

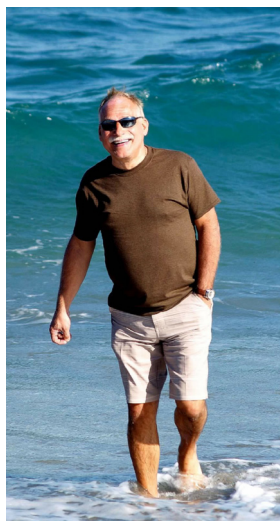


30 Positive Years

On the 30th Anniversary of AIDS Walk Delaware

An interview with Peter Chakonas

In September 1986, Peter Chakonas, of Wilmington, DE, and his friends from the Delaware Lesbian Gay Health Advocates (DLGHA), founded and organized the first AIDS Walk in Delaware. Earlier that Spring, Peter had attended the first AIDS Walk in New York City, and thought "I'm going to do this in Wilmington."



"I was 25 years old when I was diagnosed," says Peter. "It was the year after Rock Hudson died from AIDS – also known as 'Gay cancer' and the entire community was terrified. I had been feeling sick for a few weeks when I decided to go to my doctor. He left the room and came back into the room dressed from head to toe with a mask and all – like he was ready to do surgery."

"I was not prepared for the call about a week later I got from his nurse," Peter continued. "My test was positive she said. I asked if I could come in to talk to the doctor. She said that the doctor did not want to see me anymore and could do nothing for me. She said I had from six months to a year to live. Imagine how a 25 year old would take that news."

Peter went to the newly created AIDS clinic at Wilmington Hospital. He remembers being very scared and that his mother – who supported him in everything – was there with him. He met a very compassionate nurse, Arlene, who reassured him that he was healthier than many of the patients she had seen (and healthier than many of her co-workers!). Peter felt better already, but, of course, there was no treatment available; just the loving support of his mother, until she passed away about one year after his diagnosis. No boyfriend, no lover, Peter moved to Virginia Beach. It was there that his roommate, a nurse, told him about some experimental treatments being done at the National Institutes of Health (NIH). Peter drove up and got on a waiting list for the drug studies, where he had to commit to taking three drugs every day: AZT, a pill and two injections, alpha interferon and granulocyte-macrophage colony-stimulating factor (known as GMCSF) to try to boost his immune response.

30TH AIDS WALK DELAWARE, SATURDAY, SEPTEMBER 24

Register or Donate Today for AIDS WALK DELAWARE – the State's Largest HIV/AIDS Fundraiser!



AIDS Delaware and the Delaware HIV Consortium are pleased to announce that the 30th anniversary of AIDS Walk Delaware will be held on Saturday, September 24 at Dravo Plaza, Riverfront Wilmington, and at Grove Park, Rehoboth Beach. Everyone is invited to be a part of this annual event which raises funds

for local AIDS service organizations while increasing awareness about HIV/AIDS. Proceeds help support services to more than 3,700 Delawareans living with HIV/AIDS, plus prevention and educational programs to stop the spread of the virus that causes HIV/AIDS. Whether this is your first AIDS Walk, or your twenty-ninth, every walker and every dollar counts in the fight against HIV/AIDS. Register to walk today at www.aidswalkdelaware.org and ask your friends and family to join you.

www.aidswalkdelaware.org

"The first night of the treatment was like having the flu times ten," Peter said. He moved in with a close friend in DC and continued treatment, but the side effects were terrible. He went to stay with his godfather, Dale, who lived in Florida, and recuperated from the experience – which had made his hair fall out, lost a lot of weight, and drove him to physical exhaustion. Peter says this was a turning point for him, all the while continuing his experimental treatment.

About a year in half later life got better as he adjusted to the meds, and he moved back to his hometown of Wilmington, taking the Metroliner down to DC for treatment. He made friends with a frequent traveler – Delaware's senator – Joe Biden.

"He never asked about my status and I certainly never offered," says Peter, "But over time, we got to talk to each other often. I told him how I dreamed of starting and running my own

(Cont'd on page 2)

(Cont'd from Page 1 - 30 Positive Years)

business. He said 'You will do it, trust me.' He always had an encouraging word. Little did he know that I was on every type of assistance available, from general assistance to food stamps. It was how I survived while being treated."

"Just be a true person and a person of your word," he told me. "Many days when I felt so sick coming home on the train, it was Joe's familiar smile and encouragement that gave me hope. I will be grateful for his wisdom and kindness forever. He was an unexpected delight on my trip to death and back."

The following year, Peter moved to Tampa, Florida, where he met the love of his life, Michael, who was positive and also taking "the cocktail." Michael had stood him up on their first date because he was afraid to tell Peter his secret. Peter said "Welcome to my world!" After being happily together for close to 10 years, Michael passed away in 1998 and Peter was once again single. "Not a day goes by that I don't think of him."

"I was now 37 being single again and I remember the countless rejections when I told people I was HIV positive," says Peter. "A friend of mine describes it as being on the Island of Misfit Toys. 'Yes, Rudolph the Red Nosed Reindeer, no one wanted the toys because they were different.' Kind of sad that in 30 years, a lot has changed but not the stigma of HIV."

"To those who still harbor stigma and fear, try walking in my shoes for 30 years." Peter said. "I have been HIV positive and I am one of the longest living HIV cases in the state of Delaware. Yes, I was a client of AIDS Delaware at one time, on Medicaid, and used Ryan White Care Act to pay my rent. Today I don't need any of that because I own a successful business that I built from the ground up. I volunteer my time and my money to help people with HIV/AIDS. And I have watched my closest friends lose their fight with HIV/AIDS. Now I get it. Trust me, I have had this for 30 years it is not something I would wish on anyone, but it's 2016 and I'm still alive!"

"HIV does not define me," Peter concluded. "It's just one small part of who I am."

Try Walking In My Shoes



Peter Chakonas, owner of Pride Klean, Inc., and a proud Board of Trustees member of the Delaware HIV Consortium, is helping organize and recruit donations for this, the 30th annual AIDS Walk Delaware. He will be in Rehoboth at Grove Park for this year's Walk, one of two locations. Consider making a donation or registering to walk at www.aidswalkdelaware.org. Tell them that Peter sent you.

FROM THE EXECUTIVE DIRECTOR

Dear Friends of the Consortium,

I hope this newsletter finds you well – we thank you for your continued support of the Consortium and our mission! I hope you enjoyed your summer and that you are able to take some time this early Fall to relax and enjoy your friends and family.

For us at the Consortium, this is a busy time: with Fall being the time to file for grants from many foundations, we are busy looking to an AIDS-free future, identifying unmet needs, and seeing what services we can offer to get us to this goal. We are also working with our partners at AIDS Delaware to assure a successful AIDS Walk in September, and reviewing our goals and objectives for the coming year. We are excited by the promising future ahead – with new programs, services and activities to help Delawareans with HIV/AIDS improve their lives and to prevent more HIV infection.

We are grateful to Walgreens and all of our corporate and individual supporters who help the Consortium continue its fight against AIDS. We are excited that Walgreens and Iron Hill Brewery & Restaurant will be joining us again to make the 2016 AIDS Walk Delaware – September 24 in Wilmington and Rehoboth – a huge success. This year is the 30th anniversary of AIDS Walk Delaware and I hope you will support us this year by going to www.aidswalkdelaware.org and making a donation in support of the Consortium's walk teams. You can also sign up to walk with the Consortium's Walk team, either in Wilmington or Rehoboth.

We are also excited about the new programs we will be implementing in the coming months: an expanded PrEP effort, new HIV testing initiatives, a Hepatitis website, and a Hepatitis C education and linkage to care program.

Once again, I'd like to thank you for your support of the Delaware HIV Consortium and our programs, allowing us to continue to meet our clients' needs.

Until there's a cure,

A handwritten signature in black ink, appearing to read "Peter".

CASE MANAGEMENT UPDATE

In the past three years, the Consortium's Ryan White Case Management service has gone from serving 40 clients in 2013 to 254 clients statewide. With the addition of staff to serve these clients, we also have staff based in Georgetown, Sussex County and Smyrna, Kent County. In the coming months, our staff in Smyrna and Georgetown will begin serving clients once a week at Walgreen's locations in Lewes and Dover.



The Consortium's Case Management service is designed to help our clients manage the HIV infection by connecting them to needed support services, helping them with medication management, and keeping them engaged in their healthcare. If you know someone who would benefit from these support services, please call **Raphia Noubissi**, Case Management supervisor, at 302-654-5471 or email rnoubissi@delawarehiv.org.

FREE HIV COUNSELING & TESTING PROGRAM UPDATE

The Consortium's HIV Counseling & Testing Program is planning on expanding soon, with the hiring of a staff tester. The program, which is supported by fundraising and grant writing, has been successfully increasing the number of tests administered each of the past three years. Currently, we have tested more than 180 people in the six months of 2016, with one person identified as positive and linked to care. Our current program includes testing at three Walgreens locations in the Wilmington area, as well as testing by appointment at the Consortium's office.



Consortium tester, Kenya Smoke

We have applied for grant funding to expand our testing to another community-based location, and to offer Hepatitis C testing as well. The Consortium is committed to identifying members of our community who are infected and linking them to treatment. We would like to thank our partners – Walgreens, Orasure Technologies, Christiana Care and Westside Health – for the spirit of collaboration in offering this free service to our community, at no cost to the State.

CONSORTIUM HOUSING PROGRAM UPDATE

Supportive Housing. The Consortium is pleased to announce the renewal of our grant funding for our Permanent Supportive Housing program for women – WomenSpace – through the Housing Opportunities for People with AIDS (HOPWA). The residential program, operated by Connections CSP, has been approved for funding for another three years.

Rental Assistance Program. We are also pleased to report that we are now providing housing assistance vouchers for 132 households, helping provide stable housing for 138 persons living with HIV/AIDS and 91 family members. So far this year, we have been able to move 55 people off the housing waiting list. Of the 29 eligible applicants, 20 have begun receiving monthly rental assistance. Housing staff continues to work with the remaining eligible clients who are in the process of finding suitable rental housing.

Housing Outlook. For the current grant cycle, the HOPWA program which funds our housing program saw slightly decreased funding. Luckily, funding for housing through the Ryan White Act provided a slight increase, which compensated for this shortfall. The Consortium is grateful to the State of Delaware for increased funding for housing programs for people with HIV/AIDS, and we have applied for private foundation funding that will allow us to provide even more services to our clients.

PREP INITIATIVE UPDATE

In September 2015, the Consortium was awarded a grant from Gilead Sciences in support of a new education program to increase access to Pre-Exposure Prophylaxis – PrEP. As our grant period comes to an end, we wanted to report to you on the many successes of the program, which we call the Delaware PrEP Education Initiative. Here are highlights from the past year:

- A PrEP Advisory Committee was formed in collaboration with 19 representatives from state government, health system, community-based organizations, and AIDS service organizations to help steer the activities of the grant.
- A program logo and website – DelawarePrEP.org – were developed and launched as a platform for educational materials for both potential users and prescribers.
- A provider relations initiative was launched to recruit new prescribers. At the beginning, we determined that there were four prescribers in the state and our goal was eight. At this time, there are 20 prescribers at 15 locations throughout Delaware.
- A PrEP Summit was held in May with more than 200 attendees, with national and regional experts speaking, and more than 50 potential subscribers in attendance. PrEP providers continue to request education from Mid-Atlantic AIDS Education and Training Center (AETC) and then enroll as providers on DelawarePrEP.org.
- An outreach and advertising program was implemented using various statewide media. In turn, this drove traffic to the DelawarePrEP.org website, tripling traffic from April to July.

In August, Gilead announced that they would be funding continued and expanded grants for PrEP throughout the country. The Consortium is committed to continuing education about this important tool in HIV/AIDS prevention and will be applying for continued funding.

HIV COMMUNITY PLANNING FORMS POSITIVE ACTION COMMITTEE

One of the Consortium's roles in coordinating care for people with HIV in Delaware, the HIV Community Planning process, has been a state-awarded contract for many years. This role, coordinated by Community Planning Manager Tyler Berl, is to organize key stakeholders and members of the HIV/AIDS Community and to develop plans to improve both the care continuum and HIV prevention activities.

Recently, at the suggestion of the HIV Community Planning Committee, Tyler called for and met with eight volunteers who have formed a group – the Positive Action Committee – to help the Community Planning Group develop plans that are inclusive of and better designed for members of the HIV/AIDS community's needs. If you would like to participate, contact Tyler at 302-654-5471 or email him at tberl@delawarehiv.org.

EASY AS PIE, OCTOBER 10 - NOVEMBER 22

Our “Easy as Pie” fundraiser is set to begin in early October. Linvilla Orchards, Pellman Bakery, Desserts by Jekeitta, and Achenbach Bakery will be participating once again with all your favorite pies and cakes and some new choices planned! New to the menu this year are two offerings from Achenbach: **Boston Crème Cake** and **Marble Cake** (see photos right). To place an order, go to delawarehiv.org in October. We will send you an email to remind you! If you belong to a place of worship, business, or civic group and you would like to help us out with “Easy as Pie,” contact Scott at 302-654-5471 or email: smackenzie@delawarehiv.org.



2016 HOLIDAY ORNAMENTS ON SALE

The 2016 Holiday Ornaments from the Consortium are now available! This year’s ornaments are made of fine porcelain with 24-karat gold accents. This year we are offering two ornaments: “A Gathering of Hope” and “A Gift of Hope” which depicts delightful, stylized elves in a graffiti art style inspired the artwork of Keith Haring - an early pioneer in the fight against HIV/AIDS. The ornament is being sold for \$20 (+\$3 shipping and handling for online orders) as a fundraiser in support of the Consortium’s services to people with HIV/AIDS. Ornaments can be ordered at www.delawarehiv.org or at CAMP Rehoboth or PRIDE Bookstore in Rehoboth.



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