

The Pitt Men's Study

**News and Notes** 

## A History of Your Community Advisory Board

Many of our Pitt Men's Study volunteers may be unaware of our Community Advisory Board (CAB). The CAB is a group of individuals who meet monthly to serve as a link between the study staff and the community. They provide feedback to the study about community concerns, review study protocols, identify and respond to community needs, and to help recruit men into the study.

The Pitt Men's Study was among the first studies in the country to organize and implement an HIV Community Advisory Board. Today, many studies such as ours are required to organize them. Back then, there were no guidelines about organizing a Board so that it would be most effective. However, [Pitt Men's Study Principal Investigator] Dr. Charles Rinaldo determined that he would empower the Board to be independent and to create its own rules. As a result, the Board elected its own co-chairs and chose its own members.

From early on, the CAB felt an obligation to respond to HIV/AIDS beyond the boundaries of the study. Old-

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time members of the Pitt Men's Study will remember the shock that rippled through the gay community when hundreds of men found out that the new HIV antibody test had identified them as HIV positive and so likely to die in a few short years. The CAB felt called to action. At that time the PMS was the only HIV-centered and staffed program in the area other than a support group organized out of Dignity and Persad. The Study received many calls from local people for help. A sister called and wanted to know what she needed to do to take care of her brother who was returning from San Francisco with the disease. A young girl called to find out who could help her get her job back since her boss at a convenience store fired her when learning that her uncle had AIDS. Bar owners called wanting information that they could give their customers so that they could avoid the infection.



Soon the calls became too many for the Study staff and CAB members to respond to. And so the CAB set up a committee to design a new organization in Pittsburgh to begin providing care and educational services in the region. That organization became the Pittsburgh AIDS Task Force. This was only the first of many actions that the CAB members took to respond to the epidemic. They helped organize the Pittsburgh Interorganizational Council on AIDS (PICA) and the Southwest PA AIDS Planning Coalition. They lobbied Governors Thornburg and Casey for more HIV funds. They began World AIDS Day services working with Calvary Church in Shadyside in order to help lovers, families, and friends grieve since so few churches were accepting of people with HIV/AIDS.

### **Meet Your Researcher - Jeremy Martinson**

Genetic Causes of Cardiovascular Disease in the Pitt Men's Study



My name is Jeremy Martinson and I am a researcher in the Department of Infectious Diseases and Microbiology in the Graduate School of Public Health. I am conducting a research study into the genetic causes of the side effects that some men develop when they commence antiviral therapy.

It's been known for many years that HIV infection alone can affect the levels of cholesterol in the blood. Soon after the development of highly-active antiretroviral therapy (HAART) it became clear that many men receiving therapy began to develop problems with their cholesterol levels that put them at increased risk of developing cardiovascular disease. This problem - termed dyslipidemia - is separate from the problems many men had with body fat changes such as lipoatrophy and liopdystrophy. Because the symptoms of dyslipidemia were not seen in every man receiving HAART it seemed like there may be a genetic contribution to this. Some men may have changes in some of the genes involved

in the normal metabolism of cholesterol that make them more prone to develop these changes, whereas other men with different versions of these genes do not have the same problems. The issue for us as researchers was to find the gene, or genes, involved and to understand how they may be causing the problems. We have developed a couple of different NIH-funded research projects to study this, and the graduate students in my laboratory have generated some data that may help us understand how dyslipidemia may be caused.

For our first project, we developed a way of looking at changes in a large number of genes that were already known to affect the way cholesterol is used within the body. We were able to look at over 1,500 inherited genetic differences at the same time, and we looked at these changes in a sample of almost 2,000 men from Pittsburgh and from the other MACS centers. We extracted DNA from old samples already in the MACS repository and did not need to bleed anyone again for this. The results of our study showed us that some genes were indeed important in the development of dyslipidemia, and also showed us that the genetic susceptibility to this condition differed between ethnic groups. The genes that affect dyslipidemia in Caucasian populations are different to the ones that affect it in African Americans, for example. We are still working on the details of this but we should be publishing our results very soon.

We were lucky enough to get some extra research funds from the NIH under the American Recovery and Reinvestment Act (the ARRA, or "stimulus package") in 2009. This made it possible for us to develop a separate study which is looking at differences in gene activity rather than just in the DNA sequences of the genes alone. Our first study showed us what genetic variations men in the Pitt Men's Study have, and our second one will show us what those differences do. This second study is focused solely on men from Pittsburgh, and required us to collect an extra tube of blood from you all at your last visit in October 2010 - March 2011. We are still processing the samples we have collected, but it is already clear that we can detect differences in gene activity in these samples. Our next goal is to relate those differences to variation in cholesterol level, in the hope that we can identify key genes that most greatly affect the risk of



dyslipidemia. Depending on the genes involved, this may allow us to suggest different treatments, or at least to identify early those men most at risk of developing these side effects.

Lastly, I should point out why our second study was focused **solely on the Pitt Mens' Study**. I had originally planned to collect samples from Pittsburgh and from the other MACS cities, but we got donations from so many men in Pittsburgh that I was able to collect all of the samples I needed from here after all. Thank you!

## Pitt Men's Study Sponsors Play



The Pitt Men's Study, in conjunction with the Actor's Co-Op and the Lambda Foundation, will be sponsoring the play *Looking for Magic*, with performances on

December 2-4, 2011 at the Henry Heymann Theatre (in Stephen Foster Memorial) in Oakland.

Looking for Magic was written by nationally recognized Pittsburgh playwright Beverly Pollock, who lost her two sons to AIDS. Her work explores the potential heartbreak and healing LGBT families can experience when they engage with a loved one coming out, learn of a positive HIV status, or support a child during their final days with AIDS.

*LFM* is distinctive for its thoughtful portrayal, narrated from a parent's point of view, on how coming out, battling HIV and AIDS, and dealing with death and separation

can affect loved ones. This play depicts stages of confusion, anger, loss, and ultimately the healing and growth that the mother and father protagonists experience while coming to terms with their son's sexuality and the serious realities of his battle with AIDS. Because this play speaks to its audience through the lens of parents and loved ones of a gay youth with AIDS, it provides a voice and perspective rarely heard in discussions of the dangers and consequences of HIV and AIDS today.

Tickets will be available through the William Pitt Box Office (3959 5th Ave, Main Floor; 412-648-7814) and showclix.com. Tickets will be available at the door unless shows are sold out. Suggested donations are \$25 for adults and \$5 for students. Proceeds benefit The Shepherd Wellness Center

**Dec 2 & 3, show at 8pm. Dec. 4 show at 2pm**, with talkback following this performance.

## **Community Advisory Board**

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As time went on, the CAB members' efforts did not slacken. Even as they provided continued advice to the Study about its protocols, questionnaires, and tests, it kept responding to community needs as well. CAB members took a lead in persuading former Allegheny County commissioner Jim Roddey to support needle exchange in Pittsburgh, which for years had been met with resistance. The Board also worked with Persad Center to begin new local initiatives that work to prevent continued HIV infection among our young people. Recently, the CAB has been reviewing a new MACS protocol on frailty and bone density testing, as well as working with community groups to find better sources of medical care for the GLBT community

Being on the Community Advisory Board of the Pitt Men's Study is clearly not for wimps. The members of the CAB have struggled for years to combat AIDSphobia, homophobia, government indifference, and gaps in services. We salute all of those, living and dead, who served and/or continue to serve on our Board. We hope that the community will join us in recognizing their amazing contribution to all of us.



# PREMIE MILE RE

Henry Heymann Theatre in the Stephen Foster Memorial



Community Benefiting Shepherd Wellness Community, the only AIDS Community Center in Western PA.