

A COMMUNITY ADVISORY BOARD NEWSLETTER

PUBLISHED BY:

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

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Stephanie, PHACS CAB Chair:

Happy New Year to all my fellow PHACS members! Since I have become an active member and Chair of the PHACS CAB, I have learned so much. It has truly been an honor and a pleasure to have gotten the opportunity to serve as the PHACS CAB Chair these last couple of years. I have learned so much from the CAB, the researchers, and even myself. The future of PHACS relies on all of us.

Every one of us has a part, and we are all doing our best. We have such a strong, dedicated family of women and men (this includes every PHACS member, not just the CAB), and I can only see great things on the horizon! We learned from the past so we can make changes in the present and strive for a better future! It's always about, and for, the children.



Photos from the Fall 2018 Network Meeting.

Above: Stephanie and Dr. George Seage
Below: Brandon, Megan, Stephanie, and Claire

Brandon, PHACS CAB Vice Chair:

While I've only been part of PHACS since 2016, it's difficult to remember a time when I was not a part of this amazing group. I recall my first time attending a Network Meeting, where I was welcomed with open arms. I remember the first time I met Joel, Lenny, and Veronica. We spent over an hour looking for an ice cream shop that was just down the road. The cookies and cream flavor was ok, but sometimes the journey is greater than the destination.

It is such an honor and privilege, not just serving as your Vice Chair, but being a part of something greater and contributing to projects like the PHACS film series, the panel discussions at the Network Meetings, and the CAB Newsletters. I'll never forget the experiences, but the greatest part of all was finding my other family. It has filled me with great joy to spend time with each of you. It has been amazing to be able to watch every one of you grow along this journey into discovering your true potential selves that were hidden within you all along. Although we are all different pieces, we are essential pieces of the puzzle of the world. No matter what endeavors or obstacles may await you, remember that each of you are the future. I have high hopes that PHACS will continue to grow and prosper. Again, it has been a privilege serving as your Vice Chair.



Past,

Present,

FUTURE

Where do we go from here? I have gained knowledge and support by being involved in PHACS over the years. I have learned so much from the PHACS CAB monthly calls, participation on the Health Education and Communication Committee (HECC), and the Network Meetings.

I feel that education, support, empowerment, and comfort define PHACS. Through PHACS, I was given an opportunity to let my voice be heard and to accept who I am when it comes to living with HIV. Participating in the Surveillance Monitoring for ART Toxicities (SMARTT) study for my child has allowed me to grow in areas of my life that I never would have imagined was possible. I have learned to use my voice, share ideas, and help others. This knowledge came from attending monthly CAB calls, attending the Network Meetings and CAB Retreats, participating in small groups within the HECC and Women's Health WG, and attending conferences as a site CAB Chair.

"BEING ABLE TO DISCUSS HIV AND TO PROVIDE INPUT FOR STUDY PROTOCOLS ON TOPICS THAT WILL BENEFIT OUR COMMUNITIES AFFECTED BY HIV HAS BEEN THE GREATEST EMPOWERMENT TOOL IN MY PAST AND PRESENT."

PHACS has gone the extra mile to make sure that participants' voices are heard and their concerns are recognized.

Let's take a look into the past. PHACS has produced many important resources such as the [HIV Disclosure Comics](#). Reviewing the comics is a great way for new families to understand how HIV affects their everyday lives through stigma and disclosure. It was great to provide input on topics surrounding HIV and to develop resources for new comers, others in need of education when it comes to taking care of their health, and people living with HIV. The Whiteboard Video series and the Photovoice project were other amazing PHACS contributions, which helped others move forward.

It is an amazing journey for young adults to be in a long-term study that benefits both PHACS and its participants. This is especially true for young adults who will transition into adulthood and lead the way by passing the torch of greatness and success. They will show others how to take care of themselves and engage in study protocols.

The present is quite unique when it comes to studies like the Adolescent Master Protocol (AMP) and AMP for Participants 18 Years of Age and Older (AMP Up). These young adults are the future generation that will ensure healthy outcomes to help people live their best life possible. I feel confident in the future because PHACS has truly engaged the community and



empowered them to let their voices be heard.

I have been with the Children's Diagnostic and Treatment Center in Fort Lauderdale, Florida for 16 years. I have been the Chair of our CAB since 2012. Being a PHACS study mom has been awesome. It's helped me to grow a lot and to express my feelings and concerns when it comes to HIV. Being able to discuss HIV and to provide input for study protocols on topics that will benefit our communities affected by HIV has been the greatest empowerment tool in my past and present.

Moving on to what is new in PHACS, I look forward to an amazing 2019. I want to make sure that the future goals are achieved and that PHACS will continue to pave the way for those to come behind us.

Happy New Year from Site 12!

Submitted by: Exzavia

APPRECIATING THE THE PAST, → LOOKING TOWARD THE FUTURE ↓

Submitted by: University of California, San Diego CAB Members

About the past: What is one thing you were thankful for in 2018?

For all the support that we have received, both moral and physical. You are angels. Without your help, we would be in trouble.

The CAB.

That we are treated warmly and respectfully and more!

For my family, and very much for the conferences that we CAB members attend together.

My daughters.

My friend, my apartment, and new life.

I am grateful for everything; I am happy and pleased with everything we have been provided.

My children, my dog, and my health.

My family and pets!

About the future: What are some of your topics of interest for 2019 at your site?

Additional programs/opportunities for people living with HIV.

How to reduce stress

Depression and anxiety

Immigration assistance

Housing resources for people with low income

BEING Positive WHILE BEING Positive

When I realized
"THIS IS ME"
and When I Found my
People. - Brandon

I used to think that being born positive was a burden. Being young and dealing with stigma and fear of myself left me feeling like the Greek Titan, Atlas, with the world on my shoulders. I would question, *Why me? Do I even have a purpose? What joy was there in bearing this curse?*

It wasn't until I started to work in the field of HIV that I was able to channel my pain and struggles. I could transform those experiences into something greater. All I believed before were just the lies I had told myself because I was my own worst enemy. Although I struggled with my own conflicts, there were others in much more dire situations. I was also able to find my people, who are just as passionate (if not more). We support one another during hard times.

Being positive has brought me many great opportunities. It has helped me find my voice and has given me the chance to speak and be heard. It has empowered me to

stand up for a cause bigger than myself in order to make a difference. I have had the privilege of traveling to some great places. I have also had the opportunity to meet some phenomenal people including doctors, researchers, other positive people, and some celebrity advocates. I met the amazing Magic Johnson, who was a big star for me growing up. That was an awesome experience. I met the sweet Hydeia Broadbent, who was the young girl born positive who did an interview on Oprah. I met the loving Valerie Wojciechowicz, who has been a big advocate for "People First Language," which addresses stigma (read more about the concept of "People First Language" on [page 15](#)).



Brandon and Hydeia Broadbent



Magic Johnson and Brandon

Although living with HIV has been a struggle for me, I have come to realize that it is one of my greatest gifts. As said by Napoleon Hill, "Strength and growth come only through continuous effort and struggle". I will leave you all with this last quote:

"Life is a storm, my young friend. You will bask in the sunlight one moment, be shattered on the rocks the next. What makes you a man is what you do when that storm comes. You must look into that storm and shout as you did in Rome. Do your worst, for I will do mine! Then the fates will know you as we know you."

— Alexandre Dumas.

Submitted by: Brandon

THERE IS NO ME WITHOUT YOU

Rates of infection within our communities continue to rise

People are still uninterested in HIV/AIDS until it affects their home or someone they care about

I would love to see a world free of HIV/AIDS and healthy people everywhere, but that's not our reality

Let's continue to advocate for the voiceless

Let's continue to spread the word to our family, friends, and community about living a long, healthy life with the help of medications and our faith

Let's continue to love each other and support each other

We are family

To our researchers who are on the front lines, keep up the great work

Without you we would have no advancement in this epidemic.

Submitted by: Gena



UPCOMING EVENTS



February 7, 2019: [National Black HIV/AIDS Awareness Day](#)

March 10, 2019: [National Women and Girls HIV/AIDS Awareness Day](#)

March 20, 2019: [National Native HIV/AIDS Awareness Day](#)

April 8-9, 2019: PHACS Spring Leadership Retreat

April 10, 2019: [National Youth HIV & AIDS Awareness Day](#)

April 18, 2019: [National Transgender HIV Testing Day](#)

May 18, 2019: [HIV Vaccine Awareness Day](#)

May 19, 2019: [National Asian and Pacific Islander HIV/AIDS Awareness Day](#)

June 5, 2019: [HIV Long-Term Survivors Day](#)

June 27, 2019: [National HIV Testing Day](#)

PHACS THROUGH THE YEARS

Past

In the past, many babies in the United States (US) born to mothers living with HIV were born with HIV. Research showed that antiretroviral therapy (ART) could greatly reduce the risk of mother-to-child transmission. Because of that research, pregnant women living with HIV began taking ART during pregnancy and childbirth. Babies born to mothers living with HIV started taking ART after they were born as well. Today, most babies born to mothers living with HIV are born HIV-exposed but uninfected (HEU) and, thanks to ART, those born with HIV are living longer, healthier lives.

The PHACS network was established in 2005. Since its beginning, PHACS has continued to follow youth born with HIV and youth born exposed to HIV as they age into adulthood in order to gain a fuller understanding of the long-term effects of in utero exposure to HIV and ART.

PHACS addresses two important research questions around pediatric HIV:

- How safe is antiretroviral treatment (ART) in the long-term for babies who are exposed in the womb and shortly after birth?
- What are the long-term effects of HIV in adolescents and young adults who were born with HIV?

Over the years, several protocols and substudies have been implemented under PHACS, including:



Surveillance Monitoring for ART Toxicities Study in HIV-uninfected Children Born to HIV-infected Women (SMARTT)

Released November 2006

SMARTT looks at HEU youth born to mothers with HIV. The goal of SMARTT is to study the long-term safety of ART for babies who were exposed to it in the womb or shortly after birth. SMARTT continues to enroll participants into the Dynamic and Young Adult Cohorts, but is no longer enrolling participants into the Static Cohort. Current enrollment into SMARTT includes:

- 2,996 HEU youth less than 18 years of age enrolled before or at birth (Dynamic Cohort, still enrolling)
- 1,240 HEU youth less than 18 years of age enrolled before 12 years of age (Static Cohort, no longer enrolling)
- 46 HEU young adults beyond their 18th birthday (Young Adult Cohort)

SMARTT Maternal Supplement

Released July 2017

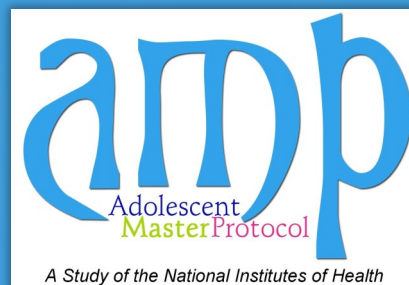
SMARTT is also currently enrolling women living with HIV into the SMARTT Maternal Supplement. We are looking at changes in HIV disease over the time period from pregnancy through the postpartum period, and any associations with HEU child health outcomes. To date, 478 mothers have given consent to participate in the SMARTT Maternal Supplement.

Adolescent Master Protocol (AMP)

Released November 2006

AMP looks at youth born with HIV and HEU youth. The goal of AMP is to learn more about the effects of living with HIV since birth. This study also looks at the long-term effects of taking ART as youth living with HIV grow up. HEU youth were included in this study as a comparison group. AMP continues to follow youth up to 18 years of age, but is no longer enrolling new participants. Participants in AMP included:

- 451 youth born with HIV
- 227 HEU youth



PHACS THROUGH THE YEARS (CONTINUED)

Adolescent Master Protocol for Participants 18 Years of Age and Older (AMP Up)

Released November 2013

AMP Up is a continuation of the AMP protocol. It looks at young adults born with HIV and HEU young adults (18 years of age and older). The study's goal is to look at the specific issues that these young adults may face as they age into adulthood. AMP Up continues to enroll and follow young adults. Current enrollment in AMP Up includes:

- 540 young adults born with HIV
- 105 HEU young adults

Adolescent Master Protocol for Participants 18 Years of Age and Older - Lite (AMP Up Lite)

Released May 2017

AMP Up Lite is a simplified version of AMP Up and was developed in 2017. It is similar to AMP Up, but involves less intensive data collection and provides participants with the opportunity to participate remotely through a web-based system. AMP Up Lite continues to enroll and follow young adults born with HIV. Current enrollment in AMP Up Lite includes 179 young adults born with HIV.

Pulmonary Complications in PHACS AMP (PCPA) Study (AMP PCPA)

Released December 2012, closed to enrollment February 2014

The AMP PCPA study looked at asthma and other chronic lung diseases in youth born with HIV and HEU youth in AMP. A total of 370 participants were enrolled. This study is no longer active.

Brain Imaging (Pilot Study)

Released March 2011, closed to enrollment January 2013

This small pilot study used Magnetic Resonance Imaging (MRI) to study the brains of youth living with HIV in AMP. A total of 40 participants were enrolled. This study is no longer active.

Memory Functioning in Children and Adolescents with Perinatal HIV Infection (MEMORY)

Released January 2010, closed to enrollment November 2012

This study looked at memory, executive functions, and medication adherence in AMP youth born with HIV and HEU youth. Executive functions are mental skills that help people plan, organize, and complete tasks. A total of 258 participants were enrolled. This study is no longer active.

Oral Health Among Participants in PHACS AMP (Oral Health Initial Substudy)

Released April 2012, closed to enrollment in January 2014

This study looked at tooth and gum diseases and oral health in AMP youth born with HIV and HEU youth. A total of 337 participants were enrolled. This study is no longer active, but a follow up Oral Health Substudy is currently active.

Newborn Evaluation for Effects of Maternal Tenofovir Use During Pregnancy (SMARTT TDF)

Released November 2010, closed to enrollment June 2013

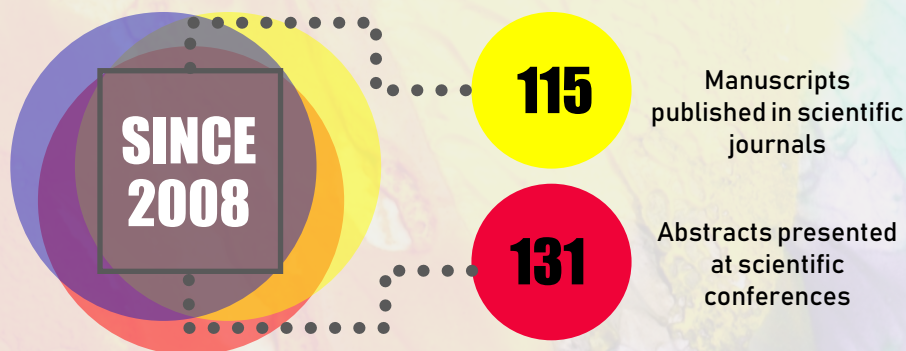
The SMARTT TDF Substudy enrolled newborn babies enrolled in the SMARTT Dynamic Cohort whose mothers took tenofovir disoproxil fumarate (TDF) for at least 8 weeks during the third trimester of pregnancy and newborn babies enrolled in the SMARTT Dynamic Cohort whose mothers did not take TDF while pregnant. The study compared bone mineral content and other growth factors between the two groups. A total of 193 participants were enrolled. This study is no longer active.

Additional past PHACS substudies included:

SMARTT: Nutrition Substudy; Reference Cohort; and Hair Study

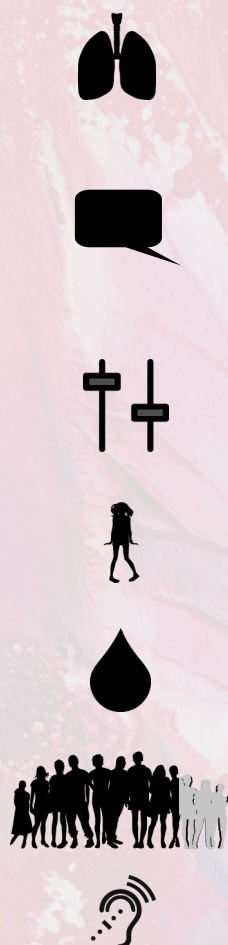
AMP: Oral Health Immune Markers; Oral Health Microbiome; Mitochondrial Determinants Component; Genomics; and Decay of Proviral Reservoirs.

PHACS THROUGH THE YEARS (CONTINUED)



Data from the studies listed on pages 6 and 7 helped inform PHACS publications and abstracts. A number of analyses support the safety of in utero exposure to specific antiretroviral medications. Some concerns have been raised about specific antiretroviral medications, including premature delivery and birth defects. A full list of [PHACS publications and abstracts](#) may be found on the PHACS website.

Key findings include the following:



- Asthma and atopic dermatitis (a skin condition also called eczema) are more common in children and adolescents born with HIV compared to HEU children and adolescents.
- Both HEU youth and youth born with HIV may have a higher risk of language impairment. However, more recent research indicates that the risk is not associated with the ART. Children exposed to HIV in the womb and whose mothers received combinations of ART during pregnancy were no more likely to have language delays than were children exposed to HIV in the womb and whose mothers did not receive these recommended treatments.
- Children and adolescents who were born with HIV and were born between 1994–2002 had higher CD4 counts (a healthier immune system) and better HIV control than those born earlier (1991–1993).
- Youth born with HIV may enter puberty slightly later compared to perinatally HEU youth. However, it seems that current ART, as opposed to what was in use from 1991–1993, may result in more normal timing of puberty.
- Among sexually active youth who were born with HIV, 62% reported having unprotected sex. Among those who had unprotected sex, 42% had detectable levels of HIV in their blood. Among the youth with detectable levels of HIV, 22% had a form of the virus that was resistant to multiple classes of ART.
- Among a subset of sexually active youth born with HIV, roughly 20% reported that they did not know their HIV status the first time they had sexual intercourse.
- Hearing loss may be more common in children who were exposed perinatally to HIV.

Additional [key findings](#) and [research summaries](#) may be found on the PHACS website.

Present

PHACS THROUGH THE YEARS (CONTINUED)

Researchers continue to conduct ongoing analysis of data from PHACS protocols while several PHACS studies are recruiting new participants and/or continuing to follow participants:

- AMP: No longer enrolling, but continues to follow participants.
- AMP Up: Currently enrolling new participants and continuing participant follow up.
- AMP Up Lite: Currently enrolling new participants and continuing participant follow up.
- SMARTT: Currently enrolling newborns into the Dynamic Cohort, young adults into the Young Adult Cohort, and mothers into the SMARTT Maternal Supplement. SMARTT also continues to follow participants.

New PHACS substudies are also recruiting participants, including: the AMP Words in Noise (WIN) study; the AMP Cardiac MR CT Pilot Study, and the substudies below.

A Re-Examination of Oral Health among Participants in PHACS AMP and AMP Up (Oral Health Follow Up Substudy)

Released in January 2018

As a follow up of participants to the initial Oral Health Substudy looking at oral health data over time, researchers will assess the risk of cavities, tooth quality, and gum disease and look for reasons for the large numbers of cavities in youth in AMP.

Cardiac Status of Perinatally HIV-infected Adolescents and Young Adults (Cardiac Substudy)

Released in June 2018

As a follow up to the cardiac echocardiogram (ultrasound of the heart) testing done with several participants in AMP, researchers will perform echocardiograms on the same youth to look at cardiac changes over time, as well as pulse wave velocity. Pulse wave velocity is a measure of blood vessel disease.

Assessment of HPV Associated Anogenital Morbidity in HPV-Vaccinated, Perinatally HIV Infected (PHIV) Adolescents and Young Adult Women in AMP (HPV Substudy)

Released in September 2018

Researchers will perform pelvic exams on young women in AMP to look for abnormalities of the cervix due to HPV. Biopsies of any abnormalities will be taken to see whether there are changes that could eventually lead to cancer or cervical disease.

Future

PHACS research priorities for the future include the following:

- Long-term health of women living with HIV, including those with born with HIV;
- Continued safety of *in utero* exposure to ART as youth age into adulthood, including safety for their children; and
- Outcomes of being born with HIV as youth age into adulthood and have children of their own.

Since it began in 2005, PHACS has made its mark on the pediatric infectious disease community and on the world. In addition to the 115 publications in scientific journals and 131 abstracts presented at scientific conferences, PHACS researchers and findings have also been featured in the mainstream media. In 2018 alone, PHACS was highlighted in 31 media sources including MD Magazine, Pharmacy Times, and TV8 Vail (read more about [PHACS in the News](#) on the PHACS website). These publications and media features highlight the contributions that both participants and researchers have made to PHACS. These contributions have led to important findings in the field of pediatric HIV that will hopefully help lead to better HIV treatments, more targeted ways to prevent poor health outcomes, and more timely HIV care. In the coming years, PHACS will continue to follow youth born with HIV and youth born exposed to HIV as they age into adulthood, as well as mothers living with HIV.

HECC UPDATE

The Health Education and Communication Committee had an exciting 2018. Since the last CAB newsletter, the short documentary *Faces of PHACS* reached its first international audience when it was screened at the 10th International Workshop on HIV Pediatrics on July 20-21, 2018 in Amsterdam! *Faces of PHACS* highlights three PHACS Peers United Group (PUG) (Young Adult CAB) members' experiences growing up with HIV, their goals for the future, and their hopes for the continuation of HIV research.

and they spoke powerfully about the experience of being part of a family affected by HIV. Many people at the workshop commented that this panel was a highlight of their day!



Alexis, Claire, and Stephanie in Amsterdam

these films. In addition, one of our own talented PUG members drafted an incredible script for the videos. The HECC and PUG are working together to finalize script edits. Once the script is in its final form, we will work with the film production group to cast actors and begin filming. We hope to present more exciting updates about this project in the next newsletter.

Another project underway is the PHACS infographics series, with the first two infographics nearing finalization. This project was created in response to feedback from sites about the participant summaries that PHACS produces. Site staff suggested that we create additional materials to help communicate PHACS results to participants in a more visual, simplistic, streamlined manner. The infographics combine PHACS results to help participants focus on the big picture findings from different WGs,

(Continued on [page 11](#))



Alexis and Stephanie on the panel



Alexis, Stephanie, and Claire

Just after the HIV Pediatrics workshop, the 4th HEU Child and Adolescent Workshop was also held in Amsterdam as part of the International AIDS Conference. CAB Chair Stephanie and her daughter, PUG member Alexis, were invited to participate in a panel discussion at this workshop,

One of the HECC's big projects currently underway is the series of "choose-your-own-adventure" videos for PHACS participants transitioning to adult health care. As we mentioned in the last newsletter, the HECC has identified a film production group in Boston eager to partner with us to produce

HECC UPDATE

Youth Born with HIV

In our study, we found that youth born with HIV may have unique struggles as they become adolescents and adults. We also learned that many show strength and resilience as they grow up.

Findings

As youth born with HIV become young adults, they may experience many of the same transitions as other people their age.



These may include new living situations, jobs, school, romantic relationships, parenthood, and new adult health care providers. Just like their peers, some may start having sex or using alcohol or drugs.

Some of our study's findings suggest that being born with HIV may add unique challenges to this transition time.

Some youth born with HIV may struggle with stigma, mental health, taking antiretroviral medicines (ARVs) correctly, or disclosing their HIV status to sexual partners.

Some youth who witnessed or experienced violence may have difficulty keeping their viral loads low. This might be due to stress, which could affect the body and/or their ability to take their medicines.



Supporting young adults in these areas can help them thrive as they get older.

What can you do?



Ask your clinic if they have a peer navigator. Peer Navigators are people with lived experiences who can help you make a plan for getting support.



Ask your doctor for a referral if you think you could use help with your mental health.



Advocate for better services and better research for youth born with HIV. Contact your study coordinator to join the PHACS Young Adult Community Advisory Board or join another local advocacy organization.



For more information, Claire Berman
Director of Health Education & Communication
clerman@hsph.harvard.edu

We worked with a graphic designer to create the first two infographics focusing on adolescents affected by HIV and ARV safety during pregnancy from the Adolescent and Young Adult WG and the Maternal Exposures WG. The graphic designer has also created templates, which will allow PHACS to continue to reproduce the same infographic format for more study results later on. The first infographics are in their final stages and will be posted on the PHACS website soon.

The PUG continued to grow in 2018 with 11 PUG members attending the 2018 PUG Retreat this past Fall! The theme of the retreat was "Self-Acceptance and Advocacy" and included several interactive PUG-led sessions. At the end of the Fall Meeting, one PUG member even showed a short video about study participation that she'd made during our retreat! The PUG hopes to continue to explore other forms of advocacy in 2019. The PUG is also in the process of electing their next Chair and Vice Chair this Spring.

In January 2019, we sent out the first edition of *Just the PHACS*, our brand new email digest about all things PHACS. We'll be sending out quarterly updates from now on to highlight recent



Bowling for PUGs in Boston

PHACS publications and news coverage, as well as other updates, resources, and of course, what the amazing people of PHACS are up to. Keep an eye out for the next edition in April 2019!

We look forward to continuing to collaborate with CAB members in 2019. CAB and PUG members, thank you so much for all you do for the CABs and for PHACS. These innovative projects would not be possible without you!

Stay up to date on the HECC initiatives by checking out the [HECC page](#) on the PHACS website.

Submitted by: Claire and Megan

Examples of the templates for the infographics

ARV Safety During Pregnancy

In our study, we have found that taking antiretroviral medicines (ARVs) during pregnancy is generally very safe. It protects the health of both the mother and the baby. And in 99% of cases in the U.S., when a mother takes ARVs during pregnancy, it prevents her baby from getting HIV.

Findings



After a baby is exposed to ARVs in the womb or at birth, our study follows the child as they grow up to see whether the ARVs affect their health in any way.

So far, we have not found any major health problems for babies and children exposed to HIV and ARVs while in the womb or at birth.



However, the timing of when mothers start taking certain ARVs can be important and can impact how ARVs protect babies' health. Your doctor can tell you the safest one for you.



When a baby is exposed to HIV and ARVs in the womb or at birth, this becomes part of their medical history. It is important to continue to follow their health as they grow up into adulthood.

What can you do?



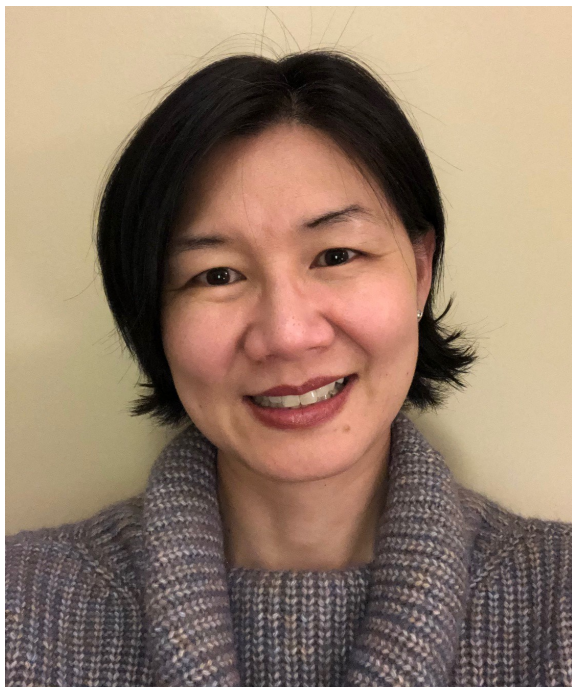
Ask your doctor which ARVs are safest for you and your baby, ask how to take them correctly.



Advocate for better services and better research for mothers living with HIV and their kids. Contact your study coordinator to join the PHACS Community Advisory Board or join another local advocacy organization.



For more information, Claire Berman
Director of Health Education & Communication
clerman@hsph.harvard.edu



Jennifer Jao, MD, MPH

My name is Jennifer Jao, and I am the new Co-Chair for the PHACS Metabolic and Nutrition Working Group. I've been involved in PHACS since 2012 when I first met Dr. Van Dyke and Dr. Geffner as they mentored me in my first PHACS concept sheet project. Since then, I've enjoyed the scientific and intellectual stimulation in research, as well as the many relationships built with PHACS members over the last several years.

I serve as an Infectious Diseases doctor. I take care of adults and children with HIV because I've taken a special interest in caring for pregnant women living with HIV and their children, as well as youth with perinatally acquired HIV. I also do research in Africa on some of the same populations as PHACS. My research focuses on metabolic complications

of HIV and antiretroviral therapy (ART) such as obesity, diabetes, high cholesterol, and heart disease.

As the daughter of Taiwanese immigrants to the United States, I grew up in a bicultural family. My father and mother came to this country during the 1960's at the height of the Civil Rights movement in Atlanta where I spent my childhood. I remember clearly growing up as a minority throughout childhood and adolescence. In college, I was a French major and almost did not pursue a career in medicine. My French training somehow came in handy when I spent time in French-speaking parts of Africa caring for patients. One of my first patients living with HIV was a young pregnant woman in Cameroon. I remember asking her if she was worried

about passing on HIV to her unborn child, prepared to give her the usual medical talk about HIV transmission rates, ART adherence, etc. Her response threw me for a loop as she said, "I cannot be sad or fearful for this pregnancy. This baby has been a blessing to me – the only thing which has brought me back into good standing among the people in my village since I was diagnosed with HIV." This patient taught me a great deal about the stigma of HIV, particularly in rural parts of Africa where there was less knowledge and education about it over two decades ago.

After finishing my residency in Internal Medicine/Pediatrics, I worked as a general internist and pediatrician for 5 years before deciding to return to fellowship training. I completed a fellowship in Adult Infectious Diseases as well as my Masters of Public Health degree at the Icahn School of Medicine at Mount Sinai in New York. This was where I was introduced to HIV maternal child research and the PHACS team. Since then I've joined the Northwestern Feinberg School of Medicine and the Ann & Robert H. Lurie Children's Hospital of Chicago as faculty and continue to work alongside PHACS and other cohorts worldwide in the area of HIV maternal pediatric research.

A TIME TO REMEMBER

The Texas Children's Hospital monthly CAB meeting was held on November 13, 2018. We had a moment of silence to remember William T. Shearer, MD, PhD, who passed away on October 9, 2018. Dr. Paul, the research team, and the CAB members all expressed their respect and love for Dr. Shearer by sharing stories and tributes about our beloved Principal Investigator.



As in previous years, the CAB members were all invited to join the HIV research staff to celebrate Thanksgiving. Dr. Paul, the research nurses, and study coordinators attended this monthly CAB meeting. The focus of the meeting was to update CAB members about current and future research studies in the International Maternal Pediatric Adolescent AIDS Clinical Trials Network (IMPAACT), the

Adolescent Medicine Trials Network for HIV/AIDS Interventions (ATN), Zika virus, and PHACS research networks. Kimbrae provided an update from the PHACS CAB conference calls and also information about the Women's Health WG. Dr. Paul also gave an update about the Ryan White Part D case management program at Texas Children's Hospital.

Two staff members from the ATN site review group also attended the meeting. They introduced themselves to the group and answered questions from the staff and CAB members. We noted that they were comfortable with the group immediately. It was really nice for the CAB members to learn more about the ATN. One ATN staff member commented that he had never seen so many CAB members at a meeting.

In December, at the request of the CAB members present at the November CAB meeting, we had our monthly CAB meeting and celebrated Christmas. Together we reviewed all of the current and upcoming research protocols in the various research networks. Leslie gave an update from the IMPAACT CAB (ICAB) and the 2019 Leadership meeting. Kimbrae gave an update from the PHACS CAB conference call and also the various protocol research teams in PHACS. We also discussed the January 2019 edition of the PHACS



CAB Newsletter. Finally, we announced that Texas Children's Hospital staff and site practices will be featured in the first edition of the "Just the PHACS" email digest (learn more about the digest on [page 11](#)). We are honored to be featured in the digest.

The Annual Holiday Party for our families was a huge success. We had 125 people attend the party this year. This included all the families, staff, and volunteers. We had a photo booth for children and families to take pictures with Santa Claus. The children also received toys, stuff animals, trinkets, and stockings full of candy. It truly was a time to remember.

Thank You Texas Children's Hospital - Baylor College of Medicine HIV Research CAB for your work and accomplishments in 2018. We look forward to 2019.

Submitted by: Theresa

VISITING THE PUG PEN AT

BRONX-LEBANON HOSPITAL CENTER

Submitted by Lenny:

In this edition of our newsletter, we decided to share a little end-of-the-year project that I found beneficial to lost PUGS out there. This took place in a city called The Bronx in New York in one of our PUG pens known as BronxCare (at Bronx-Lebanon Hospital Center). In this specific location, I was diagnosed to be perinatally HIV positive. The HIV virus was not discovered until I was 8 years old and I was not disclosed to until I was 13 years old. It was a hardship dealing with something I didn't know about, and I was not sure how to deal with it. I kept learning about HIV as time passed by and it was just difficult to do it on my own because no matter how many people said they are there for me, I felt they would never feel how I felt. Eventually at age 16, I joined a peer group at my site with people going through my same situation. That helped me because I was able to speak and spend time with people who could understand me from first hand experience, and I didn't have to keep a secret. Now I'm a senior in this group because there is a new generation of young lives like me. I'm like the big brother and they are my younger siblings. This is how my site plans on moving forward. We are pairing the seniors with the juniors, so they can be informed, advised, and guided. I didn't want the newly disclosed members to learn slowly as time went by as I did. Instead, I took it upon myself to have them know as much as I do. As a result, I planned with Claire to educate my peers, as well as telling them about PHACS/AMP by inviting her to my site in November 2018.

Submitted by Claire:

To pick up on where Lenny left off, I had a wonderful visit to the Bronx in November! I got to meet the members of the "PUG pen" he mentioned – a peer group of young adults who get together once a month at Bronx-Lebanon Hospital Center.



Lenny planned and led a great program for the group in both English and Spanish. Lenny discussed some of the facts about HIV and AIDS, and he and I did a demonstration of how to find information and resources available on the PHACS and AMP This Up websites. We also showed our young adult documentary *Faces of PHACS* to the group. In the film, three of our own PUG members tell their stories about growing up, navigating

relationships, and pursuing their goals while living with HIV. We also watched a short video produced by one of our other PUG members at the Fall YACAB Retreat (with her permission). Several peer group members said there was a lot to relate to in the stories and testimonials that our PUG members shared in these films, and that it made them think and brought up a lot of emotions. A few even said they might want to join the national PHACS YACAB/PUG group after seeing our films, so maybe you'll get to meet some of them at the next PHACS meeting! It was also great to hear more about how the members of this group support each other, with a Big Brother/Big Sister model as Lenny mentioned, and to hear more about the history of their group and the kinds of activities they plan together. I felt very lucky to have the chance to visit and learn from the members of the peer group at Bronx-Lebanon Hospital Center, and to see so many staff as well – it was a rare treat for me to see so many members of our PHACS community in person! Many thanks to the entire Bronx-Lebanon Hospital Center team for welcoming me to your site, and especially to Lenny for planning my visit with such care. I hope I'll have the chance to visit the "PUG pen" at Bronx-Lebanon Hospital Center again, and to visit and learn from similar groups doing wonderful work together at our other PHACS sites.

PEOPLE FIRST LANGUAGE

During the January 2019 PHACS CAB conference, Brandon introduced the CAB to Valerie Wojciechowicz. Valerie and Brandon work at CAN Community Health in Jacksonville, Florida. Valerie engaged the CAB in a lively discussion about "people first language." Specifically, the group talked about how language around HIV can be stigmatizing. People first language presents a way of speaking that is non-stigmatizing. Valerie and Brandon submitted the following article to explain a little more about people first language.

People first language is a type of preferred language in English. It aims to avoid dehumanizing people when talking about people with various conditions. Sometimes, people first language is referred to as language etiquette. People first language can be applied to any group who is defined by a condition rather than as a people. An example of people first language would be to say "person living with HIV" rather than "HIV-infected person" or "those who are homeless" rather than "the homeless."

Rather than using labels to define individuals with a health condition, it is more appropriate to use terminology that describes individuals as being diagnosed with a condition. People first language puts the person before the diagnosis. It describes what the person has, not what the person is.

The basic idea is to use a sentence structure that names the person first and the condition second. Another example of people first language would be to say "people with disabilities" rather than "disabled people" or "disabled." This emphasizes that they are people first. Because it is a common practice in English to place an adjective before a noun, the adjective might be replaced with a relative clause (i.e., from "an asthmatic person" to "a person who has asthma." Finally, the use of "to be" is discouraged in favor of using "to have." By speaking in this way, you can communicate the idea of a

condition as a secondary part of someone, not a something that makes up a person's identity.

The difference between the almost right word and the right word is really a large matter—'tis the difference between the lightning-bug and the lightning.

—Mark Twain

Read more about people first language in [POZ Magazine](#).

Submitted by: Valerie and Brandon

CREAM OF MUSHROOM STUFFING RECIPE

This recipe was done spur of the moment. It melted in my mouth. Enjoy! *Submitted by: Delia*



Ingredients:

- Olive oil or butter (to coat pan)
- 1 box stuffing
- 1 can cream of mushroom soup
- 1 onion (chopped)
- 1 bunch green onions (chopped)
- 1-2 tablespoons of olive oil (as needed)
- 1 can beef or chicken broth
- 1/4 cup breadcrumbs

Instructions:

- Coat a medium size baking dish with butter or olive oil and preheat the oven to 350 degrees.
- In a saucepan, heat olive oil. Add green onions.
- Gradually add the stuffing and beef/chicken broth.
- When all ingredients are mixed well in the saucepan, add the can of cream of mushroom soup.
- After ingredients are mixed, pour the stuffing mixture into the baking dish and top with breadcrumbs.
- Bake until the top is brown.

FLYING



The Peter Pan fairytale is about a little boy who didn't doubt his ability to fly unafraid.

A lesson for us:
We don't soar to the heights of beauty and being if we're afraid of mystery, afraid of being different, afraid of freedom.

Faith surrenders to the Wind, stretching arms out wide for flying to new heights of self-giving love.

The Wind is blowing...

Submitted by: Joe

RESOURCES

A Timeline of HIV and AIDS:
<https://tinyurl.com/y7tr2zjy>

Future Directions for HIV Treatment Research:
<https://tinyurl.com/y9j2tt63>

The Future of HIV Therapy:
<https://tinyurl.com/yc94v4ar>

NIH World AIDS Day Highlights:
<https://tinyurl.com/yccvge84>

Resources on HIV and Aging:
<https://tinyurl.com/ybco3gdz>

HIV Criminalization: Know Your Rights:
<https://tinyurl.com/ycpjrhfe>

National Minority AIDS Council (NMAC) Webinar Library:
<https://tinyurl.com/yaqp3bj3>



CAB GLOSSARY

Below is a list of common PHACS acronyms. Find the underlined acronyms in the word search below!

- AMP: Adolescent Master Protocol
- ART: Antiretroviral Therapy
- CC: Coordinating Center
- CIG: Clinical Investigator Group
- CM: Clarification Memo
- CS: Concept Sheet
- DMC: Data Management Center
- DOC: Data and Operations Center
- EC: Executive Committee
- ICE: Informed Consent Form
- LOA: Letter of Amendment
- PI: Principal Investigator
- SC: Study Coordinator
- SLG: Scientific Leadership Group
- SMARTT: Surveillance Monitoring for ART Toxicities Study in HIV-uninfected Children Born to HIV-infected Women
- VL: Viral Load
- WG: Working Group

WORD SEARCH

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Unscramble the "winter" words and write the letters in the boxes. Use the letters in the shaded boxes to answer the riddle at the bottom of the page.

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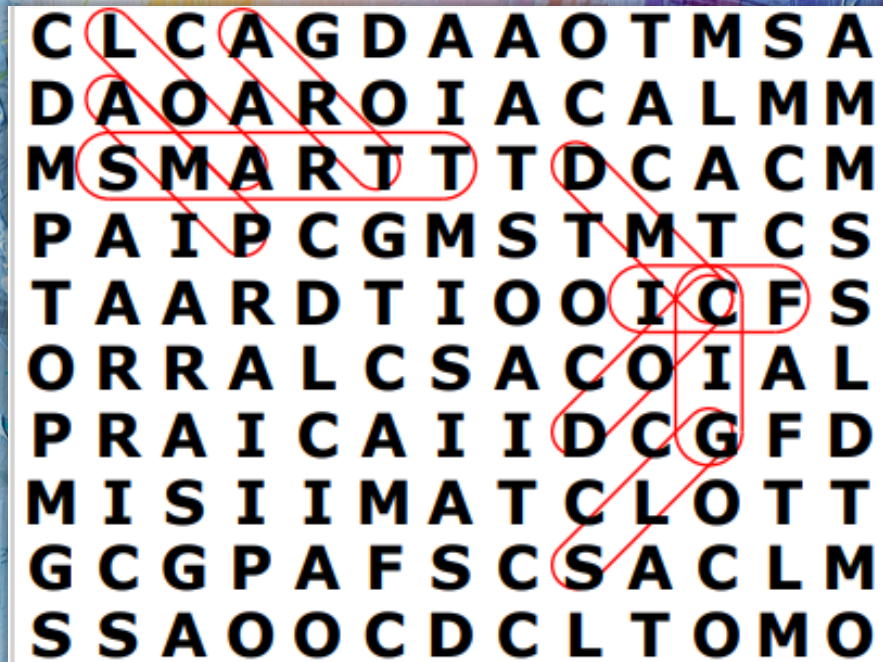
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What do you get when you cross a snowman with a vampire?

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WORD SEARCH **KEY**



WORD SCRAMBLE **KEY**

FROSTY
WINTER
SNOW
SLED
COAT
BLIZZARD
ICE
MITTENS
REINDEER

WHAT DO YOU GET WHEN YOU CROSS A SNOWMAN WITH A VAMPIRE? **FROSTBITE**

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