



British Columbia Persons With AIDS Society

“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.”

BCPWA Mission Statement

Annual Report 1998/99

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This past year the British Columbia Persons With AIDS Society provided leadership on issues impacting those of us living with HIV disease and AIDS.

Our membership continues to grow and change as this epidemic impacts new communities, cultures and populations. We now have a membership of over 4000 individuals from every conceivable community, culture, background and age.

Our Society's mission is to empower people through mutual support and collective action. This year, our collective advocacy efforts contributed significantly to improving access to new AIDS drugs and keeping their prices under control. We were successful in securing a Provincial AIDS Strategy that is flexible, dynamic and accountable to the AIDS community.

All our departments provided vital support, through the extraordinary dedication and commitment of our 125 regular volunteers and 12 paid staff. For example, there were 18,750 visits to our members lounge this past year; 748 more members received assistance from our advocates on a range of financial and legal issues; and nearly 1000 members were provided with individual counselling sessions about treatments, therapies and health issues relating to HIV disease. Our flagship publications, BCPWA News and TIP News, were re-designed to make them easier to read and more dynamic. And our web-site received a whopping 150,000 "hits" last year.

We eliminated the waiting list for the Complementary Health Fund, providing over a quarter million dollars for health related services and goods not covered by the government to our members.

The future of BCPWA holds more promise than ever before. Our collective efforts are producing results for a growing, changing membership. We deliver quality programs that are securing and providing real benefits to our membership. And we remain Western Canada's largest AIDS organization — a model of how those of us living with HIV can improve society and each others' lives.

The Support Services Department has historically been the largest and most diverse member of the BCPWA family of departments. It contains the Society's longest running program (the Wednesday Night Support Group), one of its newest (Theatre Positive), and it's largest-cost program -- the Complementary Health Fund.

As membership in BCPWA continued to grow and evolve in 1998/99, the activities of the Support Services Department underwent similar growth and diversification.

The BCPWA Lounge

The BCPWA Lounge hosts a wide range of support programs, drop-in days, peer-run groups, and evening meetings of external community organizations. Last year, there were over 18,750 member visits to the lounge — making it one of the most utilized resources in the Pacific AIDS Resource Centre.

Complementary Health Fund (CHF)

The CHF provides financial reimbursements to HIV+ members of BCPWA for alternative health goods and services not covered by government or private insurance programs. Last year, this vital program paid over a quarter million dollars to a total of 2011 members for holistic health care goods and services used to maintain their health.

Complimentary Tickets

Every year, the arts community donates tickets to movies, theatre performances, concerts and other events for BCPWA members who could not attend otherwise. In 1998/99, the estimated retail value of tickets donated was \$16,920.

Polli & Esther's Closet

This popular program provides free donated clothing and small household appliances to BCPWA members in need. With over 2300 member visits to this program last year, we set up new guidelines to make sure all members were served with greater equity.

Hairdressing

Just off the BCPWA lounge is a popular hairdressing program that provides free hair cuts to full BCPWA members. Professional hairdressers completed over 650 haircuts donating 329 hours of volunteer time!

Peer/Support Counselling

Nearly 500 individuals received peer counselling through our Peer Support Program last year. Counselors with street experience increased both the comfort level of members and effectiveness of our referrals. A four-day, professionally facilitated training seminar was held for our volunteers and a Downtown Eastside (DTES) AIDS organization to train an equal number of volunteers for both organizations.

Support Services Department

Boys R Us

As part of our efforts to support male youth involved in sex trade work, BCPWA participated in the establishment of a weekly Boys R Us gathering. Last year 35 youth attended the weekly meetings held during the evenings in the South Granville area. This initiative is being done in partnership with several other agencies

Wednesday Night Support Group

This peer facilitated drop-in support group operates in the evening in the BCPWA Lounge with potluck socials held quarterly. Last year on average, 15 members attended weekly meetings.

Neutron Lounge

To help build community and break down barriers, BCPWA participates in Neutron events to bring HIV+ and HIV- gay men together in social environments. Neutron social events were organized last year in partnership with AIDS Vancouver, YouthCo and ASIA.

Christmas Celebrations

The holiday season can be a very difficult time for PWAs who do not have a network of families and friends to be with during Christmas. Last year, BCPWA enhanced this season for our members by decorating our Lounge, providing a traditional sit-down dinner for 350 members, and organizing *Yuletown*, an event held in the Lounge that attracted 200+ people over two days. *Yuletown* was organized in partnership with AIDS Vancouver, Healing Our Spirit and the Dr. Peter Centre AIDS Foundation.

Theatre Positive

Theatre Positive presents peer created and produced innovative theatre performances about living with HIV disease. Last year, over 725 people attended performances of the theatre group at various venues including five performances at the Vancouver Fringe Festival. A writer's workshop, guided by Artistic Director Jake Thomas with visiting professionals from the Vancouver theatre community was well attended.

Retreats

Retreats are an opportunity for our members to escape from the stresses of everyday life and develop friendships and learn new skills. Two retreats were organized last year by a team of volunteers who gave over 320 hours of their time to make them a success. Seventy-five members attended 3 and 4 day retreats and benefited from the support and knowledge shared.

Income Tax Preparation

Hate to do your income tax? Who doesn't! Last year, 77 members accessed the BCPWA Income Tax preparation program, staffed by volunteers with expertise in this area.

SCHEDULE C

Schedule C Health Benefits

The Advocacy Department has had a successful year securing health care goods, food, vitamins, water and nutrients for individual members under Schedule C of the BC Benefits Program. Our Advocates won all 122 Schedule C tribunals for our members that we undertook last year. Furthermore, 100% of appeals to the Appeal Board by the Ministry were defeated by our advocates—which we estimate resulted in \$586,600 dollars of Schedule C benefits provided to these 122 members last year.

In December, the Advocacy Department and the Ministry of Human Resources began discussions aimed at decreasing the number of cases sent to the Appeal Board. Presently, while most Tribunal decisions are appealed by the Ministry, towards the end of the year we saw more cases settled before appeal hearings, allowing the Ministry to withdraw their appeal and our members to receive benefits.

The Advocacy Department has initiated, in partnership with the Ministry of Human Resources, an Advisory Committee to find solutions to Schedule C delays. The department continues to have a long waiting list for members (over 1-1 ½ years) to access the Schedule C application process.

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The Advocacy program opened 748 new files during the 1998/99 fiscal year.

Advocacy services provided to members included:

- BC Disability Benefits applications and appeals
- Schedule C applications and appeals
- Canada Pension Plan Disability applications and appeals
- Disability Trusts, Debt forgiveness
- Employment Insurance Appeals
- Residential Tenancy issues
- Human Rights Complaints
- Wills, Power of Attorney and Health Care Directives

Advocacy for the Community

Positive Change, a 120 page legal information manual, was produced by Advocacy with the assistance of the Communications department and supported by funding from the Law Foundation of BC. Additionally, several two-day advocacy training workshops were conducted for agencies in the BC interior and the Lower Mainland to enhance their knowledge of advocacy issues.

Student Legal Clinic

Our Advocacy Department, in partnership with the UBC Law Students Legal Assistance Program, expanded our evening legal clinic run by 5 law students over the winter. These students provided legal advice to members of the Society one evening every two weeks.

Prison Outreach Program (POP)

Our POP program was run by volunteers who provide telephone counseling and other direct services to prisoners in BC institutions. Last year, POP maintained a telephone service (604-527-8605) that received over 650 calls from inmates seeking support and information. Program volunteers made regular visits to Vancouver Pre-Trail, the BC Correctional Centre for Women, hospitals, and parole hearings. Additionally, our volunteers attended information fairs, or made general prison visits at Ferndale Institution, Mission Institution, Matsqui Institution, and Kent Institution.

The 1998/99 fiscal year was one of further development for BCPWA's Human Resources Department. In addition to advancing major new initiatives including a vocational rehabilitation program, volunteers and staff in Human Resources continued to meet the expanding needs of a growing BCPWA.

The Membership Registry

This program maintains the Society's membership database, identification and information packages, and statistics. In the 1998/99 fiscal year the program reported:

- 3,136 voting members, 821 associate members, and 52 group members bringing the active membership to 4009.
- the death of 53 voting members, bringing the total deceased to 1046 since the registry was developed.
- continues development of a new database to enhance data reporting, and
- training of a new volunteer to assist the Membership Registrar.

BCPWA's active membership grew to over 4000 individuals and groups -- we now represent almost one third of all HIV positive people in BC.

Our Human Resources Department experienced a fiscal year of extensive growth in all its programme areas. Recognizing the emerging interest of many of our members, Human Resources obtained board approval to develop a new program in vocational rehabilitation. Volunteers and staff in Human Resources continued to meet the needs of a diverse and expanding BCPWA.

Training, Development & Vocational Rehabilitation

This program coordinates internal and external training of volunteers and, in doing so, considers transitions and directions in HIV to provide appropriate skill development. This programme:

- provided 3 computer training courses for volunteers
- through a \$10,000 grant from the United Way and in co-operation with ASIA, Healing Our Spirit and YouthCO held a Focus Group Study on entry and return to work and training. 70 persons with HIV disease, representing youth, the transgendered, women, Asians and First Nations communities participated. This study provided support for the initiation of a new BCPWA Vocational Rehabilitation Programme
- with Access to Careers and Training (ACT), of George Pearson Centre, offered 3 Career Exploration Courses attended by over 30 Society members

Vocational Rehabilitation

- explored linkages and potential avenues of cooperation with vocational rehabilitation agencies. This has led to establishing partnerships with Alliance Health Care Services and the International Association of Machinists and Aerospace Workers (IAM Cares), and
- was awarded abstract presentations and partial scholarships to present findings on vocational rehabilitation at the BC AIDS and the International AIDS Conferences.

HR Administration

The Administration program operates the information counter, responding to over 90 inquiries per day on subjects as diverse as CHF, membership, volunteering, training, benefits and incentive programmes. As well, it provides front-line support to the volunteer coordination, membership and training and development programs. It coordinates the lunch recog-

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dition program, serving over 50 volunteer lunches per day, verifies the work of 60 incentive program participants per month, and maintains the Society's volunteer participation records.

In 1998/99, Administration:

- advanced the user-friendly database system to maintain volunteer hours and lunch voucher records; and,
- held 2 workshops to revamp administration systems, which lead to the updating of a comprehensive manual on program operations.

Volunteer Coordination

This program recruits, screens, places, orients and follows the progress of volunteers. As well, it coordinates volunteer recognition events and awards, and promotes volunteerism in sectors of the Society's work which require specialized skills. In 1998/99, volunteers and staff:

- placed over 100 volunteers in Society programmes
- obtained the sponsorship of BC Gas Limited to host a major volunteer recognition event attended by 85 volunteers and to create a new "wings pin" award for volunteers who have contributed 3 or more years of service
- recognized over 150 volunteers for their contribution with awards
- participated in the the Non-Profit Roundtable Group, the Provincial Study on volunteering and activities sponsored by Volunteer Vancouver
- obtained 10 university and college practicum students to work in BCPWA departments as part of their academic placements, and
- started the planning of a new volunteer database.

Where do you get your Treatment Information?

669 HIV+ people responded to the province-wide survey entitled Tell us Your Story that was done by Arn Schilder for BCPWA and the BC Centre for Excellence in HIV/AIDS. There are overlaps in various categories because people get their treatment information from more than one source. In some instances the low numbers of respondents make the findings indicative, at best, for particular geographical areas. However, the overall survey results are statistically significant, and there is a slightly higher representation of rural respondents compared to the current geographical distribution of HIV+ people in BC.

The top 5 sources of treatment information for HIV+ people all across BC

- My Doctor (83.9%)
- BCPWA Newsletter (63.2%)
- TIP Newsletter (48%)
- HIV-positive friends (47.3%)
- BCPWA Treatment Information Project (46.4%)

The top 5 areas in BC where HIV+ people use the Internet to get treatment information

- West Kootenay-Boundary (57%)
- North Shore (44%)
- South Okanagan (27%)
- Upper Island/Central Coast (22%)
- Vancouver (21%)

The 5 regions where doctors scored the lowest as a source of treatment information

- West Kootenay-Boundary (43%)
- Coast Garibaldi (50%)
- Capital (Victoria) (56%)
- Richmond (67%)
- North Interior (75%)

In addition to undertaking a range of education campaigns, last year the Treatment Information Department provided 994 people with individual treatment information consultations. These were provided by a team of twenty active volunteers and one paid staff.

What is the HIV status of people seeking treatment information from BCPWA?

- HIV+: 69%
- HIV-: 16%
- Newly Diagnosed: 3%
- Health Care Professional or Caregiver: 9%
- From within PARC: 9%

Who were they demographically?

- Men: 57%
- Women: 24%
- Transgender: < 1%
- Caucasian: 55%
- First Nations: 5%
- Other ethnicities or unknown/undeclared: 6%

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Community Outreach

Vancouver Native Health Society: every Thursday drop-ins (total of 49 sessions), with an average of 10 people living with HIV talking to a treatment information counsellor

Carnegie Community Centre

Monthly information tables on the street or inside the centre (total of 10 sessions). An average of 100 people living with HIV, hepatitis C, or both, dropping by to discuss their issues, and obtain literature or other information.

Treatment ABC's Workshops

Old Library (Maple Ridge), Douglas College (New Westminister), Tri-Cities Health Care Forum (Coquitlam), Vancouver Police and Native Liaison (3 times), Renaissance Men's Recovery Home (Surrey) (2 times), Renaissance Women's Recovery Home (Surrey) (2 times), Dr. Peter Centre (2 times), DERA Street Fair, High Risk Society

BCPWA Lounge

Weekly sessions on various topics (eg. Hepatitis C, nutrition, antiretrovirals, shiatsu, etc.); total of 40 sessions

Community Forums (general)

"Are HIV Drugs For Me?" - Downtown Eastside, 100 HIV+ attended
 "HIV Drugs - What's Happening to Me?" - West End, 150 HIV+ attended
 "Antiretroviral Update" - Martin Delaney - West End, 80 HIV+ attended
 "Food and Supplements for HIV/AIDS" - Dr. Chester Myers, 75 people
 "Managing Side Effects - Conventional and Complementary Approaches" - with Dr. Joss Dewet, Glen Hillson, and Alan Sawkins, 50 people

Community Forums (Post-conference updates)

Canadian Association for HIV Research,
 Geneva International AIDS Conference (West End and Downtown Eastside),
 6th Conference on Retroviruses and Opportunistic Infections (West End and Downtown Eastside),

BC AIDS Conference

(November 1998): TIP had five presentations (Vipassana Meditation, Bridging the Gap Between East and West, Managing Side Effects, Treatment Information for People with Low Literacy Levels, Complementary Therapies), and moderated 2 sessions (antiretrovirals, and complementary therapies). Two members of the team were on the planning committee of the 1998 conference.

Treatment Information Department

Age?

- Less than 18 years old: < 1%
- 18- 30 years old: 22%
- 30 - 45 yrs old: 44%
- Over 45 years old: 19%

Where were they asking from?

- West End: 24%
- Downtown Eastside: 14%
- Other Vancouver: 17%
- Lower Mainland: 6%
- Other British Columbia: 5%
- Canada: 2%
- International: 3%

How did they reach us?

- Walk-in: 48%
- Telephone: 38%
- Email and Fax: 3%

What did they ask about?

- Conventional Therapies: 14%
- Antiretrovirals: 35%
- Complementary/Alternative Therapies: 20%
- Blood Work: 17%
- Opportunistic Infections: 12%
- Referrals to doctors: 7%
- Complaints about doctors: 2%
- Other questions: 21%
- Documents provided: 50%

Training for Treatment Information Counsellors

- Immune reconstitution with Dr. Chris Tsoukas
- Neurological Complications of HIV with Dr. David Simpson
- 2 day Treatment Information Counselling Training, with guests Dr. Julio Montaner, Dr. Brian Conway, and Ms. Diana Peabody

Advocacy Issues

- access to treatment and care in the Downtown Eastside (collaborating with the BC Centre for Excellence in HIV/AIDS and lobbying the College of Family Physicians to take action), organized a community forum on the topic to bring together doctors and advocates
- HIV/AIDS Legal Network Meeting on ethical issues related to injection drug use, including providing antiretrovirals, information about street drugs, and access to clinical trials
- Health Protection Branch reform
- Drug pricing in Canada - keeping them affordable!

Research

- Collaborated on a proposal with doctors in Vancouver and the Canadian HIV Trials Network to study the effects of troglitazone on lipodystrophy
- Collaborated with investigators across Canada to develop a protocol on "Salvage Therapy"
- Side Effects research conducted and subsequently presented at 1998 Glasgow HIV and its Therapies
- Submitted proposal to National Health Research and Development Program (NHRDP) to address issues related to injection drug users in research entitled "HIV/AIDS Research for Injection Drug Users: Breaking Through the Barriers". Funding pending as of July 30, 1999.
- Participated in community-based research project called "Community Practice: What's Theory got to do with it?"

Committee Involvement

- Therapeutic Guidelines Committee of the BC Centre for Excellence in HIV/AIDS
- Canadian HIV Trials Network, Community Advisory Committee
- BCPWA Collective Advocacy Committee
- BC AIDS Conference Organising Committee
- Vancouver Richmond Health Board, Scientific and Research Committee
- Canadian Treatment Advocates Council

Documentation Dissemination

- TIP News published and distributed six issues, 20 pages each, with a distribution of 2500 - 3000. The publication has retained its national and international reputation. In the PARC Library, TIP maintained 32 slots on the information racks, and circulated documents as needed. Between April 1, 1998, and March 31, 1999, approximately 2600 documents were distributed in this way (note: this excludes handed out during consultations which are kept in the vertical files).

Communications & Education Department

S U M M A R Y

Our Communications & Education Department supports the efforts of communications initiatives throughout all levels BCPWA. We communicate information that empowers people living with HIV disease to take charge of their lives and health.

By supporting the efforts of the Board of Directors and other departments, we promote the Society's mission, programmes, special events and collective advocacy initiatives. Last year, the Society raised awareness and understanding about HIV disease to new levels in the media, through our respected bi-monthly publications and popular website.

B C P W A N E W S

- Last year, BCPWA News was completely re-designed to make the publication more visually dynamic and easier to read.
- All issues were published in print and on our website.
- Guiding the development of BCPWA News is an experienced Editorial Committee drawn from the HIV+ membership of the Society. Supporting the work of the Committee is a dedicated team of volunteers and contractors who manage all aspects of production from data entry to design and printing.
- Six issues of our flagship publication were produced last year with 5000 copies distributed bi-monthly, mainly across British Columbia, but also to HIV+ people and AIDS organizations in 62 countries world-wide.

P O S I T I V E L Y H A P P E N I N G

- A major resource of information for people with HIV disease was published with each issue of BCPWA News in the past year.
- Positively Happening provided a complete and comprehensive listing of groups, societies, programs and institutions in British Columbia serving people touched by HIV disease and AIDS. It was utilized widely by professionals, front-line workers and persons living with HIV disease.
- It was also published on the BCPWA Website electronically providing greater access to resources for people living in isolated communities.

B C P W A W E B S I T E

- BCPWA's website exceeded our expectations in its second full year of operation.
- The site provided access to information about our Society, current events, included all the major publications we produced, and contained links to over 100 AIDS Websites around the world.
- We set an ambitious goal to accumulate 100,000 hits last year (double the hits in the previous year). And by year end, we had met and beat our goal with 150,191 hits on the site and an average of 1569 individual user sessions each month -- up from 519/month the previous year.

L O O K I N G F O R W A R D

- As we moved toward the next year, the Communications and Education Department began undertaking the merger of BCPWA News and TIP News into Living +.
- Projects in development include the creation of four television PSAs to raise awareness of HIV disease and AIDS. And our website will continue to expand the wealth of information available with the goal of getting 200,000 hits on the site next year.

Fund Development

S U M M A R Y

Department

- The 1998/99 fiscal year was a year of growth and reaching out into the community for fund development at BCPWA. The mission and goals of BCPWA are the driving forces behind all of our fund raising efforts.
- We continue to strengthen our relationships with other AIDS organizations, community groups companies and individuals. This year our supporters donated more than \$360,000 dollars. This does not include the tens of thousands of dollars of in-kind support or our invaluable volunteers.

Building for the Future

- 1998 marked a year of growth for the Fund Development department. In an effort to provide a more effective, efficient and professional service we created two new positions (an Events Coordinator and a Program Assistant), invested in new database technologies and continued to lead the fund development process within the organization.

AIDS Walk '98

- The AIDS Walk is the premier AIDS awareness and fund raising event in Canada. The Vancouver AIDS Walk is the longest running Walk in the country and the largest in Western Canada with more than 6,000 in attendance in 1998. Proceeds from the Walk benefit the Complementary Health Fund at BCPWA. We are proud to report that through a new initiative to encourage more community involvement eleven other AIDS organization also benefited from AIDS Walk proceeds. This was a record breaking year. A winning combination of increased fund raising efforts and stringent cost controls led us to the highest net proceeds ever.

Care To Dance

- Care to Dance is a new fund raising event produced in partnership with the Shooting Stars Foundation. Care to Dance is a five hour dance party to have FUN and raise money and awareness for people with HIV/ AIDS. Local and international DJ's lent their talent to help create a memorable and cost effective event. The dance was a success and built the foundation for future dance parties.

Bequests and In Memorium Donations

- Loved ones who have passed away are remembered and honoured through contributions made by friends and family.
- Bequests are received from individuals who chose to leave a legacy and ensure that other's may benefit from BCPWA Services.

Community Fund Raising Events

- There are many community fund raising initiatives that support BCPWA. This year there were some outstanding contributions that deserve our most sincere thanks. A warm "thank you" to: Theatre Cares and the Shooting Stars Foundation to mention but two.

Corporate Support

There are some corporations that are leaders in philanthropic support for the community. Over the past year many companies have assisted BCPWA. A very special thank you to:

Abbott Laboratories	Agouron Pharmaceuticals
Aldo Shoes	BC Tel Mobility
Bristol-Meyer Squibb	Canadian Airlines
Capers	CKNW
Dupont Pharma	Durex Condoms
Hoffman-LaRoche	Loung Hair Studio and Spa
Merck Frosst	Milestones Restaurant
Molson	Pfizer, Roots
Starbucks Coffee	The Georgia Straight, Vancouver Sun & VTV
WestEnder & XtraWest	Z95.3
GlaxoWellcome	in partnership with BioChem Pharma