

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

KIM, PHACS CAB CHAIR:

My dear CAB members, it was an honor and privilege being your Chair. I appreciated every moment and second. I did my best to never take my role for granted, and I always put my best face on. To me, one of the best parts were the in-person meetings and retreats. It was like coming to a family reunion and actually visiting relatives who I love to see. I genuinely care about each and every one of you. I know not too many people will understand what it means to be fighting this battle, so when I let the world know that I am your Chair, I do it because I know all of you are supporting me. My favorite part of being Chair has been hearing every one of you speak about your journey and seeing all of us butterflies morph into greatness.



I know this is just the beginning of what our life journey has for us. Even though my two years as CAB Chair will be up soon, I know my relationship with the CAB members is not. The only advice I would give to future CAB Chairs is to continue to keep this CAB as great as it is. We've started a revolution of letting the world know we have a voice, and we will use it to let everyone know we will not stop until we have that cure. In the future, HIV and AIDS could just be a whisper in the history books.

LESLEY, PHACS CAB VICE CHAIR:

Wow, how the time has passed by so quickly! Election of new CAB Chairs will be happening in May and I just wanted to share with you how my time as your Vice Chair has been. First of all, thank you for electing me as your Vice Chair (in the middle of a term), and for entrusting me to help speak for us as a whole to the staff, researchers, and doctors.

(Continued on [page 2](#))

Advocating for others in this fight has always been a passion of mine, and I truly believe that your voice does make a difference. As the old saying goes, "the squeaky wheel gets the grease." Well, I'm so happy to be that "squeaky wheel" for you. I am here anytime and for anyone who needs to be heard, especially if it will help to promote the change that we need to get things done!

I have seen this CAB change for the better over the past few years. For example, look how much participation we have been getting in writing our newsletter, participation in other committees like HECC, helping to review publications and participant summaries, and also in helping to write some new studies! Let's not forget about our special time together during our CAB retreats, where we got to come together and put faces to

those lovely voices. Together we'd laugh, cry, sing, dance, break bread, color, draw, play games, and most importantly, continue to learn together. Those are the times that I will cherish the most, since we all are unique unicorns (well, I know I am!) that make up the dynamic CAB that we have today. Although I have been in this fight for 21 years now, there is still so much more to learn as technology and science continue to evolve, and I will continue to learn as much as I can. I hope to be a part of history one day to find a cure via PHACS! Wouldn't that be AWESOME? I

CONTINUED



would encourage you to constantly be willing to learn and be open-minded to any and all possibilities in this thing called "life." Never be afraid to use your voice! Happy 2017!

NEW YEAR, NEW BEGINNING

This is a new year, a new beginning, and all things will change. Happy 2017!

It has been twenty-one years for me. I only felt as though life was over once I found out that I was diagnosed with HIV. Being part of such an amazing group of people (the CAB) and being accepted for who I am not for what I am living with gives me strength to fight harder and harder each and every day. I fight not only for myself, but for others

as well. 2016 brought me through a lot of ups and downs. I realized that life is not over, it's just truly beginning.

"DON'T GIVE
UP ON HOPE
AND FAITH."

I have climbed through hoops to get to where I am now. I have wasted so much of my life living in fear. Now in 2017, I will push forward without

looking back and will have no regrets. I can see new beginnings in 2017 such as going to college to better my career and moving into my new home. I will continue to educate, empower, and help others in the same way that it was given to me. Always acknowledge that life is not over. The only thing you get out of life is what you put into it. Don't give up on hope and faith. If you have goals and dreams, reach and achieve them.

YOUR LIFE HAS A PURPOSE, YOUR STORY IS IMPORTANT, YOUR DREAMS COUNT, AND YOUR VOICE MATTERS! YOU WERE BORN TO MAKE AN IMPACT AND ALWAYS LIVE LIFE TO THE FULLEST.

Submitted by: Exxavia



NEW BEGINNINGS

Inspired by the fresh start of the 2017 New Year, the CAB chose a theme of “New Beginnings” for this edition of the PHACS CAB Newsletter. We asked the CAB to describe some of the new beginnings in their lives, as well as what it means to start anew.

There have been so many new beginnings in my life, but the most recent was the adoption of my family's new dog. It happened out of nowhere with no intention of getting a dog. We ended up at the Humane Society and a scrawny dog chose us.

He was a dog we all kind of overlooked until our third walkthrough. He was the only dog that wasn't barking and he looked sad. When we had our private interaction with this sad, severely malnourished dog, he just laid his head on us. He picked us, so we decided to give him a new beginning. By doing so, it made me realize that he was giving me a new beginning as well. I was getting this animal that ended up helping me in the end. I call him my soul dog.

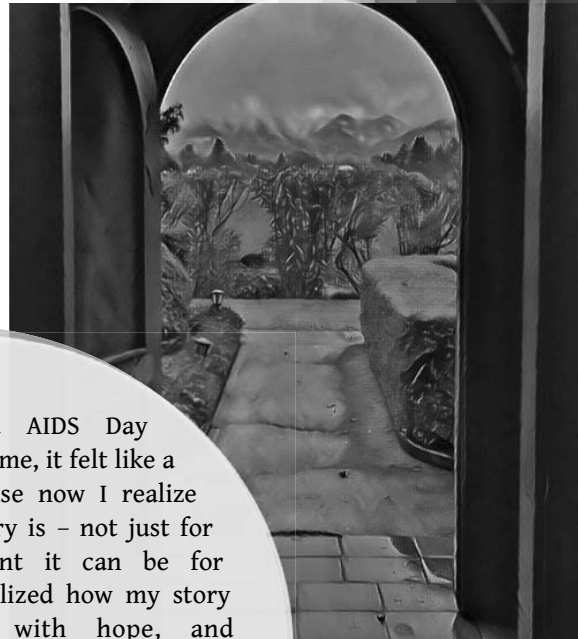
New beginnings should start with your journey of chasing a new beginning. What I mean by that is that it's okay to have a mindset that you want to start a new life, relationship, job, or just cleanse out the soul. A truly healthy person will realize they are always under construction. Even if it's a small journey, everyone can learn and find a way to have some form of a new beginning to get to a breakthrough. Just know that every journey starts with the first step. The best thing to do with a new beginning is not just talk the talk, but walk the walk.

Yes, it's okay to look back once you reach your goal and be amazed at where you started from just as long as you don't dwell on the past and fall back into old bad habits that you were rescued from.

I did a World AIDS Day presentation and to me, it felt like a new beginning because now I realize how important my story is – not just for me, but how important it can be for everyone else. I also realized how my story helped inspire them with hope, and encouraged them to share their story with me as well. A patient of mine, who is our site co-CAB Chairman, was incarcerated for 30 years. He thought that his life was over and that he would never be happy, but now he has met a woman and is getting married next month.

Regarding relapse—
know that everyday
is a new beginning.

My new beginning: I am a newly married woman to a man who looked past my flaws and accepted me the way I am. He loves me along with supporting me through being an HIV-positive woman. I am so grateful.



SITE 21: UNIVERSITY OF CALIFORNIA, SAN DIEGO-NEW YEAR'S RESOLUTIONS

I grew up here and went to the youth art group. I got a lot of help and this year I want to help others.

This year I want to get better - my health and my housing.

I know a lot of times I don't like to wait, but sometimes I wait for a door to open. I'm just going to open doors myself, all over the place! I personally want to see the Family Advisory Board (FAB) grow so I'm going to try to get more people to come to the meetings.

For a new beginning, I'm taking my medicines and I want to catch up because of lost time. I want to keep going to the doctor. It's time for me to take care of myself.

I would like all the women who are living with HIV to lose our fear. Be strong and believe in ourselves. We are not alone. Thank God we have our medications, keep going to the clinic, and rather than criticize each other, support each other.

I think we need to create more support groups.

Try to involve people in the CAB who haven't been very vocal before; everyone has a message to share.

I would like to say stay strong and be positive, no matter what comes our way. Keep our pride because we are special.

I'd like to have all the support that you women have. I am thankful you women support each other, but men like me need support too.

I think every day should start like it's a new year; leave the past behind us.

I would like to stay strong and be positive no matter what comes our way. Keep our pride because we are all special.

I don't know what to say but I want love and housing for me.

For my positive women in the program, come and support each other more. We need to support each other to succeed in care.

I know other CABs struggle with getting messages across; I hope they can communicate and bring people together.

PHACS MEMBER PROFILES



Pictured (from the left): Lourdes Richardson, RN, MSN, CCRP, Renee Smith, PhD, Karen Hayani, MD, and Alina Miller, BS.

KAREN HAYANI, MD

Hello! I'm Karen Hayani from University of Illinois at Chicago (site 15) and I'm happy to introduce myself and my team to you!

I am a Pediatric Infectious Disease Specialist and have been working with PHACS since 2007. I am originally from the state of New York. I did my training in Houston, Texas and then moved to Chicago, Illinois for my first job, taking care of babies and kids with all kinds of infections. Many of them

had HIV or were born to mothers living with HIV. I started working in the clinic with Dr. Kenneth Rich in the PHACS study, and in 2015 I became the Principal Investigator (PI) at our site. I work closely with our team (pictured on the left). We really enjoy working with children and mothers affected by HIV!

In the early years of my job, many of the babies born to mothers living with HIV had the virus. I was able to care for them in clinic and watch them grow. As new medicines for HIV became available, there were more and more treatment options so that even those with resistant viruses could get good treatment, do well in school, and be happy kids. Some of those "kids" have now grown up and are having babies of their own. Thankfully, fewer and fewer babies are now born positive due to the azidothymidine (AZT) protocol. That means that we now care for a lot of HIV-exposed babies and children that do not have HIV. Being a part of clinical research with the PHACS study allows us to keep our close relationships with the families that we have known, get to know new mothers living with HIV, and help to answer some of the questions about HIV that can only be answered by large clinical research studies. We are proud and

humbled to be a part of this very important study!

It has been really rewarding to treat families for so many years and to see all the positive changes in HIV medical care that have taken place. Getting to know families has given us insight into some of the really tough problems that families affected by HIV deal with. Whether it is getting the medicines for HIV-positive patients, transportation to clinic visits, or dealing with the stigma of HIV infection, the challenges can sometimes seem like mountains that are so difficult to climb! At our site, we have an active CAB that is run by our staff members, led by Renee, Lourdes, and Alina. The CAB meetings have been a great place for our patients to get to know each other and share their experiences dealing with HIV. We enjoy getting to know our patients in a different setting, listening to their concerns, providing them with resources, and helping them to make connections that are supportive.

We want to thank all the patients at our site for their participation! It continues to be an honor and a pleasure to serve you and work with you for a bright and healthy future for your children!

BRANDON

My name is Brandon and I was born HIV-positive. I was born into a family involved in drugs and violence. I never knew my biological parents, both of whom are deceased now. I was adopted by a loving family when I was

only a few weeks old and have been with them ever since. I had a foster sister who passed away from AIDS and I always wondered, "What significance does my life hold over hers?" I have struggled with depression, the fear of myself, stigma, and the biggest question, "Why me?" I've been considered a death sentence, a burden. I never

knew how much weight a single word could hold. After everything I went through and still being alive, I felt like I had a debt to pay, so I decided to dedicate myself, in memory of my sister and many others, to try and make a difference.

(Continued on page 6).



PHACS MEMBER PROFILES

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I worked as a Medical Assistant (MA) in pediatrics for three years. After that I felt like I wanted more out of life and wanted to make an impact. I decided to join the University of Florida Center for HIV/AIDS Research, Education and Service (UF CARES). I currently work as a Peer Navigator where I use my story to help encourage, motivate, and get patients the support they need by letting them know that they too can overcome this battle and that they are not alone. I recently used my story to give a presentation for our World AIDS

Day event we had here. Being part of PHACS has been a great experience. It was a fairly new experience to me and everyone has been very welcoming and supportive. I have to say the best thing about being part of PHACS for me has been not only the people but being able to have a voice where people listen and care.

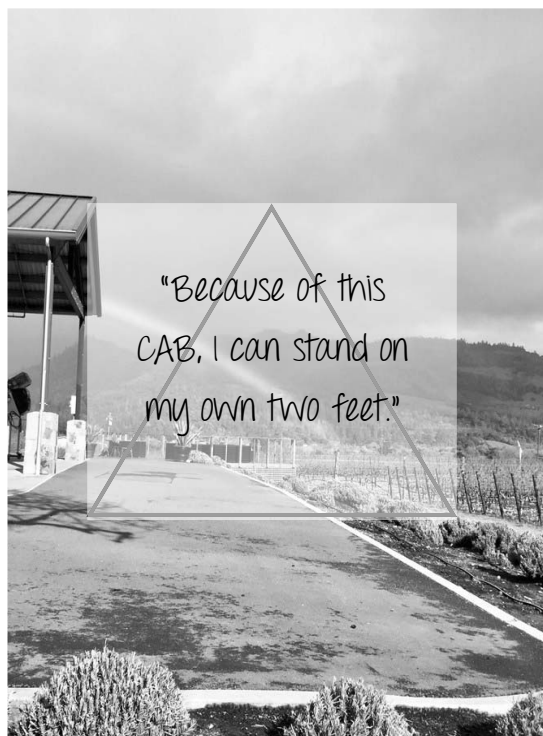
We may not always be dealt a fortunate hand in life, but it is up to us to decide how we play it. Do you crumble under the weight and

struggle of life? Or do you rise up?

"Life is 10% what happens to you and 90% how you react to it."- Charles R. Swindoll.

"What lies behind you and what lies in front of you, pales in comparison to what lies inside of you." - Ralph Waldo Emerson.

MY BEGINNING



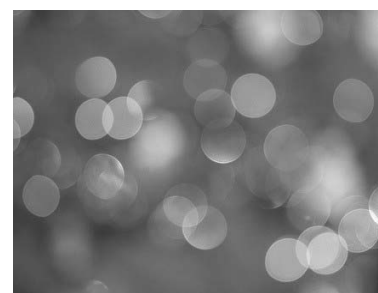
"THIS IS HOW IT ALL STARTED."

In 2002, I was very naïve about HIV/AIDS. I was very alone and had nowhere to turn to, so I ran away and immigrated to another country for help. I did that and it was the best decision I ever made. No regrets. While getting help, I got involved with the CAB. That's when my journey began. I got very educated, and at

the same time I was helping others. The CAB helped me to understand about HIV/AIDS. I felt safe. I got knowledgeable about the different research for HIV/AIDS. I became part of the Leadership, giving my views at the meetings and on conference calls. I have met a lot of people in the CAB and we really are like family - my family in this country.

I am no longer shy, naïve, and uneducated.

Because of this CAB, I



can stand on my two feet. I don't feel alone anymore. Here I am after 15 years and still going strong because of the PHACS CAB.

Submitted by: Delia

WORLD AIDS DAY



WORLD AIDS DAY AT SITE 19

On December 1, 2016, Texas Children's Hospital in Houston, Texas held the Annual World AIDS Awareness Day.

The event brings the awareness, support, and HIV education to all the staff and families walking the Auxiliary Bridge at Texas Children's Hospital. This is also a time to remember every person who has lost his/her battle to AIDS. We offer hope and encouragement to all the children and families living with HIV. Every year we give away red ribbons, HIV

informational brochures, and information sheets listing the local HIV testing sites, treatment options, and research opportunities. We look forward to 2017 as we continue providing excellent care, treatment, and research opportunities to all the children and families of Houston and the surrounding Texas cities.

Submitted by: Theresa



WORLD AIDS DAY

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WORLD AIDS DAY AT SITE 10

World AIDS Day in New Jersey included an hour of silence on the steps of Newark, New Jersey City Hall, and a day of celebration of World AIDS Day at the Terrance Ball Room.

Submitted by: Kimberly



PUBLICATIONS IN THE NEWS

BREAKING NEWS

Since the last PHACS CAB Newsletter in July 2016, PHACS has had **TWELVE** manuscripts accepted to scientific journals and **TWO** abstracts were presented at scientific conferences.

Find full citations, links to publications, and research summaries on the PHACS website: <http://phacsstudy.org>.

Publications:

"The Burden of oral disease among perinatally HIV-infected and HIV-exposed uninfected youth." This manuscript is in the *PLoS One*. Lead author Barbara Moscicki, MD is a Professor of Pediatrics at the University of California, Los Angeles and is Co-Chair of the Adolescents and Young Adults Working Group (WG).

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LIVE

PHACS CAB
NEWSLETTER

January 2017

PUBLICATIONS IN THE NEWS

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Recap:

Since the last PHACS CAB Newsletter in July 2016, PHACS has made the following contributions:

12 manuscripts accepted to scientific journals; and

2 abstracts presented at scientific conferences.

Publications:

“Genetically determined ancestry is more informative than self-reported race in HIV-infected and –exposed children.” This manuscript is in *Medicine*. Lead author Stephen Spector, MD is the Principal Investigator at the University of California, San Diego and a member of the Scientific Leadership Group.

“Brain and cognitive development among US youth with perinatally acquired human immunodeficiency virus infection.” This manuscript is in the *Journal of the Pediatric Infectious Diseases Society*. Lead author Kay Malee, PhD is a Psychologist at Northwestern University Feinberg School of Medicine and Co-Chair of the Neurodevelopmental and Neurology WG.

“Deformed subcortical structures are related to past HIV disease severity in youth with perinatally acquired HIV infection.” This manuscript is in the *Journal of the Pediatric Infectious Diseases Society*. Lead author Christine Paula Lewis-de los Angeles is a MD/PhD thesis student at Northwestern University Feinberg School of Medicine.

“Learning and memory in children and adolescents with perinatal HIV infection and perinatal HIV exposure.” This manuscript is in the *Journal of the Pediatric Infectious Diseases Society*. Lead author Sharon Nichols, PhD is a Neuropsychologist at the University of California, San Diego and a member of the Neurodevelopmental and Neurology WG.

“Associations of memory and executive functioning with academic and adaptive functioning among youth with perinatal HIV exposure and/or infection.” This manuscript is in the *Journal of the Pediatric Infectious Diseases Society*. Lead author Patricia Sirois, PhD is a Neuropsychologist at the Tulane University School of Medicine and a member of the Neurodevelopmental and Neurology WG.

“Longitudinal evaluation of language impairment in youth with perinatally acquired HIV and youth who were perinatally exposed to HIV and uninfected.” This manuscript is in the *Journal of the Pediatric Infectious Diseases Society*. Lead author Sean Redmond, PhD is a Professor at the University of Utah and a member of the Hearing and Language WG.

“Contributions of disease severity, psychosocial factors, and cognition to behavioral functioning in youth perinatally exposed to HIV.” This manuscript is in *AIDS and Behavior*. Lead author Katrina Hermetet-Lindsay, MS is a PhD Student at Lehigh University.

“Surveillance monitoring for safety of in utero antiretroviral therapy exposures: current strategies and challenges.” This manuscript is in *Expert Opinion on Drug Safety*. Lead author Rebecca Zash, MD is Research Fellow at the Harvard T.H. Chan School of Public Health.

“Insulin resistance in HIV-infected youth is associated with decreased mitochondrial respiration.” This manuscript is in *AIDS*. Lead author Jody Takemoto, PhD is an Assistant Professor at the University of Texas at Tyler.

“Roles of medication responsibility, executive and adaptive functioning in adherence for youth with perinatally acquired HIV.” This manuscript is in the *Pediatric Infectious Disease Journal*. Lead author Patricia Garvie, PhD is a Neuropsychologist at Children’s Diagnostic and Treatment Center and a member of the Neurodevelopmental and Neurology WG.

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PUBLICATIONS IN THE NEWS

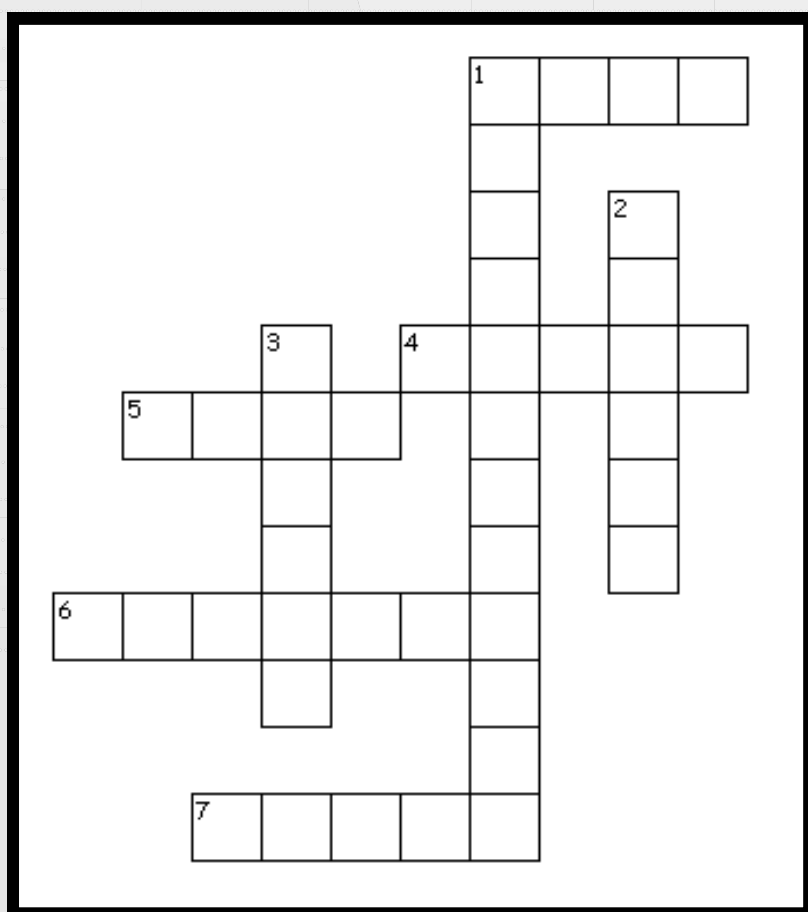
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Abstracts:

"Perspectives in community engagement: Establishing and sustaining Community Advisory Boards." This abstract was presented at the International Maternal Pediatric Adolescent AIDS Clinical Trials (IMPAACT) ICAB Meeting in Arlington, VA, June 14, 2016.

"The role of maternal vitamin D and iron status on developmental outcomes and head circumference in HIV-exposed uninfected infants." This abstract was presented at the World Congress of Pediatric Gastroenterology, Hepatology, and Nutrition (WCPGHAN) Meeting in Montréal, Canada, October 5-8, 2016.

CROSSWORD PUZZLE



Instructions: complete the crossword by referencing articles in this newsletter! Answer key on [page 21](#).

Across

1. From Jeanie's article, what felt so heavy in her hand?
4. The participant summary explored what type of disease over time in teens and young adults living with HIV?
5. This company helped create a new beginning for the community meeting space at Site 12.
6. Brandon works at the University of _____.
7. This network calls themselves, "A Sisterhood of Women Facing HIV Together."

Down

1. The goal of the first two PHACS short films is to reach whom in the study?
2. This many manuscripts were accepted to scientific journals since the July 2016 newsletter.
3. According to Dominique, individuals must act on what they _____.



LIVE WITH A PURPOSE

Every day we wake up to the sun, but at times, there are some people who just don't wake up at all. Life is fragile, but with the right care and proper steps, we can experience the wonders of what lies ahead. Now, keep in mind that if you wake up it means your day was meant to be used for a purpose. Why else should we wake each day if there was not a dream to get accomplished or a memory to be shared with a family or friend?

Life has a purpose. The time we spend will lead to the results we shall have. By taking the right actions that help us build upon who we are, the discoveries we wish to make can become real. Let's call it baby steps. When you apply this philosophy, go forward with a kind heart and a determined spirit, and then you will achieve what you desire. Embrace the New Year by taking these three steps, and watch as a new beginning unfolds.

1. BE WILLING TO GROW.
2. TACKLE OBSTACLES WITH THE BELIEF YOU CAN DO IT.
3. ACT ON WHAT YOU DESIRE.

Be willing to grow.

Learning is very important, even after high school, college, or any formal education. There are some great benefits in picking up a book. People can learn a new word, gain an understanding of an interesting fact, develop new ways to manage finances, and the list goes on and on. Learning does not have to mean reading; you can build upon yourself by having experiences. People can also learn by traveling to a new place, trying new foods, and/or listening to the stories of strangers.

There are great benefits to building upon the knowledge of the mind, and by doing so, people become better prepared for the world ahead. Be willing to grow and exercise the strengths you have. You'll be amazed at what the results lead to!

Tackle obstacles with the belief you can do it.

Self-perception is at the core of anyone's development. With each step forward you can make progress, not just physically, but also mentally. Your mind is your strongest tool. If you said to yourself, "I cannot," then you take away all possibilities and hope for the task to be accomplished. Doubt is the key cause of failure. If a person does not believe in their abilities, then the likelihood of success becomes nearly zero. Imagine how it feels when

someone tells you, "no you can't," compared to someone telling you, "I believe in you." Encouragement from others is just as important as the support within yourself. Take a moment to evaluate how you view your abilities. Do you ever think to yourself that something isn't possible? Attempt to switch your mentality. Instead of having disbelief, try to find new ways to overcome the challenge. Do not give up when it gets tough, but rather look for innovative ways to find a solution.

Act on what you desire.

So often in life we get a chance for something, but never do it. We hesitate, we question, we wait, but never take the next steps to achieve what we want most. Take a moment to think of a time when you didn't do something you wish you had. Life is constantly bringing chances to grow, but we often don't go for it. If you desire to experience something in your life, do it. Desire is only such if we do not take action.

The steps I shared are only the beginning. There are many great ways to grow and reach the goals you set for yourself. Postponing leads to never actually doing it.

Now it is up to you.

Submitted by: Dominique

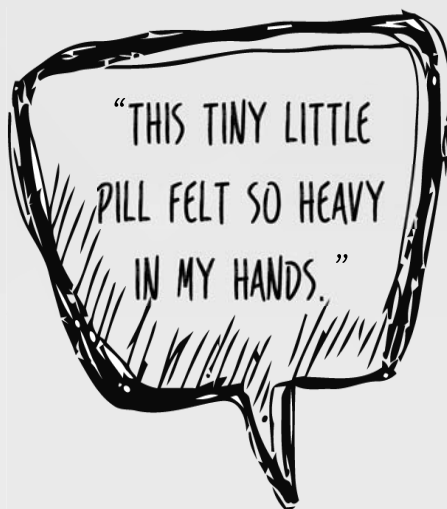
A PILL IN MY HAND

Taking HIV medications is not an easy thing. I know it firsthand. In 2015, I was prescribed HIV medications by my doctor. The idea of taking medications for the first time in nearly 14 years since my diagnosis filled me with tremendous anxiety, so I refused to start them. I just couldn't bear the thought. It was too difficult, too intense, and too much pressure on me.

I felt like I needed assistance in initiating medication use; someone to talk to, someone I could confide in, and someone I could trust who could tell me that I was going to be ok. I first decided to call my doctor. She informed me that the current recommendations were for HIV patients to take medications as soon as possible instead of waiting until their immune systems deteriorated. She said that it was important for me to take my pill because it would keep me healthy. I felt encouraged and motivated, and told her that I would start and that she had my word. The night before I was supposed to start my pill, I had a severe anxiety attack and couldn't sleep. I was restless and kept tossing and turning in my bed.

The next morning I was anxious again and had a pounding headache. My hands were sweating profusely and I felt like my heart was going to explode. I couldn't get myself to take the pill at the planned time. I ran errands that day trying to distract myself, and then returned home only to find that my pill was still waiting for me. I guess I had to face the music at that point. I separated my HIV pill

from my other medications, took the pill in my hand, and observed it for some time. This tiny little pill felt so heavy in my hand. I felt sick to my stomach and couldn't grasp the concept of taking HIV medications. This meant that the disease was real and that I had to accept that I was living with it. Before the medications, I felt free and easy because all I took were vitamins to keep my bones strong. Now this! It was too much to digest. I needed more support to start so I called a friend. She told me to look at this experience from a positive angle, to see the pill as an avenue of hope, livelihood, health, and longevity. It started to make sense; I had to stay healthy for myself and for my kids.



Even though that one pill felt heavy and overwhelming, I decided to take



it because I knew it would protect me and keep my numbers high. I now understand how it feels to take HIV meds and I even understand why some people don't. It's not easy, but guess what? It will save your life. Now, I'm excited and I've been compliant for over a year. I haven't missed a single dose. Compliance is critical with these medications so that you don't develop resistance to the virus. Talking to someone was also important for me because it made me feel like I wasn't alone in my decision-making and that I would survive this experience, and become stronger from it.

Submitted by: Jeanie

RESOURCES

CONNECT

INFORM

ENGAGE

The Body: HIV/AIDS Podcast Central:

<http://www.thebody.com/content/art47682.html>

Greater Than AIDS: Empowered Campaign:

<https://www.greaterthan.org/campaigns/empowered>

BABES Network: A Sisterhood of Women Facing HIV Together:

<http://www.babesnetwork.org/about>

The Well Project: Starting a Support Group:

<http://www.thewellproject.org/hiv-information/starting-support-group>

FHI 360: Positive Connections, Leading Information and Support Groups for Adolescents Living with HIV:

<https://www.fhi360.org/sites/default/files/media/documents/positive-connections-2013.pdf>

ON LOCATION: SITE CABS



Site 16: University of Puerto Rico Medical Center - The final activity of 2016 included a presentation by a psychologist about a study involving interviews with patients about their transitions.



"You never know how truly blessed you are until you see those glorious faces around the table."

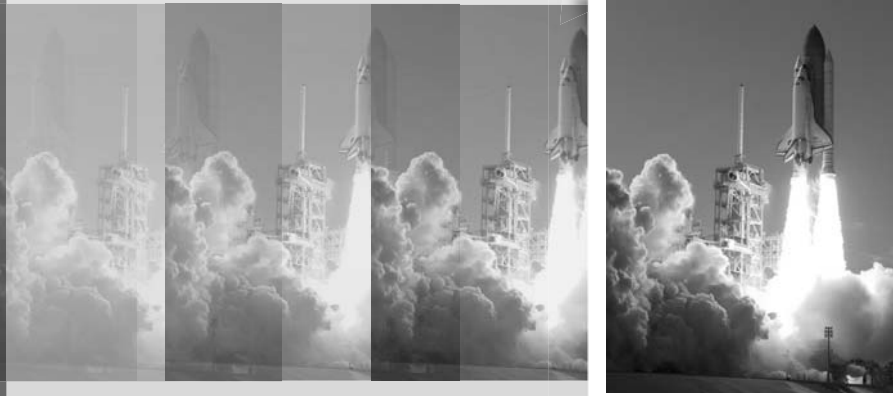
-Kim

Site 19: Texas Children's Hospital - The CAB hosted their annual Thanksgiving dinner.



Site 12: Children's Diagnostic and Treatment Center - IKEA helped create a new beginning for the site's community meeting space.

A NEW CHAPTER



Now that you've gone through an entire semester, what advice do you have for others looking to start their college education?

My advice would be to stay focused, stay smart, and keep peace of mind.

How has starting college been a new beginning for you?

Starting college has been a new beginning for me because I consider it as another chapter in my book of life. It's a new chapter of opportunities, choices, and responsibilities.

What has been the most challenging part of starting college?

The most challenging part of starting college has been staying focused.

What are you looking forward to as your start a new semester?

I am looking forward to meeting new people.

What has been the most exciting part of your new beginning?

The most exciting part of my new beginning is the opportunity to take on new challenges and meet new people.

What has been one of the biggest life lessons you've learned so far after starting college?

One of the biggest life lessons I have learned is to network with people because you never know when you are going to need those people.

Any other thoughts?

I chose a space shuttle as my picture because it symbolizes a new journey into unknown territory. To reach that territory, you have to break through the atmosphere. The atmosphere represents odds holding you back to reach that goal.

Submitted by: Gamon

CAB PLAYLIST

Below are some of the songs CAB members are listening to in 2017:

Song			Artist	Song			Artist
1	🔊	You Don't Own Me ft. G-Eazy	Grace	6	🔊	Blue Ain't Your Color	Keith Urban
2	🔊	Animals	Maroon 5	7	🔊	Careless Whisper	George Michael
3	🔊	Wonderwall	Oasis	8	🔊	Pink	Aerosmith
4	🔊	24K Magic	Bruno Mars	9	🔊	Kiss From a Rose	Seal
5	🔊	Come Down	Anderson .Paak	10	🔊	Fancy	Iggy Azalea

MY VOICE MATTERS: THE PHACS FILM SERIES



We are excited to announce a PHACS first – in 2017, we will be releasing a series of short films about our study and its participants and staff. As many of you know, we hired a filmmaker to come to our Fall 2016 Network Meeting and interview PHACS members. Over 30 PHACS members volunteered to participate in interviews, including Young Adult CAB (YACAB) members, Adult CAB members, PHACS leadership, site Principal Investigators, and Study Coordinators. We got to hear amazing, incredible stories from every single person we interviewed. We heard from clinicians and participants alike about experiencing the course of the HIV epidemic, and about what it means to them to be part of PHACS. We

heard about experiences with stigma and disclosure, and about the sense of family and belonging that many feel because they are part of PHACS. We heard from CAB members about feeling safe and understood by each other at our Annual Network Meeting. We also heard about how spending time in-person with other CAB members makes them feel more empowered to do good work when they return to their own communities around the country. We heard from staff about what they've learned from their patients over the years, the love and care they feel towards our participants, and how they've seen the epidemic evolve since the first reports of HIV/AIDS in the US appeared in 1981. A YACAB member born with HIV in 1981 told us what it was like to grow up with HIV in the 80s. Other young adults shared their own experiences navigating life with HIV. In short, the stories we heard show the depth of our connections to each other as colleagues and friends, and show our commitment to working together to do research that will benefit families all over the world.

We are now in the process of editing the first two films in our series. One is a short documentary featuring the stories of the YACAB members who were interviewed. It highlights their individual stories and hopes for the future. YACAB members also share why they participate in research and what their hopes are for PHACS moving forward. The

second shorter film features Adult CAB members and explores what it means to be connected to each other, their connections to the research study, and why their voices matter so much in research. The goal of these films is to reach other participants in the study, who may not have this type of support in their own lives, and to raise awareness and reduce stigma outside of PHACS about HIV. Sites may choose to show these films to help support recruitment and retention for the study. The final two films will be much shorter and will focus more on the story of PHACS: where we've been, what we've learned, and where we are going from here. They will also feature some personal testimonials from our wonderful CAB and YACAB members. These films are the first ever to feature our participants and staff, and they never could have happened without our CAB and YACAB, and without the dedication of our PHACS staff and leadership. A huge thank you to everyone who has worked to make PHACS and its CAB and YACAB strong over the years!

Submitted by: Claire



PHACS Clinical Sites



OUR FIGHT

My Name is Brandon. I'm 25 years old and I was perinatally infected with HIV. As I mentioned in my PHACS member profile, I was born into a family that was involved with drugs and violence, but was adopted by a loving and caring family just a couple of weeks after being born.

I know what it means to struggle with this disease. I know what it means to struggle with depression, not wanting to take medications, and just wanting to feel normal. I know what it is like to think that you are not good enough for anyone. If you do meet someone, when do you disclose? If you don't, then you might end up in jail. Can you trust them? And if so, could you bear the weight of potentially risking someone's life who you love and care about? It is a draining fight mentally and physically but this is OUR FIGHT. I am here to let you

know that you are not alone. Although having this disease is a terrible thing to deal with, it has been one of the greatest things to happen to me.

I am here to
let you know that
you are not alone.

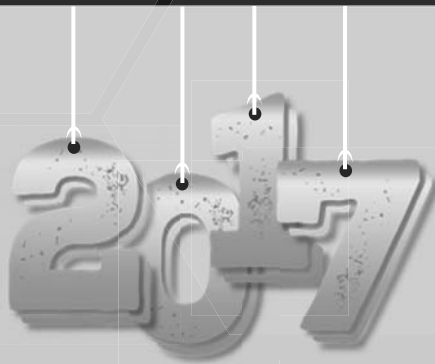
Had it not been for this, I wouldn't have been with my family I now know. It has made me humble and made me look at life differently. I had a foster sister who passed away from AIDS. We were just a few years apart. I've always wondered what significance my life holds over hers? That is why I have dedicated myself

in memory of her and many others who have passed. Life is 10% what happens to you and 90% how you react to it. If we want change, then we have to be the change; we must continue fighting for what and who we love. No matter how dark or grim things may seem, there is always hope because as Christopher Reeve said, "Once you choose hope, anything's possible."

"May we each find in ourselves the courage we forgot we have, to see the beauty we forgot is inside us, while battling the demons we forgot we can slay, on a battlefield we forgot we can win."
— Agnostic Zetetic

Submitted by: Brandon

UPCOMING EVENTS



February 7: National Black HIV/AIDS Awareness Day

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

March 13 - 14: PHACS Spring 2017 Leadership Retreat

March 20: National Native HIV/AIDS Awareness Day

April 10: National Youth HIV and AIDS Awareness Day

April 18: National Transgender HIV Testing Day

May 18: HIV Vaccine Awareness Day

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

June 5: HIV Long-Term Survivors Day

June 27: National HIV Testing Day

PARTICIPANT SUMMARY



BLOOD TEST ABNORMALITIES AND LIVER DISEASE OVER TIME IN TEENS AND YOUNG ADULTS LIVING WITH HIV

Liver disease in people with HIV can be due to many factors, including the HIV virus. Typically, we find liver disease by removing a small piece of the liver and examining it. This process is called a liver biopsy, and it can be uncomfortable and can lead to other problems, such as bleeding and infection. Some blood tests in adults have been used to tell if they may have liver disease without needing to have a liver biopsy. We wanted to study how useful these blood tests might be in teens and young adults living with HIV.

WHO PARTICIPATED



We looked at teens and young adults aged 15 to 20 years enrolled in the PACTG 219C and REACH studies. We included 1,612 youth living with HIV and 173 youth without HIV.

WHAT WE DID



One way to learn if someone has liver disease is to use a liver biopsy. This involves removing a piece of liver with a needle so it can be examined.

We looked at the levels of several blood tests that are used to tell us about the health of the liver. These included special liver tests called AST and ALT. We also looked at part of the blood cell called a platelet, which helps to form blood clots. **By looking at these levels, we were able to calculate scores that helped us to estimate the health of the liver.** We compared these scores in teens and young adults living with HIV to those without HIV and then looked at the trends in these scores over time among those living with HIV.

WHAT WE FOUND



Liver scores increased over time among teens and young adults living with HIV. High scores may be linked to unhealthy livers.

On average, teens and young adults living with HIV had higher scores than those without HIV at one of their visits (one point in time). This means that they may have had more risk for problems with their livers.

Over time, scores increased each year among teens and young adults living with HIV. Higher scores may be linked to unhealthy livers. Teens and young adults with better controlled HIV tended to have fewer high scores compared to youth with poorly controlled HIV infection.

WHAT WE LEARNED



Teens and young adults living with HIV may be at risk for problems with their liver health. Staying on medications for HIV and taking them regularly to keep HIV under excellent control is important to staying healthy.

We need more research in order to determine what these scores tell us about the risk of liver damage and disease in teens and young adults living with HIV.

C073. Kapogiannis BG, et al. Prevalence of and Progression to Abnormal Non-Invasive Markers of Liver Disease (APRI and FIB-4) among US HIV-infected Youth. AIDS 2015; <http://www.ncbi.nlm.nih.gov/pubmed/26959353>



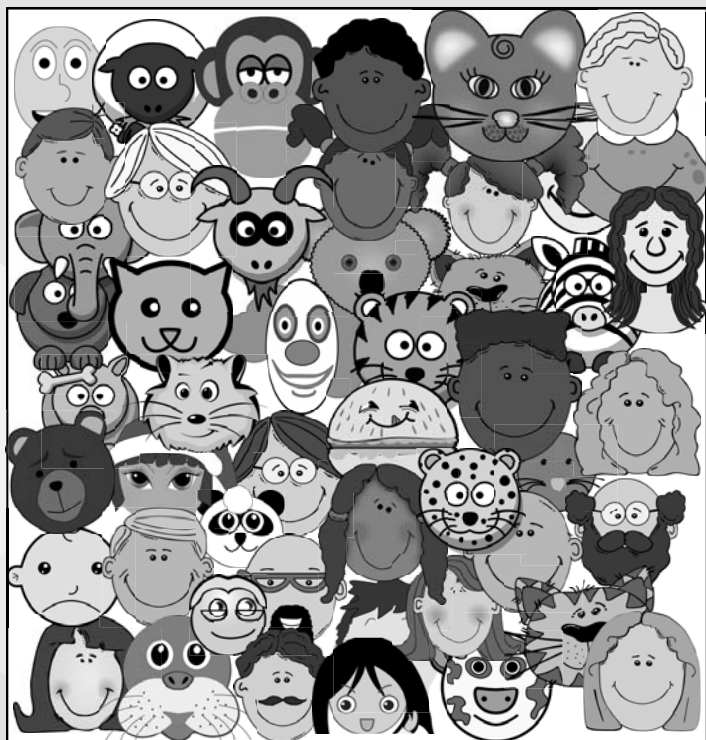
For more information, contact:
Claire Berman | Director, Health Education & Communication
cberman@hsph.harvard.edu | 617-432-1853

CAB KIDS

This edition of CAB Kids features 3 fun activities. Answer keys to activities 1 and 2 may be found on page 21.

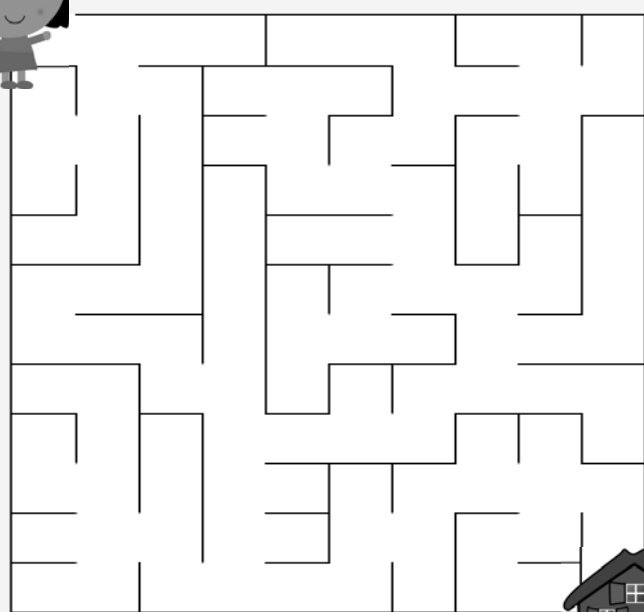
1

Look at all these beautiful faces! Can you find the panda?



2

It's cold outside! Help Macy find her way back home.



3

What sports would be hard to play in ice skates?

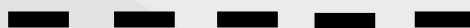
THINK ABOUT THAT!



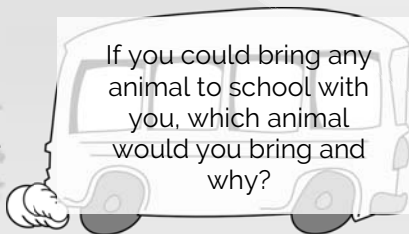
What vegetable would make the funniest hat?

A shrimp's heart is in its head

Journey through some fun facts and questions!



If you could bring any animal to school with you, which animal would you bring and why?



What's your favorite day of the week?

Say what?



A group of pugs is called a grumble.



There are about 115 species of pine trees.

What songs do you like to sing when you ride in the car?

TRANSITIONS



One of the most talked about areas of focus for PHACS has been transition to adult health care. Yet young adults in PHACS may not identify with this concept in the same way that clinicians and researchers do; they may instead think about a broader shift to adulthood. This means that the idea of transitioning to an adult health care provider may or may not be of the most importance to them, or at all. During the PHACS Fall 2016 Network Meeting, the HECC organized a panel focused on the topic of transition to adulthood and adult health care.

Panelists represented four young adult voices in PHACS joined by an adult CAB member, Principal Investigator of the PHACS Coordinating Center, Russ Van Dyke, MD, and Co-Chair of the Adolescents and Young Adults Working Group, Claude Mellins, PhD.

The goal of the panel discussion was to explore priority areas identified

by young adults around transition to adulthood and adult health care. The panel looked to explore ways these key areas can be addressed to promote positive outcomes in both clinical practice and in research.

The young adult panelists first talked about what it means to be an adult.

“It’s someone who takes responsibility for their lives, no matter what age,” said a YACAB member.

The conversation of adulthood centered around topics of responsibility, independence, and making choices.

Young adult panelists were asked to talk about areas of life that they consider to be their top priorities. Their priorities included finances, social life, money, happiness, and finding a purpose in life. Since transitioning can be a very tough process, it’s helpful to understand what strengths young adults may already have. This may include those that family members and/or health care providers don’t always see. Young adult panelists stressed the importance of not just focusing on an HIV-affected young adult’s medical health.

“Doctors are sometimes only focusing on someone’s mental state,” said a YACAB member. He then talked about the young adult perspective. Referring to young adults, he stated, “They’re seeking support even outside of medical care.”

Claude stated that there are many studies now focusing on the topic of resilience. Young adults who have

“THEY’RE SEEKING SUPPORT EVEN OUTSIDE OF MEDICAL CARE.”

had to go through struggles may have built up tools to face life’s challenges. Health care providers should look to harness some of those strengths.

Many young adults struggle to find support during their transitions. Our young adult panelists had some experience with support and education about health, as well as the skills needed to navigate the health care system. Many young adult panelists talked about the importance of family support. Some felt that they had support from their health care providers and PHACS team members. Others talked about the challenges of transitioning even with lots of support.

“Navigation of [the] health system can be improved,” said a YACAB member. “I have gotten so comfortable [at my pediatric clinic], which makes it hard to let go and transition.”

Understanding adulthood as it is perceived by young adults may help with understanding how to support them as they transition. The second part of the panel discussion focused on how PHACS sites can help to support young adults set goals and transition to adult health care.

Continued on page 20.

TRANSITIONS

CONTINUED

Feedback from the panel included:

PREPARE



- Prepare young adults to know their rights as research participants.
- Start transition conversations with youth at an early age (11-12 years old).
- Discuss transition with youth, as well as their families. Get their feedback and approval.
- Try to increasingly give young adults more responsibility.
- Look into adopting integrated case management services that help everyone get together and help youth transition.

CONNECT



- Keep young adults involved in each step of the transition process.
- Let young adults meet with their new adult health care providers before they transition.
- Help to expand a young adult's support network.
- Establish trust so that young adults trust their pediatric doctor's recommendations for new doctors.

DISCUSS



- Brainstorm a strength they have that will help with transitioning.
- Help young adults get a realistic picture of what to expect as they transition. Tell them one of the easier parts of transitioning and then one of the harder parts.
- Pay attention to what's going on outside the clinic. Try to get a well-rounded picture of the young adult. Talk about their relationships, jobs, school life, and housing. If other aspects of their lives aren't thriving, then their health may suffer as well.

As PHACS moves into exploring the complex topic of transitioning, the team is looking at how to measure the “success” of transitioning. Panelists talked about measuring success by monitoring viral load and medication adherence. A YACAB member suggested developing checklists across the sites to measure young adults' successes.

The panel discussion reflected one of

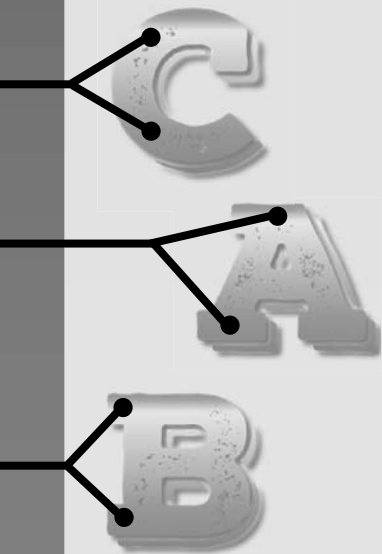
the ways that researchers can be inclusive of young adult and community member voices. The panelists commented on ways that PHACS can continue to include the community in its research initiatives. The young adult panelists encouraged researchers to reach out to the community, ask community members for feedback, and explain how research results are published. “Have the CAB weigh in on the

meaning of our results as they come out,” said Claude. “Help us think about what our results mean from a policy level as well as other levels.”

“Communicate,” said a YACAB member. “And continue showing love.”

Submitted by: Megan

CAB GLOSSARY



Acute HIV Infection: (Also known as primary HIV infection). The period of rapid HIV replication (increasing amount of virus in the body) that occurs shortly after becoming infected with HIV.

Data: Information, especially facts or numbers, collected within a protocol for examination and consideration for analysis to find bigger trends.

Food and Drug Administration (FDA): The agency responsible for ensuring the safety and effectiveness of medicines, vaccines, and medical devices approved for use in the US.

Informed Consent: The process of learning all of the key facts and potential benefits or risks about a clinical trial before deciding whether to participate. The informed consent process continues throughout the study to provide information for participants, some of whom may decide to stop participating.

Principal Investigator (PI): A medical professional under whose direction a clinical trial is conducted at a research site. A Principal Investigator is responsible for the overall conduct of the clinical trial at his/her site.

Regulatory Affairs (RA): The department within a regulated industry that involves compliance with government rules and interaction with government regulatory agencies.

CROSSWORD PUZZLE KEY

Across:

- 1. Pill
- 4. Liver
- 5. IKEA
- 6. Florida
- 7. BABES

Down:

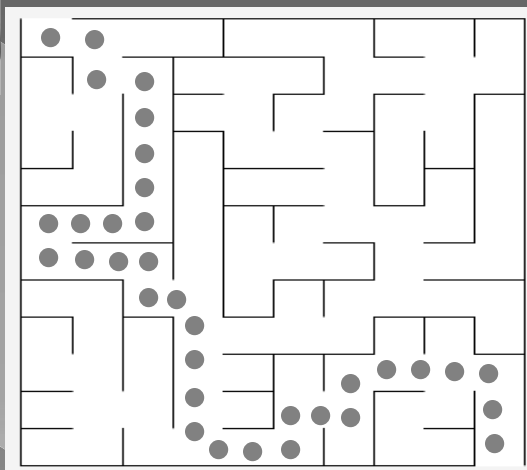
- 1. Participants
- 2. Twelve
- 3. Desire

CAB KIDS ACTIVITIES KEY

1



2



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