

# In Focus



## A COMMUNITY ADVISORY BOARD NEWSLETTER PUBLISHED BY:

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

#### INSIDE THIS ISSUE:

PHACS Member Profiles	<a href="#">2</a>
Empowerment Is...	<a href="#">3</a>
The WOW Moments	<a href="#">4</a>
The Little Girl From Africa	<a href="#">5</a>
Concept Sheet Overview	<a href="#">6</a>
You + Me = Together	<a href="#">8</a>
A Woman's Voice	<a href="#">9</a>
CAB Kids	<a href="#">10</a>
A Letter About Love	<a href="#">12</a>
My Definitions	<a href="#">12</a>
CAB Glossary	<a href="#">13</a>
Word Scramble	<a href="#">13</a>
Publications in the News	<a href="#">14</a>
HECC Update	<a href="#">16</a>
HECC Presentations	<a href="#">16</a>
Participant Summary	<a href="#">18</a>
Self-Love	<a href="#">19</a>
Resources	<a href="#">19</a>
Upcoming Events	<a href="#">20</a>
Word Search Key	<a href="#">20</a>
Word Scramble Key	<a href="#">20</a>

## FROM OUR CAB CHAIRS

Hello to my fellow CAB family. I hope that this finds you well. I want to thank all of those who helped put this newsletter together. As your Chair, it is so easy to work together with the CAB and Westat family. I also would like to thank all those who ran for the Vice Chair position because if it was not for your hard work and all of the work at your site, then this CAB would not be the great success that it is has been. To my new right hand, Lesley, I welcome you and hope this journey will be a great one!

Since the last CAB newsletter, we have had a lot of great things happen, such as the Spring 2015 Retreat where myself and others talked about stigma. Just like the virus, our main drive needs help making it be a thing of the past. I also wanted to thank you to the Young Adult CAB for their part in this fight because without their heart to fight, the need for a cure will disappear. With their help, we can now make the virus disappear. Our goal in this newsletter is to show advocacy, empowerment, and self-love. So, I challenge all to put a smile not only on someone's face, but to leave it inside their heart, whether that be a doctor, nurse, principal investigator, caseworker, or a fellow patient.

*Kim, PHACS CAB Chair*



*Delia, Kim, Megan, and Claire at the Spring 2015 Leadership Retreat.*



My name is Lesley, and I want to thank you for electing me as your new PHACS CAB Vice Chair. I am ecstatic to have this opportunity to serve you and I'm looking forward to all the new things I will learn that will make me an even better advocate and leader. I have been a member of PHACS CAB for the past year, attended the fall retreat in October 2014, and have been actively involved in the Health Education and Communication Committee (HECC) as well. My goals for the next two years are to learn as much as I can, as well as continue to advocate for those who aren't able to speak up for themselves or who are too afraid to speak out. A little bit about my personal life—I love music, I have a new love for karaoke (even though I can't hold a note but I still try), dancing, swimming, reading, anything artistic, traveling, and ironically sleeping ☺ (but I won't sleep while I'm working).

*Lesley, PHACS CAB Vice Chair*

# PHACS MEMBER PROFILES



**Laurie Dooley  
Butler, MBA**

Hi, my name is Laurie Dooley Butler. I'm a Clinical Data Manager for the PHACS Data Management Center (DMC) at Frontier Science in Amherst, New York, a suburb of Buffalo. I grew up in Buffalo where I was surrounded by a large extended family of my parents, sister, aunts, uncles and cousins. Being one of the oldest in my family, I was usually given the job of taking care of my younger sister and cousins. I found that I loved

being with children and wanted to work with them when I was older. After getting my degree in Medical Technology, I worked as a Laboratory Technologist in the Hematology Department at Women and Children's Hospital in Buffalo. It was very rewarding working with both healthy and sick children. That experience made me want to help children and their families find a healthier lifestyle. Over the next few years I became certified as a Clinical Exercise Specialist. I began making programs for families with obesity problems.

When my best friend was diagnosed with breast cancer at 38 years old, I decided to create an exercise program for breast cancer survivors. I became curious about breast cancer research. When I found out that Frontier Science had a division that was involved with breast cancer research, I was very interested in working there. I was thrilled to start my career at Frontier Science in 2004.

I loved working in the breast cancer group, but I missed working with children. When Sue

Siminski, the PHACS DMC Principal Investigator at Frontier Science mentioned there was a job opening in PHACS, I wanted to know more. I am happy to say that since 2008, I have been a part of the amazing PHACS team. Being on the CAB calls is one of the best parts of my job. The strength and determination of the CAB members to make PHACS and the lives of their children better continues to guide the project in new directions. I find calls with the CAB members so inspiring!

Outside of Frontier Science, spending time with my family, especially my grandchildren is a joy that I am so grateful for. This time of year you can find me digging in and tending my vegetable garden. Daily movement and exercise is an important part of my life. Working out and yoga help to keep me energized. I continue to help and coach cancer patients as they recover and find their way to a healthier path. All of this and working with all the people in the PHACS project truly adds up to a happy, rewarding life.

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## Exzavia



My name is Exzavia, and I am currently a CAB Representative for the PHACS and IMPAACT Networks at Children's Diagnostic and Treatment Center in Fort Lauderdale, Florida. I have been employed with Children's Diagnostic and Treatment Center since November 2000. I first started as an Outreach worker in our Comprehensive Family AIDS Program (CFAP), going into communities and working health fairs by passing out contraceptives and brochures on HIV and safety. I have also worked in the Target Outreach Pregnant Women Act Program (TOPWA), which helps to ensure no child is born positive. In this program, I attended different church, community, college and school events. I set up and ran health fairs to do HIV and pregnancy testing.

*(Continued on [page 3](#))*

# PHACS MEMBER PROFILES

(CONTINUED)

Later I became a Family Support worker and a Client Care Consultant, in which I assisted the Social Workers with their clients by doing home visits, delivering medication, and attending appointments with the clients, either at our Center or in other Care facilities.

I provide support to clients when it's needed the most by sharing my own story to help others overcome fears and to begin to live a healthier life.

I run support groups for both PHACS and IMPAACT by sharing information that I have learned in the community and updates from study findings with our CAB members.

**“YOU NEVER KNOW HOW YOU WILL AFFECT ANOTHER PERSON OR HOW A GROUP OF AMAZING PEOPLE CAN REACH OUT AND HELP ONE ANOTHER.”**

Our site CAB consists of 20 dedicated CAB members (including their spouses) who are very involved and eager to learn when I share research updates, review protocols and follow up with

questions and answers. After the meetings, the members always want more information.

What I enjoy the most about our site CAB is that it's a safe haven where CAB members can just be themselves and feel comfortable to ask any question that they have. The fact that it's such a great support system for each and every one of them is remarkable. You never know how you will affect another person or how a group of amazing people can reach out and help one another. I am currently working to start a Youth CAB to get more adolescents involved. Thanks to the research team, I have the greatest support to be able to run a great CAB.

EMPOWERMENT IS . . .

**STRENGTH**  
POWER  
HOPE  
COURAGE  
FAITH  
AUTHORITY  
SUPPORT  
NO FEAR  
DIRECTION  
ACHIEVEMENT  
CONFIDENCE  
PERSEVERANCE  
GOOD LOVE  
SPEAK ASSERTIVE  
UNCONDITIONAL TRUST  
CONFIDENCE TO LEARN  
INFORMED  
ENDURANCE  
SPIRIT  
ENABLEMENT  
ABILITY

# THE WOW MOMENTS

We all encounter unique experiences in our lives.

Not too often though, do we get a chance to reflect on those moments. It is then that we can make them a permanent part of our lives. My name is Dominique and as a lifetime scholar, I treasure moments in which I can say "WOW." Since I started my internship with Harvard School of Public Health, I have had many "WOW" moments. The great memories I have gained have been because of Claire and Megan. These two lovely young ladies are what I call the dynamic duo. They have dedicated their time to their craft and each day they paint a canvas.

During the March retreat at the Bolger Center in Maryland, the "WOW" moments were happening all over the place. I was invited by Claire and Megan to be a young adult representative for the PHACS Spring 2015 Leadership Retreat. I was not sure what all to expect, but once I arrived I was welcomed with open arms. There were professionals from Harvard, and from various different hospitals across the country from Denver to Florida who called me their colleague. I appreciated the willingness to allow me to sit at the table and provide my perspective on what HIV is and how it impacts my life.

**"...MY IDEAS AND OPINIONS DO MATTER AND THERE ARE PEOPLE WHO WILL TAKE ACTION BEHIND MY WORDS."**

While at the retreat I sat in meetings about innovative ways to encourage youth to participate in studies. The Denver site has developed a narrated video which makes you do nothing but laugh. The lively video allows the viewer to be relaxed and showed that a study does not always have to be serious. It also shows the step-by-step experience someone may have during a research visit. I appreciate what they shared and highly recommend it be shown throughout the entire network.

The "WOW" moments continued when I was asked to be a part of the stigma panel they were hosting. All together there were roughly eight people sitting in front of a group of over 100 people talking about their experiences with stigma and providing insight on how to prevent it. We first started off by defining stigma, which gave a unique outlook on stigma and its affect on today's world versus the influence it once had. I recall sharing, "Stigma is something that has drastically

reduced because of the efforts of those in this room and because of the many people that have said, *HIV will not be the end for me.*"

With the many strides made, I believe there are still challenges, but with groups like PHACS, work is being done to rid the world of ignorance.



Being born with HIV has had its struggles, but I am still living a blessed life. My experience at the meeting reminded me that my ideas and opinions do matter and there are people who will take action behind my words. I must say thank you to each of you who have committed yourselves to this cause. So many of you attempt to praise me for what I have endured; NO, it is you who deserve an applause!

My efforts and work with each of you is just beginning. My work will continue to impact lives for the better, and I will continue to smile at the "WOW" moments.

*Submitted by: Dominique*

# THE LITTLE GIRL FROM AFRICA

Greetings to all reading this story. My name is Stephanie and the virus has lived with me for 23 years. Along the way while keeping the virus under control, I was diagnosed with rectal cancer. For those of you that didn't know, I should tell you that this is one of the most deadly types of cancers. By the time you are diagnosed it's normally too late, but that's another story. However, I've been cancer-free for 2 years and 6 months! Enough about me; I'd like to tell you a story.

I met a young lady who was adopted by my rent man. We lived next door to each other. I was introduced to the young lady and her sister, who also is from Africa. They both were very sweet little girls, and we clicked the moment we met. Now, one of the little girls had a big chip on her shoulder and would sometimes argue with her parents about taking her medications. At the time, still not knowing why she is taking them, I began telling her the importance of taking your medicine, which can make you feel better.

One day I had an appointment with my doctor, and her father asked if I wanted a ride because he was heading my way, but we would have to make a quick stop and pick up his wife and daughter first. As we were pulling up to the doctor's office, I noticed that he seemed to be headed to the clinic where we have CAB meetings. At that moment, I smiled because now I was getting the picture.

I saw this as an opportunity to start a conversation with her about the importance of taking her medications.



Thankfully, her family and I attend the same church, and I also ride with them. I decided that I would find a way for her and I to be alone and

talk. I opened up the conversation by asking her why she didn't like to take her medication, and she stated, "Because they wouldn't help my problem."

I replied, "How do you know if you don't take them?"

I then started asking about the doctors and nurses who worked at her clinic and her eyes got wide open and she asked, "How do you know them?"

I explained to her that I was a member of a group called a CAB that meets at this clinic, and I know why the kids come here for treatment. I said, "Oh and, by the way, I'm HIV-positive too."

Still with her eyes wide open she said, "But you don't look like you have it," and I responded, "Because I take my meds."

She gave me a hug so tight with that beautiful smile not saying a single word. We no longer live next door to each other, but we see each other at church, and I continue talking to her about taking her medications and going to doctor appointments, and she always answers, "I know, Sister Stephanie."

Her father asked me what I had said to her because she no longer argues about taking her medications. I paused, then responded, "GIRL TALK."

*Submitted by: Stephanie*

**"She gave me a hug so tight with that beautiful smile not saying a single word."**

# CONCEPT SHEET OVERVIEW

## CONCEPT SHEET NUMBER, TITLE

CS090, Mental Health Symptoms, Diagnoses, and Service Utilizations in HIV-exposed Youth

## PURPOSE

The purpose of this study is to learn how many youth in PHACS currently have or previously have had a mental health diagnosis, mental health symptoms, and/or treatment for those conditions. We also hope to understand more clearly if there are factors in a youth's life that may be linked to having a mental health condition and to whether they receive treatment.

Specifically, we aim to answer four main questions:

1

How many youth in AMP and SMARTT have ever had or currently have a mental health diagnosis? We will answer this question using two different interview forms. This will also allow us to see if one form was better at getting this information than the other form.

2

How many youth in AMP and SMARTT are receiving or have ever received treatment for a mental health problem? What are the most common types of treatments?

3

Which factors are more common in AMP youth with mental health problems and in those who receive treatment? We will look at factors such as education; ethnicity; household income; primary caregiver; parent-child relationship; youth substance use; past health history; knowledge of HIV status; stressful life events; and mother's cognitive and mental health status.

4

How many youth are rated by themselves or their caregivers as having a severe behavior problem but do not have a mental health diagnosis, and are not getting treatment?

## WHO WE STUDIED

Youth affected by HIV (either living with HIV or exposed to HIV but not infected) may have additional challenges related to HIV. This is in addition to the stressors that other youth their age deal with. Other studies have looked at this question in different ways. Researchers have found more mental health problems and less treatment for these problems than were expected. Mental health problems can affect quality of life, health, and success in transitioning to adulthood. Understanding how big the problem is, who is most at risk for these problems, and whether they are getting the treatment they need is important as the PHACS youth age into older adolescence and adulthood.

*(Continued on [page 7](#))*

# CONCEPT SHEET OVERVIEW

## WHO WE STUDIED



## WHAT WE DID

We asked all caregivers who had children and youth five years of age or older if the children currently had any kind of emotional, behavioral, or mental health diagnosis. We also asked what type of clinician diagnosed them. We asked when they were diagnosed, and if they received any treatment for the condition, including medication or other types of therapy. We also got information from the caregiver and youth about emotions and behaviors at school, with friends, and at home.

## WHAT WE HAVE LEARNED SO FAR

Because we have not used this data before, we have spent a lot of time “cleaning the data.” This means we have been checking to make sure it’s reliable and usable. We started to take a very rough look at rates of mental health conditions. These rates may change after we have cleaned all the data.

10% Of pre-teens had at least one mental health diagnosis.

30% Of teens had at least one mental health diagnosis.

Please note that these findings are preliminary, which means they are not final.

**ADHD** Attention-deficit/hyperactivity disorder (ADHD) and depression were the most common diagnoses.

**PDD** ↑ Rates of pervasive developmental disorder (PDD) or autism were higher than expected in the SMARTT group.

## WHAT ARE THE NEXT STEPS

Once we have finished cleaning the data, we will look at the background of the group of PHACS youth whose data is included in this study. This includes youth who have HIV, and those who were exposed but not infected. We will also look at the rates of different types of diagnoses and treatments in each of those two groups. Then the statisticians (Yanling Huo and Kathy Tassiopoulos) will make “models” that will look at which of those background factors are most linked with having a mental health diagnosis and receiving treatment. Lastly, of those youth who have severe behavior problems (as indicated by parent- and self-report), we want to understand how many have a mental health diagnosis, and how many are being treated.

*Submitted by: Renee Smith, PhD*

**CAB Members, please send any additional questions or feedback about this concept sheet in progress to CAB Liaison, Megan Reznick ([MeganReznick@westat.com](mailto:MeganReznick@westat.com)).**

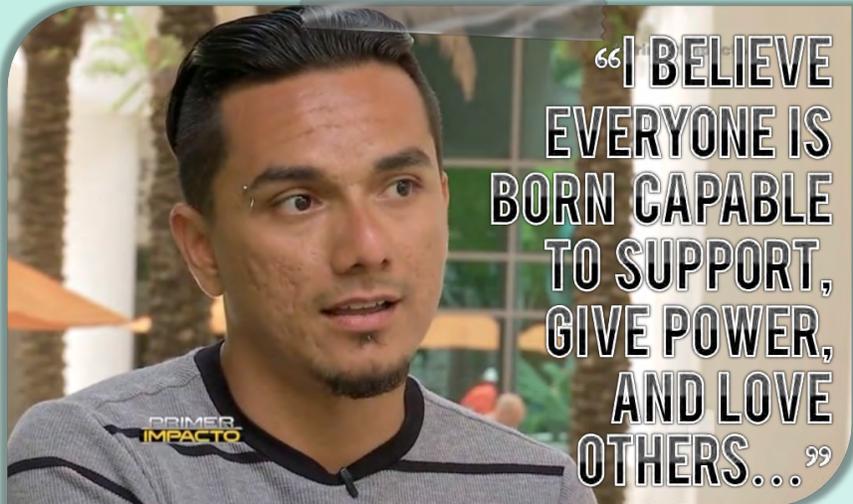
# YOU + ME = TOGETHER



show love for all who have forgotten to look in the mirror and smile at the person looking back! **ADVOCACY** is not about taking on someone else's fight; it is about fighting alongside them. **EMPOWERMENT** is not just about appointing leadership; it is about encouraging and mentoring those who want to lead and rise above but just don't know how to do that. **SELF-LOVE** is not just about being selfish or arrogant; it is about respecting and caring for yourself.

I was going to write about all the great and cool projects I've been a part of these past few months. I was going to describe how I flew to Los Angeles to shoot another campaign for a pharmaceutical company promoting healthy living with HIV. And I was also going to tell you about the awesome time I had making Public Service Announcements (PSAs), talking with local networks about my diagnosis, and posing/taking pictures for posters and billboards. But instead I'm going to write a few words of encouragement to you in hopes that you'll be motivated to at least take the first step to let your voice be heard. It's not always about *how* loud you scream and shout about your issues; it's about *who* hears your questions and concerns that matters most.

**ADVOCACY** is the public support for a cause or idea. **EMPOWERMENT** is to give power or authority to someone or something. **SELF-LOVE** is... well, self-explanatory! The truth is that none of these words mean anything by themselves unless they are used to describe someone or something.



I believe everyone is born capable to support, give power and love others, but that these must all be learned through life experiences. Someone very special in my life once told me that, "Actions show priority" and "Actions speak louder than words." I've lived my life to showcase good deeds. I do this not for the attention or praise or the paycheck (although, I do need to pay rent!), but to advocate for those who have difficulty demanding their rights; to empower those who need a few words of encouragement to fight for themselves; and to

I'm not an advocate because I'm in a [television] commercial; I'm an advocate because I'm resourceful and can provide guidance to you. I'm not empowered because I have authority over my life; I'm empowered because I lead by example. I don't have self-love because of exterior beauty or lifestyle; I have self-love because I love my interior value and, therefore, know self-worth and can share my confidence to help others!

*Submitted by: Yuri, Advocate*

# A WOMAN'S VOICE

Striving and thriving! Each year in honor of National Women and Girls HIV/AIDS awareness day, the San Diego HIV CARE Partnership for Women, Children, Youth and Families presents "A Woman's Voice: A conference that addresses HIV awareness, life skills, prevention, treatment, and advocacy." The San Diego County HIV CARE Partnership is a collaboration of consumers, providers and community members that empowers consumers, shares resources, educates the community, advocates for public policy, and plans services for women, children, youth and families living with and affected by HIV/AIDS.

A Woman's Voice 2015 welcomed women living with HIV/AIDS or at risk for acquiring HIV, healthcare providers, counselors, caregivers, outreach workers, allies of women living with HIV, and girls aged 12-18 affected by HIV.

This year, the program featured a variety of empowering events, such as exhibitors from local organizations, guest speakers, a fashion show, spoken word, raffles, and a Zumba class. In addition to empowering women to strive and thrive, the facilitators helped attendees to describe trends in prevention of HIV and treatment in women with HIV/AIDS, review the steps women can take toward positive living and working with HIV/AIDS, and identify local resources for women.

"A Woman's Voice" aims to empower women, share resources, educate the community, and plan services for women, children, youth and families living with and affected by HIV/AIDS.



*Every year it is a pleasure to attend the annual San Diego Women's HIV Conference: A Woman's Voice. We are positive women as well as positive in every aspect of our lives. This year I loved the fashion show that showed real women with their natural beauty: women who fight every single day, not just with a diagnosis but also as women, mothers, daughters, sisters, and friends. It is astounding all the planning and work that is completed to host this conference. The Zumba class was fabulous. I liked the food, and the presentation on how women living with HIV use photography.*

*Some stories were sad, but they were real, about how women see their lives. But there were also many very positive stories, and we were able to realize that as women, we can succeed and be the source of strength in our families. I am so appreciative to the organizers of this event. Thank you for everything, and I'll see you all again next year.*

**Submitted by: MR**

# CAB KIDS!

Write down the 10 underlined words in the story below. Next, find those words in the word search on page 11. See if you can find them all!



Summer is here, there, and everywhere! Did you know that summer can feel very different in the United States and Puerto Rico depending on where you are? If you look at a map you might think that summers in San Diego, California would be hot hot hot! However, the average high temperature in San Diego for July is only about 76°F. The celebrities in Hollywood sunbathe in slightly hotter summer weather where it reaches an average high of 83°F. It can get a lot hotter on the other side of the country in New York, and although it might be hot and humid, New York summers are filled with street festivals, live performances, and parades. Speaking of hot and humid, the French Market in New Orleans puts together an entire festival each June to celebrate a favorite food of the summer, the Creole Tomato. That's one festive fruit!

Each year, millions of tourists come to Chicago's Navy Pier. In addition to a fun children's muse-

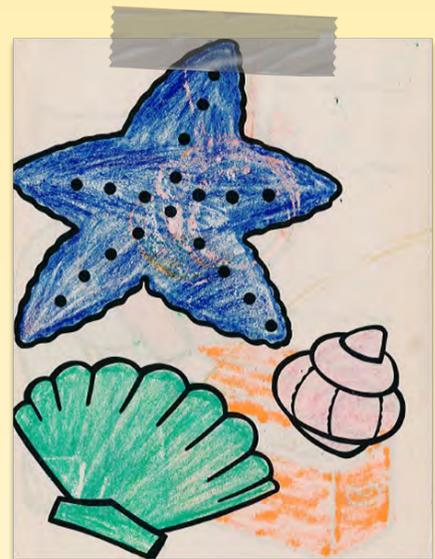
um, the Navy Pier is home to a 15-story Ferris wheel! While you're up on that Ferris wheel, maybe you can spot Denver in the distance! Denver is known as the "Mile-High City" because it is about one mile above sea level. Many people think about relaxing in Colorado on a snow-covered mountain or by the fire during winter, but did you know that Colorado can be just as beautiful and relaxing in the summertime?

One of the country's largest summer patriotic celebrations is the Boston Harborfest. This 4th of July event features both educational and entertaining programs. But 4th of July celebrations don't stop in Bean Town. Philadelphia celebrates the 4th of July like no other city. In addition to its spectacular 4th of July events, the city of Philadelphia plans a whole week of celebrations for America's birthday.

Beaches, boardwalks, and zoos, oh my! Summers in New Jersey have it all. The New Jersey Shore is a popular summer destination for New Jersey locals and tourists alike. Boardwalk hop over to Houston's Kemah Boardwalk for carnival fun. This beautiful coastal boardwalk is only 20 miles south of downtown Houston. If the shore isn't quite your scene, spend a summer day at the famous Birmingham Zoo. The zoo is home to 950 animals of 230 species. Memphis is also home to a famous zoo, but perhaps the most famous animals in Memphis are the Peabody Ducks. Each day at 11 AM, they march from their home on the roof of the Peabody Hotel, down the red carpet in the lobby, and into the hotel fountain.

They march back to the roof each day at 5 PM.

Finally, let's journey to the country's most tropical summer environments: Florida and Puerto Rico. Although Florida can be quite warm in the summer, its hundreds of miles of beaches and world-renowned theme parks attract millions of tourists each year. Not too far from the Sunshine State is the beautiful territory of Puerto Rico. Home to many beautiful beaches as well, this tropical territory is also famous for its year-round festivals; the fun doesn't end in the summer!



So you see, summer is not just a season in the United States, it's also a celebration. So, stay cool, be safe, and have fun this summer!

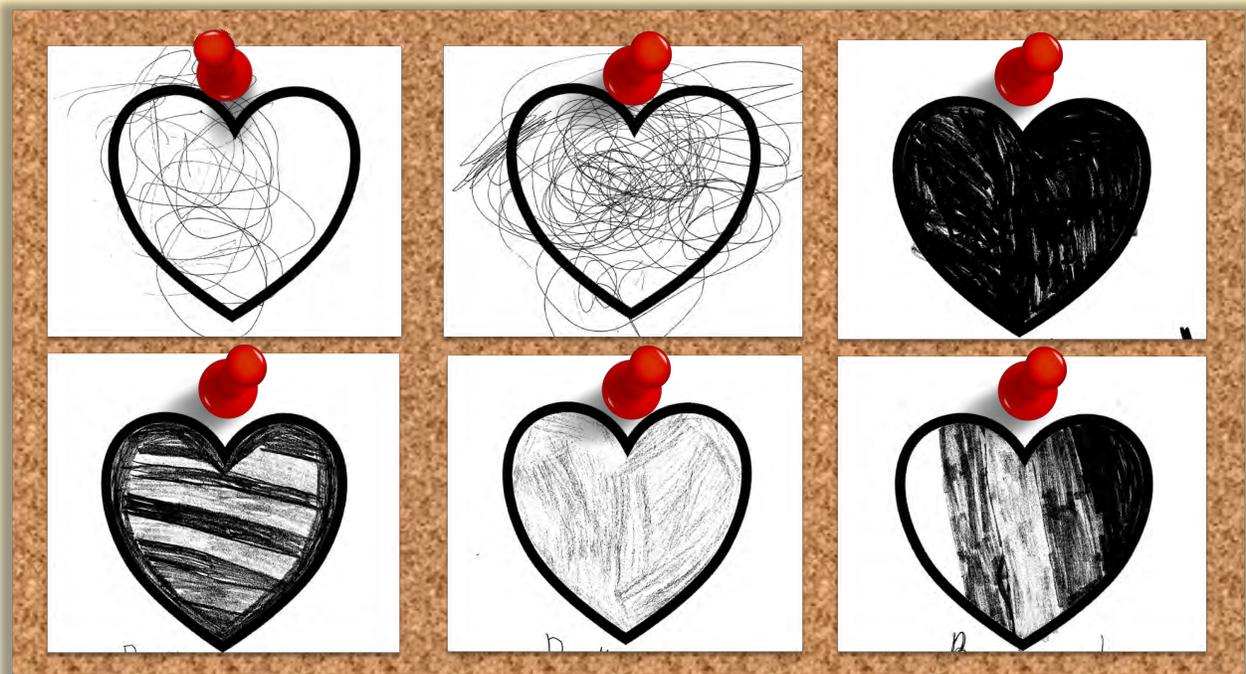
Now go to the Word Search on [page 11](#).

# CAB KIDS!

Use the underlined words from page 10 to find the words in the word search below. Answer key on page 20.



*CAB Kids spread the love!*



# A LETTER ABOUT LOVE



*Love is not an island, and it should never be hurtful or hateful.*

I would like to let all those who read this letter know that the love that they have for themselves and others is the strongest fuel for the fight against HIV and AIDS. Love should start with ourselves. No matter what your age may be, love should be uplifting, not draining. Love should be peaceful; it should not rip you to pieces. Self-love should start with ourselves!

Finally, I would like to welcome our Young Adult CAB (YACAB) and any new CAB members. Thank you for all of your support and the love of the fight to help find our cure.

*Submitted by: Ms. K*

## MY DEFINITIONS

### **EMPOWERMENT**

I am in charge of my body, my life, my being. I am not going to feel hurt, rejected, or become confused because of ignorance!

### **SELF LOVE**

I make choices about taking my medications, go to my scheduled doctor's visits, try to do some form of exercise on a daily basis, pay attention to my eating habits, do what I can to reduce stress, and the list goes on....

### **ADVOCACY**

I am willing and able to help my fellow survivors, who are in need of advice. We will spread the word out there that together we are survivors. We will fight this cause and there will be a cure someday. We have come a long way and are not giving up.

*Submitted by: Delia*

# CAB GLOSSARY



**Antigen:** Any substance that can stimulate the body to produce antibodies (Example: HIV can be an antigen).

**Asymptomatic:** Having no signs or symptoms of disease.

**Concept Sheet:** A brief proposal for a research study or clinical trial in PHACS.

**Open to Accrual:** A protocol is open to accrual when the appropriate approvals are granted and the clinical site(s) begins recruiting participants.

**Participant Identification Number:** The number assigned to a participant in a clinical trial in order to maintain the confidentiality (privacy) of the personal information collected during the trial (data). Information about the participant is identified by a number, rather than by name.

**Scientific Consultant:** A scientist who provides expertise in a specific area that may be used as part of the protocol team and/or to provide advice on a particular subject.

## WORD SCRAMBLE

Unscramble the acronyms! (*Answer key on [page 20](#)*)

1. HPCSA

5. APM

2. CEHC

6. TRTASM

3. BACYA

7. MPA PU

4. ACB

8. IDNHC

# PUBLICATIONS IN THE NEWS

Since the last PHACS CAB Newsletter in December 2015, PHACS has made the following updates:

- 10 manuscripts accepted to scientific journals; and
- 10 abstracts presented at scientific conferences.

## Publications

**“Early viral suppression improves neurocognitive outcomes in HIV-infected children.”** This manuscript is in *AIDS (2015)*. Lead author Claudia Crowell, MD, is an Assistant Professor at the University of Washington and is also a member of the Neurodevelopmental and Neurology Working Group.

**“Executive functioning in children and adolescents with perinatal HIV infection.”** This manuscript is in the *Pediatric Infectious Disease Journal*. Lead author, Sharon Nichols, PhD, is a neuropsychologist at the University of California, San Diego and is also a member of the Neurodevelopmental and Neurology Working Group.

**“Incomplete immune reconstitution despite virological suppression in HIV-1 infected children and adolescents.”** This manuscript is in *AIDS (2015)*. Lead author, Paul Krogstad, MD, is a Professor in the Departments of Pediatrics and Molecular and Pharmacology at the David Geffen School of Medicine at the University of California, Los Angeles.

**“White matter microstructure among youth with perinatally acquired HIV is associated with disease severity.”** This manuscript is in *AIDS (2015)*. Lead author, Kristina Uban, PhD, is a Postdoctoral Research Fellow at the Children’s Hospital Los Angeles.

**“Meconium Tenofovir concentrations and growth and bone outcomes in prenatally Tenofovir exposed HIV-Uninfected children.”** This manuscript is in the *Pediatric Infectious Disease Journal*. Lead author, Sarah Himes, PhD, is a Toxicology Research & Development Scientist at the Quest Diagnostics Nichols Institute.

**“Antiretroviral drugs in meconium: detection for different gestational periods of exposure.”** This manuscript is in the *Journal of Pediatrics*. Lead author, Sarah Himes, PhD, is a Toxicology Research & Development Scientist at the Quest Diagnostics Nichols Institute.

**“Meconium atazanavir concentrations and early language outcomes in HIV-exposed, uninfected infants with prenatal atazanavir exposure.”** This manuscript is in *JAIDS*. Lead author, Sarah Himes, PhD, is a Toxicology Research & Development Scientist at the Quest Diagnostics Nichols Institute.

**“Infant peripheral blood repetitive element hypomethylation associated with antiretroviral therapy in utero.”** This manuscript is in *Epigenetics*. Lead author, Carmen Marsit, PhD, is an Associate Professor at the Geisel School of Medicine at Dartmouth and a member of the Maternal Exposures Working Group.

**“Lower Newborn Bone Mineral Content Associated with Maternal Use of Tenofovir Disoproxil Fumarate During Pregnancy.”** This manuscript is in the *Clinical Infectious Diseases Journal*. Lead author, George Siberry, MD, is a Medical Officer for PHACS from the Maternal and Pediatric Infectious Disease Branch at the Eunice Kennedy Shriver National Institute of Child Health and Human Development. He is also a member of the Scientific Leadership Group and the Executive Committee.

# PUBLICATIONS IN THE NEWS

(CONTINUED)

## Publications

**"Immunity to Measles, Mumps and Rubella in US Children with Perinatal HIV Infection or Perinatal HIV Exposure without Infection."** This manuscript is in the *Clinical Infectious Diseases Journal*. Lead author, George Siberry, MD, is a Medical Officer for PHACS from the Maternal and Pediatric Infectious Disease Branch at the Eunice Kennedy Shriver National Institute of Child Health and Human Development. He is also a member of the Scientific Leadership Group and the Executive Committee.

## Abstracts

These abstracts were presented at the Conference on Retroviruses and Opportunistic Infections (CROI), in Seattle, Washington February 23-26, 2015:

**"Vitamin D status and bone outcomes in perinatally HIV-infected children."**

**"Impact of perinatal HIV exposure and/or infection on executive functions."**

**"Pulmonary complications of HIV-1 in youth: The PHACS AMP Study."**

**"Long-Term effects of in utero ARV exposure on cardiac function in HIV-exposed uninfected youth."**

**"APOL1 gene variants and chronic kidney disease in perinatally HIV-infected youth."**

These abstracts were presented at the 19th International Workshop on HIV Observational Databases in Catania, Sicily March 26-28, 2015:

**"Comparative safety of in utero exposure to atazanavir versus non-atazanavir containing regimens on neurodevelopment in HIV exposed but uninfected infants."**

**"Assessment of adverse outcomes in HIV-exposed uninfected infants and children with antiretroviral exposure during pregnancy using a trigger-based design: Results from the Surveillance Monitoring of ART Toxicities (SMARTT) study."**

**"Varicella seropositivity rates in vaccinated HIV-infected and HIV-exposed, uninfected youth."**

**"Genetic ancestry of participants in the U.S. Pediatric HIV/AIDS Cohort Study (PHACS): Is self-report of race/ethnicity sufficient?"**

This abstract was presented at the IHA Health Literacy Conference in Irvine, CA May 6-8, 2015:

**"Meet the ARV Team': Developing visual storytelling tools for maternal disclosure in the Pediatric HIV/AIDS Cohort Study."**

*Did you know that PHACS has had 52 manuscripts accepted to scientific journals and 82 abstracts presented at scientific conferences? For a full list of PHACS publications, visit the PHACS website: <https://phacsstudy.org/Our-Research/Publications>*

# HECC UPDATE

The HECC has had another productive start to the year! At the Spring 2015 Leadership Retreat in March, our team met to talk about recruitment and retention in SMARTT. Since then, two exciting projects have come out of that meeting. One is a video that talks about successes and challenges around SMARTT engagement as reported to us by over 70 PHACS CAB and clinical staff members. This video will be available as a way to start talks at our sites about recruitment and retention in SMARTT. The other project that came out of the retreat is a series of "live narration" videos. These videos will explain to caregivers in SMARTT why their family's participation in PHACS is so important. The videos will describe how the samples we collect and tests we perform during study visits have led to new knowledge about HIV. The videos will also highlight spe-

cific findings from PHACS.

This spring, the HECC also created a new template for participant summaries. The template uses health literacy principles and brighter colors. The template also uses infographics to explain PHACS findings ([see page 18](#)). In the coming months, a team of HECC and CAB members will be resubmitting a Letter of Intent to the Patient-Centered Outcomes Research Institute (PCORI). This letter will be for a study that would look at different outcomes for patients who receive support from CAB members compared to from health care providers. This was a project that many members from our two groups worked to make earlier this year. The HECC also finalized the HIV Disclosure Comics. The comics will be released before the Fall 2015 Network Meeting. The HECC CAB Subcommittee and the CAB

will be working together to create opportunities for researchers and CAB members to collaborate on concept sheets and publications. The two groups will also be working together to create a CAB poster for the Fall meeting.

The Young Adult CAB (YACAB) has also been busy working on a Photovoice project on the theme of identity: "I am who I am, not because you define me." The photos in this project will be shown at the Fall 2015 Network Meeting. Finally, the HECC successfully submitted two abstracts to conferences (see below). All of this work has been the result of a wonderful team effort, and the willingness of so many of our excellent colleagues to share their time, insight, and expertise to make these projects relevant for PHACS families and staff.

*Submitted by: Claire Berman*

## More HECC

In addition to its projects in the works, the HECC has produced many activities since its formation in December 2012.

Highlights of the HECC's Past Accomplishments:

[PHACS Website](#)

[Disclosure Comics](#)

[Inspiration Hub](#)

[YACAB](#)

[CAB Handbook](#)

[CAB Disclosure Workshop](#)

[Story Map for Young Adults](#)

# HECC PRESENTATIONS

The HECC successfully submitted two abstracts to conferences this year. The first was to the [Institute for Healthcare Advancement \(IHA\) Health Literacy Conference](#) (held May 6 – 8th, 2015). The second is to the [Graphic Medicine Conference](#) (planned for July 16 – 18th, 2015). Writing teams made up of HECC and CAB members have worked together to create these presentations.

*(Continued on [page 17](#))*

# HECC PRESENTATIONS

(CONTINUED)

## THEME: OPERATIONAL SOLUTIONS TO IMPROVE HEALTH LITERACY

At the IHA Health Literacy Conference, Claire Berman presented a poster about the HECC's audience-centered approach to creating the HIV Disclosure Comics. The poster also talked about how we used health literacy principles in the comic books to introduce children to HIV and stigma. Many people from different backgrounds attended the conference. This included health communicators, health care providers, and public health professionals from the U.S. and abroad. The theme was "Operational Solutions to Improve Health Literacy: At the Intersection of Health Literacy and the Affordable Care Act."

One definition of health literacy is "how well people are able to **find** knowledge about health, **understand** that knowledge, and **act** on that knowledge to make decisions about their own health." Many of the conference sessions looked at the role of health literacy in how people can access health care with the new Affordable Care Act. Some of the most interesting sessions talked about how

to engage people from diverse backgrounds in health care. This included how to translate health concepts into different languages and cultures. One session focused on the idea of health equity. The presenters in this session talked about health literacy, race, gender, and income as important factors in how healthy a person is able to be. The HECC's poster was very well-received during the poster session. It was exciting to see so much interest in our visual storytelling project!

## THEME: SPACES OF CARE

The theme of the Graphic Medicine Conference will be "Spaces of Care." Claire Berman will present a "Lightning Talk." A "Lightning Talk" is a short presentation that will explain how the PHACS HIV Disclosure Comics explore different spaces connected to HIV. These spaces include HIV, the body, and the family and home. The spaces also include medical clinics, and antiretroviral treatments. Our lightning talk will explain how our comics



explore these spaces in a non-stigmatizing way. The talk will also focus on how we feature diverse characters and superheroes that will engage children. In turn, when caregivers living with HIV use the comics with their children, they can create a healthy, positive, and empowering space to talk about health and HIV within the family. We hope that the comics will make it possible for a process of maternal disclosure to begin in the families that use them. This conference will feature many innovative comic book artists from around the world. PHACS will be able to make connections that may inspire new work within PHACS!

*Submitted by: Claire Berman*

# PARTICIPANT SUMMARY



## DECREASE IN DRUG AND ALCOHOL USE DURING PREGNANCY FROM 1990 TO 2012 IN PREGNANT WOMEN LIVING WITH HIV

In the early 1990s, studies found that a number of women with HIV used alcohol and drugs during pregnancy. Drug and alcohol use during pregnancy can hurt mothers and their infants. We wanted to see whether drug and alcohol use during pregnancy has changed over time for women with HIV. Understanding this change over time helps us respond to pregnant women's current health needs.

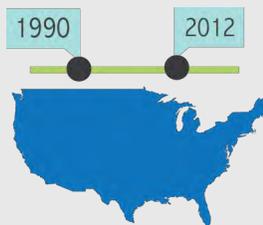
### WHO PARTICIPATED



4,408 Pregnant Women

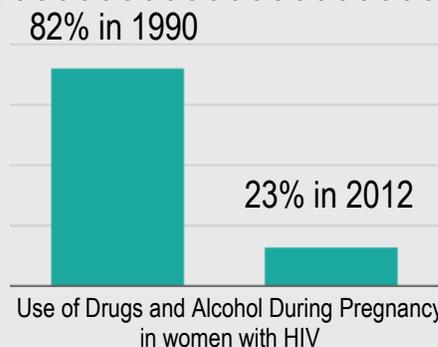
4,408 pregnant women with HIV participated. Some women were from SMARTT and some women were from another similar study called the Women and Infants Transmission Study.

### WHAT WE DID



We looked at how the percentage of pregnant women using drugs and alcohol changed over time. We compared our findings in women with HIV to rates of substance use in pregnant women in the general U.S. population.

### WHAT WE FOUND



Women's use of drugs and alcohol during pregnancy decreased substantially from 82% in 1990 to 23% in 2012. By 2005, the pregnant women in our study were similar to other pregnant women in the U.S. in terms of how many used alcohol, marijuana, cigarettes, heroin, and cocaine.

Women who used drugs or alcohol in their last pregnancy were



**5x**  
more likely



to use them in later pregnancies.

We found that women who had used drugs or alcohol *previously* during pregnancy were five times more likely to use them in *later* pregnancies.

### WHAT WE LEARNED

There is no evidence that pregnant women with HIV use substances at a higher rate than pregnant women without HIV.



Programs to further reduce substance use during pregnancy in women with HIV should focus on women who have used drugs and alcohol in past pregnancies.

C079. Rough, K. et al. (2015). Dramatic decline in substance use by HIV-infected pregnant women in the United States from 1990 to 2012. *AIDS*, 29(1), 117 – 23.  
<http://www.ncbi.nlm.nih.gov/pubmed/25562496>

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

# SELF - LOVE



*"I love being myself, I'm a very honest person, that's what I like about myself. I love my life and my family. I love my strength as a woman. I am proud of myself."*

*"I like that I am friendly and I like to help and listen a lot."*

*"Ok. It's good, the topic of loving one's self and self-esteem."*

*"I'm very dedicated, I like challenges, I have a strong character."*

*"I feel good about myself and keep going forward for myself and our children."*

## RESOURCES



**Advocates for Youth:**

<http://www.advocatesforyouth.org/hiv-home>

**Greater Than AIDS:**

<http://www.greaterthan.org>

**Positive Women's Network: Speak Up!**

<https://pwnusa.wordpress.com/pwn-usa-blog>

**She to She: Strong, Empowered, HIV Positive Women:**

<http://www.shetoshe.org>

**International Association of Providers of AIDS Care: See Us:**

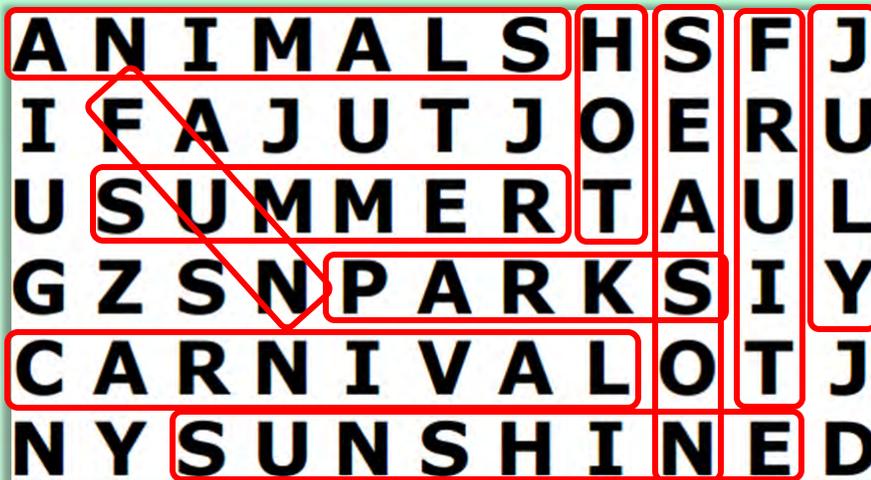
<http://www.iapac.org/seeus>

# UPCOMING EVENTS

<input checked="" type="checkbox"/>	<b>June 27:</b> National HIV Testing Day
<input type="checkbox"/>	<b>September 18:</b> National HIV/AIDS and Aging Awareness Day
<input type="checkbox"/>	<b>September 27:</b> National Gay Men's HIV/AIDS Awareness Day
<input type="checkbox"/>	<b>October 15:</b> National Latino AIDS Awareness Day
<input type="checkbox"/>	<b>October 28:</b> PHACS Fall 2015 CAB Retreat
<input type="checkbox"/>	<b>October 29–30:</b> PHACS Fall 2015 CAB Retreat and Network Meeting
<input type="checkbox"/>	<b>December 1:</b> World AIDS Day

## PUZZLE KEYS

CAB Kids Word Search Key:



Word Scramble Key:

1. PHACS
2. HECC
3. YACAB
4. CAB
5. AMP
6. SMARTT
7. AMP Up
8. NICHD

Please send all questions, comments, and suggestions for the CAB Newsletter to **Megan Reznick** at

[MeganReznick@westat.com](mailto:MeganReznick@westat.com).