

Live and Learn

What do these seven PHAs have in common? All attended AIDS 2006 as participants of CATIE's Learning Institute, a project designed to enable community delegates from across Canada to maximize their experience at the conference. Now it's "time to deliver" their lessons from the world's biggest AIDS confab.

Interviews by **Ronnilyn Pustil**

JOHN BAKER, 39

Outreach coordinator, AIDS Committee of Newfoundland and Labrador St. John's
Diagnosed in 1993



HIGHLIGHT: I felt connected to AIDS on a global level and learned what it's like to live with HIV in other parts of the world. I met some wonderful folks from many countries and heard their stories on how they access treatment and get—or don't get—what they need.

TREATMENT INFO: The work on microbicides is very interesting. Now, for the first time, we may have an opportunity to put some power over this virus in the hands of women.

TAKE-HOME MESSAGE: We have the knowledge and the will to stop this virus. We need the G8 leaders to keep their promises. It's "Time to Deliver!"

ACTION PLAN: For those of us able to stand up and fight for the rights of PHAs, we must. There are whole populations being destroyed because of stigma and discrimination. In the West we must fight for those who are unable to do so locally and globally.

LASTING BENEFITS: I can now see the AIDS epidemic from a global perspective.

HARLON DAVEY, 42

Master's student, University of Toronto Toronto
Diagnosed in 1990



HIGHLIGHT: Seeing friends I haven't seen for a while and networking with people from around the globe who share a

similar vision and hope to educate, inform, prevent and address the complexities attached to HIV/AIDS—and ultimately find a cure.

TREATMENT INFO: Entry inhibitors represent a new treatment strategy that prevents the HIV virus from docking on the CD4 receptors and entering the CD4+ cell. Intuitively, it seems like a logical strategy.

TAKE-HOME MESSAGE: To reduce the spread of HIV, we need to address global issues, such as the disparity of wealth and power, universal access to medical treatment, gender inequality and the stigmatization of marginalized groups.

ACTION PLAN: To talk about HIV and give it a face so it carries less of a stigma.

LASTING BENEFITS: Attending a conference with so many dedicated and inspiring people and powerful voices has given me courage and confidence.

PIERRE DUBOIS, "over 60"

Active member of MIELS-Québec and COCQ-Sida Quebec City
Diagnosed in 1995

HIGHLIGHT: I felt a sense of belonging to this large community of PHAs and those affected by HIV/AIDS. It was very emotional for me. I was proud that this event took place in my country. I felt at home as soon I arrived in Toronto.

TREATMENT INFO: Without a doubt, it was the necessity to intensify research on new treatments, as so many PHAs have an urgent need for new agents to counter mutations and therapeutic failure.

TAKE-HOME MESSAGE: "Time to Deliver," the conference theme, suggested

that it's time to bring our knowledge and experience to the whole world through prevention and treatment access programs. The speeches by Bill and Melinda Gates and Bill Clinton were high points, supporting research to allow women around the world to take control of their bodies through prevention technologies in development.

ACTION PLAN: The participation and commitment of PHAs has

been very important in forcing decision-makers to enact prevention and treatment policies providing universal access. We must not abandon this commitment. We have to continue being present at different levels of decision-making in order to bring about policies that give greater access around the world. Also, frontline activists should be able to cede their places to a new generation of PHAs born after the 1980s with their own viewpoints and ways of dealing with the epidemic.

LASTING BENEFITS: The knowledge and experience have broadened my horizons.

B.C. ZEPHYR (pseudonym)

Retired; Volunteer AIDS activist Vancouver
Diagnosed in 1995

HIGHLIGHT: The fact that the two Bills—Gates and Clinton—are throwing the combined financial weight of their incredibly large foundations into the search for a vaccine and, hopefully in the future, a cure for HIV.

TREATMENT INFO: As there is not much hope of either a cure or vaccine



within the foreseeable future, prevention advocates are recommending two approaches until an effective vaccine can be found: for females, microbicides, which will be a major benefit to women in Third World countries; for males, the old STD prevention measure used by American forces in World War II—circumcision. Both have proved to reduce but *not* eliminate transmission rates.

TAKE-HOME MESSAGE: In countries where government leaders provide active and knowledgeable leadership instead of ignoring the problem and hiding as far away from this disease as they can, the rates of transmission decrease and the rates of HAART adherence are way higher. Botswana (which has strong governmental support for AIDS services) and Zimbabwe (where the government offers very little support) are textbook examples of these opposites. In Canada, the Conservative government follows more in the style of Zimbabwe.

ACTION PLAN: Safe injection sites save people's lives and prevent HIV and HCV transmission. It's time our government leaders overcame their hang-ups about the ethical and moral objections to these sites. I've written several newspaper articles criticizing the government about this. We need to write and pressure our local MPs or community leaders to support these projects.

LASTING BENEFITS: I've been asked to do some workshops and presentations where I can use my knowledge of HIV to help in the daily lives of PHAS and maybe even prevent a few cases of further transmission.

DANIELLE LÉVESQUE, 51

Member of Women's Health Promotion Committee, MIELS-Québec
Quebec City
Diagnosed in 1986

HIGHLIGHT: Bill and Melinda Gates' speech—with their realistic vision, influence and defined commitment—gave a lot of hope. As I was hospitalized for three days, I didn't attend as much as I had hoped.



TREATMENT INFO: Microbicides provide a glimmer of hope, especially for Africa. Being so unobtrusive, they may prove an efficient prevention method that women could use without having to explain anything. I was disappointed, in fact shocked, that there were no lipodystrophy workshops.

TAKE-HOME MESSAGE: The fight isn't over yet. Despite all the research and effort from groups around the world, AIDS and its outcomes are moving faster than we are. We need to intensify our efforts and continue the battle.

ACTION PLAN: To be on the lookout for new information, keep on top of the issues, share knowledge, expose inhumane situations and get loudly indignant about any injustice.

LASTING BENEFITS: There is this compassion and solidarity that unite all the different countries, and it is strong. Despite all the obstacles, so many men and women are ready to jump into action. I feel motivated to continue the fight against AIDS with my peers. I realize that it is really worth getting involved given the possible results. And that's encouraging.

EDWARD W. STEELE, 65

Retired; Volunteer peer support
Counsellor, Vancouver Island Persons
Living with AIDS Society
Victoria
Diagnosed in 1987

HIGHLIGHT: The incredibly strong, clear and dynamic role of women and children's programs (lectures, abstracts, marches). I also was inspired by overseas actions in South and Eastern Africa spearheaded and supported by Stephen Lewis and his foundation.

TREATMENT INFO: Integrase inhibitors in Phase II trials show much promise. And when it comes to adherence, in Africa and East Asia health professionals are using various tools to help patients take their drugs effectively.

TAKE-HOME MESSAGE: There is much to be done in the underdeveloped world in small community and regional areas—creating access to affordable drugs, centralizing rural services, addressing poverty, providing clean water and empowering

women. There is greater need for follow-through for funding in terms of treatment options and services, of which women are most in need. Canada must do more regarding generic drugs, specifically for pregnant women.

ACTION PLAN: I'm mentoring people in younger generations to carry the torch in the area of treatment information and expanded knowledge.

LASTING BENEFITS: Sharing the accumulated information with BC's communities through newsletters, meetings and regional conferences.

GUY LAFRAMBOISE, 45

Health Promotions Committee
Volunteer, MIELS-Québec;
Board member, CPAVIH
Quebec City
Diagnosed in 1993

HIGHLIGHT: The PHA Lounge allowed me to meet people from all around the world. I sat at a table with a guy from Texas, a couple from San Francisco and another guy from Mauritius—all PHAS.

TREATMENT INFO: We have to get behind vaccine research. One day it will revolutionize treatment for those recently diagnosed and those who have been on triple therapy for years.

TAKE-HOME MESSAGE: In Bill Gates' speech at the Opening Ceremonies, he stated that if the issue of AIDS had been in women's hands it would have been resolved long ago. I'm glad to have had the opportunity to hear this straightforward and generous man.

ACTION PLAN: Imagine—wearing a condom is still a taboo in Texas in 2006! So now when I speak in high schools in the province of Quebec, I tell them to protect themselves. I'm adamant that young people use safer-sex practices. I use a condom while still having good, healthy sex!

LASTING BENEFITS: All 24,000 delegates were on an equal footing. Whether PHAS, doctors, scientists or celebrities, we were all there to move things forward—and will continue to do so. +