

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

It is that time of year again – newsletter time! I wish I had tons of inspiring messages for everyone, but I was finding that during these times it was hard to be inspired. Behind every door there just seemed to be more and more bad news. I wish I could say that I had been on all the calls. I wish I could say that I had been there for everyone like in the past, but unfortunately, that was not the case. This time it was not about how I could be there for all of you, but how you have been there for me. I had even found myself wanting to yell "I hate you, COVID!"

This newsletter theme is about finding solace in community. At first, I struggled with this because I was telling myself that I had not found solace. I wondered how there could be any solace with so much loss. You know what, though? I found that this PHACS community is so powerful. I do not think any of us realize exactly how much we help one another out, especially when we need it the most.

"over the last few months, I realized that I had solace this whole time, right here with all of you, my PHACS family."

Over the last few months, I realized that I had solace this whole time, right here with all of you, my PHACS family. You have provided me with so much comfort. So, if anyone is having a hard time finding their solace in community, do not forget that you have this PHACS community. We are all here for each other. It is okay to reach out and ask for that comfort. Believe it or not, someone is in your corner.



Pictured: Stephanie (CAB Chair) and Lexi (PUG Member)

CAB MESSAGES OF SUPPORT

Over the past several months, the CAB came together to meet during bi-monthly Town Halls. The CAB invited PHACS clinicians and researchers to talk about important topics related to COVID-19. These included general questions about COVID-19, mental health and coping, pregnancy, PHACS and the CAB, and living through COVID-19 and HIV. In addition to these informative discussions, the CAB used the time during these calls to connect with one another. During one Town Hall, CAB members talked about the importance of **solace in community** and how meaningful it can be just to hear each other's voices on the other end of the line. At the end of that call, CAB members shouted out to each other in a wave of supportive sentiments. Even after the call had ended, CAB members continued to submit messages of support to help their fellow CAB members feel connected to each other even though they could not connect in person.

The following messages of support were submitted by CAB members:

"Stay focused and healthy. Reach out to [a CAB member] if you need support or even if you are scared."

"Hang in there everyone. This too shall pass, and we will overcome it."

"I'm not sure what to say. I'm sorry we have to go through this. Wash those hands, and call your case manager if you need help."

"Thanks for being so open and for sharing your experiences and concerns. Thanks for the great questions."

"I LOVE YOU ALL. YOU
HAVE MADE A
DIFFERENCE IN MY
LIFE. YOUR VOICES
GIVE ME HOPE AND A
SENSE OF BELONGING.
YOU ARE MY FAMILY."



PHACS CAB

(Continued on page 3)

CAB MESSAGES OF SUPPORT

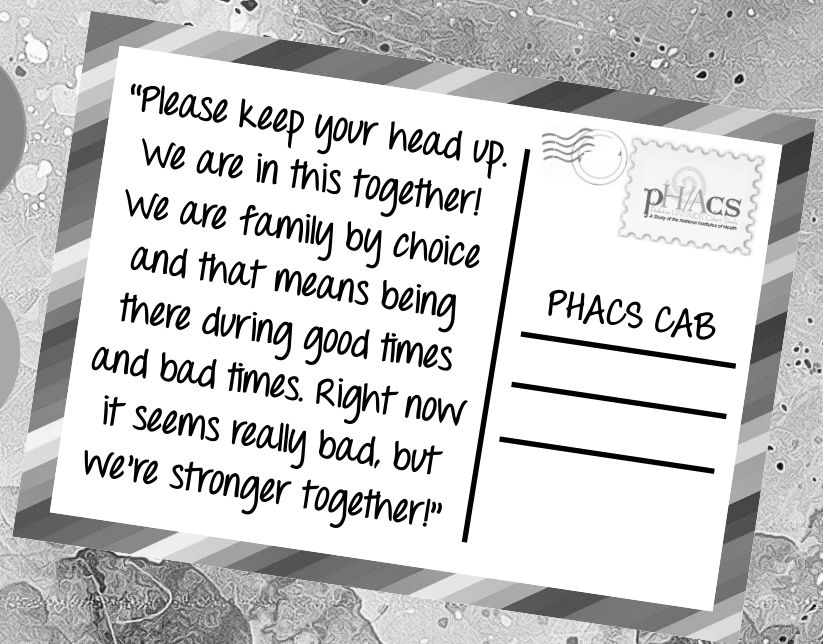
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"You are supported with thoughts and prayers. Breathe if you can. If you're from Alabama [you know] it can be difficult to breathe because of the pollen count (HAHA), but taking a deep breath can really re-center you. We're here to support one another."

"In these uncertain times, we have to stay encouraged. Protect yourself and your family at all costs. Have faith and love each other."

"Just pray and [seek] strength while we're going through this pandemic. Hug your family members tightly because this is what's going on. It's real. I hope everyone is doing well."

"I just love you all."



"My wish is for everyone to stay safe and strong. Although this is a huge bump in the road for our world, I have faith that we will get through this together. I look forward to when we can resume our study visits and reconnect in person. Until then, know I am sending love and peace to all."

"I am always here if you need me!"

"It is important for all of our members to know that there are so many wonderful people, who are really here to share and support each other in numbers. We are strong. United we stand in our goals to help our community and our members, who are doing this important work."

SOLACE IN COMMUNITY

Reflecting on the theme of solace in community, CAB members talked about the importance of being involved in a community like the PHACS CAB during good times and hard times.

The following quotes were submitted by CAB members:



"PHACS studies learn about families and people over time. The researchers benefit from staying connected to the community. Being involved in the CAB is important when times are good or hard. Your experiences can improve the study and help others learn more about how to support people living with or affected by HIV."

"It is important to be a support for those who may need it. Some of us can feel confused or alone when times get tough. We need to understand that COVID-19 is part of a new era in life. We need to learn better ways of taking care of ourselves. We need to learn how to stay safe while trying to remain healthy through these difficult times."

"It is important to be involved with your community during good times and bad because being a support and foundation for others is part of being an advocate and a leader in the community. During hard times you can see the true heart of a person. This is because it is easy to be there for someone when there is a lot of joy, but the hardest and biggest fights happen during the toughest times in life. We all signed up to be part of this fight and that means we have to fight during the sunshine, as well as when it rains."

"There is always the opportunity to share opinions and information about your community. Sharing during difficult times may be especially important as not everyone can share their voice due to work, childcare responsibilities, or illness."

"Being involved in a community is a way of knowing what is going on around you. You will learn information that you can share with others."

(Continued on page 5)

SOLACE IN COMMUNITY

(CONTINUED)

"Having a sense of community unites us. Being part of a community can make us feel as though we are part of something greater than ourselves. It can give us opportunities to connect with people. Reaching out within our communities can feel like a saving grace in a world wracked by coronavirus and fear. A person within a strong community never feels alone. People within a community are supportive of each other. Within a community, you can learn from others about how they got through tough times and what kept them motivated!"

"Community involvement is a positive experience because it always feels good to have people around! You can be supported and support others."

"It is important to be involved in this community because it is about us, our children, and our way of life. We work together to hold each other accountable."

"It is important to be involved in a community because you never know what a person is going through. Picking up this newsletter may make them feel better about what is happening."

"I like being involved in my community during good times and bad because I like sharing the knowledge that I have gained. I like receiving knowledge, and I love helping others."



"It is important to be involved in a community because you never know when you might save someone's life."


"During good times and bad times, it is important to provide help and support where and when it is needed in the community. It is important to demonstrate that we are stronger, better, and closer than ever."

"It is important to be involved in a community to be able to provide education, emotional support and counseling, and peer support. Together we can identify coping skills and information about community resources."

"Being involved in a community helps give me a sense of purpose. During bad times, community involvement brings me happiness and understanding. During good times, it just makes everything so much better."

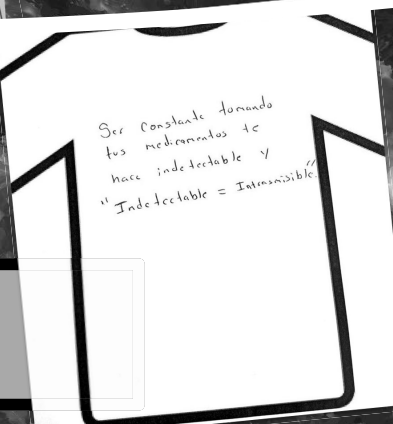
UNIVERSITY OF CALIFORNIA, SAN DIEGO FAMILY ADVISORY BOARD T-SHIRT DESIGNS

The January 2020 edition of the PHACS CAB Newsletter followed a theme of "Undetectable=Untransmittable (U=U), Adherence, and Relationships." Following that, the University of California, San Diego (UCSD) Family Advisory Board (FAB) discussed U=U at their next FAB meeting. The site also registered as a U=U program. Several attendees were not familiar with U=U and were very happy to discuss it together. The group came up with t-shirt designs to promote U=U in the community. The following are t-shirt designs submitted by UCSD FAB members (designs written in Spanish have been translated into English):

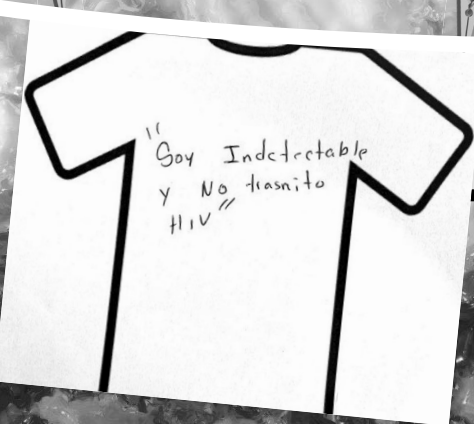


"U=U Life, quality, hope, future"

"Constantly taking medication makes you undetectable, and undetectable = untransmittable"



Ser constante tomando tus medicamentos te hace indetectable y
"Indetectable = Intransmisible"



"Soy Indetectable y No transmito HIV"

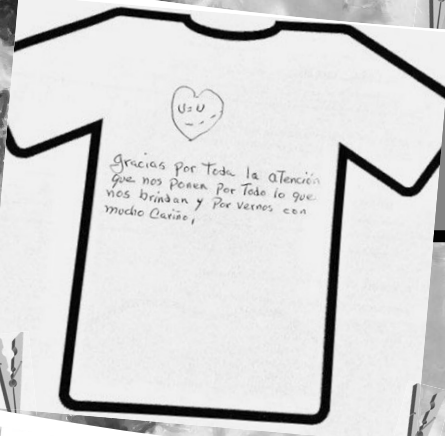
"U=U"



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UNIVERSITY OF CALIFORNIA, SAN DIEGO FAMILY ADVISORY BOARD T-SHIRT DESIGNS

(CONTINUED)



"Thank you for all the attention that you give us and for everything you provide and for seeing us with such care"

"Love is equal to love, It cannot be destroyed by a virus"



"2 people holding a heart"



"We are all the same"



"Love"



"Undetectable = Untransmittable"



RAINBOW AFTER THE STORM

Right now every time you turn on the news, it is one more time to get angrier, sadder, and more disgusted. It is like you can no longer trust that this world will ever be a loving place. Sometimes it feels like the storms are so strong that your foundation has been shook so badly that no matter where you go, you can never be protected from emotional or physical harm.



REMEMBER, THE RAINBOW WILL COME.

I want you to visualize that every tear is a raindrop falling on a seedling planted deep within fertile soil. Once that seedling drinks the nourishing rain, it will grow into a strong, life-giving tree. I believe that is what our PHACS family is right now. We are a rainbow of support, waiting to come out after the storm is over. Yes, we are going to have tears. Yes, we are going to have pain, but each one of us is here to nurture each other. We are here to let one another know that we will be a mighty oak, a strong tree planted next to a stream of nourishing water. Time will pass. Once the storm is gone, we will see the rainbows again. So, stand strong and hold on. Remember, soon your rainbow will shine through! I love you all!

Submitted by: Kimbrae

B E L O N G I N G



Relationships are inherent to being here on Earth. Everyone and everything is connected to all the rest.

The global spread of the coronavirus is demanding that we get through this together.

Yes, forces of resistance will fight for individual rights, but that way of thinking only leads us into darkness.

Nature herself has always whispered the truth of an irreversible belonging among all creatures, as well as with the soil, the waters, the heavens. Relating to one another with love is in our DNA.

Let's act like who we are!

Submitted by: Joe

The Health Education and Communication Committee (HECC) has had a busy start to the year! Since March, the HECC has been meeting bi-monthly to discuss important topics related to the COVID-19 pandemic.

Together with the CAB, PUG, and PHACS researchers and staff, the HECC has had a series of rich discussions about racism and health disparities. These important conversations have been in the context of COVID-19 disproportionately impacting communities of color in the US due to structural racism. The discussions have also centered on the widespread protests across the country this spring against long-standing police brutality and racism. In particular, the group has expressed the importance of creating space for PHACS staff and participants to share their stories of experiencing racism while ensuring that they retain ownership of those stories and how they are told. The HECC plans to continue these important discussions and take action to create those spaces and to make recommendations for addressing racism as we move into PHACS 2020.

The CAB, PUG, and HECC had a strong presence at the 23rd International AIDS Conference (AIDS 2020: Virtual)! This year, the conference was held virtually from July 6-10, 2020. Also, several pre-conferences were held the week before the main conference, including the 6th

MY LIFE, MY STORY: GROWING UP WITH HIV



AIDS 2020: My Life, My Story
Growing Up with HIV

Workshop on Children and Adolescents HIV-Exposed and Uninfected. For this workshop, **Kimbrae** (CAB) and her son **Gamon** (PUG), and **Stephanie** (CAB) and her daughter **Lexi** (PUG) recorded a conversation with each other in a [StoryCorps](#) format. They asked each other questions about HIV, stigma, advocacy, and maternal disclosure.

Enise, Vice Chair of the PUG, recorded an oral presentation titled "My Life, My Story: Growing up with HIV." This aired on demand during *AIDS 2020: Virtual*. This powerful presentation was part of a session called "The very long and winding road for young people living with HIV: Stories and solutions from youth to youth" and was available under the On-demand Bridging and Symposia.

Both presentations are posted on the [PHACS website here!](#)

Since January 2020, the HECC has distributed two editions of *Just the PHACS*, the email digest about all things PHACS. These digests include recent PHACS

publications and news coverage, resources, and contributions from CAB and PUG members. The next edition will be released in October 2020. You can find all editions here: <https://phacsstudy.org/Education-Hub/Quarterly-Digest>.

In the last edition of the newsletter, Enise and Claire wrote about the Choose-Your-Own-Adventure video on transition to adulthood. The HECC submitted an application to the Harvard Center for AIDS Research, but unfortunately, it was not funded. The HECC plans to explore alternative avenues for funding this project in PHACS 2020.

We look forward to working with the CAB and the PUG on these exciting HECC projects. CAB and PUG members, thank you for everything you do for the community and for PHACS. Advocacy comes in many forms, and we deeply appreciate all the different ways you advocate. We cannot express enough how these incredible projects would not be possible without the contributions from all of you!

Submitted by: Claire and Megan



AIDS 2020: StoryCorps Discussion about HIV and Maternal Disclosure

CELEBRATING “SISTERLOVE”

Earlier this year, PHACS CAB member Gena, was nominated to participate in a gala celebrating members of the 10th annual class of the Leading Women's Society. These amazing women were brought together by the SisterLove organization.

It was a gala celebrating women living with HIV for over 20 years. We have been advocating in the community for over 10 years. It is a society of over 250 women and counting. I was nominated by my mentor, and was chosen! It is an honor to be part of such an amazing group of women.

Read more about Gena and the gala in the March 2020 Edition of POZ:

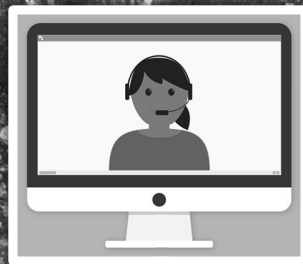
POZ—Leading Women: Honoring 30 years of SisterLove

Check out the [SisterLove website](#) to learn more about this groundbreaking group.

Submitted by: Gena



Photo by Katy Beltran for POZ



SPRING 2020 VIRTUAL RETREAT



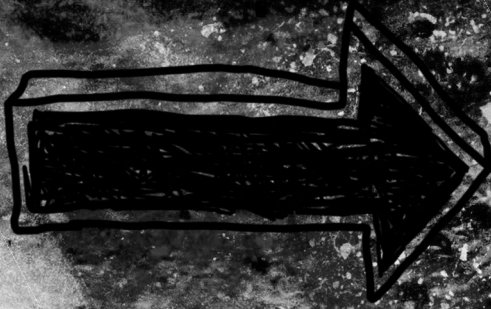
Due to COVID-19, the PHACS Spring 2020 Retreat was held virtually for the first time on April 20 - 21, 2020. Over 160 people in PHACS tuned in online, including researchers, staff, study coordinators, and CAB and PUG members. Dr. George Seage gave the plenary about how PHACS is responding to the coronavirus pandemic. The two jam-packed days included a presentation and panel on COVID-19 and PHACS, as well as presentations from an array of recent PHACS studies. We had two outstanding presentations from our two PHACS Early Career Investigator Award recipients, Drs. Sahera Dirajlal-Fargo and Stephanie Shiau. Finally, we heard from the Working Groups about their achievements and future plans, from the HOPE study investigators about their plans for women's health in PHACS, and about the changes proposed for the next five years of our collective work together in PHACS 2020.

All presentations can be found behind the login on the [PHACS website](#). Additionally, the entire virtual retreat can be streamed [here](#)! Each presentation is posted separately. You can watch one presentation at a time, or sit back and watch the whole retreat!

UPCOMING EVENTS

- **September 18:** National HIV/ AIDS and Aging Awareness Day
- **September 27:** National Gay Men's HIV/AIDS Awareness Day
- **October 15:** National Latinx AIDS Awareness Day
- **December 1:** World AIDS Day





PHACS MEMBER PROFILE



MEDEA JONES GABRIEL, RN, BSN

I am the PHACS AMP and AMP Up Study Coordinator for Site 20 (Tulane University Health Science Center). I have been working with PHACS for the past ten years. I am so excited to be part of the PHACS family. The long-term

relationships with the families in our pediatric clinic allows me to have an edge on being a patient advocate for my research participants. In the time I have been working with PHACS, I have been a member of the Adolescent and Young Adults Working Group (WG). Additionally, I served as a Site Representative for the AMP Up protocol for several years. These roles have allowed me to fight for you, the research participants. I am able to present evidence to let the team know if something may work in our study or not. On the other hand, I let the team know if

they are asking for something that participants may not feel comfortable doing. We never make any decisions without feedback on how something will affect our participants.

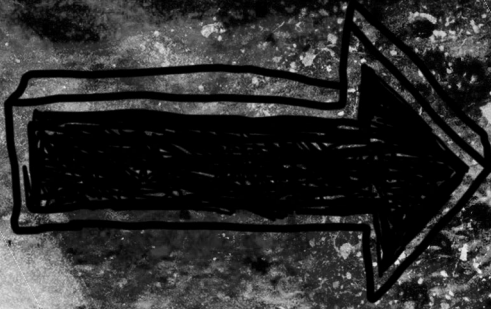
Recently, my fellow Study Coordinators elected me to represent them on the PHACS Clinical Investigators Group (CIG). I provide the CIG with information on what is going on at the sites.

I am a lifelong resident of New Orleans, Louisiana, except for a 5-year relocation after Hurricane Katrina. I am a Graduate of Louisiana State University School of Nursing (LSU). GEAUX TIGERS (in my Coach O. voice)! I am a Tiger on Saturday and a Saint on Sunday. That is, I root for my football teams faithfully.

I have always been a Pediatric Nurse and worked in settings where I was able to forge long-term relationships with my patients. That is another reason PHACS has been a good fit for me.

I spent the first five years of my nursing career working in a rehabilitation unit at Children's Hospital in New Orleans beginning in 1996. My patients had been in car accidents or experienced stroke. It was at this time that I was introduced to Camp Nursing. This was a wonderful thing. I was working and having fun with patients, who were resilient.

(Continued on page 13)



PHACS MEMBER PROFILE

(CONTINUED)

I worked at the Children's Hospital Amputee Camp (CHAMP Camp). These kids would not let missing a limb hold them back from doing anything. Imagine playing Twister with someone who was missing a left arm. They would all say, "Ha Ha!" if they were missing whatever limb the turn called for. Having fun with my patients is right up my alley.

I left Children's Hospital around 2001, after my father died. I could not face being home without my daddy, so I started travel nursing. My best friend and I traveled to California several times on nursing assignments. We would look up the hottest attractions in the area, but would usually end up shopping at the massive outdoor markets called "swap meets."

In 2003, I finally settled down at Baptist Hospital of New Orleans Hospital, a Tenet Health facility. Yet again, I was in a unit with long-term patient relationships, the Neonatal Intensive Care Unit (NICU). If they were born too early, some of our babies would stay in care for up to four months. This was another satisfying journey on my path. I love to teach families how to take care of their precious, vulnerable babies. I stayed at this hospital until Hurricane Katrina hit New Orleans in 2005. It was the hardest thing to prepare those mothers to separate from their babies. The babies had to fly to other facilities by helicopter. It was so hard for me to turn those babies over to strangers. I was their

nurse. I protected them. I helped to keep them alive. Now, I had to send them on a helicopter ride to an unknown location. Shutting down our NICU was the hardest thing I ever had to do in my nursing career. Fortunately, Tenet Health had another position in a NICU in Dallas, Texas. This was particularly helpful because not only did I lose my job, but I lost my home and my city for a little while. Tenet Health was later purchased by Baylor University.

"We are constantly trying to work on a plan to help our patients live the best lives for themselves."

Texas was nice, but it was not home. The food wasn't right. The music wasn't right. My hair wasn't right. I had to make it back to New Orleans. Rebuilding took some time and money, but my family and I pulled through. I needed a job back home. The NICU that took over my old facility was scared to take a chance on me because I was living far away in Dallas. That is when I changed my focus to a research career. I searched for a

position based in an academic facility. I had some of the knowledge, most of the experience, and a lot of the personality to be hired as a PHACS Study Coordinator by Dr. Margarita Silio and Dr. Russell Van Dyke in Tulane University's Pediatric Infectious Disease Department. I learned how to do research. I had to study to learn more about HIV and how my new patients survived and lived well with it. I was already experienced in all the nursing stuff, so I hit the ground running. Once again I was working in another field of nursing where my patient relationships were long-term. We have a family here at Tulane. We are constantly trying to work on a plan to help our patients live the best lives for themselves. We provide a connection to resources when they need it. We hold hands if we have to. We fuss through the muck sometimes because we care. We have fun outside the clinic, too. We have Christmas parties for our patients. Last summer, I got zoo tickets for families to have another outing with our staff and our families. That was a blast. I put on bake sales with my teammates annually to raise money to send our patients and me (or another staff member) to Camp Hope. Camp Hope is a camp in Texas for children living with HIV. Yep, I get to be a camp nurse once again; how wonderful is that? Life certainly goes full circle. I hope we can continue all of our activities for our families when the pandemic is over.

BEING HUMAN



Blessings on you today!

When confronted with our own failures,
we sometimes say, *After all, I'm only human.*
More accurate is, *I'm not yet fully human.*

The human journey has been a movement
beyond simply trying to survive,
to evolving dimensions of consciousness,
with an ever-expanding awareness of how we are
connected to other humans and to everything else,
and how being connected becomes communion.

Specifically, we are becoming more and more aware
that compassion is basic to being human, and that
do for others what you want them to do for you
is what's right and good in relationships.

We know in our bones and in our hearts
that communion is better than conflict,
peace better than war, love better than hate.

Everything is connected to everything else,
and communion is both the imperative
of the present, and our destiny.

With gratitude for a new day!

Submitted by: Joe

**"WE ARE BECOMING MORE AND
MORE AWARE THAT COMPASSION IS
BASIC TO BEING HUMAN..."**

CAB GLOSSARY

Adverse Event (AE): Any unwanted symptom a participant experiences in a clinical trial. It may or may not be related to the study intervention or study medicine.

Case Report Form (CRF): A form used to collect data for a research study.

Clinical Trial: A study designed to learn about the potential beneficial effects, usefulness, and safety of something in human participants. This could be a drug, biologic, or device.

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

Solace: Help or comfort in a time of stress or sadness.

Standard Operating Procedure (SOP): Written documents that describe in detail how a procedure should be done.

PLATE PUZZLES

Instructions: PHACS investigators and staff hold many titles! We've listed nine (9) of those titles below. Try to figure out which titles are abbreviated in the following license plates. ([Answer key on page 17](#)).

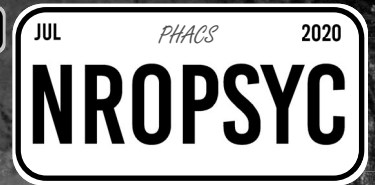
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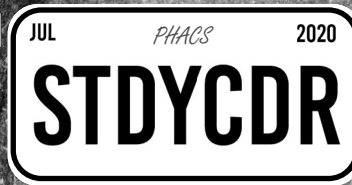
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7



2



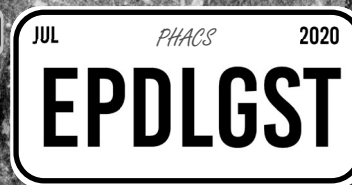
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6

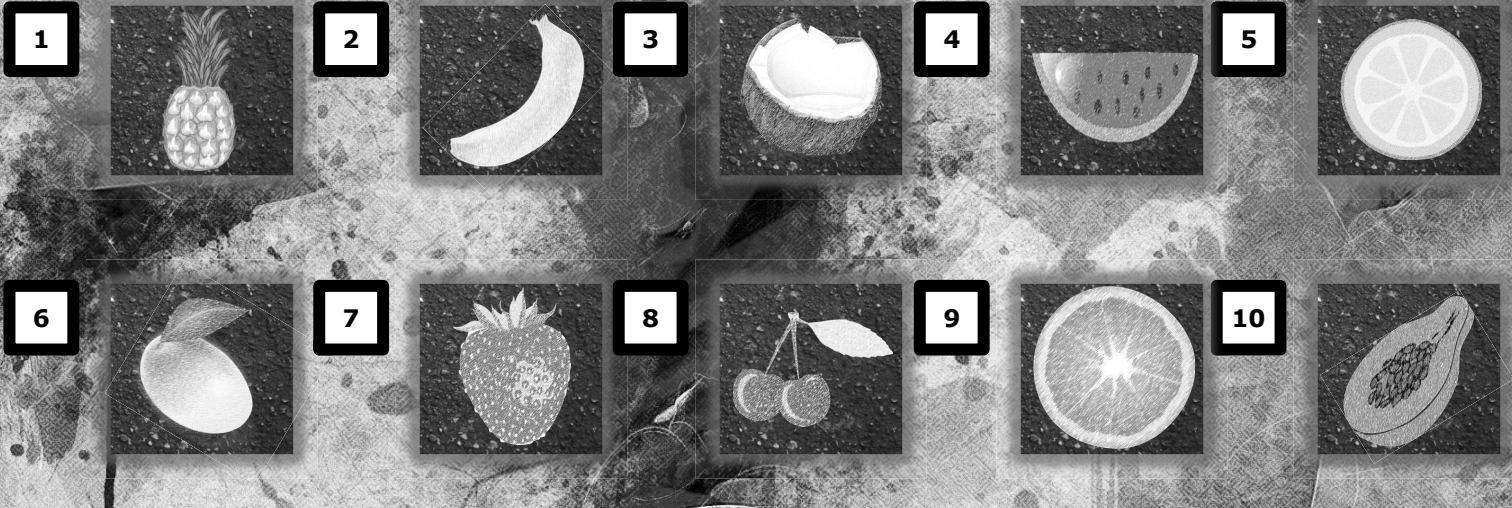


9



CAB KIDS

Instructions: Write down the name of each fruit then find the name of the fruit in the word search!
([Answer key on page 17](#)).



P I N E A P P L E G E E G E L
 S T R A W B E R R Y N R O W Y
 A B N C O C O N U T L I M E L
 L A N G O O H R I R N E G C U
 P N N A I E E E G C P N E Y W
 P A P A Y A N P R M A S W E M
 M N N L O W E N P R R G C R R
 W A T E R M E L O N Y P T A E

PLATE PUZZLES KEY

- | | | |
|---------------------------|--------------------|----------------------|
| 1. Principal Investigator | 4. Data Manager | 7. Neuropsychologist |
| 2. Study Coordinator | 5. Biostatistician | 8. Study Nurse |
| 3. Epidemiologist | 6. Medical Officer | 9. Audiologist |

CAB KIDS KEY

- | | | | | |
|--------------|---------------|------------|---------------|------------|
| 1. Pineapple | 2. Banana | 3. Coconut | 4. Watermelon | 5. Lime |
| 6. Mango | 7. Strawberry | 8. Cherry | 9. Orange | 10. Papaya |

P I N E A P P L E G E E G E L
S T R A W B E R R Y N R O W Y
A B N C O C O N U T L I M E L
L A N G O O H R I R N E G C U
P N N A I E E E G C P N E Y W
P A P A Y A N P R M A S W E M
M N N L O W E N P R R G C R R
W A T E R M E L O N Y P T A E

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