



Presentation to the Select Standing Committee on Finance and Government Services

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Members of the Government, members of the Committee, Invited Guests, Ladies and gentlemen of the public, thank you for the opportunity to contribute to the work of this Committee on this matter of fiscal urgency presently before the Government of British Columbia.

In shaping your budget and budget priorities for the coming years you have a challenging and daunting task. I would not presume to advise you about the details nor direction of your efforts. If I am effective here today, you will understand more clearly, the huge human and financial benefits - delivered year upon year by the consumer-based health movement. More exactly, my task is to explain, as I can, the way the BC Persons with AIDS Society saves health care dollars, improves the condition of its members, and empowers us to return to work and perform the important work of developing public policy and improving treatment effectiveness. I will endeavor to explain how our critical mass of efforts has created a peer-driven Society which performs a critical role in peoples lives as information centre, as healing centre, as brother and sister, and neighbour and friend - our Community. We have developed the voice of experience through thousands of HIV+ British Columbians who thereby collectively share that knowledge with our province's Doctors and Health Providers, with Regional Health Authorities and Health Canada. From Research to education to care treatment and support of Persons with AIDS, from outreach to counseling, the experiences of those thousands of British Columbians create a community where peers come to learn, to serve, and to contribute to improved health for all British Columbians.

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. Since 1985, this has been our mission. As any of you who have worked with us will know, we do so with dedication, zeal, and courage. Our successes over the past 16 years have brought a shift in the burden of health care delivery so that persons with AIDS now play a sizable role in patient education, treatment research and volunteer participation in treatment counseling, ethics bodies, in addition to our substantial contributions to national, local and provincial policy and health care delivery itself.

Since your task is to assess prudent public investments, as Treasurer of BCPWA, I will turn to the matters of financial consequence which bring us here, today.

During the past fiscal year the provincial government spent 10.4\$M. on community AIDS Organizations. 90.3% of this money went to AIDS

Service Organizations -formed to do a particular job - mostly AIDS Information, Prevention and support programs. The other 10% of your AIDS Community dollars went to support the 2 grass roots consumer PWA groups in BC, - BCPWA, and Victoria PWA. What have Persons With AIDS done with their 10% of the community money?

I have brought modest folders of our work for each of you members of the Committee and will distribute them shortly.

These contain

Summary Sheet
Annual Report,
A copy of my remarks, here, and

The Living+ Magazine . It is unique in its scope and thoroughness. The Canadian AIDS Treatment Information Exchange calls it, "an excellent resource," and Dr. Michael O'Shaughnessy, the chief of the BC Centre for Excellence in HIV/AIDS states, " As treatment of HIV disease becomes more complex, the need for HIV positive persons' perspectives is absolutely necessary. Living+ is an invaluable resource and a source of practical information". It is one of a kind – in BC, in Canada, perhaps anywhere. It is produced with countless volunteer hours, contributions from experts across the country, and with financial support, in part, from you, the Government of BC. This came from a partnership that started between our provincial government and us. It goes to every AIDS Doctors and every one of our 3,600 members across the province who provide us with an address, and sadly, for the moment, not much further. Your confidence and support have allowed us to secure matching funds from other sources to bring us to 3500 copies - and we are presently engaged in negotiations with a corporate sponsor who wants to distribute Living + across the country. We can all be proud of the depth of its reporting and the scope of its success. It helps keep people with HIV healthy through accurate and current treatment information. It keeps AIDS doctors up on current research and the issues of their patients, and it keeps our provincial community united through a shared experience of stories and articles from around the province and across the country. Our communications department creates two electronic forums to compliment our print materials. First the Website, which will be unveiled in 2 weeks – just prior to our AGM, and also, the BC AIDS News, the only AIDS news service by and for British Columbians concerned with AIDS. Your support of these communications programs accounts for about a fifth of your financial support to BCPWA this fiscal year.

Our Treatment Information Program also receives about fifth of your support - it has been matched nearly dollar for dollar by corporate and Health Canada contributions. The pharmaceutical industry

recognizes the achievements and excellence in the programs designed and delivered by persons With AIDS. Though we do not hesitate to bite the hand that medicates us - if we feel circumstances warrant it, mostly, we benefit from an arms-length yet co-beneficial and co-supportive relationship with the pharmaceutical industry. A recent independent audit of AIDS Treatment programs across Canada had the highest praise for the mostly volunteer BCPWA TIP program. This success has inspired spin off partnership programs - from the Health Canada partnership in our Complimentary Therapies Project, to our joint efforts with private industry and the BC Centre for Excellence in HIV/AIDS to operate "*ABCs on the Road*" - an "AIDS Primer" with Doctor and nurse and treatment counsellor with AIDS - touring 26 towns and cities in BC. Without contributions from the public, the corporate, and the health care sector, this landmark program would not be saving lives.

The Third 20 % slice of Provincial money goes to various support programs and we are proud to provide peer counselling, 3 healing retreats each year, and *Poly and Esther's Free Clothing Store*, along with a dozen other programs to alleviate poverty and lessen the personal difficulties of this illness.

Only one tenth of your support is dedicated to Our Advocacy Department which helps people with HIV and AIDS when they are most in crisis. When they don't know their rights, can't figure out a government procedure, or require help with their will our team of professional-led volunteers help our members secure their rights and eligibility for financial support in numerous settings - where the issues are technical and legally complex. With the recent completion of the ACTION KITS, persons with HIV/AIDS learn how to tackle the top ten challenges we face in advocating for our own health, legal, and financial security. These KITS were developed through a grant from the Law Foundation with technical support provided by the province of BC. In financial terms, this Department secured \$1.6 Million Dollars in health, emergency and insurance benefits for our members – this year alone. The Ministry of Health assists with about half of the operational funding for this program. The return on investment of nearly 700% reflects a prudent investment for our members – and a respectable return for your provincial support.

the Last 30% of your support allows us to unite as a membership, to administrate our efforts and supply a modest computer and office system for our Society to do its business. Our operations funding allows us to concentrate considerable efforts on additional fundraising. So successful were we that 45% of our gross revenues last year came from sources other than governments. Please come see us in action. Our door is always open to you, and we will be proud to show off our modest

assortment of handy me down tables and donated chairs - I'm afraid ours are more Spartan than even most government offices.

As you can see, we strongly believe in the need to build synergies as much between government and private sector, as between doctor and patient. Community will not materialize from thin air, however. It requires those private, public, and voluntary sector synergies. We match every paid staff hour at BCPWA with a volunteer hour, and we match every Provincial Dollar with a Dollar Seventeen from private, public and corporate support. There is not another AIDS organization in the country, much less the province that can site such dedication of purpose or prudent fiscal management.

Is our job, then done? I am afraid it is not. There are 3 rising challenges for our next 3 budget years - yours and ours.

ONE - AIDS PREVENTION - Infections are rising again, and nowhere, yet, in government plans are persons with AIDS targeted as participants in the prevention of the spread of AIDS. It sounds shocking to say it, but it's a terrible oversight on everyone's part. It will take this government sharing resources dedicated to prevention with Persons With AIDS and the groups that represent them. We are the only community that can spread AIDS and we are the logical community to prevent it. Help us with that work.

TWO ACCESS to Treatment and COMMUNITY BASED RESEARCH - Recent studies estimate a third or more of those with AIDS in the DTES¹ of Vancouver do not receive the medicines needed to control the virus. Studies show those with HIV are significantly more prone to Hepatitis C infection than those without. Add to a body challenged with AIDS - a liver disease - and death is all too often the result. We must find a way to reach and enable these people to make healthy choices. A healthier person with AID is less likely to succumb to opportunistic infections and less likely to result in hospitalization. We hope you will work with us to try some new approaches to propose crucial positive health habits through combined peer and professional approaches.

Our community is desperate for information on such a quickly changing epidemic. The quicker we can develop strategies that have adjusted to the changing face of the spread of AIDS, the more accurate our campaign to help the right people make healthy choices. The message that works is best developed by and with those infected and delivered by peers. Our membership holds the key to prevention and health behaviour - we need your support for the information technology to do research and respond appropriately to the needs of Treatment and Prevention.

¹ DTES is an acronym for the "DownTown EastSide" neighbourhood in Vancouver.

THREE - A HOME FOR the AIDS Community. The 2 largest AIDS Organizations in the province accounting for 20% of your Community AIDS Dollars will be without a home in less than a year if we are unable to find new quarters. We are under the gun now, and the writing is on the wall and it is a high rent wall in a high rent neighbourhood. After thorough strategic planning and much soul searching the largest, by staff, AIDS Service Organization in the Province, AIDS Vancouver and the only provincial AIDS Consumer Organization, BCPWA each support continuation of the current cohabitation and economies of scale we share through computer, security, and office environments.

To tackle these challenges we will need every support possible from the public sector to partner with our corporate and health care community to develop solutions to these most daunting challenges facing the AIDS community in the next 3 years. To slow the spread of the illness and lessen its affects, we must continue to enjoy your support and the support that your endorsement breeds with private and public funders. We hope you will continue to see BCPWA as partners with you in the frontline battle against AIDS and it devastating effects.

Again, thank you for this opportunity to speak with you today.

/jda