

Testimonials from Volunteers,

Staff and Advisory Board Members

Twenty-five years! Why, it seems almost like yesterday when a prominent Pittsburgh gay activist contacted me to ask, or should I say, beg me to enlist in the Pitt Men's Study. As a forty-two year old gay male who had been witnessing friends and acquaintances become infected with this hither-to-unknown and increasingly fatal disease, he really didn't have to beg me. I willingly jumped at the chance to be able to do something, no matter how small it might be, to help medical research determine the cause of this disease recently named AIDS.

Twenty-five years translates into a quarter of a century and more than one third of my lifetime. I did not realize that when I enrolled in the study, I would still be a participant twenty-five years later. In the early years, I, like most, was hoping for a quick discovery of its cause that would lead to a rapid development of an effective treatment and prevention with a vaccine. Sadly, it was not to be so; and thus began a prolonged study of the cause, effects, treatments and prevention of AIDS.

As one of the earliest volunteers, I have witnessed an evolving troupe of staff; and I must say that it has been a great pleasure on my part to have been able to interact with each and every one during my visits—all of the current staff, those who have gone on to other endeavors, and those who have passed on.

Sometimes when I feel that I'm really not making a viable and significant contribution to AIDS research, an article appears in our news letter telling of a recent development or advancement in the study that was achieved at the Pitt Men's Study. This information, when combined with successes elsewhere and published in the news media, dispels my doubts and reaffirms for me the importance of all volunteers, regardless of their HIV status; and it doesn't matter if they are part of the PMS or another study group any where else in the world.

In eight years, I will be seventy-five, and if I am fortunate to live that long, I will have lived three quarters of a century. If I am still part of the PMS, I will have spent over 42% of my lifetime in this study. How long will I be able to effectively continue as part of this valuable research? I do not know. However, if I'm with the study for another twenty-five years, I will be ninety-two and will have spent over half of my life in the study! If I am still alive then, I will have outlived both of my parents; and no doubt by that time, I fully expect to have a weakened body and some degree of dementia.

When I am no longer able to participate in this study, for whatever reason, I know that I, along with all of the other unknown volunteers world wide, both living and deceased, will have had, in some way, made a significant contribution to the eventual eradication of AIDS and to the overall improved health of the world.

Somewhere between now and when I may reach ninety-two, if I do, I hope that we can stop the counting. However, if I am unfortunate enough not to be here by the time that the counting ends, I hope that we continue to count the years until it is no longer necessary.

Kenneth

I was hired to work at the Pitt Men's Study in 1994 as a technician at the Pittsburgh clinic and soon learned how to interview participants, organized community outreach events, make appointments, and draw blood—thanks to the training and expertise of all the staff. Although I worked in a bunch of different settings, this was my first professional job where I met the most wonderful staff who became my extended family. It truly was the best experience in my life professionally, and working for PMS prepared me for a future in public health. It was also a really great way to be connected to the gay community in Pittsburgh. Seeing men come into the study day in and day out, providing much of their time to help fight the disease or to find a glimmer of hope by donating blood samples, offering up their personal information—it was and still is a true research project where everyone is working towards that same light at the end of the tunnel, no more deaths to HIV, and gave me something to be proud of each day.

Well, I know now from my experience in the field that we have not gotten to that end. However, so much progress has been made by the likes of the physicians, researchers, clinicians, support and laboratory staff, community advisory members, partner organizations, and the list goes on...all working towards that end. There is no study of its kind and no group of more dedicated staff and volunteers working towards helping those living with HIV/AIDS.

Thanks for all the hard work and dedication of all involved in MACS and for the unbelievable amount of HIV research the study has garnered. I truly appreciate being part of this history.

Matthew Moyer MPH

Research Specialist

1994-2004

I've been going to the Pitt Men's Study since it first began. My best friend and I signed up and enjoyed going to Pittsburgh just to see what was happening in the big city. We both lived about two hours away in small town America. I remember going to a few

different locations for the tests, before going to where they are given now. After about 3 years my friend moved to Virginia and he dropped out of the study. I had a few other friends who went for awhile but they all dropped out also. Twenty two years ago I met my partner and he began coming with me to my appointments. I told him he should sign up and he did so now we go together. The staff has changed as time moved on but everyone there was always very friendly. Thank you to all who are involved with this great study. We enjoy our visits twice a year to the big city, but as Dorothy said there's no place like home.

John

January 14, 2000

Dear Friends:

Thank you so much for your recent invitation to an "Evening of Celebration." Although I cannot be present, I wanted to share my thoughts and will be thinking of you all on the evening of February 15th, 2000.

I remember those early fearful years, years full of uncertainty and doom, marked by countless losses of friends and loved ones. The time was 1987. I was diagnosed the previous year and had given myself two, maybe three years to live. I felt lonely, frightened and ostracized by a relatively unknown disease. HIV then was synonymous with "terminal" and "hopeless." My hidden secret lived within me, shrouded by shame, guilt and hopelessness, reminding me each day of my mortality. One day I heard of the Pitt Men's Study and made an appointment.

The Men's Study made me feel so welcome and provided a source of hope. The staff, so caring and non-judgmental, made quite an impression. I remember one day I visited a Pittsburgh hospital for a blood draw. After the secretary interviewed me for my health history and insurance information, she promptly disinfected my seat once vacated.

I don't need to tell you how I felt at that moment. After finishing school, I moved to San Francisco. I was given information by the PMS that I could continue as a volunteer via the "LA Men's Study," a sister base. After moving to SF, I was fortunate enough to enter a Combivir Study, which I believed saved my life.

The Men's Study has provided hope and invaluable research data to arm ourselves against this terrible disease, whereas, many others have turned their backs on us based on moral and self-righteous judgments founded upon hatred and ignorance.

The years since then have been bittersweet, whereas, I have maintained reasonably stable health but have bid final farewells to many loved ones affected by HIV. Now at 42, I continue to maintain hope for a cure against HIV.

A "celebration" indeed! A celebration of our heroism, perseverance and continued efforts to learn ways to battle and win the war on HIV. I extend a heartfelt thank you and "God Bless" for all your support in our efforts together.

Volunteer (Name has been removed to protect confidentiality.)

OLD AIN'T BAD

In 1983 or 1984 (I really don't remember the exact date because my memory, like my hair, is fading quicker than I would like to remember), I read a New York Times article about a gay disease that was being called GRID—Gay Related Immune Deficiency Syndrome. The article described sexually and drug addicted “deviants” as those most susceptible, and even though I didn't see myself that way, I was alarmed.

A short time later, I heard that seminars were being taught at Pitt to discuss what we know now as “safer sex.” I decided to go to the seminar and that single decision, when I was 19 years old, saved my life. There were two men I remember clearly: Tony Silvestre and Kerry Stoner. I wanted to be like them—committed, passionate and caring. Gay role models in the early 1980's were hard to come by, but I happened upon two.

I don't remember much about the room in the Iroquois building, but I do remember the presentation. They pulled out condoms, lube and a HUGE dildo. They demonstrated how to put on a condom and [explained] the science that was known about the disease.

After class I asked Kerry if my then boyfriend and I should start using condoms even though we'd not used them up to that point. Kerry said, “Yes, since the cause is still unknown, start wearing condoms tonight.” I have been using them ever since. It astonishes me that I have been wearing condoms for twenty-five years. I wish I could write something pithy here, something like “if you were to lay out all the condoms I have used in my lifetime end-to-end, they would stretch to Iowa and back,” but I couldn't even guess how many condoms I have used, or men for that matter.

When I look back at my life and think that I have staved off HIV and have remained negative when so many of my friends and acquaintances are dead, it isn't pride that fills my head, it is gratitude. What a wonderful group of men that came before me and my generation and helped so many survive. Those guys gave up their time and lucrative careers to help me and countless others stay healthy. Men like Tony Silvestre, Kerry Stoner and Charles Renaldo. How could I possibly find words to thank them for teaching me how to live over the past 25 years?

I remember when I was a HIV Prevention Specialist, teaching people about HIV was like screaming into a cave; I rarely knew if anyone heard me. Well, I am shouting back now

to Tony, and Kerry and all those that came before me. I heard you and I am so grateful you were there.

Reflections from a former PMS Board Member

My name is Rich and I am 57 years young. I just celebrated my 3rd anniversary with my boyfriend. I am a person living with HIV. I thank my doctors, nurses, friends and family members as well as organizations and services in the Pittsburgh area for my quality of life. At the top of the list is the PMS.

I started coming to the PMS in 1985 when my doctor was afraid to treat me because I was gay. He suggested that I go to the PMS for further treatment.

I was negative on my first visit to the PMS but found out that I was positive after my second visit and blood draw in March 1986. I was so glad that I had the kind people at PMS inform me of being HIV positive. They told me that I would be OK and that they were here to help me. They gave me hope and even suggested getting involved with PTEU where I was in the famous 0019 Study for AZT. I was also in many other studies at PTEU, hoping that I could help in the discovery of a cure for AIDS, as well as finding treatments for the side effects that so many HIV+ people were getting and dying from.

I remained healthy until 1992 when I came down with KS. My T-cells were dropping steadily and now I had full blown AIDS. I had been on AZT, since the 0019 study made it available (I was originally on the very high dose in the study and I think that helped keep me healthy for so long). Now my life and health was going to change and I looked like I was going to die within a year. These were the years where one or two patients with AIDS were dying every week. By Sept 1993, after a year of chemotherapy, I was too ill to work and I was told to make arrangements for my funeral.

I still made my 6 month visits to PMS (never missing one – even though I was very weak and sick) where I was treated with love and compassion by some of the greatest people that I was blessed to have treating me. They were not afraid of touching me (hugging me) giving me hope to hang on. My T-cells fell to five in 1994 and in April CMV took my right eye. Luckily I had great health care and great doctors to treat me. PMS were the ones that directed me to the right doctors when something went wrong. When the KS was covering my face they told me that have radiation treatments would successfully remove the KS. The treatments worked.

I bounced around zero T-cells for two years and finally the miracle drug D4T arrived in limited quantities. I was near death and had to be carried into Sam Golden's office—but after 2 weeks on D4T, I was able to walk again. I became a famous member in one of Sam's case studies presented in Japan at an AIDS conference.

PMS worked with my doctors and with those 6 month visits reports. The PMS staff encouraged me not to give up. Neuropathy in my feet made walking difficult and it seemed only the people at PMS had suggestions on what to do to help. 3TC came along and finally Crixivan and the "Triples." My quality of life was now improving and the staff at PMS were still there as my cheerleaders to help me to keep on fighting. They gave me direction and guidance that kept me alive and gave me hope. People look at me today and have no idea what I had gone through because I look so much better.

My theme song is "I will survive" and thank you staff and doctors of the PMS, my friends, for encouraging me to fight, and to not miss a dose of my medicine no matter how bad the side effects. Thank you for all the hugs, smiles and encouraging words. You all made a difference and are the reason that I am a person "LIVING with HIV" today. I have never missed a 6 month check up and even though I am healthy for a "Long Time Survivor," I still need those encouraging words from the great friends that I have met over the years at the PMS.

Richard

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The Pitt Men's Study
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