

**A COMMUNITY ADVISORY
BOARD NEWSLETTER
PUBLISHED BY:**

**Pediatric HIV/AIDS Cohort
Study (PHACS) Community
Advisory Board**

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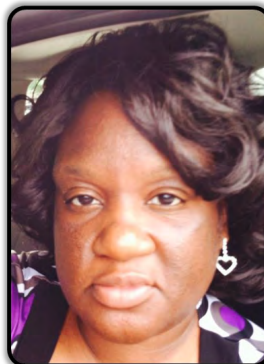
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FROM OUR CAB CHAIRS

As the PHACS CAB Chair, I have many roles and responsibilities that go along with making a difference. My ultimate goal as Chair is to be all I can be with representing the PHACS CAB. This is a new beginning and role of expectations within my life. Finishing the race of accomplishments is my goal. Everyone has a story to share and being Chair will be a rewarding experience. In the role of Chair, I am hopeful to bring 110% to the conference calls and meetings while learning from everyone involved. I wish to bring new ideas and wonderful outcomes with this journey. Thank you all who had an involvement with electing me as Chair; may we begin this wonderful adventure together.



Dolores, PHACS CAB Chair



My fellow CAB members, I hope that I have found you in great cheer. I usually talk about any and everything. I always try to do my best to stay in a positive voice, but not today. Being your Vice Chair and always living by the motto that I will be a voice for the voiceless, I will not and cannot hold my tongue. I am talking about stigma and all the hate that goes with it. When my fellow human beings are going through hate, a part of them is lost and can feel as though they are less than the dirt under their shoes. I hope that all of you who read this will stand up to fight and help end all hate, whether it's inside or outside of the medical community.

Help me in becoming a strong voice to those who may not have the courage to speak up for themselves. Use your tongue to love, not to lash out. Help to heal the broken hearted, and to bring peace to those who hate and who stigma has brought to pieces. So let's not give hate the light of day anymore, but let our voices bring those who are hurt by hate into the light. My CAB family knows this: the more hearts we heal from stigma and hate, the stronger voices we will have to bring victory to our fight.

My word of the day is conscience. Conscience is defined as the sense of knowing if something is good or bad; a sense of right and wrong.

Kim, PHACS CAB Vice Chair

PHACS MEMBER PROFILES



Barbara Moscicki, MD

My name is Barbara Moscicki (not an easy name to pronounce but sounds like Moshchitski). I am the daughter of Polish immigrants who came here in 1950 to seek a better life post WWII. My father was a doctor. He started his training in Poland and then finished it in Italy post war. He wanted his two kids (me and my older brother) to become doctors since he saw that as a way for a better life. He got his wish (he was very stubborn)! I grew up in small, small town (3,000 people) in the middle of Illinois. I went to Northwestern University Medical School in Chicago, Illinois. I went to Vanderbilt University in Nashville, Tennessee for my resident training. After that I went to do a fellowship (more training) in Adolescent Medicine and Epidemiology at The University of California San Francisco (UCSF). After that I did another fellowship training (clearly I was having problems about facing a real job) at Stanford University

doing virology (study of viruses). I finally got a real job back at UCSF in 1985 and am now Professor of Pediatrics. My major area of interest has always been Sexually Transmitted Infections (STIs). This includes chlamydia and human papillomavirus (HPV). I study behaviors that may cause these infections, as well as how the body responds to them. I got involved in HIV studies back in 1993 when I became a member of Reaching for Excellence in Adolescent Care and Health (REACH). This was a nation-wide program much like PHACS but focused only on adolescents who got their HIV through sex or drug use. We did lots of similar studies to PHACS on sex and drug behaviors, STIs, and immune responses. I also have lots of other 'hats,' including seeing clinic patients. I also teach medical students, pediatric residents, and fellows.

One of the biggest/longest studies I started began in 1990. We enrolled around 1,500 girls aged 13-21 years. We followed them every six months with lots of questions and exams for 24 years. These were incredibly dedicated women. They were not HIV-infected but wanted to help us out, and we were so appreciative of this. Each visit was an interview and a pelvic examination where we took a lot of samples from the cervix. I was interested in understanding how women got HPV. I wanted to identify behaviors that may cause these infections, and how the body could handle the infection and actually get rid of it. My laboratory started doing specific tests that could see how the immune system was responding to the infection. HPV is best known in that some infections (not all) can lead to cervical cancer. HPV can also cause cancer of the anus, vagina, vulva, and of the mouth. We had

over 70 papers published in this area and these studies were used as important information for setting up the new United States guidelines for cervical cancer screening in young women.

In PHACS, I'm involved in several studies including understanding what are the influences on adolescents' use of marijuana and alcohol, sexual behaviors (such as not using condoms) and of course, HPV. We are planning a study to look at how well the HPV vaccine works in HIV-infected youth. In addition, I had a study that examined what was going on in the mouths of HIV-infected children. We had dentists come in and examine the youth in AMP and check for disease. The study collected a bunch of samples from the mouth. We plan to examine markers that may tell us something about when disease of the gums starts. These include looking at the immune response and looking at the types of bacteria living in the mouth (and there are a bunch of those; even if you use Scope mouthwash, you cannot get rid of these bacteria). Turns out that most bacteria that live in our mouth are very friendly and in fact we need them to have a healthy mouth. When the "good" guys go away, the bad bacteria can grow. We are studying what makes the good guys go away.

I feel really privileged to be part of the PHACS research family. The stars of the family are the kids who are willing to give their time to help others, the families that make sure the kids make their appointments, and of course, that help all the youth be as healthy as possible. Working with this family is one of the best parts of my job!!!

PHACS MEMBER PROFILES

Ana Puga, MD



Hi, my name is Ana Puga and I am a Principal Investigator for PHACS at Children's Diagnostic and Treatment Center (CDTC) in Fort Lauderdale, Florida. CDTC is a non-profit community-based clinic for children and youth with special needs. I am a native Floridian with Cuban and Spanish heritage. I wanted to pursue Pediatrics since I was a 12-year

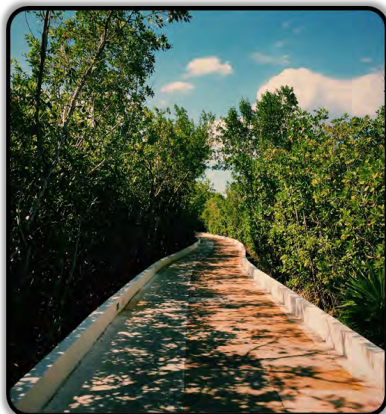
-old volunteer candy striper at Miami Children's Hospital. I earned my medical degree at Ponce School of Medicine in Puerto Rico. I then completed my residency and specialty training in Pediatric Infectious Diseases at Jackson Memorial Hospital/University of Miami under the mentorship of Dr. Gwendolyn Scott. I chose Miami because I wanted to train in a place with a significant focus on HIV. During medical school, I became interested in working in this field. For the past 18 years, I have had the privilege of working in the Comprehensive Family AIDS Program at CDTC in clinical care and research. It's been very exciting to be part of the progress we have had in HIV disease! I am passionate about working on HIV until the cure. I know it's going to happen sooner than we imagine!

I have been fortunate to work on several NIH-funded research networks since my first week at CDTC. I have been involved with PHACS since it started. I truly enjoy the research part of my job because it brings hope to my patients and it gives back to others by enhancing what is known about this disease in

a scientific manner. I am honored by the enthusiasm of our CAB in participating in research. They give us feedback to allow us to continue to grow in better ways. I enjoy going to camp every summer with our HIV-infected children and watching them have so much fun even when taking their medications, without having to worry about stigma and discrimination that often still affects their everyday lives in school and community. I hope one day camp will no longer be needed because no other child will be born with HIV and those living with it will be able to live openly and freely every day in their homes, schools and jobs.

Spending time with my niece, nephew and three godsons is what I most enjoy! In my spare time, if I'm not with them, I'm enjoying good food and wine with friends. I also like traveling or spending time on our boat fishing or snorkeling. I love to cook and have parties. I love to relax on the beach or by doing conscious connected breathwork and am a certified breathworker.

Lesley



My name is Lesley and I am a soul survivor. I have been living with the virus since the tender age of 16 and despite it all, I'm still here and marching in this fight 19 years later. I found out about my status when I was seven months pregnant with my second son who, by the way, is totally healthy. In my early years back in 2000, I started to become this great gladiator that I am today. I started out in this fight by helping other youth like myself by working locally in the Ryan White Agency. I became educated by attending classes to help me better learn and know my rights. I also was a Peer Leader for the Houston Ryan White Planning Council. I traveled to Washington, D.C. on many occasions to tell Congress and our State Representatives that denying us funding will hurt and destroy so many families. I left the field for a while, but have gotten more involved in the Texas Children's Hospital CAB over the last couple years.

In addition to my advocacy work, I love traveling, listening to music, dancing, watching movies, and sleeping. I have four healthy children of my own, and have just become a new grandmother! All my children are negative. I want others to know that this virus is not you and will never be you. You are a soul and can use your power to help others become survivors.

FALL 2014 NETWORK MEETING & CAB RETREAT—DISCLOSURE & STIGMA

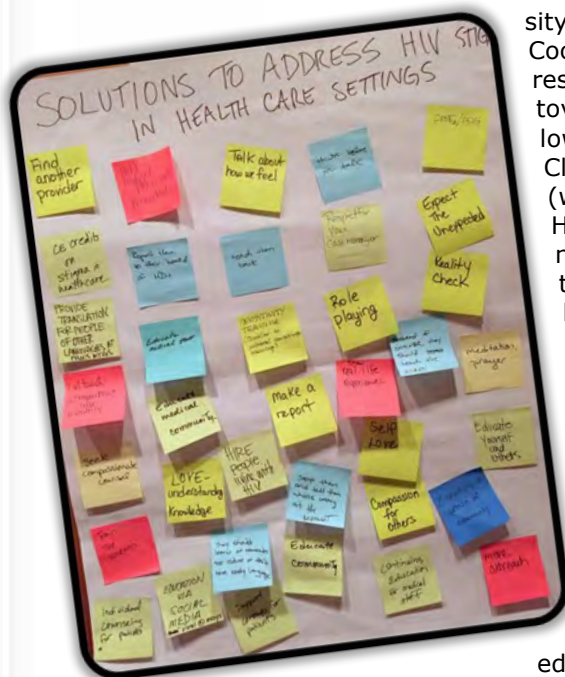
CAB Retreat Disclosure Workshop

As part of the 2014 CAB retreat, the CAB held an interactive workshop on disclosure. This workshop was created by a team of Health Education and Communication Committee (HECC) and CAB members. The goal was to explore and normalize the many attitudes and beliefs about HIV disclosure and non-disclosure. This exercise focused on understanding the role of CAB members as advocates in the world. CAB members first anonymously rated their own comfort level (on a scale of 0 – 6) within different scenarios about disclosure. For instance, scenarios talked about disclosure within a family setting; unintentionally learning someone else's status from a child or another caregiver;

deciding how to react to a friend's stigmatizing comments about HIV; having one's status unintentionally disclosed to a child during a doctor's visit; and explaining HIV study participation to a boss when asking for the time off. The worksheets were then collected and redistributed. Each person was holding someone else's anonymous answers. We talked about our reactions to each scenario as we moved around the room. This helped us to showcase different places on the spectrum based on the sheet we were holding. This workshop was an exercise in thinking about how each of us would feel when presented with various opportunities to act as HIV advocates. Our being spread around the room gave a very visual display of the range of attitudes

and comfort levels. It showed that there is no one "normal" or "correct" way to be an advocate. It also showed that both disclosure and non-disclosure can be healthy, empowering choices. No matter where we fall on the spectrum of comfort around disclosure, we are in good company. Some CAB members reported feeling more empowered in their own attitudes about HIV disclosure after this workshop. Several CAB members plan to use this exercise with their site CABs. The disclosure worksheet can be found on the PHACS website: <https://phacsstudy.org/Education-Hub/Disclosure-Wheel>.

Submitted by: Claire Berman



HECC Stigma Workshop

At the 2014 Fall Network Meeting, the HECC decided to focus its session on HIV stigma in health care settings. Mariam Davtyan, Univer-

sity of Southern California Study Coordinator, first presented the results of her HIV Stigma Photovoice project. This was followed by a workshop led by Claire Berman. Participants (who included CAB members, HECC members, Study Coordinators, Principal Investigators, and Research Scientists) brainstormed with Post-it notes around three topics: "What does HIV stigma in health care settings look like?" "What are the outcomes?" and "What are solutions to address HIV stigma in health care settings?" The responses that came out of this session were wide-ranging and illuminating. They included themes around judgmental attitudes, and institutional and universal stigma. Themes also included stigmatizing health care behaviors (i.e., wearing double gloves to treat someone with HIV), and how HIV stigma may cross paths with other kinds of stigma. Outcomes of HIV stigma

included mental health problems, reduced adherence to HIV medications, and avoiding health care. Some workshop participants felt so passionate and engaged with the topic that we continued brainstorming solutions for these outcomes for twice the intended length of the session (see photo)!

As a result of this session, a new multidisciplinary HIV Stigma Task Force of HECC members, CAB members, Study Coordinators, Principal Investigators, and Research Scientists came together. This group has already met several times since the Fall Meeting. They plan to research and address HIV stigma across a range of settings. This will help us to better understand how stigma affects different aspects of quality of life, and how it affects recruitment and retention in PHACS. As we move forward, our strengths and passion as a PHACS team will help us contribute to positive change for people affected by HIV!

Submitted by: Claire Berman

FALL 2014 NETWORK MEETING & CAB RETREAT—PANEL DISCUSSION

Working with Youth Affected by HIV/Youth Community Involvement Panel Discussion

As part of the 2014 CAB retreat, the CAB held a panel discussion about working with youth affected by HIV and youth community involvement. Four CAB members representing various PHACS sites participated on the panel. Yuri led the interactive discussion and encouraged participation from all CAB attendees.

Dealing with youth can be a battle on its own, but working with youth affected by HIV is whole different kind of war. On top of facing typical issues of adolescence such as dating and puberty, HIV-positive youth face additional issues, including disclosure and medication adherence. During the 2014 CAB Retreat, I was honored to be asked to moderate a panel discussion addressing the issues of youth with HIV and their community involvement. Our distinguished community panelists included four CAB members from the United States and Puerto Rico.

Among them were two post-transition youth with lots of personal insight on the topic. The panel discussed many issues including:

- 1) Trust;
- 2) Common-ground between youth and providers;
- 3) The importance of keeping the youth participants entertained to provide an at-ease atmosphere; and
- 4) Providing lots of education.

In order to create a sense of community with youth, it's vital that the youth have access to resources which will help them in times of need. Resources may in-

clude a peer educator, a nurse or a list of emergency contacts at the clinic. Outings, support groups, social networks were also mentioned in the discussion in order to create a welcoming environment for the youth because we all know that kids love to interact with each other. Last but not least, it's crucial to motivate and encourage youth, the next generation of our CAB, to be educated, informed and vocal about their future in our community. It is up to us, the more experienced members, to pave the way for them and show them how we've accomplished our goals so far. By providing support and mentoring them in community advocacy, we will then prepare them to be the next leaders of the world. I want to thank the panelists for providing their voice and experience for us at the CAB Retreat. You all are inspiring us to be better at our jobs by empowering your youth, just as you continue to do every day. Thank you!

Submitted by: Yuri

UPCOMING EVENTS



- 📅 **February 7:** National Black HIV/AIDS Awareness Day
- 📅 **March 10:** National Women and Girls HIV/AIDS Awareness Day
- 📅 **March 17-18:** PHACS Spring 2015 Leadership Retreat
- 📅 **March 20:** National Native HIV/AIDS Awareness Day
- 📅 **April 10:** National Youth HIV/AIDS Awareness Day
- 📅 **May 18:** HIV Vaccine Awareness Day
- 📅 **May 19:** National Asian and Pacific Islander HIV/AIDS Awareness Day
- 📅 **June 8:** Caribbean American HIV/AIDS Awareness Day

STIGMA POEM

S is for the silence I get when you are around

T is for the torment I do to myself because I feel as though I've done something wrong

I is for the inherent trust of the caregiver that went so very wrong

G is for the many generations that are still dealing with you even today

M is for me, the person that is an empty shell that will never be filled

A is for away from me that I hope we all will say someday soon

Submitted by Miss K.

UNRAVELING HIV STIGMA

"Sometimes I wish I had cancer," said a close friend of mine who had been living with HIV/AIDS for years. Having lost many loved ones to cancer, I was first offended by the statement and asked why she would say such a horrible thing. She replied, "...because when you have cancer, people console you, they don't abandon you and treat you like you're dirty." At first I couldn't make peace with this statement and fought to make her realize that cancer was no joke and that she should never wish for something so dreadful. I even shared an experience of losing my young cousin to cervical cancer. Her statement haunted me for many years and heightened my curiosity about stigma. I simply wanted to understand what she meant. Fortunately, my research affiliations with University of Southern California (USC) and its Community Advisory Board (CAB) afforded me the opportunity to find out.

In 2012, I asked members of USC's CAB, consisting of women living with HIV who represented the needs of communities impacted by HIV/AIDS, to talk about stigma during monthly meetings. Their stories were astonishing and how I wished that everyone could hear them. One woman reported that her father refused to sit next to her at family gatherings when he found out she was positive. Another revealed that a doctor had encouraged her to have an abortion because she would be an unsuitable parent. A third woman expressed that her HIV status was made into a public manifesto by her "so-called" friends and family members. Outraged and deeply saddened by these accounts, I decided to work on a project that would allow women to engage in critical dialogue about their experiences with HIV stigma. Perhaps they could even share their stories with larger audiences in hopes of inspiring change. I also wanted to be unique in my approach and include an artistic element that

could facilitate self-expression. Ten remarkable women participated in the project and told their stories of HIV stigma. They also took photographs to bring their stories to life. Below are some of the photographs they took to describe their experiences with stigma:

Photograph 1 is a memory of a medical visit. A physician placed a pair of gloves on a stethoscope before performing an exam. The woman behind Photograph 2 avoided the dentist for many years because she had been previously refused care by a dentist due to her HIV status.

1. Doctors should know better!



2. Stigma and decay!



UNRAVELING HIV STIGMA (CONTINUED)

Photograph 3 is an emotional expression of feeling imprisoned by the disease because of its stigma. Photograph 4 is a snapshot of removing labels from HIV medication bottles due to fear of being discovered.

All of the women informed me that dealing with stigma was at times harder than managing the disease itself. Some said that even though taking their meds helped them stay healthy, the stigma of having HIV tarnished the quality of their lives and gave rise to unnecessary pain

and suffering. They were adamant that more efforts were needed from scientists and the HIV community to combat this global stressor that had already devastated too many people. What was perhaps the most unexpected revelation was that critically reflecting about their experiences with HIV stigma and taking photos to capture those thoughts made them stronger and raised their self-esteem. Some reported feeling empowered to engage in advocacy work while others made peace with their diagnosis and refused to allow it to

define them. The most compelling benefit reported by participants was that continuing to fight was the only option they had left and it was their obligation to get out there and spread the word about the perils of stigma.

Equipped with their photographs and respective narratives, study participants attended several health-related community events and told their stories to audiences consisting of administrators, policymakers, and medical providers. Unsurprisingly, the sight of women expressing their struggles with HIV stigma elicited a powerful emotional reaction from audience members. I stood in awe as attendees shook their heads in disbelief, cried when photographs were described, and nodded in acknowledgment of the hurt and affliction endured. Some audience members approached the speakers at the end of the talks and asked how they could join the fight against HIV stigma. They had made a HUGE impact! It's amazing what a woman with a camera can do! The war against HIV stigma may be far from over, but there are armies of brave women and men all around the world who are willing to position themselves in the frontline to battle this injustice and violation of basic human rights.

Stigma discredited and devalued my friend, reduced her to a mere medical condition, questioned her moral status, broke her spirit, and silenced her. This is why she had wished for cancer. Even though many years have passed since her diagnosis, she still recalls her stigma accounts with remarkable detail as though they happened yesterday. I now understand more than ever why she had wished for cancer. She was longing for love and support, and that's not too much to ask for.

Submitted by: Mariam Davtyan, PhD Student (UC Irvine), Project Manager (Site #5, USC)



3. Bound by HIV!



4. Taking Labels off Medication Bottles!

PHACS CAB PURPOSE AND MISSION



All clinical sites participating in PHACS are expected to have a Community Advisory Board (CAB). The purpose of the CAB is to seek input from community representatives in order to reflect the interests of participants and caregivers in PHACS. The PHACS CAB is also a forum for local CAB members to share resources and support.

The mission of the PHACS CAB is to serve as a connection between researchers and community members in order to improve and optimize clinical research studies for children/families who are participants, and who are most affected by the research.

CDC CAMPAIGN



Having worked in the HIV field for nearly 10 years now (gee, I'm getting old!), I've seen and experienced stigma from mild to wild. It really saddens me when I hear people say, "It's a gay disease," or "You can get it through kissing or even by coming in contact with anything they touch like eating utensils." HIV stigma is real, and it continues to be a crippling factor for us to comfortably live a fear-free life. We are always second-guessing who to tell about our status out of fear and/or rejection.

I decided to stand up, do what most can't, and carry out our message to the masses and media: I AM HIV POSITIVE! When I became part of a national campaign titled, "HIV Treatment Works," one of my messages was to convey a message of support and hope for those who think we are different:

"When I'm not working, I keep busy with boot camp, swimming, weight-lifting, meditation, traveling and—oh yeah—karaoke! I know that the more control I have over my HIV, the less power I give to the virus."

The more I empower myself to stand up to ignorance and stigma, by educating others and sharing my story, the less I have to hide behind HIV, and instead I stand in front of it! Please support our community (*your* community) and educate! Check out the CDC campaign (see below and on [page 10](#)), as well as my story at: <http://www.cdc.gov/actagainstaids/campaigns/hivtreatmentworks/index.html>.

Submitted by: Yuri

CDC CAMPAIGN (CONTINUED)



I refuse to let HIV get in the way of my busy schedule. I even have a cell phone app that reminds me to take my HIV meds. When I'm not working, I keep busy with boot camp, swimming, weightlifting, meditation, traveling and—oh yeah—karaoke. I know that the more control I have over my HIV, the less power I give to the virus. I take control by taking my HIV medication every day.

Get in care. Stay in care. Live well.
cdc.gov/HIVTreatmentWorks



WORKING GROUP UPDATES

The CAB asked the PHACS Working Group (WG) Co-Chairs to respond to several questions regarding the current status of their respective WGs. This request was in response to the CAB's desire to participate in and stay updated on WG progress. A complete list of WG updates may be found on the PHACS website under the "CAB Retreat and Network Meeting Documents" section: <https://my.phacsstudy.org/cab/CAB-Resources>.

The following updates are summaries from each WG:



Adolescent Behaviors WG

Co-Chairs:

Claude Mellins, PhD
Barbara Moscicki, MD
Katherine Tassiopoulos, DSc

Purpose

The purpose of our WG is to ask questions about the different behaviors of adolescents and young adults in PHACS. We are interested in the ways these behaviors affect their physical and mental health outcomes. Finally, we are also interested in their readiness to be young adults.

CAB Contribution

In the medical research community, we see everything from a medical research point of view. Our educational blinders sometimes prevent us from understanding the whole picture. That's where you come in, the CAB. The CAB helps us to see the whole picture. For example, we may study the rates of pregnancy in young HIV-infected women and be concerned about potential HIV transmission. However, CAB members can

redirect our focus. They can remind us that these young people are growing into the age where they are beginning to want to start families, and that this is an occurrence that may be welcomed and considered a positive, hopeful one.

Another example is that we may be focused on the high incidence of sexually transmitted diseases in males 18 years of age. We may attribute this to the lack of circumcision. However, we may miss information about the lack of available services provided to males versus females by Medicaid. It may take you, a CAB member, to point out that there are programs in Medicaid for female reproductive health but none for males. A program is on the way for males. Someone in the community took notice. It may take you, a CAB member, to help us get it right.

Future Goals/Plans

We plan to continue to study adolescent behaviors and how they affect our study participants' health. We are interested in the risky behaviors that some young people might participate in. But we are also interested in healthy behaviors that young people choose to practice. We also plan to spend time studying the transition of young people affected by HIV into young adulthood, and their success in finding work, continuing school, and forming relationships.



Cardiopulmonary WG

Co-Chairs:

William Shearer, MD, PhD
Paige Williams, PhD

Purpose

The purpose of the Cardiopulmonary Working Group (CPWG) is to give scientific direction and support to studies of the heart and lung within PHACS. The CPWG has 10-20 experts in heart and lungs medicine. Many experts also study the immune system. Some are also experts in pediatrics, biostatistics, and epidemiology.

CAB Contribution

Several of the new proposed studies will require extra tests to be done in AMP or SMARTT. The CAB can make very helpful contributions to the design of these studies. CAB members can give input on how their children will handle the procedure and how likely they would be to participate in certain studies.

Future Goals/Plans

New studies will include proposals to look at children in the AMP study. We want to study heart biomarkers and vitamin D. In addition, we want to study the genetic makeup of youth born to mothers with HIV in the PHACS AMP studies. This will help us to better understand why some youth are more likely to have heart or lung complications. These proposed genetic studies will take the PHACS project well into the next era of HIV medicine. It will help us look at the role of genetics in diagnosis and management of HIV infection in youth of all ages.

The CPWG will also be looking at cells in the immune system called Natural Killer (NK) cells. These cells play an important role in fighting viruses in the body. Some studies have shown that NK cells may play a role in HIV infection and HIV complications, such as whether someone with HIV develops asthma. The CPWG will be studying the role of NK cells in HIV and lung complications.

WORKING GROUP UPDATES (CONTINUED)



Complications WG

Co-Chairs:

Kunjal Patel, DSc
Russ Van Dyke, MD

Purpose

The primary aim of the Complications WG is to identify complications of HIV disease and evaluate their associations with antiretroviral (ARV) therapy. Our WG focuses mainly on the AMP participants in PHACS. We study youth born with HIV and uninfected youth born to mothers with HIV.

CAB Contribution

The CAB has a critical role in all aspects of research. From the moment of capsule development, CAB input is needed to help us understand how we can improve feasibility of studies that may require clinical input. The CAB can also help us understand how we can better communicate with the CAB about the status of ongoing projects and results. This can be accomplished by: active participation on conference calls; asking questions about specific areas of research; sharing personal experiences that may contribute to future research; bringing information from this group back to the CAB; and inviting Complications WG leaders to participate in CAB conference calls when there are issues/questions that need clarification.

Future Goals/Plans

The AMP Up protocol will allow us to learn about the course of HIV as our youth born with HIV age into adulthood. We want to know how both the infection and the youth's immune system change over time. We want to know what happens to the

abnormalities we have found as the youth age. We also want to know whether any new problems develop. Specific questions include whether we will see the development of immune problems, heart problems, liver disease, or kidney disease.



Hearing/Language WG

Co-Chairs:

Mabel Rice, PhD
Peter Torre, PhD
Tzy-Jyun Yao, PhD

Purpose

The purpose of the Hearing and Language WG is to provide scientific leadership to the PHACS project for studies of hearing, speech impairments and language impairments in PHACS.

CAB Contribution

We recently requested input from CAB for questions to include in the PHACS October retreat for discussion at the WG session on the agenda. Feedback from the CAB helps us to talk about hearing, speech and language impairments of relevance to the larger PHACS group and to the community representatives. We always welcome suggestions for how to better share our research findings with the PHACS community.

Future Goals/Plans

Our goals include further studies of growth of children with hearing, speech, and language impairments. We also want to continue to look at how HIV treatment or exposure can affect risks for impairments and possible effects on social outcomes or school achievement.



Maternal Exposures WG

Co-Chairs:

Deborah Kacanek, ScD
Kenneth Rich, MD

Purpose

The purpose of the Maternal Exposures WG is to look for factors that occur during pregnancy for mothers with HIV, which can affect the health of their children. Although transmitting HIV from mother to baby is uncommon currently in the U.S., we are looking at whether women's use of HIV drugs during pregnancy affect their children. To study this, we focus on many factors in pregnancy. Factors include the severity of the mother's HIV disease, the antiretrovirals (ARVs) they take, and pregnancy complications. We also focus on substance use and psychological and social factors, including mental health, timing of pregnancy care, and income. The pregnancy outcomes we focus on include the length of pregnancy, whether the woman had a cesarean section or vaginal delivery, and growth outcomes at birth and young ages.

CAB Contribution

We are very interested in CAB members' ideas on how to expand our research agenda. We would like to know from CAB members what their most pressing questions and concerns are about pregnancy and outcomes for mothers, their infants and children that they think would be important for us to study. We also have appreciated input from the CAB on the best way to approach mothers on obtaining small samples of hair from the mother and baby to look for evidence of ARV use during the pregnancy.

WORKING GROUP UPDATES (CONTINUED)

Future Goals/Plans

We would like to continue our study of the safety of ARVs and other exposures during pregnancy and early childhood. Now that we have data gathered at multiple time points in children's lives, we are interested in changes over time in some of the outcomes we examine. We are also interested in a wide range of genetic and biological factors, as well as factors in the children's environment. We will be expanding our collection of data about the mother's health during pregnancy, which will help improve our studies in the future.



Nutrition, Growth, and Metabolism WG

Co-Chairs:

Denise Jacobson, PhD
Tracie Miller, MD

Purpose

The purpose of our WG is to try to understand how youth with HIV, or who were exposed to HIV, grow. We want to understand what factors might cause these youth to have problems with under or overnutrition. We are also interested in understanding why they sometimes have problems with high lipid levels (cholesterol, triglycerides), have diabetes, or show signs that they will develop diabetes. We are looking at why these youth might have risk factors for heart attacks or strokes at an earlier age than expected. In addition, we are evaluating how strong the bones are in these youth and if they have greater number of fractures than the average youth and if so, why that would be.

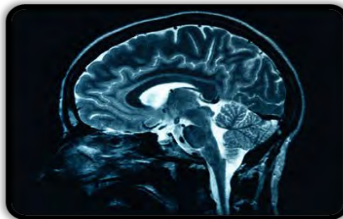
CAB Contribution

As we follow the youth into young adulthood, it is extremely important to try to keep the youth and young

adults engaged. This is because some of the problems that we are finding now may only get worse in later adulthood. Therefore, making sure the youth come in for regular check-ups will help us monitor them. The CAB can certainly help get the word out on why it is important for them to keep coming in to the clinic.

Future Goals/Plans

We will continue the work we are doing. The PHACS study is very important because it is tracking youth into the future. Because the study is doing that, we have the ability to see what might be causing the youth to lose or gain weight, have high lipid levels, be more prone to bone breaks, or develop diabetes.



Brain Development and Mental Health WG

Co-Chairs:

Rohan Hazra, MD
Kay Malee, PhD
Renee Smith, PhD
Katherine Tassiopoulos, DSc

Purpose

This WG is a team of people who are interested in the health and development of children, teenagers and young adults affected by HIV. This includes youth who were born with HIV or who are uninfected but born to mothers with HIV. We are interested in learning how HIV and HIV medications affect brain development, learning, and the emotional-well-being of youth and young adults. We try to figure out how health and development change if HIV disease becomes more severe over time. We also realize that HIV is only one of many aspects of life

that affect how well each person grows, learns, solves problems, and functions by themselves. Therefore, we try to take into account the impact of children's family and home environment. We also take into account their school life and social support, and their neighborhood and community. We try to understand how stressful life events and protective factors affect youth and how some of them cope better, even though they face many challenges in their lives.

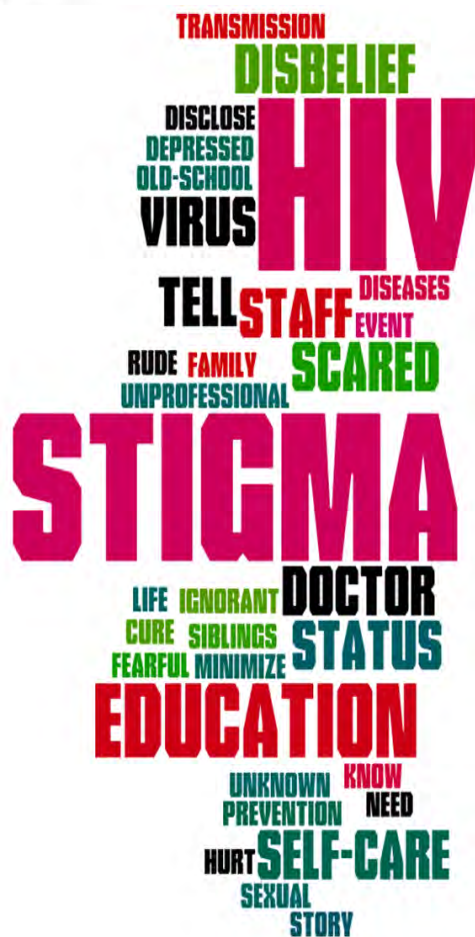
CAB Contribution

We invite CAB members to participate in meetings/discussions of proposed projects to offer advice and feedback. CAB members can suggest research questions of interest to family members and PHACS participants. CAB members can also contribute by attending WG meetings at PHACS meetings, talking with leadership and members of the WG, and sharing what we all learn together with the members of their local CABs.

Future Goals/Plans

We hope to continue to work together to achieve the goals and aims of PHACS. More specifically, we hope to continue to study the results of past and ongoing evaluations of youth in PHACS. By doing this, we will understand the many strengths of youth and families affected by HIV. We will understand aspects of their development that may be affected by HIV and ongoing treatment. We will be able to come up with possible interventions and therapies that could support youth and their families when problems exist. We may also learn how to prevent difficulties by working together with youth and families before problems become very serious. Through our collaboration with PHACS participants and families, we hope that all youth and young adults will have better opportunities for good health and a productive adult life in the future.

TESTIMONIALS ABOUT STIGMA



During my time of disclosing to certain family members about my status, I first was scared of how they would receive me. Then I thought, "Oh well, it's better that they hear it from me than from someone else, or be at an event where I am disclosing to the audience and their months drop." My family was fearful of the unknown. I made an attempt to minimize their fears of "not knowing" by offering HIV 101, delivering brochures, and sharing my story. I started explaining to them about the many faces of HIV, how long I have been living with the virus, and what needs to happen with self-care.

My reaction at first was of how ignorant they were. I kept in mind all people are not educated about HIV

transmission and prevention, especially those who are "old school." Education is a tool not many individuals receive unless it lands in his or her backyard. This means he or she can become infected.

The advice I would offer a person who is currently suffering from stigma is to live your life to the fullest with HIV. Remember taking care of self is key. Offer help to those who don't understand HIV with education and statistics on how people are no longer dying from HIV. Explain how being diagnosed with HIV is no longer a death sentence. Someone can die from a car accident or heart attack first before dying from HIV if he or she is taking care of themselves. Explain and help those non-believers to become believers, and if by then they don't get the message, you have to leave them in their disbelief.

was on their foot. How would they feel?

Submitted anonymously

"I WAS HURT,
SCARED, SAD,
AND DEPRESSED
ALL AT ONCE!"

My stigma story comes in two forms: one with the doctor who informed me of my status and then with my siblings.

The doctor said, "See, this is what happens when you be out there sleeping around and getting all these sexual transmitted diseases. One day it will lead up to you getting HIV, the one you can't get rid of." It was my first time getting anything! I was HURT, SCARED, SAD, AND DEPRESSED all at once! She was rude and unprofessional!

With my siblings, all I'm going to say is that I regret it to this day. I regret that I ever told them I was HIV-positive. This is because when they get mad at me, they tell everybody! The bad thing about it is that I thought they would be there for me when I needed them. PUT GOD FIRST AND KNOW THAT HE IS YOUR CURE!!

Submitted anonymously

WHAT IF THE
SHOE WAS ON
THEIR FOOT?
HOW WOULD
THEY FEEL?

Medical staff and stigma may go hand and hand. They sometimes don't understand and are afraid also. Professional staff may talk behind a patient's back and at times make a person feel unwelcome. Training on how to deal with people or the public can minimize some of their disbeliefs. What if the shoe

PUBLICATIONS IN THE NEWS



Since the last PHACS CAB Newsletter in June 2014, PHACS has had six manuscripts accepted to scientific journals and has had three abstracts presented at scientific conferences.

Publications

"Congenital anomalies and in utero antiretroviral exposure in human immunodeficiency virus - exposed uninfected infants." This manuscript is in *JAMA Pediatrics*. Lead author Paige Williams, PhD, is a Senior Lecturer on Biostatistics at the Harvard School of Public Health and is also the Co-Chair of the Cardiopulmonary Working Group.

"Immunodeficiency in children starting antiretroviral therapy in low-, middle and high-income countries." This manuscript is in *JAIDS*. Lead author Manuel Koller, DrSc, is a Senior Statistician at the Institute of Social & Preventive Medicine (ISPM), University of Bern in Switzerland.

"Influence of age at virologic control on peripheral blood human immunodeficiency virus reservoir size and serostatus in perinatally-infected adolescents." This manuscript is in *JAMA Pediatrics*. Lead author Deborah Persaud, MD, is the Director of the Infectious Disease Fellowship Program at Johns Hopkins University.

"Distortion product otoacoustic emission data in perinatally HIV-infected and HIVexposed but uninfected children and adolescents." This manuscript is in the *Pediatric Infectious Disease Journal*. Lead author Peter Torre PhD, is an Associate Professor of Audiology at San Diego State University and is also the Co-Chair of the Hearing/Language Working Group.

"Cardiac effects of in utero exposure to antiretroviral therapy in HIV-uninfected children born to HIV-infected mothers." This manuscript is in *AIDS (2015)*. Lead author Steve Lipshultz, MD, is the Chair of Pediatrics at Wayne State University School of Medicine and is the Chair of the PHACS Cardiology Task Force.

"Dramatic decline in substance use by HIV-infected pregnant women in the United States from 1990 to 2012." This manuscript is in *AIDS (2015)*. Lead author Kathryn Rough, MS, is a student at the Harvard School of Public Health and is also a member of the Maternal Exposures Working Group.

Abstracts

This abstract was presented at the Organization for Human Brain Mapping, in Hamburg, Germany June 8-12, 2014:

"Altered Structural White Matter Networks in Youth with Perinatally Acquired HIV."

This abstract was presented at the 6th International Workshop on HIV Pediatrics in Melbourne, Australia July 18-19, 2014 and at the 20th International AIDS Society Meeting July 20-25, 2014:

"Prevalence of and Progression to Abnormal Non-Invasive Markers of Liver Disease (APRI and FIB-4) among US HIV-infected Youth."

This abstract was presented at the American Society for Bone and Mineral Research in Houston, Texas September 12-15, 2014:

"Fractures in Perinatally HIV-infected versus HIV-exposed Uninfected Children and Youth."

PARTICIPANT SUMMARY

Youth with HIV and Overall Risk of Heart Disease

Previous studies have looked at one risk factor at a time for heart disease. In this study, we looked at many risk factors together to see if children who were born with HIV and take HIV medications have an **overall** higher risk for heart disease. We used a measurement called the PDAY score to calculate this overall risk.

What kinds of issues did we look at?

The PDAY score adds together many different risk factors for heart disease. These include obesity, exercise, diet, smoking, and cholesterol levels. A higher score meant higher risk. It shows the likelihood of **current** damage to the blood vessels in the heart. If there is damage now, there is a higher risk for developing heart disease later in life.

Who we studied

- 165 youth born with HIV who were 15 or older at their most recent PHACS visit (as of April 1, 2012)

What we did

We calculated the most recent PDAY score for each adolescent. We didn't examine their hearts directly.

We compared youth with high PDAY scores to youth with low PDAY scores. We looked at possible difference between the groups like age, gender, ethnicity, CD4 counts, HIV viral load, and use of HIV medications, like protease inhibitors.

For more info, contact:

Claire Berman
Director, Health Education & Communication
617-432-1853
cberman@sdac.harvard.edu

What we found

About half of the youth had high PDAY scores. Current CD4 count was not a factor in having a high PDAY score. But youth were more likely to have a higher PDAY score if they:

- were male
- had taken protease inhibitor drugs with the drug ritonavir
- had an AIDS-defining illness in the past

What we learned

Youth with HIV may be at higher overall risk for early damage to the heart. This puts them at higher risk for heart disease later in life.

Some ARVs like protease inhibitors may increase cholesterol in some people, which could increase risk of heart damage. But the risk of **not** taking ARVs are much higher because having poorly controlled HIV disease leads to far worse health overall.

Because of this, it is especially important for youth with HIV to talk with their doctors about other ways to reduce their overall risk for heart disease. Examples might be eating a healthy diet, exercising regularly, and choosing not to smoke.

Reference Info:

Concept Sheet #Co40
2013. *Circulation*.



WORLD AIDS DAY 2014



Every December 1st we recognize World AIDS Day. This year, several site CABs participated in events, and reflected on the significance of World AIDS Day.

Reflection

My first World AIDS Day hit me in the heart. I had just started to get informed and to know that I was not alone. At this time, when I looked at the face of HIV, I did not see my face looking back. I felt so alone. A great friend of mine asked me to go to an art show with her. I went because I loved art, but little did I know this show would change my life and help mold me into the leader that I am trying to become today. The art show featured the quilts of those who had lost their lives to the fight. Every quilt I saw brought more tears than any chick flick I had ever seen in my whole entire life. I made a promise to her and myself that I would stand up for those who fought for me and now are gone. I said I would not let them die in vain after living in all that hate, stigma, and pain. I hope someone who reads this gets the spark into their heart and helps fight with me to end this battle for good.

Submitted by Miss K.

Event in San Juan, Puerto Rico

A group of empowered individuals got together to create a World AIDS Day ribbon on December 1, 2014 in San Juan, Puerto Rico. It served as an anti-stigma activity and promoted HIV-testing.

This life-size World AIDS Day ribbon was put together at the Parque Sixto Escobar. Aerial photos were taken from a small plane.

Submitted by: Juan and Carlos



WORLD AIDS DAY 2014 (CONTINUED)

Miami Celebrates World AIDS Day 2014

Submitted by: Yuri



RESOURCES

The Stigma Project:

<http://www.thestigmaproject.org>

International Conference on Stigma Conference Archives:

<http://www.whocanyoutell.org/conference-archives>

HIV/AIDS Stigma:

<http://www.thebody.com/content/art12405.html>

Stigma Action Network:

<http://www.stigmaactionnetwork.org>

The Sound of Stigma:

http://www.poz.com/articles/sound_of_stigma_2776_23873.shtml

Reduction of HIV-Related Stigma and Discrimination:

http://www.unaids.org/sites/default/files/media_asset/2014unaidsguidancenote_stigma_en.pdf

Reducing Stigma and Discrimination Related to HIV and AIDS: Training for Health Care Workers:

http://www.engenderhealth.org/files/pubs/hiv-aids-stis/reducing_stigma_participant_english.pdf

Dealing with Stigma and Discrimination:

<http://www.aidsmap.com/stigma/Dealing-with-stigma-and-discrimination/page/1260726>



ESTABLISHING A SITE CAB



Yuri gave a lecture aimed to highlight the importance of creating a CAB at clinical sites, in order to provide a better understanding of participants' concerns about research.

Presentation Summary:

Have decisions about medical research always included the community? No, not at all. Community participation in research is provided through the formation of committees called Community Advisory Boards or CABs. Community participation in research is relatively recent. It was the beginning of the

HIV epidemic in the U.S. that sparked community members affected by the virus to insist that they be given an official role within research networks and protocol teams so as to be heard by researchers and by government agencies funding HIV research and care.

Some steps for establishing a site CAB include:

First, identify potential CAB members. Then, create a mission statement. Finally, establish a structure, create rules, and suggest leadership roles; now you have a brand new CAB!

Creating a CAB is not as simple or as easy as "1,2,3." It requires passion, dedication, determination, and vision, among other logistical planning. I've worked for the University of Miami in the field of HIV for about nine years now and have been exposed to the world of research and CABs. I was fortunate and humbled this year to have

been invited to the "Maternal/Child Health Clinical and Translational Research Forum" lecture series to present about community involvement and how to create a CAB.

My lecture primarily focused on emphasizing the importance of community input/feedback to researchers. I'm happy to say that I used both the IMPAACT and PHACS CABs as exemplary guides when it comes to creating and maintaining a successful CAB leadership. Instead of me talking their ears off, I turned this into a round-table discussion to share ideas about consumer involvement and the benefits of patient-based community priorities for future clinical trials. In the end, we all agreed that consumer feedback is vital before, during, and after a protocol is in place. Lastly, I'm happy to report that I was contacted two days later to form and lead the CAB for the Miami Center For AIDS Research.

Submitted by: Yuri

PHACS CAB GOALS—2015

1. Focus on stigma reduction projects and efforts;
2. Share resources between site CABs;
3. Develop interactive webinars for CAB members;
4. Focus on coping mechanisms;
5. Give ongoing feedback to PHACS researchers; and
6. Keep updated on PHACS research, scientific terminology, and CAB activities.

CAB GLOSSARY



Bias: Unknown or unacknowledged error created during the design of a study that could influence the results.

Epidemiology: The study of when, where, why, and how a disease occurs in a population.

Intervention: An action undertaken in order to change what is happening or might happen, especially to prevent something undesirable. For example, teaching the ABCs of HIV prevention is an intervention designed to reduce the risk of HIV transmission.

Prophylaxis: Treatment to prevent a particular disease or to prevent recurrence of an ongoing infection that has been brought under control.

Stigma: Disapproval associated with a particular circumstance, quality, or person.

WORD SEARCH

Directions: Find the CAB Glossary terms listed above (Answer Key on [page 21](#)).

S	A	I	E	O	I	I	A	B	E	I	M	T
Y	G	O	L	O	I	M	E	D	I	P	E	S
N	O	I	T	N	E	V	R	E	T	N	I	T
O	E	H	E	X	N	V	B	I	G	E	N	I
X	P	M	R	H	N	E	H	I	M	E	N	G
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P	R	O	P	H	Y	L	A	X	I	S	R	A

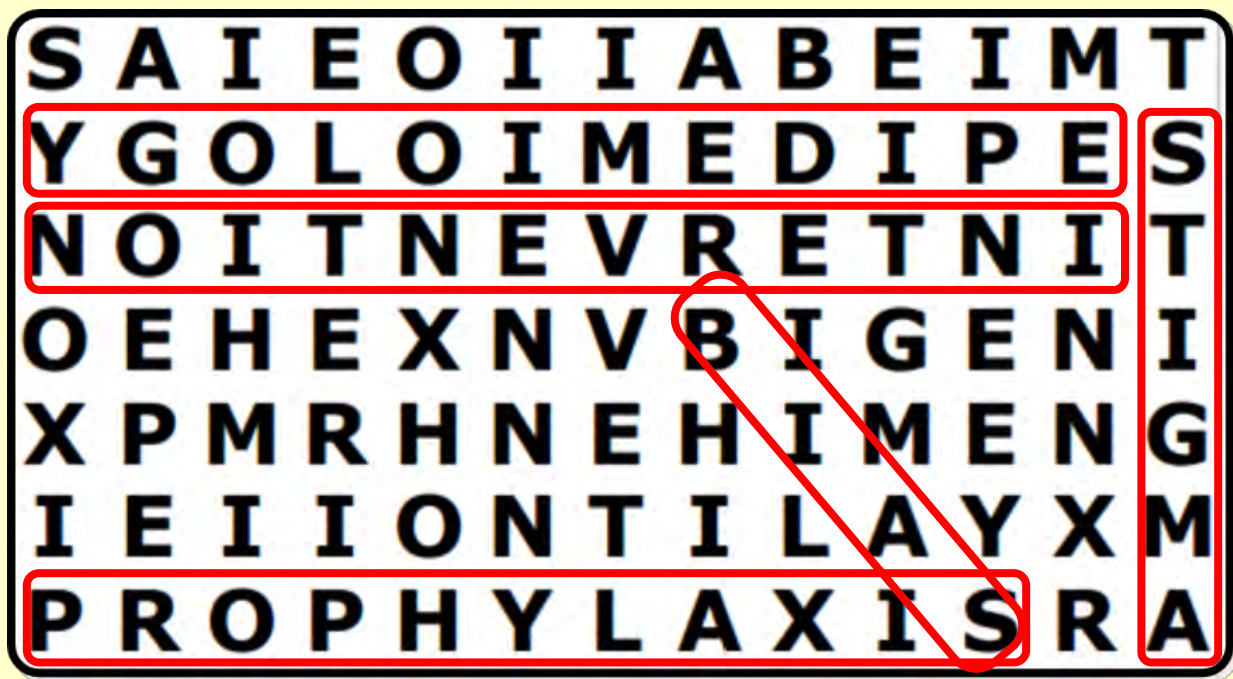
PHACS WEBSITE—SIGN UP!

Have you heard the news? There is a new PHACS website! **All** CAB members are encouraged to register as a CAB member and create a personal account on the new PHACS website. Registered CAB members have access to newsletters, activities and involvement, conference call minutes, resources, and the CAB glossary. Follow the steps below to start your website registration:

1. Go to <http://www.phacsstudy.org>.
2. Click "Register" in the upper right corner of the PHACS homepage.
3. Fill out the "Personal Info" form. Choose "CAB Member" from the "Member Role" drop-down menu. CAB members have special permissions on the new PHACS website, including access to a CAB-member only forum. *Please note that the avatar/photo feature is optional.*
4. Fill out the "Choose a Password" and "Confirm Password" forms.
5. Click the box below the "Register My Account" button to agree to the [Terms of Use](#).
6. Click "Register My Account."
7. A PHACS website-administrator will contact you via email to approve your account.

Questions? Please contact Megan Reznick (MeganReznick@westat.com) and/or Claire Berman (cberman@hsph.harvard.edu) for more information.

WORD SEARCH KEY



Please send all questions, comments, and suggestions for the CAB Newsletter to **Megan Reznick** at MeganReznick@westat.com.