

A COMMUNITY ADVISORY BOARD NEWSLETTER

PUBLISHED BY:

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

INSIDE THIS ISSUE:

I am a Survivor	2
Impossible	3
Fighting Stigma from Within	4
What My CAB Means to Me	5
HIV Long-Term Survivors Day	5
Focusing on the Future	6
Sources of Strength at the	7
University of California, San	
Diego	7
Surviving AIDS	8
A Comic About my Hero	8
What is Survival	9
Endurance, Strength, Survival	9
Puerto Rico's Hard Times	10
Site 10 Easter Egg Hunt	11
The Butterfly and the Sunflower	12
To be a Patronus	13
Inspirational Quotes	14
PHACS Member Profiles	16
HECC Update	18
Sources of Strength	18
Upcoming Events	19
Participant Summary	20
Discussions from the Spring 2017	23
Leadership Retreat	24
AMP Up Lite	26
PHACS Women's Cohort in	27
SMARTT Studies in	28
Development	28
Publications in the News	29
Resources	30
CAB Glossary	30
Word Search	30
CAB Kids	30
Word Search Key	30
Spot the Difference Key	30

FROM OUR CAB CHAIRS

STEPHANIE, PHACS CAB CHAIR:

I want to first thank everyone for giving me the opportunity to work for you as the PHACS CAB Chair. Kimbrae and Lesley left some big shoes to fill! As Chair, I will strive to make sure our ideas are heard. I feel I have a great set of skills to share, from listening to speaking. I work to understand many views, and overall, I have a ton of passion for helping others. I have been an active member of the PHACS CAB for two years. Prior to that, my children and I took part in many research studies. I have been a public speaker for several years. I love learning and educating others. I used to be a preschool teacher and even owned my own daycare. I now work in customer service at a skating rink. Each one of these jobs has taught me that communication is key. I am open to all communication, and I want people to feel comfortable to reach out to me.



Stephanie and Brandon at the
Fall 2016 CAB Retreat

Now on to the good stuff – the theme of this newsletter. The theme is “Endurance, Strength, and Survival.” What does this mean to me?

(Continued on page 2)

BRANDON, PHACS CAB VICE CHAIR:

I'd like to thank everyone who nominated and elected me to be Vice Chair. It is an honor to serve alongside each and every one of you, and I look forward to continue working with you all, not just for PHACS, but to better the future for us and for those to come. I've only been part of PHACS for about a year now. I was given the opportunity to attend the Fall 2016 Network Meeting and CAB Retreat, where everyone was so welcoming and caring. I'm currently a Peer Navigator for University of Florida Center for HIV/AIDS Research, Education and Service (UF CARES) in Jacksonville, Florida. I help educate, motivate, and encourage patients with my story, while connecting them to the proper resources they require. My goal for PHACS is to make it much bigger than what it is currently, by providing the opportunity to network with others who are fighting for the same cause. I want to pave the road for others and inspire them to be future leaders, not just in HIV/AIDS, but to be leaders of the world.

FROM OUR CAB CHAIRS

(CONTINUED)

Well, I have to start by thinking about what it would be like if I didn't have the support system I have. I'm blessed to have family and friends, who don't see me as Stephanie with HIV. They see me as just Stephanie, someone who sometimes talks too much, can be emotional, loves roller skating, or as the almost crazy cat lady. These

same people are there for me when I am having a tough day. They're there when I want to cry or complain about HIV. This support from others gives me my strength. With this support and strength, comes my endurance. We are all dealt different cards in life, and I'm not blind to my luck; I know how lucky I am. Many people living with

HIV don't have the kind of support I do. They cannot talk about it due to the fear of shame and stigma. This is why I give back to the community. I use these blessings to be the voice for those who can't speak. I found my purpose in life, and that is my survival.

I AM A SURVIVOR

Strength is something that you might have to work hard to achieve—strength to get out of bed, strength to get out of the house, strength to just do something. Other times, strength is something that rubs off of you like the smiles of your children, the encouragement from your husband, the love that God pours down on you, or the support of your spiritual leader. For me, strength comes from knowing that I made it through the trials and tribulations of yesterday, knowing that I have the opportunity to make today better.

helped me to succeed. Life definitely throws many obstacles our way, but it's how we choose to endure and overcome them that determines our outcome. I choose to climb over those obstacles. I choose to

Survival is a must, even though

Survival

Strength

there are plenty of times when it feels like people are purposely trying to get in the way of you not only surviving, but conquering this thing we call life. I run my life and my choices. I make the next day better than today. For me, God is the focal point of my strength, my endurance, and the key to my survival! I will survive so that my children can survive and my husband can be right along side me. I am a survivor!!!

Submitted by: Anonymous

Endurance is a powerful word. Endurance is what has

show my children that there's never an obstacle too big to overcome. I have the power and drive within me to never give up. Sometimes knowing that I have eight children always looking up to me (no matter how old or young) is a true motivation to succeed.

Endurance



IMPOSSIBLE

Is it “impossible” or “I’m possible?”

Resilience: The power or ability to return to an original form or position after being bent, compressed, or stretched; elasticity.

For our purposes, resilience is also the ability to recover readily from illness, depression, and/or any adversity. It’s buoyancy.

We have all struggled. We have all been through our own crucibles, whether it be drugs, prison, fear, and/or ignorance. We continue to battle our own demons within ourselves and in the world; sometimes our battles are mentally and physically draining, some days more than others. This is why, more than ever, we must find that inner strength and realize



IMPOSSIBLE

that we are stronger than we think we are. We can learn to endure through any struggle. Sometimes we must ask ourselves, “What am I fighting for?”

Life can feel like a constant battle, but we must continue to feed our minds and fight. We should continue to tell ourselves that anything is possible. We must remind ourselves that no matter how difficult the struggle, we can make it through. Les Brown said, “You want to see yourself beyond your circumstances? You gotta challenge to see yourself beyond your challenge, see yourself with the challenge already resolved.”

Mike Norton said, “We are each the masters of our own reality; when we become self-aware to this: absolutely anything in the world is possible. Master yourself, and become king of the world around you. Let no odds, chastisement, exile, doubt, fear, or ANY mental virii prevent you from accomplishing your dreams. Never be a victim of life; be its conqueror.”

Now it’s up to you—is it “impossible” or “I’m possible?”

Submitted by: Anonymous



Endurance

1. *The fact or power of enduring or bearing pain, hardships, etc.*
2. *The ability or strength to continue or last, especially despite fatigue, stress, or other adverse conditions; stamina.*

► **FIGHTING STIGMA FROM WITHIN**



► Well, it's no secret that HIV has a bad rap. The real question is, should it? I think it's fair to say that a lot of people think, yes it's a sexually transmitted disease, and can kill you if not treated. Let's take a step back and talk about HIV. When you tell someone you're HIV positive, most, if not all, think, "Oh my gosh, how did you get it?" It's because of that very

question that I had a very hard time ever telling anyone that I was HIV positive.

There are millions of people on this earth living with HIV. Some were born with it; others got it through blood transfusions, sex, needles, or other means. The big picture is, it should not matter how someone got HIV. It doesn't help someone to remind them about how they got HIV. It isn't helpful to think, "Oh good, now that I know how you got it, let me help you share your grief." It should be as simple as "Let's get you the care and support that you need so you can live a healthy life."

We live in a world where people feel that they need to be in each other's personal lives. Ever heard of someone getting a divorce? Our first question is always, "Why?" or "What happened?" Instead, maybe we should be thinking, "How can I help you through this difficult time?"

I used to feel this way while growing up. I remember the shame and guilt that HIV has caused me, but also feeling that I am not like others who got HIV during their lifetime. I felt like if I had to tell people I was HIV positive, I would also mention that I was born with it. Hence, I don't want people to judge me. Let me be the first one to say, I was wrong, and I was adding to the stigma of HIV. I had no idea that later in life I would soon be fighting the stigma I was causing. I was young and didn't see the big picture of HIV; I think so many people miss the big picture. Get tested, know your status, and fight alongside others who are HIV positive. Let them know, "Hey, I am on your side and won't judge you." Only together as one can we end HIV, instead of adding to the shame and guilt that people who are HIV positive already experience.

HIV is now very treatable. I have been on the same medication for almost 12 years and lived with HIV for 34 years. I also have a wonderful wife and three wonderful children, who are all HIV negative. It's also important for the world to know that once HIV is treated, you can have a family and live a very normal happy life. It's really what life is all about – living it to the fullest.

Submitted by: Andrew



WHAT MY CAB MEANS TO ME

Over the years in PHACS, I have gained friendships, education, and knowledge that have helped me in every aspect of my life. We may all live in different states and cities, but our goal remains the same. We've been through similar challenges that we continue to face every day.

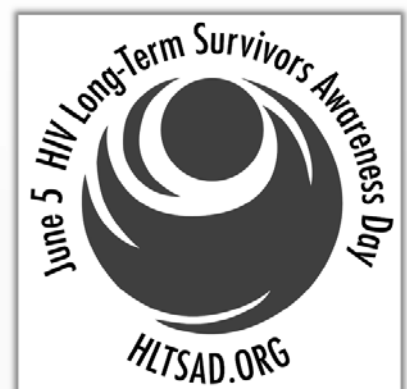
"CAB" for me stands for endurance, strength, and survival. **Endurance** means to strive for your best, never doubting yourself, and making it to the finish line. Follow your goals and dreams no matter how big or small. **Survival** means having faith that you will overcome any obstacle in your path and trusting every decision you make in everyday life challenges. **Strength** means living with decisions we make in our lives. Through encouragement and support, together we can continue to educate and better our communities, along with ourselves.

Submitted by: Exzavia

HIV LONG-TERM SURVIVORS DAY

2017 marks the 21st anniversary of the use of Highly Active Antiretroviral Therapy (HAART). Many consider HAART to be one of the major revelations in HIV care today. HAART helped shift HIV from a death sentence to a manageable lifelong illness. Since 2014, June 5th has been declared, "HIV Long-Term Survivors Awareness Day." This declaration serves to honor those who have contributed to the fight against HIV, and subsequently, to its long-term survivors. While the world has come a long way in this fight, June 5th serves as a reminder that the fight is not over.

To learn more about HIV Long-Term Survivors Awareness Day, [visit the "Let's Kick Ass-HIV Long-Term Survivors Declaration" webpage.](#)



FOCUSING ON THE FUTURE

Current college student and Young Adult CAB (YACAB) Vice Chair, Gamon sat down for a Question and Answer (Q & A) session about his academic endurance, strengths, and goals for the future.

Q What are you studying in school?

A I am studying biology. My major is in Life Sciences.

Q Why have you chosen to go into the medical field?

A I have chosen to go into the medical field because of two reasons: 1) I love to help people, and 2) I like science, so I figured, why not?

Q Who influenced you the most to go into the medical field?

A The person who influenced me the most to go into the medical field would most definitely be my mother.

Q What are your goals?

A My goal in life is to become a very successful Perfusionist.

Q Wow, a Perfusionist—an important and specialized profession you don't hear about every day. How did you decide on that?

A Well, my ultimate goal is to be a Cardiologist, but first becoming a Perfusionist will definitely help me sharpen the tools I'll need to become a Cardiologist.



Did you know?

A Perfusionist uses a heart-lung machine to monitor a patient's heart during heart surgery and other surgeries involving the heart. The heart-lung machine is an artificial blood pump. This machine helps to pump blood throughout the patient's body while the surgeon operates on the heart.

Q Why do you want to study the lungs and heart?

A The heart and lungs have always fascinated me for some reason.

Q What has helped you to stay focused in college?

A My friends and family have really helped me stay focused in college.

Q What advice do you have for others looking to study in the medical field?

A The advice I have for others is to stay focused, do the right thing, and trust in God [and/or any other spiritual guide] to guide you to the right path.

Submitted by: Gamon

UNIVERSITY OF CALIFORNIA, SAN DIEGO

SOURCES OF STRENGTH



“With the help of my friends and the support that the support groups offer, we are strong for our children.”



“All the help I’ve received from the groups that I’ve had the opportunity to attend, and especially my faith in God.”



“Taking my medicine, going to support groups, and listening to stories of others have all helped me to continue with my personal care, including going to my doctor.”



“[I stay strong] with much more unity and communication.”



“[Strength from many sources]:
1. My children;
2. Thinking positive;
3. Having a person [in whom] I can confide; and
4. One can tell themselves, “I’m strong for my own self.”

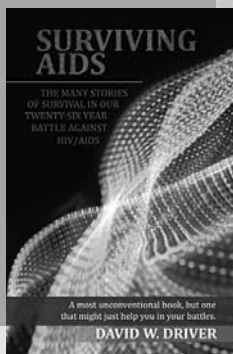


“I would love to support the stopping of spreading HIV and AIDS.”



“Sharing support, directing, managing, talking, and asking to go hand in hand together with others who are like us.”

SURVIVING AIDS



Meet David—David is a father, site CAB member, and author of the book, “Surviving AIDS,” This inspirational story chronicles David’s family’s journey through diagnosis, pregnancy, and life twenty-six years later. Diagnosed as a child, David’s daughter was expected to live a very short life, but is now enjoying the best health she has ever had due to her medical care.

One Amazon user described the book as, “a true story, told from the heart.” Another Amazon user explained, “As we read this story, it opened our eyes up to how we need to reach out for help when going through such a battle.”

Check your local library or view/buy “Surviving AIDS” through the following retailers:

[Amazon](#)

[Barnes & Noble](#)

[Google Play Store](#)

A COMIC ABOUT MY HERO



1 I was once in a deep depression because I never understood how the world could be such a cruel and cold place, especially because of those who have so much. I began trying to fill the void with materialistic things such as comics, statues, and figures, but none of it was ever enough; it was just a temporary fix. I began to lose faith in the world, faith in others, and faith in myself.

2

It wasn't until I talked to one of my dearest friends, who believed in me and pushed me to be the person I am now. She reminded me of Les Brown's inspiring words, "Sometimes you have to believe in someone else's belief in you, until your belief kicks in." She also introduced me to her amazing daughter. I once wrote her a letter, asking her, "If I gave you \$100, what would you do with it?" She replied, "I'd feed the homeless and hungry." She was so motivated that she even came up with a design/logo for her organization that would help the homeless and hungry, "Helping Other People Eat (HOPE)."



PICTURED ABOVE IS
HER DESIGN/LOGO
FOR
"HOPE."



3

I was so inspired and motivated by her response and actions that I took some of my collection, sold it, and gave her some of the proceeds. Due to our schedules, we decided to donate it to the American Cancer Society in memory of her grandmother, who passed away.



AMAZING!



4

This young girl's desire to help others has taught me that we all have this unique gift to touch and affect one another. She reminded me that strength comes in all shapes and sizes—anyone can be a hero. Most of all, she has shown me that there is always hope that shines bright. This is why she will forever be my hero.

Submitted by: Brandon

WHAT IS SURVIVAL?

Survival means being able to live in the moment, even when things are challenging and difficult. It means keeping my head above water, even when it feels like I'm about to drown. I get my strength from my Lord. I believe His words comfort me. He gives me strength and peace. He is the constant in my life.

Survival to me means to make the best of whatever life has in store.

Survival for me is taking care of myself.

Submitted by: CAB Members

ENDURANCE, STRENGTH, SURVIVAL

Sometimes, the darkness feels overwhelming. Lately, we have been bombarded by negative stories in the news about the world around us and may be wondering, where is this world going? This is on top of dealing with our own pressing matters, whether it be financial, health, family, or relationship issues. At times, the weight of it all may seem like too much, as if you might crack or cave in. Sometimes we wonder, why me? Why must we go through so much? What is it all for? Are we just staying afloat as we sail through this storm? Given these hardships, what gives you your strength to persevere and endure such adversity?

“...it isn’t about ourselves, but instead, it’s about being aware of all the lives you touch.”

I work as a Peer Navigator here at University of Florida Center for HIV/AIDS Research, Education and Service (UF CARES). I am supposed to be a symbol of hope, using my story to help encourage and motivate my patients. However, at times I struggle trying to be the man I want to be. It feels as though the world around me fears me, and what courses inside of me feels as if I were a sin, a curse, a burden. At times, my life feels like a deadly balancing act as I try to do what is right for myself, while trying to be the voice and backbone to do what is right for my patients. I’ve come to realize that sometimes it isn’t about ourselves, but instead, it’s about being aware of all the lives you touch. So, I continue to press on in this battle for those who weren’t given the opportunity to fight, for those who are too afraid to fight, for those who gave so much, and for those who matter and mean the most to me in the hopes and dreams of a better tomorrow.

Submitted by: Brandon

PUERTO RICO’S HARD TIMES

Puerto Rico is a territory of the United States of America. It is an island with a tropical climate. Despite its size, it contains a diversity of ecosystems. The most popular of these ecosystems is the beaches, which are ranked as some of the most beautiful in the world.

While this small island contains beautiful sights for tourism, it is enduring an economic crisis. The crisis of the Puerto Rico colony started in 1996. This was the time when the federal government of the United States ended an important program. The program involved

providing incentives to attract manufacturing industries. This decision took its final toll in 2006.

(Continued on page 10)

PUERTO RICO'S HARD TIMES

(CONTINUED)

That same year, in the aftermath of the program's end, another crisis occurred. Since 2006, the gross product and employment rate have gone down, and the population has decreased. Thus, the recruitment of patients for PHACS has been difficult. This is because we have no control over the people who move to the mainland, and those who come back to Puerto Rico. Finally, in 2017, Puerto Rico could not pay the economic debt and declared federal bankruptcy; this caused problems for the economy.

Another one of the challenges that Puerto Rico faced occurred from 2015 to 2016. That problem was the Zika virus. The Zika virus may be transmitted by the Aedes Aegypti mosquito. This mosquito can be found in many places, including Puerto Rico. The common symptoms of Zika include severe headaches, skin problems, fever, body pain, pink eye, and joint pain. It is considered a disease that is relatively slow and limited. The

virus may also be transmitted through sex. In 2015, it was discovered that the virus could be transmitted from mothers to babies during pregnancy. Babies born with or exposed to Zika could possibly develop a condition called microcephaly (my-kroh-SEF-uh-lee). Microcephaly is a condition where the brain does not grow properly. Babies with microcephaly often have smaller heads. In extreme cases, microcephaly can be fatal. In Puerto Rico, people feared for pregnant women and their children. This caused Puerto Ricans to come together to learn how to prevent Zika. One of the ways to prevent Zika transmission during sex is to wear a condom. Another method of prevention is for women to get yearly checkups with their gynecologist. Unfortunately, there is no cure for Zika. However, there is hope because scientists are still researching Zika.

Puerto Rico graces the Caribbean waters and the Atlantic Ocean with



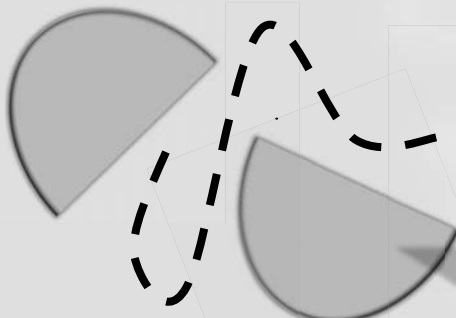
cheerful people, amazing food, extraordinary culture, and beautiful sights. This territory has the challenge to reinvent itself out of this difficult situation. As Puerto Ricans, we need to face these challenges together because history has taught us that we cannot win a situation without the unity of our people.

Submitted by: Joel Pagán, MD

SITE 10 EASTER EGG HUNT

Rutger's New Jersey Medical School hosted an Easter Egg Hunt in April for patients and their families.

Submitted by: Kimberly



THE BUTTERFLY AND THE SUNFLOWER



Survival and endurance can seem unachievable when even getting out of bed seems impossible.



I want to tell you a story about a beautiful butterfly, who reverted back to her cocoon. On a beautiful Tuesday morning, the sunflower that gave her life and nourishment sadly went away. The relationship with this sunflower has been a journey with some good days and some bad days. Some days, she wanted to live and listen to other sunflowers, but she always returned to the sweet nectar, nourishment, and love of her life-giving sunflower. She never thought that

one day she would be burying the sunflower in that cold, hard dirt, but she knew life happens that way sometimes.

Everyday, another sunflower offers nectar nourishment to the butterfly, but no other flowers seem to taste and love the same. All that the butterfly wished was for one more day to lay in the bosom of that sunflower, and feel her beautiful wings in the sun. Until one day, the butterfly was sitting on a rock because she refused to deal with anything or anyone else. Her sunflower came to her in a dream and told her, "It's okay, my sweet butterfly," she said.

"...no one can ever replace your sunflower, your butterfly, or even your heart, but they left seeds of love with you, and it's your job now to let them grow."

"I know you will metamorph into something God intended you to be. I also left plenty of seeds so the world will know that your sunflower has

been here. You need to carry those seeds on to help nourish the world."

That's when the song of the butterfly was released, and she slowly started to extend her wings.

I know in this world survival means a lot of things. Surviving the loss of a loved one feels as though your heart and your wings have been clipped, but I will tell you, my CAB brothers and sisters, if you ever need us, we are here. Most of all, I know that you can survive in this world. Even if you may not want to endure because a part of you is gone, turn to your friends. I would never want you to be in that type of pain; however, I am not trying to dismiss your pain. I still wake up in tears sometimes, and wish I could hold my sweet mother one more time, but I know she would want me to survive while enduring. I also know that no one can ever replace your sunflower, your butterfly, or even your heart, but they left seeds of love with you, and it's your job now to let them grow. Remind the world how amazing they were.

Submitted by: Kimbrae



To be a Patronus

** Note: This story contains spoilers about the Harry Potter book series.*

The story I'd like to share is about sanctuary, and about creatures called Patronuses from the Harry Potter series.

My Nana has always been one of the few people on Earth who really understood me. This past April, she had to go into the hospital for what seemed like a resolvable health issue, but sadly, it instead turned out to be the beginning of a rapid decline in her health. I and a lot of other out-of-town family flew immediately home to St. Louis, and for the next five days, we all took turns sitting with her around the clock in the ICU. We held her hands, talked to her, stroked her hair, and watched her vital signs like hawks. She was on a ventilator and couldn't talk, but she was never alone. We stood around her bed in a circle and surrounded her with her favorite songs, her favorite psalms and Bible verses, and her favorite poems. We draped her with a beautiful prayer shawl that the hospital gave us, and

we placed homemade crosses made out of palms for Palm Sunday on her lap. In her final hours, we sang her everything from Beatles and Cat Stevens songs to Catholic hymns to a Hebrew prayer.

One of the songs we sang to her is called "Courage," which I learned from a Jewish activism group I'm part of, which in turn borrowed it from South African activists. The lyrics are:

Courage, my friend / you do not walk alone / I will walk with you / and sing your spirit home.

(Listen to the recording [here](#). We can sing it together at the Fall Meeting!)

One of my favorite chapters in the entire Harry Potter series is "The Forest Again" at the end of the 7th and final book. In it, Harry's parents (Lily and James), his godfather (Sirius), and his mentor (Lupin) – all of whom have passed away – are described as Patronuses keeping Harry safe on his own walk toward death. A Patronus is a magical spell, a silvery-white guardian that forms a shield and protects a person from the cold and danger of evil creatures called Dementors. In the story, Lily, James, Sirius, and Lupin form a protective sanctuary around Harry that allow him to pass unharmed through the

...I think that we, the living, were also her Patronuses, forming a beautiful, warm sanctuary around her and walking with her until the very end.

cold of the Dementors and the dangers of the Forbidden Forest.

It occurred to me as we sang the Courage song in the hospital that we were embodying the lyrics in the same way that Harry's parents, Sirius, and Lupin do in the book. I imagined that we formed a cocoon around my Nana, hopefully protecting her from the literal and spiritual coldness and sterility of her hospital room. I hope she was surrounded by her late husband, her parents, and her brother, all coming back to get her - but I think that we, the living, were also her Patronuses, forming a beautiful, warm sanctuary around her and walking with her until the very end. Though she was in and out of consciousness, I am sure I saw tears streaking down the side of her face as we sang to her.

(Continued on page 13)



A Patronus in the form of a stag.

To be a Patronus

(Continued)

So it's no wonder that on the evening she died, as I crawled into bed in the early hours of the morning, I turned instinctively to that specific chapter of Harry Potter as my own little sanctuary and comfort. It felt similar to the way some might reach for a beloved Bible verse or Torah or Quran passage.


Sometimes a sanctuary of people we love can help us endure and survive to the next moment in a difficult situation. Sometimes it can help us

to accept and ease pain. And to be a Patronus can remind us of love in the face of loss. To be a Patronus takes love, compassion, and acceptance. Who have you been a

Patronus for? Who or what have been your Patronuses?

Submitted by: Claire

Below is a letter we found, from my Nana to her 9 children.

*Don't ever be afraid;
you are too much loved
to have to fear.* 

INSPIRATIONAL QUOTES

"You gain strength, courage, and confidence by every experience in which you really stop to look fear in the face. You are able to say to yourself, 'I lived through this horror. I can take the next thing that comes along.'"

-Eleanor Roosevelt

"Joy is prayer; joy is strength; joy is love; joy is a net of love by which you can catch souls."

-Mother Teresa

"Strength does not come from physical capacity. It comes from an indomitable will."

-Mahatma Gandhi

"Endurance is not just the ability to bear a hard thing, but to turn it into glory."

-William Barclay

"Every great dream begins with a dreamer. Always remember, you have within you the strength, the patience, and the passion to reach for the stars to change the world."

-Harriet Tubman

"No one saves us but ourselves. No one can and no one may. We ourselves must walk the path."

-Buddha



"Kites rise highest against the wind - not with it."

-Winston Churchill

"You have power over your mind - not outside events. Realize this, and you will find strength."

-Marcus Aurelius

Submitted by: Brandon

PHACS MEMBERS PROFILES



MURLI PURSWANI, MBCHB, FAAP

Hello everyone, my name is Murli Purswani. I am a Pediatric Infectious Disease Specialist, practicing in the South/Central Bronx borough of New York City. It has been a blessing and a pleasure to be part of the PHACS community. I am excited to share with you a little bit more about my background.

I was born and raised in Jaipur, India, along with my six other siblings. We are now spread across the globe, with my brother and sisters living in Thailand, Ghana, Texas, and Sri Lanka. It is hard to get together for a family reunion, but I feel lucky that I have family in such diverse parts of the world. My international family has exposed me to the rich experiences of learning about communities through food, culture, and art. They

have instilled in me a love for travel and exploration.

I attended medical school in Accra, Ghana, where my father, who was the most important role model in my life, was also practicing medicine. I met

and married my wonderful wife in India and we started our lives as newlyweds in West Africa, where we had two beautiful daughters. I brought my family to the United States in 1998 after completing my pediatric residency in Washington D.C., and an Infectious Disease fellowship at The New York Hospital. Eventually, I became an attending physician at Bronx-Lebanon Hospital Center. I was blessed with my third beautiful daughter, the first American Citizen in our family, and I have quickly become surrounded, and outnumbered, by some pretty amazing, strong-minded women!

We worked very hard to build our program in Bronx-Lebanon. One of the ways we did it was by keeping all our HIV-exposed but uninfected (HEU) babies in our care, instead of transferring them to the regular pediatric clinic after we had established that they were not infected with HIV. Over the years, we have developed such close

relationships with these families. PHACS has provided a wonderful mechanism for our children to access neurodevelopmental (brain) testing, other services in our hospital, and the opportunity to stay in care. Our CAB members were all recruited from these families and they have helped us build a bridge between the community and our PHACS research agenda. They are full of interesting ideas and thoughts and always willing to look at new studies to find ways to make the consent forms easier for parents and patients to understand. We look forward to our annual Christmas party with our families every year. We appreciate the interesting food they cook for us when we are able to organize summer barbecues, and we are definitely due for one this year!

I still enjoy authentic Ghanaian cuisine right here in the Bronx, as well as my wife's delicious homemade Indian food. I currently live in Westchester County, a suburb of New York City. As a teenager I played soccer (really called "football" in the rest of the world) and badminton. I enjoy watching football; World Cup soccer every four years is one of my highlights! It's also fun making time in the evenings during our research meetings after a long day of work to watch that all-American sport of baseball with friends and colleagues.

PHACS MEMBERS PROFILES

(CONTINUED)



ANGELA ELLIS, BS

Hello all! I am Angela Ellis, one of the PHACS Clinical Data Managers at Frontier Science in Buffalo, NY. I was born and raised in Buffalo and love my city! I was always interested in science, so after high school, I attended Buffalo State College and earned a degree in Forensic Chemistry. After graduating, I worked in a chemistry

lab at a local pharmaceutical company analyzing eczema treatments. While there, I learned that the laboratory environment wasn't for me. I began working for our local chapter of the National Multiple Sclerosis Society and helped with fundraising efforts and community outreach. I enjoyed working with our clients and realized I was more interested in the health-related field. After this realization, I accepted a position as a Donor Screening Specialist at Upstate New York Transplant Services, which is our local organ, eye, tissue, and blood donation center. I helped to facilitate tissue and eye donation from local donors to help save others' lives. While this job was extremely rewarding, it was also very stressful.

I learned about an opening at Frontier Science and while I was new to the field of HIV, I was very interested. I started at Frontier Science in January 2011 as a Laboratory Data Manager and quickly learned a lot! As a

Laboratory Data Manager, I worked on protocols on the PHACS, AIDS Clinical Trials Group (ACTG), and the International Maternal Pediatric Adolescent AIDS Clinical Trials Group (IMPAACT) projects. I learned what a special project PHACS was and loved working on it! In early 2014, I was given the opportunity to work exclusively on the PHACS project as a Clinical Data Manager. I thoroughly enjoy working with the PHACS Leadership and the staff at our sites. The PHACS community is very tight-knit, and I love how involved our adult and young adult CABs are! It has been an honor to meet some of you at the PHACS Meetings, and I look forward to your sessions at every meeting.

When I am not working, I am spending time with my family and our two cats. My son just turned 3 years old and keeps my husband and me very busy! In my free time, I also enjoy cooking and reading.



KIMBRAE

My name is Kimbrae. I am a CAB member from Houston, Texas and help represent Texas Children's Hospital. I have been a CAB member for over five years and during this time, I served in both the Chair and Vice Chair positions, as well as numerous subcommittees for PHACS.

My journey began back in 1997, when I found out that I was three and a half months pregnant and was HIV positive; that is when my name began to be associated with advocacy and having a voice for the voiceless. I became educated so that I can help fight any stereotypes that may be associated with having the disease. I plan to continue with this role until there is a cure.

(Continued on page 16)

PHACS MEMBERS PROFILES

(CONTINUED)

My main objective is to make sure that no one across this world will ever feel unloved, unworthy, or stigmatized in any way that would make him/her feel as though they are not a human being. I hope people know that there are others out there like them who are willing to fight with them or just love them, whether it's the beginning of their journey or farther down the road. This was my main reason for joining the CAB. I hope my contributions at my local CAB and during our monthly CAB conference calls, participating in committees and

writing teams, and submitting to these newsletters will help generations to come.

I am a single mother of an awesome son, who is also the Young Adult CAB (YACAB) Vice Chair. He is my inspiration and the biggest part of my heart. Some of my best interests are reading – I love everything from John Grisham to Zane. I am an avid cook, and I have been in love with cooking ever since I could remember. As a small child, I was always either in my mother's or my grandmother's kitchen learning

how to do things the homemade way. I also have a yearning love for history. My love for history might explain my fascination with all different types of history museums. However, my favorite thing in life is the life cycle of the butterfly. I believe this fascination came from my inner soul. The journey of a butterfly can be a difficult one, but once they've reached the stage where they can spread their wings and fly, no one on earth can ever deny the beauty that they possess.

HECC UPDATE

Dear PHACS CAB members,

The Health Education and Communication Committee (HECC) has had another busy start to the year. Here are some of the updates from our committee:

PHACS Films: We have completed three films (the "Faces of PHACS" youth documentary; "PHACS Community Voices" CAB film; and a short version of the youth film), and we have also created 30 short clips of PHACS CAB and YACAB members, staff, and clinicians for the PHACS website. We are continuing to work on an additional film with the Harvard media office using footage from

study visits at Tulane and Boston Children's. As part of our dissemination plan for the films, we will be submitting the films to a number of film festivals and conferences. So far, we have shared the films with the IMPAACT network and have submitted the youth documentary to several health communication conferences, including the American Public Health Association (APHA) Global Health Film Festival, the Vail Film Festival, and the New York Short Film Festival. Additionally, the "PHACS Community Voices" CAB film was shown during the poster session at the HIV Pediatrics Workshop in Paris, France in July 2017. In the future, we plan to



submit the films to the International AIDS Conference, the HIV Story Project, and additional international film festivals.

You can find all completed films here on the PHACS website.

(Continued on page 17)

HECC UPDATE

(CONTINUED)

One Love Conference: The One Love conference for young adults living with HIV was held from July 23 – 28th, 2017 in Boston, and I'm happy to report that we had 10 PHACS participants from 3 sites who attended free of charge, thanks to the sponsorship of both PHACS and One Love.

“HIV, Health Literacy, and Communities of Color” Conference Panel: Claire was invited to present on a panel at Tufts University School of Medicine on June 16th about the work that the HECC and CAB have done to address health literacy in the context of research and in working with communities of color. CAB members Theresa and Kim from Texas Children's volunteered to work with Claire and Megan to create a presentation on PHACS' strengths and challenges in this regard. The team decided to focus on the following topics from PHACS' perspective: 1) strategies for building a health-literate organization; 2) addressing the role of HIV and other stigma in health literacy; 3) community engagement in the research process; and 4) creating audience-driven narrative approaches to health literacy. Claire will give a presentation to the CAB on an upcoming call about some of the topics discussed at the workshop.

Whiteboard Videos: We have received feedback from CAB members, study coordinators, the

HECC, and YACAB members to help us choose appropriate topics for a new series of very short whiteboard videos about informed consent. We will once again work with Booster Shot Media to create these videos. If you would like to be part of the team working on this project in the coming months, please let Claire or Megan know.

“Choose Your Own Adventure” Video for Young Adults: We are working with a new health communication intern from Tufts, Marwah Hassounah, to create a “choose your own adventure”-style video for young adults. To watch the video, a viewer has to actively participate by making small decisions for the main character along the way. While we know that transitioning to adult health care is a big focus for researchers and clinicians, we have heard from young adults that it's not necessarily the main focus of their lives. That's why our video will feature a storyline chosen by our YACAB members. It will likely feature a young adult in their regular day-to-day life, while demonstrating several skills related to transitioning to adult health care. It will also show how some self-advocacy or empowerment skills are transferrable to other settings beyond health care.

Exploring New Collaborations: The HECC has had the opportunity to explore some

new potential collaborations this year. The Public Radio International show “The World” is featuring a radio series on adolescent girls and HIV as part of their “Across Women's Lives” series. Kunjal and Claire met with one of the journalists for this series, who would like to pursue a radio story that would center on a young woman living with HIV who is pregnant. Through her story, she would explore many other topics (such as stigma, medications, disclosure, etc.). Additionally, Brandon (our new CAB Vice Chair) has identified another potential collaboration with “Let's Kick ASS,” a project on long-term survivors of HIV/AIDS. Here is a short video you can watch about them: <https://www.youtube.com/watch?v=nt16-hdSRMA>. We will be exploring a potential collaboration with them moving forward as well, given the many long-term survivors who participate in PHACS.

We are looking forward to a busy rest of 2017, and to working with you all on these projects!

Submitted by: Claire, HECC Co-Chair

Reminder:

All HECC initiatives may be found on the PHACS website. Additional CAB resources, protocol documents, and analyses are located behind the login. If you don't already have one, please consider creating an account on the PHACS website to access these resources. [Create your account here.](#)

SOURCES OF STRENGTH

I get my strength from my faith. I grow stronger every day while mentoring youth living with HIV in my community.

Being on CAB calls for me is empowering because it lets me know that I am not alone, and that whatever you put your mind to, you can do with the support of the positive people surrounding you. This is a true strength for me.

All of you women [in PHACS] give me strength. All of my support system—my friends and my family—give me strength to keep going, to give me that endurance.

Whoever you are, whether you have HIV, cancer, diabetes, or mental illness – you are loved. You can conquer anything you put your mind to. Be encouraged! I am turning 42, and I have been HIV positive for 23 years. I was diagnosed at 19 with 3 T-cells. Live life, be encouraged, think differently, and make a difference. We all can make a difference in our own way.

As long as I'm able to help others, especially the ones who don't understand it, and when they see it from a positive perspective and you can explain to them and be a part of their life, help them grow, and know that if they do exactly what they need to do, they'll be okay. That actually gives me strength and courage. I try not to let HIV define who I am. I know it's a part of my life, and it's something that I have to live with. I do the best that I can to take care of myself. I always encourage others to do the same thing. I try to extend that strength to other people.

Submitted by: CAB Members

UPCOMING EVENTS



September 18: National HIV/AIDS and Aging Awareness Day
September 24: PHACS Fall 2017 YACAB Retreat
September 25—26: PHACS Fall 2017 Network Meeting
September 27: PHACS 2017 Fall CAB Retreat
September 27: National Gay Men's HIV/AIDS Awareness Day
October 15: National Latinx AIDS Awareness Day
December 1: World AIDS Day

PARTICIPANT SUMMARY



STARTING HIV MEDICATIONS DURING PREGNANCY AND GROWTH IN UNINFECTED YOUTH AT TWO YEARS OF AGE

Many pregnant women living with HIV take antiretroviral medications (ARVs) during their pregnancy. They take them for their own health and to protect their babies from getting HIV. We wanted to know if ARV exposure during pregnancy could affect how youth grow in the first two years of life. We also wanted to know if the time when a mother starts taking ARVs affects how youth grow. If youth do not grow as they should they may be at greater risk for health problems when they get older.

WHO PARTICIPATED



We studied 509 two-year-old youth without HIV in SMARTT. We included youth whose mothers starting taking ARVs during pregnancy.

WHAT WE DID

ARV Abbreviations	
Tenofovir	TDF
Emtricitabine	FTC
Zidovudine	ZDV
Lamivudine	3TC

We looked at growth in two-year-old youth whose mothers started taking ARVs in the first trimester of pregnancy. The growth measures were weight, height, weight-for-height, triceps skinfold thickness, and head circumference. We did the same study for youth whose mothers started ARVs in the second trimester.

We studied the effect of TDF+FTC compared to ZDV+3TC. We also studied boosted protease inhibitors (bPI) and non-boosted protease inhibitors (non-bPI) on growth.

WHAT WE FOUND



On average, weight, weight-for-length and head circumference were high. Height and thickness of triceps were in the normal range.

In youth whose mothers started ARVs in the first trimester, we found some difference by ARV type. The youth exposed to TDF+FTC tended to be heavier and heavier for their height than youth exposed to ZDV+3TC. Youth exposed to TDF+FTC tended to have less thick triceps than those exposed to ZDV+3TC. BPI was not associated with growth.

Next, we looked at growth in youth who mothers started ARVs in the second trimester. We did not find any differences in growth by type of ARV.

WHAT WE LEARNED



There may be differences in growth depending on when a mother started ARVs in pregnancy and what type of ARVs she used. We need to follow the youth longer to see if the differences continue over time. We also need to do more studies to see if a larger weight gain affects health when they get older.

C058. Jacobson DL, et al. Growth at age two in HIV-exposed uninfected children in the US by trimester of maternal antiretroviral initiation. PIDJ 2016; *In press*



For more information, contact:
Claire Berman | Director, Health Education & Communication
cberman@hsph.harvard.edu | 617-432-1853

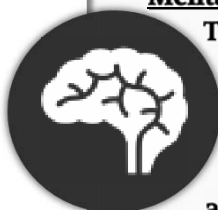
DISCUSSIONS FROM THE SPRING 2017 LEADERSHIP RETREAT

The goal of each PHACS Leadership Retreat is for PHACS leaders to come together to make decisions about the future scientific direction of the PHACS project. This year, on the first day of the retreat, the attendees broke out into small groups to brainstorm priority areas for a Women's Cohort (for mothers living with HIV enrolled in the SMARTT study). The breakout groups talked about developing studies using data that has already been collected and studies that will require collection of new data. The groups also talked about combining or comparing data between PHACS and the Women's Interagency Health Study (WIHS). After the brainstorm, the attendees voted on the top research priorities ([Learn more about the PHACS Women's Cohort in SMARTT: Studies in Development on Page 24](#)).

Dr. Ellen Chadwick, MD presented the discussions from the Women's Cohort sessions to the PHACS CAB and asked for the CAB's valuable feedback and insights during the March 2017 CAB conference call. These are the scientific priorities for a PHACS Women's Cohort for the next few years:

Women's Cohort

**Priorities
Using
Data That
Has
Already
Been
Collected**



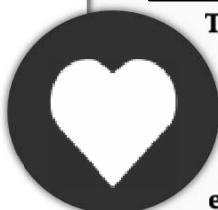
Mental Health in Women Living with HIV

The team will look specifically at the post-partum period (the time right after a woman has a baby). The team wants to look at mental health and substance use disorders in women living with HIV. They will compare mental health in two groups: 1) mothers who were born with HIV and 2) HIV-positive mothers who were not born with HIV. Researchers will look at whether a mother's mental health or substance use might affect their child's mental and behavioral health. Participants in this study will be mothers of children in the SMARTT study.



Health of Women Living with HIV During and After Pregnancy

This study will look at mothers who had more than one pregnancy while participating in PHACS. The team will look at changes in the mothers' antiretroviral medications (ARVs), CD4 counts, and viral load with more than one pregnancy.



Relationship Between Health Problems in Pregnancy and Heart Disease Risk in Women Living with HIV

The team will look at the relationship between pregnancy conditions in women living with HIV and their later risk of heart disease. The conditions are gestational diabetes, preeclampsia, and high blood pressure. Gestational diabetes happens when pregnant women who don't have diabetes have high blood sugar during pregnancy. Preeclampsia causes high blood pressure during pregnancy, bad headaches, swelling in the hands and feet, and protein in urine. These conditions increase the risk of heart disease later in life. The team will study whether women with these conditions during pregnancy are more likely to develop diabetes and high blood pressure after pregnancy. The mothers in SMARTT will be compared to mothers of the same age in the general population.

(Continued on page 21)

DISCUSSIONS FROM THE SPRING 2017 LEADERSHIP RETREAT

(CONTINUED)

How HIV and Antiretroviral Medications May Change Women's Long-Term Bone and Reproductive Health

This study will look at long-term bone health in women living with HIV. It will also look at the effects of HIV and antiretroviral medications on women's long-term hormonal health and menopause (reproductive health).



Mental Health and Substance Use Disorders During Pregnancy

The focus of this study will be to study mental health and substance use disorders during pregnancy in women living with HIV. The team is interested in learning about how a mother's childhood trauma might affect her during pregnancy.



HIV Disease Status During and After Pregnancy

The team will look at "viral load rebound" and lost-to-follow up of women during the first 1-2 years after having a baby. Viral load rebound happens when someone who was previously undetectable later has detectable HIV in their blood.



Priorities Using New Data

Priority Using Data From WIHS



The team will assess the impact of HIV and antiretroviral medications on long-term health problems. They might look at whether a woman's age and HIV symptoms could cause worse brain functioning and memory, heart disease, and/or bone problems.

Genomics

During the second day of the Spring 2017 Leadership Retreat, the attendees met to discuss how to study the relationship of genomics (the study of a person's DNA) with the outcomes of HIV and HIV treatment. This discussion was a follow up to one of the top research priorities for AMP and AMP Up identified at the Spring 2016 Leadership Retreat.

Dr. Russ Van Dyke, MD presented the discussions from the Spring 2017 Leadership Retreat to the PHACS CAB and solicited the CAB's valuable feedback and insights during the May 2017 CAB conference call. Dr. Van Dyke reviewed the genomics discussions for AMP/AMP Up. The scientific priorities for the PHACS genomics studies in the coming years are on the next page.

(Continued on page 22)

DISCUSSIONS FROM THE SPRING 2017 LEADERSHIP RETREAT

(CONTINUED)

What is genomics?



Genomics is the study of a person's genes (DNA) and seeing how they relate to different outcomes, including both developing illness and remaining healthy. Some changes in genes can make a person more likely to have an illness. Other gene changes can protect a person from getting an illness.

How do gene mutations affect health?

Changes in gene structures (mutations) can affect health. Genomics can help researchers understand why drugs work better in some people, why HIV disease progresses, and why side effects develop. Many participants in AMP and AMP Up have given DNA samples that are currently being analyzed (sequenced).



How will PHACS research genomics?



We are analyzing all the genes in the DNA from PHACS participants. We will compare differences in the gene mutations between children with various health conditions. The Human Longevity Institute in San Diego, California is doing this study. They will also be compared to a much larger number of children in an international database. The database includes information on a large number of people with different backgrounds and conditions. The database can tell us which gene changes are normal and which ones are associated with certain diseases. The database is like a gene dictionary. For example, there are genes associated with autism, and researchers want to look at these genes in PHACS participants. This research will tell researchers if any children in PHACS have mutations connected to autism. It will also show whether these mutations affect children with HIV differently.

The PHACS team will continue to figure out the best ways to study these important topics. The team plans to talk about the progress made thus far during the Fall 2017 Meeting.

Submitted by: Drs. Russ Van Dyke and Ellen Chadwick



AMP UP LITE

The Adolescent Master Protocol for Participants 18 Years of Age and Older - Lite (AMP Up Lite), the newest PHACS protocol for young adults, was released in May 2017.

AMP Up Lite has similar goals to the AMP and AMP Up studies but has shorter study visits. Young adults can also participate in AMP Up Lite without ever needing to come to a study clinic. Clinic staff see that some of their patients, as they get older, can't make it to the clinic for long study visits. AMP Up Lite lets these young adults be part of research studies in a way that works for them.



500

AMP Up Lite will enroll participants at study clinics that participate in PHACS, as well as at many study clinics that have not previously participated in PHACS studies. The goal is to enroll 500 young adults who have been living with HIV since they were born. They will be asked to take part in the study for 6 years. You can visit the PHACS website for a more detailed description of the surveys and the information to be collected.



Most participants will go into the study clinic for their first study visit. At this time they will sign an informed consent form, answer some survey questions, and have some measurements taken and blood drawn. After that, participants mainly complete online surveys that can be done anywhere they can log in to the internet. The online survey can also be read to the participant if they are not able to complete it on their own.



There is another blood collection at Year 5, which could be done at a commercial lab (like Quest) if participants can't get to their study site or doctor's office. Much of the information needed to answer the research questions in AMP Up Lite can be found in participants' medical records. Participants will be asked to share their medical record with the study.



An important difference between AMP Up and AMP Up Lite is that after the first visit, all participants enrolled at non-PHACS sites will be transferred from their study clinic to the PHACS Data and Operations Center (DOC) at the Harvard T.H. Chan School of Public Health. Participants who join the study at PHACS sites have this option as well, but it is not a requirement.

Training for this new protocol is underway. Our hope is that this new study will be a good option for young adults who want to be part of study but cannot get to a clinic. We look forward to sharing more information about this study after it gets started!

Submitted by: The PHACS Data and Operations Center (DOC)

PHACS WOMEN'S COHORT IN SMARTT

STUDIES IN DEVELOPMENT

The PHACS Women's Cohort Team is working with the PHACS CAB to develop a research agenda to study the health of women living with HIV in PHACS. Although SMARTT focuses on the health of children, we also collect limited data about the health of SMARTT mothers. We plan to expand the types of data we get from women so that we can learn more about how HIV affects women's health before, during, and after pregnancy. We are writing concept sheets using data that has already been collected on women's health. There are currently three capsules and concept sheets in process. The first concept sheet, led by Kate Powis, will talk about trends in antiretroviral (ARV) use in pregnancy from 2007 through 2016 among women living with HIV in the SMARTT Dynamic Cohort. The main research questions are:

What percent of women receive ARV regimens during pregnancy that are "preferred" regimens according to the U.S. guidelines?

Which women do not receive "preferred" regimens and why?

Is the percent different depending on the calendar year when the women took the medication?

Preferred regimens are the ARVs that the US Department of Health and Human Services (DHHS) Panel on Treatment of HIV Infected Pregnant Women and Prevention of Perinatal Transmission advises health care providers to give to women living with HIV during pregnancy. This study will learn about the number of women who receive ARV regimens that are considered preferred regimens. The team will also try to find out what makes a woman more or less likely to get a preferred regimen in pregnancy. Since 1994, DHHS has been publishing and updating guidelines that list preferred regimens. These regimens are recommended for women living with HIV during pregnancy. The guidelines are updated regularly, based on safety and effectiveness data. Preferred regimens change based on the most up-to-date scientific data. This will be the first study to look at what ARV drugs are given during pregnancy, if they are consistent with treatment recommendations, and why some women may be on ARVs other than those that are preferred.

(Continued on page 25)

PHACS WOMEN'S COHORT IN SMARTT

STUDIES IN DEVELOPMENT

(CONTINUED)



Brigid O'Brien is developing a second capsule to look at repeat pregnancies in SMARTT. Over 700 of the children in SMARTT are siblings. The team will look at women's health across these repeat pregnancies. Specifically, they will look at SMARTT women who have had more than one pregnancy while enrolled in SMARTT.

Ellen Chadwick and Lisa Haddad are developing a third capsule. This capsule will look at high blood pressure and other related disorders during pregnancy among SMARTT women. These conditions will include the life threatening condition, pre-eclampsia. Pre-eclampsia is a condition involving high blood pressure, swelling, and/or damage to another part of the body. We want to see if there are changes in how often complications

happen to women. We want to relate that to when antiretroviral medications (ARVs) were started during pregnancy. We also want to know whether the complications could be related to any particular ARV. This study will look at the ARVs used during pregnancy. It will also look at the occurrence of these conditions with high blood pressure in pregnancy and poor birth outcomes. Poor birth outcomes include delivery of a baby before the due date or a baby being smaller than it should be at delivery. We will look at these to see if any particular ARV is associated with high blood pressure, that is, in turn associated with a poor birth outcome. For this study, we will use data contributed from women enrolled in the SMARTT study. We will also use data from the Women and Infants Transmission Study (WITS), AMP, and AMP UP. Combining data from these studies will allow us to look at the various ARVs that have been used in pregnancy over time. It will also allow us to look at the issue of high blood pressure in pregnancy.

Before the Women's Cohort team was put together, several articles about women's health had already been published in PHACS. These include a paper led by Kay Malee on

“We want to use new data that we plan to begin collecting in the next year.”

the mental health of mothers living with HIV in SMARTT. There was a paper led by Jennifer Jao on pre-term delivery and birth weight outcomes of babies born to women who were born with HIV vs. women who got HIV later in life. There was also a paper led by Heather Watts about ARV use and risk of preterm birth in PHACS SMARTT. There was a paper by Kathryn Rough about calendar trends in substance use during pregnancy. Finally, there was also a paper by Ray Griner about trends in ARV use in pregnancy during the earlier years of SMARTT. In the future, we plan to write concept sheets about new topics, including those identified as priorities at the PHACS Leadership retreat. We want to use new data that we plan to begin collecting in the next year.

Submitted by: Deborah Kacanek, Jennifer Jao, Kate Powis, Lisa Haddad, and Ellen Chadwick

PUBLICATIONS IN THE NEWS

Since the last PHACS CAB Newsletter in January 2017, PHACS has made the following contributions:

11

manuscripts accepted to scientific journals; and

6

abstracts presented at scientific conferences.

Publications

“Newborn hearing screenings in human immunodeficiency virus-exposed uninfected infants.” This manuscript is in the *Journal of AIDS and Immune Research*. Lead author Peter Torre, PhD is Co-Chair of the Hearing and Language Working Group (WG).

“HIV-1 DNA decay dynamics with early, long-term virologic control of perinatal infection.” This manuscript is in *Clinical Infectious Diseases*. Lead author Priyanka Uprety, PhD is a Clinical Microbiology Fellow at Penn Medicine, University of Pennsylvania Health System.

“Growth at age two in HIV-exposed uninfected children in the US by trimester of maternal antiretroviral initiation.” This manuscript is in the *Pediatric Infectious Disease Journal*. Lead author Denise Jacobson, PhD is Co-Chair of the Nutrition, Growth, and Metabolism WG.

“Lower total and regional grey matter brain volumes in youth with perinatally-acquired HIV infection: associations with HIV disease severity, substance use, and cognition.” This manuscript is in *Brain, Behavior, and Immunity*. Lead author Christine Paula Lewis-de los Angeles is an MD/PhD Neuroscience Graduate Student at Northwestern University Feinberg School of Medicine.

“Association of risk of viremia, immunosuppression, serious clinical events, and mortality with increasing age in perinatally human immunodeficiency virus-infected youth.” This manuscript is in *The Journal of the American Medical Association, Pediatrics*. Lead author Anne Neilan, MD is an Infectious Disease Physician at Massachusetts General Hospital.

“Long-term pulmonary complications in perinatally HIV-infected youth.” This manuscript is in the *Journal of Allergy and Clinical Immunology*. Lead author, William Shearer, MD is Co-Chair of the Cardiopulmonary WG.

“Delay in sexual maturation in perinatally HIV-infected youth is mediated by poor growth.” This manuscript is in *AIDS*. Lead author Andrea Bellavia, PhD is a Postdoctoral Fellow in the Department of Environmental Health at the Harvard T.H. Chan School of Public Health.

“Blood lead levels and neurodevelopmental function in perinatally HIV-exposed, uninfected children in a US-based longitudinal cohort study.” This manuscript is in *AIDS Research and Human Retroviruses*. Lead author Katherine Tassiopoulos, DSc is Co-Chair of the Adolescents and Young Adults WG.

“Associations of low vitamin D and elevated parathyroid hormone concentrations with bone mineral density in perinatally HIV-infected children.” The manuscript is in the *Journal of Acquired Immune Deficiency Syndromes*. Lead author Denise Jacobson, PhD is Co-Chair of the Nutrition, Growth, and Metabolism WG.

“Prevalence of periodontal diseases in a multicenter cohort of perinatally HIV-infected and HIV-exposed and uninfected youth.” This manuscript is in the *Journal of Clinical Periodontology*. Mark Ryder, DMD is a Professor at the University of California, San Francisco School of Dentistry.

(Continued on page 27)

PUBLICATIONS IN THE NEWS

(CONTINUED)

Publications

"Impact of the perinatally acquired HIV disease upon longitudinal changes in memory and executive functioning."
The manuscript is in the *Journal of Acquired Immune Deficiency Syndromes*. Lead author Kay Malee, PhD is Co-Chair of the Neurodevelopmental and Neurology WG.

Abstracts

The following abstracts were presented at the Conference on Retroviruses and Opportunistic Infections (CROI) in Seattle, Washington, February 13-16, 2017:

- "Predictors of switch to second-line ART in HIV positive children: a global analysis."
- "TDF/FTC in pregnancy shows no increase in adverse infant birth outcomes in US cohorts."
- "Plasma Heme-Oxygenase-1 is associated with cognitive decline in children with HIV."
- "Biomarkers of cognitive decline in perinatally-infected children with HIV."
- "HPV4 vaccine immunogenicity and efficacy in perinatally HIV-infected adolescents."

The following abstract was presented at the American Auditory Society Scientific and Technology Meeting in Scottsdale, Arizona, March 2-4, 2017:

"Words-in-Noise data from PHACS perinatally HIV-infected and HIV-exposed young adults."

RESOURCES



Let's Kick Ass: AID Survivor Syndrome:

<http://letskickass.org/aids-survivor-syndrome>

Stronger Than You Think You Are—Motivational Video:

<https://www.youtube.com/watch?v=p-PqLpKdkOg>

POZ: Long-Term Survival:

<https://www.poz.com/article/longterm-survival>

Ask the HIV Doc:

<https://www.greaterthan.org/got-questions-askthehivdoc>

The Body: HIV/AIDS Blog Central:

<http://www.thebody.com/content/46169/hiv-aids-blog-central.html?ic=3001>

CAB GLOSSARY



Baseline Data: Information gathered about the participant before study treatment begins. To study the effect of a treatment, baseline information is compared with information gathered later in the trial.

Capsule: In the context of a proposal for a PHACS, a capsule is a brief outline of a proposed study.

Co-Enrollment: Participating in more than one clinical trial at the same time.

Concept Sheet: A brief proposal for a research study within PHACS.

Immunity: Protection against or resistance to a disease.

Study Coordinator: The staff member at the clinical site who serves as the primary contact for participants and ensures that the studies are conducted appropriately.

WORD SEARCH

Instructions: Find the glossary terms in the Word Search below.

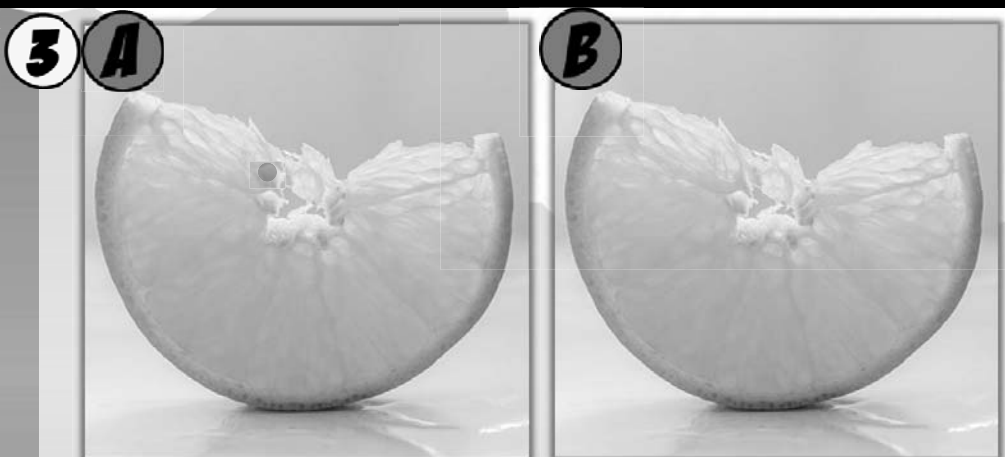
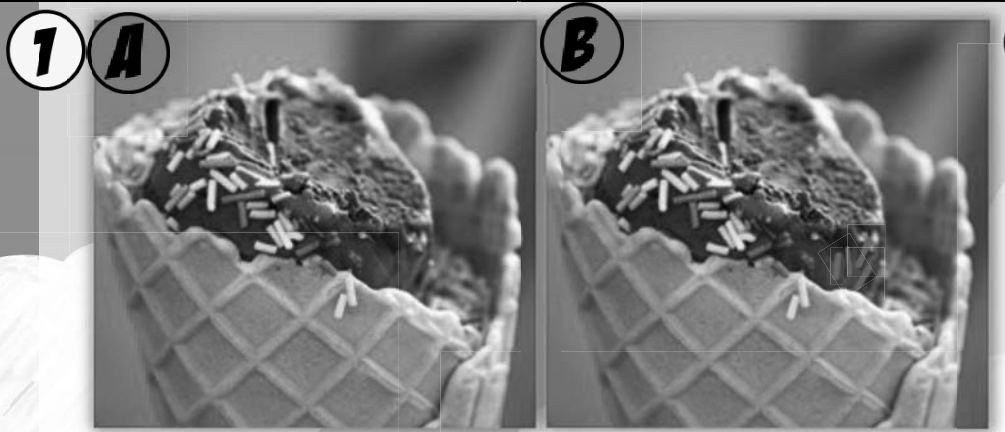
(Answer key on page 30)

C	N	O	S	T	P	D	R	H	U	C	A	D	T	T	U	Y
A	C	C	B	R	I	T	O	S	E	I	M	S	A	O	O	T
P	A	D	B	A	S	E	L	I	N	E	D	A	T	A	D	I
S	T	U	D	Y	C	O	O	R	D	I	N	A	T	O	R	N
U	C	S	C	R	P	C	T	T	E	T	M	I	C	A	I	U
L	C	C	R	U	E	T	O	E	M	D	T	P	S	A	E	M
E	R	E	N	S	E	O	T	T	E	N	L	P	U	A	H	M
T	E	E	H	S	T	P	E	C	N	O	C	E	T	D	D	I
T	N	E	M	L	L	O	R	N	E	O	C	T	O	T	L	T

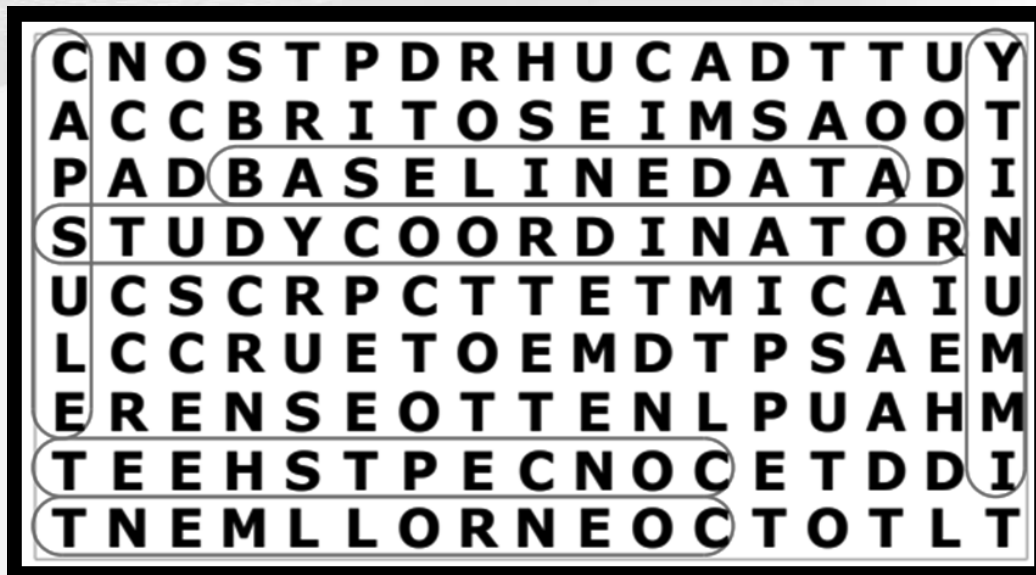
Spot the difference!

Look at the pairs of pictures below and find the difference in each picture.

(Answer key on page 30)



WORD SEARCH KEY



SPOT THE DIFFERENCE KEY

1
B

2
B

3
A

4
B

Key:

- There is an extra cluster of pink sprinkles
- There is a ladybug on the leaf.
- There is an extra brown piece of pulp.
- There is an extra dinosaur toy on the beach.

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