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Public Health Agency of Canada Agence de santé publique du Canada



AIDS NB TIMELINE

1985: AIDS NB Founded

1987: Incorporation, Helpline Begins

1988: 1st Execitive Director: Elaine Sussy

1990: 1st Arts Gala

1993: 1st Fredericton AIDS Walk

1996: AIDS NB and PHA Network of NB split

1998: Proclamation Scandal

1999: Last Arts Gala, Needle Exchange Begins

2002: 1st NB World AIDS Day Breakfast

2005: Loss of the Helpline

2007: 1st Red Tie Affair, Northern Office Opens

Early History

AIDS New Brunswick was started as a kind of rebellion. People involved with HIV in New Brunswick were told that the government would only require a number to identify people who had tested positive, and that only a person's doctor would know if he or she had tested positive. Grace Getty was working as a public health nurse at the time, and received reassurances from the chief medical officer that this was the case. However, she subsequently learned at a medical conference that district medical officers were going to doctors and collecting names of people who had been infected by the virus. It turned out that HIV/AIDS had been added to the communicable disease registry, which was reportable by name and not number, and that no provisions had been made for confidentiality. Outraged by this, Grace Getty, who had just completed her Master's thesis on the health and wellness of gay men, reached out to the gay community in or-



Executive Directors of AIDS NB: Elaine Sussey Claude Olivier Haley Flaro Jo Lang Nick Scott der to put a face on the disease. She connected with Hal Heinz. It was around his kitchen table in 1985 that he, Jim Goltz, and Grace Getty met and decided to create a non-profit organization that

would help those living with AIDS. They called it AIDS New Brunswick because they felt that there was a need for a provincial organization that would support communities throughout New Bruns-



Nick Scott, Ted Gaudet, Steve Patterson, Elaine Sussey

wick. Jim Goltz became the first board president. Anne Rowe was also instrumental in the founding of the organization. However, she was not able to be part of the initial group, as she was currently working as a civil servant for the department of health. She was aware of different AIDS groups spreading around the country and she was able to help the organization get funding. She later became the organizations first secretary.

Grace Getty reminisces: "From the very beginning we were an advocacy group that were there to kind of hold the government's feet to the fire." The group immediately went to the chief medical officer in the province, Dr. Dave Walters, who had made the promises concerning the confidentiality of HIV testing. He explained that the change was due to the fact that they had to protect the blood supply. However, he refused to admit that they were linking the list to the blood donor list. Despite this, around the province many different ERs were becoming equipped with lists of people who were known or suspected to have

HIV/AIDS. The lack of confidentiality was devastating to the community. Gay rights were far behind at the time, and a person could still be fired from their job just for being gay. Because of this many people were refusing to be tested and lived in fear. Anonymous testing was being performed in Maine, and volunteers from AIDS New Brunswick would take people across the boarder to get tested.

From the beginning there was a great emphasis on educating the community. When the organization was founded, it was known how HIV/AIDS was spread. However, there was still a lot of misinformation concerning the subject. Grace Getty, as a public health nurse, considered it vital that AIDS be discussed in a scientific, non-dogmatic way. In the early years, the organization did not have the resources to make their own educational materials so they often drew their materials from Toronto's organizations. They disseminated this information

by going to schools and community centres as well as sending speakers out to talk to the public.



AIDS New Brunswick is the community charity of Aitken House at UNB

They specifically targeted the gay community, as they were the most impacted, and many gay bars were generous enough to allow AIDS New Brunswick volunteers to distribute information in their establishments. In those early days everyone who worked for the organization did so on a volunteer basis. Almost immediately a board was formed to oversee the organization.



AIDS New Brunswick was employee of the year in 2010 for the Canadian Mental Health Association for the Fredericton/Oromocto Region Every task that the organization dealt with also had a separate committee. There

were committees for education, advocacy, networking, and so forth. These committees and the board were originally staffed by the founding members, but as more volunteers joined they expanded to accommodate them. Within a year, they developed the helpline. In 1988, the organization had received federal funding and decided to hire an executive director. Elaine Sussey, a social worker, was hired as the first executive director. It was decided that the office needed a continual presence and Elaine Sussey was instrumental in forming links with other AIDS societies across the country and with the burgeoning PHA community.

Page 11

Helpline

In October 1987, AIDS New Brunswick began operating a helpline. It was originally started because of the high volume of phone calls to the organization from people not only looking for information about AIDS, but also from people with AIDS looking for help. It was decided that AIDS New Brunswick needed to operate a toll-free line in order to better help their clientele, as many of them lived throughout the province and many lived below the poverty line. It was almost a year before AIDS New Brunswick was able to obtain the provincial funding necessary for the helpline. The kinds of calls that were received varied greatly. Some people were only looking for information, some were looking for counseling, some were looking to vent, and some people just wanted to connect with someone. In 1999 an enhanced database for gathering information related to HIV education and prevention was put into place. This system allowed for a greater level of analysis to be done with the helpline data.

Early on in its history, Grace Getty discovered that the government wanted to shut down the helpline and replace

it with their own, which would be staffed by public nurses. She and Elaine Sussey



AIDS New Brunswick once shared office space with Healing Our Nations

Page 13

immediately attempted to contact the health minister for a comment on the situation. However, the health minister refused to respond to their calls. Getty then contacted local MLAs, who claimed not to know of any such thing. The press at that point had caught wind of the plan and started requesting interviews. Getty and Sussey decided that they would hold a press conference, but before they did so they contacted the Premier's office to explain that they had been unable to contact the minister of health, and that they had been contacted by the press. Shortly after the press conference, Grace was called by the minister of health, who wanted to meet with them. When the health minister was confronted with the accusations. he steadfastly denied it. However, within

a month, Getty and Sussey were once again called into the minister's office.



In 2003 the helpline had 1,745 calls They were treated to ads for a tollfree line that was staffed by public nurses. However, at this point it was only going to be a research study on the viability of

such a service, and the health minister assured Grace that they would return funding to AIDS New Brunswick helpline after the study was finished.

Although the funding for the helpline was initially returned, the helpline was shut down in favour of the government run telecare. This was a major blow to





On June 26 ,1995 a tree was planted at Odell Parkcommemorating thosewho have died fromHIV/AIDS the organization, which lost two staff positions: the Program and Education Coordinators. Both were specially trained to deal with phone calls from the

helpline. At the same time, the public health nurses that were handling telecare were only prepared to discuss medical issues, and the counseling aspect of the helpline was lost, to much public dismay. Telecare also began forwarding its AIDS related calls to AIDS New Brunswick. AIDS New Brunswick started an Infoline, which is for anyone who wants to call in for information on the virus. Unfortunately, without the funding for a social worker or councilor, the Infoline is unable to help the community to the same extent that the helpline did. The loss of the helpline also had repercussions that echoed throughout the entire organization. The loss of the Program and Education Coordinators meant that many of their responsibilities were shifted on to other staff members. Also, the loss of the helpline ushered in a period of frequent staff turnovers in the organization, which hindered its ability to function at full capacity.



PHA Network of NB

In 1996 there was a schism between the PHA community and AIDS New Brunswick. It was over PHA emergency funds that AIDS New Brunswick managed on behalf of the PHA community. The PHA community successfully convinced the Public Health Agency of Canada to allow them to take the special funding away from AIDS New Brunswick. On top of this, throughout the history of AIDS New Brunswick there had always been a tension due to the allocation of funds. AIDS New Brunswick was founded to emphasize both the support of PHAs and to focus on prevention and education. Many PHAs felt that AIDS New Brunswick allocated too much of its funds to prevention and education and not enough to helping them. The PHA community then created their own organization, which they called The PHA Network of New

Brunswick. Unlike AIDS New Brunswick, The PHA Network of New Brunswick was staffed entirely from PHAs from the province. The Network was governed by

six board members and a president, and it employed two staff members. Ted Gaudet was made the first president



Starting in 2008 the public library in Fredericton began housing AIDS New Brunswick's resource library materials creating HIV/AIDS section that continues to be updated yearly.

of the organization. They offered many of the same services that AIDS New Brunswick offered to the PHA commu-

Page 19

nity, including counseling, a newsletter, and gatherings. Because of this, AIDS New Brunswick phased out many of its PHA services, referring clients to the Network for them. The helpline did continue to run, although it received calls on a much less frequent basis. After Ted Gaudet stepped down as president, the Network experienced problems in leadership. The accountability of the Network was questioned and it lost much of its funding. Ted Gaudet stepped in to try to save the Network, but it was too late and it collapsed only a few years after its creation. After the Network collapsed, the PHA community returned to AIDS New Brunswick, which once again began running all of the PHA services that had been deferred to the Network. However, this was done on

fewer resources as the funding from the Public Health Agency of Canada was never returned.. Although The PHA Network of New Brunswick failed, it was a triumphant show of power and community for PHAs living in New Brunswick.

"It didn't last very long, but for me it was the best show of empowering a community to take action against something that we knew was essential for us, as a community." –Ted Gaudet



Arts Gala

The Art Gala was one of AIDS New Brunswick's highest profile fundraising events. It spanned a decade, running from 1990 until the last one on November 20th 1999. It was started by a volunteer, who had close ties with the local art community. She was able to convince many artists to donate their works for the event. It was an auction and a dance with some food and entertainment. It ran for several years before the energy and expense of putting it on outweighed the money raised from fundraising. People were starting to suspect that people were looking for bargains more than they were trying to help the organization. On top of this the arts community was experiencing donor fatigue from the yearly event.

Red Tie Affair

The Red Tie Affair is a major fundraising event that was intended to be the suc-



Anne Moore and Tracy Rickards

cessor to the Art Gala. It was started by Anne Moore, the chair of the funds development committee,

in 2007. The previous year, AIDS New Brunswick was forced to cancel its annual fall forum for PHAs. The event was created in order to make sure that the organization would not need to cancel the forum again. Because of this, all proceeds from the Red Tie Affair go to the PHA fund, which is used to finance retreats and forums. At the first Red Tie Affair, participants would meet at the Crowne Plaza Hotel for hors d'oeuvres, and then go to one of four participating restaurants: Brew-

bakers, Crowne Plaza



In 2010, AIDS NB had 3285 volunteer hours

Hotel, Racines, or The Blue Door. After dinner, the guests would return to the Crowne Plaza for dessert and entertainment. In subsequent years, the Red Tie Affair lowered the amount of participat-

"In past years, we focused more on the dining experience. With the weather, we didn't want to have people roaming the streets in the dead of February, so we've focused the event more around the entertainment." - Nick Scott



AIDS NB Cookbook

Page 25

ing restaurant, until the fourth annual Red Tie event was held entirely at the Crowne Plaza. The Red Tie Affair had always involved entertainment, but the fourth Red Tie Affair focused more heavily on it as all guests remained in the same place the whole night. This entertain-

ment included Steve Patterson and 80s cover band Pretty in Pink, both of which were used heavily in the Affair"s promotions.

Needle Exchange

The Needle Exchange was the brain child of AIDS New Brunswick founder Grace Getty and former Board President Margaret Dykeman. It was formed in 1999. The Fredericton police force was having problems with used syringes being left out in public, especially along the waterfront. The police then decided that they would like to begin a harm reduction campaign. Grace Getty, who was watching the announcement on television, immediately called the police department and volunteered to create a harm reduction committee. The committee was not under AIDS New Brunswick, despite the fact that several of its members sat on it. It took about a year for the committee to get support from the province, create a training procedure, and start the Needle Exchange. Margaret Dykeman

commented that "[the needle exchange] was an evolution of where HIV was going in the 90's-2000's. This was because drug users were at a high risk of HIV infection due to the fact that many of them shared needles.



In 1999 the Needle Exchange took in over 3,000 used needles and gave out over 1,600 clean needles Originally, the Needle Exchange operated out of the ambulance bay in the Victoria Health Centre, and was staffed

by volunteers. However, problems arose due to confidentiality. This was due to the fact that the ambulance bay had very bright lights, and it was a struggle to keep them down so that people would

be more likely to come to the exchange. Eventually, due to a decreasing turnout, the committee decided to



In 2010 the Needle Exchange gave out 76, 644 needles and took in 44, 565. 367 clients used the service 1,115 times.

place the Needle Exchange under AIDS New Brunswick and move it into their offices. The reasoning behind this was to have a higher level of confidentiality, and to have a dedicated staff member involved with it who could better keep track of the data in order to get better support from the province. The province originally gave the Needle Exchange supplies instead of direct funding. However, in 2008 the province decided to stop supplying the Needle Exchange and instead began funding it so that the Needle Exchange would be responsible for its own staff and supply needs. This led the organization to partner itself with AIDS Saint John and SIDA AIDS Moncton for its supply needs. The idea behind the partnership was to get a better price for their supplies by ordering in bulk.

"If this service didn't exist it would be a terrible shame. People would start using their old rigs and HIV and Hep C would start to rise again. People come here and they feel safe. this is a nonjudgmental space, and for many it is the only one they have. I hope that this service never goes away"

- Anonymous

Health & Wellness Committee

The Health and Wellness Committee is the PHA arm of AIDS New Brunswick. It was originally called the PLWHIV/AIDS



The Expenses of the Arts Gala increased by 629.5 percent between 1990 and 1998 Committee of New Brunswick, but it changed its name to The Health and Welfare Committee

of People Living with HIV and AIDS in New Brunswick until 2009, when it was changed again to simply The Health and Wellness Committee. The organization of the committee has changed over the years. Originally the PHA community would vote on a steering committee of six people who essentially were The Health and Wellness Committee. In time, it was changed so that all PHAs who wanted to be part of the committee would be part of it, and the steering committee would act as a coordinators of the committee's activities. The purpose of the committee is to ensure that PHAs have a voice in AIDS New Brunswick. They are responsible for helping AIDS New Brunswick organize PHA retreats, forums and newsletter, as well as suggesting improvements to their programs and suggesting new ones.

"It's just a very commonsense way for the community to come together and agree on something." Ted Gaudet

PHA Retreats and Forums

The PHA Retreats and Forums are some of the most important events that AIDS New Brunswick does for the PHA



community. Originally, they were funded by Health Canada and the (AIDS Community Action Program) ACAP. These organizations put a special emphasis on skill building and knowledge transfer, so the bulk of the events were spent

in seminars and presentations. After these organizations stopped funding the events, AIDS New Brunswick was forced to find other ways to fund them, such as the Red Tie Affair. The format of the events is now far looser. There is still an emphasis on skill building, but now there is more time for PHAs to network and talk to each other. As Ted Gaudet points out, "New Brunswick is very rural, so how often do you get to chat with someone from Edmunston, or Bathurst, or someone from St. Stephen?" The retreats and forums are a very rare opportunity for the PHA community to come together, share information, and grow as a community.

"Last year when the forum was cancelled, that really hit me hard. Then Jocelyn [Paul] died in March very suddenly....I said this is enough. We need to make sure that this does not fail again this year, we really need to do something about this fall forum to make it happen" - Anne Moore

Page 33

AIDS Walk

The AIDS Walk started with the Canadian AIDS Society (CAS). They were trying to spread the AIDS Walk movement across Canada to the local AIDS groups. AIDS New Brunswick partnered with CAS and Fredericton's first AIDS Walk was in 1993. After a period of time with CAS, AIDS New Brunswick noticed a sharp decline in the participants of the AIDS Walk. In order to combat this, AIDS New Brunswick decided to partner with the Stephen Lewis foundation with the hope that by partnering with a high profile foundation like Stephen Lewis, the AIDS Walk would see a higher turnout. The Stephen Lewis foundation at the time was being very heavily publicized for its work with AIDS in Africa. Also during this time, organization of the AIDS Walk shifted more heavily to St. Thomas Univer-



AIDS Walk

sity, as main proponents of partnering with Stephen Lewis

were closely affiliated with the school. During its time being partnered with the Stephen Lewis foundation, the AIDS Walk experienced unprecedented popularity, and the event quickly grew in size. As part of its partnership with Stephen Lewis, half of the proceeds of the march would go to the foundation, which in turn sent that money for aid in Africa. This stipulation was a problem with many PHA's in the community, who thought that it would be better to have all of the money go to help those locally instead of sending half of it to Africa. At the same time, there was criticism that the walk was no longer about AIDS prevention, and lacked community involvement. This criticism



2006 a cookbook was developed for the PHA community. In 2010 a revised edition came out. stemmed from the fact that the walk had become dominated primarily with students, and outside community

involvement was dropping. Despite students being a major target in AIDS awareness and the large turnout that they brought, many people in the


community felt that the AIDS Walk was turning more into a student event than

a community one. Also, due in part to the fact that it was primarily students who participated, the AIDS Walk was



The Jocelyn Paul Memorial Skills Building fund for PHAs was started in 2004 in order to allow clients to attend national skill building events.

not making very much money for the organization, which only further exacerbated the situation with the PHA community. In 2008, due to PHA objections and disappointing fundraising returns, AIDS New Brunswick decided to no longer partner with the Stephen



Memorial Tree in Odell Park Lewis foundation, which led to a falling out with St. Thomas the subsequent year. The AIDS Walk was relocated away from the school. Afterwards AIDS New Brunswick went back to partnering with CAS. After ending the partnership

with Stephen Lewis, participation and publicity for the event dropped significantly, especially among students. Due to the dwindling participation, the AIDS Walk made about as much money for the organization as when it had been partnered with Stephen Lewis.

Procalamation Scandal

In 1998, AIDS New Brunswick made local headlines because of a scandal involving the local government and gay pride. Mayor Brad Woodside was asked to give a welcoming address to AIDS Walk participants that year. He was unable to attend due to family commitments, so instead Councilor Joel Richardson volunteered to participate and give the address on behalf of the mayor. Prior to this time, Mayor Woodside was very hesitant to allow a proclamation of gay pride days in Fredericton and had been steadfastly blocking the issue for a decade. Two days before the AIDS Walk, Councilor Richardson was quoted by the Daily Gleaner in a story called "Proclamation Debate Lives" backing mayor Woodside's beliefs against a proclamation for gay pride days, and saying: "Why couldn't a group like the Hell's Angels, why couldn't they have a Hell's Angels Day? It's their right and choice." Both he and mayor Woodside wanted to simply remove the institution of proclamations altogether. AIDS New Bruns-

wick and the gay community were extremely upset that the councilor had compared gay people to a



In 2010 Mayor Brad Woodside attended the Fredericton AIDS Walk for the first time

known criminal organization, and AIDS New Brunswick asked the Councilor not to attend the AIDS Walk. Despite this, Councilor Richardson did attend the AIDS Walk, but was not asked to speak. He felt that he was being discriminated against, and that his views on the proclamation and gay pride had no bearing on his views on HIV/ AIDS and the AIDS Walk. He stated that AIDS New Brunswick was being bigoted against heterosexual people. The Executive Director at the time, Elaine Sussey, issued a statement to the press in which she stated "I would like to emphatically state that HIV does not discriminate nor does AIDS New Brunswick. Our reaction would have been the same if discriminatory remarks had been made toward any group we serve." From the beginning, AIDS New Brunswick, like all AIDS organizations, had a focus on gay men. The reasoning behind this is because they are at the greatest risk. However, AIDS New Brunswick was not founded to only

serve the gay community. Jim Goltz, the first president of AIDS New Brunswick, concerning the founding of the organization, stated that "we decided to create a community-based organization with representation from all corners of the community." **Councilor Richardson publicly** demanded an apology from the organization, or he threatened that he would file a human-rights complaint against them because he was discriminated against by not being allowed to speak at the AIDS Walk. Elaine Sussey stated to the press that AIDS New Brunswick would not apologize.

"We're not discriminating against him in terms of providing him with any kind of public service. If Richardson has a need for AIDS education or support, the organization will be there for him. But when it comes to events AIDS New Brunswick hosts, it can invite whomever it likes to speak. That's not a public service." - Elaine Sussey



Page 43

World AIDS Day Breakfast

World AIDS Day has been commemorated around the globe since 1988. In 2002 the three New Brunswick AIDS organizations began hosting a breakfast on World AIDS Day. This was started by the Executive Directors of each organization: Haley Flaro from AIDS New Brunswick, Julie Dingwell from AIDS Saint John, and Debbie Warren from SIDA AIDS Moncton. When the Lieutenant Governor Herménégilde Chaisson became the honourary patron of the New Brunswick AIDS organizations, he hosted the event. The breakfast is by invitation only and it allows the organizations a chance to raise HIV/AIDS awareness among policy makers. When Graydon Nicholas became Lieutenant Governor, he continued being a patron for the local AIDS organizations.

Northern Expansion

From an early time in AIDS New Brunswick, the organization was involved with the North



2009 AIDS New Brunswick received the MAC AIDS Fund Grant for the Positive Nutrition Program of the province, specifically with Bathurst. An early board member headed up a small volunteer presence in the

area. The presence was eventually lost, but in 2007 AIDS New Brunswick received the funding to hire someone part-time in order to open an office and work with the francophone community. An office was established in the Bathurst Youth Centre. In 2009, AIDS New Brunswick was approached by the government to work with the francophone youth in the north of the province. Because of this, AIDS New Brunswick was able to hire another part-time staff member in the north, who would work primarily with the youth. The first hired was Tanya Amberman. However, since receiving funding for another part-time staff member, AIDS New Brunswick in Bathurst has varied from having two part-time staff members and one fulltime. In 2010, the office was moved to the Keystone Development building.

Ted Gaudet



Ted Gaudent and Elaine Sussey

Ted Gaudet is AIDS New Brunswick's longest serving member, having joined in 1993, and along with James Lord Edwards is one of the major spokespersons for the PHA community. He was diagnosed

with HIV in Vancouver in 1988. After returning to the Maritimes, it was suggested by his family that he contact AIDS New Brunswick, which he joined as a client. He became the chair of the PHA Committee the following year. AIDS New Brunswick had frequently had problems putting a face to the virus because of the social stigma involved in disclosing HIV status. In 1994, he went public and allowed AIDS New Brunswick to use his face.

"I discussed it with my family and made the decision that the only way to move forward is to start putting my face to HIV, so I went public and had CTV come and do a live interview and I talked about being HIV positive and The PHA Committee."

He was employed on a short-term contract to organize and coordinate a fundraising event for AIDS New Brunswick's 10th Anniversary in 1996. Also in 1996, the PHA community broke off from AIDS New Brunswick and started the PHA Network of New Brunswick. Ted Gaudet acted as its first president. When the network broke up, Gaudet,



Ted Gaudet's Prizes: 2002 Medal Recipient: Queen's Jubilee Medal for Community Work 2001 Medal Recipient: UN International Year of the Volunteer: New Brunswick 2010 City of Fredericton Unsung Hero Award

along with the rest of the PHA community returned to the organization. He became a board member for the first time in 1999, and he has subsequently sat on the board three more times: 1994-5, 2002-03 and 2010-present. Gaudet is currently active in the PHA community, acting as a spokesman for AIDS New Brunswick and as the chair of The Health and Wellness

Page 49

Committee.





This is dedicated to the memory of those who have passed away as a result of HIV/AIDS in the last 25 years.

If your loved one passed away from this disease and you would like AIDS NB to commemorate their life in our newsletter, please contact _____.



Special Thanks

AIDS New Brunswick would like to thank the following contributors for their assistance in assembling this history project:

Alana Lawson Nick Scott Diedre Smith Jennifer Dion Matthew Smith Ted Gaudet Grace Getty Margaret Dykeman Gayle MacDonald Haley Flaro Jim Goltz Samire Ismaili

Conclusion

"We chose to do the 25th anniversary history project because we wanted to do something to commemorate the rich past of the organization and its contribution to the national [AIDS movement]. We wanted to raise the profile of the organization and raise the awareness of what this organization has accomplished and their value to the community. The history project tells a struggle that is familiar to all non-profit organizations in our efforts to serve the community. It is an opportunity for the organization and the community to stop and take note of what has been accomplished and to take note of where the organization has come from and how we want to handle things differently. It allows us to see who we are." - Nick Scott

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Page 53