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TORONTO PWA FOUNDATION
We Stand Together

Charitable Organization
Registration Number: 023739440

494 Yonge Street, Suite 2010
Toronto, Ontario M4Y 1X3

(416) 925-7112

Toronto People With AIDS Foundation



AIDS worker gets city award

AIDS patients' self-help group crippled by 16 deaths in month



The Pride of Toronto
PROUD 103.9 AND G.I.B.S. Pool & Hot Tub

JOY DRIVE 2009
FAMILY FUN FILLED DAY
GAMES, CLOWNS, MAGICIANS

COW PATTY
If the square...

CLAY
JULY BLACK, JEFFERY STRAKER, RICHARD RYDER
MAY 15, 2011 - 1PM NATIONAL BALLET THEATRE

Making a positive difference

A reflection on 25 years of PWA supporting the HIV+ and broader community

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Thanksgiving 2011...
Pride Toronto... Triangle Program...
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PWA was formed in a time of community grief and anger, when people with HIV/AIDS were fighting for basic needs, voice and visibility. A small group of people living with AIDS responded by forming PWA to provide support to people living with AIDS. PWA created itself as a fundamental reflection of community, affirmation, welcoming space, and hands on practical support that let people reclaim their lives. Over two and a half decades, as HIV has transformed into a more manageable disease, the essence of PWA has remained unchanged: a leader in impacting what it means to live a meaningful life with HIV, a leader in advocating for and providing the kind of support people with HIV need in healthcare, in public policy, and in day to day care. For 25 years, PWA has been at the forefront of HIV activism and practical support, transforming the face of HIV, one person at a time. PWA is many things: it's the Essentials Market, it's staff who try to access every possible resource for clients, it's the profound stories shared through the Speakers Bureau, it's the community rite of passage of the Bike Rally, it's activism and leadership, and it's a community space where people come, even when they don't "need" to, "just to be around people who are laughing."

People who describe the early days of PWA talk about it as being "scrappy," under-resourced, so direct that donors' cheques were sometimes immediately signed over to the clients. There were days when "every time you walked in, people

"PWA has been a safety net. It is part of the fabric of support that any community needs to thrive. It really speaks to how we care for one another in our community."
—community volunteer

would tell you someone had died." The people who founded PWA probably wouldn't have anticipated a day where gay men with HIV might be married and able to adopt a child. They might not have anticipated the diversity of people with HIV, all working together. They might not have expected the later embrace of harm reduction, poz prevention and the breadth of community support embodied by the Bike Rally. But they would recognize the ongoing issues of stigma, and the conversation about criminalization, and the fight for resources. And they would recognize the essence of PWA as meaningful involvement, affirming space, community builder, activist, leader and provider of practical support.

This document is an attempt to capture some of the voices and stories that have made up PWA over those 25 years. This is more of a scrapbook than a formal history, capturing just a few of the snapshots of people and moments that have made up the two and a half decades. Throughout the document, we have highlighted some **milestone moments** and a few **faces of PWA**. These moments and individuals represent some of the pivotal changes

"I want to give back" is often the principal reason why we hear people want to volunteer. From their volunteering experience, isolation decreases, dormant and new skills and strengths awaken and a sense of purpose, of making a positive difference emerges. This is why volunteers and staff return week after week, year after year. We become part of a greater whole – part of the enduring spirit of PWA. From this we become healed and more whole ourselves. This to me is the enduring legacy of PWA for which I am eternally grateful." – Suzanne Paddock, Director of Programs & Services

DEFINITIONS

PWA = Toronto People With AIDS Foundation **PHA** = people living with HIV/AIDS **ASO** = AIDS Service Organization

and meaningful involvement of individuals that have impacted PWA and our community. These are just a sampling of stories and faces – there have been hundreds of volunteers, dozens of staff, thousands of clients, thousands of supporters. The voices in this project are an attempt to demonstrate and honour the incredible power and contributions of every member of that community.

PWA's Changing Logos



Mission Statements

Promoting the dignity and self-sufficiency of people living with HIV/AIDS.

PWA exists to promote the health and well-being of all people living with HIV/AIDS by providing accessible, direct and practical support services.

We engage people living with HIV/AIDS in enhancing their health and well-being through practical and therapeutic support services and broader social change, and we inspire them to live into their dreams and discoveries.

Over 25 years, PWA has provided critical services to more than 8,000 individual clients, delivered more than a quarter of a million meals, distributed more than \$3.7 million to clients to support treatment costs.

The PWA Speakers Bureau volunteers have shared their personal stories with approximately 285,000 individuals in an effort to reduce stigma and transmission rates. Volunteers have provided more than 750,000 hours, and more than 50,000 individual donors have supported PWA.

Taglines Over The Years

We Fight Together

We Stand Together

Friends For Life

Making a positive difference

What it Felt Like: 1980s

"I was one of the Sisters of Perpetual Indulgence, who were active 1981 – 1986. When AIDS started, people with AIDS were being treated as lepers. Hospital trays were left out in the halls. Even some doctors would speak from the door of the room. People were lonely and isolated. The Sisters talked it out together and made the decision to do visits based upon scientific knowledge and what made common sense. We'd get calls about someone in hospital and would go and visit. There was a lack of accurate info – a huge gulf of fear and ignorance. As a Sister and later – I personally didn't fear contamination through casual contact —it was illogical for the infection to be air-borne or that you could become infected by just hugging someone else. Sexual transmission made the most sense."

– Harold Desmarais

"There was huge discrimination in employment, and people got fired for being known to be a gay man with AIDS."

"In the early AIDS conferences, there were no voices of people with HIV/AIDS. The organizers seemed to have the attitude 'why would we have these people, we have scientists.' In 1985, in Montreal, we stormed the stage and shoved a mic in Tim McCaskell's hand. It was the last time they didn't have positive voices."

"I was there around 86, 87. I was involved with Casey House. I felt the most empathy and sympathy with PWA because it dealt with people in the most direct way. Aside from PWA, ACT was the only organization at that time doing such work. During this time, there wasn't much aside from discrimination and harassment. It was a terrible, terrible, terrible time for gay men— it was the fear, the illnesses, disfigurement. It was always hard to raise money. People were afraid to come to the hospice." – James Wakeford

"PWA's office was on 464 Yonge St., in 1988. The Executive Director was John Hamilton (and then Tom Nash). The first Benefits and Assistance worker was Wayne Fitton and drop-in coordinator was Richard Bender. This was the first drop-in for PHAs. It was the first social environment for PHAs to get peer support. And a way of normalizing chaos. It was a haven. Along with Wayne and Richard, Paul Maingot was public speaker and Connie Gardner was admin support."

– Yvette Perrault, community partner

First Home

Early in 1988 PWA opened its first permanent office at 464 Yonge St. with one, then two, then a small group of dedicated staff, mostly HIV+ themselves. There was a drop-in, social activities, practical services – a safe space for people with HIV/AIDS to be together, to learn and support one another. PWA helped with the most basic needs: gave out money on the days they had it to give, helped PHAs get social assistance, housing and advocated for their rights.



"We didn't have resumes, all we had was us and a massive need to fill."

–Thomas Egdorf, former PWA staff person

"One night there was a faux funeral march that stopped outside Toronto General Hospital. There were clinical trials for aerosolized pentamidine for a typical phenomenon at the time – available in the States but not in Canada. It was having overwhelming results. The way the trial was set up, a certain % of people had to die first before the trial could be concluded! Trials planned to kill a dozen people to prove what is already known from US! PWA and AIDS ACTION NOW! were making runs to Buffalo to bring it back for clients in Toronto. Bootleggers!" –Glen Brown, AAN!

"In my first week working at PWA, in 1988, 15 new clients came in. They came with their stories, with fear, and with no money. I had application forms, and could help them get connected to government benefits. I remember sitting there, thinking, the only difference between us is my pay cheque and that was insecure – our funding was always insecure." –Wayne Fitton, former PWA staff



Developments in response to HIV/AIDS

1981

■ **US Centers for Disease Control (CDC) receives reports of unusually high rates of rare diseases in young gay men in LA and New York City.**

■ Initially called GRID (Gay-Related Immune Deficiency).

■ Reports of cases among injection drug users.

■ First articles on the new disease appear in The Body Politic, Canada's gay newspaper in Toronto.

1982

■ **Disease renamed Acquired Immune Deficiency Syndrome: AIDS.**

■ Transmission linked to blood and sexual transmission.

■ First cases of AIDS reported in Canada.

1983

■ Gays in Health Care and Hassle Free Clinic hold a public forum in Toronto in April. The AIDS Committee of Toronto (ACT) office opens in July.

■ Canadian Red Cross advises high-risk groups of gays, Haitians not to donate blood.

■ AIDS becomes a reportable disease to Public Health in Ontario.

PWA as Hands on, Practical Support

From the beginning, PWA's most fundamental role has been to provide hands on practical support, including; access to food, housing, funds to reimburse treatment costs, haircuts, vitamins. Holistic therapeutic services like acupuncture, massage and other complementary therapies to improve health and quality of life have a long and important history with PWA and have grown significantly over time.

"PWA is one of a kind – from connecting clients to government services to the Essentials Market to the naturopathic clinic, haircuts, yoga and massage."

"In the late 1990s, I pulled six agencies together, including PWA, ACT, Meals on Wheels (Mid-Toronto Community Services) etc, got a grant from the OHTN, did a feasibility study and created Food for Life. I was thrilled that PWA took on the program."

– James Wakeford

"The "Wakeford's Wagons" program of meal delivery really went beyond the constructs of the walls of the agency. One of my friends had AIDS and was very sick, and some of his friends thought he needed food. Paul Landers, one of the best case managers, worked with him and placed him on Food for Life. Even though my friend had a few friends by his side, it was Wakeford's Wagons' volunteers' interaction with him that really mattered. The interaction made him feel special. He got better until he passed."

"We had one call during this time from June Callwood. She knew a lawyer whose client had died of AIDS at Casey House, and he wanted his money to go to a person with AIDS. He asked ACT and PWA to identify someone. PWA and ACT together proposed money go to services to benefit more people, and described our ideas to the lawyer, who spoke with the family. They agreed. Money to be able to bridge people for, 1, 2, 6 weeks until into the system. Money was earmarked for emergency financial assistance." –Wayne, former PWA staff

"Before we had the office on Yonge St, PWA volunteer leaders, had been meeting at Chuck Grochmal's kitchen table, writing cheques. They met anywhere they could. People needed money, an apartment they could afford and food. The BSA contribution bridged the gap between needing help before getting onto government assistance. I'd call Paul Fairly the treasurer and ask, is this a green letter day, to give money out or a red letter day (no money available)?" – Wayne Fitton, former PWA staff



Essentials Market Volunteers

"PWA's collaboration with the AIDS Bereavement and Resiliency Program of Ontario helps a lot at a time of loss. It especially helped me recently, when I was a witness to a friend's suicide. PWA has always found a way to give me help or make referrals – it's my 'go-to' place."

"The change in the Essentials Market in 2010, from a food bank model to a grocery store model has really made a difference for clients. It reduced potential stigma and created choice, which clients really like. They're shopping just like they would shop anywhere else."

Developments in response to HIV/AIDS

1983

■ At the National Lesbian and Gay Health Conference in Denver, Colorado, People with AIDS adopt the Denver Principles, which define self-empowerment.

■ ACT holds the first AIDS Awareness Week.

■ Canadian Red Cross begins testing blood donations for HIV.

■ Death of actor Rock Hudson from AIDS makes headlines.

1984

■ Discovery of virus linked to AIDS; later named Human Immunodeficiency Virus (HIV).

1985

■ 1st blood test for HIV available in Canada, but what will results mean when there are no treatments? Community calls for anonymous testing.

■ 1st Canadian AIDS Conference in Montreal where organizing the Canadian AIDS Society begins.

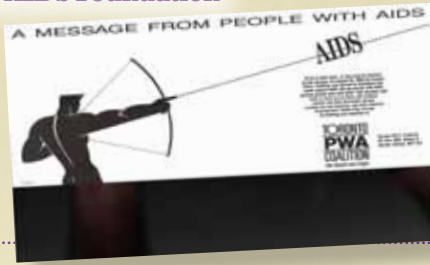
■ Ontario Minister of Health announces the Ontario Public Education Panel for AIDS (OPEPA).

■ ACT organizes the 1st AIDS Vigil in Toronto.

Toronto People With AIDS Foundation

1986

■ August, 1986 a small group of people with AIDS meet and form the Toronto PWA Coalition. Includes Jim St. James, Ray Barnard and Russell A. who later become President, Secretary and Treasurer. They start organizing. **"We Stand and Fight"**.



"When I came in to PWA in the summer of 1989 it was already set up. The folks who set it up need to be honoured in a very profound way for making it happen ... the Boards were amazing. Staff were really brilliant at helping –they had great compassion. It was so practical, so hands-on. Someone was going to benefit directly: food, housing, a massage, even from the advocacy. You could see someone getting helped. A client came in. They stabilized them, got them on Family Benefits Assistance, and on housing lists, gave them a bit of money... the amount of stress reduction provided was palpable. People did not know what to do. They were in shock. That alone justifies the PWA Foundation. That's already a huge monument to supporting our own."

–Tony Di Pede, former Board member and Chair

"A big part of what makes PWA special is listening. If people are coming in bitching about something a lot, PWA asks "what can we do about this?" For example in the mid 90s – people were returning rice and beans to the foodbank, and I asked why? It turned out they didn't know how to cook it, what to do with it. So we had a cooking class and showed how to cook and use rice and beans, other simple, affordable meals. Found a cook-book from Foodshare. Helped people understand how nutrition is important when living with HIV and gave them tips about combining foods to get more nutrition. I remember one client and volunteer– his breakfast was coffee and a cigarette. With the classes, he was bringing in creative pasta salads for lunch. Changes happened with basic knowledge and creating an interest in food."

–PHA and former PWA staff

"[A lot of our programming was so grass roots]. I remember Richard Bender, was 24, had AIDS. An artist. He was Drop-in Coordinator but we had no programming money. But he was very creative. He went out and

found people to volunteer – to cut hair, teach art, give massages. He applied for City funding and got \$15,000. Artist Steve Walker – who died in February 2012 – came and did art lessons, encouraged people to draw and connect with each other. It was PHAs connecting with each other through programs. Steve did an exhibition of their work." – Wayne Fitton, former PWA staff

"There are two boys, each about 10 years old, who have connected with PWA at different times over the last 5 years. They got connected through family volunteer roles and both ended up taking on such inspiring levels of initiative and commitment to PWA. Each collected donations from their friends, families, schools and communities. They were so proud of their work but I don't think they have any idea of the huge impact they have made by raising awareness and normalizing HIV/AIDS amongst their circles let alone truly understanding the impact their gifts make in the lives of people living with HIV/AIDS." – PHA and PWA staff



Developments in response to HIV/AIDS

1986

■ Ontario AIDS Network (OAN) forms.

■ 2nd Canadian AIDS Conference and Canadian AIDS Society's 1st AGM is held in Toronto.

■ Good Shepherd opens Barrett House, a 5-bed AIDS hospice, in Toronto.

■ It's determined that people with HIV/AIDS are protected against discrimination under the Ontario Human Rights Code.

■ The Ontario Legislature amends the Ontario Human Rights Code to ban discrimination based on sexual orientation.

■ AIDS becomes the leading killer of men aged 35 to 44 in Toronto.

■ Toronto is the 1st city in Canada to develop an AIDS strategy including funding for community-based organizations.

Toronto People With AIDS Foundation

1987

■ PWA incorporates as a not-for-profit May 11 as the Toronto People With AIDS Foundation.

■ Core PWA group meet where they can including a temporary office at Casey House before it opens.

■ TICOT (The Imperial Court of Toronto) and SPEARHEAD fundraise for PWA from their start.

■ Early Financial Assistance for PHAs: Distributed \$13,524 Oct 29, 1987- March 1988.

■ PWA takes a pause from operations in October after the death of 16 members.

What it Felt Like: Early 1990s

"People were dying and the docs and government didn't care. I had a friend in the hospital who was dying, and I was told by the doc, 'because of your choices, you deserve this.'"

"It was a tough time on the Board, because we had such limited funds, and the needs of the people living with HIV were so great."

"I remember someone I knew from CLGRO, (Coalition for Lesbian and Gay Rights in Ontario) a strikingly beautiful man. The disease ravaged him. He became blind in one eye. The difference between who he was and who he came to be was horrific. People were physically destroyed before they died." – Harold Desmarais

"You had to be determined to help when you're losing your own friends. We didn't implode from our pain, we became resilient" – Yvette Perrault, community partner

"I started working as a Benefits and Assistance Case Manager in 1990. In my first five years, I was helping people before they died. The next five years, I was helping them get better." – Pamela Bowes, former PWA staff

"Not only did staff have to deal with clients who were affected, the same staff had to deal with their own personal issues of being HIV+."

"It was both an exhilarating and depressing time in the gay community. There were lots of fundraisers in the community for PWA at the time, but no one wanted to be associated with a PHA on any personal level." – Bill Handley, PWA staff

"As a PHA, I got lots of info and support through PWA. It helped me to live with HIV better. I saw PHAs living their lives, fighting, not succumbing, and building an understanding of social issues." – Bill Handley, PWA staff

"There were times when there was a lack of social change and justice analysis. It's important to have leaders who share core values and see the bigger picture, have respect for process and ethics. Then you can ride through the differences – how to learn, how to advocate, find common purpose. PWA was not alone in having times of friction and tension. It was a familiar story for the ASOs as they developed. It was called 'storming'. There were tensions at times between Board and staff, between members and the agencies. People got hurt – it got painful. It's important to remember the context for these developing organizations – an

environment of anger, fear and deaths, multiple losses. People were passionate, the stakes were very high with so few treatment options."

"When I started in 1993, people were dying. So many people we lost. One day I came to work and by the time I made it past reception I had heard of 3 people dying. We were a group of misfits trying to get stuff done as best we could and it was always busy. Always people in reception, with staff, from the moment we opened to the moment we closed. PWA was very poor, resource-deprived. Staff was a tight group. We looked out for each other. One of the best places I ever worked. It was our passion, not a job for any of us." – Thomas Egdorf, former PWA staff

Supporting diverse community needs

In the early 1990s *Hola!* was born out of the need for Latinos who were dying and not having the knowledge of treatment available in Spanish. Today, because of PWA's contributions in operational support and physical space, *Latinos Positivos* has grown in membership and leadership. PWA provided concrete operational support and leadership to many organizations, often managing funding grants and providing physical space. PWA's support fostered the development of these organizations in helping to meet emerging and unique needs – *Voices of Positive Women*, *Committee for Accessible AIDS Treatment (CAAT)*, *Toronto HIV/AIDS Network (THN)*, *Circle of Care*, *Latinos Positivos*, *Positive Straight Men*.

Developments in response to HIV/AIDS

1987

■ AZT, the first anti-HIV drug is approved in the U.S. and Canada.

■ National March on Washington for Lesbian and Gay Rights includes 1st national display of the AIDS Memorial

Quilt; followed by AIDS activists demo and arrests.

1988

■ Casey House Hospice opens, founded by June Callwood. Fife House Foundation forms to

provide supportive housing for people living with HIV/AIDS.

■ Several ethno-cultural AIDS groups begin forming in Toronto.

■ AIDS ACTION NOW! (AAN!) has founding meeting and its 1st news conference attacking federal government for lack of action on treatment access and drug trials.

Toronto People With AIDS Foundation

1988

■ Toronto People With AIDS Foundation obtains an office in January next to ACT at 464 Yonge St.

■ First full-time Benefits & Assistance Counsellor supports PHAs to get social assistance.

■ PWA becomes a registered charity.

■ PWA's Chair speaks at AIDS ACTION NOW!'s first news conference. There will continue to be overlap between AAN! members and PWA.

■ Toronto premiere of Larry Kramer's play *The Normal Heart* raises funds for PWA.

PWA as Community Builder

PWA is a hub that connects people, strengthening community through meaningful activities and services, fundraising, artistic and awareness events, and by making it easier for clients to access services offered by other agencies. In addition to creating community among individuals, PWA has been an innovative partner with other agencies and organizations.

“The holiday party for clients is especially moving because during the holidays it is difficult for some clients with the feeling of loneliness and despair. The holiday party allows them a chance to be around other people to have fun and feel safe about being HIV+.”

“I was deeply moved by the people I met and the generosity I witnessed during my time at PWA. And the humour, the way that people used laughter to keep death at a distance. I am proud of the leaders who served during my time— Laurie Edmiston, John Miller (interim ED), and Murray Jose. And the staff and volunteers, including the Board and Bike Rally participants and so many others. And I will never forget the clients who made everything come to life, especially at the Annual Holiday Dinner. Most of all I miss the people who are no longer with us.”
—Bob Sirman, former Board Chair

“A gay couple that owned a guesthouse up north made their services available to staff for staff self care. During the years of this service being available to PWA staff, one client, who had a three or four year old son, was very ill. One of the Benefits and Assistance staff advocated for the client to be able to spend a week there even though the service was only for staff. The couple really bonded with the client and her son. It turned out the couple had been trying to adopt for a very long time and were unsuccessful. Much to the couple's surprise, when she died shortly after, she left guardianship of her son to the couple, who ultimately adopted him.”



Board members help with Holiday Hampers

“It's good to know the holiday food hampers make a difference. I am hoping to get my son involved. He's 8. Get him involved and get him to see what's out there.” —Sonny Handley, former volunteer and son of staff Bill Handley

Pride Award PWA float 1991



“In the 1980s and 90s, the activities PWA organized helped people deal with the overwhelming sense of loss. You didn't just lose one person, but many acquaintances and friends. It felt like death was stalking the community... Most of us weren't prepared to deal with death.” —community member and former board member, Harold Desmarais

Developments in response to HIV/AIDS

1988

■ Federal Minister of Health and Welfare, Jake Epp, is burned in effigy in an AAN! demo, held to protest lack of action on AIDS, while a national AIDS conference is held in Toronto.

■ Canadian AIDS Society publishes “Safer Sex Guidelines: A Resource Document for Educators and Counsellors”.

■ The first World AIDS Day is held December 1st.

■ The Names Project Canada begins the Canadian AIDS Memorial Quilt.

Toronto People With AIDS Foundation

1988

■ One of PWA's early members is Chuck Grochmal. Chuck's XTRA's column on living with AIDS runs from April 5, 1988 to Jan 24, 1990 (he died shortly after at Casey House).

1989

■ PWA receives core funding from the Ontario Ministry of Health and Long-Term Care. Means more staff and more programs.

■ PWA's Drop-in centre provides a safe space for PHAs and provides information sessions, yoga, massage, haircuts and more.

■ The PWA Speakers Bureau outreach begins, including speaks in schools.

"I've been involved with TICOT – The Imperial Court of Toronto – previously the Trillium Monarchist Society – since its inception 25 years ago. It makes sense that TICOT and PWA are sharing their 25th anniversaries this year, since TICOT has supported PWA with fundraisers from the beginning. There were so many deaths in the early years. PWA has made life worthwhile for so many people, including close friends of mine, with food, medication and help with housing. PWA makes life less hopeless." –Michelle Dubarry

George MacIntyre, known for his art depicting buildings of significance within our community, has lived with HIV since 1982, and became involved with PWA in 1990/91 when Paul Maingot got him involved as a volunteer. He recalls "that we were all like a family", and attributes much of his motivation to carry on, to the support he has received from PWA and others in the community.

"PWA feels like family, for staff, clients and volunteers. There is harmony among staff. I consider PWA my 'chosen family' – this is very important to me – as most of my support comes from this family."
–PHA, volunteer, former PWA staff

"The experience of loss is different when you have a supportive community."

"Community first, agency second."

"PWA is organic, true to self, richly engaged with people, relevant." –Yvette Perrault, community partner

In 2007, for the agency's 20th anniversary, PWA created a new tradition for a World AIDS Day memorial. Later partnerships resulted in the current annual Community Carnation Memorial.



Developments in response to HIV/AIDS

1989

■ The 5th International AIDS Conference is held in Montreal. Activists take over the opening stage on behalf of people living with AIDS demanding more action from governments.

The *Montreal Manifesto*, an international bill of rights for people with HIV/AIDS, is published.

■ AAN! publishes 1st issue of AIDS Update (later named Treatment Update).

■ Black Coalition for AIDS Prevention (Black CAP) forms.

■ Deaf Outreach Project is hosted at ACT in cooperation with the Rainbow Alliance for the Deaf and others. Now a program with the Ontario Association of the Deaf.

Toronto People With AIDS Foundation

1990

■ PWA and every AIDS Service Organization in Ontario, led by AIDS ACTION NOW! oppose attempts to classify HIV/AIDS as “virulent” and subject to quarantine orders.

1991

■ New Treatment Resource Centre provides information on *Living With AIDS* and produces easy to understand treatment information

1992

■ PWA establishes a Foodbank specifically for people living with HIV/AIDS.

■ PWA supports Voices of Positive Women and administers funds until 1994.

What it Felt Like: Mid to Late 1990s

Introduction of HAART (Highly Active Antiretroviral Therapy) 1996

The introduction of HAART in 1996 totally changed the face of HIV/AIDS in the community. HIV seemed less the death sentence it was five years before and the lives of many people with HIV and AIDS turned around. PWA had to adapt its services to reflect the new possibilities.



Pamela Bowes, former PWA staff

“In 1996, I met with a counselor to help me address some of the challenges I had to face on a daily basis. He asked me how many people I knew who’d died in the past year – and was shocked when I listed the number of deaths of clients and staff during one year.” –Pamela Bowes, former PWA staff

“I was diagnosed in 1994. I knew nothing about HIV and was quite terrified. I was feeling very ill, and was told I would only have two years to live. I met David Kelley at a meeting at Voices of Positive Women, and he encouraged me to be on the Board. Tony DiPede was Board Chair then, and he told me something that stayed with me: if one of us isn’t safe, none of us are safe.” –Louise Binder, former Board member & Co-Chair



“Louise Binder emerged in the mid 1990’s, as a strong voice on women’s issues and a treatment activist. She was on the Board of PWA, became Chair of Voices of Positive Women and challenged all of us at the ASOs to respond better to the needs of HIV positive women. A fearless treatment activist with AIDS ACTION NOW!, she was a founder of CTAC (Canadian Treatment Action Council).”

“Protease inhibitors were out so people were not dying anymore; there was hope –HIV was no longer considered a death sentence. But the challenge shifted from death to dealing with new medications. Lipodystrophy was now rampant; resistance to drugs.” –John, volunteer

“Everyone thought we should just be grateful that we had these new meds and were often living longer. There was no recognition of the continuing health challenges, let alone the huge psychological and emotional shift that was required. People called it the Lazarus Effect (returning from the dead) but the analogy I liked best was that it was like trying to turn around the Titanic. Everything about your life, your identity and your preparations had been leading towards death. When death is taken away as the expected outcome, you’re completely lost.”

“Death was an ugly piece of the reality. The community was very good at celebrating a life rather than mourning a death. I took that with me.” –Su Brideweser, former volunteer and Board member

Developments in response to HIV/AIDS

1990

■ The Works, a needle exchange program for injection drug users, is set up by Toronto Public Health.

■ The first national Aboriginal Conference on HIV/AIDS is held.

■ The federal Health Minister, Perrin Beatty, announces the first National AIDS Strategy.

■ Canadian HIV Trials Network and the Canadian Association for HIV Research are formed.

■ AAN! organizes a major demonstration to protest the call to allow quarantine of HIV+ people by Ontario’s Chief Medical Officer of Health. The plan is stopped.

■ The Teresa Group begins serving children affected by HIV and AIDS and their families.

Toronto People With AIDS Foundation

1993

■ PWA works with non-profit housing providers to secure dedicated units for people with HIV/AIDS.

■ **PWA and ACT move to 399 Church St.**

■ PWA receives the first grant to a Canadian HIV/AIDS organization from the M•A•C AIDS Fund.

■ The Good Samaritan Dinner is held for volunteers (most of whom are PHAs). This event later becomes PWA's Annual Holiday Dinner.

■ PWA supports and administers funds for Positive Straight Men.

PWA as Activist and Leader

PWA's role in social change, activism and leadership has always been based on promoting "whole person" health for people living with HIV and AIDS, and advancing knowledge about health and the needs of people living with HIV/AIDS. This focus has gone through different cycles over time, and as the largest agency in Canada providing direct support services to PHAs, is always directed at ensuring that the voices, stories and needs of people with HIV/AIDS are a central part of the public, research and policy agenda.

"PWA is changing the meaning of HIV one person at a time."

"There was a big shift a few years back when people started living longer. PWA is doing an awesome job to help support people living. Now I feel the pharmaceuticals are only marketing drugs that are marketable. There is a feeling of complacency. I'm glad to see the activism and resurgence of AIDS ACTION NOW! in the past few years, and how it fits with PWA's stance."

"Treatment activism was critical in the mid 90s. James Kreppner (deceased) was unassuming, brilliant and compassionate and a PWA Board member and Co-Chair. He was a powerful force and an important treatment activist with his work on CTAC, Haemophilia organizations, Krever Inquiry on the safety of the blood system to name a few. He was straight, a hemophiliac and

he believed in the need for all PHAs to work in unity. James was a lawyer and he was invaluable to our work at PWA. He was the best negotiator and saw his work, advocacy and activism as a sacred trust. Most of all James never forgot that the dignity, rights and well being of all PHAs was at stake. I miss and admire his absolutely indomitable spirit."
—former Board member

"With PWA and others, we were all fighting for drugs. Most of my friends died. It was a struggle to make our needs known and accepted. We were working with the government and the pharmaceuticals – the process lasted for years. This actually never stopped. We got catastrophic drug coverage in 1995." – James Wakeford

"In the early days, when clients tried to access housing, the staff at those agencies would speak to them through holes or behind booths so they wouldn't be infected with AIDS. And when clients were placed in affordable housing, other tenants would fear they would be bitten in the elevators and infected. In 1992, PWA began working with Metro Housing to put their clients on a priority waiting list. PWA became a leader with this venture, and other 'disability' groups started to adopt this practice."
– Pamela Bowes, former PWA staff



Developments in response to HIV/AIDS

1991

■ AAN's Treatment Information Exchange (TIE) project becomes the Canadian AIDS Treatment Information Exchange (CATIE).

■ The Red Ribbon makes its debut at the June Tony Awards.

■ Ontario AIDS Bureau is established.

■ Prisoners' HIV/AIDS Support and Action Network (PASAN) forms in response to the emerging AIDS crisis in the prison system.

■ 1st Canadian AIDS Awareness Week.

1992

■ Ontario's Ministry of Health establishes anonymous HIV-testing sites.

■ Canadian HIV/AIDS Legal Network forms.

Toronto People With AIDS Foundation

1994

■ PWA participates in education of U of T Medical Students in 1994-95 and receives award.

■ PWA supports and administers funds for Positive Youth Outreach (currently a program at ACT).

1995

■ PWA holds the OVATION! Namesake Awards to honour members of the community who have made a significant difference in areas including HIV primary care, art, legal assistance and more.

■ The HIV & AIDS Legal Clinic Ontario (HALCO) is established in partnership with the AIDS Committee of Toronto and the Toronto People With AIDS Foundation.

“Some doctors were rejecting PHAs left, right and centre (to sign off on disability applications). Or when Toronto Public Health decided they wouldn’t fund any groups that would not state that PHAs should abstain from sex. That’s not the way to talk to sentient beings; it’s insulting and it doesn’t help prevention. At that point we received a significant portion of our funding from the city, but we decided it was unethical and too offensive. We publicly informed Toronto Public Health we would not accept their funding under those conditions. And they relented.”
– Tony DiPede, former Board member and Chair

“While working with my Peer team, I realized that their involvement with PWA has increased their confidence and their understanding of their right to be sexual. Peers also move from being subdued to taking on leadership roles both internal and external of PWA. Poz prevention also builds connections with other ASOs and gives people a language to defend their rights. PWA is a safe space to explore this.”
– Mikiki, PHA, volunteer and former PWA staff

“The move toward criminalization implies that people who have HIV should not be sexual. PWA has a role in combating this, through public conversations about poz prevention and holding people accountable. These same people would shame gay, HIV+ men for wanting/having children.” – PHA, volunteer, former PWA staff

“During the time I’ve been involved with PWA, there has been a blossoming discussion about HIV and criminalization. You can’t criminalize a disease. Toronto Public Health’s mandate is to control disease. Our mandate is to empower clients.” –Andrea Westbrook, former PWA staff

“Today, HIV has increased much more in already marginalized communities. PWA has been a leader in recognizing and implementing best practices around social determinants of health. This is a visionary movement.” – Mikiki, PHA, volunteer and former PWA staff

“The AIDS sector’s gift to the world has been the transformation of other sectors. We engage with other sectors and they become more sensitive – meals on wheels partnership is an example.” – John Miller, former Interim Executive Director



Developments in response to HIV/AIDS

1993

■ The AIDS Memorial in Cawthra Park opens.

■ Krever Commission is established to investigate HIV in the Canadian blood supply.

■ Africans in Partnership Against AIDS (APAA) forms.

1994

■ The Greater Involvement of People Living with HIV (GIPA) Principle is formalized at Paris AIDS Summit, with 42 countries signing on.

■ After years of pressure from AAN!, the Ontario government announces that a catastrophic drug program will be implemented in 1995. Becomes the Trillium Drug Program.

Toronto People With AIDS Foundation

1995

■ PWA continues to obtain co-op commitments for dedicated units for PHAs.

1996

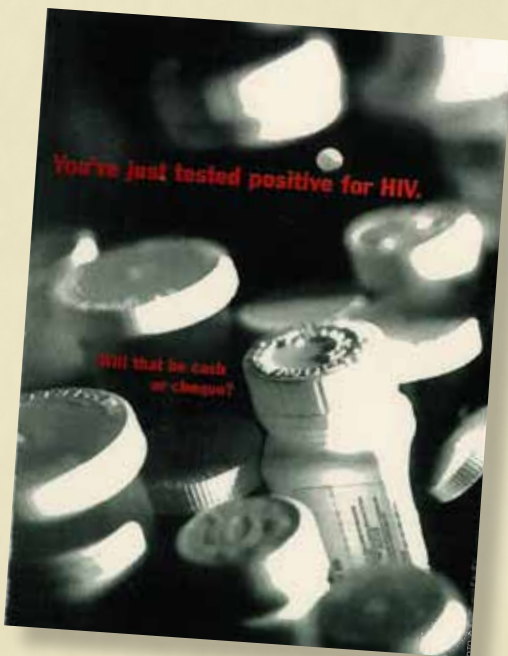
■ Sutherland Chan partners with PWA to provide the first student massage clinic for PHAs.

■ PWA transitions its on-site services to people living with HIV at Jarvis building to Fife House.

■ PWA holds its 2nd OVATION! Awards.

“PWA has initiated so many controversial and important programs – financial assistance to reimburse medical costs and medical marijuana, a needle exchange program and harm reduction, and the Food for Life program to ensure that clients got food with good nutritional value. So much of PWA’s success comes from working well with community partners like Fife House, OHTN and CATIE.”
–Laurie Edminston, former Executive Director

“PWA has helped people reformulate dying from AIDS to living with HIV. PWA helped people with how to make plans for living as most people were already planning for their funeral. They are now making plans for retirement and depend on PWA to meet their everyday needs. . . . People in Canada can be charged for infecting someone with HIV based on just hearsay. PWA is an avid advocate in the decriminalization of HIV non disclosure. HIV in Canada is very political, but PWA has written great and useful position papers. PWA thinks before they speak.” – PWA staff



Treatment Bulletin Titles from 1990’s Treatment Information Series

Medicinal Marijuana: the straight dope

PCP: Not the kind that gets you high

HIV Treatments: Understanding the cocktail

For Your Eyes Only: CMV Retinitis

A Public Cervix Announcement: Positive women and cervical disease

Waste... Not! HIV-related weight loss

MAC Attacks! What are MAC and MAI?

Developments in response to HIV/AIDS

■ On World AIDS Day, December 1st, 3 AIDS groups, serving the Southeast Asian communities, form Asian Community AIDS Services (ACAS).

■ Over 30,000 people are estimated to be living with HIV/AIDS in Canada.

1995

■ Dr. Charles Roy publishes his ground-breaking research *Living and Serving: Persons with HIV in the Canadian AIDS Movement*.

■ 2-Spirited People of the First Nations incorporates.

■ The South Asian AIDS Coalition becomes the Alliance for South Asian AIDS Prevention (ASAAP). Ontario Aboriginal HIV/AIDS Strategy, AIDS Bereavement Project of Ontario and Philip Aziz Centre begin to provide services.

Friends For Life Bike Rally

“PWA had the faith, forethought and flexibility to stand behind the bike rally in the early years. When we first brought the idea forward, PWA was willing to take a risk on new ideas that other agencies were reluctant to support. I really felt embraced and supported to bring this idea to life. Laurie Edmiston, the ED at the time, just knew it was the right idea and put her personal energy behind us. I remember she also made a commitment to ensure that this was a positive experience for all participants in year one. I am not sure anyone believed that we would make any money in year one at PWA but somehow they had faith that this would be a good thing. PWA also embraced me as a volunteer. I quickly became part of the fabric of the organization as co-chair of the Bike Rally. For years I felt very much a part of PWA and was given license to grow this event with support.”

–Danny Nashman, co-founder of the Bike Rally with David Linton (deceased)

“My first connection with PWA was the Bike Rally.

I was part of the first five rallies. Up until that point, my only connection with HIV had been Act UP and ACT – which were political and educational.

I was impressed with PWA’s approach, where people were the main focus. I stayed involved with the organization and was on the Board for 7 years. My hope was to improve the quality of life that HIV had taken away. PWA made me a more compassionate person – less self-centred.” - James Anok, former Board member

“The Bike Rally has a profound impact on the participants’ lives and changes them immensely – this is what charities should be doing. People can learn a lot about themselves through this event and renewing my faith in the phrase ‘Anything is possible.’”

–Raymond Helkio, volunteer and former PWA staff



First Friends For Life Bike Rally – 1999

The first Friends For Life Bike Rally raised \$44,498, and gave PWA the potential for significant self-generated revenues that would lessen the reliance on government grants. This also brought with it a need for stronger relations with a broader community of stakeholders, including potential sponsors and business leaders. Over time, the Bike Rally became a sustaining event for PWA, and has become one of the largest fundraiser in Canada. It embodies community, visibility and personal accomplishment at its best, and became a “rite of passage” for people to participate and to find strength and possibilities that they’d never imagined for themselves, and to touch people in many communities with awareness about HIV.

Toronto People With AIDS Foundation

1997

■ Series of pamphlets is produced on treatment issues along with *Ask Your Questions* sessions.

■ PWA continues to assist PHAs with housing referrals.

1998

■ PWA begins only needle exchange specifically for PHAs.

■ Naturopathic Clinic partnership begins with the College for Naturopathic Medicine (currently offered at the Sherbourne Health Centre; a newer partner allowing for growth of the clinic).

PWA as meaningful involvement

PWA recognizes the transformative power of participation. Engagement runs through all elements of PWA, and is centred around providing the resources that enable all people involved in PWA to find their own pathways to meaningful involvement – involvement in their own health and well-being, in community, in providing services, in imagining and living into their dreams. The “Greater Involvement of People Living with HIV (GIPA)” Principle was formalized at the Paris AIDS Summit in 1994. PWA has been a forerunner for GIPA over its entire history.

“It’s the first organization with PHAs as staff who walk its talk, filled with hope and making the ugly beautiful.”
–Yvette Perrault, community partner

“If I had to describe GIPA, I’d describe PWA. I was diagnosed in 2004, when I had just found out I was pregnant. I was referred to PWA by St. Mike’s, who thought PWA might be able to help because I couldn’t afford the whopping price tag of the meds I needed. I have three phrases to describe PWA: Nitto [my case worker] medication, and my son’s negative. Nitto went above and beyond to make sure I got access to the meds I needed through the Trillium drug plan and other ways of accessing meds in a very short period of time. He was also the first person who disclosed his status to me, and I was blown away – “you’ve been positive for so long and you still seem so healthy.” PWA gave me my life back... I’m now a member of the Speakers’ Bureau, and know

that by sharing my story, especially as a mother, I can help people out. The speakers are my support and my new family.” –Tara, PHA, volunteer and community partner

“When I came to PWA, it was very important to me to have Nitto as a case worker, since he self-identified as having HIV. It was refreshing to see PWA implementing the GIPA principles, as people were getting fired elsewhere for having disclosed that they were HIV positive.”

“Jim St James and I met at ACT. In 1986, when I was Chair, he came to explain to me about the new group he and other PHAs were forming. It was about having an organization of their own.” –Joan Anderson

“There is something powerful about going out and telling your story again and again to a bunch of strangers. Each time the audience learns something about HIV and each time you learn something about yourself. It is a therapy that you can’t get sitting in a chair.” –Claudia Medina, community partner and former PWA staff

“Sometimes, I feel such a huge responsibility to be able to share experiences of living with HIV/AIDS in a way that inspires others and honours the experiences of myself and more importantly, others who may not have the voice or opportunity.” –PHA & PWA staff member

Developments in response to HIV/AIDS

1995

■ **New family of anti-retroviral drugs called protease inhibitors is approved in the U.S.**

1996

■ The success of Highly Active Antiretroviral Therapy (HAART) is the big news at the 11th International AIDS Conference in Vancouver. **HAART becomes standard treatment.**

■ Ontario begins Viral Load Testing.

■ PHAs form the Canadian Treatment Action Council (CTAC).

Toronto People With AIDS Foundation

1999

■ First Bike Rally - Friends for Life - raises \$44,498.

■ PWA adopts provocative position to support medicinal marijuana.

■ ACT & PWA develop the "Employment Action Program" for PHAs to update their skills, provides help with resumes and places them in jobs. Currently an ACT program.

2000

■ PWA develops a new Strategic Plan.

2001

■ PWA offers workshops on HIV/AIDS medications, nutrition, alternative therapies and other topics.

"PWA is one of the few organizations in which GIPA/MIPA is visible, since it is assumed most of the staff is HIV+, which creates a distinct culture. And this principle doesn't just stop with staff; we engage others through GIPA/MIPA." Mikiki, PHA, volunteer and former PWA staff

"PWA asks its clients what they need; just because we are 'professional', it doesn't mean we know what people's lived experiences are." – PWA staff

"PWA really takes a strength-based, client-centred approach. The number of clients who are volunteers really speaks a lot about the value of the services PWA provides." –Andrea Westbrook, former PWA staff

"From the beginning, PWA has lived and breathed GIPA. When I was volunteer coordinator, about 80% of the volunteers were PHAs. Eight out of twelve staff were HIV+. It made a difference." –Thomas Egdorf, former PWA staff

"Of course, being HIV+ doesn't automatically bring you any greater insight or skill. However, given PWA's history as being so grounded in our roots of PHA engagement, there simply are some opportunities that have emerged when the right skills, knowledge AND lived HIV+ experience have combined that have resulted in profound change and growth for PWA. Such public leadership (including volunteer, staff and Board representation) has contributed to PWA being seen as a key leader at every level of the HIV response (regional, provincial, national and even international) when it comes to reflecting an agency that is PHA driven." –PHA and PWA staff



Christine, Speakers Bureau Volunteer & Greg Downer, staff

"Paul Maingot brought this amazing group of people together and created the Speakers Bureau to put a face on AIDS."

AIDS worker gets city award



Headline in XTRA! May 1990 for Paul Maingot (later deceased)

Developments in response to HIV/AIDS

1997

■ Canadian Aboriginal AIDS Network (CAAN) forms.

1998

■ HIV/AIDS diagnosis is added to ODSP (Ontario Disability Support Program) after efforts by PWA and other groups in Ontario.

■ Canadian Blood Services assumes full responsibility for Canada's blood supply system.

■ Canadian Working Group on HIV and Rehabilitation (CWGHR) forms.

■ The Wellesley Hospital, known for its HIV care, is closed after a tough battle. Community supports the development of Sherbourne Health Centre.

Toronto People With AIDS Foundation

2002

■ PWA launches the Food for Life (Wakeford's Wagons) meal delivery partnership program.

■ PWA begins the Pie In the Sky Thanksgiving fundraiser for PWA's Food Programs.

■ Treatment & Information booklets are produced that are later updated with CATIE for national distribution.

2003

■ PWA partners with the Committee for Accessible AIDS Treatment (CAAT) to develop the HIV Medication Access

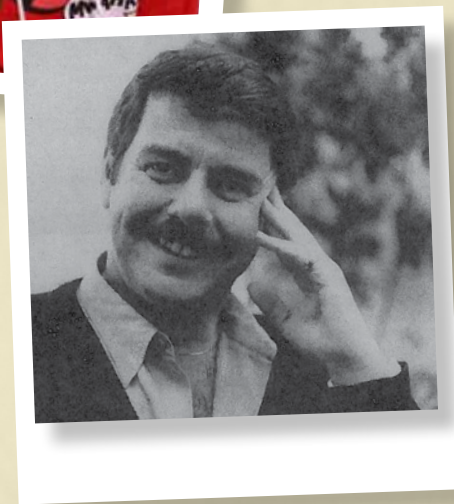
Project for PHAs facing access barriers related to their immigration status. Becomes a PWA program within a year.

A Few of the Faces of PWA



Emmy, volunteer

Emmy is the youngest long-term volunteer PWA has ever had. She started volunteering regularly when she was 7 years old, when her mother started working for PWA. Her time in the community has given her very early insight that people with HIV are "just like everybody else." She describes her personal impact moment as discovering that Nitto, a case worker who became her friend, was HIV+. Her first reaction was "will he die?" Losing Nitto was very difficult.



David Kelly, (deceased), former Executive Director, PHA, Activist, Community Leader

"David Kelley was a light during the 90s... he always connected the dots."... "I feel he was the most compassionate, patient, sensitive, inclusive and amazing human being. At Pride one year, he marched carrying the banner 'Poz Straight Man,' and was happy to do so, even though he was gay. I was with him when he died."

Developments in response to HIV/AIDS

1999

■ HIV treatment effective in reducing mother-to-child transmission during pregnancy.

■ Ontario HIV Treatment Network (OHTN) forms with Dr. Anne Phillips & Murray Jose of PWA as co-chairs.

■ Committee for Accessible AIDS Treatment (CAAT) forms to improve treatment and service access for PHAs who are immigrants, refugees and without status.

2000

■ 1st Canadian National Conference of Women and HIV/AIDS is held.

■ The Greater Involvement of People Living with HIV (GIPA) Principle is endorsed by 189 United Nations member countries as part of the Declaration of Commitment on HIV/AIDS.

2001

■ More than 40 million people worldwide are estimated to have HIV/AIDS, half are women and nearly 25 million have died.

Toronto People With AIDS Foundation

2004

■ Proposal to amalgamate PWA and ACT does not receive required support by PWA Members.

■ Amalgamation discussions help to identify PWA & ACT partnership opportunities and to clarify PWA's work as a separate agency.

2005

■ PWA participates in regional HIV services planning process and later becomes Trustee and host of the Toronto HIV/AIDS Network (THN). Murray Jose, PWA Executive Director becomes Co-Chair.

2006

■ PWA leads creation/coordination of PHA Lounge at the International AIDS Conference in Toronto.

■ PWA begins long partnership as beneficiary of *Home + Style* fundraiser.

Rick Rocheleau (deceased), volunteer fundraiser

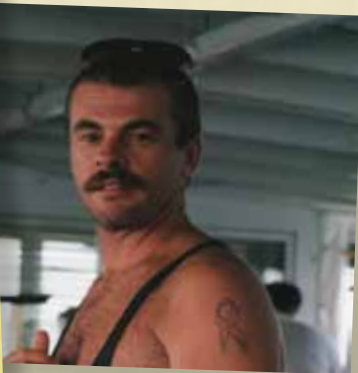
Rick was diagnosed HIV+ in 1989 and met Daniel Poitras who raised money for PWA. Rick helped Daniel with vitamin drives and it became a mission to raise money for PWA. He organized events, "Cow Patty Bingo" at the Riverdale Farm, and the challenging "Blade '94 Tour." He, Daniel, and Savoy, rollerbladed to Ottawa over several weeks with his dog Jesse, as well as Mark and Kelly for support. They raised funds for PWA and did education events, raising funds for the local AIDS group in towns on the way to meet the federal Minister of Health in Ottawa. "Everywhere we spoke on the tour, I'd be the person who was affected by HIV and Rick would be the person who was infected. When the Blade Tour ended, the police were escorting us up Church Street, and we both started crying, it was such a powerful experience. [before the tour] I couldn't face going up to the AIDS Memorial. When I came back, I'd changed. I'd gotten stronger and I was able to go up to the Memorial."—Buddha Daniel Poitras



Tony Di Pede, former Board member, Chair

A demonstration in 1989 ignited Tony's anger about what was happening to the community and turned him from "being a suburban fag living a quiet life in Etobicoke" into an activist. There were 2 staff when he arrived and 16 when he left in 1997. "To be honest, a lot of it is a big blur. We were growing an organization, doing advocacy, and dealing with our own diagnosis. I think I was also running away. The more I got involved, the less I had to feel. Numbers of clients jumped. Everything expanded faster than could be handled. And people were dying so rapidly, in dizzying frequency... It's hard to imagine that in the midst of all that emotional turmoil, things got done. Many people only knew that they had AIDS when they got really sick and died within a year. Three years was a long-term survivor."

"These are better times – for some. That's why PWA is there and needs to be until the epidemic is over. They make life better for a lot of a people."



Developments in response to HIV/AIDS

2002

■ HIV becomes the leading cause of death worldwide in people aged 15-59.

■ The Global Fund to fight AIDS, Tuberculosis and Malaria is created.

2003

■ *InSite*, North America's first supervised injection site, opens for drug users in Vancouver's Downtown Eastside.

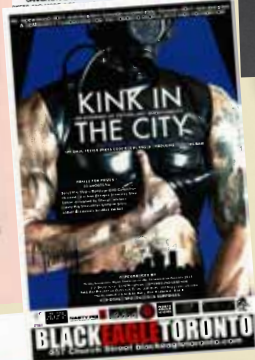
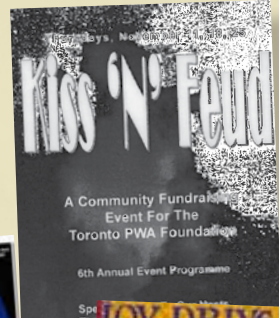
■ Sherbourne Health Centre opens.

■ Estimated HIV prevalence in Ontario is 20,260.

2004

■ Inaugural meeting of African and Caribbean Council on HIV in Ontario (ACCHO) which is officially launched in 2005.

25 years of Community Support



TICOT (The Imperial Court of Toronto) has raised approximately a quarter of a million dollars over 25 years for PWA.



2007

■ PWA's 20th Anniversary.

■ PWA provides early leadership as part of the new Ontario Working Group on Criminal Law + HIV Exposure.

■ MLT (Mr. Leatherman) Steve Martin and the annual *Pride & Remembrance Run* support PWA in fundraising.

■ Annual 103.9 PROUDFM *Joy Drive* helps stock the shelves at PWA's Foodbank.

■ PWA develops a new Strategic Plan.

2008

■ The 10th Friends for Life Bike Rally raises \$1,214,627; the 10-year total passes \$5 million and more than 300 cyclists participated supported by a crew of almost 100: "As Long As There's a Reason...There's A Ride".

A Few of the Faces of PWA

Murray Jose, PWA Executive Director and PHA

"I was at a weekend workshop for Gay Men's Sexual Health Alliance and we were asked to name someone you would like to honour – over half the attendees named Murray."
– Glen Brown



David Kelley, at the time he was Executive Director of PWA, encouraged and supported Murray to get involved in HIV work. Eleven years later, Murray followed in David's footsteps and joined PWA as the new Executive Director. Murray's identity as an openly HIV+ gay man contributed to the leadership that helped PWA grow in profound and exciting ways including national leadership on Poz Prevention programming and the GIPA/MIPA (Greater & Meaningful Involvement of people living with HIV/AIDS). Murray also introduced using a strength-based approach to planning which became an important shift in the community response to HIV/AIDS.

OVATION! Awards

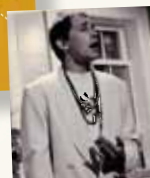
PWA gave out awards in 1995 and 1996 to recognize the "individuals and businesses for their dedication and commitment to assisting people living with HIV/AIDS". OVATION! was inspired and initiated by Jim Murrant (former Board and staff member) who passed away before they were held.



Dr. Phil Berger



Tom Stewart (David Kelley's partner) & Jim Gaylord (deceased, former staff)



David Sereda – Powerful Love



June Callwood & Dinah Christie.



Dr. Chester Myers (deceased) and then Toronto Mayor, Barbara Hall

Developments in response to HIV/AIDS

2005

■ Regional planning process (2005-07), funded by the Ontario AIDS Bureau, creates strategic plan for HIV services for Toronto.

■ Estimated 57,000 people living with HIV/AIDS in Canada.

2006

■ The 16th International AIDS Conference (AIDS 2006) is held in Toronto.

■ AIDS deaths fall but serious health complications emerge.

■ Ontario introduces point-of-care rapid HIV tests.

2007

■ Criminalization of HIV and lack of rationale for charges from case to case a growing concern.

Toronto People With AIDS Foundation

2008

■ PWA is the Honoured Group at Pride.

■ PWA and the AIDS Vigil Committee partner to make PWA's World AIDS Day Community Carnation Memorial a larger community event.

■ **PWA moves to a larger space at 200 Gerrard St. East, to meet service needs and create "a welcoming space".**

2009

■ Poz Prevention resource materials, developed in partnership with the Gay Men's Sexual Health Alliance, are recognized nationally and internationally as ground breaking.

A Few of the Faces of PWA



**Laurie Edmiston,
former Executive Director**

One of the key impacts Laurie had on PWA was through her leadership and willingness to take on controversial issues. Laurie worked with staff and Board to introduce harm reduction programming and an agency position and support for accessing medicinal marijuana. These were difficult and risky initiatives but were critical to choices that PHAs needed for their health and well-being and Laurie didn't shy away from them.

"When Laurie started as ED in the 90s, she was quite pregnant. We loved her from the start. She knew we worked hard, and was respectful. Most days were the same – busy, no time to stop, people coming and going, a craziness, mayhem. She handled it all."

Brian Smith, longtime volunteer

Brian has been volunteering (mostly in the Essentials Market) for 17 years, 10 hours a week – more than 8,000 volunteer hours. Brian is "committed, caring, and knowledgeable about the needs of clients ... and has also extended his kindness outside of PWA – like neighbours, clients, and other volunteers."

Ron – "Client #4" (deceased)

"One story that sticks with me is the situation of Ron or Client #4 as he liked to call himself. He was often around PWA helping out and very friendly. I didn't know much about his personal life or relations outside of PWA, but when he died, staff told me that because he had no family, Public Health was required to hold his body for a period of time before they could do a public cremation and burial. It was incredibly difficult and heartbreaking for myself and other staff to think of this individual whom we had come to know, that his body was sitting in what we perceived as such indignity along with the idea that perhaps we were the only people who would hold his memory alive." – Murray Jose, Executive Director and PHA



Brian Smith

Developments in response to HIV/AIDS

2008

■ 17th International AIDS Conference in Mexico City.

■ Estimated 65,000 persons in Canada infected with HIV. Estimated 13,127 live with HIV-Hep C Co-infection.

2009

■ 5th Annual Ontario Gay Men's Sexual Health Summit; this year's theme is Poz Prevention.

■ Opening Doors, an annual forum for PHAs and service providers is re-initiated in Toronto.

2010

■ 18th International AIDS Conference in Vienna. "Vienna Declaration" bases drug policies on evidence and supports harm reduction.

■ United States travel entry ban on PHAs officially ends January 4th .

Toronto People With AIDS Foundation

2010

■ PWA presents a poster at the International AIDS Conference in Vienna highlighting Poz Prevention.

■ The Foodbank's transformation to an Essentials Market is complete.

■ Love Bowl begins – Valentine's themed bowl-a-thon.

2011

■ The Bike Rally raises 1,26 million for an overall total of 9.1 million.

What it Felt Like: 2000s

"On my second day on the job, Murray was making a presentation, and I was amazed to see that he could move from swearing to crying within minutes – I really got the frustration that we have to face as workers in the ASO world and how ignorant people still are about HIV/AIDS and that people have to die before they can get their needs met." –former PWA staff

"Back in my home country, the rate of HIV was very high, so it was kind of a relief to be in a country where the infection rate was low. But I felt stifled to talk about HIV – I was afraid of how people would treat me. In Zimbabwe, it was common language, but people in Toronto were more sheltered to talk about the infection. Talking about HIV felt like the nightmare of going through the immigration process. People in Toronto seemed to be behaving as if I brought HIV from Africa to Canada." – a client who arrived in Canada from Zimbabwe in 2006, now a Speakers Bureau member

"During the amalgamation talks, it was both a wonderful and horrible time to be part of the organization. There were some pretty traumatic situations. Long time clients and volunteers were on opposite sides of the debate and had to continue working together. Afterwards, the biggest opportunity was PWA's ability to move. The old space was always a challenge" –John Miller, former Interim Executive Director

The story of the not-merger (in different voices) 2003

"It struck many of us at the time that the conditions were ripe for transformative change at PWA and we saw a joining of forces with the AIDS Committee of Toronto as an opportunity. Together we could pool resources, avoid competition, strengthen services, eliminate overlap, reinforce the leadership role of PHAs. We worked together to this end for many months and when a vote was held the majority of members in both organizations supported amalgamation, but in the case of the Foundation that majority was just 65% and not the 66.6% required by our by-laws. A second vote was held and the result was the same. The moment had passed and the two organizations continued on their separate ways."

"It was an extraordinarily stressful time, but it made us really question what the organization was about. The navel gazing and discussion of all the sides gave us the ability to be really clear about who we were there for."

"The end result was the decision of the people, not the people in charge... Both PWA and ACT continued on to grow, meet different needs, and both agencies grew stronger."

Developments in response to HIV/AIDS

2011

■ Communities, including LGBT and HIV/AIDS groups, organize to protect vital services during City of Toronto Core Service Review.

■ An estimated over 16,000 people are living with HIV in Toronto.

■ The World commemorates 30 years of AIDS

2012

■ City of Toronto proposed Budget threatens service cuts, including community AIDS programs. City Council saves many services by two votes in January.

■ The International AIDS Conference returns to the U.S., to Washington D.C.

Toronto People With AIDS Foundation

2011

■ CLIMAX community partnership fundraiser 2010-11.

■ **Engaging, Building Capacity, Empowering Dreams: PWA's 2011-2016 Strategic Plan.**

2012

■ PWA now supports the following programs as trustee: Committee for Accessible AIDS Treatment (CAAT), Toronto HIV/AIDS Network (THN), Circle of Care, Latinos Positivos.

■ TICOT – community fundraising supporter from PWA's start – has it's 25th Anniversary.

■ PWA receives Award of Excellence from the Canadian Working Group on HIV and Rehabilitation.

PWA as Affirming and Welcoming Space

PWA has always seen one of its roles as being a socially inclusive, safe, diverse and open space, where people experience affirmation, joy and inspiration, and have creative and meaningful expressions of our experiences, lives and knowledge. This emotional impact is echoed in its physical space.

“Would it be all right if I came back for a coffee and just to listen to the people laughing?”

“Once you're a client, you're always a client.”

“I feel like I've been given a great deal of dignity just by being here.”

“I met a client who was a typical successful professional. I discovered that on the inside, he was really falling apart, struggling with being newly diagnosed. PWA was the ground for him that allowed him to continue on in life with family and friends.”

“PWA is a family. It's refreshing how PWA accepted me as a Trans Woman and how I was included as part of the Speakers Bureau. There is always continued support, and my involvement in the agency makes me feel as if I belong – which is huge for transgender people.”

–Christine, PHA and PWA volunteer

“Accepting people the way they are has always been a key attribute for PWA” – Elisse Zack, community partner

“I've heard a story many times from one of PWA's staff about a time when he was at a critical turning point in his life and trying to get back on his feet. He literally had no food to eat and finally had to ask for support at PWA's food bank. He was coming from a job interview and dressed formally but the staff and volunteers didn't question or judge him but simply offered practical food for his nutritional needs and emotional support through their interaction and respect. In time, he ended up becoming a PWA staff person himself, which is amazing to see that experience come full circle where he now contributes to others having that same positive experience of PWA that he received when he most needed it.”

–PHA and PWA staff

PWA and its space “gives me the image of a pair of hands open and welcoming, gentle and offering, reaching out and lifting up.”

–Rick Kennedy, Ontario AIDS Network

Developments in response to HIV/AIDS

2012

■ The Supreme Court of Canada makes a new, very disappointing, ruling on criminalization of HIV non-disclosure that will impact

PHAs and challenge public health strategies for years to come. PWA continues to play a key role in this issue with

HALCO, PASAN and other partners on the Ontario Working Group on Criminal Law and HIV Exposure.

2012

■ A volunteer-led Community Garden adds to PWA Food Programs.

■ Based on the Strategic Plan, 5 new programs begin, that fundamentally change volunteer support & engagement.

■ PWA marks its 25th Anniversary – honours the community that responded to HIV/AIDS and built PWA.

What it Feels Like: Today

“There are fewer deaths and people are going to have to live with us because we are not going anywhere. ”

“Stigma is the worst piece of it right now. Five years ago – surprise! – my baseline bloodwork revealed I was HIV+. There was nothing physiologically. HIV is only my work and popping three pills a day, but the stigma is overwhelming. I’m always making assumptions of what other people are going to think of me. I can live with HIV otherwise.” – PWA staff

“In the early days, PWA was more of an HIV “old boys club” – pretty homogenous group. Now there’s more diversity among staff, volunteers, directors, and it feels inclusive.” – long time volunteer

“This HIV stuff, is not for your everyday camper... it seriously fucks up your life and, not in a pretty way!” – client who could not be interviewed for this project because his health issues were too severe – he pointed out that “each and every day” can be a challenge to a person with HIV/AIDS.

“As clients get older, we are facing new issues around long-term support.”

“PWA is seen as a support hub for gay men, and PWA is seen as a ‘sacred space’ for people infected and affected by HIV/AIDS. The tide has turned with regards to loss of lives – we could forget about the trauma other people faced, but PWA holds this memory with great responsibility and takes this memory seriously.” –Mikiki, PHA, volunteer and former PWA staff

Shift to new space – 2008

When PWA did its 2007 strategic plan, the idea kept coming up that the physical space at PWA should be as affirming and welcoming as the services. Someone made the connection that PWA should feel like the PHA Lounge at the 2006 International AIDS Conference in Toronto, whose creation PWA had led. One of the first actions from the strategic plan was to move to 200 Gerrard Street. The move helped PWA deepen its identity as an organization after the non-merger, and enabled it to be more and more creative about its services and welcoming environment.

“Someone thought we should not be celebrating twenty five years because we are celebrating AIDS. But we are celebrating how far we have come.” –Candice

Developments in response to HIV/AIDS

2012

■ The Ontario Accord – is affirmed as a statement of solidarity with the principles of greater

involvement and meaningful engagement of people living with HIV/AIDS.

■ PWA is the first ASO to formally endorse and adopt the Ontario Accord which was developed by a process

facilitated by the Ontario AIDS Network (OAN).

PWA as a place to dream again

Deeply entwined with practical support is PWA's role in facilitating and supporting clients to determine their own pathways, naming their own dreams – recognizing that making choices and gaining a sense of control over one's life is a central aspect of health and well-being.

“One night [in the early 1990s] at the office at Church and Carlton, we were doing the crafts program, making fimo broaches, and it was snowing, and it became a blizzard. Cliff, a local florist, had heard of the program, and he arrived with two helpers carrying boxes and boxes of flowers. We opened them up and were surrounded by flowers in the midst of snow. Everyone went home with a floral arrangement. It was magical.”
–Su Brideweser, former volunteer and Board member



Teddy bears from the 1990's crafts program

“When we were young, I was an actor and my partner was a dancer, and we were meant to have this amazing artistic life. Then my partner died and I started fundraising for PWA. The dream of acting got put on hold – there were more important things to do. After working on and off for different ASOs, a few years ago, I got to play Sweeney Todd in a community theatre production. I'm sure I wasn't any good, but I was always meant to play Sweeney Todd.”–Adrian Betts, community partner and former PWA staff

“PWA gave me my life back” –multiple clients said these same words

“PWA gives hope, affirmation and encouragement, especially to newly diagnosed people!”
–Paul, longtime volunteer

“I was diagnosed on a Friday afternoon at 6:15 on April 15 2003, I came into PWA and ACT on Monday, and it was suggested that I connect with PWA and get a worker. That was Nitto. This was the low point in my life – the worst year. I'd ended a 17 year relationship, lost my housing, lost my business and I had serious mental health concerns – depression and suicidal ideation. When the doctor mentioned I should look into ODSP (Ontario Disability Support Program), I thought that was another diagnosis! PWA literally saved my life. I had already planned to kill myself. I'd spent all my money, did some partying, said my goodbyes. Then I got a call from my worker Ingrid, and she'd found housing for me and I could move in right away. I thought “damn, I was going to kill myself in three days!”

“PWA was a welcoming community. I was isolated, and I found people here to speak to. I made friends. I'm sure I would be dead if I wasn't HIV + – it was more of a blessing than a curse because I started taking better care of myself. I can't imagine life without PWA. They connected me to all the services that gave me my life back.”

“Volunteering gave a lot of people a new meaning to life. PWA was a shoulder to depend on. It wasn't a hand out; it was more of 'a lift up'. PWA offered hope and reason to live.”

"I see constant examples of individuals who come to PWA (often through volunteer roles where they don't have to be identified as HIV+) and slowly emerge from these 'cocoon' they've created to protect themselves emotionally and literally transform into these amazing and beautiful human beings that inspire and support themselves and others. Somehow, PWA creates a space and supports that transformation!"—Murray Jose, PWA Executive Director and PHA

A Few of the Faces of PWA

Darien Taylor, former Board and staff member

Darien was one of the very first women with HIV in Canada to get involved in treatment activism and to open up the HIV movement to include women living with HIV. As both a staff and Board member with PWA over the years, she championed the growth of PWA and community response and was co-founder of Voices of Positive Women to which PWA gave early operational support.

"Darien has been such an important mentor to me, as I've learned to make meaning of my life as a positive young woman. She has so much history and wisdom

— I feel lucky to have had her as a guide."

—PHA and community activist

Suzanne Paddock,

"Suzanne is one of those people who doesn't like the spotlight but has a huge impact. She's been at PWA for 9 years, and she embodies deep compassion and caring for others. She's such a thoughtful, incisive listener, and she just cuts to the heart of what's most important, then uses that insight to make sure that the programs and services get stronger and stronger. She combines a pragmatic emphasis on practical support with continually reminding everyone that PWA is the place where people can dream new dreams again, that we have to serve the whole person." —PWA staff



Kenneth Poon, Speakers Bureau volunteer

Kenneth has been HIV+ for a very long time and in recent years also living without sight. He has endured failing health and nearly died. Gradually he fought his way back, is healthy, active and working. Kenneth shares his stories to educate others. As part of PWA's Speakers' Bureau, "Kenneth Poon tells his story of resilience in such a modest and dignified way. He lights up the room."

The Feel of Wednesdays

Wednesdays, our busiest day of the week, start off slow. The first shift of volunteers and staff arrive before the office opens. Front Desk volunteers brew our donated coffee, Essentials Market volunteers and staff don aprons and nametags and unload food deliveries from Second Harvest, FoodShare and local bakeries. The rest of staff open their calendars and check voicemail – everyone anticipating.

Fast forward to noon – the second shift of volunteers and staff arrive. More and more clients and visitors appear – some for the first time, others for the 100th. The slow, mellowness of the morning has gone. Everyone moving a bit faster with the flurry of people starting to arrive, the constant ringing of the Reception phone, opening of the elevator doors and all the resulting activity required to meet needs, make connections – whatever we can do to help.

At 2pm the Essentials Market opens and the Lounge and Activity Centre are brimming with people. Some are joking and laughing, some sitting quietly, some pacing around – impatiently, anxiously. Essentials Market volunteers whiz by on their way to serve the just delivered donated pastries and brew more coffee. People begin to head down the stairs to the Essentials Market. Front Desk volunteers offer constant greetings and inquiries of help – getting up and tracking down information. Service Access volunteers sit with people and assist with problem-solving when a request or a question is complicated or out of the ordinary. Intake volunteers walk new clients around the office introducing them to staff and showing them the space.

Staff walk up and down the hall escorting people – helping out with financial assistance cheques, ODSP inquiries, how to access medication (because I only have a 2 day supply left before I run out), booking a massage, an acupuncture (what about yoga, when is that?), talking about volunteering, getting harm reduction supplies, connecting for food delivery, getting some tokens, picking up movie passes. Does anyone know where the van keys are? Philanthropy and Finance & Administration are busy processing cheques, getting the mail, troubleshooting a computer issue, thanking a donor – every interaction is an opportunity.

By the evening, the pace slackens. The first shift of volunteers and staff has gone home, the second shift remains and the third shift has arrived; we are open late tonight 'til 8pm. As the evening winds down, more people gather around the Front Desk – like at a kitchen during a house party. Again, more laughter and joking around – to help relieve the stress of the day, have fun. Then the closing routines begin – mop floors, clean coffee pots, shred papers, wipe counters, replace empty toilet paper rolls, logoff computers, lock the elevator, turn off lights, set the alarm, lock the front door – good night everybody, see you tomorrow.



Making a Positive Difference

25 years of volunteer governance and leadership

Members of PWA's Board of Directors and Staff

Founding Board Members

James St James
Raymond Barnard
Russell A.

Rodney Polich
Chuck Grochmal
John Hamilton
Brian Ford
Brian Gilchrist
Paul Fairley
Alan McMurray
Arthur Ward
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Pamala Beavis
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Theresa Dobko
Thom Mackinnon
Thomas Egdorf
Todd Minerson
Tom Eatock
Tom Miller
Tomas Manjarrez
Tommy King
Tony Dacosta
Tracy Ribble
Tutsirai Makuwaza
Wayne Cook
Wayne Fitton
Wendy Robbins
Winthrop Booth
Woodrow White

Acknowledgements

As a member of the Toronto HIV+ and broader community and on behalf of PWA, it is with great humility that I convey appreciation for the development of this document. This project is a result of over 60 individual interviews, extensive reviews of historical documents and community knowledge. The impact on those involved has been profound and we have witnessed and experienced a wide range of powerful emotions. Underlying the work has been a commitment to honour the past, both individuals and experiences and reflects the inspiration that was shared and experienced by everyone in these conversations. It has truly been an honour to help lead this project and I hope that we have successfully conveyed the powerful and inspiring impact that PWA has had over 25 years.

In particular, we would like to acknowledge the following individuals for their contribution to this project:

Community members who shared their personal recollections and stories.

Cate Creede: Author

Joan Anderson: Facilitator and collector of community history

Interviewers: Christian Hui, Dave Sktich, Stafford Henry, Cory Garlough, Brian Scott, Jag Parmar, Robert Tomas

Review Team: Joan Anderson, Suzanne Paddock, Cate Creede, Robert Tomas, Murray Jose, Joanna Mackie, Stafford Henry, Mila Thirasack, Kristen Lawrie

Design: Raymond Helkio

Potential Group: Coordination and support

We gathered information, images and history from many sources. In particular we are grateful to:

Canadian Lesbian and Gay Archives (CLGA)

Project Remember www.projectremember.ca

Ontario AIDS Network

AIDS Committee of Toronto

—Murray Jose, Executive Director

The Essence of PWA: Into the future

If the history shows anything, it's that PWA has an essential DNA: affirming, community-creating, supportive, concretely helpful, creating space and resources for living as fully as possible. The Strategic Plan developed in 2011 captured the essence of PWA over its first 24 years as a foundation for moving into the future.

Vision: We live in affirming, sustaining communities where we find inspiration and support for our dreams, health, well-being and meaningful contributions.

Mission: We engage people living with HIV/AIDS in enhancing their health and well-being through practical and therapeutic support services and broader social change, and we inspire them to live into their dreams and discoveries.

Strategic directions/themes – future of PWA

Capacity Builder

Enhance awareness, resilience, strength, knowledge and skills among PHAs and the broader community.

Welcoming and Healing Space

A space where people experience affirmation, joy and inspiration and have creative and meaningful expressions of our experiences, lives and knowledge.

Creative Connector

A vibrant hub that connects people, creates communities and facilitates access to diverse services.

Health and Well-being Champion

Champion the self-determination and control over individual health and wellness and the inclusion of PHAs in educating healthcare providers.

Practical and Therapeutic Program Delivery

Incorporate the Engagement Cycle and increase the intentionality of therapeutic impacts within the provision of foundational practical support services.

“PWA is a critical part of keeping our shared history alive and never allowing our communities to forget the incredible sacrifices and resilience that is a part of our past.” —PHA and PWA staff



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