



## **HIV+25 SURVEY ASKS WHERE ARE WE IN CANADA TWENTY-FIVE YEARS AFTER DISCOVERY OF THE VIRUS**

### **Canadians living with HIV/AIDS say strong stigma still exists, more education and better treatments are needed**

OTTAWA, Ontario – November 24, 2008 – Twenty-five years after the discovery of the human immunodeficiency virus (HIV), a large majority of Canadians living with HIV/AIDS still feel stigmatized and there is still a strong need for further and continuing education, outreach and better treatments. These are the key findings of the “HIV+25” survey released today.

Conducted in collaboration with five key Canadian AIDS Service Organizations, the survey asked 381 people living with HIV/AIDS across Canada about the impact of the disease on their lives, explored their level of knowledge and their satisfaction with healthcare and current treatments.

“The HIV+25 survey is important because it illustrates the great burden that continues to be borne by people living with HIV/AIDS in Canada and that the disease affects all sectors of society regardless of sexual orientation” said Stephen Alexander, Programs Consultant at the Canadian AIDS Society (CAS), one of the AIDS Service Organizations which partnered on the survey. “These findings demonstrate the need for further and continuing education to eradicate stigma attached to being HIV-positive and for greater and improved resources and support services to help people cope with being HIV-positive and overcome the barriers that still exist for them.”

#### **The impact of living with HIV/AIDS**

The survey clearly illustrates how people living with HIV/AIDS (PHAs) continue to fight against a huge stigma associated with the disease, as stated by a large majority (82%) of respondents. Just over half (52%) said it impacts their ability to find a job, 44% mentioned that their co-workers are not aware of their HIV-positive status.

Further, 55% stated they feel depressed and almost as many (45%) reported feeling isolated as a result of living with HIV.

“I and most of the people I know who are HIV-positive feel the stigma associated with our disease,” said David, person living with HIV/AIDS (PHA). “I always hesitate to tell anyone I’m HIV-positive because I know the reaction will often be negative and will change what they think of me. It impacts almost every area of my life.”

#### **Education still needed for everyone**

The survey clearly identified the need for more education, for both PHAs and, to a lesser extent, healthcare providers. More than half the respondents, 55%, are somewhat, not very or not knowledgeable of the treatments available. A third (34%) are not fully informed regarding the complexities of the disease. The survey found that the less knowledgeable PHAs are about HIV and treatments, the less adherent they are to their treatment regime. This can have an important impact on treatment outcomes, as adherence is crucial for treatments to be effective. However,

while half the respondents said they want to be more involved in their treatment decision, the majority are not aware of the latest classes of anti-retroviral medications.

“Clearly more education is needed for everyone, and necessitates further targeted approaches and studies of the different sub-groups,” said Doris Peltier, APHA Advocate & Aboriginal Women and Leadership Coordinator of the Canadian Aboriginal AIDS Network (CAAN). “Healthcare providers need information on the latest treatment trends and advances. PHAs need help in managing their disease and the treatments. We also need to educate the general public to better understand HIV/AIDS in the 21st century so we can reduce the prejudice and misunderstandings that are still so prevalent. We have the groups that are capable of doing this, but they need resources to be able to deliver effectively.”

In seeking information about HIV and its treatments, most respondents (87%) look to their physician and 70% turn to their local AIDS Service Organization, making these the two leading sources of information for PHAs. Among the 26% of respondents who mentioned that the support from their community organization has worsened over the last five years, 76% mentioned that this was because there are not enough services and lack of funding. Since physicians and AIDS Service Organizations are the two main sources of information, they need improved and greater financial resources in order to maintain existing programs and expand needed programs to satisfy the needs of PHAs and growing demand for services.

### **Need for effective and better-tolerated treatments**

While current treatments for HIV have significantly contributed to the quality of life for PHAs, important fears and real concerns remain, indicating need for continued research and innovation. The major concern cited by respondents about their treatments is that the virus would become resistant to the medication, possibly reducing its effectiveness over time. An overwhelming 93% of respondents indicated that they want a treatment that attacks HIV in new ways to avoid the virus becoming resistant.

Side effects are also an important issue. While 82% of respondents take HIV anti-retroviral treatment and 66% are achieving the treatment goal of an undetectable viral load, most have experienced side effects which affect their day-to-day life. Fatigue was cited as a side effect by 68% of those on treatment, while 53% mentioned sleep disturbances and 48% diarrhea. Of respondents who are not taking HIV anti-retroviral treatment, 28% cited too many side effects as the reason. An overwhelming 91% of respondents indicated that they want a treatment with fewer side effects. Treating PHAs with better-tolerated medications could improve their quality of life.

### **About the HIV+25 survey**

The HIV+25 survey was conducted nationwide by P/S/L Research Canada between May 28, 2008 and August 19, 2008 and funded by Merck Frosst Canada.

Results were obtained by means of a Web survey completed by 381 people living with HIV/AIDS in Canada. The results are considered accurate to within 5%, 19 times out of 20. Additional research is required to further explore the needs of different subgroups.

Survey partners are:

- Canadian AIDS Society (CAS)
- Canadian Aboriginal AIDS Network (CAAN)

- AIDS Committee of Toronto (ACT)
- Coalition des Organismes Communautaires Québécois de Lutte contre le Sida (COCQ-Sida)
- AIDS Community Care Montreal (ACCM)

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