

A COMMUNITY ADVISORY BOARD NEWSLETTER

PUBLISHED BY:

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

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IN FOCUS

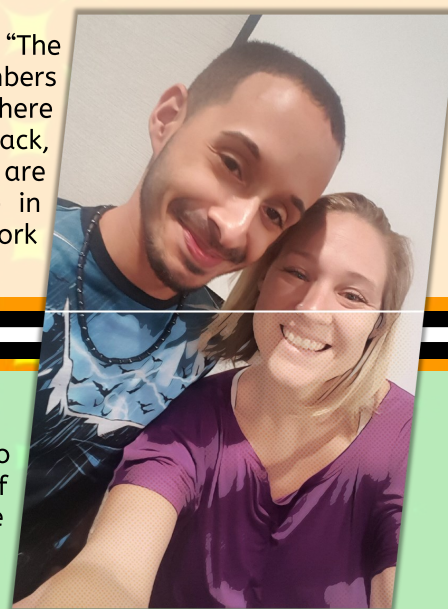
FROM OUR CAB CHAIRS



STEPHANIE, PHACS CAB CHAIR:

The PHACS CAB newsletter is something I feel many of us look forward to; I know I do. Since the last newsletter, Brandon and I traveled to Maryland for the PHACS 2018 Spring Leadership Retreat. We did our best to represent the CAB. Even though, scientifically speaking, some of the sessions were difficult to understand, they were very insightful (read more about the retreat on [page 17](#)). This month, my daughter and I have the opportunity to represent PHACS and our CAB in Amsterdam, The Netherlands at the HIV-Exposed but Uninfected (HEU) Workshop attached to the International AIDs Conference. We will do our very best to represent the PHACS community there.

Just to touch on this newsletter's theme of "The Importance of CABs in Research" – CAB members are very essential in research. Without us, there would be no feedback and without feedback, things never get better. Never forget that we are important! I cannot wait to see everyone in September at the PHACS 2018 Fall Network Meeting and CAB Retreat.



BRANDON, PHACS CAB VICE CHAIR:

We have come a long way on this journey to better understand and improve the lives of people living with HIV and AIDS. It seems like yesterday when the epidemic first hit. It hit at a time when people were fighting for their lives to gain access to medical care, and to not only be treated as equals, but as human beings. In the early days of the epidemic in the United States, the disease was known as "gay-related immune deficiency" (GRID). Back then, it was believed that only those part of the "4-H club" (people from the country of Haiti, men who identified as homosexual, people who used heroin, and people who have a blood clotting disorder – hemophiliacs) were at risk. HIV/AIDS was considered a death sentence and zidovudine (AZT) was a person's only hope.

The HIV/AIDS epidemic hit at a time when Ryan White, a courageous 13-year-old young man from Kokomo, Indiana took on the United States Congress and the world, just so that others could have an opportunity for a much better and normal life. The importance of a Community Advisory Board (CAB) is not necessarily about us, but it is for those who do not have a voice or the opportunity to be the voice of the community. It is to honor and remember those who fought and sacrificed everything yesterday, so that we may have a glimmer of hope today. Finally, it is to realize that what we do not only affects us now, but also impacts all those around us, including those who will come after us.

THE IMPORTANCE OF CABS IN RESEARCH

We asked the PHACS community about the importance of CABS in research. The following quotes were submitted by PHACS CAB members, investigators, and study coordinators!

PHACS is lucky to have such outstanding CABS. I often say that we have the most active CABS that I have been involved with in over 35 years of clinical research. CAB members provide important input into defining our priorities for PHACS and invaluable insight into the design and implementation of our studies. The interactive panel discussion at the Fall 2017 Network Meeting is an excellent example of the important insights that the CABS provide us as investigators and how open and productive the dialogue is between investigators and the CABS. It was truly outstanding and made me very proud.

DR. RUSS VAN DYKE

I've always felt like the importance of the CAB has to do with helping researchers understand the importance of the kinds of questions they're asking the community. Also, the CAB helps researchers during the development of the visit schedules, laboratory assessments, and other things related to study visits. The CAB provides input about how the research may affect study participants, and whether something is going to make them more or less likely to participate in a study. The CAB also provides input about how feasible a study will be for participants and their families.

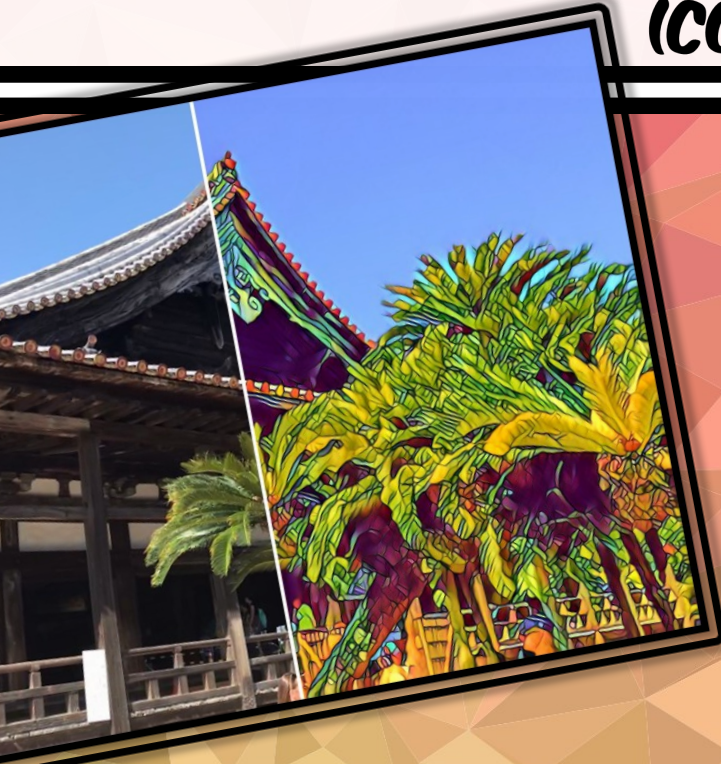
It is wonderful to receive input from a wide range of people and places. This helps to sculpt research efforts.

The community is an integral part of what we do. The CAB helps us direct the focus of our clinical studies. A strong CAB contributes to a strong PHACS agenda.

CAB involvement in research ensures that the patient/client remains at the center of the research. The CAB members are a vital link between the researchers and the study participants. CAB involvement in PHACS provides clarity to the researchers on how best to approach a study/study participant. Also, CAB involvement in PHACS provides clarity to the participants/potential participants on the importance of conducting these studies and the individual benefits from being in the study and the greater relevance.

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THE IMPORTANCE OF CABS IN RESEARCH (CONTINUED)



The importance is the contribution that a study can give to the entire community. The contribution helps continue the advances in technology, medicines, and stopping the virus.

In research, at times we get caught up in the rigor of good science, solid methodology, having enough statistical power, asking questions that fill gaps, and those are all very important. However, the CAB provides a critical perspective; they put a face and a story behind our objectives, and help us prioritize those aims that may change the quality of life for those living with HIV, everywhere. In PHACS, the CAB has directly or indirectly provided insight, wisdom, and context to every stage of the research process, from conception to design to interpretation of results. We are better researchers for hearing and heeding their voices.

The PHACS CAB is highly valued for its contributions to the work of PHACS. CAB members have a unique perspective on the strengths, goals, challenges and needs of individuals and families affected by HIV. We are grateful that PHACS CAB members will continue to teach us and guide our ongoing research, education, and advocacy.

The CAB provides valuable perspective on HIV issues that affect their daily and future lives, which are therefore important to study. The CAB keeps the researchers grounded and focused on critical issues. The CAB may identify issues that researchers have not considered. The CAB can explain the importance of research to their non-CAB colleagues to help them understand how research has enabled progress in prevention, treatment and improved quality of life for those living with HIV. Thank you, CAB, for all you do!!

CABs and the continuum of research are important to me, my four kids, and my husband so that we may be healthy. Being healthy helps me to provide for my children.



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THE IMPORTANCE OF CABS IN RESEARCH (CONTINUED)

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CABs provide critical input, both in planning research protocols, as well as making sense of the data that we collect. The relationships developed with the CABs go well beyond science, providing a window into the lives and challenges of families living with HIV. They have enriched the PHACS experience for all of us. One just has to take a look at the impact that the CABs have had on the PHACS website and the PHACS Film Series.

”



There is no research without the community, period (#NothingAboutUsWithoutUs). However, the partnership between researcher and community is an important one. Researchers bring scientific expertise; community leaders bring lived expertise. Like a two-sided coin, both aspects are necessary, beneficial, and help to fuel one another.

The reason why CABs are so important is because CABs help the community leave a legacy not only for themselves, but also for the world around them. That stick, that injection, that prick, those long waits, those hospital stays, and those CAB meetings will not only affect your family, but will also affect generations to come. You never know if your participation is that one key in research that may be the beginning of the development of the great vaccine!

The CAB is important in research because the members offer important insight regarding agenda setting and study visit improvements.

We need to continue the research for new consumers who find out their status. Also, we need this research so that we can come up with new medications. Sometimes people who are HIV-positive become immune to the medication. This means we need our research to continue to find a cure for people living with this disease.

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THE IMPORTANCE OF CABS IN RESEARCH (CONTINUED)

The concept of the Community Advisory Board for the PHACS program has been going extremely well and has proven to be a great success. The concept involves lay public reaching out to the university to better understand how it changes the present and future of patients and supporters. On the other hand, the university desperately needs a mechanism inside the lay organizations to communicate with them, and to try to understand their concerns about the impact of clinical trials. The lay public has responded well to the invitation of universities to assist them in this process of clinical trials, and the extremely rapid publication rate of PHACS investigators. These publications have facilitated interaction between CABS and clinicians. Collaboration has become the order of the day. Because of the PHACS CAB program, Drs. Russ Van Dyke and George Seage have been able to expand the scope of investigations beyond the early results of clinical research, and so many experts previously not interested in HIV research in children have now found common ground with previous investigators in the PHACS program.

I BELIEVE THE PHACS CAB PROGRAM SERVES AS A MODEL FOR OTHER RESEARCH PROGRAMS SPONSORED BY THE NATIONAL INSTITUTES OF HEALTH.

All in all, the PHACS CABS have become an integral part of capsule, concept and protocol development, and wise comments from the lay public now are easily expressed in the PHACS program. Thus, there has been a tremendous benefit having this integration of efforts by CAB members and investigators. Both CAB members and PHACS investigators look forward to a good future that will reap benefits on society.

DR. BILL SHEARER

As a stakeholder, research participation is important because it saves lives. Even in failure, we find successes, which makes the fight worth the struggle.



Research and CABS are so important to anyone involved, including anyone living with HIV and AIDS. I know how important research is (which helps impact the fight) because I look at it everyday when I look into the eyes of my HIV-exposed but uninfected son. All mothers should be able to have that feeling in the future.

THE IMPORTANCE OF PHACS AND THE CAB TO ME


The importance of the CAB is that it gives the community a voice, and participation in the CAB allows the community to share their important opinions that help influence decision-making for PHACS study participants. PHACS has changed the meaning of a healthier lifestyle for youth who are infected with and/or exposed to HIV. The wonderful thing about PHACS and the CAB is the empowerment and support it provides to the youth and adults who participate in PHACS.

When asking study participants what they have gained from being a part of PHACS, many have said they consider the experience to be life-changing. This is because they are being provided with information that is beneficial to them, but most importantly, they are leading the way for others who may need the same encouragement and support they have received.

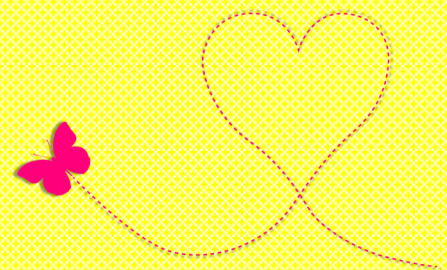
Being involved with PHACS for over five years as a CAB member and a study participant has helped me and my family learn how to disclose to my children, family, and others. Having monthly meetings has been a way of keeping study participants and the community engaged in research. This helps the community learn what research is happening, what is in the works, and the study outcomes. My CAB has progressed in so many ways through involvement in CAB meetings. We look forward to being around others without the stigma that is attached in so many communities. We work to change the way someone feels about attending medical appointments, as well as helping others with adherence to medications. Most importantly, being a part of PHACS and the CAB has provided a safe haven for many. To me, PHACS and the CAB provide information to the community about research participants and the benefits of helping others.

When asked to describe the importance of PHACS and the CAB in research, I think about family.

Submitted by: Exzavia



***OUR FAMILY IS
A CIRCLE OF
STRENGTH
AND LOVE.
WITH EVERY
BIRTH AND
UNION IT
GROWS.
EVERY CRISIS
FACED
TOGETHER
MAKES THE
CIRCLE
STRONGER.***



CAB MEMBER MOTIVATION

I am passionate about health education and outreach. I stay motivated so that I may pass on learned information to others who can benefit as well.

Every day I want to continue contributing to my community with my knowledge of medicine. I want to be able to give better service.

Just working with everyone, no matter who anybody is, what color they are, what religion they are – just being able to help someone. That's my mission.

The thing that really keeps me engaged is that I don't feel like a guinea pig. I feel involved in the process. We provide feedback, so we actually see the progress. Also, I stay engaged for my children. Hopefully one day, we will find a cure.



Life is my motivation!

The reason why I stay engaged in the CAB is because of the people who fought before me. In my prayers, we will be the end of the front line. I want whoever comes behind us to see the strength we had.

RESOURCES

Recommendations for Community Engagement in HIV/ AIDS Research:

<https://daidslearningportal.niaid.nih.gov/node/6907>

The Role of Community Advisory Boards: Involving Communities in the Informed Consent Process:

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1446908>

"PHACS Community Voices" Community Advisory Board Film:

<https://youtu.be/gal0cJwL2vc>

CAB Handbook:

<https://phacsstudy.org/Education-Hub/CAB-Handbook>

PHACS CAB Homepage:

<https://my.phacsstudy.org/cab>



ALL IT TAKES IS ONE

I DEDICATE THIS STORY TO JENNIFER ANGEL, MY SISTER ASHLEY, AND TO ALL THE OTHERS WHO HELPED PAVE THE ROAD FOR US.

My life has been a journey. Although it hasn't always been an easy one, it has been a memorable one, but I can't say I did it all alone. There have been many faces on this road. Some of those faces have helped me a great deal, from family, friends, doctors, and even strangers. People come in and out of our lives all the time, but sometimes a special person enters your life and you don't know why they are there. You know they were meant to be there and are there for a reason. This is the kind of person who you don't let go of because you realize someone like that doesn't come around very often.

I have a friend, who touched my life, whose finger prints have never faded. She is a special someone who saw the best in me and believed in me when no one

else did. She believed in me even when I didn't believe in myself. I've learned from her that sometimes you have to believe in someone else's belief in you before you can believe in yourself. She taught me that although we may experience some dark and difficult times, we must never be the victim. We must take control of our lives. Most of all, she taught me that sometimes a friend can be the greatest cure. She is one of the reasons why I became the person I am today, and that is why she will always hold a special place in my heart. All it takes is one person to believe in you, and in

the end only one person to truly make a difference.

Submitted by: Brandon



***"TO THE WORLD YOU MAY BE ONE PERSON; BUT TO ONE PERSON YOU MAY BE THE WORLD."
-DR. SEUSS***

***"WE OURSELVES FEEL THAT WHAT WE ARE DOING IS JUST A DROP IN THE OCEAN.
BUT THE OCEAN WOULD BE LESS BECAUSE OF THAT MISSING DROP."
-MOTHER THERESA***

MY TRAILBLAZER



The person I have chosen as a trailblazer is Tori Williams. She has worked and volunteered in the Houston HIV community for over 30 years. She has worked with our county commissioner on making sure that our cause is not forgotten, even with the changing of the guards. For the past 19 years, she has been the Director of the Office of Support for the Houston Ryan White Planning Council, where she assists over 60 volunteers on a day-to-day basis. She helps them understand and carry out their responsibilities within the Ryan White program. As part of her duties, Tori co-facilitates Project LEAP (Learning, Empowerment, Advocacy, and Participation). Project LEAP is a comprehensive training program designed to encourage people living with HIV/AIDS to become active participants in local planning bodies. This is where I first got to know her and understand how important advocacy was. I was a newly diagnosed HIV-positive person, who had a fire to fight for those who look like me but didn't know how to advocate for themselves. She, along with a group of like-minded people, is the reason why I am here today. I was on the planning council and attended Project LEAP, which helped me to gain insight on why and how to fight for our voices to be heard.

I salute you, Tori Williams, for being a part of the first soldiers in the fight against HIV and AIDS in the city of Houston. Most of all, I salute you for training soldiers like me who have taken up the cause, and like you, will not stop until there is a cure.

Submitted by: Kimbrae

AN INTERVIEW WITH DR. SHEARER

Dr. William Shearer is and always has been a true trailblazer. He leads a hospital full of trailblazers and fighters, like myself. I wanted to let the world know if had not been for him, Texas Children's Hospital wouldn't have had a CAB; I wouldn't have known what PHACS was and how it could help my family. He makes sure our concerns are always being heard by the hospital. I am so honored to share my Q&A with this great person because, to not know him is like not knowing a living piece of history.

Submitted by: Kimbrae and Dr. Bill Shearer

Q

Do you remember the first time you enrolled a pregnant mother into the first Pediatric AIDS Clinical Trials Group (PACTG) protocol?

A

The first time I enrolled a pregnant mother living with HIV to a perinatal AIDS drug trial protocol, there was great apprehension because of first exposure of a newborn baby. It was a perfect study. We all rejoiced because it was a double blinded placebo-controlled drug trial that showed true evidence of the effectiveness of zidovudine. After that success, the pace of the investigation of perinatal HIV research picked up. Soon after, centers around the country were testing possible AIDS drugs to prevent mother-to-child transmission. After that, the transmission rate of an HIV mother to her baby plunged from 25% to less than 1%.

How did you feel when you held that first baby?

Q

Our pediatric AIDS research nurses (Chivon McMullen-Jackson, Shelley Buschur, Terry Raburn, Valerie Nichols, and Norma Cooper) and HIV social workers (Theresa Aldape, Gloria Sierra and Carlis Polk) brought the baby for me to hold, and like every other baby, it felt warm and fuzzy.

A

How hard was it to fight with the bureaucratic red tape to get more funding in the beginning of the HIV/AIDS epidemic while knowing that babies were dying?

Q

Government and national agencies were desperate for drugs to treat children who were already HIV-infected, and to find the best drugs to prevent perinatal transmission. In the late 1980s and early 1990s, the National Institutes of Health (NIH) was given a mandate to take care of this unexpected problem. It was apparent that funding was the key reason for this success of our efforts of preventing new perinatal transmission. Investigators initially were discouraged by the lack of funding and the long time it seemed to take to fund centers of excellence, which is the Pediatric AIDS Clinical Trial Group (PACTG). It was gratifying and rewarding when their efforts were given the full support by the NIH and the Centers for Disease Control (CDC).

A

(Continued on [page 11](#))

AN INTERVIEW WITH DR. SHEARER (CONTINUED)

Q

What was your initial reaction when you realized that the trial was working and that you had your first HIV-free child due to the clinical trials program?

A

Immense satisfaction. A deep sense of camaraderie and brotherhood as we reached out into all sections of society to combat this epidemic. It was gratifying to meet investigators from around the country who were experiencing the same feelings that resulted from this clinical trials program.

Q

How ecstatic were you when you realized that one of your initial babies was able to transition out of the program?

A

It gave me a sense of belonging to a special historical achievement, when perinatal HIV transmission was interrupted. Those infants will remain HIV-free (so far as we understand now). Children who are engaged in these ground-breaking studies should be followed for several decades in case new implications arise.

UPCOMING EVENTS

September 16: Fall 2018 YACAB Retreat

September 17-18: Fall 2018 Network Meeting

September 19: Fall 2018 Adult CAB Retreat

September 27: National Gay Men's HIV/AIDS Awareness Day

October 15: National Latinx AIDS Awareness Day

December 1: World AIDS Day

**SAVE THE DATES!
FALL 2018 NETWORK
MEETING AND CAB
RETREATS**

PHACS MEMBER PROFILES



LIZ SALOMON, EDM

My name is Liz Salomon, and I am the new Program Director for the PHACS Data and Operations Center (DOC) at the Harvard T.H. Chan School of Public Health. I am only a few months into my new position, but I couldn't be happier to be here and am so grateful to be a new member of the PHACS family!

I began working in HIV/AIDS in the Research and Evaluation Department at Boston's Fenway Community Health Center shortly after I finished graduate school in 1998. I studied education for social and political change, and qualitative and participatory research with a particular focus on working with Lesbian, Gay, Bisexual, Transgender, and Queer (LGBTQ) youth. I began working at The Fenway at a time when my partner's brother had recently been diagnosed with HIV/AIDS. My brother-in-law was diagnosed with HIV at a time when antiretrovirals were just becoming available, but his disease had already progressed too much to make him a candidate for most treatments.

He decided to become a research participant at the National Institutes of Health (NIH) where he donated his time, specimens, and life story to the discovery of new treatments. He hoped that those who would come after him would not have to experience what he went through in the earlier days of the HIV epidemic. In his life and through his passing, my brother-in-law became my source of inspiration for doing the work that I started doing back in 1998. He and my many other friends and family members living with HIV/AIDS today continue to inspire me to do the work that I continue to do every day.

During my initial time at The Fenway, I got to work on behavioral interventions in both primary and secondary prevention funded through the HIV Prevention Trials Network (HPTN). I worked on HIV vaccine trials funded through the HIV Vaccine Trials Network (HVTN) and microbicide acceptability studies funded through the Microbicide Trials Network (MTN). I also worked on adherence projects, community needs assessments, and many other amazing projects with incredible participants and community members, who participated in CABs, advising us along the way.

What I'd initially thought would only be a few years at The Fenway turned into more than nine, but when the funding ended on one of my main projects in 2007, I decided to try something new. I left The Fenway to help

run the Massachusetts General Hospital (MGH) Clinical Research Program's Education Unit, where I helped train clinical investigators and their study staff on how to best do clinical research. I missed my work in HIV research desperately, so when The Fenway Institute invited me back four years later to work as the Project Director for Community-Based Research in their newly-funded Adolescent Trials Network (ATN) site, I jumped at the opportunity.

During my second time at The Fenway, I directed "Connect to Protect Boston" and "The SMILE Program." Both of these projects together worked to examine the power of racial justice and health equity-focused community mobilization and structural (program, policy, and practice-level) change as a means of primary and secondary HIV prevention for youth in Boston. I was given the opportunity to start The Fenway's first Youth CAB. I served as a self-care interventionist on a LGBTQ youth of color participatory action research project called, "Our Health Matters." I was also given the opportunity to be a protocol team co-chair on a research project that looked at HIV across the continuum of care for transgender and gender non-conforming youth. This project was created in collaboration with a special youth CAB.

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PHACS MEMBER PROFILES

(CONTINUED)

After five incredible years working on the ATN, funding restructuring once again ended my projects at The Fenway, and I transitioned into applying the skills I learned from this experience to serve as the Director of Programs at a small start-up non-profit called, "Primary Care Progress." This organization works with health professions students and practitioners across the United States to inspire, nurture, and activate leadership, innovation,

and advocacy among inter-professional teams of primary care change makers.

But like during my time at MGH, I desperately missed my HIV research work, so when I found the Program Director position at the PHACS DOC, I couldn't have been more excited. I am thrilled to have the opportunity to work with and learn from youth, young adults, moms, caregivers, community members, and

researchers through this project. I am looking forward to getting to know all of you in the PHACS CABs in the years to come.

When I'm not working, I love to spend time with my wife and 13 year old twins, ride my bike, swim, and practice and teach yoga. My email is lsalomon@hsph.harvard.edu and I welcome being in touch at any time!

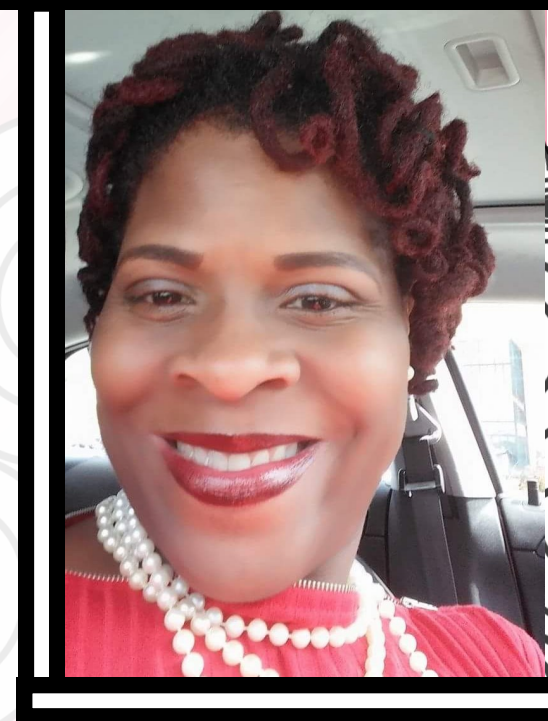
GENA

In 2001, as a volunteer at the University of Miami, I began advocating for youth in Miami, Florida. Today, I am a Peer Education/Patient Advocate in the Pediatric Infectious Disease Department at the University of Miami, a Ryan White Part D-funded site. We care for infants, youth, women, and families living with HIV/AIDS. My recent accomplishments include being accepted into the National Minority AIDS Council, Building Leaders of Color Program. This program seeks to engage people living with HIV in leadership opportunities to improve care for persons living with HIV.

I am involved in many activities in my community including: participating as a member of the Miami Dade County HIV/AIDS

Partnership (our Ryan White Part A consortium of providers); participating as a speaker for Miami Dade County Public Schools; volunteering with the Alpha Phi Alpha fraternity young men's mentoring program; and working with the 5000 Role Models Mentoring Program. I am working on starting a non-profit agency focusing on youth and staying healthy. This agency will be named "So Let's Talk About It" because it's that thing that people don't want to talk about until it's a little late. My role in our program at the university focuses on improving adherence to treatment and medication with our young patients using motivational interviewing techniques. This helps me to help youth living with HIV have better health outcomes before they transition to the adult world of HIV care.

I can say that I was welcomed



into this CAB by Stephanie, Delia, Dr. Gwendolyn Scott, Dr. Ana Garcia, and Grace Alvarez.

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PHACS MEMBER PROFILES (CONTINUED)

They have really helped me become familiar with what our CAB site stands for. I am always so excited to hear what advancements have happened since our last meeting. What I have learned most about research is that we are always researching something, and the findings can be very exciting! Our CAB members are all very active in the community. They spread the word about research opportunities and do a really great job keeping myself and our team involved in outside community events.

I enjoy family time with my husband, mom, and dad. I also enjoy spending time with my 84-year-old grandmother, who is such an inspiration to me. I enjoy family gatherings and spending time with my new fur baby, Sparky.

I can personally say that I am so happy to be a part of such a dynamic force in research. I am thankful to have met other awesome consumers from New York, Texas, Fort Lauderdale, Louisiana, Tampa, Colorado, and beyond. I do believe that we have to continue the conversation

loudly with our community because HIV is still such a stigmatized issue! We all have a voice in the matter. If I can encourage anyone reading this newsletter, I would say, stand tall, speak up for what you need, live life to the fullest, and remember self-care. Those who know me know I don't know what self-care is (haha), but you all will be proud of me because I am working on incorporating self-care in my life! Thank you for the opportunity to share a little about myself and the team.

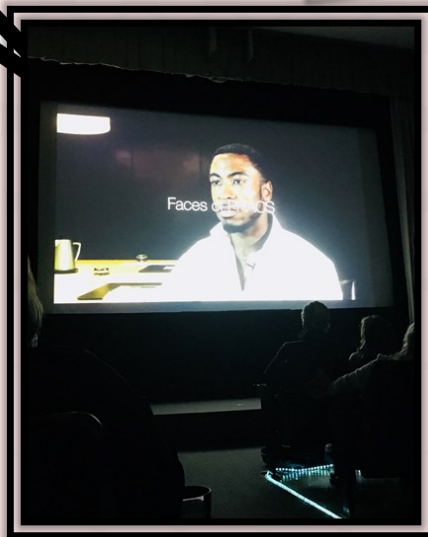
NEW CAB CALL GROUND RULES

- If joining the CAB call late, wait to announce names until the end of the call.
- Respect each other's time – limit responses to less than a couple minutes at a time.
- Make sure everyone has a voice – let everyone get a chance to speak. Be mindful of others who haven't gotten a chance to share. Take turns talking.
- Confidentiality – what is said on the call stays on the call.
- Questions are always welcome at the appropriate time.
- Respect each other's opinions – allow others to share freely without criticizing or giving advice.
- Mute the phone when not speaking.



HECC UPDATE

The Health Education and Communication Committee has had a busy six months! One exciting piece of news is that Megan, Andrew, and I took a trip to the red carpet in April 2018 to present the short documentary, *Faces of PHACS*, at the Vail Film Festival high in the mountains of Vail, CO. This was the world premiere of *Faces of PHACS*, which highlights three PHACS Young Adult CAB members' experiences growing up HIV positive, their goals for the future, and their hopes for the continuation of HIV research. There were two screenings of the film, which was one of only four short documentaries accepted to the festival. Each screening was followed by a Q&A session, when Megan, Andrew, and I were able to answer questions from the audience. This was the first time we screened the film for a general audience, and we were happy to hear feedback about how much viewers learned about HIV – particularly pediatric HIV. This reminded us of just how far we still have to go in terms of raising awareness! Many viewers expressed how moved they were by the stories that Dominique, Andrew, and “Maria” shared in the film, and that it opened their eyes to a part of the experience of living with HIV that some were previously unaware of. Megan, Andrew, and I also had the chance to be interviewed by the



press during the film festival, including by several local reporters covering the festival. Megan and I even appeared on local TV. *Faces of PHACS* will also reach its first international audience when it was screened at the 10th International Workshop on HIV Pediatrics on July 20-21 in Amsterdam, The Netherlands!

Also this spring, we worked closely with the Adult and Young Adult CABs and partnered with Booster Shot Media to complete a series of four whiteboard videos that will help support the informed consent process for young adults enrolling in one of our PHACS protocols. The videos will be one part of the overall informed consent process. Rather than replacing any part of the consent, they will be available to

study coordinators and young adults as a way of using visuals to help illuminate concepts that may be less familiar, such as repository samples, privacy and confidentiality, and the potential impact of participation in PHACS. Adult and Young Adult CAB members were very instrumental in creating these videos, and YACAB members even chose the voice they liked best for the narration. We hope that sites will be able to start using the videos soon.

We have a few big projects in the works for the second half of the year.

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HECC UPDATE (CONTINUED)

Some of you may remember the work we did last fall on a series of choose-your-own-adventure videos for young adults transitioning to adult health care. We are pleased to report that we've found a local student film production group in Boston that is very eager to partner with us to produce these films. The HECC and the YACAB plan to work with them for the remainder of the year, first honing the script, then filming, and finally, doing post-production work such as editing.

Finally, we have long heard feedback from sites about the participant summaries that PHACS produces and a desire for additional materials that can help communicate PHACS' results to its participants. PHACS has produced so many publications now (109 at the time of this writing!) that it can be difficult to have time to read every single summary. We also wanted to find a way to make it easier for participants to see the big picture from PHACS' results. We decided to work with a graphic designer to make a series of infographics that will provide a visual summary of overall findings on certain topics in PHACS (i.e., adolescent health or maternal health). We hope that the infographics will help participants see how different journal articles are related to



each other, and to see the overall message about PHACS' findings so far.

We look forward to lots of great collaboration in the coming six months, and to seeing many of you in person at the Fall Meeting. I want to offer my heartfelt thanks for all you do for the CAB and for PHACS. As you can see from above, your participation is crucial—we could not do any of this without you!

Submitted by: Claire

HECC LINKS:

"FACES OF PHACS" DOCUMENTARY:

<https://tinyurl.com/y8emt64r>

VAIL FILM FEST LOOK LIVE: FACES OF PHACS RED CARPET INTERVIEW:

<https://tinyurl.com/ybe7uln9>

PEDIATRIC HIV/AIDS COHORT STUDY DOCUMENTARY PLAYS VAIL FILM FESTIVAL:

<https://tinyurl.com/ybhncdep>

FINAL DAY OF VAIL FILM FESTIVAL HONORS FILMMAKERS AND THEIR ART:

<https://tinyurl.com/y9kqolb4>

INFORMED CONSENT VIDEOS:

<https://tinyurl.com/y8oqtcvh>

TAKEAWAYS FROM THE SPRING 2018 LEADERSHIP RETREAT

THE MACS AND WIHS COMBINED COHORT STUDY

MULTI CENTER AIDS COHORT STUDY



WOMEN'S INTERAGENCY HEALTH STUDY



The MACS and WIHS research teams are in the process of putting in an application to NIH to move forward as a combined study. Researchers will study long-term complications between the two cohorts. Long-term complications may include heart disease, lung disease, blood systems, inflammation, sleep, substance use, aging, menopause, menstrual patterns, cancer, and viral load and the effect of antiretroviral (ARV) treatment over time. Researchers will also look at societal issues such as support, stigma, and discrimination.

ADDITIONAL MATERNAL DATA COLLECTION FOR SMARTT DYNAMIC COHORT BIOLOGICAL MOTHERS



ADDITIONAL MATERNAL DATA COLLECTION FOR SMARTT DYNAMIC COHORT BIOLOGICAL MOTHERS



NOW OPEN AND ENROLLING

Mothers of SMARTT Dynamic Cohort participants before birth before less than five years of age.



WHAT WILL BE STUDIED



The research team will look at pregnancy outcomes such as:



Blood pressure during pregnancy



Viral response during pregnancy



Illness during pregnancy



Retention in health care

WHAT'S NEXT



PHACS researchers also applied for a grant for a follow-up study to study these mothers, but the NIH decided not to award the grant at this time. PHACS plans to reapply for the grant to conduct a larger study looking at mothers' health over a long period of time.

OTHER STUDIES IN PROGRESS (CONTINUED ON [PAGE 18](#))

CARDIAC AND PULMONARY IMAGING STUDIES



PHACS researchers will be doing Magnetic Resonance Imaging (MRIs) of the heart to look for heart problems in youth living with HIV. This is a pilot study that will be done at Boston Children's Hospital.

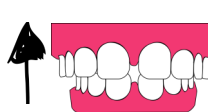
ORAL HEALTH FOLLOW UP STUDY

The *initial* study found the following were increased for both HIV+ and HEU youth in AMP:

CAVITIES



INFLAMMATION



The *follow-up* study will look at oral health data over time.

TEMPORAL ANTIRETROVIRAL PRESCRIBING TRENDS FOR PREGNANT WOMEN LIVING WITH HIV

PHACS researchers looked at data of pregnant women from:

2008 TO **2017**

Women who had never been pregnant before or who just started ARVs during pregnancy were more likely to be prescribed currently "recommended" ARVs. Women who had been on ARVs for many years were less likely to be prescribed "recommended" ARVs.

TAKEAWAYS FROM THE SPRING 2018 LEADERSHIP RETREAT (CONTINUED)

OTHER STUDIES IN PROGRESS

HUMAN PAPILLOMA VIRUS (HPV) SUBSTUDY



This study will enroll young women born with HIV who have received the HPV vaccine.



WHY IS THIS STUDY BEING DONE?



PHACS data suggests that the HPV vaccine may not seem to work as well in protecting against cervical disease in young women born with HIV as those without HIV.

WHAT WILL BE DONE IN THIS STUDY?



Pelvic exams to look for abnormalities of the cervix due to HPV.



Biopsies of abnormalities to see whether there are changes that may lead to cancer or cervical disease.

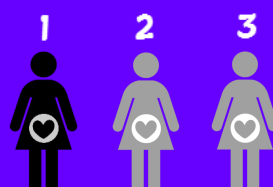
REPEAT PREGNANCIES IN SMARTT

WHAT WAS STUDIED

This study looked at changes in viral load (VL) and CD4 counts, and ARV medications in pregnancy between the first pregnancy and subsequent pregnancies of mothers in SMARTT.



IN



WHAT WAS FOUND

Many of the mothers had suppressed VLs during pregnancy, but frequently after pregnancy the VL would rebound into the detectable range. During a second pregnancy, the VL fell again and was slightly lower at the end of the second pregnancy than it was after the first pregnancy.



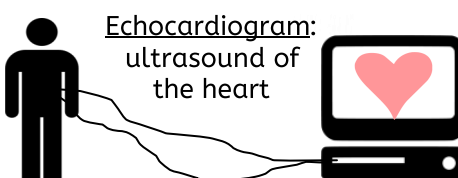
SMARTT HOSPITALIZATIONS

This study looked at rates of hospitalization of youth in SMARTT compared to children in the US who were not born with or exposed to HIV.



Results suggested that youth in SMARTT had almost two times the rate of hospitalizations and infection-related hospitalizations in the first two years of life.

ARV USE AND CARDIAC ECHOCARDIOGRAM RESULTS IN AMP

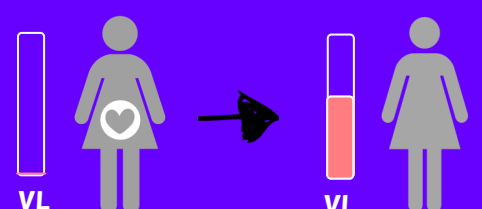


Echocardiogram: ultrasound of the heart

PHACS used echocardiograms to learn whether heart problems may be related to ARV use among youth in AMP. Results suggested that youth taking a protease inhibitor had better heart function than those taking other ARVs. Zidovudine was linked to a minor negative effect on the heart. Overall, the research suggested that heart function was very good in youth with good access to ARVs.

POSTPARTUM HEALTH OF AMP UP YOUNG WOMEN

This study found lower rates of pregnancy in women born with HIV, but 42% did have a pregnancy.



VLs were not always suppressed when the women got pregnant. During pregnancy most of the women reached undetectable VLs, but after the baby was born the VLs often became detectable again.

TAKEAWAYS FROM THE SPRING 2018 LEADERSHIP RETREAT (CONTINUED)

GENOMICS STUDIES IN PHACS

GLOSSARY TERMS

- **Genomics:** The study of a person's genes (DNA) and seeing how genes relate to different outcomes, including both developing illness and remaining healthy
- **Genome:** Part or all of a person's DNA
- **Whole Genome Sequencing:** Process by which researchers can map out the entire set of a person's DNA

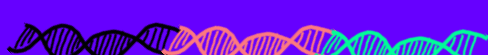
STATUS OF PHACS GENOMICS RESEARCH

- Researchers in PHACS have completed whole genome sequencing on most participants in AMP.
- Genome sequencing data has been transferred to a database.
- PHACS will study how the genetics of participants in PHACS influence their health outcomes including why some ARV medications work better in some people than others, how HIV disease progresses, and why side effects develop.

STATUS OF PHACS GENOMICS PROJECTS

USING NETWORKS TO MAP BIOLOGICAL DRIVERS

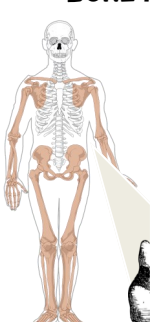
Gene mutations are changes in gene structures. Most health outcomes actually happen when a whole cluster or family of genes contains many different minor mutations.



GENES WORK TOGETHER

Researchers in PHACS may consider looking at genomic data from other studies to understand the results from the genomes of PHACS participants.

PHACS GENOMICS PROJECT AND BONE MINERALIZATION

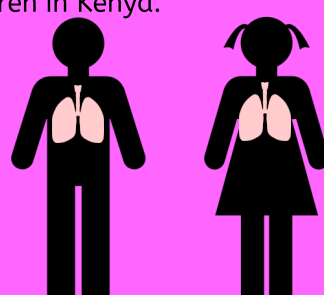


Many participants had Dual-energy X-ray absorptiometry (DXA) scans. These scans can help researchers look at bone density.

PHACS researchers want to look into how the genomes of participants in PHACS impact the association between ARV exposure, HIV, and their outcomes related to bone density.

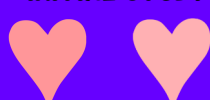
CHRONIC LUNG DISEASE AND IMMUNE IMBALANCE IN U.S. AND KENYA YOUTH WITH PERINATALLY ACQUIRED HIV

Researchers are looking at lung function data collected in AMP. The goal is to compare the data with data from a study done in children in Kenya.



STATUS OF PHACS CARDIAC SUBSTUDY

INITIAL STUDY



A cardiac echocardiogram study was done several years ago in AMP that showed there were small differences in the hearts of youth born with HIV and HEU youth.

WHAT WILL BE DONE IN THIS FOLLOW-UP STUDY?



WHY IS THIS FOLLOW-UP STUDY BEING DONE?



- Echocardiograms will be done on the same youth to see if there are any changes.
- Researchers will also look at pulse wave velocity. Pulse wave velocity is a way to measure blood vessel disease.

The reason this research is being done is because previous studies have suggested that there may be a higher rate of premature heart and blood vessel disease in youth born with HIV.

Please note that additional findings, study details, and updates on studies in progress may be found in the May 2018 CAB Call Minutes: https://phacsstudy.org/cms_uploads/CAB%20Minutes/2018/2018.05.24_CAB_Minutes.pdf.

Submitted by: Drs. Ellen Chadwick and Russ Van Dyke

PUBLICATIONS IN THE NEWS

Since the January 2018 PHACS CAB Newsletter, PHACS has made the following contributions:

11 Manuscripts accepted to scientific journals; and

11 Abstracts presented at scientific conferences

Manuscripts

“A multicenter study of diet quality on birth weight and gestational age in infants of HIV-infected women.” This manuscript is in *Maternal and Child Nutrition*. Lead author Tracie Miller, MD was the Director of the Division of Pediatric Clinical Research at the University of Miami and Co-Chair of the Nutrition, Growth, and Metabolism Working Group (WG).

“Growth and pubertal development in HIV-infected adolescents.” This manuscript is in *Current Opinion in HIV and AIDS*. Lead author Paige Williams, PhD is a Senior Lecturer on Biostatistics at the Harvard T.H. Chan School of Public Health and Co-Chair of the Cardiopulmonary WG.

“Non-communicable diseases in adolescents with perinatally acquired HIV-1 infection in high-income and low-income settings.” This manuscript is in *Current Opinion in HIV and AIDS*. Lead author Steve Innes, PhD is a Clinical Researcher at Stellenbosch University and Tygerberg Children's Hospital.

“Birth outcomes for pregnant women with HIV using tenofovir-emtricitabine.” This manuscript is in the *New England Journal of Medicine*. Lead author Kathryn Rough, SD is a Research Scientist at Google.

“Is there a higher risk of mother-to-child transmission of HIV among pregnant women with perinatal HIV infection?” This manuscript is in *Pediatric Infectious Disease Journal*. Lead author Christopher Goodenough, MD is a doctor at the University of Texas Medical School at Houston in the Department of Surgery.

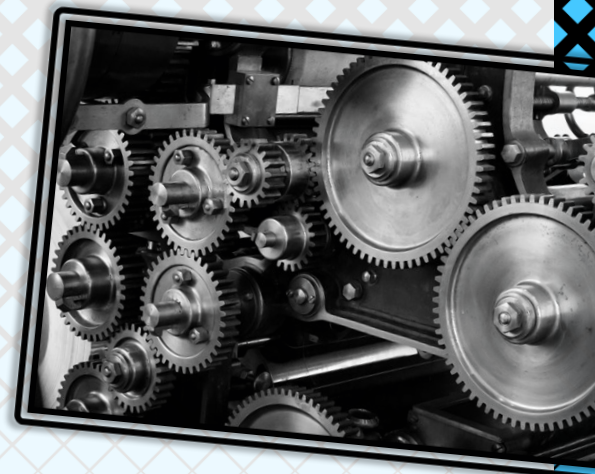
“Trends in neonatal prophylaxis and predictors of combination antiretroviral prophylaxis in U.S. infants from 1990–2015.” This manuscript is in *AIDS Patient Care and STDs*. Lead author Paige Williams, PhD is a Senior Lecturer on Biostatistics at the Harvard T.H. Chan School of Public Health and Co-Chair of the Cardiopulmonary WG.

“Cardiac and inflammatory biomarkers in perinatally HIV-infected and HIV-exposed uninfected children.” This manuscript is in *AIDS*. Lead author Jay Wilkinson, MD is a Research Professor of Pediatrics at Vanderbilt University and a member of the Cardiopulmonary WG.

“Development and reliability of the Prospective Memory Assessment for Children & Youth (PROMACY): a preliminary study in a non-clinical sample.” This manuscript is in *Applied Neuropsychology*. Lead author, Patricia Garvie, PhD is a Pediatric Psychologist at Children's Diagnostic and Treatment Center and a member of the Neurodevelopmental and Neurological Disease WG.

“Oral microbiota in youth with perinatally acquired HIV infection.” This manuscript is in *Microbiome*. Lead author Jacqueline Starr, PhD is a Lecturer on Oral Health Policy and Epidemiology at Forsyth Institute.

(Continued on [page 21](#))



PUBLICATIONS IN THE NEWS (CONTINUED)

“The utility of the national death index in identifying deaths in a clinic-based, multi-site cohort: the experience of the Pediatric HIV/AIDS Cohort Study.” This manuscript is in *Journal of Acquired Immune Deficiency Syndromes*. Lead author Julie Alperen, DrPH is the Administrative Director at Brigham and Women's Hospital.

“The epidemiology of adolescents living with perinatally acquired HIV: A cross-region global cohort analysis.” This manuscript is in *PLOS Medicine*. Lead author Amy Slogrove, PhD is Pediatrician and Epidemiologist at Stellenbosch University.

Abstracts

The following abstracts were presented at the Conference on Retroviruses and Opportunistic Infections (CROI 2018) in Boston, Massachusetts, March 5-7, 2018:

- “Metabolic outcomes in obese HIV-exposed uninfected children: comparison with NHANES.”
- “Mental health diagnoses, symptoms, and service uptake in U.S. youth with PHIV exposure.”

The following abstracts were presented at the 22nd International Workshop on HIV and Hepatitis Observational Databases (IWHOD) in Fuengirola, Spain, March 22-24, 2018:

- “Pregnancy rates and postpartum virologic control among perinatally HIV-infected young women in the US.”
- “Outcomes of second-line antiretroviral therapy (ART) in HIV-infected children: a CIPHER cohort collaboration global analysis.”
- “Cumulative measures of viral load burden in pediatric HIV research.”
- “Assessing complex combination antiretroviral regimens in HIV observational studies: applications to cardiac status of perinatally HIV-infected children.”

The abstract titled, “*Faces of PHACS: A Youth Documentary*” was presented at the Vail Film Festival in Vail, Colorado, April 5-8, 2018.

The abstract titled, “Cardiac and inflammatory biomarkers in perinatally HIV-infected and HIV-exposed uninfected children” was presented at the Pediatric Academic Societies Meeting in Toronto, Ontario, Canada, May 5-8, 2018.

The following abstracts were presented at the International AIDS Conference in Amsterdam, Netherlands, July 23-27, 2018:

- “Maternal disclosure to perinatally HIV-exposed but uninfected (HEU) young adults in the Pediatric HIV/AIDS Cohort Study (PHACS).”
- “Social media and technology use for HIV research among young adults in the Pediatric HIV/AIDS Cohort Study (PHACS).”
- “Ability to manage health after transition to adult care is associated with retention in care among young adults with perinatal HIV infection.”

CAB GLOSSARY



Acute HIV Infection: The period of rapid HIV replication (increasing amount of virus in the body) that occurs shortly after becoming infected with HIV.

Case Report: The record that tells something unusual about what has happened with a single patient. Case reports led doctors to identify AIDS and later, HIV.

Institutional Review Board (IRB): An independent group of professionals designated to review and approve the clinical protocol, informed consent forms, study advertisements, and patient brochures to ensure that the study is safe and effective for human participation.

Liaison: Person serving as a link or connection between individuals or groups.

Toxicity: Ability to poison or otherwise harm the body.

QUIZ

Test your knowledge using takeaways from the Spring 2018 Leadership Retreat! Answer key on [page 24](#).

1. What is a genome?

- A. Blood
- B. Part or all of a person's DNA
- C. A specialized part of the human brain
- D. A whimsical lawn decoration, thoughtfully named Gene

2. Who are being enrolled in the Additional Maternal Data Collection for SMARTT Dynamic Cohort Biological Mothers?

- A. Mothers of SMARTT Dynamic Cohort participants before birth before less than five years of age
- B. Mothers of PHACS researchers
- C. Mothers of AMP Dynamic Cohort participants before birth and up until children reach four years of age.
- D. Mothers of SMARTT Static Cohort participants up until children reach 17 years of age

3. Increased amounts of _____ were found in HIV+ and HEU youth in AMP in the initial oral health substudy.

- A. Pain and gum tears
- B. Cavities and headaches
- C. Flossing aversion and inflammation
- D. Cavities and inflammation

4. What is an echocardiogram?

- A. Heart scale
- B. Ultrasound of the foot
- C. Photography social media for the heart
- D. Ultrasound of the heart

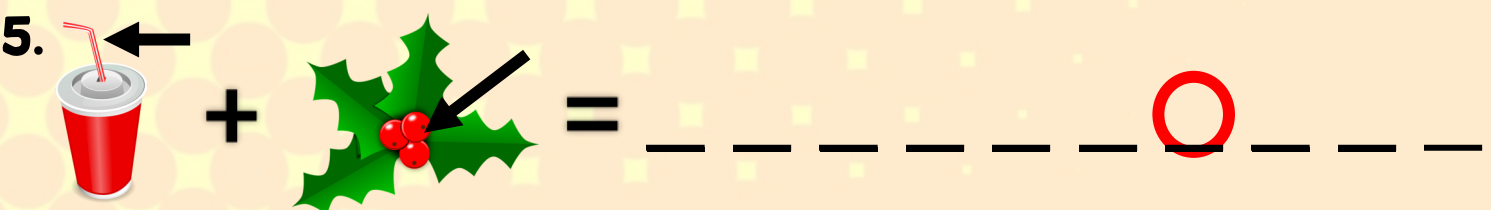
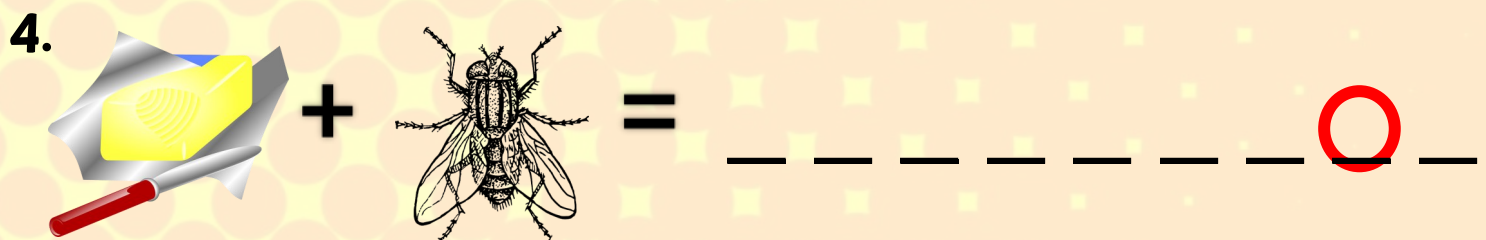
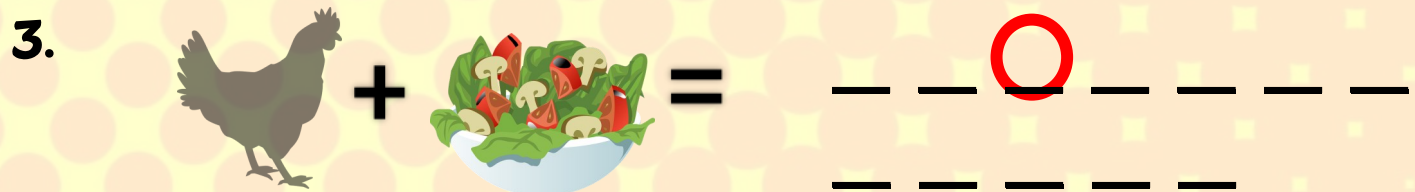
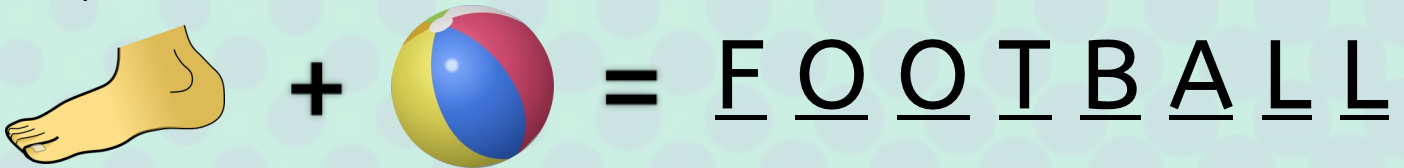
5. PHACS will study how the genetics of participants in PHACS influence their _____.

- A. Hair color
- B. Health outcomes
- C. Personality
- D. Willingness to jet ski

CAB KIDS!

Use the pictures in each item to sound out words. At the end, put together the red bubble letters to spell a hidden word! Answer key on [page 24](#).

Example:



Hidden word:      

QUIZ KEY

1. B
2. A

3. D
4. D
5. B

CAB KIDS KEY

1. SEALION
2. MONKEY
3. CHICKEN SALAD
4. BUTTERFLY
5. STRAWBERRY

Hidden word: S M I L E

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