



In Focus

A COMMUNITY ADVISORY BOARD NEWSLETTER PUBLISHED BY:

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

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FROM OUR CAB CHAIRS

Hello and Happy New Year, my fellow CAB members! I pray and hope that I have found all of you in a good space and a good place. In this newsletter issue, we will be dealing with mental health—and good mental health must start with ourselves. Please remember that there is nothing and nobody who can **ever steal our true joy if we don't give them the power.** Yes, there are things in our lives that are tough and hard; sometimes we feel we will never be able to get through them, but there is always hope. I am here to remind you that there are things in our past that we can't change and that may be very difficult to overcome, but fear is what it is here. As powerful as this four letter word is (l-o-v-e), the other four letter word (f-e-a-r) is far more powerful. Remember that good mental health starts with self-love. Please remember that I am here if you ever need me. I know for a fact we have wonderful staff liaisons, coordinators, nurses, doctors, and most of all, fellow CAB members who are there if we need them.



**Megan, Lesley, Claire,
and Kim at the Fall
2015 CAB Retreat**

Kim, PHACS CAB Chair



Many people who do not live with HIV are quick to tell **us to be positive. That's one of the problems; we are POSITIVE** (pun intended)! It really does take a toll on **our lives, and it's hard not to let it take a toll on our** mental health as well because of dealing with things such as stigma, feeling like an outcast, and even possible danger in our lives. I can only give you my perception because of my experiences. For many years, I have dealt with bouts of depression and anxiety. I could tell you that things will get better on their own and all that, but honestly it takes work—a lot of work.

(Continued on page 2)

FROM OUR CAB CHAIRS

(CONTINUED)

"FIND WHAT WILL
GIVE YOU PEACE
OF MIND AND
SANITY TO
BECOME
A BETTER YOU."

I put myself in therapy in the sixth grade. My counselor at school was my best friend. I was fortunate enough to figure out early on in life that when something is not right, you have to be able to confide in someone that will help you with your situation. Notice that I went to my **counselor** and not my peers.

I recommend to anyone with bouts of depression, anxiety, mood disorders, or anything else that causes your mind to wander and makes you feel like everything is not ok, to please seek professional help. A therapist can help you to talk about the things that you are feeling, to get the tools you need to cope, and eventually to be able to empower and help someone else. In many communities, especially communities of color, there is great stigma around anyone even saying the words, "therapist," or "shrink," but this is a new age and knowledge is power. Get yourself in to see a mental health professional if it feels right for you; I DO! Finally, a few other ways to de-stress yourself that I have found helpful are keeping a journal, coloring and painting, listening to music, exercising, and doing anything



fun!!! Find what will give you peace of mind and sanity to become a better you. ☺

Lesley, PHACS CAB Vice Chair

2015 CAB EXPERIENCE

I have had great experiences in 2015 working with PHACS. I had the opportunity to be part of the Health Education and Communication Committee (HECC) and share ideas with a group of amazing people. I was able to share what I have learned from PHACS with my CAB, and it was a great privilege to give back what others have done for me as a participant in PHACS research. I hope and will

try to make 2016 be as great as last year with continued education, support, and empowerment for all of our families.

I'm currently working with our youth CAB to create a group of young adults that can build a great leadership and support system. Our goal is to help educate youth on how important it is to be involved with their

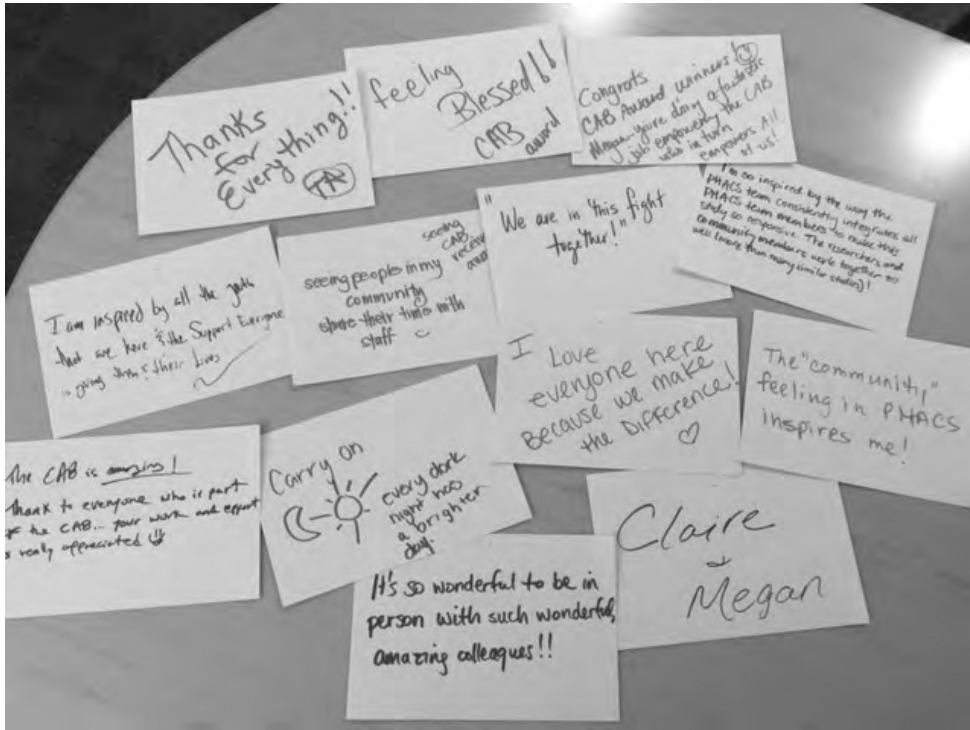
health care decisions and remind them that their voices matter.

I will continue to do my part in PHACS as a representative and a member, hoping that anyone I meet in the future will also be able to be empowered with making better health choices and advocating for others as I do.

Submitted by: Exzavia



INSPIRATION HUB



This year at the Fall 2015 Network Meeting, PHACS members were invited to share what inspired them from the Network Meeting of medical professionals, CAB members, caregivers, participants, research support, and technical support. Responses were posted on a poster board display.

For more PHACS inspiration, please visit the Inspiration Hub on the PHACS website:

<https://phacsstudy.org/About-Us/Inspiration-Hub>

Submitted by: Claire Berman and Megan Reznick



PHACS MEMBER PROFILES



Ellen Chadwick, MD

Hello! I am so pleased to have recently joined the PHACS Family as Chair of the SMARTT protocol. To give you a little of my background, I grew up in a family of four outside of Washington, DC. I moved to Chicago, IL after medical school to do my training in Pediatrics. My life in the field of Pediatric HIV/AIDS began while I was an Infectious Diseases fellow at Children's Memorial Hospital in Chicago, IL. At that time, no one even knew a virus caused this new disease which

seemed to occur only in gay men. It was soon known that women, babies and children could also be affected. One of my patients was the first child in the state of Illinois to go to school with HIV. This was during the same time that the national news was reporting that Ryan White was being excluded from school in Kokomo, IN because he had AIDS. We made a huge effort to educate the school district and community about how safe it was for children with HIV to be in school. It helped that I was eight months pregnant and could show everyone that I was not afraid to hug and care for my patients. Soon, the concerns died down and school attendance is no longer an issue for our patients. **Over time, my partners at Children's Memorial and I got funding for research that would make new HIV drugs available to children.** In the process, we built our Pediatric HIV program which provides complete care to babies, children and adolescents exposed to and living with HIV. We have some of the most dedicated nurses, social workers, therapists, project researchers, and community members on the planet, and could not function without each and every one.

Starting in 2005, I began to travel to Kenya, South Africa and Ethiopia. My travels were part of the International Center for AIDS **Treatment and Prevention's** program. The goal of the program was to train health care providers on prevention of HIV transmission and care of babies living with HIV. Some of these trainings were at the largest hospital in the world. In that hospital, 20 to 30 babies were born to HIV+ mothers every day. At my first visit, HIV drugs were not available in many parts of Africa, but fortunately, these drugs are now in much better supply.

When I'm not working, I like to spend time with my husband and two grown children. I also love to read books, exercise and cook.

While I have participated in PHACS as a researcher for many years, I just joined the leadership group at the end of 2015. I have enjoyed getting to know all the wonderful people who make up the PHACS **community and hope that I'll have** an opportunity to meet more of you in the coming months!

Stephanie

I've been positive since 1999. Since my diagnosis, I've had my ups and downs—many more ups than downs. At my site, I simply started by having my children involved in studies, speaking in and around the community, sharing my story, trying to spread HIV awareness, and fighting to end the stigma. More recently I was invited to learn more about PHACS, and

to get more involved with the study and the PHACS CAB, as well as to get involved in our **site's Family Advisory Board (FAB)**. Lately, I'm really big into research for HIV. I want to know more. When I learn some information, I want to go on and learn even more. Outside my world of HIV, I love roller skating, playing roller derby, rink hockey, and teaching kids or adults how to skate. I love the feeling of roller skates on my feet. I love hugging my daughters.

Spending special moments with my husband and girls is what makes me happy. I enjoy watching TV shows, movies, and reading books. I'm that person who is down **for an adventure, but I'm also** down to hang out at home and do nothing. I simply love living and being nice to people I don't know (and of course the ones I do know). Oh, and I love cats! Next to kid cuddles, cat cuddles are the best.



ON LOCATION: SITE 12

Children's Diagnostic and Treatment Center (Site 12) had the amazing opportunity to hold a Research Participant Appreciation event in July 2015 for 92 guests. The event was held to thank our many participants for their many contributions to the AMP, AMP Up and SMARTT studies. It was also a good venue from which to touch base with the participants, to update contact information, and remind them of upcoming study visits.

The event was a fun-filled evening for both the parents and the children. The event was catered by a local barbeque restaurant and plenty of **Thank You** cake was enjoyed by all. To highlight how participants are making an impact in research, Dr. Puga gave a presentation on the latest PHACS summaries and gave them the opportunity to ask questions about research.



The children were in another area with a Super Hero themed photo booth, face painting, games and hand print paintings.

Our CAB liaison, Exzavia, presented a CAB poster and explained the role of the CAB in research.

The families reported that they really enjoyed the event. Thanks for helping us put this event on for our participants!

Submitted by: Dr. Puga, Dr. Garvie, Sandra Navarro, Dia Cooley, Amy Inman, and Exzavia

UPCOMING EVENTS

9

Monday

1

February 7: National Black HIV/AIDS Awareness Day

March 10: National Women and Girls HIV/AIDS Awareness Day

March 15-16: PHACS Spring 2016 Leadership Retreat

March 20: National Native HIV/AIDS Awareness Day

April 10: National Youth HIV/AIDS Awareness Day

May 18: HIV Vaccine Awareness Day

May 19: National Asian and Pacific Islander HIV/AIDS Awareness Day

June 8: Caribbean American HIV/AIDS Awareness Day

June 27: National HIV Testing Day

ON LOCATION: SITE 20



Photo by Chris Granger, NOLA.com | The Times-Picayune

For over 10 years, the Department of Pediatrics at the Tulane University School of Medicine has thrown a lively holiday party at the clinic.

"We do this to bring joy and happiness to our patients and their families," said Study Coordinator, Karen Craig. **"It's a great way to celebrate Christmas, and it's also a great way to interact with them for a good time versus coming in for a sick visit or something like that."**

This year's party was held on December 16, 2015. Highlights of the event included crafts, food spreads, presents for the children, and even live music

played by staff members including PHACS's own Principal Investigator, Dr. Russ Van Dyke!

Of course, the most anticipated event of the day was the arrival of Santa, escorted by the Louisiana State Police Troop B.

"Santa coming in a squad car is just too good," said Dr. Van Dyke. **"The kids go nuts. And I think the troopers have been unbelievable. They've been great. They've been really supportive."**

In addition to serving as **Santa's unofficial sleigh,** the Louisiana State Police Troop B sponsored the annual holiday party and this year, the clinic honored the troopers with an official recognition award thanking them for their support and generosity from 2005–2015.

CAB members attended and also helped run the holiday party.

"Right now they can just have fun, just enjoy," said Tatania, CAB member. **"That's what this time of year is for, not to be worried and stressed out about a lot of things."**

The party is much anticipated by patients and their families, **but it's also a special time for staff to spend quality time with their patients in a more relaxed environment.**

"It's very special," said Karen. **"We get to see them play. We get to see their smiles when they pick a present. It's totally awesome. It makes me think of when I was a little girl and how much I liked seeing Santa and Christmas. It's just everything that a holiday should be."**

*Submitted by: Karen Craig
Medea Jones Gabriel, and
Tatania*



Photos by Chris Granger, NOLA.com | The Times-Picayune



ON LOCATION: SITE 19



On December 1, 2015, we held the Annual World AIDS Awareness Day at Texas Children's Hospital (TCH). It is the time when we offer awareness, education, and support for all of our staff and families walking the TCH Auxiliary Bridge. Also, it is a time to remember people who have lost the battle to AIDS as well as those continuing to struggle with HIV. Every year, we give away red ribbons, offer brochures on HIV/AIDS prevention, and have handouts listing the local sites that provide HIV testing and treatment. The event is always welcomed by the TCH and the Baylor College of Medicine staff and all of our families walking the bridge.

Submitted by: Theresa Aldape

ASHLEY'S RECIPE

Ingredients:

For the meal:

- Steak
- Spinach
- Frozen broccoli cuts with cheese sauce package

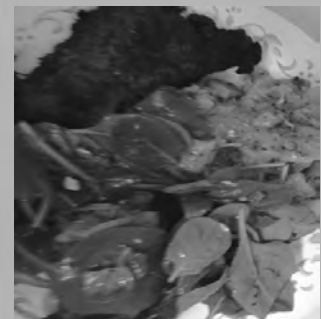
For the spinach dressing:

- 3 sour oranges
- Sugar (to taste)
- 1 garlic clove (chopped)

Instructions:

1. Cook frozen broccoli cuts with cheese sauce according to package instructions
2. Pan fry steak in vegetable oil
3. Combine spinach dressing ingredients
4. Lightly toss spinach with dressing

Ashley's Recipe



Ingredients:

For the meal:
Steak
Spinach
Frozen broccoli cuts with cheese sauce package

For the spinach dressing:
3 sour oranges
Sugar (to taste)
1 garlic clove (chopped)

Instructions:

Cook frozen broccoli cuts with cheese sauce according to package instructions.
Pan fry steak in vegetable oil.
Combine spinach dressing ingredients.
Lightly toss spinach with dressing.

FALL 2015 CAB RETREAT AND NETWORK MEETING

Lagniappe Awards



The PHACS leadership created the "Lagniappe Awards" approximately four years ago in order to "give a little extra" back to those individuals that give so much to the PHACS Network. Lagniappe

simply means a "small gift". This "small gift" is given as a memento of appreciation to PHACS members, who have been nominated by their peers for their contributions within the PHACS

Network. This year, certificates of appreciation and decorative masks were presented as awards.

At the Fall 2015 Network Meeting, the PHACS leadership unanimously decided to present one of the awards to the CAB. Dr. Russ Van Dyke noted that the CAB members play a vital role in the research of PHACS. Without their feedback and support, PHACS would not be what it is today. He also highlighted **PHACS's appreciation for the CAB's increased involvement and initiative with many PHACS projects.**

Dr. Bill Shearer also received the Lagniappe award this past year for his many years of significant contributions to the PHACS project. Dr. Shearer is Co-Chair of the Cardiopulmonary Working Group and Leader of the PHACS Publications Committee.

Submitted by: Danish Siddiqui and Megan Reznick

The PHACS Network Meetings provide CAB members with an opportunity to voice community concerns directly to PHACS investigators and site staff members. CAB representatives will continue to attend future meetings to help optimize PHACS for the children and families involved in this exciting study.

For the past five years, CAB representatives have participated in the Fall Network Meetings. The CAB has also held annual in-person retreats for the past three

years. The PHACS CAB Retreat and Fall Network Meeting took place on October 28-30, 2015 in Bethesda, MD.

This past year, the CAB presented a poster during the poster session at the Network Meeting. The CAB chose to use this opportunity to highlight the following:

- The purpose and mission of the CAB;
- CAB Leadership;
- CAB accomplishments and collaborations;
- Site CABs and resource sharing; and
- Future directions.

(Continued on [page 9](#))

CAB Poster

FALL 2015 CAB RETREAT AND NETWORK MEETING

(CONTINUED)

CAB Poster



In addition to highlighting the CAB's overall purpose and structure, the poster detailed the CAB's collaboration with other PHACS teams. CAB members actively participate in PHACS committees and give feedback on PHACS protocol teams.

Seven CAB members are active members of the Health Education and Communication Committee (HECC). Four CAB members have served as community representatives on PHACS substudy teams. The titles of these substudies are: "Newborn

Evaluation for Effects of Maternal Tenofovir Use During Pregnancy Substudy," "Oral Health Among Participants in PHACS PH200 – Adolescent Master Protocol (AMP)," and "Pulmonary Complications in PHACS AMP Substudy." The poster also sought to focus on CAB-generated productions and resources such as:

- PHACS CAB Disclosure Fact Sheets;
- PHACS CAB Role and Responsibilities List;
- Community Concerns and Priorities Lists;
- PHACS CAB Vice Chair and Chair Roles and Responsibilities List; and
- PHACS CAB Newsletters.

The CAB poster may be found in the CAB Retreat and Network Meeting Documents section of the PHACS website:

<https://my.phacsstudy.org/cab/CAB-Resources>

Submitted by: Megan Reznick

Fall 2015 CAB Retreat Resources:

<https://my.phacsstudy.org/cab/CAB-Resources>
Resources may be found in the "2015" folder.

Fall 2015 Network Meeting Resources:

<https://my.phacsstudy.org/document/192/2015-10>
Resources may be found in the "2015-10" folder.

See [page 15](#) for information about signing up for the PHACS website.

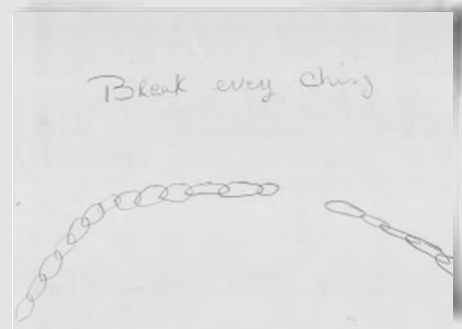
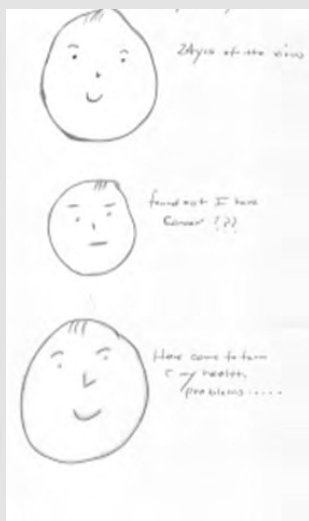
Resources

FALL 2015 CAB RETREAT AND NETWORK MEETING

(CONTINUED)



At the Fall 2015 CAB Retreat, Claire Berman led the CAB through a storytelling exercise. In this exercise, CAB members were encouraged to tell a story about a time when they had to make an important decision related to their health. The group took turns telling their stories first by writing them down, then by drawing the story, and finally, by telling the story aloud. Below are CAB members' stories expressed through drawings.



(CONTINUED)



WHAT IS CAB LEADERSHIP?



I believe it is very important to have some form of leadership because it helps keep the CAB to stay focused and it helps the new CAB members learn how to find and use their voices. I think one of my main purposes as a CAB leader is to keep the CAB running like the well-oiled mechanism that it has become. The CAB works to help show the world that until this virus is wiped out, we can never stop researching, advocating, or just fighting. Most of all, never let any CAB members feel that they are not the shining stars that we, as well as their sites, see them to be. I have learned that this group is like a big tree, and for it to grow, we all need to do our part for today and for future seedlings (CAB members) to come.

Submitted by: Kim

I believe that it is important to have CAB leaders, such as myself, in order for newer and other CAB members to see someone that has been or is going through what they have been through. CAB leaders like that are historically more relatable and will potentially bring out the leadership qualities in someone else. CAB leaders help groom others to help them one day possibly take the reins in this fight. No one leader is the same. Each leader will have their strengths and weaknesses, and I have learned this by seeing firsthand how to best handle certain things. I see my purpose as a CAB Leader as having the responsibility to advocate for my peers, families, and future generations in order to be sure that our voices are heard. I appreciate this opportunity to serve. Thank you for choosing me.

Submitted by: Lesley



The CAB Chairs we have as leadership for our PHACS CAB (CAB Chair and CAB Vice Chair) are people who are very much involved in the community. Their children, family, and friends are infected or affected and involved in clinical trials. They know about PHACS inside and out and can relate to our CAB members. They know where CAB members are coming from, how they feel, and what they are going through; they can relate. The reason why the PHACS CAB has been so successful is because the CAB Chairs knows what we need. Besides the fact that they are part of the CAB and participate in CAB activities like going to retreats, the CAB Chairs have formed a bond with the CAB members, and we consider ourselves as one family.

I have learned that we are all there for the same purpose. We are in the CAB not only to educate ourselves and other CAB members, but also to be very involved for our children and their future. We have worked very hard over the years, and we should continue to make the CAB a success. The purpose of CAB Leadership is to take our knowledge and share it with the community. We seek to educate others about research, to get involved in research and to let them know that there is hope. With knowledge from the PHACS CAB, we can help improve our site CABs.

I was the Vice Chair and then Chair of the CAB over the span of four years. Being involved with the PHACS CAB has educated me a lot about HIV medications, the different research studies going on, and other important health information. Most of all (believe it or not), I have learned how to talk in front of people. I gained a lot of confidence in myself because of being part of the CAB Leadership. If you have not thought of this, being a CAB Chair or being a CAB member is a great addition to your resume.

Submitted by: Delia



SMARTT VERSION 5

The newest version of the Surveillance Monitoring for HIV/AIDS Treatment Toxicities (SMARTT) study is now undergoing its final touches. Here are some of the exciting changes in the works for SMARTT participants and caregivers in Version 5:



New SMARTT Young Adult Cohort: Starting soon, when participants turn 18 years old they will be asked to join a new Young Adult Cohort of SMARTT. We recognize that it is important to continue to follow children and youth in SMARTT as they become young adults. We also know that their changing lives might make it harder for them to come to the clinic for visits. In the Young Adult Cohort, participants will have only one clinic visit at 18 years old. After that visit, they will have only one set of surveys to do every year. The surveys are done online and take about a half an hour. Participants can do them any place they have access to the internet.

We have used online surveys in AMP Up, another PHACS study for young adults. Participants in that study said they enjoy doing the surveys on their own on a computer. Most participants agree that the surveys are interesting and easy to use. As a SMARTT participant approaches 18 years, clinic staff will discuss with his/her caregiver whether the Young Adult Cohort is a good fit for their child.



New Study Visit Schedule: Clinic visits for youth ages 13, 15, and 17 had been put on hold due to funding cuts, but now they are starting up again. The visits will be shorter than before. Also, with CAB input we learned that maternal disclosure of HIV infection and HIV stigma are two areas that we need to know more about. Caregivers will now be asked more questions about these topics at these study visits.



Fewer Tests at Study Visits: The Point-of-Care ("POC") lactate measure will no longer be done at SMARTT visits. Looking at lactate levels may help us figure out if the medications used to prevent HIV transmission from mother to baby during pregnancy cause cell damage. The POC lactate test was done with blood taken with a finger stick. The study team agreed that measuring lactate levels at every visit was no longer necessary. Lactate will still be measured for participants with some diagnoses. But stopping regular lactate testing will reduce the number of blood draws that participants will have at a visit.



Updated Informed Consents: Lastly, the informed consent and repository consent forms were updated. We made the language clearer than before. We also combined the form that asks for permission to be in the study and the form that asks to store blood for future tests. The changes will make the process of consenting to this next protocol version easier for caregivers and participants.

We look forward to having you continue the study with SMARTT Version 5! Please feel free to reach out to your study coordinator with any questions you might have.

Submitted by: Julie Alperen and the Data and Operations Center (DOC)

PUBLICATIONS IN THE NEWS

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

9

manuscripts accepted to scientific journals; and

5

abstracts presented at scientific conferences.

Publications

"Default mode connectivity in youth with perinatally-acquired HIV." This manuscript is in *Medicine (2015)*. Lead author, Megan Herting, PhD, is a Postdoctoral Research Fellow in the Department of Pediatrics at Children's Hospital Los Angeles/ University of Southern California.

"Prevalence and persistence of varicella antibodies in previously immunized children and youth with perinatal HIV-1-infection." This manuscript is in the *Clinical Infectious Disease Journal*. Lead author, Murli Purswani, MBChB, is the Principal Investigator at Bronx-Lebanon Hospital Center. He is also a member of the Executive Committee.

"Acylcarnitine profiles in HIV-exposed, uninfected neonates in the United States." This manuscript is in *AIDS Research and Human Retroviruses*. Lead author, Brian Kirmse, MD is a Pediatric Geneticist in Washington, DC.

"Prevalence of and progression to abnormal non-invasive markers of liver disease (APRI and FIB-4) among US HIV-infected youth." This manuscript is in *AIDS (2015)*. Lead author, Bill Kapogiannis, MD is a Medical Officer in the Maternal and Pediatric Infectious Disease Branch at the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD).

"CD4+ and viral load outcomes of antiretroviral therapy switch strategies after virologic failure of combination antiretroviral therapy in perinatally HIV-infected youth in the United States." This manuscript is in *AIDS (2015)*. Lead author, Lee Fairlie, MBChB, is the Director of Child and Adolescent Health at the University of the Witwatersrand in Johannesburg, South Africa.

"Declining incidence of systolic left ventricular dysfunction in HIV-infected individuals treated with highly active antiretroviral therapy." This manuscript is in the *American Journal of Cardiology*. Lead author, Stacy D. Fisher, MD is an Assistant Professor of Medicine at the University of Maryland School of Medicine.

"Antiretroviral exposure during pregnancy and adverse outcomes in HIV-exposed uninfected infants and children using a trigger-based design: The SMARTT Study." This manuscript is in *AIDS (2016)*. Lead author, Paige Williams, PhD, is a Senior Lecturer on Biostatistics at the Harvard T. H. Chan School of Public Health. She is also a member of the Executive Committee and Co-Chair of the Cardiopulmonary Working Group.

"Learning and memory in children and adolescents with perinatal HIV infection and perinatal HIV exposure." 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.

"Phenotypic co-receptor tropism in perinatally HIV-infected youth failing combination antiretroviral therapy." This manuscript is in the *Pediatric Infectious Disease Journal*. Lead author, Allison Agwu, MD, is an Assistant Professor of Infectious Diseases at Johns Hopkins University School of Medicine.

(Continued on [page 15](#))

PUBLICATIONS IN THE NEWS

Abstracts

These abstracts were presented at the International Association of Providers of AIDS Care in Miami, Florida June 2015:

"Executive and memory functioning and medication adherence among youth with perinatally acquired HIV."

"The role of pharmacy refill measures in assessing adherence and predicting disease measures in youth with perinatally acquired HIV (PHIV)."

This abstract was presented at the AIDS Impact Conference in Amsterdam, Netherlands July 28-31, 2015:

"Contributions of disease severity, psychosocial factors, and cognition to behavioral functioning in youth perinatally exposed to HIV."

This abstract was presented at the 30th International Papillomavirus Conference & Clinical and Public Health Workshops (IPV 2015) in Lisbon, Portugal September 17-21, 2015:

"Oral HPV in Perinatally HIV Infected Youth: Data from the Pediatric HIV/AIDS Cohort Study (PHACS)."

This abstract was presented at the 6th International Conference on Stigma in Washington, DC November 20, 2015:

"Innovative Approaches to Reducing Stigma Through Research Community Advisory Boards."

PHACS WEBSITE REMINDER

In this newsletter, there are several helpful links to resources posted on the PHACS website. Although many of the pages on the PHACS website are public, there are even more resources behind the login. All CAB members are encouraged to register as a CAB member and create a personal account on the PHACS website. Registered CAB members have access to newsletters, activities and involvement, conference call minutes, resources, and the CAB glossary. Follow the steps below to start your website registration:

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

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

PARTICIPANT SUMMARY



CHILDREN BORN WITH HIV AND THE MEASLES, MUMPS, AND RUBELLA (MMR) VACCINE

Most children and teens with HIV have strong immune systems and respond well to vaccines due to antiretroviral therapy (ART). But many of these older children and teens got vaccines when they were very young, before they started ART. This means they may no longer be protected by those vaccines. This study used blood testing to see if children in AMP still had protection from measles, mumps, and rubella (MMR).

WHO PARTICIPATED

649 youth in AMP
Ages 7 - 19



There were two groups: 428 youth born with HIV, and 221 youth without HIV who were born to mothers with HIV. All youth had given blood samples at AMP study visits between 2007 and 2009, which were stored for later use.

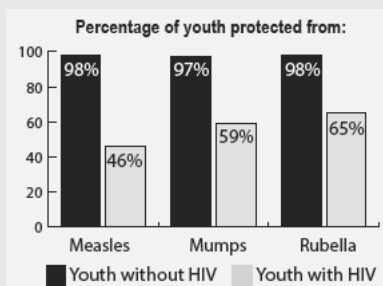
WHAT WE DID



The youth were from 14 clinical sites across the country

We used the most recent blood sample from each participant. The Centers for Disease Control and Prevention (CDC) tested the stored blood samples for antibodies to measles, mumps, and rubella. We compared the youth with HIV to the youth without HIV. We then analyzed the information to find out which factors were important for how youth made antibodies after vaccination.

WHAT WE FOUND



Most (98%) of youth with HIV had had at least one MMR vaccine in the past. Most (93%) were also on ART and in very good health, with an average CD4 count of 754 and low viral loads.

However, youth with HIV were much less likely than youth without HIV to be protected from measles, mumps, and rubella. This was true even though they had received the vaccine.

WHAT WE LEARNED



Children with HIV who received the MMR vaccine before starting ART may not be protected against measles, mumps, and rubella later in childhood. It is recommended that these children get the vaccine again after starting ART. This study helped change the national policy at the CDC about recommendations for childhood immunizations.

C052. Siberry, G., et al. Immunity to Measles, Mumps, and Rubella in US Children with Perinatal HIV Infection or Perinatal HIV Exposure Without Infection. Clin Infect Dis 2015; 61(6): 988-995. www.ncbi.nlm.nih.gov/pubmed/26060291

For more information, contact:

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HECC UPDATE

The Health Education and Communication Committee (HECC) had a very productive year in 2015! None of our work would be possible without the involvement of many CAB and Young Adult CAB (YACAB) members, as well as collaboration with the CAB as a whole. Here are a few of our key accomplishments from this past year:



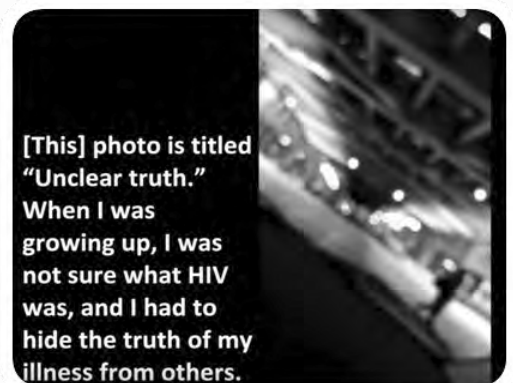
With the help of the CAB, we made some key character revisions to the HIV Disclosure Comics. After many months of hard work, we released the final comics in early Fall 2015 and presented them in a poster presentation at the PHACS Fall 2015 Network Meeting. We also had a chance to present the comics at three other conferences last year: the IHA Health Literacy Conference, the International Conference on Comics and Medicine, and the 6th International Conference on Stigma. Currently, we are working on creating an evaluation of the comics so we **can find out how well it's working** for caregivers who use it with their children.



The HECC and CAB worked together with Booster Shot Media to create PHACS' first whiteboard video, "The Blood Droplet's Humble Beginnings to Global Fame." This short video can be shown to caregivers during study visits to explain how PHACS uses the blood samples donated to the study by their children, and to report some of the main findings of the study.

The Young Adult CAB (YACAB) and CAB worked on their first joint project this year – a Photovoice video featuring photos taken by CAB members **on the theme of "Identity: I am who I am, not because you define me," along with captions** written by the photographers. The compilation of photos celebrates the diversity of experiences and identities by showing how individuals themselves define them. The video is available on YouTube and the PHACS website and will hopefully be shown to PHACS participants at sites.

This is only a sampling of what the HECC and CAB have worked on together this year – we have



also created a new template for participant summaries together, and have begun many more projects together (including expanding the comics to reach a wider audience). We also presented as a Working Group to all attendees at the PHACS Fall Meeting this year, giving us the chance to share our accomplishments with a much broader audience, including clinicians, researchers, and site staff. The HECC and CAB thank all of you for the effort you put into PHACS every day!

Submitted by: Claire Berman

CAB GLOSSARY



Class (of medicine): A group of medicines that work in the similar way to treat a disease or health problem.

Clinical Endpoint: In a research trial, a clinical endpoint refers to a disease, symptom, or sign that is one of the indicators of whether or not a treatment is safe and effective.

Data Analysis: Studying and interpreting a set of information. Studies like PHACS use data analysis to determine the outcomes of the study.

Executive Committee: The governing body of PHACS, with overall responsibility for the scientific, budgetary, and administrative aspects of the project.

Post-Exposure Prophylaxis: Anti-HIV medicine given to help prevent HIV infection after a high-risk exposure to HIV (such as injury from a contaminated needle, or sexual assault).

Scientific Consultant: A scientist who provides expertise on particular scientific questions in order to help meet the goals of PHACS.

WORD SEARCH

Instructions: Use the CAB glossary terms above to find the words in the word search. Please note that multi-word glossary terms and together as one word in the word search.

(Answer key on [page 21](#)).

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

CAB KIDS

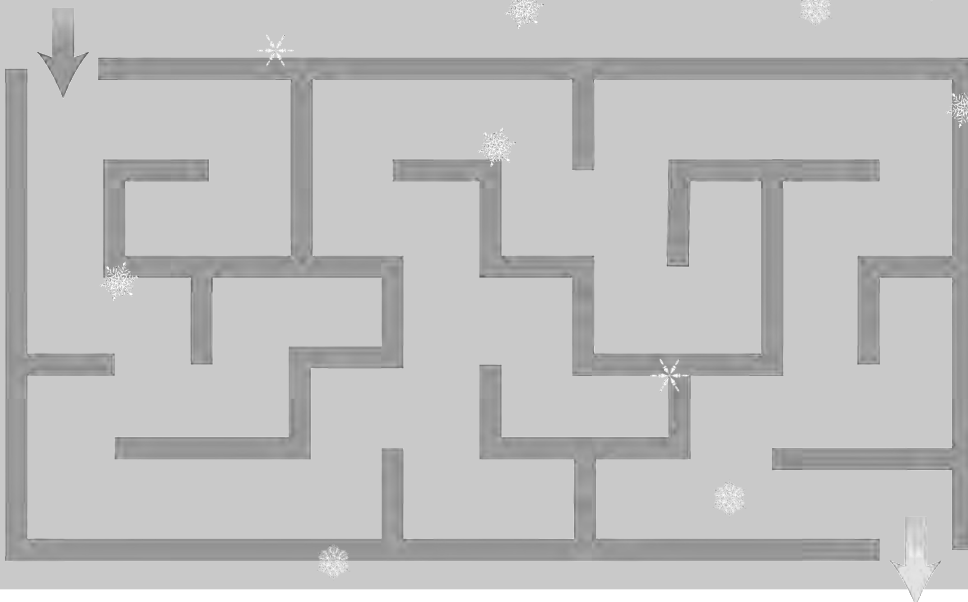
Did you “Snow”?

Let it snow! Winter is here, which for many parts of the United States, means cold temperatures, high winds, and of course—snow! Here are 10 interesting facts about snow:

1. Snow is formed when water vapor in the air freezes to form tiny ice crystals. This happens when the temperature is very cold in storm clouds.
2. Snowflakes are formed from tiny ice crystals. There can be as many as 200 ice crystals in a single snowflake!
3. Snow that is light and fluffy is often called “powder.”
4. Snowstorms with high winds are often called, “blizzards.” Blizzards are also associated with intense snowfall.
5. 5,834 people participated in the largest snowball fight ever recorded. This fun fight was held in Seattle, Washington on January 12, 2013.
6. Snowflakes form in many different shapes.
7. The largest snow maze ever recorded was 18,255.59 square feet. The maze was created by the Fort William Historical Park in in Thunder Bay, Canada.
8. Thundersnow happens when there is both thunder and lighting during a snowstorm.
9. In some areas, snowfall makes roads too dangerous for school buses. On these days, some schools may cancel **classes for a “snow day!”**

Maze

Instructions: Help the reindeer find his way through the snow maze. Start at the **red** arrow and find your way to the **green** arrow.

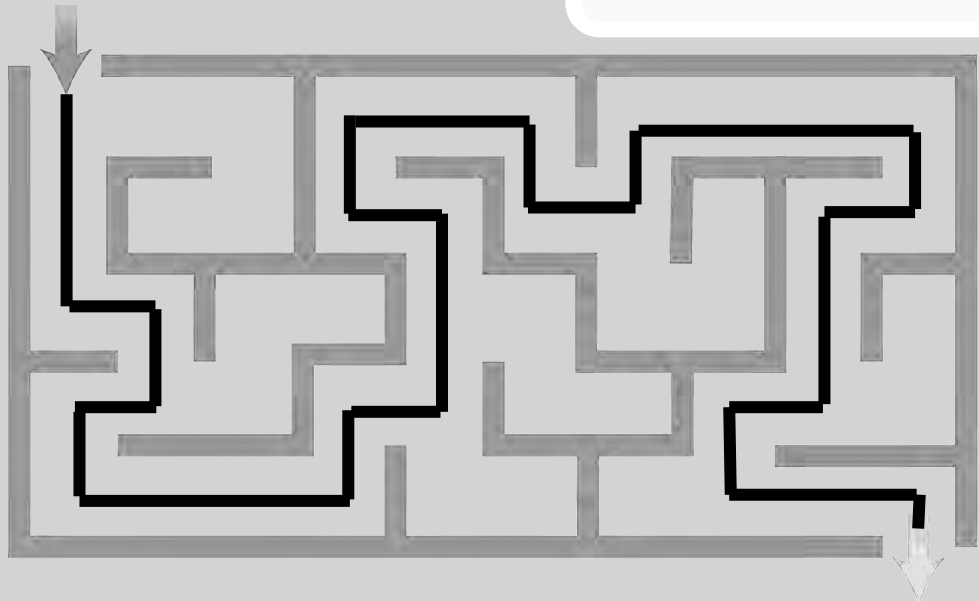


Arts and Crafts

1. Using a pencil, draw a big heart on the colored paper (see heart picture to the left).
2. Using scissors, cut the heart shape out of the colored paper.
3. Turn your heart upside down.
4. Squirt one paint color onto your left hand and a different paint color onto your right hand.
5. Press your left hand down on the left side of the heart and hold for 5 seconds.
6. Press your right hand down on the right side of the heart and hold for 5 seconds.
7. Let it dry for at least 2 hours.



Maze Key



MENTAL HEALTH RESOURCES



National Institute of Mental Health (NIMH):

<http://www.nimh.nih.gov/health/topics/hiv-aids/hiv-aids-and-mental-health.shtml>

AIDS.gov:

<https://www.aids.gov/hiv-aids-basics/staying-healthy-with-hiv-aids/taking-care-of-yourself/mental-health/>



HIV, Mental Health, and Emotional Wellbeing:

<http://www.aidsmap.com/HIV-mental-health-emotional-wellbeing/page/1321435/>

Mental Health Matters:

<http://hab.hrsa.gov/newspublications/careactionnewsletter/may2009.pdf>

How do I Find HIV Support Groups Near Me?:

<http://www.hivplusmag.com/just-diagnosed/2014/03/31/hiv-101-how-do-i-find-hiv-support-groups-near-me>



There are a variety of mental health services at each of the 21 PHACS clinical sites. Please contact your site's neuropsychologist, doctor, or nurse for more information about site-specific mental health services. If you aren't sure who to contact, please ask CAB Liaison, Megan Reznick (MeganReznick@westat.com), to help connect you to your site's personnel.

WORD SEARCH KEY

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

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