IN FOCUS

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

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FROM OUR CAB CHAIRS

As Chair for the PHACS CAB, it gives me great pleasure and honor to say thank you for electing me to help with making a difference in the HIV/AIDS epidemic. As a person working in the field for many years, I am eager to see others become involved and begin to inform and empower those around them who maybe infected or affected by HIV/AIDS.

I am seeking empowerment and to empower others, strength and to strengthen others by building relationships and moving forward. I will take all recommendations as Chair and hope to make a difference in the lives of others. I hope to conquer this epidemic we battle on a day-to-day basis. I am not sure what the future holds, but I will say there is hope in the future of HIV/AIDS research. Again, I thank you for electing me Chair.

Dolores, PHACS CAB Chair

Hello, my fellow CAB members, or should I say, my new family. I wanted to say "hello" and tell you a little about who is behind the name, Kim. I am a mother first, a big sister of eight, and a CAB member at the Texas Children's Hospital of Houston. I am a simple person. I love to cook, fish, and knit.

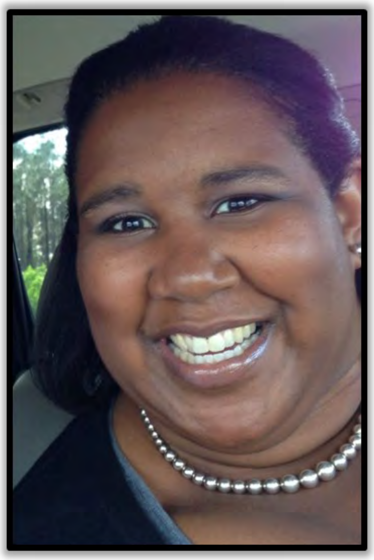
I wanted to take on this role so I can be a strong and impactful fighter in this cause! My dream is to live long enough to be around for a cure. I am a person who is 90% open, so if you need me I'm here! Fear brings on severe cases of the "woulda, shoulda, coulda." We all started with a little fear, but together we will not only reject fear, but we will show the world how strong our voices can be!!

My word of the month is escapism. Escapism is defined as an escape from unpleasant realities through day-dreams or other mental diversions.

Kim, PHACS CAB Vice Chair

PHACS MEMBER PROFILES

Kristi Stowers, BSH



Kristi is a Study Coordinator at Site 14—The University of Florida at Jacksonville and the Chair of the Study Coordinator Group.

My name is Kristi and I am the Lead Clinical Research Coordinator at University of Florida Center for HIV/AIDS, Research, Education and Service (University of Florida CARES) at the University of Florida, Jacksonville in Jacksonville, Florida. I have education in Community and Public Health, Nursing, as well as Health Education. I am currently working to finish my Masters degree in Public Health. My passion is Public Health; specifically, Maternal and Child Health. In 2008, I made the choice to move to Pediatric Infectious Disease, and it was one of the best decisions that I have made. I would have never guessed 15 years ago I would be working in research and truly enjoying it. Research has developed into something that is very interesting to me and I am truly passionate about it. Six years ago, I began working on the PHACS study, specifically SMARTT. Two years later, I was study leader, and one year ago I became the Study Coordinator Chair. One of my goals this year is to have a stronger PHACS CAB. Unfortunately, this has been a challenge at my site because of families being uncomfortable with disclosure.

I have been very fortunate to be involved with PHACS since almost the beginning. I have been working on the PHACS study since 2008. I enjoy being a part of research and advising the importance of participation in research. I enjoy working with families and showing them that they can still have a normal future with minor changes. I try to give families the insight to research and explain the benefits. I hope my efforts yield some bigger impact to the research of HIV. If I can give a little insight and help families feel less stigma and make a little impact, that is good enough for me. I love having the connection with families at my site in PHACS. It has been wonderful to see the babies grow to kindergarteners and the kindergarteners grow to adolescents, and the adolescents into adulthood.

Family is the most important to me. In my spare time, I love spending time with my family and friends. My hobbies include shopping, traveling and Disney World. I also like to bake, watch football (Go FSU!! However, I get paid by UF), and play tennis.

Stephanie

I am a twenty-three-year survivor of the virus and have had the pleasure of working with research for the last ten years. I am a mother of a child born positive. He is the reason I chose to get involved because at the time of his birth, there were not any medications beside AZT available for kids. I decided that I wanted my child to live. That was my open door to joining and learning about research. During this time, I was introduced to a beautiful young lady named Anna Wyman, who took me under her wings, taking me to my first conference in Washington. At the time, she was a part of Pediatric AIDS Clinical Trials Group. After listening to the stories shared, I knew this is what I needed to be a part of. Since that day, I have given my time continuing to be active not only with pediatric research, but any other parts of the HIV/AIDS network.

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PHACS MEMBER PROFILES (CONTINUED)

I decided that my work still needed me to do more, so I chose after first disclosing to my family that I would become open about being positive. It was one of the hardest decisions I had ever made, but if would help others to get tested, I was willing. At one point, I had to stop speaking about my status here in Miami because my son was not ready for his friends to know his status. He had started wasting and he felt people would know about him, so I took my story on the road. I was told that he was at a point where the medicine they were giving him had stopped working and there was not much more they could do for him, but because of my involvement in research, I found one that worked for him. He will be twenty-three in September and is undetectable. I owe research my son's life, and that is why it's so important for me to continue being active with research, hoping that another mother could share her happy moment as I have.

RESOURCES

The Body: Telling Others You Have HIV/AIDS:
http://www.thebody.com/index/telling.html

My Mum has HIV:
http://www.xilef.net/mymumhashiv/MyMumHasHIV-Web.pdf

Positive Women's Network: Disclosing your HIV status:
http://pwn.bc.ca/hiv-community/disclosing-your-hiv-status

It's Good 2 Talk: Sharing Your Diagnosis with Your Children:
http://ppclondon.org.uk/downloads/good2talk.pdf

AIDS Meds: To Tell or Not to Tell: Disclosing Your HIV Status:
http://www.aidsmeds.com/articles/Disclosure_7568.shtml

Children Now: Talking with Your Kids About Tough Issues, HIV/AIDS:
http://www.childrennow.org/index.php/learn/twk_aids

AIDS Action Committee: Disclosure:
http://www.aac.org/get-info/health-library-topics/disclosure-telling-others.html

The Well Project: Talking with your Children About Your HIV Status or Your Children's HIV Status:
http://www.thewellproject.org/en_US/Womens_Center/Talking_With_Your_Children_About_Your_Status.jsp

DISCLOSURE TESTIMONIALS

My disclosure story is just one of many that in my heart should have never happened, yet it did 15 years ago. I found out about my HIV when I was three months pregnant. To most like myself, for a small moment I was happy beyond word, until the doctor told me that I was positive. I told him he had to be mistaken because I was not that type of girl, but the fact of it was who *is* the type. The guy I was so madly in love with was bisexual and I had no clue. The reason that I am sharing my story is because I don't want anyone else to ever be in the dark like myself. If you love someone, get tested; it may save you or someone you love!

Recently, my daughter spontaneously decided to disclose her HIV status to some friends at school. Though we have completely disclosed to family and close friends, we had not done so at her school. However, she felt that it was important to her that her friends were aware of her status, and she broke the news. Here is her account of how it went (with Mom's grammar and spelling editing):

One day I was playing with my friends at recess, and I tripped and fell on the blacktop. My knee started bleeding really bad, and it kinda hurt. My friends rushed over and tried to help me clean my leg. I told them I was fine, and that they didn't need to help me; all I needed was for them to help me up. One of them still kept trying to reach near my leg, so I told them not to touch my blood or anybody's blood. Then I went to the nurse and got cleaned up and put on a Band-Aid. When I came back, we were in the cafeteria.

Everybody kept asking me, "Why were you acting so weird? Why couldn't we touch you on your knee? It was just a little blood, not a big deal."

I answered them, "It was a big deal. You're never supposed to touch anyone's blood because you don't know what they have." I could tell they weren't really paying attention and didn't think I was making sense. I was frustrated because it's like kids don't know anything! I felt like I needed to talk to people about HIV and stuff—how you can get it and how you can't. Like just get up on the school stage and talk about it or something, but I couldn't. If I just walked on the stage like that during lunch, I could get in big trouble. And anyway, I would be nervous to do it by myself. I can get on stage and do stuff with other people, but by myself I would get nervous and start to sweat a lot and feel like I have to pee! So I decided to just tell my friends instead of everybody.

"Guys," I said, "Don't freak out or tell everyone in the whole school this." I said to myself, calm down and relax. "I have something to tell you. I have HIV."

They looked surprised. "How did you get it?" they asked.

I said, “My mom had HIV and didn't know, so I got it too. “

"What if you touch someone?"

"If I touch someone, you won't get it. But you shouldn't touch someone's BLOOD, because HIV is in the blood."

“Guys,” I said, “Don't freak out or tell everyone in the whole school this.” I said to myself, calm down and relax. “I have something to tell you. I have HIV.”

"What if you don't know you have it? Could we have it?"

"No, you would know if you did something where you might get it. Like get born with it, or have sex [Mom's note: we've talked about sex, but I never used the actual word and didn't even know she knew it! That's a conversation in itself...] without using protection or share shots. You go to the doctor, and they can tell you if you have it."

"How did your mom get it?"

"IDK," I said. "It doesn't matter how. Even if you have HIV, you can still be a normal person."

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DISCLOSURE TESTIMONIALS
(CONTINUED)

Even though I told my friends I had HIV, everything was still okay. Everybody was acting the same. Well, not everybody. Mary was acting funny with me. When I went into the bathroom, she would leave. When we had science lab, she would switch partners. Outside, she would play with other friends, but not with me. I knew it was about my HIV, but I couldn't prove it.

I got lucky one day at recess. My allergies were really bothering me, and I had to stop playing and sit down. My eyes were watering really bad, so I was rubbing my eyes and stuff. Mary came over and said, "I saw you stopped playing. Are you crying?"

"I'm not crying," I said.

"Yes, you are! Your eyes are watering!" she said.

Before I could explain it was my allergies, she said, "It's okay. I know what's wrong. You're sad because I won't play with you anymore, right?"

I said, "Why don't want to be my friend? Is it about the HIV?"

"I AM your friend!" she said. "I just don't want you to touch me, that's all. My mom says if anybody has AIDS, stay away from them. They can give it to you, and you can die right away. I don't want to get it, so I want to be your friend, but just not the normal way."

I could NOT believe it. "Your mom is wrong!" I said. "She doesn't understand about HIV. Do you really think someone is going to die in 5 seconds if someone with HIV touches them? Then why aren't you dead? I've touched you all school year. Why isn't the teacher dead? Why isn't the whole class dead?"

"I don't know…" she said.

I cut her off. "You go to the doctor, right?" I asked.

"Yes," she said.

"Well, did the doctor tell you have HIV? No, he didn't. It's not that easy to get. Ask your doctor if you don't believe me."

"My mom is smart," she said. "She wouldn't lie about this."

"Maybe she wouldn't lie, but even smart people can make a mistake," I said. "What your mom said is not true. Look, if you don't want to touch me, then I don't want to be friends. I don't need a friend who is scared to be around me."

"I DO want to be friends!" she said. "Is it okay if I only touch you a little though? My mom said if I play with you, I have to be careful."

I still thought it was silly, but I decided to be nice. "Okay," I said. "We can still be friends. Just stop acting so freaked out about it."

"I promise I'll try," she said.

I don't know if I trust her, but I'll give her another chance.

My daughter ended first grade last week, and it was full of mixed emotions for both of us for many reasons. Though I am happy she will be moving on, it is with a heavy heart that I say farewell to her teacher. He has been a phenomenal educator as well as a good friend to us. Mr. T (to protect his privacy) has a true passion for educating youth, particularly foreign language learners. He searches for ways to help make learning fun as well as challenging for his students. He opens up to them, and shares personal stories to make his lessons come alive, and he utilizes technology on a regular basis in unconventional ways to help the kids become more savvy. He emphasizes the importance of living "green" in a variety of projects throughout the year. And he treats the students with respect and expresses genuine concern for their happiness and well-being. I suppose this is why my daughter selected him as the first person she chose outside of family and close family friends to disclose her HIV status to. In that, he will always be a special "first" for us, even outside of his other positive attributes.

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DISCLOSURE TESTIMONIALS

(CONTINUED)

One day, my daughter decided that she wanted to tell her teacher, Mr. T, about her status. I wasn't certain at first if she was serious, as it was something she said in passing. But then she mentioned it again. And again. And again. It became something she brought up daily. She was convinced that he wouldn't have a problem with her diagnosis and felt very strongly about sharing it with him. I wasn't sure what to think. After all, although disclosure is not required where we live, I'd already voluntarily informed the Medical Director of our school district. I didn't see the need to also share with people at her school campus. But I didn't want to censor my child either.

After we discussed it at length, we decided that she and I would meet with her teacher during his conference period within the next two days and tell him. We chose that date because she felt an urgent need to talk about it, but Mr. T's policy was that he needed a minimum of 24 hours notice to schedule meetings with parents to avoid time conflicts. This gave me a day to email him and set up the meeting.

But...life happens. The next day was crazy, crazy, crazy at work, and emailing him totally slipped my mind until I got home that evening. I emailed him and hoped for the best. But I didn't get a response until the next morning (the day of the hoped-for meeting). In his email, he stated he hadn't read my message until he returned to the classroom that morning, and unfortunately he already had a meeting scheduled with another parent. Could we meet the next day instead?

> “My heart was racing. This wasn’t the way I’d planned it at all.”

My heart sank when I read his words. Earlier that morning, while dropping my daughter off at school, she'd happily reminded me that today was the day of our "portant” meeting with her teacher, and told me not to be late. "Yes," I wrote, "We can meet tomorrow. I apologize for writing so late; my daughter really wanted to meet today, but I understand that you're already booked. Please tell her that I won't be coming by today. Thanks for accommodating us."

That afternoon when I picked her up, she skipped over to my car, hopped in, and casually mentioned while buckling her seat belt, "I told Mr. T."

"You did what?" was my reply.

"I told him that I have HIV. He told me you couldn't come today, so I decided to tell him by myself."

"What happened? What did he say?" I asked.

"He was fine, can we stop at Smoothie King?" she said breezily. My heart was racing. This wasn't the way I'd planned it at all. I'd wanted to come in and have a discussion armed with my HIV handouts, a list of URLs about HIV, and be mentally prepared to answer questions. That clearly wasn't going to happen. Now what?

The next morning, I prayed on my way to the school for the meeting, which now seemed to be in vain. I signed in at the office and Mr. T arrived punctually as always and greeted me with a smile. "The kids will be out of library in a few minutes, and then I can bring her to join us," he said, referring to my daughter. I told him that wasn't necessary; he and I could meet alone.

> “[He] told me that he knew and that he felt very honored that my daughter trusted him enough to tell him about her status.”

We sat down in the classroom and stared awkwardly at each other. I took a deep breath and started to speak, but Mr. T jumped in before I could say very much, and told me that he knew and that he felt very honored that my daughter trusted him enough to tell him about her status. He said that he thought she was a very brave, very special girl, and that he would respect her privacy.

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DISCLOSURE TESTIMONIALS
(CONTINUED)

Then he asked if there was anything more he could do in the classroom to ensure that the other kids didn't get HER sick, pointing out the bottles of hand sanitizers on each desk and the Lysol and cleaning wipes located near some of the centers.

I was so touched by his reaction that I really couldn't find words at first. Then I thanked him for understanding, and we proceeded to have a very interesting discussion about HIV and adoption. We were so engrossed in conversation that we almost went over the allotted time! Afterward, I thanked him and left.

And....And, well, nothing! He continued to treat her the same as always--kindly, but not like she was a danger, "different" or in need of pity or sympathy.

One day, months later, she got hurt on the playground. She came home with a bandage over a scrape that had clearly broken the skin and bled.

Apparently Mr. T cleaned the wound without any fanfare, bandaged her up, and sent her back to play. I didn't get any calls from work to pick her up, or any email as an FYI. It was treated the way it would have been if any child in her class had gotten hurt...as a minor incident.

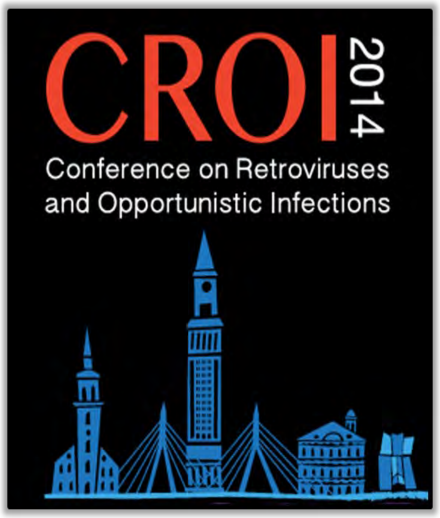
So thank you, Mr. T, for all that you do, and for all the people out there like you. You judge a person by who they are rather than by three letters on a piece of paper. Thank you for helping to build my daughter's confidence this year and helping her to learn that disclosure doesn't have to have disastrous results. Thank you for challenging her in her schoolwork, and for the many conversations we've had regarding school, behavior, and various issues. I always felt that you respected me as a valuable part of my daughter's academic and overall growth.

Thank you for being who you are.

IN MY LIFE

In my life
I wouldn't say I've had it too hard
too bad
not bright
And it's not about what I've been through
dealt with
thrived in
It's about the people who've been by my side
friends
family
lovers
In my life I would say I have it all.

CROI 2014



PHACS was represented at the 2014 Conference on Retroviruses and Opportunistic Infections (CROI) with an amazing two oral presentations and seven posters. CROI is one of the most important worldwide meetings about HIV. We were proud to share so many of our projects with others doing HIV/AIDS work and with the community.

One oral presentation looked at babies born to HIV+ mothers who used the antiretroviral medicine tenofovir while pregnant. The study used a DXA scan (a type of x-ray) to check the amount of calcium in the bones of these babies. Bones with more calcium are stronger and less likely to break. We found that tenofovir use in pregnancy was associated with lower amounts of calcium in the newborns' bones. Dr. George Siberry, one of the PHACS Medical Officers at the National Institutes of Health, was the study's lead author and presented the study. Dr. Denise Jacobson is a PHACS Data and Operations Center (DOC) Senior Epidemiologist and was one of the study's authors. She said that they were very happy with the amount of attention the study got.

"It was fun and just a little scary to see the results presented in front of so many people," she said.

Go to the link below to see Dr. Siberry discuss the study at a press conference:

http://www.hivandhepatitis.com/hiv-related-conditions/hiv-bone-loss-osteoporosis/4574-croi-2014-newborns-exposed-to-tenofovir-have-lower-bone-density-video

The other oral presentation was on a study that looked at older youth who had successfully managed to keep the amount of HIV in their blood at very low levels (undetectable). The researchers looked at the amount of HIV in their white blood cells. They found that there was less HIV in these cells if youth had started treatment before they were one year of age and had undetectable levels of HIV in their blood for a very long period of time (an average of 10 years). Dr. Deborah Persaud was the study's lead author and presented the study. The study has been accepted for publication in the journal *JAMA Pediatrics*.

Dr. Russ Van Dyke heads the PHACS Coordinating Center and was an author on the study. He said, "The presentation was very well received. It's a hard topic to study, and the results suggest that there is a benefit in starting treatment early in infancy."

This year, CROI was held in Boston, MA. This is where the PHACS DOC is based at the Harvard School of Public Health. The DOC hosted a CROI PHACS dinner for more than 20 clinicians and researchers. Attendees agreed the dinner was a great success. They were grateful to spend time with their colleagues and to learn more about each other outside of their roles on PHACS. It also served as an impromptu birthday celebration for Dr. Van Dyke, Dr. George Seage (head of the PHACS Operations Center), and Dr. Paige Williams (Senior Statistician at the PHACS DOC)!

To see all of the CROI presentations and posters, visit the member area of the PHACS website:

https://my.phacsstudy.org/document/22/accepted-abstracts-conference-presentations-and-published-manuscripts

(Submitted by Julie Alperen, DrPH)

SITE CAB Q & A: SITE 16

One of the purposes of the PHACS CAB is to serve as a mechanism through which the site CABs can share ideas and resources. This year, the PHACS CAB focused many efforts on networking between site CABs.

The hard-working and energetic CAB at Site 16 (University of Puerto Rico) supports and empowers its members to advocate for community voices in research. Juan talks about some of the challenges and successful CAB practices at Site 16.

What does your CAB usually talk about during site CAB meetings? What activities do you participate in during site CAB meetings?

Since I've been in the University of Puerto Rico's CAB (2010), we have talked about the IMPAACT network and the PHACS network conference calls. We go through the conversations and review the minutes from the conference calls and then we debate, add up, and react to the information. We also discuss news and information from different magazines like POZ, Positively Aware, and others.

Besides magazines, we retrieve and bring more things to discuss from local and international newspapers, clinical investigations, articles from health magazines, and anything related to HIV/AIDS or health issues that might impact our CAB's community.

During our CAB meetings, we always provide snacks. Sometimes, this functions as an icebreaker for members to start the meeting.

If there are new members, we introduce each member, CAB liaisons, clinic personnel, and the Principal Investigator. We explain the purpose of the CAB, confidentiality, and importance of the CAB. Assigning different articles, news, and topics to discuss to different members can be challenging. We do this because we try to encourage every member to participate during the meetings. This is a way to empower them and make them feel that they are working for the community.

Some meetings take place through activities outside the clinic, like at health conferences, conservatories, or community encounters. We also use media relevant to the topics discussed in our CAB.

What kind of activities (outside of site CAB meetings) does your site CAB participate in? Tell us why these activities are important to you and your site CAB.

We invite the members to different health conferences, conservatories, community encounters, and meetings.

We have also participated in sport benefits from other institutions, and activities at other HIV/AIDS clinics. These activities are important for me and our site CAB because it diversifies the methods of providing information, running CAB meetings, empowering members, and facilitating community involvement.

Outside activities are an important aspect to keep the CAB members motivated to keep coming to our CAB. It also encourages them to continue providing information and feedback. It helps them continue teaching others about HIV/AIDS and its prevention, and motivating others to come to our CAB meetings.

What are the best ways your site CAB has worked to keep CAB members involved in your site CAB?

During the time I've been in our site CAB, I've seen that the empowerment and the information brought from the conference calls are very important aspects to keep CAB members at our site. Another thing that keeps CAB members coming to our meeting is the variety of information provided.

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SITE CAB Q & A: SITE 16
(CONTINUED)

Since we bring different health news, articles, and information important to our CAB members in addition to HIV/AIDS information, we create a more welcoming meeting.

Even though we are not a support group, indirectly, we are one. Sometimes we discuss matters from our CAB members that can be addressed and helped through the help of other CAB members and other contacts.

Finally, the invitations to different activities outside our meeting from different entities also keeps the members motivated to come back for more "benefits" like these.

Do site staff members come to your site CAB meetings?

We have staff members from our site at our meetings. Our CAB Liaison, Study Coordinator, and Principal Investigator come to our meetings.

It is important to have them at our CAB meetings because they help us with clinical terms, explain things that we might not completely understand, and give overviews of what's happening in the clinic.

How does your site CAB learn about PHACS, including study findings?

We talk about protocols, participant summaries, and press releases. We not only talk about the actual topics from the conference calls, but we also compare them to other protocols and studies.

We also mention other studies currently running in and outside our clinic, and within and outside PHACS.

What is your favorite part about being involved with your site CAB?

My favorite part of being involved in our CAB is that I feel that I'm working for the entire community, not only for the HIV/AIDS community. Bringing information to our CAB members and others is one of my purposes in life.

What have you gained by being a part of your site CAB?

By being a part of our site CAB, I've gained more knowledge, maturity, confidence, friends, tons of information, life experiences, empathy, more ways to look at life and the world, the importance of education and prevention, and many other things.

Since I have more information and education, it gives me the power to educate others and talk more securely about HIV/AIDS and other topics with confidence. I don't think I feel more supported, yet I feel that I support others.

Why is community involvement in the research process so important?

It is essential for the research process since community input will let the researchers know in advance if a study might work or not. It also gives the research process validation and specific data before and after the research.

What plans does your CAB have for the future? Do you have any goals for the coming year?

Fortunately, the incidence of HIV/AIDS in the pediatric community in Puerto Rico has been reduced to not having new cases for many years. Unfortunately, this has reduced our opportunity to keep our site working because of different aspects. We do hope that we can continue to have our CAB meetings and members for many years to come.

Even though there's been a reduction in funding across many studies, we would like to have more meetings, activities, and opportunities for the CAB members to be involved. Since every site has different difficulties and needs, maybe the network can work with sites individually. This would help each site and prevent future situations for all CAB sites.

(Submitted by Juan)

For more information about current site CAB preferences and practices, please view the CAB Handbook on the PHACS website:

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

DELIA'S GOODBYE LETTER

It was an amazing four years working closely with the PHACS team and Leadership.

Four years ago, I was asked to join the PHACS CAB Leadership. I hesitated for a while because I thought that I did not have it in me. This was the best decision I ever made to accept the role as the Vice Chair and then Chair.

The Vice Chair role gave me a lot of confidence in myself, showing me that anything is possible. I remembered when I first introduced myself at my first Network Meeting, I thought that I would have a heart attack. My heart was pounding really hard.

> "The Vice Chair role gave me a lot of confidence in myself, showing me that anything is possible."

Our conference calls were also heart pounding for me. I remembered on one call, I actually froze. All I could hear from Rosia was, "Delia, are you there?" From that time I said, "No, this has to stop!" I had to put myself together. I was there for a purpose. People had confidence in me; that's why I was chosen to be the Vice Chair.

> "It is very important to work as a team. Communication is also important, and most of all - dedication."

My fear did not stop me because I know that nothing comes easy. I got involved a lot during my role as Vice Chair. More and more, I gained confidence in myself because as part of the PHACS CAB, you are respected, and your contribution is always appreciated.

I attended the Network Meetings and got more knowledgeable. Eventually, I felt more at ease with speaking to an audience and talking to the Leadership and researchers. What actually broke the ice for me was meeting the people I hear on the calls every month. They are very polite and always respect my contributions.

After my two years as the Vice Chair, I felt that I was ready to go on with the role as Chair. I prepared myself for this role and I had a lot to offer. Being the Chair is not a joking matter. You have to be a dedicated person and love what you are doing. It is very important to work as a team. Communication is also important, and most of all – dedication. Without these important aspects, our CAB would not have grown so well. Right now the PHACS CAB is flourishing because we are a strong team.

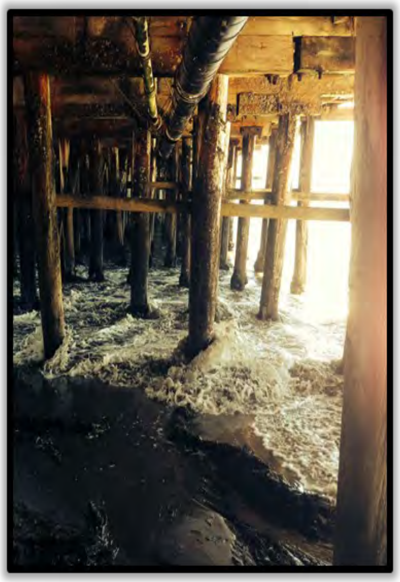
Megan and I have worked so well throughout the years. We communicate on a regular basis and never had a problem completing a task. It did not matter whether it was big or small. Megan, thank you for believing in me. I don't think that my role as Chair would have been possible without your help and support. This is very important.

My term is up, but I will still be involved in the CAB. I will continue to contribute and to be part of a great team.

Thank you for making me this person I am today. I am strong!

(*Submitted by Delia*)

INADVERTENT DISCLOSURE



When should you speak?

As a CAB member, I sometimes forget that how no matter how much things have changed, there are still some individuals in the medical profession that may be closed-minded and are still stuck in the 1980s. I took my son to have a medical check-up and ended up standing up for the fight.

A young physician disclosed my status without my permission. If this was not bad enough, she never really took the time to understand how she was wrong. I had to file a complaint with the head physician, not only for my nerves, but so this won't happen again to me or anyone else. I think the part that made me the most upset was that in her mind, everyone was wrong but her, including the staff, the paperwork, and the computer. Yes, she did apologize, but because she never owned up to her mistake, it felt insincere. I kept thinking, "If I were a new client, would I have come back or brought my child back to care?" I hope whoever reads this recognizes that everyone, regardless of who you are, should never take confidentiality for granted because you may lose someone's life!!

(Submitted by Miss K.)

Inadvertent disclosure is one of those topics that has "lawsuit" written all over it. No matter how good your intentions are, when thinking about disclosing someone's HIV status, you must think twice (even three times) before you say anything…to ANYONE! Every situation is complicated, but the rule of thumb is that providers must not, and should not, disclose HIV status without a patient's consent.

I'm not as familiar with other states, but there are laws in the state of Florida for HIV testing and results:

"Providers" refers to any staff belonging to a medical facility, community clinic, testing site, health department facility or branch.

Florida Statute 381.004 – HIV testing:

Nobody is allowed to disclose your test results (status) to a third party without your written consent, and that is particularly directed to medical providers and health department employees.

Providers often feel obligated to disclose the patient's status to sexual partners to "limit exposure and prevent possible infection." However, the law prohibits this action, including disclosure to family members. My suggestions for providers are as follows:

- Discuss the situation with your supervisor and the director of the program;
- Educate fellow provider(s) about state laws regarding disclosure; and
- Have a social worker present when this conversation is taking place.

Suggestions for patients:

- Ask the provider the reason why he/she feels the need to disclose your status.
    - ◊ Talk to a social worker about this matter; and
    - ◊ Speak with the director of the clinic/program about the situation, if necessary.

(Submitted by Yuri)

STAFF DISCLOSURE WORKSHOP

PHACS Site 19, located at Texas Children's Hospital, held a disclosure workshop on November 13, 2013 for the research staff. The team consisted of registered nurses, case managers, and social workers. The purpose of the workshop was to train the staff and provide them with effective tools to assist parents with disclosing their HIV status to their children. The trainers for the workshop were Debra A. Murphy, Ph.D., Director, Health Risk Reduction Projects Integrated Substance Abuse Programs, Dept. of Psychiatry, the University of California at UCLA and Diana Payne, Ph.D. Project Director, HRRP UCLA Research Center.

The training presented was called, "Track II." This was an eight-hour interactive workshop that allowed staff to role-play as parents and staff members. The research team received valuable information and is using these tools to help caregivers bridge the gap on disclosure. We would like to thank Dr. Debra Murphy, Dr. Diane Payne and Dr. Julie Alperen for supporting our desire to be trained regarding HIV disclosure.

(Submitted by Norma and Theresa)

GOODBYE, LYNNE MOFENSON

After a long and distinguished tenure, Lynn Mofenson, the Branch Chief at the Maternal and Pediatric Infectious Disease Branch of the Eunice Kennedy Shriver National Institute of Child Health and Development, will retire from the NIH this summer. Lynn launched the Pediatric HIV/AIDS Cohort Study in 2006. Fortunately for the HIV/AIDS community, she will not be leaving the field. Lynn will move to the Elizabeth Glaser Pediatric AIDS Foundation, where she will continue the important contributions she has made to the field.

To read more about Lynn's accomplishments in the field of HIV/AIDS research, see our profile of Lynn in Volume 4, Issue 2 of the CAB Newsletter (available on the PHACS website behind the login).

PARTICIPANT SUMMARY

Mental Health and Substance Use in Mothers Living with HIV

Mothers living with HIV sometimes have stressful lives. They may be at risk for mental health problems. These problems could include sadness, hopelessness, worrying, or problems with alcohol or drugs. We wanted to find out whether mothers living with HIV have high rates of mental health problems. We also wanted to see whether they receive treatment for these issues.

Who we studied

1,341 women whose children visited medical clinics where the SMARTT study is done

- 1,223 mothers living with HIV
- 128 HIV-negative mothers

What we did

We asked all 1,341 mothers questions about their emotions, behaviors, alcohol and drug use, and other health problems. Mothers noted whether those problems made it hard for them to care for their families. 689 of the mothers living with HIV also completed a follow-up interview several years later.

What we found

- At the first evaluation, 35% of all mothers had mental health problems. This is higher than the national average for adults.
    - There were no differences in rates of mental health or substance use problems between mothers living with HIV and HIV-negative mothers from similar communities.
- Post-Traumatic Stress Disorder (PTSD) was the most common problem reported by mothers. This was because of high rates of traumatic events in their lives.
- There were 238 mothers with mental health problems at the first evaluation. Of these, **61%** still had mental health problems at their follow-up evaluation.
- Mothers living with HIV were **more likely** to have ongoing mental health problems if:
    - it was hard for them to do normal daily activities;
    - they had lower income; or
    - they had used alcohol or illegal drugs during their pregnancy.
- Most (83%) mothers with mental health problems were **not** receiving mental health care.

What we learned

Mothers living with HIV are at risk for mental health problems. These problems may also be related to traumatic or stressful events in their lives, unstable resources, or a lack of support. Sometimes these problems go on for several years.

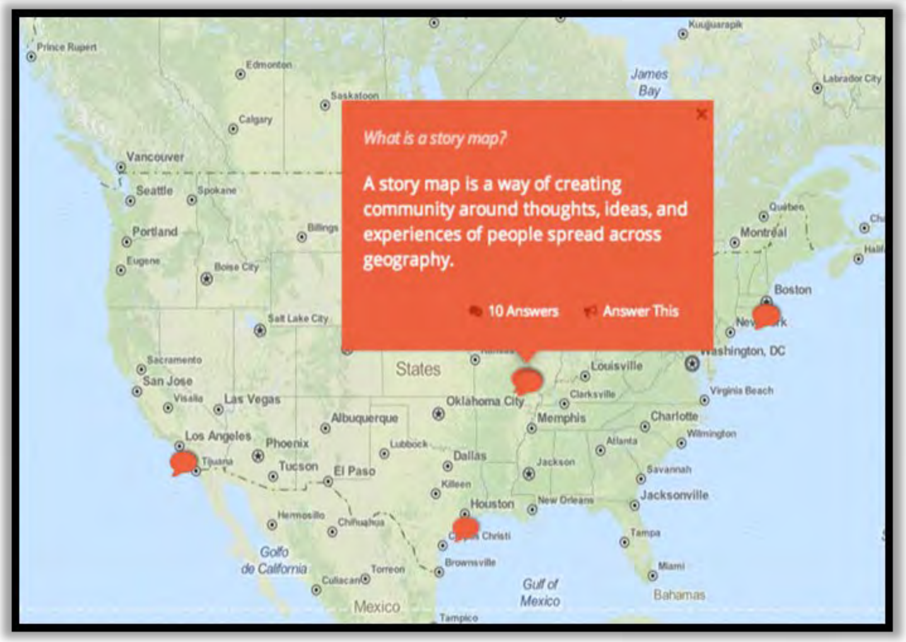
Effective treatment is needed for mothers living with HIV to help them feel better, stay healthy, and care for their children. Mental health care integrated with medical care may improve their access and reduce barriers to treatment.

Reference Info:
http://www.ncbi.nlm.nih.gov/pubmed/24759063
Concept Sheet #C052
2014. JAIDS 65(5), pp. 526-534.

pHACS
A Study of the National Institutes of Health

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

MAPPING YOUNG ADULTS' STORIES



What is a story map?

A story map is a way of creating community around thoughts, ideas, and experiences of people spread across geography.

10 Answers Answer This

Many of you know that a new website for AMP Up young adult participants was launched earlier this year. This website came about with the help and guidance of young adults in PHACS from around the country. Claire Berman and Deborah Kacanek prepared a presentation for the Youth + Tech + Health Conference (http://yth.org/ythlive/about) which Claire presented in San Francisco, CA on April 7, 2014.

YOUNG ADULT VOICES

With the launch of the AMP Up protocol in 2014, we wanted to find out from youth and young adults why they might choose to remain in the PHACS study as they transition into adulthood. We wanted to ask what engages them. And we wanted to develop a website for study participants that young adults would shape and guide.

Over the last year, Claire Berman and Deb Kacanek conducted focus groups and interviews with 59 young adults and CAB members at eight AMP clinical sites around the country. Young Adult Community Advisory Board (YACAB) members also advised us on an ongoing basis. We learned from young adults and their caregivers about their technology use, their reasons for participating in a long-term study about HIV, and about their relationship to HIV.

DESIRE TO CONNECT

Young adults told us about their desire to connect with peers in a private, secure environment. They told us about the importance of creating space where HIV is something shared. At the same time, they didn't want HIV to be the primary focus or something that defines their entire identity. They also told us some of the reasons they participate in an HIV study. Although incentives play a role, many participate out of a desire to help others. These young adults feel that that their being in the study will benefit someone else. Many also participate because it is a chance to learn about HIV and about transitioning into adulthood.

STUDY SURVEYS AND OTHER RESOURCES

Based on these discussions, we worked with a company called Emerson Media to develop a private, secure website for young adults who sign up for the AMP Up study. This website links young adults to their yearly online AMP Up surveys. It also features many resources on young adulthood. Topics were suggested by young adults and include employment, housing, moving to a new state, health insurance, navigating public housing, dating and relationships, sexual health, transition to adult health care, traveling and studying abroad, and many others.

STORYTELLING

One of the core features of the website is a story map. This feature allows young adults from around the country to submit brief and anonymous thoughts and responses to questions that young adults pose to each other. While HIV may be an added layer to the answers that some young adults provide, it was important to young adults that the website not be only about HIV. Examples of questions include:

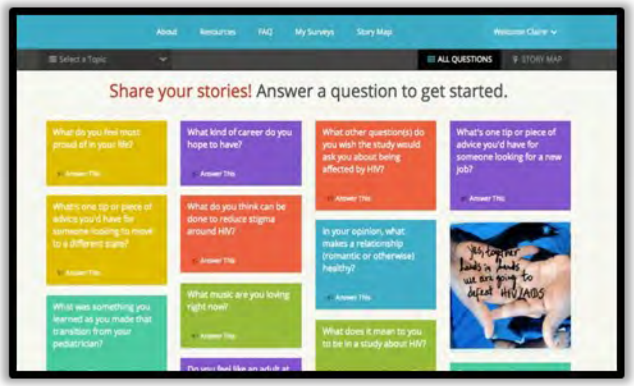
- In your opinion, what makes a relationship healthy?
- What was something you learned as you transitioned from your pediatrician to adult care?
- Why do you participate in a study about HIV?
- What music are you loving right now?

(*Continued on page 16*)

MAPPING YOUNG ADULTS' STORIES
(CONTINUED)

HOW THE STORY MAP WORKS

1)



Share your stories! Answer a question to get started.

What do you feel most proud of in your life?

What kind of career do you hope to have?

What other question(s) do you wish the study would ask you about being affected by HIV?

What's one tip or piece of advice you'd have for someone looking for a new job?

What's one tip or piece of advice you'd have for someone looking to move to a different state?

What do you think can be done to reduce stigma around HIV?

In your opinion, what makes a relationship (romantic or otherwise) healthy?

What was something you learned as you made that transition from your pediatrician?

What music are you loving right now?

What does it mean to you to be in a study about HIV?

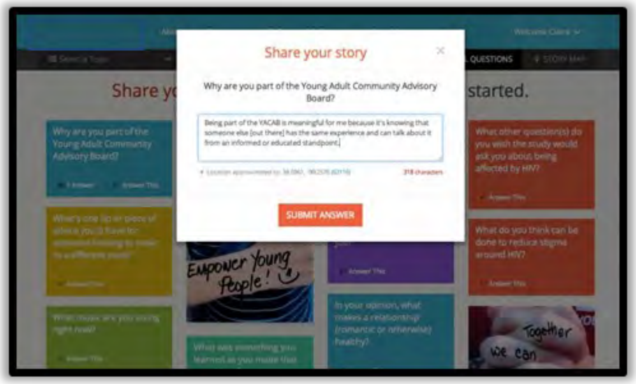
1) This is the landing page for the story map. Users can browse and answer questions, which are color-coded by category. Questions are geared towards offering practical tips and information about transition to adulthood. They also offer support and personal stories about HIV.

2) This is what it looks like when a young adult enters a story. The story can be up to 500 characters long.

3) This is how a story appears on the map.

(Submitted by Claire Berman, MPH)

2)



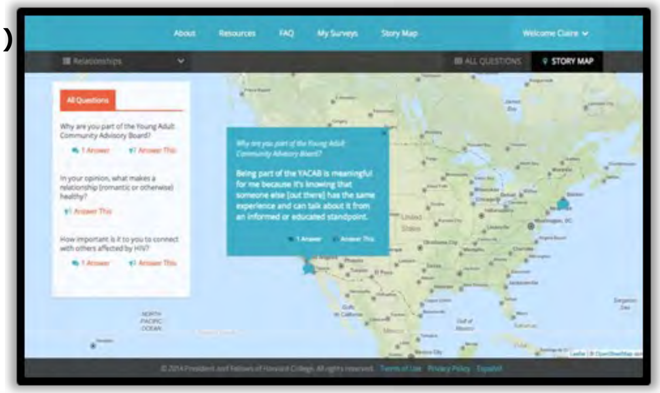
Share your story

Why are you part of the Young Adult Community Advisory Board?

Being part of the YACAB is meaningful for me because it's knowing that someone else [out there] has the same experience and can talk about it from an informed or educated standpoint.

318 characters

3)



Why are you part of the Young Adult Community Advisory Board?

In your opinion, what makes a relationship (romantic or otherwise) healthy?

How important is it to you to connect with others affected by HIV?

Why are you part of the Young Adult Community Advisory Board?

Being part of the YACAB is meaningful for me because it's knowing that someone else [out there] has the same experience and can talk about it from an informed or educated standpoint.

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AMP UP UPDATE

AMP Up, the new study for young adults in PHACS, has officially opened! Several participants had their first visits in May, with many more on the schedule. Everything so far has run smoothly. All online assessments have worked well, and the feedback on our first visits is positive. We also had our first participants register for the young adult story mapping website (see page 15)! Almost half of all young adults in AMP are eligible to move to AMP Up, so it's very exciting to see AMP Up get off to a successful start. We are especially grateful to the Young Adult CAB for giving their time to improve the AMP Up visits for all participants.

PUBLICATIONS IN THE NEWS

Since the last PHACS CAB Newsletter in December 2013, PHACS has had three manuscripts accepted to scientific journals, had thirteen abstracts presented at scientific conferences, and produced three participant summaries.

Publications

"Discordance of Cognitive and Academic Achievement Outcomes in Youth with Perinatal HIV Exposure." This manuscript is in the *Pediatric Infectious Disease Journal.* Lead author Patricia Garvie, PhD, is a Psychologist at the Children's Diagnostic and Treatment Center and is also a member of the ND and Neurological Disease Working Group.

"Elevated aspartate aminotransferase-to-platelet ratio index in perinatally HIV-infected children in the United States." This manuscript is in the *Pediatric Infectious Disease 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.

"Safety of in utero neonatal ARV exposure: cognitive and academic outcomes in HIV-exposed, uninfected children age 5-13 years." This manuscript is in the *Pediatric Infectious Disease Journal.* Lead author Molly Nozyce, PhD, is a Neuropsychologist at Jacobi Medical Center. She is also a member of the ND and Neurological Disease Working Group.

Abstracts

These abstracts were presented at the Conference on Retroviruses and Opportunistic Infections (CROI) in Boston, Massachusetts March 3-6, 2014:

"Lower newborn bone mineral content associated with maternal use of tenofovir disoproxil fumarate."

"Early Viral Suppression Improves Neurocognitive Outcomes in HIV-infected Children."

"Insulin Resistance in HIV-Infected Youth Is Associated with Decreased Mitochondrial Respiration."

"Steady Decline: Temporal Changes in Substance Use by HIV-Positive Pregnant Women in the US."

"Abnormal fatty acid oxidation in HIV exposed uninfected neonates in the United States."

"Prevalence and Predictors of HIV Resistance Among US Children and Youth with Perinatal HIV"

"Incomplete Immune Reconstitution in HIV Infected Children with Virological Suppression."

"Congenital Anomalies and in utero Antiretroviral Exposure in HIV-exposed Uninfected Children."

"Virologic Control by Age 1-Year Significantly Reduces Proviral Reservoirs In HIV-Infected Youth."

This abstract was presented at the Youth + Technology + Health (YTH) Conference in San Francisco, California April 6-8, 2014:

"Storytelling for Retention: Developing a Story Map to Engage and Retain Young Adults in the Pediatric HIV/AIDS Cohort Study."

(*Continued on page 18*)

PUBLICATIONS IN THE NEWS
(CONTINUED)

These abstracts were presented at the 18th International Workshop on HIV Observational Databases in Sitges, Spain March 27-29, 2014:

"Fractures in Perinatally HIV-infected versus HIV-exposed Uninfected Children and Youth."

"Learning and Memory in Children and Adolescents with Perinatal HIV Exposure and/or Infection."

This abstract was presented at the 9th Annual International Conference on HIV Treatment and Prevention Adherence in Miami, Florida Jun 8-10, 2014:

"Roles of medication responsibility, executive and adaptive functioning in adherence for youth with perinatal HIV."

Participant Summaries

"Youth with HIV and Overall Risk of Heart Disease."
View this participant summary on the PHACS website: https://phacsstudy.org/cms_uploads/research_summaries/English/2014-02_Youth_With_HIV_and_Overall_Risk_For_Heart_Disease.pdf

"Youth with HIV and Risk of Substance Use."
View this participant summary on the PHACS website: https://phacsstudy.org/cms_uploads/research_summaries/English/2014-03_Youth_With_HIV_and_Risk_of_Substance_Use.pdf

"Mental Health and Substance Use in Mothers Living with HIV."
View this participant summary on the PHACS website: https://phacsstudy.org/cms_uploads/research_summaries/English/2014-05_Mental_Health_and_Substance_Use_in_Mothers_Living_with_HIV.pdf

CAB GLOSSARY

Confidentiality: Keeping personal information private. Personal information collected during a clinical trial is not recorded or transmitted with name, date of birth, or other types of personal information.

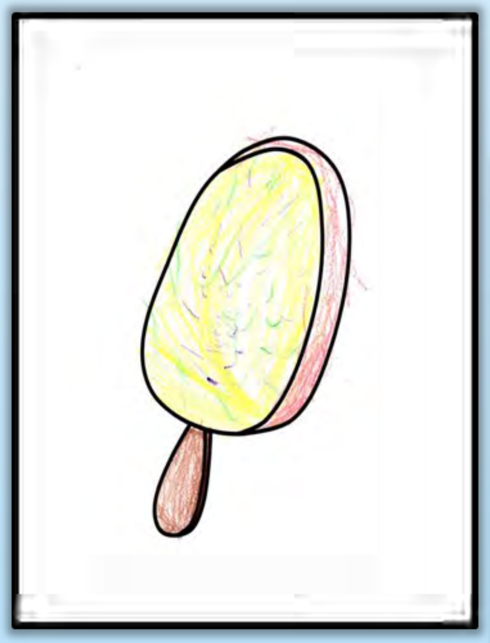
Disclosure: Informing another person or persons of one's HIV infection status.

Evaluations: The tests or examinations done during the course of a clinical trail to check the health status of participants.

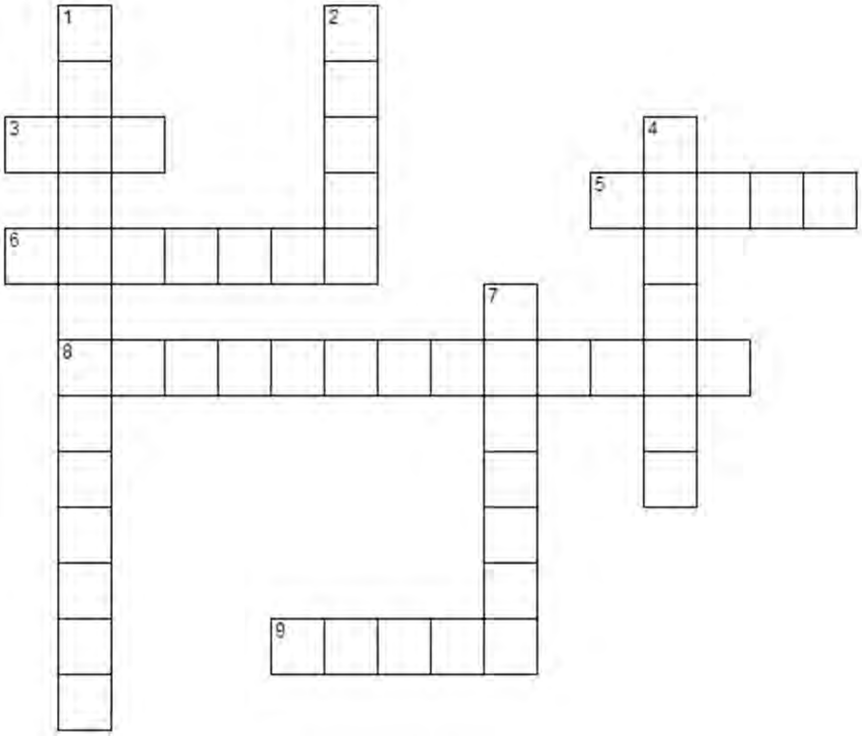
Peer Educator: A person who provides information and training to a person with a similar background or characteristic.

Protease Inhibitors (PIs): A major category of anti-HIV medicines that block the action of the enzyme protease, which is needed for the virus to make more HIV.

CAB KIDS - ICE CREAM!



CROSSWORD PUZZLE



Hint: All answers can be found on the new PHACS website: http://phacsstudy.org.

Across:

3. AMP Up is a continuation of which PHACS protocol?
5. He is the PHACS Principal Investigator at the Data and Operations Center (last name).
6. This state houses three PHACS sites.
8. The newest PHACS committee: Health Education and ___________ Committee.
9. How many main studies are under PHACS?

Down:

1. This Working Group studies the long term effects of HIV and anti-HIV medicines.
2. He is the PHACS Project Scientist at the National Institutes of Health (last name).
4. This state houses four PHACS sites.
7. He is the PHACS Principal Investigator at the Coordinating Center (last name).

(Answer key on page 24)

RECIPE

Baked Curried Chicken

(Submitted by Delia)

Ingredients:

- Chicken
- 2 tablespoons lemon juice
- 2 cans chicken broth
- 2 tablespoons lemon juice (for sauce)
- Curry powder (to taste)
- Onion powder/onions (to taste)
- Salt (to taste)
- Garlic powder or 1 garlic clove
- Black pepper (to taste)
- Paprika (to taste)

Directions:

1. Preheat the oven (400 degrees).
2. Rinse the chicken and pat dry.
3. Brush 2 tablespoons lemon juice and vegetable oil or butter (optional) on the chicken.
4. Place the chicken in the oven and bake for 30 minutes.
5. In a saucepan mix together ingredients.
6. Pour curry sauce over chicken.

STORYTELLING RESOURCE

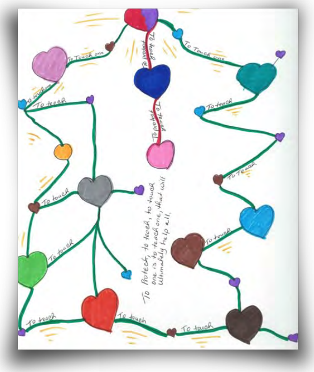
Call for Stories for New Disclosure Resource!

Caregivers in PHACS have told us that deciding whether and when to disclose their HIV status to their child can be a significant challenge. Over the last year, we have learned about the complexity of this issue by listening to CAB members, clinical site staff, and other experts in disclosure. The most important thing we have heard that there is no "one size fits all" approach to disclosure. It is different for each person and their situation. Some caregivers may feel that it isn't the right time to disclose to their children. For others, different factors may be playing a role. They might feel a fear of rejection or a fear that their child will tell others. They might also feel unprepared to answer children's questions.

Caregivers have shared that it would be helpful to hear about how others in similar positions have made this decision, and how they went about disclosing. In response to this, PHACS is creating a resource to offer support in deciding whether to disclose. The resource will be available both online and in print. Caregivers will be able to hear from each other about disclosure challenges and successes. This will help them decide what is right for their own situation. It will also offer a way for caregivers to learn from stories that are most relevant to their own situation. CAB members suggested a variety of story topics. They wanted to hear how others decided when to disclose and how they explained what HIV is to children. They also wanted stories about reframing HIV as a chronic illness, how to answer children's questions, and about common reactions children might have.

We would love to include your stories! Here's what you should know about submitting your story:

- All stories are welcome from any PHACS clinical site, no matter how long or short.
- You can choose to make your story anonymous when it's published.
- Stories can be submitted in any format (i.e., handwritten or typed documents, photos, videos, artwork, etc.).
- You can work with your clinic or with Claire or Megan to submit your story.
- We'll ask you to sign a story release, even if it's published anonymously. This is for legal reasons.



Above is an example of visual storytelling submitted by a CAB member.

If you are interested in sharing your story, please let your study coordinator know or contact Claire Berman—617/432-1853 (cberman@sdac.harvard.edu).

UPCOMING EVENTS

- **September 18:** National HIV/AIDS and Aging Awareness Day
- **September 27:** National Gay Men's HIV/AIDS Awareness Day
- **October 15:** National Latino AIDS Awareness Day
- **October 21:** PHACS CAB Retreat
- **October 22-23:** PHACS 2014 Fall Network Meeting
- **December 1:** World AIDS Day

DISCLOSURE COMICS

Soon there will be an exciting new resource from the Health Education and Communication Committee (HECC) available: HIV Disclosure Comic Books! These comics will be part of the larger storytelling disclosure resource for caregivers living with HIV, described on page 21.

The HECC worked with a health communication graduate student and artist named Lauren Gaffney to create two comic books called “What is HIV?” and “Living with HIV.” Many PHACS CAB members advised us throughout the process. CAB members told us that the most important topics to cover first were how to explain HIV in an age-appropriate way, and how to normalize and reframe HIV so children are not afraid for their caregiver. They also offered guidance and feedback on the colors, characters, and the storyline in each comic. Each person who contributed to these comics helped make them more useful and relevant for caregivers and children around the country.

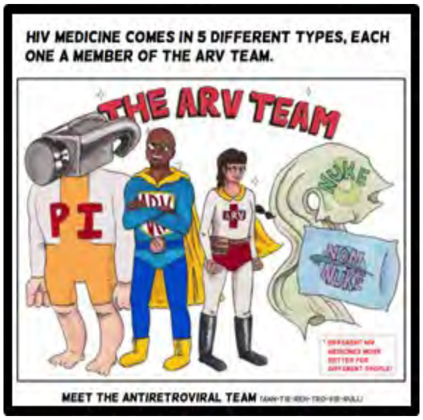
The HIV disclosure comic books are tools caregivers can use to disclose to their child(ren). They are meant for caregivers to use primarily with 9 – 12 year old children. Because disclosure is a process that takes place over time, the comics are versatile. Each comic can be used on its own or together, and caregivers can use them at any time before, during, or after disclosure. Each one also comes with a Caregiver Guide with tips for how to use the comics and for how to prepare for and approach disclosure.

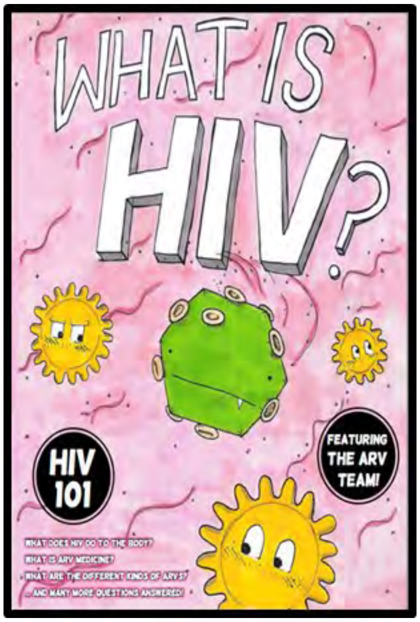
“**What is HIV?**” helps caregivers explain what HIV does in the blood. It also shows how antiretrovirals (ARVs) work together as members of **The ARV Team** to fight HIV and protect the body’s T cells.

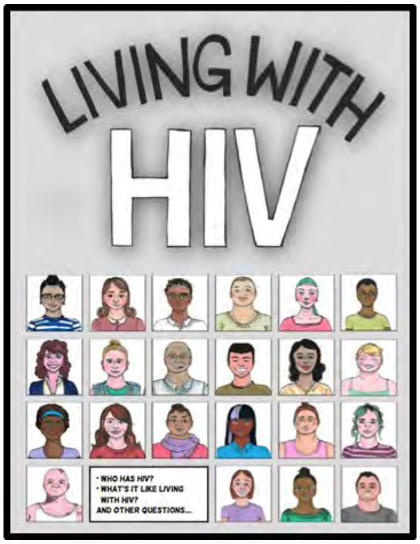
“**Living with HIV**” helps caregivers address stigma and the fears that some children may have about their caregiver’s health. It shows first that you can’t tell who has HIV and who doesn’t just from looking at people. It shows ways that HIV is **not** transmitted and describes how people living with HIV may have to navigate certain things because of their HIV, but are still just as normal as anyone else is.

The HIV Disclosure Comic Books and Caregiver Guides will be publicly available on the PHACS website (phacsstudy.org) to view, download, and print.

For more information about the storytelling disclosure resource or the HIV Disclosure Comic Series, please email Claire Berman (cberman@sdac.harvard.edu).







CAB HANDBOOK

The PHACS Health Education and Communication Committee (HECC) CAB Subcommittee presents the CAB Handbook!

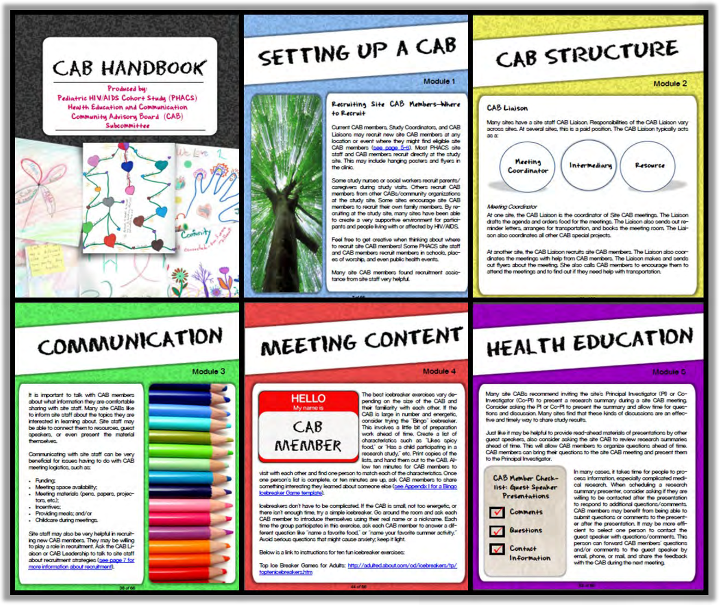
Through collaborative efforts with PHACS Study Coordinators, Site CAB Liaisons, and the PHACS CAB, the HECC CAB Subcommittee created the CAB Handbook. This dynamic resource was developed to provide site staff, current CAB members, and mothers/caregivers with guidelines for creating and sustaining successful site CABs.

The CAB Handbook consists of the following five modules, each filled with helpful current CAB practices and preferences:

1. Setting Up a CAB
2. CAB Structure
3. Site Cab Communication
4. Meeting Content
5. Health Education

The CAB Handbook may be accessed publicly on the PHACS website: https://phacsstudy.org/Education-Hub/CAB-Handbook

For more information or questions regarding the CAB Handbook, please contact Megan Lukschander (MeganLukschander@westat.com).



CAB HANDBOOK

Produced by:
Pediatric HIV/AIDS Cohort Study (PHACS)
Health Education and Communication
Community Advisory Board (CAB)
Subcommittee

SETTING UP A CAB

Module 1

Recruiting Site CAB Members—Where to Recruit

Current CAB members, Study Coordinators, and CAB Liaisons may recruit new site CAB members at any location or event where they might find eligible site CAB members (see page 5-6). Most PHACS site staff and CAB members recruit directly at the study site. This may include hanging posters and flyers in the clinic.

Some study nurses or social workers recruit parents/caregivers during study visits. Others recruit CAB members from other CABs/community organizations at the study site. Some sites encourage site CAB members to recruit their own family members. By recruiting at the study site, many sites have been able to create a very supportive environment for participants and people living with or affected by HIV/AIDS.

Feel free to get creative when thinking about where to recruit site CAB members! Some PHACS site staff and CAB members recruit members in schools, places of worship, and even public health events.

Many site CAB members found recruitment assistance from site staff very helpful.

CAB STRUCTURE

Module 2

CAB Liaison

Many sites have a site staff CAB Liaison. Responsibilities of the CAB Liaison vary across sites. At several sites, this is a paid position. The CAB Liaison typically acts as a:

Meeting Coordinator

Intermediary

Resource

Meeting Coordinator

At one site, the CAB Liaison is the coordinator of Site CAB meetings. The Liaison drafts the agenda and orders food for the meetings. The Liaison also sends out reminder letters, arranges for transportation, and books the meeting room. The Liaison also coordinates all other CAB special projects.

At another site, the CAB Liaison recruits site CAB members. The Liaison also coordinates the meetings with help from CAB members. The Liaison makes and sends out flyers about the meeting. She also calls CAB members to encourage them to attend the meetings and to find out if they need help with transportation.

COMMUNICATION

Module 3

It is important to talk with CAB members about what information they are comfortable sharing with site staff. Many site CABs like to inform site staff about the topics they are interested in learning about. Site staff may be able to connect them to resources, guest speakers, or even present the material themselves.

Communicating with site staff can be very beneficial for issues having to do with CAB meeting logistics, such as:

- Funding;
- Meeting space availability;
- Meeting materials (pens, papers, projectors, etc.);
- Incentives;
- Providing meals; and/or
- Childcare during meetings.

Site staff may also be very helpful in recruiting new CAB members. They may be willing to play a role in recruitment. Ask the CAB Liaison or CAB Leadership to talk to site staff about recruitment strategies (see page 7 for more information about recruitment).

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MEETING CONTENT

Module 4

HELLO
My name is
CAB MEMBER

The best icebreaker exercises vary depending on the size of the CAB and their familiarity with each other. If the CAB is large in number and energetic, consider trying the "Bingo" icebreaker. This involves a little bit of preparation work ahead of time. Create a list of characteristics such as "Likes spicy food," or "Has a child participating in a research study," etc. Print copies of the lists, and hand them out to the CAB. Allow ten minutes for CAB members to visit with each other and find one person to match each of the characteristics. Once one person's list is complete, or ten minutes are up, ask CAB members to share something interesting they learned about someone else (see Appendix I for a Bingo Icebreaker Game template).

Icebreakers don't have to be complicated. If the CAB is small, not too energetic, or there isn't enough time, try a simple icebreaker. Go around the room and ask each CAB member to introduce themselves using their real name or a nickname. Each time the group participates in this exercise, ask each CAB member to answer a different question like "name a favorite food," or "name your favorite summer activity." Avoid serious questions that might cause anxiety; keep it light.

Below is a link to instructions for ten fun icebreaker exercises:

Top Ice Breaker Games for Adults: http://adulted.about.com/od/icebreakers/tp/toptenicebreakers.htm

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HEALTH EDUCATION

Module 5

Many site CABs recommend inviting the site's Principal Investigator (PI) or Co-Investigator (Co-PI) to present a research summary during a site CAB meeting. Consider asking the PI or Co-PI to present the summary and allow time for questions and discussion. Many sites find that these kinds of discussions are an effective and timely way to share study results.

Just like it may be helpful to provide read-ahead materials of presentations by other guest speakers, also consider asking the site CAB to review research summaries ahead of time. This will allow CAB members to organize questions ahead of time. CAB members can bring their questions to the site CAB meeting and present them to the Principal Investigator.

CAB Member Checklist: Guest Speaker Presentations

☑ Comments

☑ Questions

☑ Contact Information

In many cases, it takes time for people to process information, especially complicated medical research. When scheduling a research summary presenter, consider asking if they are willing to be contacted after the presentation to respond to additional questions/comments. CAB members may benefit from being able to submit questions or comments to the presenter after the presentation. It may be more efficient to select one person to contact the guest speaker with questions/comments. This person can forward CAB members' questions and/or comments to the guest speaker by email, phone, or mail, and share the feedback with the CAB during the next meeting.

COOKING SHORTCUTS

A great way to make your life easier and even save you money is the use of cooking shortcuts. Shortcuts allow you to eliminate throwing out extras and even help you to take advantage of sales or buying food in bulk. Come up with your own variations to the following suggestions and remember that cooking at home is always better for you and your family because you can control the ingredients like salt, oil, and sugar, and even do away with the use of processed foods or artificial flavors.

Use an ice cube tray or small plastic bags to keep extra wine or broth fresh and in small portions for future cooking. Simply freeze the leftover portions and use them when you need them.

You can take leftover herbs like basil and oregano and freeze them, but if you want to take it up a notch, putting them in a food processor or blender with a bit of water can create a liquid herb infusion that you can always keep on hand.

Don't buy frozen pancakes or waffles; instead make a larger batch and freeze the extra ones. You don't need to defrost them; just put them in the toaster oven like you would with the ones you get from the freezer aisle.

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COOKING SHORTCUTS
(CONTINUED)

Don't toss brown bananas in the trash because they are too ripe; cut them up and freeze them in plastic bags for smoothies.

Aside from freezing, use the weekend to cut up vegetables for use in salads during the week (that way there is no excuse to not take one to school or work). You can also get a head start on your weekly cooking by sautéing onions, garlic and mushrooms for cooking meats or tofu, or use your extra time to make broth for soups.

Pasta sauce that is premade in a jar can be healthy, but you need to make sure the ingredients are simple (tomatoes, water, herbs); usually buying an organic variety ensures this. Whether you make your own or buy it in a jar, there are many uses for this sauce. Put a tablespoon or two of pasta sauce (adjust quantity to your preference) the next time you make a simple veggie soup; even add some beans, rice, quinoa, or pasta and you have a quick minestrone.

Use pasta sauce mixed with soy sauce and some honey or brown sugar instead of store-bought barbecue sauce. Take some pasta sauce, add diced tomatoes, basil, and oregano and top on some sliced toasted baguette (brush with oil before toasting if you like). You can even make salsa with leftover pasta sauce by combining it with diced tomatoes, onions, green/red peppers, jalapenos (optional), and cilantro (optional).

Take leftover potatoes (roasted or boiled) and add them to an omelet the next day. You can even use them for making veggie patties or fish cakes by mashing them and then combining them with a beaten egg, bread crumbs, tuna or salmon, vegetables (carrots, peas, celery, etc.), herbs, salt and pepper, and baking or frying them.

Using a marinade to make meat tender or give tofu more flavor is a wonderful way to make sure your meal is better. Usual marinades include wine or even buttermilk for chicken. But canned coconut milk is a great way to start off a curry dish. Just marinate chicken or tofu in a bowl with the coconut milk for about two hours.

(Submitted by Monica)

CROSSWORD PUZZLE KEY

Across:	**Down:**
3. AMP	1. Complications
5. Seage	2. Hazra
6. Florida	4. New York
8. Communication	7. Van Dyke
9. Three	

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