

FROM OUR CAB CHAIRS

A COMMUNITY ADVISORY BOARD NEWSLETTER PUBLISHED BY:

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

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Stephanie, PHACS CAB Chair:

Happy New Year! The CAB had a very exciting 2019. Since the last newsletter, the CAB participated in the 2019 Fall CAB Retreat and Network Meeting. There were 20 CAB members from 11 sites in attendance, and 4 were new CAB members! The retreat followed a more interactive format than previous retreats. We participated in small group break-out sessions, discussing topics such as disclosure and research summaries. All together, we reviewed 12 research summaries, which are now available on the Research Summaries page on the PHACS website. Another first for this retreat was that several PHACS Leadership members attended different CAB sessions. Ellen, George and Russ answered our questions and discussed important topics such as Undetectable=Untransmittable (U=U), antiretroviral medications, and disclosure. Liz led us through a session called "Mindfulness and Movement: Self-Care for CABs." We talked about the importance of caring for ourselves so that we can continue to care for others as we serve as advocates for the PHACS community (read more about CAB members' self-care tips on [page 4](#)).



Claire, Stephanie, Megan, and Exzavia at the 2019 Fall CAB Retreat and Network Meeting

In addition to all the activities at the retreat, the CAB also conducted its first capsule review in October 2019 with Deb Kacanek on her capsule, "Violence Exposure and HIV Care Outcomes Among Young Women with Perinatally and Non-perinatally acquired HIV." We are currently in the process of finalizing a list of pre-capsule review questions with the Working Group (WG) Co-Chairs so that we can pilot more capsule reviews in 2020.

Finally, I want to say thank you to the CAB members and all collaborators who helped make 2019 a stellar year for the CAB. We are looking forward to continuing this great work with all of you in the next year and the coming decade!

Exzavia, PHACS CAB Vice Chair:

Happy New Year to my PHACS family! 2019 was an awesome year. Now that we have moved into 2020, let's think about what we can offer PHACS. Together, we are an amazing group of people. My New Year's resolution is to be better than the year before. I want to continue to help others and provide my very best in whatever task that may come before me.

In this newsletter we will talk about U=U in this new era of life thanks to research and research participants. U=U is so true because it means that treatment as prevention could stop new infections from occurring. I see U=U working in my community by providing information through education and assuming responsibility for taking care of yourself and others. Let's continue to educate and share what we have learned with our communities. U=U is so promising, and for some people it can be easy to adhere to just by taking medication and staying in medical care.

U=U AND ME

Undetectable=Untransmittable (U=U) is a campaign aimed at explaining that people living with HIV who maintain an undetectable viral load (the amount of HIV in the blood) by taking their antiretroviral medications as prescribed cannot transmit HIV to their sexual partners.

The CAB discussed U=U at the 2019 Fall CAB Retreat and talked about how many people in the community still do not know about U=U. The CAB encouraged each other to share their stories and personal feelings about U=U in order to spread the message in the community.

We asked the CAB to define what U=U means to them. The following quotes were submitted by CAB members:

U=U is important. Most people do not seem to fully understand what it means. Personally, I have been speaking about it on social media. The community seems to have concerns about it. It can be hard because my local health department seems to support the science but not the message. It seems they only encourage people to take pre-exposure prophylaxis (PrEP) medications like Truvada. They also want to help us get to zero new transmissions, but they need to do a better job of getting the message about U=U out there. Many more conversations need to take place.

I think U=U is very helpful and informative for people in relationships. It helps people be aware and stay healthy. The knowledge shows us that if we continue to accept new information, we can live long lives.

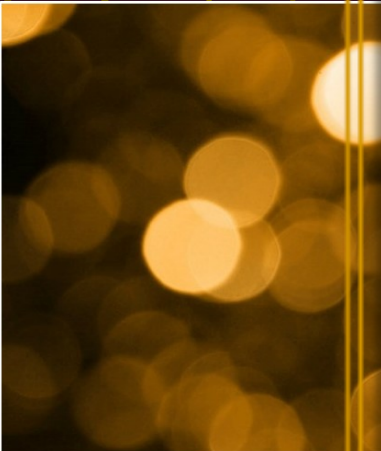
U=U is helping to fight stigma against those living with HIV. U=U affects people and couples in all different communities.



(Continued on page 3)


U=U AND ME

(CONTINUED)



I would like to say that U=U and PrEP are very important topics when it comes to ending the epidemic. However, these are not the only tools we should be discussing in my opinion. It is important to have supportive community engagement activities discussing reproductive health. I feel that our community is still not aware of the advances that are being made in HIV care. Our communities still have misconceptions about risk factors and what it really means to be at risk.

The stigma is still very real, even many years later. Newly diagnosed people may not retain all information shared at the time of diagnosis. Speaking about living a long, healthy life with HIV should be a topic for discussion. The most important thing is to make sure our communities know about U=U and knows that there is life after diagnosis. Life includes you and all of our dreams and aspirations, even when living with HIV.



U=U means a lot for me and my family. I have been with my husband for 15 years. I have taken medication, adhered to it, and am undetectable. My husband has never received a positive diagnosis and he is still undetectable. Through all these years and having three children together, my children are all negative and my husband is negative. I would say U=U is huge for me.

I have been single for a very long time. I would say that having the information [about U=U] gives me comfort that I can approach a new relationship differently or with more information. It gives me a sense of hope that I can have an open dialogue about HIV and prevention.

SELF-CARE ADVICE

Throughout the year, CAB members serve as advocates in the PHACS study for themselves, their children, and the greater PHACS community. During the 2019 Fall CAB Retreat and the December 2019 PHACS CAB call, CAB members talked about the importance of self-care. CAB members talked about how caring for others starts with caring for oneself.

We asked CAB members to share advice from their own personal experiences about best practices in self-care. The following responses were submitted by CAB members:

WHAT COPING SKILLS HAVE WORKED FOR YOU IN DEALING WITH TOUGH TIMES?

- What has worked for me, and still does, is listening to music and dancing. Exercise also helps me.
- I like to find some time to create events or activities with my children and friends.
- Sometimes I come into the clinic and help out or help out the community.
- I like to pray and breathe. When I pray, I realize that I can make it through the day. At the end of the day, I celebrate that I made it through the day.
- I have learned to talk to someone, or write my feelings down in a journal to avoid the negative feelings that can accumulate. It really helps me to let people know how much I appreciate them in the present moment instead of feeling regret for not doing so.
- My faith, prayers, family, and friends always work for me.
- I like to cry, pick myself up, and move forward. I also talk a lot with friends. That's what helps me the most. I guess you could say I unload it.
- I speak with a relative I can trust. I also work to build a social life through church and do a little sightseeing.
- What helps me is prayer and concentration.
- I go to therapy weekly. I also have a psychologist who I see monthly. They assist me in coping with my ongoing issues.
- I talk to family members who may be going through the same pain as I am. I listen to them for a full minute and then they listen to me for a full minute.
- I pray, talk to a friend/loved one, and meditate.
- I try to stay positive.

(Continued on page 5)

SELF-CARE ADVICE

(CONTINUED)

HOW DO YOU CARE FOR YOURSELF ESPECIALLY DURING THE HOLIDAYS?

I try to stay focused on my CAB. I also work out, stay at home with my children, play games, make dinners, and go out to Japanese restaurants.

Try to get some personal "me" time – whether it's taking a break sitting in my closet away from the kiddos or locking the bathroom door and taking a break in there.

I like to practice positive affirmations in the morning to promote good energy throughout the day. For the holidays, I like to cook and clean out the clutter to prepare for the new year. Also, I write in my journal to reflect on the lessons I have learned and to appreciate the great moments.

Self-care is always the best care. Take time to do something just for you even if it is some alone time for yourself. In general, my self-care is doing anything I feel like doing even if it is out of my normal routine.

This year I have not been in much of a holiday spirit. I have felt very overwhelmed. It has been an emotional rollercoaster at work and my house has been constantly messy. So, I went and got a pedicure, watched Christmas movies, and stayed at work where I can skate for a while away from the stress of family. It has helped to take time just for me, even if only for an hour.

I care for myself by interacting with family as much as possible.

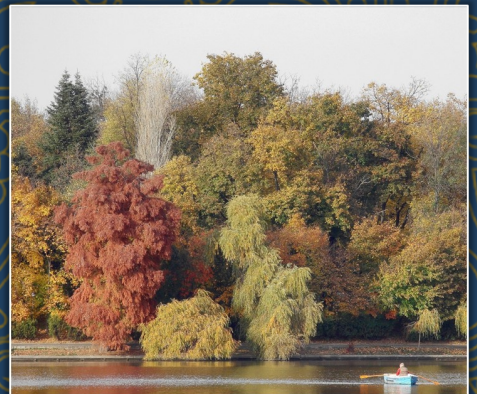
I try to watch what I eat and how I eat.

I pamper myself with facials, manicures, and pedicures. Buy yourself something nice.

I dance to my favorite music.

Get plenty of rest.

(Continued on page 6)



SELF-CARE ADVICE

(CONTINUED)

WHAT WORDS OF WISDOM DO YOU HAVE FOR CAB MEMBERS STRUGGLING WITH SELF-CARE?

You have to take care of yourself. You can always start with baby steps. Go get a manicure or a pedicure. Do something small just for you. Over time it will build and you will start doing more to care for yourself. You can't care for others if you are not well. It starts in your mind. Now go get that pedicure!

Self-care can be as simple as putting lotion on your skin when you get out of the shower. Take that time to care for yourself. I like to say a prayer because it makes me feel like I am not alone or doing things by myself. Prayer helps me feel like I have support in the darkest times, which carries me through. I also like to read the "Footprints" poem and say the "Serenity Prayer."

Don't give up. Keep trying different things. You will find the one that vibes with you!

For me, I started with walking for a few weeks. Then I jogged two blocks for the next two weeks. It helped me to sing a song that I could remember; nothing sad, only joyful. I continued this until it became a habit. Now I feel the results of my self-care.

Live, laugh, love. You only have one life. Live it with no regrets.

I like to take some time for myself. I like to do the things I enjoy. I buy myself something I need, go to the movies by myself, or volunteer my time somewhere, such as a nursing home.

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SELF-CARE ADVICE

(CONTINUED)

WHAT WORDS OF WISDOM DO YOU HAVE FOR CAB MEMBERS STRUGGLING WITH SELF-CARE?

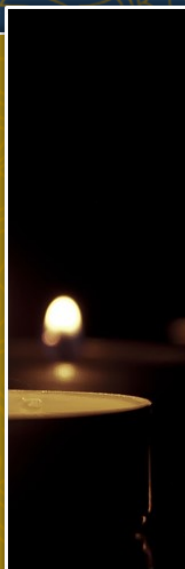
I would like to say that you are important. You are loved. You are valued.

I don't have any children yet, but I understand what parents do. Parents put their children and family first before worrying about themselves. I want all parents, siblings, and cousins who are involved in this dynamic CAB family to be encouraged. Remember that we are a family. We love you. If you feel like there is nothing you can do on a hard day, just remember that you are valued and you are loved.

You don't have to do it on your own. It always gets better. Remember, we have each other!

Take care of yourself – mind, body, and spirit. Start exercising, try to eat better, and take time out to do the things that you love to do.

Learn to love yourself.



PHACS MEMBER PROFILES



*Christine
Kwon, BS*

Happy New Year PHACS! My name is Christine Kwon. I am a study coordinator at Site 9's Children's Hospital Immunodeficiency Program (CHIP) clinic located at Children's Hospital of Colorado in Denver, Colorado. Since joining the PHACS team in my native state five years ago, I have learned a tremendous amount from PHACS families and this impactful network. In my starting role as a Research Support Assistant, I provided administrative, event planning, and data support for our team's study coordinators across multiple studies and networks. I remember planning and attending my first

summer pool party that our clinic hosts for our clients and research participants. This was when I was able to put faces to names and connect with study participants and their families. After a little while, I moved into a Study Coordinator role. Now, I work primarily on the SMARTT protocol along with a couple of IMPAACT and industry studies. I also provide back-up support for the AMP and AMP Up protocols. When families come in every (or every other) year, their visits are packed with neurodevelopmental testing, blood draws, exams, questionnaires, and/or surveys, but I love to hear how things are really going. I am in awe of, and warmed by, the honesty and altruism that our PHACS families show up with at each visit. Their bright faces inspire me, as I know they do for many of us in the network, to continue our work. I also really enjoy being a part of these longitudinal studies (that take place over time) because you get to see families grow. You get to hear of their accomplishments, challenges, and aspirations. Hearing from families while poolside is one of my favorite traditions of CHIP.

I have also been serving as a PHACS Network Study Coordinator Vice Chair since June 2019. Working on the Study Coordinator Retreat for the Fall 2019 Network Meeting has shown me the great depth of knowledge, skill, and compassion our network's site staff apply to their work every day across the country. I am excited to work with them.

Outside of work, I enjoy Colorado, the state in which I was born and raised. The mountains keep me here. I like to spend weekends snowboarding with my family during the winter, and camping over the summer. I have a

mountain bike. I want to ride with my husband someday, but I am a little hung up on the idea of crashing over my handlebars, which seems to be a common occurrence in mountain biking.

I attended the University of Denver (DU) and got a degree in Cognitive Neuroscience. While attending DU, I was active with minority student associations and immigration groups because I come from an immigrant and minority background. I was not particularly involved in HIV awareness or testing groups but by good fortune, after having taken a break from work to be with my first child during infancy, I came across an opening with CHIP, and applied. I remember applying to this position and thinking about a fellow classmate from high school. This classmate was shy and rather withdrawn. One day, a rumor spread through the school that this classmate had HIV and that's when stigma reared its ugly head. Suddenly, the whole school knew this classmate's name and sought out any personal (dis)information they could find. There was gawking, ostracizing, and hateful speech that blew like the wind through the school. As PHACS works on collecting more information about stigma and disclosure, I am glad to be a part of the change toward a more accepting, kind, and mindful society. I am grateful to work in an environment where PHACS families feel they can honestly and safely discuss sensitive, personal topics such as disclosure.

I hope the new year brings more opportunities for growth, bonding, and kindness for the wonderful people in the PHACS Network.

PHACS MEMBER PROFILES

(CONTINUED)



Sherry

When I was diagnosed, I lost my identity. The only thing I had in my mind was to self-destruct, because at that moment life was over for me. After years of struggling with depression, I met with Dr. Guadalupe Morales Avendano for help at Los Angeles County (LAC) + University of Southern California (USC) Medical Center. Dr. Morales Avendano had always encouraged me to join the Maternal, Child, and Adolescent Adult Center MCA Spanish CAB multiple times, but I wouldn't go to the meetings. One day, I decided to go and I met three other members of the CAB. I

could not have imagined the amount of support I would receive just by being present at a Spanish CAB meeting. The Spanish CAB group became the support system that I was missing for so long. The group discussions were informative. It was an open door to share our stories with others who know exactly how it feels to have a diagnosis. I have found my own strength by listening to other CAB members share how they dealt with stigma and disclosure. My involvement in the Spanish CAB has helped me look within myself and regain what I had lost, my self

-worth. Currently, I am the Co-Chair of the Los Angeles County Women's Caucus Meeting.

I decided to go back to school and pursue higher education in Psychology. My educational journey has contributed to my self-esteem and inner growth. School has allowed me to regain pride in my abilities, something I'd lost sight of. I am on the President's Honors List. Last year, I was inducted into the Psi Beta Psychology Honor's Society, and I even received a scholarship. I had been a dropout with no educational background. Receiving awards was something new to me. I have learned that it is not about who is smart and who is not. It is about developing a mindset to learn and deciding whether or not to hold yourself back. This whole process has given me a new perspective that I can share with my family and others. I have also developed a passion for learning about nutrition and exercise after taking a weight training class. I noticed positive changes in my mood by being consistent in my exercise regimen. I feel that my physical strength translates directly to my mental strength. My new mantra that has helped me when I do have bad days is:

"It is going to be okay because it always gets better."

I am grateful for Dr. Morales Avendano and our Spanish CAB members for believing in me and helping me see light in my life again.



UNIVERSITY OF PUERTO RICO CAB IN 2019

The University of Puerto Rico CAB President, Joel Pagan, MD, participated in a 5k run for World AIDS Day.

Our CAB had our first youth meeting on November 23, 2019. There were many topics discussed. The pharmaceutical company, Gilead Sciences, Inc. brought in a doctor to discuss adherence and new antiretroviral medications. A psychologist talked to us about how to improve mood, how to be more positive in life, and more. The CAB President, Joel Pagan, MD, talked about the CAB's mission statement and the importance of the work the CAB has done. He also talked about a new project that the CAB is planning for 2020 that involves the recruitment of more young adults into the CAB. The meeting was a complete success. We hope to have another similar activity next year and invite other CAB groups from the United States!

Submitted by: The University of Puerto Rico CAB



CAB MEMBERS

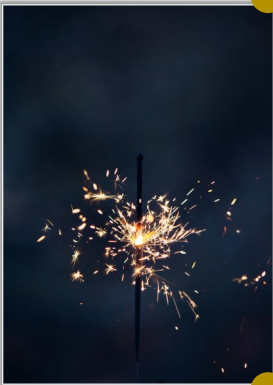
CONNECTING



We are a family. CAB members can reach out to those in their city. Lesley invited me to lunch after our December CAB call to make sure I was good. It is important to do more than just say our names.

Submitted by: Kimbrae

UPCOMING EVENTS



- February 7: National Black HIV/AIDS Awareness Day **#NBHAAD**
- March 10: National Women and Girls HIV/AIDS Awareness Day **#NWGHAAD**
- March 20: National Native HIV/AIDS Awareness Day **#NNHAAD**
- April 10: National Youth HIV and AIDS Awareness Day **#NYHAAD**
- April 18: National Transgender HIV Testing Day **#TransHIV**
- April 20-21: PHACS 2020 Spring Leadership Retreat
- May 18: HIV Vaccine Awareness Day **#HVAD**
- May 19: National Asian and Pacific Islander HIV/AIDS Awareness Day **#APIMay19**
- June 5: HIV Survivors Day **#empowered2thrive**
- June 27: National HIV Testing Day **#HIVTestingDay**

TULANE UNIVERSITY HOLIDAY PARTY

The 15th annual Pediatrics Christmas Party, sponsored by the Tulane Department of Pediatrics Infectious Disease staff, Louisiana State Police, and the Tulane University Police Department, was held on December 13, 2019. The New Orleans PHACS site staff donate their time and effort by holding biannual bake sales to help cover some of the costs involved. We have found that this event helps with retention of our study population. Our older AMP Up participants even come to volunteer their time. Tulane University Police officers stepped up this year and donated more than 300 toys and 29 bicycles! The Louisiana State Police has been donating toys and gift cards since we began in 2004. Dr. Russ Van Dyke (PHACS Principal Investigator, Coordinating Center) and the band Delta and the Ramblers always entertain. Dr. Margarita Silio, the site AMP and AMP Up Principal Investigator, continues to provide additional door prizes that keep families engaged in the party until the end. Dr. Patricia Sirois, our site Psychologist, and the staff's families are also always available to help out. It is a fun time for all!

Submitted by: Medea



(Continued on page 13)

TULANE UNIVERSITY HOLIDAY PARTY

(CONTINUED)



“LEAVE IT IN THE WATER”:

Choose-Your-Own-Adventure Series Update



This past fall, the Health Education and Communication Committee (HECC) and Peers United Group (PUG) continued to work together on drafting a script for the Choose-Your-Own-Adventure series on transition to adulthood! Led by PUG Vice Chair Enise and Boston-based filmmaker Amir Dixon, several members of the HECC and PUG have been developing the main characters and storylines. The video series, “Leave it in the Water,” will follow four young adult friends in Miami, Florida who are all affected by HIV—Corey, Brian, Melody, and Hope—as they navigate friendship, isolation, autonomy, stigma, self-love, self-control, intimacy, vulnerability, and grief.

Part of the novelty of this resource is that it will be interactive, asking the viewer to make choices for the main characters as the video progresses. How the scene continues will depend on what the viewer chooses for the characters. At the same time, we do not want to create a binary of “good” and “bad” choices. Instead, we want to show characters making the best choices they can in the moment and feeling capable of dealing with the consequences later. Additionally, this resource will feature characters with different experiences with HIV and different racial and socioeconomic backgrounds, and who are confronting various aspects of adulthood. We would like to make this resource available at PHACS sites and beyond for young adults affected by HIV as a tool that can help them feel supported in (and connect them to resources about) their transition to adulthood and adult health care. We want the video to help them feel more confident in their ability to handle the responsibility of adulthood and managing their own health care.

The team also submitted an application for funding from the Harvard Center for AIDS Research to produce and pilot this resource starting in 2020. We expect to hear their decision by the end of January.

Submitted by: Claire and Enise

PEER AWARD

Monica, a site CAB member from the University of Southern California (USC), recently won the Peer Award from the Los Angeles Women's HIV/AIDS Task Force for her dedication to serving the community affected by the HIV/AIDS. The award was presented to Monica with the following acknowledgement of her work:

"Monica is a passionate and strong community advocate. Her goal is to help and improve the lives of people living with or at high risk for HIV. Monica has been working with the HIV community for 17 years, during which time she has helped to increase our program's presence in the community and build relationships with individuals, community groups and other organizations in support of the HIV community."

Submitted by: Guadalupe



RESOURCES



[Prevention Access Campaign: U=U](#) (Website)



[HIV Undetectable=Untransmittable \(U=U\), or Treatment as Prevention](#) (Website)



[Undetectable is Prevention](#) (Pamphlet)



[HIV: Journey to Undetectable](#) (Video)



[Your Roadmap to Undetectable](#) (Pamphlet)

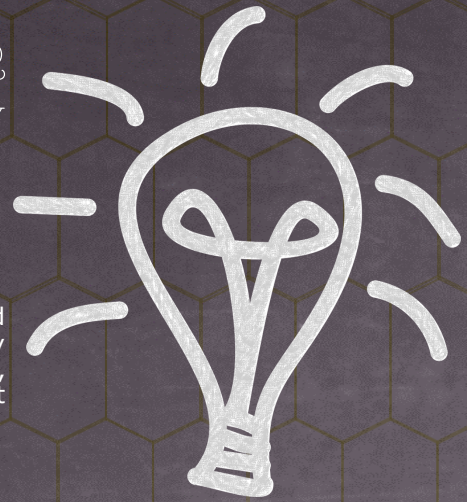


[HIV/AIDS Treatment](#) (Website recommended by Exzavia!)

2020 GOALS


THE FOLLOWING GOALS FOR 2020 WERE SUBMITTED BY CAB MEMBERS:

- * At the PHACS CAB level: Engage more in outreach, trainings, and events. At the site CAB level: Create a goal to save money throughout the year so our site can have a Christmas party, interact with the community, or visit other CABs to learn about what they do so we can bring some feedback to our site CAB.
- * Provide input and participate more in the CAB calls.
- * In our site CAB, we are always brainstorming ways on how to inform the community about HIV prevention. Maybe we can have a larger scale of brainstorming by having periodic check-ins on our CAB calls.
- * 2020 will be full of surprises. As a CAB, I feel as though our first meeting should go over how we can give our best as usual to make PHACS CAB input better than ever. We know that they hear us when we speak. We should ask both ourselves and the PHACS researchers for their input to be able to provide feedback to make PHACS where we want it to be in 2020.
- * Getting more involved. I'd like to see the CAB leave their footprints all over PHACS, in a good way.
- * I want to get to know my CAB members. We should swap ideas and become more involved. We should do outreach, network, and explore training workshops.
- * I want to participate more in the CAB.
- * 2020 is going to be a phenomenal year. Let's love like never before. Let's thrive like never before. Let's push our families to achieve their goals like never before. Let's live life to the fullest. Most importantly, let's all THRIVE. To those of us living with HIV, listen to your body. To those of us affected by HIV, love—because without love there is no peace. Thank you for your love and support. Always remind others that caring for people should be everyone's number one goal. It is the one selfless act you can do and it is a really great character trait.
- * I want to learn more and help others.





“GRACE WORD” POEM



Some days are special,
and Christmas is a most special one.
What about this day after Christmas?

For some of us, it's a day of gratitude
for yesterday's light that is still shining,
the warmth of family unity and communion,
the assurance of ongoing support and love.

For some of us, this day after is marked by
sadness and loneliness over family strife,
with a sense of darkness hovering over us,
with little hope for changing what has been.

For most of us, there's light and darkness,
so that, if we're alert to what this day holds,
we can more intentionally be present with
and caring for others whatever their day.

For all of us, this day after is an opportunity to
receive and share the light.

Bless you this day!

Submitted by: Joe

GLOSSARY



Audio Computer-Assisted Self-Administered Interview (ACASI): A survey system administered on a computer, designed to offer participants a comfortable and private way to answer questions about sensitive topics.

Clinical Trials Network (CTN): A group of hospitals and clinics in different locations that cooperate to develop and conduct clinical trials related to preventing or treating a specific health problem. Participants from many different locations may enter the same clinical trial.

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

Protocol Chair: The person who has the leadership role on the team that develops the protocol and is responsible for oversight of the conduct of the protocol.

Undetectable Viral Load: A viral load test result showing that the amount of virus in the blood sample is too low to be detected by a laboratory blood test. The goal of all antiretroviral medications is to help people achieve an undetectable viral load.

ACRONYM ACROBATICS

Instructions: Select the correct acronym description. ([Answer key on page 20](#)).

1. SMARTT

- A. Surveillance Monitoring for ART Toxicities Study in HIV-uninfected Children Born to HIV-infected Women
- B. Scientific Maternal ART Trial
- C. Slippery Marbles Always Roll Too Terribly

2. AMP

- A. Adolescent Master Protocol
- B. Adolescent Maternal Protocol
- C. Adolescent Meat Protocol

3. AMP Up

- A. Adolescent Master Protocol Upper Puberty
- B. Adolescent Maternal Protocol Under Press
- C. Adolescent Master Protocol for Participants 18 Years of Age and Older

4. CAB

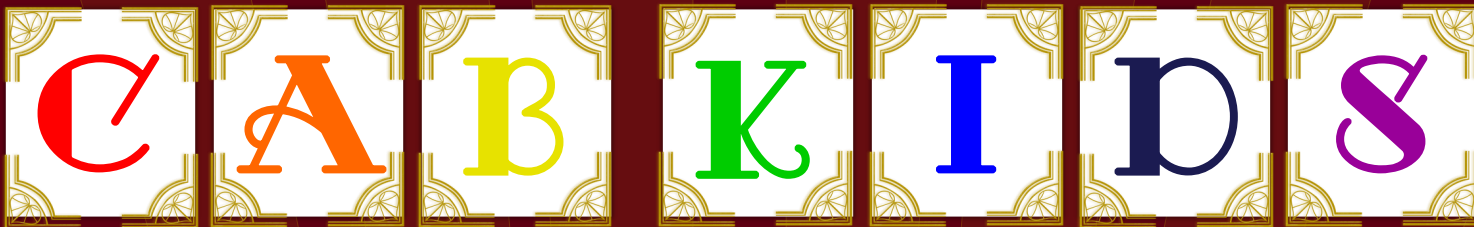
- A. Communities Always Building
- B. Community Advisory Board
- C. Community and Builders

5. ART

- A. Antireinfection Treatment
- B. Antiretroviral Therapy
- C. Antiretroviral Tabs

6. SLG

- A. Scientific Leadership Group
- B. Science Living Guild
- C. Scientific Lines Group



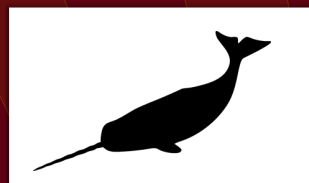
Crossword by picture! Fill in the crossword puzzle numbers with the name of the animal for each number. ([Answer key on page 20](#))

Across

2



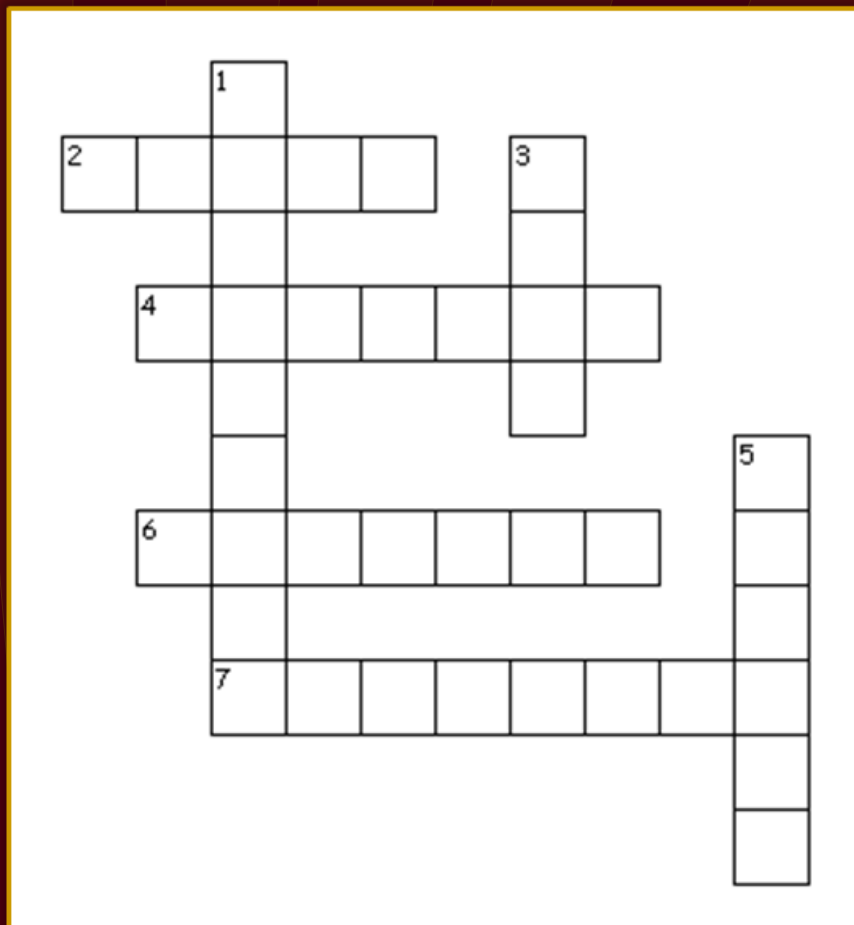
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6



7

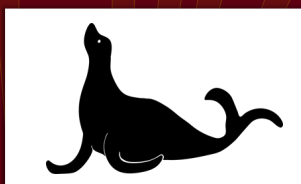


Down

1



3



5



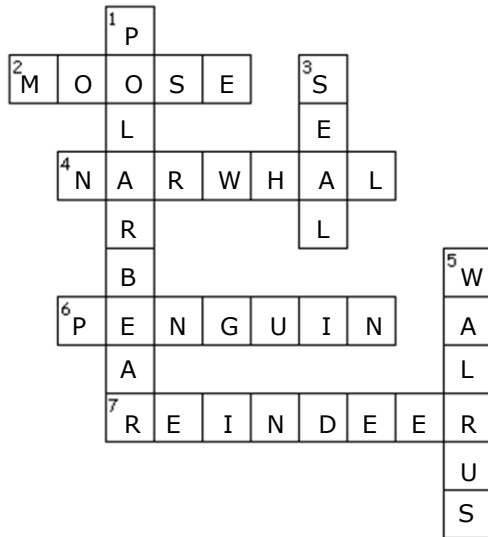
CAB KIDS KEY

Across:

- 2. Moose
- 4. Narwhal
- 6. Penguin
- 7. Reindeer

Down:

- 1. Polar Bear
- 3. Seal
- 5. Walrus



ACRONYM ACROBATICS KEY

1. A

2. A

3. C

4. B

5. B

6. A

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