WALK Committee facilitated increased awareness and revenue for the Society. BCPWA's second signature fundraising event, *AccolAIDS*, was extremely successful in April 2005, grossing $90,000 for the Society's programs and services. The Society also undertook community and third party events, including a sold-out benefit screening of *Brokeback Mountain*, which raised $1,800 for BCPWA.

The Communications and Education Department had a record-breaking year in 2005/2006. The annual number of web site hits reached an all time high of almost 92,000, an increase of over 40% from the previous year. It also secured an unprecedented 100 media placements through local, provincial, and national media outlets

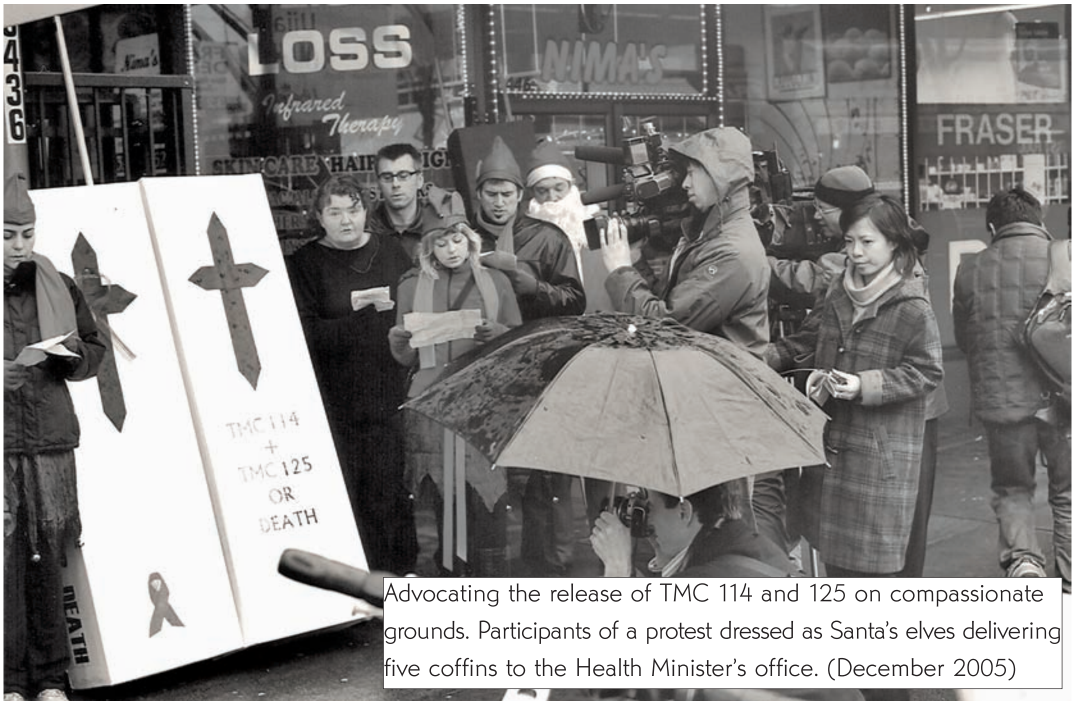
The Treatment Information and Advocacy Department also exceeded expectations and projections in 2005. In March 2005, web-based Advocacy *Action Kits* were created as a self-advocacy tool for members seeking up-to-date information on welfare and seniors benefits, as well as current advocacy issues for persons with disabilities. The new online format of the *Action Kits* allowed members from throughout BC to immediately access a range of information; it also provided other organizations with a user-friendly referral source of information for their clients. During this same year, the Advocacy Program partnered up with the Oak Tree Clinic to develop MNSB applications for children. These applications had a 100% success rate during 2005 and 2006. In addition, in 2005, BCPWA's two advocates obtained $222,939 in debt forgiveness and $155,806 in new benefits for members. Also in 2005, the Treatment Information Program made 20 Treatment ABCs on the road community visits, conducted 29 workshops, created four new treatment information pamphlets, and coordinated six issue-specific community forums.

By 2005, BCPWA's Treatment Information Program had become a national and international model. As an indicator of its prestigious reputation, BCPWA was requested to present its Treatment Information Program at the 2005 North American AIDS

Treatment Forum (NATAF) in Mexico. The program also received approval for a poster presentation at the 2006 International AIDS Conference in Toronto.

The Prison Outreach Program (POP) has consistently increased harm reduction, self-care, advocacy services, and access to the Complementary Health Fund for inmates since its inception in 1992. One of its greatest accomplishments has been providing extensive information and education on HIV/AIDS within provincial and federal prisons. Despite having only one paid Program Coordinator in 2005, POP staff and volunteers delivered 34 treatment and prevention workshops in provincial and federal prisons, developed 31 new materials, distributed 5,514 fact sheets or brochures to inmates and staff, and responded to 1,211 telephone calls from HIV-positive inmates on its toll-free POP line. BCPWA was also instrumental in the Correctional Service of Canada's introduction of six safe tattooing sites in various prisons across Canada in 2005. This pilot project was designed to curtail the transmission of blood-borne diseases via underground tattooing, a significant factor in Hepatitis C and HIV infection.

In December 2005, new AIDS drugs TMC 114 (darunavir) and TMC 125 (etravirine) showed promise for individuals with resistant strains of HIV. Access to these drugs became a major political issue during that month when five PWAs who were failing salvage therapy were denied the medications under Health Canada's Special Access Program (SAP). Knowing that these individuals would likely die without treatment, BCPWA staged three protests outside of Health Minister Ujjal Dosanjh's campaign and constituency offices, advocating the release of TMC 114 and 125 on compassionate grounds. In the last protest, participants dressed as Santa's elves delivered five coffins to the Health Minister's office, representing the lives that would end without immediate treatment. The protest resulted in Health Canada agreeing to a kind of ad hoc drug trial, initiated by Dr. Julio Montaner of the BC Centre for Excellence in HIV/AIDS, that effectively granted access to these medications to the five individuals failing salvage therapy.



Advocating the release of TMC 114 and 125 on compassionate grounds. Participants of a protest dressed as Santa's elves delivering five coffins to the Health Minister's office. (December 2005)

In February 2006, BCPWA was selected as the 2006/2007 recipient of the BC Association of Broadcasters' Humanity Award. The prestigious award entitled the Society to extensive broadcast media exposure, for one full year, valued commercially at roughly $3 million. Enlisting the support of Canadian advertising agency Cossette Communications Group, the BCPWA's Communications and Education Department focused their efforts on creating a hard-hitting advertising campaign to address the issue of HIV-related stigma. In July 2006, a year-long province-wide campaign to end HIV-related stigma was launched, receiving widespread media attention. BCPWA Chair Paul Lewand explained that the "campaign highlight[ed] the impact of living in a culture that appears polite and accepting on the surface, but still harbours deep rooted prejudices that are expressed in subtler ways."[35] The campaign included three components: a series of two provocative television and radio ads, a web site <*www.endHIVstigma.ca*>, and a toll-free information line (1.866.443.AIDS) staffed by BCPWA Society volunteers.

The Positive Prevention Program was revitalized in October 2006 with the hiring of a new Director of Prevention. While reestablishing ties with community partners and working to raise the profile of Positive Prevention, the department's re-launch began with a regular column in *living* ⊕ magazine and the creation of a resource for newly diagnosed individuals. Titled *Breaking the News*, this initiative focused on assisting HIV-positive individuals in identifying first steps after diagnosis and served as a resource for additional information and services. Through partnerships with the BC Centre for Excellence in HIV/AIDS and other key organizations, *Breaking the News* achieved provincial distribution through emergency rooms, community health clinics and public health nurses.

Also, in October 2006, the second provincial Positive Gathering took place in Vancouver. This three-day conference brought together 225 HIV-positive individuals and allies from across BC to network, share experiences, and to empower, support, and educate one another other. The 2006 Positive Gathering was the result of program and logistical planning by BCPWA Board and staff as well as representatives from ten community-based AIDS organizations serving diverse populations across BC. The conference was structured on the theme *From Decade to Decade: Living Life Well* and included content for people living with HIV and AIDS at all stages of the life cycle, from youth to seniors. Workshops also addressed issues and experiences of relevance to diverse communities impacted by HIV, including women, heterosexuals, people of colour, and Aboriginal peoples.

Ocotber 2006

Conclusion

BCPWA has had an eventful and sometimes tumultuous history—a proud and important two decades. As former Chair of BCPWA Glen Hillson once described the Society:

> ***BCPWA was born of a realization by a small handful of courageous PWAs that to overcome the stigmatization of AIDS and to have a fighting chance of survival, those afflicted would need to work together. As in the beginning, the core element of BCPWA is its mission of empowerment, mutual support, and collective action. That, and, in the words of Kevin Brown, that "we are run exclusively by and for HIV-positive people…" At the same time, it is vital to include and respect others who desire to work with us. Issues of social justice affect everyone. And affecting real change requires support. At BCPWA, what we are able to achieve is the product of finding the right balance of volunteers and paid staff to ensure the necessary skills and organization are in place to support and facilitate our work.***[36]

Since 1986, the BC Persons With AIDS Society has been dedicated to empowering people living with HIV disease and AIDS through its vision of empowerment, mutual support, and collective action. Unique among other major AIDS organizations in Canada, BCPWA's consumer-driven foundation and operating structure ensure the goals and direction of the Society reflect those of its members. The Society's work is carried out collaboratively by volunteers and staff, both members and allies, who share a commitment to BCPWA's mission.

Reflecting on our 20 year history—amid the many struggles, challenges, and losses—the BC Persons With AIDS Society can take great pride in our courage, strength, and achievements. Still, with no cure for HIV disease on pharmacy shelves and new infections still prevalent, the need for consumer-driven programs and services for people living with HIV/AIDS remains crucial. BCPWA Society will endeavor to provide support, foster personal empowerment, advocate for rights and freedoms, and engender hope in persons living with HIV and AIDS until the need no longer exists.

British Columbia
Persons With AIDS Society

Department Histories

BCPWA Departments

The backbone of the British Columbia Persons With AIDS Society has been, and continues to be, its volunteers. The organization started out as purely volunteer-operated. The hiring of staff has helped the Society manage its rapid growth over a relatively short period of time. From BCPWA's start in 1986 with 15 – 20 members, to an astounding 4,400 members in 2006, the organization's scope and work has expanded vastly in relation to its size. In order to support the work of the organization, paid staff has been required. In 1995 there were seven staff working for BCPWA; today, there are more than 25.

The history of BCPWA departments is also intrinsically linked to the work of its volunteer Standing Committees. Initially, these committees carried out all of the work of the organization, but over time their mandates have gradually shifted to assume more of a governance role. The organization's unique governance system was fully operationalized in 2000, ensuring that all departmental Standing Committees would be chaired by a Board member. Committees also include designated staff members, department volunteers, and other interested members. Paid staff has a voice, but no vote. This structure ensures that the BCPWA membership continues to exercise active and decisive control over the work and operations of the Society. Therefore, in examining the history of the departments we must also simultaneously examine the history of the Standing Committees that govern their corresponding departments.

Board of Directors

The Board of Directors has been of paramount importance to both the creation and operation of the organization, supplying both the vision and the drive for BCPWA. Directors are responsible to the membership and therefore are required to act in accordance with the Mission Statement and Core Philosophy and Beliefs of the Society.

In its early years, the Board had a more informal structure, with an ever-changing collection of members conducting weekly business meetings to deal with the day-to-day administration of the organization. The first formal Board of Directors was elected at the first Annual General Meeting on January 16th 1987. Also, at this AGM, four Standing Committees were created—Personnel, Finance, Program, and Advocacy—to assist with Society operations in each department, and to provide a structure of accountability to the Board of Directors. In 1995, a modified Carver model of governance was adopted. Currently, the Standing Committees are: Board and Volunteer Development, Community Representation and Engagement, Communications and Education, Information Technologies, Positive Prevention, Membership Engagement, Personnel, Executive, Finance, Fund Development, Support Services, and Treatment Information and Advocacy. Numerous sub-committees and working groups also meet on a regular basis, including: *living*⊕ Magazine, Membership, *AccolAIDS*, AIDS WALK for LIFE, Positive Gathering, End HIV Stigma Campaign, Needs Assessment, and others.

Operations and Administration

The Operations and Administration Department was established very early in the history of the organization. The Coalition's first paid employee was hired to attend to the various administrative functions of the growing organization.

Early in 1989, the position of General Manager was created in order to aid the improvement and expansion of the Coalition's programs and to assist in the advancement of program and service delivery. During that year, Chris Sabean was hired as the first General Manager of the PWA Coalition. Successors as General Manager of the organization were Kathryn Eggert, who was hired late in 1993; Christine Gordon who was retained for seven months as the Acting Executive Director in 1996; and Ross Harvey, who joined the organization as Executive Director in 1997 after a national search. In 1995, in order to assist the Executive Director, an Executive Assistant was hired. This position, held by Katharine McEachern until 2003, eventually developed into Manager, Executive Operations.

Throughout the early years of the Coalition, Warren Jensen, the Treasurer, managed all financial matters. Michael Lawrence was hired as the organization's bookkeeper in 1991, eventually becoming the organization's permanent Finance Coordinator. An additional part-time Finance Assistant position was added to the department in 2002.

In 1995 an Executive Assistant was hired, and through increased responsibility this position eventually became Manager, Executive Operations. With the Operations and Administration Department firmly established, the organization was free to grow into what it what it has become today. It was not until 2002 that Operations and Administration saw any further changes.

In that year, the Operations and Administration Department expanded to include the Manager of Human Resources and the Assistant Manager of Human Resources. These positions had previously operated under the Member and Volunteer Services Department which oversaw all volunteer services, personnel activities, and membership-related functions. However, the decision was made to consolidate all human resources functions, for both paid staff and volunteers, into one department, and to remove these activities from those relating to membership. The management of membership services was turned over to the newly created Director of Member and Volunteer Services and Database Administrator, while the Manager of Human Resources assumed responsibility for providing operational and administrative support to the Positive Gathering Standing Committee.

In early 2003, the Operations and Administration Department was further consolidated to include all functions of Member and Volunteer Services. The title of Assistant Manager of Human Resources was changed to Volunteer Coordinator. This new position entailed recruiting volunteers, providing appropriate volunteer training, and ensuring a mutually beneficial relationship between BCPWA and its volunteers. The Manager of Executive Operations position was re-named Office Manager. The Director of Member and Volunteer Services and Database Administrator position was re-named Manager of Information Technology. This position continued to oversee the work of the Membership Office while also maintaining the IT systems and the Project Talk database; in addition, the position also assumed responsibility for the supervision and daily operations of the Internet Café, a drop-in computer lab originally established by the Support Services Department.

Today, as in the early years of the organization, the Operations and Administration Department continues to engage wholeheartedly in two major functions: to support and facilitate the governance work of the elected Board of Directors (including community representation and engagement efforts, and departmental governance through the Standing Committee system), and to maintain the financial and administrative infrastructure as the foundation on which all other BCPWA departments do their work and provide the services and activities for which BCPWA is known.

Support Services

Apart from Operations and Administration, Support Services was the earliest department created in the organization. This department's mandate was firmly established as one of the four original committees, the Program Committee, created at the Society's 1st Annual General Meeting. This committee was created to develop and implement support services for PWAs, including support groups, workshops, peer counseling, out-of-town retreats, healing circles, a library, and funding for alternative and holistic therapies.

Jackie Haywood, who is currently the Director of Support Services, was one of the first staff employed by the organization in 1987. She was initially hired to perform administrative work but this grew into managing counseling and related programs as they emerged. Her work grew into the support services area and this department has had the broadest range and most extensive volume of services within BCPWA. It became apparent that a second staff person was required to help run this department and in 1995 a Support Services Program Assistant was hired. In 2002, to better suit Union guidelines, this position was re-designed and re-named the Coordinator, Member Services.

The Support Services Department offers programs and services designed by members, which enhance social support networks, improve quality of life, promote self-care, and enable peer-driven activities to operate in safe, respectful environments. Department Director Jackie Haywood has stated that the role of the department is "to offer members safe environments to interact with peers and receive services in a non-judgmental and empathetic fashion. It has now grown, with 45 volunteers, as a way for peers to support peers."[37] It is important to note that the Wednesday

Evening Support Group remains the longest running HIV/AIDS support group in Vancouver, started by HIV-positive gay men in 1985 as the Body Positive Support Group. The group has operated under the auspices of Support Services since the department's creation.

Communications and Education

For many years, the communications and education function of BCPWA took place under the Advocacy Department of the organization. One of the primary roles of the Advocacy Committee was to promote a positive image of people living with HIV/AIDS and the committee created the Media Relations and VIP Relations Project to ensure that the Society's voice was heard. Another project that was created was the Speakers Bureau, one of the Society's most effective tools in ensuring that the public viewed the *human face* of AIDS, particularly in the early years of the epidemic.

In 1995, the Coordinator of Communications and Marketing was hired, creating the Education and Communications Services Program. One of this program's early mandates was a focus on media relations. In the 1994/1995 fiscal year, the Society developed a more sophisticated and professional communications strategy including an Annual Media Plan and cutting-edge corporate publications. The other focus for the department was educational programming. The Society's increased focus on communications and education provided the impetus for the creation of new policies and procedures to manage media interactions through an emergency response team. This team allowed the organization to rapidly respond to pertinent issues arising out of press releases or news stories and facilitated credible relations with key media contacts. In addition, production of *BCPWA NEWS* became the responsibility this department.

During 1999, *BCPWA NEWS* and *TIP NEWS* were consolidated and *living*⊕ magazine was launched. A half-time Managing Editor and an Art Director were hired in the Communications and Education Department to support the increased professional quality of this new publication, to ensure continuity, and to bring these services in-house.

Department Histories

The Communications and Education Department's mandate has expanded over the years. This department currently seeks to inform the membership, PWAs, AIDS service organizations, health care workers, and the general public about current issues facing those infected and affected by HIV/AIDS. This is accomplished through the publication of *living*⊕ magazine; the development and maintenance of BCPWA's web site, the dissemination of weekly electronic newsletters to members and subscribers; the creation and distribution of *Positive Living Manual;* the production of relevant communication resources; and effective media relations.

Fund Development

The first step to the formation of this department was in the creation of the Fund Development Committee in 1991. This committee was created to separate the overall financial planning of the Society from the fundraising function and was mandated: to develop and draft fundraising strategy; to develop and draft a fundraising policy and related administration policies; to develop community contacts beneficial to the Society; to initiate fundraising campaigns; and to monitor the fundraising activities of the Society. Much of the fundraising work of this committee was contracted to outside fundraising consultants.

In 1996, a decision was made to bring the Society's fundraising activities in-house. As a result of this decision, the Fund Development Department was created in 1997 to achieve longer-term financial security. During this period, government funding was declining and the Society faced further funding losses. The department's responsibilities included: AIDS WALK and other fundraising initiatives, including the maintenance of community collection boxes.

The Fund Development Department's scope has increased considerably since its creation. Some of the projects that have been implemented in recent years include: direct mail campaigns; a monthly giving program; major gift solicitation programs; community and third party events, and a second signature fundraising event known as *AccolAIDS*, an awards gala celebrating achievements in the BC AIDS movement.

Treatment Information and Advocacy Department (TIAD)

In 2002, BCPWA decided to streamline responsibilities and allocate more staff time to provide front-line services by amalgamating the individual departments of Advocacy, Treatment Information, and the Prison Outreach Program to create one Treatment Information and Advocacy Department (TIAD). While this department functions as a cohesive unit, each sub-department has its own history.

Treatment Information

In 1991, the Treatment Information Program (TIP) was created and was run by a dedicated team of volunteers. Prior to being established as its own department, Treatment Information was a project within the Advocacy Department. In September of 1996, the Treatment Information Program established its own department through the hiring of the Coordinator of Treatment Information.

TIP has been an essential program for BCPWA's members. As Paula Braitstein, former Director of Treatment Information stated: "AIDS treatment activism taught me that medicine does not belong to doctors and science does not belong to scientists. People living with HIV/AIDS have contributed enormously to the kind of research that has been done in this field, and have changed the paradigm about how that research gets done."[38] TIP has been a key player in the community-based research conducted by the Society, often in collaboration with other organizations, and has contributed to significant advances in HIV/AIDS treatment.

The programs of TIP are extensive and have included: individualized information counseling; educational workshops, presentations; Question and Answer (Q&A) sessions; treatment related articles for *living*⊕; the creation and distribution of treatment information pamphlets; plain English HIV/AIDS treatment information materials; the Complementary and Alternative Medicines (CAM) project; the development and implementation of HepHIVe, a collaborative project with Vancouver Native Health; outreach; treatment advocacy issues; and presentations of the program provincially, nationally, and internationally.

Prison Outreach Program

The Prison Outreach Program (POP) has been a very important program for BCPWA. As Michael Linhart, former POP Coordinator, explained: "POP started when I called [from prison]. I was freshly diagnosed and I had no resources available to me. One trained peer counselor came out (in 1991), and POP pretty much started *ad hoc* and expanded from there."[39] This program was volunteer run for many years and did groundbreaking work in supporting incarcerated HIV-positive people who would not otherwise have access to these services.

Starting in 1993/1994, Complementary Health Funds (CHF) were made available to prisoners who could access the program. Volunteers made hospital visits to inmates, provided citizen escorts and coordinated awareness events on Prisoners' Justice Day. In 1996, the Prison Outreach Program (POP) toll-free phone line was created to provide support and information to prisoners who telephoned; the line operated from 4pm – 10pm, Wednesdays through Sundays. During 1996, volunteers on the POP line fielded approximately 10 –15 calls a week; by 2005 that number had almost doubled.

In 1999, after eight years of operating POP without any provincial or federal funding, BCPWA took the unprecedented step of creating a half-time paid position to support the volunteers working in prisons. Also in 1999, the newly hired Coordinator co-chaired a breakthrough HIV conference in Vancouver for corrections staff and the public on health, addictions, and social justice.

In 2005, POP had only one full-time paid program Coordinator, but staff and volunteers still delivered 34 treatment and prevention workshops in provincial and federal prisons, developed 31 new materials, distributed 5,514 fact sheets or brochures to inmates and staff, and responded to 1,211 telephone calls from HIV-positive inmates on its toll-free POP line. BCPWA was also instrumental in the Correctional Service of Canada's introduction of six safe tattooing sites in various prisons across Canada in 2005. This pilot project was designed to curtail the transmission of blood-born diseases via underground tattooing, a significant factor in HCV and HIV infection.

Individual Advocacy

Advocacy has been a cornerstone of the BC Persons With AIDS Society and was structured into the governance and operations of the organization at its earliest stage. At the first Annual General Meeting held in 1987, the Advocacy Committee was created. Its mandate was to examine and employ political strategies to carry out the Coalition's mission of improving quality of life for PWAs. This committee was to develop a public image, deal with the media, publish a newsletter, maintain a speakers bureau, facilitate drug studies and treatment investigations, and participate in community relations and networking with other AIDS organizations. The committee proved to be a leader in advocating and lobbying for the rights and concerns of people living with HIV/AIDS within the BC AIDS community, and at provincial, national, and international levels.

Department Histories

The Advocacy Committee was particularly active and engaged in 1991, and because of increasing demands, a full-time Advocacy Manager was hired to serve as facilitator and resource person for this function. The committee and the Manager continued to work on the many projects under six categories: individual advocacy, collective advocacy, government liaison, international relations, networking, and public relations.

Throughout 1991 there was an increased demand for information and assistance by individual members covering major issues confronting PWAs including: treatment access; legal issues; discrimination in housing, employment, and immigration; breaches in confidentiality; and problems with government ministries and policies. This increase in demand led to the creation of the Individual Advocacy Project in 1992, where volunteers were trained to deal with basic advocacy issues and were scheduled for shifts in the office to assist in responding to the demand for services. In 1995, an Individual Advocacy Services Coordinator and two full-time Advocates were hired to meet the needs of the Individual Advocacy Project.

The Advocacy Department continued the Society's public relations and communications work, which was one of the primary roles of the Advocacy function, until 1995 when a Coordinator of Communications and Marketing was hired; subsequently, the Advocacy and Education/Communication functions of the organization became separate although departments continued to collaborate on initiatives, especially those requiring public relations or media.

Today, the Individual Advocacy Program provides services to assist members obtain social assistance, Monthly Nutritional Supplement Benefits (MNSB), and CPP Disability benefits. Advocates also help members apply for debt forgiveness, and provide legal guidance on residential tenancy issues, notary services, wills, and more. In addition advocates schedule appointments for members at a student legal clinic in partnership with the UBC Law Students Legal Assistance Program. In 2005, the Advocacy Program designed and launched Advocacy *Action Kits*, plain English step-by-step guides for members to advocate for their own to access government benefits and resolve personal legal matters.

Tarel Quandt, the director of Treatment Information and Advocacy from 1999 to 2006.

Influencing Changes

PWAs at the Table:

i) Health Act

On July 7th 1987, Bill 34, controversial Amendments to the Health Act, was introduced to the British Columbia legislature. This Bill would enable Medical Health officers to order HIV-positive individuals, whose sexual practices were considered "unsafe," into "isolation, modified isolation, or complete quarantine, such quarantine to last no longer than one year."[40] Reaction from local PWAs was immediate and uniformly in opposition, as they realized that the implications of the amendments to the Health Act were possible isolation, quarantine, and disregard for civil liberties.

To protest against this senseless quarantine initiative, the Society lobbied, through a letter-writing campaign, every MLA in British Columbia, reminding them that persons living with HIV/AIDS had not forfeited their rights as citizens of the province just because they had this disease, and that the control of HIV/AIDS would not come through enforced isolation but through education.

On August 27th 1987, Kevin Brown, Chair of the Vancouver PWA Society at that time, and Sharon Holtzberg, a former employee of the Society, met with the provincial Minister of Health, the Hon. Peter Dueck, at his office in Victoria. No resolution resulted from this meeting, but the Society was firm in communicating to the Minister the prospect of abuses occurring under Bill 34, as well as its violation of human rights.

On September 26th 1987, in collective opposition to Bill 34, the Society organized a march through the streets of downtown Vancouver and a rally of more than 200 people on steps at the Vancouver Art Gallery. The work of PWAs was rewarded: Bill 34 was never passed in the legislature and this discriminatory law was not ratified.

ii) Denver Principle

The Denver Principle was a statement formulated by a group of PWAs in the United States in 1983. In 1993, the Society formally endorsed The Denver Principle. It challenged the labels *victims* and *patients* imposed upon people infected with HIV/AIDS; according to the Denver activists, the former term implied defeat and the latter suggested passivity, helplessness, and dependence upon the care of others.

The Denver Principles were intended to state the rights of people living with HIV/AIDS, to ensure that they had equitable access to quality medical treatment and quality social supports, and to empower individuals in making informed decisions about their lives through the acknowledgement of their right to choose or refuse their treatment modalities.

iii) Standard of Care

There had not been a baseline standard of care for HIV/AIDS until late 1993. The absence of standards and lack of a clear organizational framework significantly impaired health care providers' ability to deliver care, and inhibited the interplay of different bodies within health care communities. Consequently, this led to an inability to accurately calculate the cost of HIV care or to determine the cost/benefit relationship of various models of care. The lack of information did not permit planning of programs or allocation of appropriate resources. The *Care Survey* and the *Migration Survey* represented two attempts by the Society to break this impasse. These efforts pushed Health Canada to complete standards of care in late 1993 that were to be utilized by general practitioners within a community context.

Access to HIV/AIDS Drugs

Beginning in the early 1980s, the AIDS epidemic led to a more realistic appraisal of the limitations of medicine in society. As research and studies gradually unraveled the mysteries and complexities of HIV/AIDS over time, it became obvious to PWAs that a single pill could never cure their illness. The need to access HIV-related information and knowledge became increasingly evident as more and more PWAs came to recognize knowledge and self-empowerment as critical tools in maximizing health potential. The fight to obtain access to HIV drugs and information, therefore, remained a primary concern for AIDS activists and AIDS community groups. Throughout the years, BCPWA has played an influential role in the fight for access to and approval of HIV/AIDS drugs.

Late in 1985, a local doctor applied to the Federal Health Protection Branch for the release of experimental AIDS drugs on compassionate grounds. His application was denied on the basis that there was no viral testing lab in BC. In response, the first Canadian demonstration by AIDS activists took place in Victoria in March 1986. This action became the first of many political protests led by local PWAs. The event also sparked the formation of what would subsequently become the British Columbia Persons With AIDS Society and firmly rooted the organization's history in activism and advocacy.

The fight to obtain access to experimental drugs proved to be a strong, uniting force. In 1986, PWAs submitted a petition of 3,000 signatures to the Federal Health Protection Branch, requesting the government grant local AIDS doctors permission to write their own protocols for experimental drug testing and conduct their own drug trials independent of the Branch.

On August 17th 1986 the first victory for the Coalition was won: Jake Epp, the Federal Health Minister, and Jim Nielson, the Provincial Minister, announced that a viral testing lab would be constructed in Vancouver. For the first time in western Canada, blood could be tested for HIV, providing an infrastructure for doctors in which to effectively monitor the impact of experimental drugs.

The issue of access to experimental drugs continued to be a rallying point and a prime concern for members of the Vancouver PWA Coalition. In October 1986, Greg Smith, Coordinator of the AIDS Centre for Disease Control in Ottawa, announced that AZT would not be made available to Canadian PWAs, even on compassionate grounds. In response to this announcement, the Coalition began a letter-writing campaign to Members of Parliament (MPs) to demand that AZT be released to PWAs. Due in part to these efforts, Kevin Brown became the first person in Canada to legally obtain AZT in December of 1987.

Another problem related to AZT access was its high cost. While all other provinces covered the entire cost of the drug (approximately $8,000 a year), the BC government only covered 80% of the cost under Pharmacare. This policy left individuals taking AZT paying as much as $2,000 per year.

Organized opposition to the Social Credit government and its drug policies came on October 27th 1989 at the Social Credit Convention where members of the Vancouver PWA Society distributed over 200 leaflets. The leaflets called for full funding of AZT and other promising AIDS treatment drugs, and demanded an end to government policies based on discrimination and punitive attitudes. This low-key presentation was well received by most of the delegates that were approached. In part as a result of these efforts, the Provincial Government established the British Columbia Centre for Excellence in HIV/AIDS at St. Paul's Hospital in Vancouver in 1992. The British Columbia Centre for Excellence initiated the drug program in which selected drugs were distributed without charge to most HIV-positive British Columbians.

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The introduction of protease inhibitors (PIs), announced at the XIth International Conference on AIDS in Vancouver in 1996, raised false hope among many medical professionals and the AIDS community when researchers hailed this new class of drugs as a promising new weapon against AIDS. The announcements created an impression that a cure had been discovered, and HIV/AIDS had become a "chronic manageable illness." However, these drugs quickly proved *not* to be a cure for HIV/AIDS and created new problems due to their exorbitant prices and harsh side effects.

In response to the complexity of issues arising from the introduction of combination anti-HIV therapies, BCPWA took a leadership role in the formation of the Canadian Treatment Advocates Council in 1996 (subsequently re-named Canadian Treatment Action Council (CTAC)). The CTAC was designed to provide an ongoing structured relationship related to treatment and access issues directed at both pharmaceutical companies and consumers in order to share information regarding access to HIV drugs.[41]

The fight for drug access was not over by 1998. Since 1996 no new AIDS drugs had been approved in Canada. After a series of protests and advocacy on the part of BCPWA, Health Minister Allan Rock finally activated a process for reviewing and reforming the drug review process. Glen Hillson, former Board Chair, was one of the members selected in a team of community representatives to continue to advocate for reform of the drug review process at the Health Protection Branch.

Problems associated with the high cost of anti-retroviral drugs continued to exist in the 1990s. As new drugs entered the market, drug companies increased prices up to $5,000 per year for a single drug in a cocktail therapy, making accessibility to drugs an even more critical issue. AIDS activists went public with their anger, staging a protest at the Canadian HIV/AIDS Research (CHAR) conference held in Victoria in early June 1999. Glen Hillson was one of the activists who communicated to the media the importance of holding the line on drug prices.

In response to the pressures exerted by activists, the Patent Medicines Pricing Review Board (PMPRB) decided to reverse its earlier decision on the price of certain drugs. The PMPRB's commitment to lowering the price of these drugs was a crucial step in slowing the upward spiral of prices for new AIDS medications.

In 2005, two new AIDS drugs, TMC 114 and TMC 125, showed promise for individuals with resistant strains of HIV. The issue became political when five British Columbians living with AIDS and failing salvage therapy desperately needed these new medications. Their specialist, Dr. Julio Montaner of the BC Centre for Excellence in HIV/AIDS, contacted Health Canada's Special Access Program (SAP) to obtain the experimental drugs for his patients. His request and a subsequent appeal were denied, suggesting that PWAs would have to wait for official approval of the drugs in order to begin treatment. Knowing that the five people could more than likely die while waiting, BCPWA staged three protests outside of Health Minister Ujjal Dosanjh's campaign and constituency offices to demand the release of TMC 114 and 125 on compassionate grounds. Ultimately, in order to secure Health Canada cooperation, Dr. Montaner set up his own clinical trials for the five patients so that the drugs could be used in combination outside of the SAP guidelines.

Because of the complexity and ever-changing nature of the disease, struggles to access HIV drugs will likely continue for years to come. The BCPWA Society is committed to advocating for better drug access in order to ensure improved quality of life and health for all PWAs.

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Live Organ Transplants

BCPWA has fervently advocated for the availability of liver and other live organ transplants for PWAs in both British Columbia and Canada. Until the fall of 2003, PWAs were denied liver transplants despite evidence that HV-positive and HIV-negative patients had an equivalent survival rate. Since 2003, BC has been one of the few provinces where HIV-positive people are assessed for transplant eligibility. To date, only one kidney transplant has been performed on a PWA patient in BC (in 2004), but a liver transplantation procedure has yet to be performed. The reasons for this situation relate to the conditions that PWAs must meet in order to be deemed eligible for a transplant. BCPWA has been focusing its efforts on easing the BC Transplant Society's guidelines for HIV-positive people. Currently, the BC Transplant Society guidelines are as follows:

- ***HIV-positive patients must fulfill all required criteria for liver transplantation candidacy that non-HIV infected individuals must fulfill.***
- ***HIV-positive patients must have an absolute CD4 count of 200 or more; however, in certain circumstances, provisions could be made to accommodate a lower CD4 count.***
- ***HIV-positive patients must be on HAART medication while they are on the waiting list.***
- ***HIV-positive patients must have an undetectable viral load at the time of transplantation.***

The last two conditions of these guidelines exclude many HIV-positive patients from eligibility. Due to a high level of liver toxicity, patients may not be able to tolerate HAART, but require a liver transplant in order to resume HAART. Furthermore, patients not taking HAART are likely to have a higher viral load and lower CD4 count, jeopardizing their eligibility under conditions 2 and 4. For PWAs to be treated equally under transplant regulations, the guidelines must be changed.

International AIDS Conferences

The Vth International AIDS Conference, held in Montreal in June 1989, marked the first appearance of BCPWA Society on the world AIDS map. The opening ceremonies included a video of Kevin Brown, Chair Emeritus, criticizing the government for its inaction with respect to AIDS. The credibility of the organization was firmly established at the conference; this was due in part to Don deGagne, a member of the Society who worked very hard to ensure a strong visible PWA presence at the conference.

The XIth International Conference held in Vancouver, from July 7th – 12th 1996, was significant for the Society because for the first time conference organizers included the community sector on the agenda of what was still a largely scientific conference. The organizers recognized the need to listen to the voices of people living with HIV/AIDS and to respect the expertise of frontline AIDS workers. During the conference, BCPWA and the other agencies from the Pacific AIDS Resource Centre showed the world some of the innovative local approaches developed to meet the needs of people living with HIV disease in British Columbia.

Health Promotion and Human Rights for PWAs

> ***When I started to keep plugging along, I feel very much diminished that the disease is taking its toll on me. I'm very thin. I've lots of aches and pain. And there was a time last summer when I thought I was dead. But somehow I have a will that won't give up. And I keep fighting for life. Life is enjoyable, so much beauty in the world, so much to accomplish.***
>
> Kevin Brown, co-founder of PWA Coalition[42]

Building on the leadership of Kevin Brown, the BCPWA Society lives on as a strong and vital group in the fight against AIDS, and continues to inspire PWAs across Canada and elsewhere to empower themselves. Kevin's strong message of hope, and his statement that PWAs "are part of the solution, not the problem," encouraged many HIV-positive individuals to take control of their lives through making sound decisions, and fighting AIDS-related discrimination. Kevin's efforts to put a human face to AIDS also led to a new paradigm in the doctor-patient relationship as research and medical communities slowly came to realize that the voices of PWAs were critical in understanding the myriad realities of AIDS.

On November 21st 1986, *The Ottawa Charter for Health Promotion*[43] was presented at the First International Conference on Health in Ottawa. In this conference the Charter defined health promotion as "the process of enabling people to increase control over, and to improve, their health", and emphasized that health promotion "is not just the responsibility of the health sector, but goes beyond healthy lifestyles to well being."[44] The Ottawa Charter not only acknowledged AIDS organizations as equal partners with healthcare professionals in the promotion of health, but also encouraged community agencies and caregivers to continue their fights for better health services and quality of life for people with disabilities.

The Society embraced this definition of health promotion and supported its members in becoming active participants in their treatment, in spite of opposition from local doctors who expressed concerns about the treatment information disseminated in the *Vancouver PWA Newsletter* (re-named *BCPWA NEWS* in 1993). As one doctor stated: "…[the newsletter] causes confusion in my patients' minds [because] your information is sometimes inaccurate or incomplete [and] now patients waste my time with questions."[45] Regardless, the Society maintained the position that it was important to report on controversial matters in a fair and responsible way so that readers could understand the developments that affected them. The Society's position was that informed patients were better equipped to be full partners in their own care and that understanding increased compliance with new treatments.

A conference for people living with HIV/AIDS, held in the fall of 1991, fell very much in line with BCPWA founding Chair Kevin Brown's vision. The purpose of the conference was to identify mechanisms for acknowledging the violation of human rights. Organized, presented, and attended exclusively by PWAs from around the world, the conference made a strong statement in the declaration of rights for people with HIV and AIDS, and reaffirmed their entitlement to intervene, interfere, and step forward in the face of injustice and discrimination. In addition, access to treatment and research was identified as a fundamental human right.

This declaration of human rights for people living with HIV and AIDS at this conference, coupled with the definition of health promotion put forth by the Ottawa Charter, enabled AIDS organizations to continue their battles for equitable access to AIDS treatment and research, and for improved quality of life and health for PWAs.

Emergence of Harm Reduction

In the fall of 2000, the City of Vancouver adopted the *Four-Pillar Approach,* already practiced in some European countries, to address problems of drug use and its underlying causes of poverty, poor health, and social degradation that afflict injection drug users (IDUs) in Vancouver's Downtown Eastside (DTES). The four pillars are: prevention, treatment, enforcement, and harm reduction.

One of the most pressing issues related to drug use has been the transmission of HIV disease through the use of shared needles. Prior to 1993, injection drug users accounted for less than 3% of new HIV infections in Canada. For the first time, in 1993/1994, IDUs outnumbered men who have sex with men (MSM) among those testing newly positive for HIV. And Vancouver's Downtown Eastside, which is the poorest urban neighborhood in Canada, has the highest incidence of HIV among injection drug users in North America.

Since the outbreak of the HIV epidemic, BCPWA Society has promoted harm reduction measures such as safer sex through the use of condoms amongst gay men and incarcerated populations. To reduce HIV transmission among IDUs, the Society supports the philosophy of harm reduction, which treats addictions as a public health issue rather than a criminal justice issue, and advocates for needle exchanges and safe injection facilities to reduce harm through safer drug use.

BCPWA activists were founding members of the Harm Reduction Action Society, which was instrumental in organizing pressure for a legally-sanctioned safe injection site in Vancouver. This became a reality in 2003 with the opening of *in*Site, in Vancouver's Downtown Eastside.

Subsidized Housing

In September 1988, the BCPWA Society and the Vancouver Housing Registry (VHR) identified housing as a critical issue for PWAs. One of the most pressing issues facing people with HIV/AIDS was that of affordable housing. With their income dropping to $658.00 per month in government disability payments, members often found themselves unable to continue living in their original homes, where the rent alone was greater than their monthly income.

In 1989, when it was announced that McLaren House would possibly open up 32 more units of affordable housing for PWAs, the Society received over 100 phone calls from members inquiring about how they could access those units. The need for clean, affordable housing was evidently urgent and critical for many PWAs whose weakened immune system made them susceptible to further health complications.

In response to these critical housing needs, the Society established the PWA Housing Subsidy Program in 1990 to create housing initiatives and stimulate housing proposals. BCPWA, in conjunction with AIDS Vancouver and McLaren Housing Society, also initiated discussions with the Ministries of Health and Social Services and Housing to fund a Housing Needs Assessment. In addition, a partnership with AIDS Vancouver and the YWCA Housing Registry lead to the formation of the Housing Needs Project, which worked towards identifying the housing needs of PWAs and providing more affordable housing. By July 1990, the Society had already participated in several rallies, including going to Vancouver City Council Chambers with the BC Coalition of the Disabled (subsequently re-named the BC Coalition of People with Disabilities (BCCPD)) and other interested groups, to demonstrate the urgent need for clean, comfortable, and affordable housing for PWAs. The Society also took part in a march from Denman Street to Robson Square where a rally was held to voice the concern for adequate and affordable housing.

Finally, in December 1990, the British Columbian Housing Commission, at the request of the Ministry of Health and after long and persistent lobbying on the part of BCPWA, awarded the Society an allocation of 25 portable housing subsidies persons living with HIV/AIDS. And in 1991, the British Columbia Housing Managements Commission, at the request of the Ministry of Health, allocated the Society an additional 19 subsidies. Along with the housing subsidies came the increased need for effective administration of the program. Therefore, in 1994, BCPWA established Wings Housing Society to continue the work of the Vancouver PWA Housing Program and to administer what would eventually grow to 111 subsidies for PWAs funded by British Columbia Housing Management Corporation. Today, BCPWA still maintains representation on the Board of Directors of Wings Housing Society. Evidence of the importance of housing to the Society is found in an existing clause in BCPWA's Constitution that states as one of its purposes: *to operate as a charitable institution (without profit to its members) to acquire, construct, provide, maintain, lease, own, and manage real estate or any interest therein including one or more low-rental housing projects for persons with HIV/AIDS.*

Provincial Campaign to End HIV-Related Stigma

Early in 2006, BCPWA was awarded British Columbia Association of Broadcasters (BCAB) 2006/2007 Humanity Award. This prestigious award facilitated the production of a major anti-discrimination advertising campaign valued commercially at $3 million. BC radio and television broadcasters committed to air two 30-second advertisements for a period of one year. Commencing on July 1st 2006, the campaign showcased two hard-hitting advertisements that highlighted common assumptions and prejudices surrounding persons living with HIV/AIDS and forced viewers to examine their own biases.

The largest advertising agency in Canada, Cossette Communication Group, volunteered to finance the conceptual development and production of the ads while their associates at Steam Films agreed to direct and film the television spots. In addition, Fjord Interactive Marketing and Technology, a division of Cossette, designed and programmed a campaign web site <*www.endHIVstigma.ca*> that provided additional information on discrimination and stigma.

The campaign was a product of collaboration between BCPWA, the BCAB, Cossette, and numerous associated businesses who shared a genuine belief in the cause and a commitment to eradicate stigma associated with HIV/AIDS. The campaign is a major achievement for BCPWA and a significant marker of the Society's 20 year anniversary.

THOUGHTS SPEAK
VOLUMES

It's time to change the way we think about HIV & AIDS

Top Issues

Schedule C Fight

In 1996, BCPWA's Advocacy Department started submitting applications for additional monthly allowances for members to obtain health goods under Schedule C 2(1)(l) (originally Schedule F) of the Employment and Assistance for Persons with Disability Regulation administered by the Ministry of Human Resources. Schedule C 2(1)(l) provided the following benefit:

- ***any other health care good or service not otherwise covered in [other subsections of Schedule C]***
- ***a person is facing a life-threatening health need, and***
- ***no other sources of funding are available to the person.***

The department successfully interpreted this section to require the Ministry to provide people living with HIV additional financial support for quality nutrition, vitamins, complementary therapies, and other health care needs. By 2002, the Society had secured over $6.4 million in Schedule C allowances for people living with HIV/AIDS. In spite of this success, these awards were hard won. Initially losing all Schedule F and C applications in 1996, BCPWA began succeeding after a year of refining legal arguments. In addition, the Society approached the Ministry to request legal reform on the issue of additional monthly health allowances. In the fall of 1998, the Ministry responded to BCPWA's concerns by asking key stakeholders and experts to participate in an advisory group on Schedule C Benefits. In 1999, the group began to meet with the aim of developing recommendations. BCPWA sent three representatives to join an eight month consultation process.

The Emergence of Schedule C

In 1996, the increase in applications under Schedule C occurred in response to the Canadian Pension Plan (CPP) crisis. Prior to the fight for Schedule C benefits, many PWAs relied on CPP disability benefits as well as income assistance (welfare) benefits from the Ministry. However, changes to the legislation in the mid-1990s re-defined the term *income*. CPP disability benefits were defined as "unearned income" and were deducted from income assistance / welfare benefits. Because of this deduction, many PWAs' incomes were dramatically reduced.

To resolve this crisis, the Advocacy Department began using the Schedule C 2(1)(l) to access additional financial assistance every month for members' urgent health needs. The department argued that malnutrition was a constituent factor in the progression of HIV to AIDS. Based on this contention, it was argued that vitamins, nutritional supplements, food and purified water were vital requirements for PWAs and met the legislative criteria of a "life threatening health need." However, the application process for Schedule C allowances was not easy. The Ministry summarily denied every application it received, forcing members to appeal the decision through a lengthy process. Even after years of success at tribunals and subsequent successful appeals to the Appeal Board, the Ministry continued to deny each new application submitted.

The Buddy Program

The Buddy Program, a hugely successful initiative of the Society's Advocacy Department, was initiated in June 2000 as a self-empowerment-based model of advocacy and a way to provide volunteer assistance to members who had been waiting for assistance to access healthcare benefits under Schedule C. In September 2000, the department developed and implemented a comprehensive six-week volunteer training program for Buddy Program volunteers. During that fiscal year the department held two training sessions involving 18 volunteers, most of whom were members of the

Society. In the first seven months of the 2000/2001 fiscal year, the Buddies logged over 1,200 volunteer hours while they were learning and implementing the complex skills required to advocate for Schedule C benefits. A great deal was accomplished through the Buddies' dedication and hard work. They interviewed members, assessed budgets, researched health issues, liaised with health professionals and government workers, prepared legal arguments for tribunal, presented at tribunal, and some Buddies wrote Appeal Board submissions. During the same fiscal year, Advocacy Program staff and/or volunteers attended, with members, 78 tribunals, and wrote 84 Appeal Board submissions.

The Call for Legal Reform – Formation of the Advisory Group

Because of the onerous nature of the application process, very few community groups took on the challenge of Schedule C submissions. The result of this was that, after three years of advocating for an additional monthly allowance for members, BCPWA had almost 500 people on their Schedule C waiting list. Members had to wait, on average, more than two years for an appointment with an advocate, and it took an additional year to complete the entire application process. By 1998, at least 60 people on this list had died while waiting for their applications to be processed.

In the face of these tragedies caused by the Ministry's abuse of the appeal process, BCPWA started lobbying the government for legal reform. In the fall of 1998, the Ministry responded and set up an advisory group consisting of three representatives from BCPWA; three representatives from the BC Centre for Excellence in HIV/AIDS; one community palliative care specialist; one nutritional specialist; Vancouver-Burrard MLA Tim Stevenson and his Constituency Assistant; and four representatives from the Ministry of Health and Ministry of Human Resources.

During the eight month consultation process, BCPWA pushed hard for reform to the onerous process imposed by the Ministry.

The Victory and the Loss

After six years of battle and advocacy efforts by BCPWA, the Ministry instituted a streamlined benefit for food, water, and vitamins for PWAs. In the fall of 2001, new legislation introduced the Monthly Nutritional Supplement Benefit (MNSB) and the Schedule C subsection 2(1)(l) was repealed. While the new benefit provided a quick, simple application process, the repeal of Schedule C 2(1)(l) regrettably revoked access to many other benefits available to the larger disability community. Throughout the advocacy process, BCPWA had strongly argued that any new benefit must not hurt other disability groups. Unfortunately, what the government gave with one hand it took away with the other—to the disadvantage of other people with disabilities. However, the advocacy efforts also positively impacted larger groups because infant formula, a nutritional supplement for children failing to thrive, and condoms were made available province-wide for all recipients on welfare.

Unfortunately, under the newer MNSB legislation, there is no provision that entitles dependant children to MNSB benefits. Whether due to an oversight or an intentional omission, BCPWA advocates have been using Section 69 of the Employment and Assistance for Persons with Disabilities Regulation to secure benefits for HIV-positive children whose parents are on income assistance. To date, all MNSB applications for children have been approved.

Membership Demographics

The Society's mission statement asserts: *The British Columbia Persons With AIDS Society exists to enable persons living with AIDS and HIV disease to empower*

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themselves through mutual support and collective action. From our personal struggles and challenges come our courage and strength. The Society has stood firm in the philosophy and practice of working with all people infected with HIV. Throughout the history of BCPWA, this has required changes in policy and programming as the demographics of those infected have changed and diversified.

In Vancouver, the first patients with HIV were gay men. These few cases quickly turned into an epidemic within the gay community, devastating the lives of those infected and affected by the disease. The Society was created in response to this epidemic and it was gay men that led the organization through its fledgling years. However, over time, increasing rates of infection began to emerge in other populations, including injection drug users (IDUs), women, Aboriginals, prisoners, youth, and the elderly. Diverse populations were impacted by the disease, and BCPWA responded.

As the membership demographic of the Society has changed, BCPWA has endeavored to respond with updates to policy and programming. But with such rapid changes, it has been difficult to ensure that all needs are being met. Wayne Campbell, former Chair of the Board stated, "those that are still doing the majority of the work are the groups first recognized as being affected (gay men). They are still a large percentage of the working Board of Directors."[46] And as Dr. Michael Rekart, Director of STD/AIDS Control at BC Centre for Disease Control, stated: "It's always hard to try and offer help and outreach to people not of the same demographic as yourself."[47] In spite of this, the organization endeavors to fulfill its mission statement, to listen to its membership, to recruit a diverse selection of members to the Board and other volunteer positions, and to advocate for the changing needs of its constituency.

Funding Implications

The Establishment of the Provincial AIDS Secretariat

The establishment of the Provincial AIDS Secretariat in 1992 was a project that required a great deal of commitment from and collaboration with the Society. It brought together many partners of the British Columbia AIDS Network and led to the beginning of a separate HIV/AIDS division within the Ministry of Health. This new HIV/AIDS division did allow frontline agencies to work directly with the Ministry but this did not ensure that provincial funding was equitably distributed.

The decisions of the Provincial AIDS Secretariat affected the way that money was distributed in the province. Because members of the Secretariat were primarily representatives from AIDS service organizations and not PWAs, there was a tendency for money to be distributed not by following the epidemiology but in response to the lobbying of members of the Secretariat. Much of the money was disseminated outside of the Lower Mainland, which meant that funding was not targeted to those people who were most vulnerable to the disease; for instance, the Downtown Eastside of Vancouver was vastly underrepresented. Nonetheless, in 1992, one million dollars was allocated to BCPWA through the AIDS Secretariat, which allowed the organization to expand its infrastructure and services. It wasn't until 1998, and the declaration of a "health emergency," that substantial financial resources were devoted to the fight against HIV/AIDS in Vancouver's Downtown Eastside.

National AIDS Strategy (NAS)

The development of the National AIDS Strategy began with a June 1989 commitment by the Minister of National Health and Welfare, Perrin Beatty, at the Vth International Conference on AIDS in Montreal. At this conference, the Minister recognized community-based and non-governmental organizations as key partners in the efforts to fight and reduce harm caused by HIV/AIDS. During the conference, Don deGagne, a member of the Board of Directors of the Vancouver PWA Society, spoke to the Minister personally about specific PWA issues (i.e., international travel and participation by PWAs on advisory boards). On September 18th 1989, Don deGagne was appointed by the Minister to join the National Advisory Committee on AIDS (NAC—AIDS), a committee that made recommendations to the Minister on activities leading to the implementation of medical care, research and other strategies for the diagnosis, treatment, control, and prevention of AIDS in Canada.

After a year-long consultation process with groups across Canada—community-based groups, health care providers, researchers, provincial governments, municipal governments and others—the Department of National Health and Welfare presented the first formally written official attempt at a comprehensive federal policy on AIDS in June of 1990: *HIV and AIDS: Canada's Blueprint and Building an Effective Partnership: The Federal Government's Commitment to Fighting AIDS*, two documents which formed the basis of the National AIDS Strategy (NAS) in 1990.[48]

Following the release of the first phase of the National AIDS Strategy on June 28th 1990, community AIDS groups and activists expressed little optimism regarding its efficacy. As Don deGagne commented, "If you ask me if I'll still be alive when this strategy is implemented, if this is going to save my life, I'd have to say no. I'd like to see things move faster. Where's the money to plug in programs? We need the resources and they're not there right now."[49]

Missing from the Strategy were certain key elements, including: sexual orientation as prohibited grounds for discrimination in the Canadian Human Rights Act; the elimination of unreasonable travel restrictions for PWAs; AIDS prevention programs for incarcerated populations; and above all, increased funding for community groups to ensure their viability in delivering care and service at required levels.

In recognition of the problems of inadequate funding for community-based AIDS organizations in Canada, the federal government approved the National AIDS Strategy, Phase II (NAS II) in March 1993. To continue the efforts to stop the spread of HIV/AIDS and provide services for those infected, Cabinet approved $203.5 million – $40.7 million each year for five years—beginning in April 1993.

However, the problem of inadequate funding continued to exist, especially in light of the government's declining interest in renewing the Strategy that was due to expire in March 1998. In an attempt to bring this issue of funding back on to the political agenda, BCPWA submitted a petition to Ottawa, urging Prime Minister Chrétien to renew the NAS II. On July 7th 1996, the Society again took a leadership role in leading a community-based protest to draw attention to the actions of former Minister of Health, Dianne Marlow, who had signed a bill that eliminated the option of bringing forward a new National AIDS Strategy. Without a new or renewed NAS, federal funding for AIDS would have dropped from $42 million to $10 million—a 75% cut. The march took place during the 1996 XIth International AIDS Conference in Vancouver and received worldwide media coverage, which contributed significantly to the renewal of the National AIDS Strategy in 1997. On October 17th 1997, the Society developed a briefing paper on the proposed National AIDS Strategy Phase III, re-stating the outstanding issues and demanding total commitment from the government in making the fight against HIV/AIDS a priority. Problems related to access to treatments, the lack of research priorities, and the needs for optimal care for people living with HIV/AIDS were among the outstanding issues identified.

On World AIDS Day, December 1st 1997, after much lobbying and advocacy efforts on the part of BCPWA in collaboration with groups such as the Canadian AIDS Society (CAS), Allan Rock, Minister of Health, introduced the third phase of the National AIDS Strategy. Re-naming it the Canadian HIV/AIDS Strategy, Rock committed $42.2 million per year, restoring the budget to the original level promised during Phase II.[50]

AIDS WALK for LIFE

The British Columbia Persons With AIDS Society was the first organization in Canada to hold a fundraising WALK event for people living with AIDS. This inaugural WALK, held on June 15th 1986, involved a 10km walk around the Stanley Park seawall. Due to the success of the event, which raised $7,900, a tradition began that gradually spread across the country. This annual event has undergone four name changes. The event was originally known simply as the WALK-a-thon; then in 1991 the name was changed to WALK for AIDS. Next, in 1996, the name AIDS WALK was adopted. In 2005, the Society joined the national campaign to rename and re-brand the event the WALK for LIFE. And, finally, in late 2006, the national WALK partners agreed to restore the word AIDS into the branded name: AIDS WALK for LIFE. This event has played a critical role in increasing community awareness while raising much needed funds for direct services for persons living with HIV/AIDS, including BCPWA's Complementary Health Fund (CHF).

In 1992, BCPWA resolved that 20% of net proceeds from the 1992 WALK for AIDS would be distributed among other AIDS organizations for direct services. Organizations that received WALK grants over the years included: AIDS Vancouver, AIDS Vancouver Emergency Assistance Fund, A Loving Spoonful, ASIA, Black AIDS Network, Canadian Hemophilia Society BC Chapter, Downtown Eastside Youth Activities Society (DEYAS), Dr. Peter AIDS Foundation, Dr. Peter Centre, Healing Our Spirit, McLaren Housing Society, PARC Ave. Grocery, Positive Women's Network, Vancouver Meals Society, Vancouver Native Health, Victoria PWA Society, Wings Housing Society, and YouthCO AIDS Society.

By 1996, the AIDS WALK had doubled in size every year and had expanded to be held, that year only, simultaneously in two locations; the Vancouver AIDS WALK took place around Stanley Park and the Fraser Valley AIDS WALK took place at the South Surrey Youth Centre. At this time, numerous volunteers supported the AIDS WALK and pledges accounted for 80% of the funds required by the Complementary Health Fund (CHF).

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In 1998, the Community Partner initiative was introduced to include other AIDS service organizations in the high profile WALK. Community Partner organizations raised funds by using WALK pledge sheets that were coded specifically and uniquely to each participating group. Sixty-five percent of the funds raised by each partner were allocated back to these organizations, to be used for direct services for PWAs. The remaining 35% of the funds raised was allocated to BCPWA to cover expenses associated with the Community Partner Program (i.e., print and promotional materials, administrative resources specifically allocated to the Community Partner Program, data entry of the more than 14,000 event pledges, and mailing costs associated with tax receipting). The Community Partner initiative has been very successful. Particularly in the early years, participating organizations increased both their revenue and their prospective donor base (approximately $69,000 in 2001 versus $46,000 in 2000). In more recent years, however, revenues raised by the partners have been fairly consistent, between $41,000 (2004) and $46,000 (2005).

As a result of the success of Vancouver's AIDS WALK, the Canadian AIDS Society (CAS) took the initiative to implement the AIDS WALK in 120 cities across Canada. Although AIDS WALKs throughout the country continued to have an influence in the greater community, they were generally not bringing in as much revenue as in the earlier years. Melissa Davis, former Director of Fund Development stated, "Special events are generally very difficult to maintain … I believe we are the only major city last year [2000] in Canada that actually increased revenue from the previous year's WALK." [51]

Despite trends throughout the country, the 2003 AIDS WALK broke all records, raising almost $479,000. The following year was also successful, but revenue began to decline over the next few years. BCPWA decided that the best way to secure increased revenue in the future was to join the national WALK for LIFE campaign. In 2005, the Vancouver WALK for LIFE had a new look to reflect the national affiliation. And revenue has gradually increased again, back to higher levels, with over $420,000 raised in 2005 and more than $430,000 in 2006.

The humble start of Vancouver's AIDS WALK-a-thon has set an example for the rest of Canada as a successful fundraising and community awareness tool while helping to improve the quality of life of persons living with HIV and AIDS.

BCPWA Complementary Health Fund (CHF)

The Complementary Health Fund (CHF) has been one of BCPWA's longest running programs. It was created when PWAs realized that existing health coverage, traditionally provided through the provincial healthcare system and private insurance companies, did not meet their essential health needs. Because PWAs were still becoming ill and suffering deteriorating health despite medical coverage and various disability pension plans, the Society devised the CHF in 1992 to provide qualifying members free access to purified drinking water, vitamins, alternative therapies, and other health services not covered by public or private insurance plans. Initially financed through community fundraising efforts, money for the CHF is currently raised through revenue from the AIDS WALK for LIFE. Since the program's inception, the CHF has represented a step forward in removing PWAs total dependence on health care professionals and government agencies as well as movement towards self-empowerment. Over the years, millions of dollars have been provided to PWAs for vital health items and services. As Jackie Haywood, Director of Support Services stated:

> ***The Complementary Health Fund initiative makes a huge difference in people's lives. The important thing is that it's done respectfully, so that people can go out and choose what they want as complementary therapy. They aren't handed a bottle of vitamins; they take charge of their own well-being.*** [52]

BCPWA has faced many challenges in ensuring equitable access to the CHF. One of the ongoing challenges has been the decision as to where to set the ceiling for maximum monthly reimbursement amounts. When the 1998 AGM voted to eliminate the CHF wait list, it was expected that there would be a flood of new applicants more than sufficient to bankrupt the CHF at its then ceiling of $100/month.

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In anticipation of such a response, that ceiling was lowered to $35/month. It eventually became clear that the ceiling was too low, preventing eligible members from taking reasonable advantage of the fund and discouraging potential new applicants. On that understanding, the ceiling was raised to $55/month on January 1st 2000, and was lowered once more to $45/month on May 1st 2002 due to limited available funds. As a result of increasing revenue from recent AIDS WALK for LIFE events, the CHF increased to $55/month in April 2003 and has remained stable at that level since that time. The following is a partial list of eligible expenses reimbursed by the CHF: purified water (no designer labels); vitamins and supplements; body work by pre-approved therapists/practitioners; complementary alternative therapies; over-the-counter medications (i.e., aspirin, Tylenol); counseling by pre-approved practitioners/counselors, and community centre health/fitness memberships.

Position Papers

The British Columbian Persons With AIDS Society is an organization that often takes controversial stands in its fight for the rights and needs of its members. Sometimes this has required that the organization write papers that reflect positions adopted by membership.

The Society's first position paper entitled *Choices: A Position Statement on Euthanasia* was adopted on May 10th 1994, and took a controversial stand on the topic of euthanasia. The importance of the role of the Society was summed up in the first paragraph of the preamble: "The British Columbia Persons With AIDS Society is mandated to empower our members by providing information about all available health care options and advocating for safe access to all health services. Where services do not exist, or are unavailable, the Society works on behalf of its membership to ensure that each individual has real choices."[53] This advocacy role extended to fighting for the rights of its members to die with dignity: "The British Columbia Persons With AIDS Society is mandated to empower our members by respecting each individual's choice regarding euthanasia and advocating for safe access to health services."[54]

BCPWA has taken positions and endorsed those taken by partner organizations in order to ensure the rights, needs, and wants of its members. The Society has clearly expressed their opinions on issues such as: adult guardianship, no fault insurance, *the Freedom of Information and Protection of Privacy Act*, the implementation of comprehensive harm reduction programs in federal prisons, the legalization of medical marijuana; and the 50th anniversary of the *Universal Declaration of Human Rights*.

Some position papers have been written and presented to particular audiences to highlight topics that concern the rights of PWAs. These papers included: *Vocational Rehabilitation and Rehabilitation Services in the Context of HIV infection*, prepared by BCPWA in consultation with Health Canada in 1998; *BCPWA Submission to the Pharmacare Review of the Ministry of Health Services,* submitted in September 2001; *BCPWA Presentation to the Select Standing Committee on Finance*, presented by Jeff Anderson, Treasurer of BCPWA, in October 2001; *BCPWA Presentation to the Select Standing Committee on Health*, presented by Glen Hillson, former Chair of BCPWA, in October 2001; *BCPWA Presentation to the Reference Drug Program Consultation Panel,* presented by Glen Hillson, former Chair of BCPWA, in January 2002; and *BCPWA Presentation to the Select Standing Committee on Justice and Human Rights*, presented by Glen Hillson, former Chair of BCPWA, in February 2002. Position papers from 2003 included: *Strategic Initiatives: Addressing the Epidemic of HIV and Hepatitis Co-infection in British Columbia; Study on Prescription Drugs; Presentation to the Standing Committee on Finance*; and *Dealing* *with AIDS in Canada: The Unmet Challenge*. The most recent position paper adopted by the Society is entitled *HAART as Prevention: A Positive Perspective*, adopted on August 2nd 2006.

These influential papers have situated BCPWA as a respected and progressive partner in the fight against HIV/AIDS. Copies of all of these papers are posted on the Society's web site <*www.bcpwa.org*>.

Research

BCPWA has been an important leader in community-based research on issues impacting the lives of persons with HIV and AIDS. Much of the Society's work on these issues has taken the form of surveys, and many of these surveys have been undertaken in partnership with other organizations. This research has been fundamental to making significant changes in policy and practice throughout the Society. The surveys have also been a very important governance tool, allowing the membership the opportunity to voice their hopes, desires, and concerns for the organization. Because the Society's mission is to enable persons living with AIDS and HIV disease to empower themselves through mutual support and collective action, it is important to have a vehicle through which members can have their voices heard.

Three surveys were undertaken by BCPWA in 1993. The first, *Membership Survey*, was mailed out with the newsletter and received a 20% (around 200 people) response rate; this survey asked members their opinions about controversial issues that were pressing for the Society. One such question related to the issue of accepting money from pharmaceutical companies; the consensus was that the Society could accept money from drug companies as long as there were no strings attached. Members also stated the importance of the Society balancing health information from the medical profession as well as complementary and alternative therapies to create a comprehensive approach to treatment.

The *Care Survey* was distributed by BCPWA and undertaken in partnership with the British Columbia Centre for Excellence in HIV/AIDS. Results were used to help the Society plan and lobby for future HIV/AIDS support, treatment, and care demands for members.

Finally, the *Migration Survey* was conducted, also in partnership with the British Columbia Centre for Excellence in HIV and AIDS. The objective of the survey was to understand how the need for social support, treatment, and care affected where HIV-positive people decided to live. Survey results showed that migration appeared to occur soon after diagnosis and was linked to the dramatic and sudden decline in gross annual income after infection. Ultimately, the study found that migratory patterns significantly impacted health care delivery, especially in large urban centres such as Vancouver and Victoria, and that socioeconomic policy had an impact on the lives of PWAs in British Columbia.

BCPWA, in partnership with the British Columbia Centre for Excellence in HIV/AIDS, undertook another groundbreaking survey in 1995 in response to the proposal to revamp the social security system and in an attempt to influence change. This survey, entitled *Taking Care of Ourselves,* explored quality of life issues for people living with HIV disease and AIDS, and was used to inform decision-makers about the daily realities and challenges faced by persons living with HIV and AIDS. The detailed questionnaire, distributed to the membership of BCPWA, resulted in 583 responses. The survey examined differences in demographics—gender, age, ethnicity, and geographic location—and also looked at the health and quality of life of the respondents. Questions about housing were also included. Results suggested that there was not enough affordable, accessible, acceptable housing in the Lower Mainland for PWAs and that there was a greater need for a continuum of care.[55]

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In 1999, 669 HIV-positive people responded to a province-wide survey entitled *Tell Us Your Side of the Story*. This survey examined from whom, where, and when people access treatment information. The top five sources of treatment information for HIV-positive people across British Columbia were: Doctor, 83.9%; BCPWA NEWS, 63.2%; TIP NEWS, 48%; HIV-positive friends, 47.3%; and BCPWA Treatment Information Project, 46.4%. These results showed that BCPWA was the second most trusted resource to for HIV-related treatment information after doctors. The results of this survey were used both as an advocacy tool in the Schedule C fight and for BCPWA's ongoing fundraising efforts.

Another survey that was influential in shaping the content of *living*⊕ Magazine was entitled *Now It's Your Turn to be the Editor of living⊕ Magazine*, conducted in 2000. This survey was distributed to readers and members; 84% of respondents stated that the magazine had improved their knowledge of treatments. Changes and improvements to the magazine were implemented as a result of this survey, including more original content and a greater focus on rural issues.

In September 2004, BCPWA once again distributed surveys to its members in an effort to ensure that the Society's communications resources (*living*⊕ Magazine and the BCPWA web site) were meeting the needs and expectations of the membership. After evaluating the feedback, the Society learned that 94% of *living*⊕ Magazine readers thought the magazine's articles were easy or very easy to read, and 82% of readers had either significantly or very significantly increased their understanding of HIV/AIDS. As a complement to the bi-monthly magazine, a weekly eNews resource was launched in 2006 to provide members with a greater volume of local, national, and international treatment information and news as well as weekly updates about the Society.

The first Community Based Research (CBR) program for HIV/AIDS is housed at BCPWA. This program exists to assist HIV/AIDS-related community organizations conduct pertinent research, and lends its support in helping ASOs to develop funding proposals and implement research. Between September 2003 and March 2004, this CBR assistance project undertook an *Environmental Scan* to asses the capacity of community-based organizations to engage successfully in community-based research and evaluation initiatives. Community-based research allows PWAs to participate in studies instead of just being subjects; this approach facilitates transparency and accountability.

Pacific AIDS Resource Centre (PARC)

Early in the organization's history, Alex Kowalski had envisioned a one-stop-shop for PWAs. This dream became the foundation for the Pacific AIDS Resource Centre (PARC). PARC was created in 1992 and was a partnership between some of Vancouver's most established and most influential HIV/AIDS organizations. The British Columbia Persons With AIDS Society, AIDS Vancouver, and the Positive Women's Network moved into PARC at 1107 Seymour Street in July 1992.

PARC provided more opportunities for collaboration and cost-sharing between the organizations. Some of the joint ventures fostered by this move included: the PARC Training Project, which provided AIDS sensitivity training to personnel from the Ministry of Social Services; the provision of weekly testing for TB; the development of the Health Promotion Project; and the creation of the PARC Library, providing the most up-to-date and comprehensive materials on HIV/AIDS in a single collection. When established, the library's collection of AIDS-related materials included over 2,500 books, hundreds of journals, newsletters, videos, and audio tapes—an ever growing collection that came to be viewed as an essential resource for PWAs, the public, and the media.

Sharing physical space and resources led the BC Persons With AIDS Society, AIDS Vancouver, and the Positive Women's Network to undertook an extensive capital campaign in 1993 for the purpose of raising funds for PARC. The campaign goal was to raise $3 million for building renovations and create an endowment fund that would cover continuing operating costs of PARC. A benefit concert entitled *Arias for AIDS* was organized with the support the Vancouver Opera Chorus and Orchestra. Although the goal of the capital campaign was not reached, enough funds were raised to make the required renovations to the building, including the installation of an elevator to the second floor.

In 1996, the PARC Diversity Working Group was created in order to ensure that all were welcome in the building. The Working Group consisted of both staff and volunteers who addressed the issue of diversity and representation within PARC and the environment of the PARC building. Part of the vision statement for this Working Group states:

> ***We, the membership, volunteers and staff at PARC endeavour to reflect the diversity of all communities affected by HIV and AIDS. This includes individuals of any age, race, religion and beliefs, culture, ability, economic level, and health status. We are men, women and transgendered. We are different sexual orientations. We value that diversity. We are dedicated to creating respectful supportive environments and expect that all who come to PARC will extend to all those they meet here. Therefore, we at PARC act to promote the inclusion of all.***[56]

As the programs and services of all three organizations continued to grow, it became apparent that physical space at PARC was too limited. This was one reason why, in August of 2000, the Positive Women's Network decided to leave PARC in order to secure substantially larger quarters and a physical setting that was more suitable for the organization's unique needs. A similar situation occurred with AIDS Vancouver, which moved its administrative offices to a different location in July 2002. However, in order to ensure consistency for members of PARC, AIDS Vancouver maintained its client services in the PARC building. Due to these changes, BCPWA centralized its service and office space and, in 2001, signed a 10 year lease agreement for 1107 Seymour Street.

Community Partnerships

To ensure the active promotion of the needs and concerns of persons living with HIV/AIDS, BCPWA made a commitment, early on, to promote partnerships with other HIV/AIDS organizations in Canada and internationally. To this end, the Society has been an active member of the Canadian AIDS Society (CAS); the National Advisory Committee on AIDS (responsible for advising the Federal Minister of Health on HIV/AIDS issues); the Canadian Treatment Action Council (CTAC); and the Steering Committee of the International PWA Network. BCPWA also played an instrumental role in the formation of the National Network of Persons Living with HIV and AIDS.

In 1992, another very important partnership was formed between BCPWA and the British Columbia Centre for Excellence in HIV/AIDS. Since then, BCPWA members have participated on various committees at the Centre to ensure adequate representation from PWAs. The Society has also collaborated with the Centre on numerous community-based research studies

Another organization that BCPWA assisted in establishing was the Pacific AIDS Network (PAN). PAN was formed in 1995 following the collapse of

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the BC AIDS Network. BCPWA, AIDS Vancouver, and AIDS Vancouver Island collaborated on the formation of this umbrella organization. BCPWA played the role of the Society of Record for PAN during its early years, and continues to hold representation on the PAN working group. The Pacific AIDS Network presently has a membership of over 55 community-based AIDS organizations from around the province that collaborate on issues affecting the AIDS community.

In addition to its commitment to work in partnership with other HIV/AIDS organizations, BCPWA has also cultivated relationships with other organizations that share similar mandates. In 1990, a strong working relationship was established with the BC Coalition of People with Disabilities (BCCPD), and in 1993 a joint venture was undertaken between the two organizations to plan a national AIDS and Disability Conference. In 1994, BCPWA appointed a member to represent the Society at the British Columbia Coalition of Persons with Disabilities Board of Directors. BCPWA is also an Affiliate Agency of United Way; an Affiliate Agency meets the same high standards of service delivery and accountability as a Member Agencies but does not receive ongoing funding from United Way. In addition, and in response to the increase in membership from the Aboriginal community, BCPWA joined the Canadian Aboriginal AIDS Network (CAAN) in 1999. BCPWA maintains collaborative relationships and affiliations with numerous other organizations, a reflection of its commitment to work in partnership with others in order to achieve the highest standards of information, care, and support for its increasingly diverse membership.

Staff and volunteers assembling to march in BCPWA float at Gay Pride, 2001.

Board Members

The organization would like to acknowledge the tremendous work of all of the members of the Board of Directors over the past 20 years. Without their dedication and vision we would not have become the organization we are today. We list all past and present Directors here in commemoration and gratitude for their tremendous accomplishments.

Jeff Anderson

Michel Arsenault

Joshua Austin

Christopher Barnes

Denise Price Becker

Pierre Beligond

Derek Bell

Robin Bernard

Claudia Brabazon

Ken Buchanan

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John Goedhart

Nicholas Gray

Bert Hanson

Jim Harron

Al Hawkins

Bruce Hayre

James Hebb

Glen Hillson

Bernd Hoops

Stuart Hossack

Fausto Iocchelli

Gary Jackson

Darren James

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Keith Jewers

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Alan Kennard

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Janet Wilson
William Woodfine
April Vallee

Notes

[1] *An External Evaluation of The Vancouver Persons With AIDS Society,* p.21

[2] Ibid.

[3] Ibid.,p.22

[4] Ibid.,p.23

[5] *Persons With AIDS Working Together: Kevin Brown and the Vancouver Persons with AIDS Society.* Video. Shane Lunny Productions Inc., 1989.

[6] Interview with Jackie Haywood by Rana Hakami. July 18, 2001.

[7] Interview with Don deGagne by David Lewis. *Global AIDS News*. January 15, 1993.

[8] Letter from Don deGagne to The Hon. Perrin Beatty, Minister of Health and Welfare. May 15, 1990.

[9] "Working Together: Towards a National AIDS Strategy in Canada." Submitted by The Canadian AIDS Society, September 19, 1989. p. 22.

[10] Dixon, John. *Catastrophic Rights: Experimental Drugs and AIDS*. New Star Books Ltd.: Vancouver, Canada, 1990. p. 16.

[11] "Knowledge: Our Best Hope for Control of Our Lives". *Vancouver PWA Newsletter*. Issue 44. Jan-Feb 1991. p. 1.

[12] "About Us". Victoria Persons with AIDS Society. <www.vpwas.com/thesociety.html>

[13] *Ottawa Charter for Health Promotion.* Presented at First International Conference on Health Promotion, Ottawa, 21 November 1986. Prepared by The World Health Organization. <www.who.int/healthpromotion/conferences/previous/ottawa/en/>

[14] Ibid.

[15] BC Centre for Excellence in HIV/AIDS. *Annual Report*, 1992–1993.

[16] "The Denver Principles". *Vancouver PWA Newsletter*. Issue 63. January 1993. Pp. 1.

[17] Minutes of Meeting of the Judicial Committee of the Privy Council. Government of Canada. P.C. 1993–1879. October 4, 1993.

[18] "Terms of Reference: Neighbourhood Advisory Committee." St. Paul's Hospital. 1994.

[19] Cernetig, Miro. "Budget Rebellion Hits AIDS Conference." *Globe and Mail*. Tuesday, June 14, 1994. P. A2.

[20] *Choice: A Position Paper on Euthanasia*. Prepared by the British Columbia Persons With AIDS Society. Adopted May 10, 1994. Preamble.

[21] Ibid.

[22] *Canadian Human Rights Commission Policy on HIV/AIDS*. Prepared by Canadian Human Rights Commission. <www.chrc-ccdp.ca/legislation_policies/aids-en.asp>

[23] Shilder, Arn. "The Social Security Debate: Part II". *BCPWA NEWS*. Issue 82. February/March 1995.

[24] Brabazon, Claudia. "The Housing Needs of People Living with HIV/AIDS in British Columbia: A Community-Based Assessment." Wings Housing Society. January 1996.

[25] *Toward 2000: BCPWA Strategic Plan, 1995 – 2000.*

[26] "The PARC Diversity Working Group." *BCPWA NEWS*. Issue 90. June 1996.

[27] "Election '96." *BCPWA NEWS*. Issue 90. June 1996.

[28] McIlroy, Anne. "Ottawa attacked for complacency on AIDS." *Globe and Mail*. July 6, 1996. P. A1.

[29] "History." From Canadian Treatment Action Council web site. <http://www.ctac.ca/english/history.html.>

Notes

[30] Letter from Patricia Rowe, Manager, HIV/AIDS Relations, GlaxoWellcome to Kathryn Eggert, Executive Director BCPWA. Re: Community Treatment Advocates Council (CTAC). July 19, 1996.

[31] Beaulne, Pierre. "Is the Cocktail Party Over?" *Xtra! West*. No. 114. December 25, 1997.

[32] "Supreme Court Ruling Will Harm HIV Prevention." Prepared by Canadian AIDS Society. Sept. 3, 1998. <www.cdnaids.ca/__85256BC300750E3D.nsf/(search)/95722BEF3D5AD2AD85256BC800633202?opendocument&highlight=cuerrier.>

[33] Kendall, Tamil. *Optimal Environments for Integrated Care: Complementary and Alternative Medicine in HIV Management in British Columbia*. BCPWA Society, 2001.

[34] Ibid, p. vi.

[35] Lewand, Paul. "25 Years of AIDS in BC Marked With Hard-Hitting Provincial Ad Campaign." Media Release. 29 June 2006.

[36] Hillson, Glen. "Taking Stock: A Year in Review". *living* ⊕. Issue 9. Nov/Dec 2000. Pp. 4.

[37] Interview with Jackie Haywood by Rana Hakami. July 18, 2001.

[38] Interview with Paula Braitstein by Rana Hakami. July 18, 2001.

[39] Interview with Michael Linhart by Rana Hakami. July 12, 2001.

[40] "A Personal Reaction from Nicholas Gray." *PWA Newsletter*. Issue 11. P. 4.

[41] "History." From Canadian Treatment Action Council web site. <www.ctac.ca/english/history.html.>

[42] *Persons with AIDS Working Together: Kevin Brown and the Vancouver PWA Society*. Video. Shane Lunny Productions Inc., 1989.

[43] *Ottawa Charter for Health Promotion*. Presented at First International Conference on Health Promotion, Ottawa, November 21, 1986. Prepared by The World Health Organization. <www.who.int/hpr/archive/docs/ottawa.html>

[44] Ibid.

[45] "Knowledge: Our Best Hope for Control of Our Lives". *Vancouver PWA Newsletter*. Issue 44. Jan–Feb 1991. P. 1.

[46] Interview with Wayne Campbell by Rana Hakami. July 19, 2001.

[47] Interview with Dr. Michael Rekart by Rana Hakami. August 2, 2001.

[48] Palmer, Don E. "HIV/AIDS for BC and Canada: Everyone's Concern". The University of British Columbia: Vancouver. 1992.

[49] Starrat, Douglas. *PWA Newsletter*. Issue 39. P. 11.

[50] "Advocacy Alert". Canadian AIDS Society (CAS). December 19, 1997.

[51] Interview with Melissa Davis by Rana Hakami. July 31, 2001.

[52] Interview with Jackie Haywood, conducted by Rana Hakami on July 18, 2001.

[53] *Choice: A Position Paper on Euthanasia*. Prepared by The British Columbia Persons With AIDS Society. Adopted May 10, 1994.

[54] Ibid.

[55] Brabazon, Claudia. "The Housing Needs of People Living with HIV/AIDS in British Columbia: A Community-Based Assessment". Wings Housing Society. January 1996.

[56] "The PARC Diversity Working Group." *BCPWA News*. Issue90. June1996.