

A COMMUNITY ADVISORY BOARD NEWSLETTER PUBLISHED BY:

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

INSIDE THIS ISSUE:

| Little Joshua in Puerto Rico | 2 |
|--|-----------|
| Every Seed Counts | 3 |
| Shining Star | <u>4</u> |
| How I Go Above and Beyond | 5 |
| Thank You | 5 |
| Above and Beyond | <u>6</u> |
| Seven Tips for Going the Distance | Z |
| Spotlights | <u>8</u> |
| Helping Seniors | 2 |
| Upcoming Events | 2 |
| PHACS Member Profiles | <u>10</u> |
| Resources | <u>11</u> |
| Working Together for Families in Puerto Rico | <u>12</u> |
| HECC Update | <u>15</u> |
| Winter is Coming | <u>16</u> |
| Recipe | <u>16</u> |
| Publications in the News | <u>17</u> |
| CAB Glossary | <u>18</u> |
| Word Jumble | <u>18</u> |
| CAB Kids | <u>19</u> |
| Word Jumble Key | <u>20</u> |
| CAB Kids Key | <u>20</u> |
| | |

IN FOCUS

STEPHANIE, PHACS CAB CHAIR:

Let me begin by wishing everyone a Happy New Year. I feel 2018 will be just as great, if not better than 2017. We were quite busy in 2017. I believe we had more great CAB involvement from the members. My hopes and goals for 2018 include not just continuing involvement in PHACS, but also to increase participation in the CAB including on the CAB calls, and in the PHACS studies, such as the Women's Health Administrative Supplement.



MEGAN, BRANDON, STEPHANIE, AND CLAIRE AT THE FALL 2017 CAB RETREAT

The Fall 2017 Meeting was great. We had so many CAB members help make the CAB's presence known by asking questions, starting discussions, and being involved. I absolutely loved the bracelet activity and how it enabled the CAB members to introduce themselves to the PHACS team. I hope it's something that we can continue. I really look forward to helping lead the CAB through 2018.

BRANDON, PHACS CAB VICE CHAIR:

Happy New Year! 2017 was a busy year for the CAB. During the Fall 2017 Network Meeting, the CAB was more involved in the discussions and presentations than ever before. There was a great energy from both the Adult CAB and the Young Adult CAB (YACAB). The YACAB also had an empowering presence at the meeting. The group continued to grow and give a voice to the community members throughout the year. During the YACAB Retreat, the YACAB gave great feedback, which will help inform the HECC "Choose Your Own Adventure" videos (read more about the status of that project on page 15). At the CAB Retreat, the Adult CAB reflected on its successes and failures to help create positive goals for 2018. The CAB plans to work on those goals in the coming months. My goal for the CAB is for it to continue to excel in each and every aspect of life, and that we continue to test and push our limits to go above and beyond in the hopes of creating a better tomorrow not just for ourselves but for the future.

LITTLE JOSHUA IN PUERTO RICO

The final activity of 2017 for the University of Puerto CAB was at "Little Joshua," a home for children ages 1-3. After Hurricane Maria, Little Joshua had many needs. The CAB donated toys, essential items, and especially much love.

Submitted by: Joel







EVERY SEED COUNTS

We live in a world where there has been so much pain and suffering lately, whether it be from natural disasters or others hurting one another. It feels like this world is full of those who need help, but those with the power and resources could care less. So, we go on with our daily lives, standing by doing nothing and saying, "How come no one does anything about it?"

"SOMETIMES, EVEN THE
SLIGHTEST GESTURE OF
KINDESS CAN BE THE
GREATEST GIFT TO SOMEONE."

The only thing necessary for the triumph of evil is for good men to do nothing.-Edmund Burke.

Ask yourself, are you a good person if you stand by and do nothing? Sometimes, even the slightest gesture of kindness can be the greatest gift to someone.

I remember a patient of mine I met a while back, who was this little old and very kind country fellow. As I watched him with watery eyes, he told me that some of his family found out about his status and kicked him out of the house out of fear. Although he wasn't perfect and was dealing with other issues, he was trying to get back on the right path and better himself. Hearing this story hit me hard because I know what it is like to want to love but people end up fearing you. I knew I couldn't stand by and do nothing, so I asked him if he'd had anything to eat. He replied no, so I went and bought him some breakfast. Now some of you may say, "Great Brandon, you fed him once, so what does that accomplish?" You might also say, "Don't you know the saying 'Give a man a fish, you feed him for a day, teach him how to fish and you feed him for a life time'?" I don't believe that. Yes, I've had patients to whom I've given clothes, food, and money who've used me. Yes, I might have just fed him for a day, but I believe by doing that you can restore someone's faith humanity to let them know that not everyone has turned their back on them, and that there is still hope. A few weeks went by and I was at McDonalds (clogging my arteries :-)), and I saw my patient. He came over to me, drinking his Ensure, and told me that he was currently living with his son and grandkids, and that he was doing better as he was in the process of getting his license back. I'm reminded of a story I read

called, "Superman Peace on Earth." In this story, Superman tries to end world hunger, but despite his best efforts he sees that the project was too big for one man, even if he is a Superman. He said, "Give a man a fish and he eats for a day, teach him to fish and he eats for a lifetime." He went on to say, "I ask everyone to share what they have with those who need it. Their knowledge, their time, their generosity. Especially with the young, for on them rests our future, and all hope of a true Peace on Earth." In the end, he recalls the words that his father taught him on the farm, "...not every seed will make it, but all of them deserve the chance to grow." I believe that we each have within us the gift to touch another's life, because if we don't do something. who will? In the end, we are all we have, and we are all worth saving.

Submitted by: Brandon

SHIIII STAR







PHACS CAB member Exzavia recently won the Children's Diagnostic and Treatment Center's (CDTC) Quarterly Shining Star Award! Below is an excerpt from the award:

Exzavia has been working at CDTC as a Family Support Worker since 2000. She is dedicated to ensuring that pregnant women with HIV have access to medication to ensure that infants are not born with HIV. She works hand-in-hand with Care Coordinators in the Comprehensive Family AIDS Program (CFAP) to ensure that patients have support, someone to follow up with any questions, and to assist with running support groups. She is the CAB representative for IMPAACT and PHACS. She helps coordinate the youth support group. She also participates in the PHACS Health Education and Communication Committee (HECC) and in on the CFAP Family Advisory Board. Exzavia sits on the Board of Directors for Legal Aid, acting as a community representative.

Exzavia is kind, gentle, and empathetic. Clients at CDTC relate to her, and she is the best role model CDTC could hope to find. A while back, Exzavia was meeting with a newly diagnosed patient, who had trouble coping with her diagnosis and all the medications she needed to take, and was refusing to follow through on her regimen. Exzavia was able to relay her personal story and offer hope. The patient changed her mind and began the regimen because Exzavia was non-judgmental and met the patient where she was emotionally.

Recently, Exzavia has helped a family in need when the mother died unexpectedly leaving three small children that needed support. Exzavia's passion for helping others comes across immediately and everyone at CDTC is a better person because they know her. For this and so much more, CDTC is proud to have Exzavia as CDTC's Quarterly Shining Star.

Submitted by: Exzavia

To me, "Above and Beyond" means going out of your comfort zone such as doing or saying something to help someone else without any benefit to one's self. It might mean seeing a stranger looking sad and giving them a compliment to brighten their day. It means giving your time to help someone in need. Sometimes it's speaking up for someone who may not be able to do so themselves. It means so many things. It's not one-size fits all.

HOWIGO
ABOVE AND
BEYOND

Some people don't have time to give, so they give money. Others like myself don't have money, so we give our time. We give food out of our pantry. We give our time to listen, even when we're really not in the mood. It's not about us, so we listen anyway. I'm not always at my best; really, none of us are. We all have our own struggles, but going above and beyond is not making it about our personal struggles. It's about helping or being there for another person's struggles. It's about putting our selfishness aside and being selfless. It's not waiting for someone to do something for you, but rather, it's about you doing something for others.

Submitted by: Stephanie

THANK YOU

Dear Readers,

Happy New Year! We would like to thank the many families involved with research studies and those who also act as Family Advisory Board (FAB) or Community Advisory Board (CAB) members on behalf of the University of California San Diego. The contributions of volunteers are critical to the success of our program for both research and clinical care. We are so pleased that many of you have participated by serving on the advisory boards, assisting with planning committees and conference calls, and by encouraging others to attend study and health visits. Some have even been generous enough to travel hours away, for days at a time, to participate in leadership training opportunities in order to further assist the community. Given this month's newsletter topic, "Above and Beyond," we would especially like to thank our volunteers for the invaluable encouragement they provide to others, exceptional dedication, and generosity of their precious time. Your support is really appreciated! Thank you so much for your important contributions!



Looking forward to working together in 2018!

Submitted by: Staff at the University of California, San Diego

ABGUE AND BEYOND



Going above and beyond means someone who goes outside their job description and really empowers a person to make them feel special and taken care of.

To go above and beyond means to do everything possible, plus more to get the desired results.

Going above and beyond means going the extra mile to help someone and to see the outcome of the help.





Going above and beyond means that I can do all things within me to help others. I really feel that we can have better outcomes when it comes to all these pressing topics if we just let go of the ignorant thoughts and educate our friends and family. We must find strength within ourselves to live life to the fullest without feeling defeated just because we happen to have a chronic ailment. I beat myself up for many years because I thought less of myself. I did not feel I was important. I did not feel I was loved.



Someone
who goes
above and
beyond is someone
who goes out of their
way to help others.

Going above and beyond is giving it your all when the world says and thinks differently. It's working not for pay or praise, but because it's the right thing to do.



To me, going above and beyond means reaching my goals. It means going for more. It means not stopping at just one thing. It means accomplishing multiple goals.



SEUENTIPS FOR ROMATHE OBTAICE

Submitted by: Brandon

Find a reason or purpose for going above and beyond, whether it be to better yourself or to better someone you care about.

Hold vourself accountable because too many times we depend on others. Sometimes we believe someone else will handle the situation. and then we're disappointed when nothing happens.

Step out of vour comfort zone because life can be pretty repetitive. It is up to us if we want to be the change. Try something new, change your thoughts, break the status quo, and don't blend in when you were meant to stand out.

Don't get discouraged. There are going to be times when it feels like a losing battle when the people who are on the same team as you turn against you. When people say no, you must say YES. Whatever you truly want, you must believe and prove that it is yours, and you are going to have it.

Surround yourself with like-minded and positive people. It's easy to be a product of your environment. Don't surround yourself with negative people or energy drainers that keep you from fulfilling your true purpose. You only get one life, one chance; don't sacrifice vour dreams. Remember. you were meant for something more.

Give it your all. Remember to ask yourself, "how much is it truly worth to you?" When you say you have nothing left to give. remember you can give your time or your energy. Whatever it may take, try to make an effort to do it. The last thing you want to feel is full of regret, knowing that things could be better, but you decided to give only a little bit, or even worse. that you gave up on yourself.

but don't get blinded since during our journey we sometimes tend to lose the fuel, fire, and passion we first had within ourselves. This may be because we've allowed so much to impact us along the way. You must remember the reason you started your journey and press on. Don't let anyone put out your light. Sometimes, we are so focused on our goals that we lose sight of who we are and where we came from. Hold on to those you love and always remember the journey, but most of all, never forget who you are.

Stay focused

SPOTLIGHTS



WE ASKED CAB MEMBERS TO TELL
US WHO GOES ABOVE AND BEYOND
IN THEIR LIVES. RESPONSES
BELOW WERE SUBMITTED BY CAB
MEMBERS.



I can say my family is a great support, but this will have to go to my husband, Marcus. He goes above and beyond for me. He is support. He is strong. He reminds me every day why I should continue to take my medications. You see, I still have moments when I don't want to take these medications. I can be honest with him. As a team, we work on adherence, and when I feel depressed, I talk to him about it. He reminds me why he is my partner in life.

My best friend.

My family.

The staff at Texas Children's Hospital (TCH): Chivon McMullen-Jackson, RN, BSN is always here and available. William Shearer, MD, PhD helps patients inside and outside the site. Thersa Aldape, because she is always available to help the research nurses. She also provides social work on an ongoing basis, not just for the patients who come in for their study visits. She also coordinates activities for families affected by HIV and chairs the CAB. She keeps the families involved in the activities at TCH.

Not only do they all help us at the site, but there have been numerous times where some of us have been going through personal situations, such as needing housing, losing a loved one, or just needing a shoulder to cry on, and they have been there for us.

My families! They are very supportive of me and my children. Anything I want to do to better myself, they are there for me.



HELPING SEMORS



UNIVERSITY OF PUERTO RICO MEDICAL CENTER CAB:

The CAB held an activity at a nursing home last year. The CAB delivered articles of first necessity after Hurricane Maria. The group was able to give joy, love, and support to those who needed it.

Submitted by: Joel

UPCOMING EVENTS



FEBRUARY 7: NATIONAL BLACK HIV/AIDS

AWARENESS DAY

MARCH 10: NATIONAL WOMEN AND GIRLS HIV/AIDS

AWARENESS DAY

MARCH 26: NATIONAL NATIVE HIV/AIDS AWARENESS

DAY

APRIL 9-10: PHACS SPRING LEADERSHIP RETREAT
APRIL 10: NATIONAL YOUTH HIV & AIDS AWARENESS

DAY

APRIL 18: NATIONAL TRANSGENDER HIV TESTING DAY

MAY 18: HIU VACCINE AWARENESS DAY

MAY 19: NATIONAL ASIAN & PACIFIC ISLANDER HIV/

AIDS AWARENESS DAY

JUNE 5: HIV LONG-TERM SURVIVORS DAY

JUNE 27: NATIONAL HIV TESTING DAY

PHACS MEMBER PROFILES



ALEXIS

Hi! My name is Alexis. I am a junior in high school. I just recently turned 17. I love my family, cats, and playing sports. I

play field hockey in the fall, water polo in the winter, and swimming in the spring. Just this past September, I had the privilege of attending the PHACS conference in Maryland (my first time on the east coast). It was such a wonderful experience. I learned so much about the studies that I have participated in for as long as I can remember. I got to meet some amazing people who organized the conference, doctors, and the outstandingly strong women who attended as well. I also got the opportunity to speak about my life, knowing about my mom's HIV status, and how it has affected me.

I look back and realize that I much. I have learned so experienced some amazing things and I would do it again in a heartbeat! I definitely am a huge advocate. I love educating people who may not knowledgeable about HIV and AIDS, and shutting stereotypes. Correcting information that people have about HIV is really important to me. I think the first step to stopping HIV is teaching people about it, and that is something that I can do to help the cause.



GRACE ALVAREZ, FMD/MPH

Hello all! My name is Grace Alvarez and I am the Site Coordinator at the Miami site, located at University of Miami (UM) and I am honored for the invitation to tell you a little bit about me.

I was born in Saint Paul, Minnesota a few years ago (don't ask how many, you just

need to know I am young :-)) while my parents were doing their post-graduate studies. After they finished, we moved back to their country of origin and I was raised from a very young age in Venezuela.

In Venezuela, I went to medical

school and while studying medicine I met my wonderful husband. Soon after graduation, we decided to come to the United States (U.S.) to look for new career opportunities and a better quality of life to start our family.

Here we have been very lucky, always surrounded with wonderful people from all around the world who support our growth as professionals and individuals, learning a new language, new habits, improving our knowledge about different aspects of our career and sharing a variety of multicultural experiences in this beautiful Florida city.

Continued on page 11

PHACS MEMBER PROFILES CONTINUED

I started my professional career in the U.S. working as a Case Manager. This position gave me the opportunity to learn about the health system in this country and get involved with the community. After a couple of years, I applied for a Research Assistant position at UM, where Dr. Gwendolyn Scott, our Principal Investigator, gave me the opportunity to get into the fascinating world of clinical research.

I began working in the AMP protocol, and started learning on the very first day in this role; I spent almost three years in charge of this study. At the same time, I went to graduate school to learn more about the U.S. healthcare environment, clinical research opportunities, and more topics that I believe will help me develop even further in my career. In 2011, I earned a Masters degree in Public Health.

Shortly after that I decided to fulfill another aspect of my life and left my position when my first child (Victoria) was born. After three years, I was presented with the opportunity to come back, this time in a new role, as a PHACS Site Coordinator. This position gave me the opportunity to learn more about SMARTT, AMP UP, and to work directly with our CAB members and all the activities that are part of PHACS.

Now, I am working as a Site Coordinator for PHACS and IMPAACT; it is a very exciting opportunity and a new challenge that I assumed with enthusiasm and responsibility. Every day we have something new to learn, and working on these research protocols has been one of the most gratifying experiences in my career.

Two years ago, we had our second

child, our son Samuel and since then I share my time as a mom, wife, and researcher. I enjoy dancing Flamenco and sleeping (when my kids allow it).

In September of this past year, my colleagues from PHACS gave me a really amazing surprise, the National PHACS Award for Research Excellence in Study Coordination. For me, this was a real honor and incentive to keep doing what I love and to put more effort every day to doing things right.

My plans for the future are to keep growing in my research career. I want to get my certification as a Research Professional and keep helping in the contribution of knowledge to offer a healthier life to our communities.

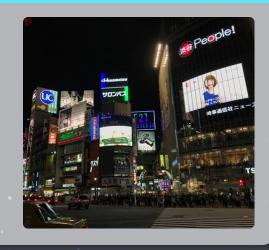
RESOURCES

4 Totally Realistic Ways to Make a Difference in the World: https://tinyurl.com/ycstagua

10 Ways To Help Others That Will Lead You To Success: https://tinyurl.com/y7wosbgh

Why Helping Others Actually Helps Yourself: https://tinvurl.com/vbfm4hzg

Volunteer Match: https://tinyurl.com/ydxb2wgr



UORKING TOGETHER FOR FAMILIES IN PUERTO RICO



Assembled backpacks lined up, waiting to be packed into boxes.

This fall, in the wake of Hurricane Maria, PHACS team members from around country worked together on a relief effort for Puerto Rico. On September 20th, 2017, Hurricane Maria (a Category 5 storm) hit Puerto Rico with devastating force and left residents without reliable access to water, food, electricity, and many other necessities. The provision of critically needed aid extremely slow and, in some places, practically non-existent. Weeks after the hurricane, many

residents were still struggling to meet their basic needs – with the poorest and most vulnerable particularly affected.

In the aftermath of the hurricane, staff at San Juan City Hospital reached out to PHACS leadership with an urgent request for supplies, describing the dire situation on the ground for patients, families, and staff. They sent a specific list of materials that were desperately needed, including water filters, solar chargers, batteries, mosquito nets and repellant, feminine hygiene



The last packing station for backpacks.

products, first aid kits, and disinfecting wipes, to name a few. Staff from both Harvard T.H. Chan School of Public Health and



Staff assembling backpacks at Lurie Children's Hospital.

Ann and Robert Lurie Children's Hospital in Chicago worked to respond as quickly as possible. While Lurie Children's Hospital staff secured a large donation that allowed them to purchase the requested supplies in bulk, staff at Harvard set up an Amazon registry that would allow people to purchase individual items, according to their own budget. Lurie Children's Hospital staff assembled backpacks, loading them boxes. which amounted to two pallets worth of supplies.

(Continued on page 13)

UORKING TOGETKER FOR FAMILIES IN PUERTORICO

CONTINUED



Nearly 225 donated water filters stacked in an office at Harvard.

The staff at San Juan City Hospital and the University of **Puerto Rico Medical Center were** working around the clock to deliver babies and provide quality health care to their patients, all while battling scant electricity and other overwhelming challenges every day. Meanwhile, UPS packages began flowing into our Harvard offices, sometimes in four or five large shipments each day. We scrambled to unpack, catalog, and store each shipment before the next one arrived. Within just a few weeks, nearly 2,000 donated items had arrived via the Amazon registry, and our offices were stacked high with boxes of toilet paper, tampons, water filters,

energy bars, flashlights, and many other items.

The next challenge was to find a way to get the supplies to our clinics in San Juan as quickly as possible, where many staff and patients continued to live without electricity, clean water, and a reliable food supply. Over the course of many (many!) calls requests and to every organization and company we could think of, we connected with another staff member at Harvard working on Puerto Rico relief efforts. Her partner, it turned out, is in charge of chain supply logistics at the Massachusetts



Pallets of backpacks and supplies ready for shipping at Lurie Children's Hospital

Institute of Technology (MIT) and happened to have just received an offer from JetBlue Airlines to transport medical supplies to Puerto Rico for free.



Staff at Harvard about to depart for Boston Logan Airport with supply kits.

We were elated at this stroke of luck, and at the power of building community around our various relief efforts. On Halloween, we had a huge "packing party" with a supply backpack assembly line. Our PHACS team and a group of other Harvard volunteers packed 113 large waterproof backpacks full of supplies within 36 minutes – surely some sort of record. We rented a U-Haul and loaded it with 94 boxes of supplies (about 2,600 pounds) and set off for Boston Logan Airport.

(Continued on page 14)

UORKING TOGETHER FOR FAMILIES IN PUERTORICO

CONTINUED



A car filled to the brim with backpacks for University of Puerto Rico

We delivered the boxes to JetBlue, packing them onto pallets and wrapping them in clear plastic and signing them over to the kind folks in JetBlue's cargo facility.

When the shipment arrived in San Juan just a few days later, staff from our clinics were ready and waiting at the airport to collect the boxes and start distributing the much-needed supplies to their patients and families. Harvard staff continued working to find a way to deliver hundreds of solar chargers and cans of aerosol bug spray – these items are much trickier to send

than one might think, since they are not allowed on passenger jets and require a specially trained worker to prepare them for shipment. However, we succeeded in delivering those items to Puerto Rico just after the Christmas holiday, and we are happy to say that all donated registry items are now right where they should be—at our San Juan clinics or with the families who need them.



University of Puerto Rico staff with backpacks stacked at clinic.

We cannot imagine the conditions faced by our families and staff in Puerto Rico since the hurricane, or by our colleagues at San Juan City Hospital and the University of Puerto Rico Medical Center as they continued

working to provide the best medical care possible for their patients. We thank our Puerto Rican staff for initiating this relief effort, and we thank our entire PHACS community for whatever role you played in supporting them – whether it was purchasing an item from the registry, circulating the request to your own networks, helping to pack, load, and deliver supplies, or any other role you played. Witnessing such overwhelming generosity from our community has been a beautiful experience.

Additional photos may be found on the PHACS website:

https://tinyurl.com/yafsrfox

Submitted by: Claire



Staff at San Juan City Hospital showing the contents of a supply backpack.

HEGIPATE

Dear PHACS CAB Members.

The Health Education and Communication Committee (HECC) has an exciting year ahead. Here are some of the updates from our committee:

PHACS FILM SERIES

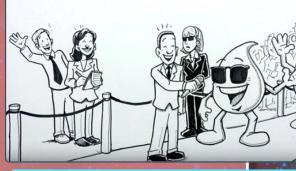
Since the last edition of the newsletter in July 2017, Claire presented the "Faces of PHACS" youth documentary at the American Public Health Association (APHA) Global Health Film Festival. Clips from all three of the films ("Faces of PHACS" youth documentary; "PHACS Community Voices" CAB film: and a short version of the youth film), have been posted on the PHACS website. We are continuing to work on an additional film with the Harvard media office using footage from study visits at Tulane University and Boston Children's Hospital. This year, we plan to submit the films to several additional scientific conferences and film festivals.

"CHOOSE YOUR OWN ADVENTURE" VIDEO FOR YOUNG ADULTS

Over the last year, we worked with a health communication graduate intern from Tufts, Marwah Hassounah, to create a "Choose Your Own Adventure" video for young adults. Marwah worked with the HECC, Study Coordinators, CAB members, and YACAB members to create a storyboard for the videos. Using this video, PHACS young adults will have the opportunity to actively participate by making small decisions regarding health care for the main character. Each decision leads to a unique scene based on that decision. Ultimately, the video will model health literacy skills that will support a health transition to adult health care for The HECC is participants. currently working on editing the script for the storyboard with filming expected to be completed later this year.

WHITEBOARD VIDEOS

The HECC has teamed up again with Booster Shot Media (BSM) to create four short videos about informed consent. These videos help complement written informed consent forms, and will be used for in-clinic and remote consenting. Based on feedback from study participants and PHACS team members, the videos will focus on three separate topics: 1) Repository; 2) Privacy and confidentiality; and 3) How participating in the study helps others. The HECC recently made edits to the script and the videos are currently under production at BSM.



YACAB

The YACAB welcomed several new members in 2017, many of whom attended the PHACS Fall 2017 YACAB Retreat Network Meeting. The retreat theme centered around "Living Beyond the Virus." Sessions led by YACAB members focused on topics such as Leadership, success, and failure; Creating life image boards; Relationships, life skills, and disclosure; Feedback for the "Choose Your Own Adventure" video; and Goals. In 2018, the YACAB will be focusing increasing YACAB membership with a recruitment strategy. The group will also address improving communication within the YACAB.

We're excited to welcome a busy 2018, and to collaborate with the CAB, YACAB, and the PHACS research team on these projects!

Submitted by: Megan and Claire

WINTER IS COMING

Winter is coming. Is your fire ready for the battles?

Winter is coming. Those who were advocates and fighters rose to the cause, so that we may have the livelihood we have now, are getting tired weak and have just plain have moved on to their Heavenly Plains.

It's time for us, more than ever, to stand up and be the long-lost kings and queens of fire. I stand here saying that I am ready to be here for all of you.

I am ready as I have been for so many years by giving my mind, body, and soul to research and finding a cure.

And I do promise as long as I have breath that I will fight because it is the fire that is fueling my heart and soul.

So, I challenge you. Do you still have that flame? Are you ready to continue to pass the torch until there's a cure?

Once winter does come, we will not only survive, but we will be able to say the only reason there was a cure was because we continued to pass the fire to generations to come.

In other words, together we can defeat winter.

Now everybody must stand up and use their fire to defend the wall.

Submitted by: Kim

RECIPE

Sugar Cookies

Ingredients:

- 11/3 cups flour
- 1/4 teaspoon baking powder
- 1/2 teaspoon baking soda
- 1/4 teaspoon salt
- 1/2 cup unsalted butter (1 stick)
- 3/4 cup sugar
- 1 egg
- 1/2 teaspoon vanilla extract

Directions:

- 1. Preheat oven to 375 degrees F.
- 2. Mix together flour, baking soda, baking powder, and salt.
- 3. In a separate bowl, beat the butter and sugar together until smooth. Beat in egg and vanilla.
- 4. Add the dry ingredients into the butter/ sugar mixture and blend until smooth.
- 5. Roll teaspoons of dough into balls, place on a cookie sheet.
- 6. Bake 8-10 minutes, or until golden.

Submitted by: Anonymous



PUBLICATIONS IN THE NEWS



SINCE THE JULY 2017 PHACS CAB NEWSLETTER, PHACS HAS MADE THE FOLLOWING CONTRIBUTIONS:

- 7 MANUSCRIPTS ACCEPTED TO SCIENTIFIC JOURNALS; AND
- 1 ABSTRACT PRESENTED AT A SCIENTIFIC CONFERENCE

"Birth weight and preterm delivery outcomes of perinatally vs. non-perinatally HIV-infected pregnant women in the U.S.: Results from the PHACS SMARTT study and IMPAACT P1025 protocol." This manuscript is in the Clinical Infectious Disease Journal. Lead author Jennifer Jao, MD, MPH is an Assistant Professor at Icahn School of Medicine at Mount Sinai and a member of the Maternal Exposures Working Group (WG).

"Prospective memory in youth with perinatally-acquired HIV infection." This manuscript is in *Child Neuropsychology*. Lead author Lynette Harris, PhD is a Neuropsychologist at Baylor College of Medicine and a member of the Neurodevelopmental and Neurological Disease WG.

"Mediation analysis for censored survival data under an accelerated failure time model." This manuscript is in *Epidemiology*. Lead author Isabel Fulcher, MA is a Biostatistics Doctoral Candidate at Harvard T.H. Chan School of Public Health.

"A hierarchical modeling approach for assessing the safety of exposure to complex antiretroviral drug regimens during pregnancy." This manuscript is in *Statistical Methods in Medical Research*. Lead author Katharine Correia, MA is a Biostatistics Doctoral Candidate at Harvard T.H. Chan School of Public Health.

"Improvement in lipids after switch to boosted atazanavir or darunavir in children/adolescents with perinatally acquired HIV on older protease inhibitors: results from the Pediatric HIV/AIDS Cohort Study." This manuscript is in *HIV Medicine*. Lead author Jennifer Jao, MD, MPH is an Assistant Professor at Icahn School of Medicine at Mount Sinai and a member of the Maternal Exposures WG.

"Changes in insulin sensitivity over time and associated factors in HIV-infected adolescents." This manuscript is in *AIDS*. Lead author Mitch Geffner, MD is a Professor of Pediatrics at Children's Hospital Los Angeles and a member of the Scientific Leadership Group (SLG).

"Risk for speech and language impairments in HIV-exposed uninfected children at 3 and 5 years." This manuscript is in *Pediatric Infectious Disease Journal*. Lead author Mabel Rice, PhD is a Distinguished Professor at the University of Kansas and Co-Chair of the Hearing and Language WG.

Abstract

The following abstract was presented at the 21st International Workshop on HIV and Hepatitis Observational Databases in Lisbon, Portugal, March 22-24, 2017:

"Trends in neonatal prophylaxis and predictors of combination antiretroviral prophylaxis in US infants from 1990-2016."

CAB GLOSSARY



Benefit: A good, positive, or useful effect.

<u>Confidentiality</u>: Keeping personal information private. Personal information collected during a clinical trial is de-identified to protect the privacy of research participants.

<u>Efficacy</u>: In medicine, usefulness in treating or preventing a medical problem.

<u>Protocol</u>: A detailed plan that sets forth the objectives, study design, and methodology for a clinical trial. A study protocol must be approved by an IRB before implementation.

<u>Sponsor</u>: The entity that initiates a clinical investigation, but does not actually conduct the investigation. The sponsor may be an individual or pharmaceutical company, governmental agency, academic institution, private organization, or other organization.

<u>Standard of Care</u>: A treatment plan that experts agree is appropriate, accepted, and widely used for a given disease or condition.

WORD JUMBLE

<u>Directions</u>: Unscramble each word below using the CAB glossary words. Then use the letters in each circle to unscramble a hidden word. (Answer key on page 20)

OCRFDOAEARNTSA
IITFCNYTNEDIOAL
TIEEBNF

OORSOPS
FOECAFIC
LORPOOTC

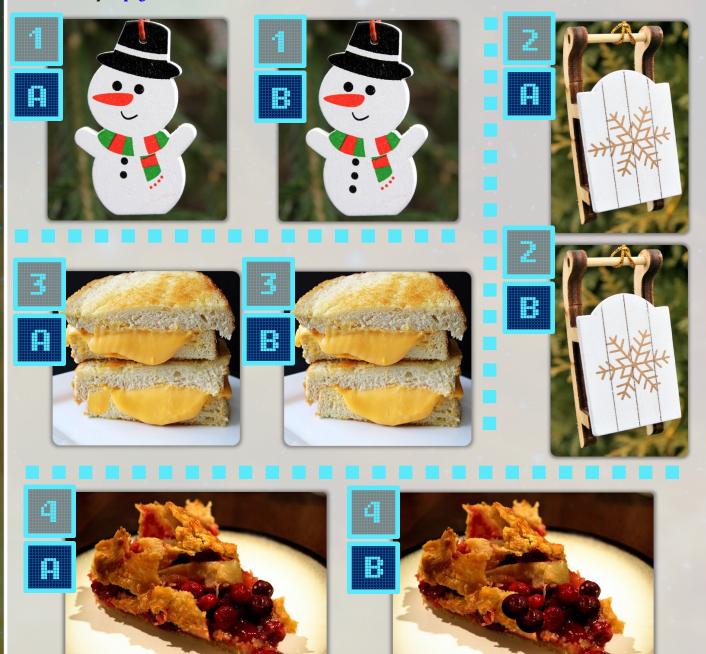
HIDDEN WORD:

CR'S KIUS

SPOT THE DIFFERENCE!

Look at the pairs of pictures below and find the difference in each picture.

(Answer key on page 20)



WORD JUMBLE KEY

STANDARD OF CARE CONFIDENTIALITY BENEFIT

SPONSOR EFFICACY PROTOCOL

HIDDEN WORD: BEYOND

CAB KIDS KEY



- There is a third button on the snowman's
- The left arm of the snowflake is longer than the others.
- 3. There is an extra piece of cheese on the lower grilled cheese slice.
- There are two extra berries on the left side of the pie.

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