

IN FOCUS



A COMMUNITY ADVISORY BOARD
NEWSLETTER
PUBLISHED BY:

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

Hello, my fellow CAB members. I hope to have found you all staying cool during this hot summer. We have reached the middle of the year and it is almost time for the CAB Retreat. I can't wait to hug and see all of you in person. The Spring 2016 Leadership Retreat in Baltimore, Maryland was awesome. It was so hands-on, which made the experience memorable. (See [page 17](#) for more information about the new SMARTT and AMP/AMP Up priorities from the Spring 2016 Leadership Retreat).



Lesley, Claire, Kim, Mary Anne, and Megan at the Spring 2016 Leadership Retreat

I also wanted to say, please get out of the house this summer! Look for free and educational things to do for yourself and your family. Knowledge is power, and in our business it can make us superheroes.

Kim, PHACS CAB Chair

Greetings, my fellow beautiful beings! It's that time again, to come together as a community to share our ideas on how we can be better advocates and have overall healthier lives. As we embark on this new season of our lives, I would like to remind everyone to please stay hydrated. Drink plenty of water! Did you know that by drinking the proper amount of water daily, you will have healthier looking skin, shinier hair, and your blood will flow properly? Heck, your entire body will do better!

On a more serious note, the CAB has been involved with the new SMARTT and AMP/AMP Up research priorities, and will continue to help develop them to give feedback as the projects move forward this year. I look forward to hearing your voices on one or all of our CAB calls, and also look forward to seeing you in September! Remember, stay hydrated in your body and in your community! Peace and blessings!

Lesley, PHACS CAB Vice Chair

MEET THE NEW

YACAB CHAIRS

ANDREW, CHAIR

Ten Things About Me:

1. I am married to an amazing woman, and we will be celebrating our 11th year anniversary this October.
2. I have three beautiful children – they are ages 7, 4 and 2.
3. I have been HIV-positive for almost 34 years. I can't say with complete confidence that I am the oldest person living with the disease, but I am pretty sure I am at least one of the oldest living people perinatally infected, meaning born with HIV.
4. Kids who are born with HIV and not treated usually die around ages 3 – 7. I started taking medication when I was 8 years old.

5. I am currently "undetectable." No, it doesn't mean I am a ninja. This phrase relates to the amount of virus detectable in my blood, although it still can be hidden in other parts of my body. It also means that the medicine I take every day is working!

6. Both of my parents died from AIDS. My dad died when I was 4; my mom when I was 8.



7. None of my brothers and sisters are HIV-positive, just my parents and I. The virus will end with me.
8. I grew up with my aunt, uncle, and their four children, my cousins. I call them my mom, dad, brothers, and sisters because that's what they are to me.
9. I grew up very rarely telling people I was HIV-positive. Only a few family members outside of our immediate family and a couple close friends knew. This was to allow as normal of a childhood as possible for me.
10. For the first time, I can be completely honest with myself and others. This has taken me a very long time to be comfortable with (almost 35 years!). I know HIV has a negative stigma, but it doesn't have to, and I want to help change that. It is a treatable disease, and you can live a normal life with it; I am proof of that. I want to educate people so that we can get past the "How" you got the disease to "How" you are living your life with it. There are many miracles in the world, and I believe my life is one of them. I am not the only one, and we all have stories to tell. If you feel drawn to share my story, please do. I would love to be part of the change in how we talk about HIV.

GAMON, VICE CHAIR

Hi, my name is, Gamon. I would describe myself as an ambitious young leader who is willing to go as far as I can to help others. My life started off as a young boy, growing up in Texas and being raised by a single mother. I participated in some football during junior high school and high school. I also played the cello. I am now currently enrolling into a university. My name is Gamon, and I'm here to make the world a better place.



PHACS MEMBER PROFILES



RENEE SMITH, PHD

Hi, I'm Renee Smith! I am one of the three Co-Chairs of the PHACS Neurodevelopmental and Neurology Working Group. I'm also a site psychologist at the University of Illinois at Chicago (UIC) PHACS site. I've been working on PHACS since it began in 2006. I started working with youth affected by HIV early in the epidemic at the Walter Reed Army Medical Center in Washington, D.C. The U.S. military was coming up with a program to understand the effects of HIV on service members and their families who got HIV after enlisting. It was a tough time to work in this field. Many medications were not yet very advanced. Youth who were

born with HIV sometimes had medical and developmental challenges. Shortly after, I began working at the National Cancer Institute of the National Institutes of Health where some very exciting research was happening. Doctors were able to offer a new treatment called, "IV AZT" to youth who were very sick with HIV. Some had lost developmental skills, and were not able to walk or talk. After treatment, many regained some of their skills. This was a sign of hope that medications could be effective at reversing some of the damage that the virus had caused. However, families still faced many challenges, as the country was struggling with stigma. This included for youth who were HIV-positive due to blood transfusions.

When I moved to the Chicago area, I began working at UIC with the WITS and PACTG studies. We studied questions about HIV transmission from mothers to babies. We studied if or how that affected a child's development. It was again a time of great hope as new medications were developed. We understood more about how medications could help a child's growth as well as their overall health. It has been fascinating and bittersweet to work in this field over two decades and witness the progress and skilled science that allows us now to help others manage this condition.

One of the most wonderful experiences in my career in HIV research has been working with families affected by HIV. It's been particularly wonderful to work on PHACS. We have so many empowered participants who are active in the research process and willing to share their stories so openly. I am so grateful they have allowed and even invited me to understand the experiences of life through their lens; the struggles of living with HIV, and for some, the unexpected opportunities it has brought to them. I so appreciate that as a team of researchers, we have done our best to stop and listen, and create new spaces. This has allowed us to create a stronger, more authentic team approach that includes doctors, nurses, participants, psychologists, and other health care workers. We work together to answer the most important questions in the field of HIV research and improve the lives of those affected.

Personally, I have eight roommates. I have a husband, two grown youth and their partners (all recently came home to roost – to save money and study for the next round of schooling), and three dogs. Thankfully, we exist pretty harmoniously. I like to garden (veggies), walk with the pups, read, and laugh with my roommates.

PHACS MEMBER PROFILES

JOEL LIZARDI, MD

Hello! Warm and special greetings from the Caribbean, in Puerto Rico. It's a pleasure for me to be recently joining the PHACS family; it's a special opportunity for my professional career. To give you a little bit of my background, I'm from Caguas, Puerto Rico. I have a Bachelor's degree in Natural Sciences and a Doctorate in General Medicine.

Since I was young, I have been known for being a public servant. For example, I have helped with environmental protection, served the public in academics, and I have helped look for homes for animals from the animal shelters. At this moment, I'm working as the president and leader of the CAB of Centro Medico University

of Puerto Rico. Our CAB contributes to the community in many ways. Our CAB has attended the Gay Parade to support the LGBT community, attended events on the International Day of HIV/AIDS, and other related events in the community. It's important that the community be part of our group. This is because the community is the heart and motivation of our CAB. I also dedicate part of my time to giving diverse speeches to youth about sexual education, drugs, and other topics. It's important to reach this key group of the community since they're the future of our country.

In my free time, I like to go to the gym to work out. I also love to work with the different plants that I have at my home. I like to venture around the island and learn about the diverse cultures



that Puerto Rico has to offer as well as other worldly cultures. In the near future, I want to apply to my psychiatric residency. I want to create a health professional group dedicated to the service of our community and the whole world.

I'm excited to be able to join the PHACS family, and hope to offer as much help as I can give. May the sky be the limit!

HECC UPDATE

The Health Education and Communication Committee (HECC) has had a busy 2016 so far! Here are some updates on what we've been working on so far this year:

HIV Disclosure Comics: We're excited to announce that the comics will be presented at ComiCon International in San Diego this July! Claire Berman will

be on a panel talking about the role of comics in health care. The HECC is thrilled to have this opportunity to show the world how our superhero ARV team works together to fight HIV. Rumor has it that Claire will even be dressing up as one of the ARV superheroes....stay tuned for pictures!

Additionally, the comics will soon

be available in Spanish! We are very grateful to Sandra Navarro at Site 12, who (with support from Dr. Ana Puga) worked to translate them into Spanish.

Finally, the HECC will have the opportunity to talk about the comics on the Comics and Medicine Podcast in August.

(Continued on page 5)

HECC UPDATE

IMPAACT CAB Presentation:

Megan Reznick and Claire Berman were invited to give a presentation to the IMPAACT CAB during their network meeting. On June 14th, Megan and Claire gave a presentation on what we learned from our PHACS CAB about strategies for creating and sustaining CABs. The presentation focused on the insights, experiences, and wisdom that the PHACS CAB shared with us in creating the CAB handbook. Megan and Claire also presented ways for CABs to be a part of research studies. We showed the PHACS whiteboard video and Photovoice video. Being at the IMPAACT meeting was a great chance for us to share some of the PHACS CAB's great work. It was also a great opportunity to learn from the IMPAACT CAB about some of their best practices. We hope it was just the beginning of a long collaboration with the IMPAACT CAB!

Research updates: The HECC is continuing its efforts to do formal research around issues that the CAB has identified as priorities. These priorities include stigma, disclosure, and health literacy. Currently, the HECC is working to find a funding

opportunity for us to continue the work around stigma that we started last year with the CAB. Another important update is that coding for the focus groups and interviews that Claire and Deborah Kacanek did at 8 AMP Up sites is nearly completed. Coding is where responses from the focus groups and interviews are put into categories. This helps researchers to understand the results of the study. And finally, Claire is leading a small team to publish a paper about the process of creating the HIV Disclosure Comics. The goal of this paper will be to show other studies how they can create health education materials in equal partnership with CABs through taking an audience-centered approach. This paper will also share the wisdom that caregivers shared with us around their personal disclosure decisions.

PHACS Network Meetings:

At the Spring Leadership Retreat, the HECC had a productive talk about our research and project priorities over the coming years. The group decided that stigma, disclosure, health literacy, and transition to adult care were the most important topics for us to focus on. We talked about the possibility of creating additional video projects. These may include a

whiteboard video to explain informed consent to young adults who might sign up for a study online. They may also include short videos that would feature people connected to PHACS discussing stories about, and research on, perinatal HIV. At the Fall Network Meeting, we will be featuring a panel discussion on a topic of interest to the CAB and researchers.

Young Adult CAB: The Young Adult CAB (YACAB) is growing each month with new members! We have had wonderful participation in the last 6 months. We are very excited to have elected our first Chair and Vice Chair (see [page 2](#)). The YACAB has been very helpful in developing and reviewing new stigma and disclosure tools for SMARTT version 5. They have also been planning new projects. Potential topics include transition to adult care, stigma, and disclosure. For the second year in a row, we will be welcoming several YACAB members to our Fall Network Meeting.

Submitted by: Claire

HECC PROJECT LINKS

[HIV Disclosure Comics](#)

[CAB Handbook](#)

[Photovoice](#)

[Whiteboard Video](#)

[YACAB](#)

Community is love, faith, hope, strength, encouragement, respect, and a feeling of fellowship with others as a result of sharing common attitudes, interests, and goals.

Community means a group that is committed to working together. It is individuals who celebrate together and heal together.

Community Advisory Board means that we are one group with one cause. Our cause is to advocate, speak up, empower, network, and be there for each other, always!

Community means a safe environment to live and to have raised my son!

Community is a oneness of a group of people who service each other.

Community means coming together for your community and sharing information.

A community is a village of support.

Community means sharing common goals.

I feel it from friends, family, doctors, social workers, and medical staff.

I feel strength from my family, who support me in whatever I do.

I feel love in my community when we cheer each other on. I feel it when we take pictures together to remember one another. I feel the strength of the community when we work together and support each other, even when our ideas vary.

I feel it from all my supporters; from every single one of my friends and family who are really truly supportive and understanding of the things that are going on in my life whether it happens to be HIV or it happens to be something else I'm dealing with.

I find love and strength from this special CAB. I have a great support system, but sometimes my family doesn't understand the things I'm going through and sometimes you need that little pick me up to help you fight on.

WHAT IS COMMUNITY? WHERE DO YOU FIND LOVE AND STRENGTH IN THE COMMUNITY?

ADDRESSING HIV STIGMA IN HEALTHCARE

Stigmatization of people living with HIV/AIDS (PLHIV) compromises prevention efforts and treatment compliance. It also makes it difficult for PLHIV to remain engaged in their care. Stigma involves and reinforces social exclusion in which communities impacted by HIV are blocked from certain rights and opportunities. Stigma can also make people more vulnerable to getting HIV. This is because stigma can keep people from appropriate and timely access to care. Stigma has been linked to poor individual, social, and health outcomes. These outcomes include not adhering to HIV medications, loss of social support, and depression. About one half of PLHIV experience some form of stigma associated with their status. A lot of that stigma is received in health care settings and within provider-patient interactions. Unfair treatment of PLHIV in health care settings may include excessive preventive measures, as well as testing and disclosing HIV test results without informed consent. It may also involve

neglecting patients and/or refusing to treat them. Stigma reduction, therefore, is critical for improving patient outcomes.



The CAB of LAC+USC Maternal, Child, & Adolescent Center (Site 5) has taken an active role in combating stigma in health care settings. Currently, the CAB is participating in a research study. In this study, CAB members deliver a three-part HIV stigma reduction intervention to healthcare workers. Participating healthcare workers include

doctors, nurses, and medical assistants. The intervention consists of HIV and stigma-related education. During the intervention, CAB members also promote contact between health care workers and PLHIV. The study also includes coming up with practical solutions to stigma in the workplace. The CAB plans to deliver this intervention to over 100 health care workers from two university-based health care settings in Los Angeles. The study will take place over a period of one year. This study, headed by Site 5's CAB, aims to influence knowledge about HIV and related stigma as well as attitudes towards PLHIV. The study also hopes to promote awareness of HIV and related stigma in health care settings. CAB members have had intensive intervention training with the study's Principal Investigator. The first session is set to be delivered in August 2016.

Submitted by: Mariam and Jeanie

COMMUNITY INVOLVEMENT: SITE 9

Community involvement is a big part of the Children's Hospital Immunodeficiency Program (CHIP) CAB. The goal of the CAB is to involve community members in the CHIP clinic and research. The CAB seeks to get

feedback from the community about research. The CAB works to offer education and resources about HIV. The CAB also provides support. Throughout the last year, the Children's Hospital Colorado CHIP CAB has had a lot

of events and activities to involve the community. Those activities promoted discussion, education and support.

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COMMUNITY INVOLVEMENT: SITE 9

On June 23, 2016, our site hosted an "Evening Out" event. Community members went to a presentation by PHACS Principal Investigator and Protocol Chair, Dr. Russ Van Dyke. There was a dinner and childcare at the event. This helped parents to see the presentation and hear study results while their children had more kid-friendly entertainment. We got great feedback from attendees who liked the opportunity to get together with providers, study coordinators, and other families.

Every year, CHIP throws a pool party for all of its patients and their families. The CHIP CAB members was, of course, always invited. This year, the pool party was held on July 14, 2016 at a neighborhood pool with giant slides and fountains. The pool party last year received great feedback from the community. The event was a casual and relaxed evening. Families came to eat dinner, swim, play, and catch up with providers and other family members. This event was an absolute success. Over 100 CHIP-affiliated parents, kids, and CAB members attended! Additionally, our very own CAB leader works tirelessly to make positive change throughout the community. Kari Hartel, the CAB coordinator, spends a lot of time coordinating the CHIP CAB meetings. She also spent a lot of time working as the Co-Chair of the Colorado Mod

Squad. This group works to update and lessen the effects of HIV criminalization in Colorado. The group works to update laws and create new ones. Just this year, the group passed SB 16-146. This bill got rid of two HIV criminalization laws and updated a third law.



On May 5th of 2016, CHIP had a Youth Event Game Night at a local GameWorks center. This event helped make an environment where young people affected by HIV could come and share their experiences and meet others who may have had similar experiences. During this game night, youth CAB members and patients talked over dinner.

We also had the pleasure of listening to a CHIP CAB member, share his experiences



as the guest speaker. Youth left feeling as though they could relate to him. They also had a fun time playing the arcade and video games.

CHIP CAB members attend many CHIP events, but they can also put together their own events. The CHIP CAB prides itself on its confidential, supportive, and educational events. Transportation is always given to members when requested. Snacks or dinner are also provided. The CHIP CAB will continue to support its members by providing interesting opportunities for its members to engage the community, connect with each other, and learn about the progress being made in the field of HIV-related health.

Submitted by D'Andra and the CHIP CAB

COMMUNITY INVOLVEMENT: SITE 12

At Children's Diagnostic and Treatment Center (Site 12), our CAB members have participated in several community activities. We believe community involvement is very important. It takes everyone in the community to get involved as we work to fight the HIV epidemic. Being active in the fight against HIV gives us strength, support, and encouragement. We also feel a sense of empowerment, we gain understanding of issues in the community, and we get to show that we care about our community.

Recently, a few of our CAB members got to participate in an HIV testing event in honor of National HIV Testing Day. A local organization here in South Florida teamed up with nationally known hip hop artist, Trick Daddy. We had an HIV testing drive. Each person that got tested was given a FREE ticket to see Trick Daddy live in concert. The event was a huge success and we were so happy to be able to participate.

Additionally, our adult CAB members went to a day filled with fun, excitement, and education. This event was called, "Growing Together – A Powerful Women's Movement." We also participated in a community forum discussion about sharing and learning related to HIV in Broward County. By getting involved in



your community, you allow your voice to be heard!

We have had many events with youth in our Living Your Fullest Everyday (LYFE) group. Our youth have their meetings every other month. Recently, they had a day at The World AIDS Museum as a group while supporting one of our young adults who was being interviewed at the event. These young adults have also participated in an event at a local community high school to see a mobile "Saving Grace" exhibit. This exhibit was put on by the Westside Gazette in a community where HIV is sometimes a missed

opportunity. A video of the exhibit can be found on YouTube. Whenever there's something new to the community, it is shared in a flyer or posted throughout our center.

Community involvement gives us strength, support, and encouragement. It helps us to feel empowered, have a sense of understanding, be caring, and share concerns. We are always striving for the best outcomes when it comes to health. Making sure your voice is heard will always reassure you that you matter.

Submitted by: Exzavia

COMMUNITY INVOLVEMENT: SITE 14



These are some photos from the University of Florida, Jacksonville (Site 14) from different health fairs, National HIV Testing Day, and a few other affairs we attended in the community.

Submitted by: Gloria



COMMUNITY INVOLVEMENT: SITE 19

The CAB at Texas Children's Hospital (TCH)/Baylor College of Medicine (BCM) formed in 1991. CAB members are direct stakeholders and indirect stakeholders. Direct stakeholders include parents, grandparents, and foster parents. They also include other caregivers who care for youth living with or exposed to HIV. Indirect stakeholders include HIV researchers, staff from community-based organizations, HIV advocates, and healthcare providers. They also include state, city, and county representatives. The CAB includes team members from the International Maternal Pediatric Adolescents AIDS Clinical Trials (IMPAACT) Network and PHACS. CAB members also come from other studies at TCH and/or BCM.

Our purpose is to provide CAB members with updates on HIV/AIDS research at TCH/BCM. The CAB's mission is address concerns from CAB members in order to continue to improve the quality of life of youth, young adults, pregnant women, and families affected by HIV.

The CAB has three goals. Goals include:

- 1) Provide CAB members with an update on HIV/AIDS research at TCH/BCM;
- 2) Provide education about research study development and ethics; and
- 3) Address community concerns about local, state, and federal

services for youth and women living with HIV.

The CAB meets every month at TCH. All potential CAB members are invited by the CAB Liaison or CAB members. They are invited to share their ideas and updates. CAB members give feedback at face-to-face meetings, in emails, and phone conversations. Logistical support at each meeting includes mileage reimbursement, free parking, lunch, and childcare. Confidentiality, privacy, honesty, integrity, trust, and mutual fellowship are important at all CAB related meetings and events.

2016 COMMUNITY ACCOMPLISHMENTS

- The TCH/BCM CAB Chair was elected to the Vice Chair IMPAACT CAB (ICAB) position. She works closely with CAB members and researchers from around the world. She also presents at the annual Scientific and CAB Retreats.
- The TCH/BCM Chair and the CAB Liaison (TCH Staff-Social Worker) put together the CAB meeting agendas. They ran the meetings and provided training. They also prepared the minutes after each meeting.
- The PHACS CAB Chair and Vice Chair are TCH/BCM CAB members. Additional CAB members are invited to the PHACS Retreats. One of our young adults was elected as Vice Chair of the PHACS YACAB in June 2016.
- Youth CAB members attended local CAB meetings, annual conferences, and conference calls. They voiced their unique concerns and networked with other youth living with HIV.
- The TCH/BCM clinical investigators and research staff gave updates on research studies at CAB meetings.
- Direct stakeholders reviewed study protocols and fact sheets. The community gave input to the investigators by email or conference calls.
- Indirect stakeholders were invited to the large CAB Meetings held 1-2 times per year at TCH. Researchers and staff provided all stakeholders with HIV/AIDS education and research. They also provided clinical care opportunities for youth and pregnant women. These partnerships are critical. This is because study protocols must have the support of the entire community to be successful.

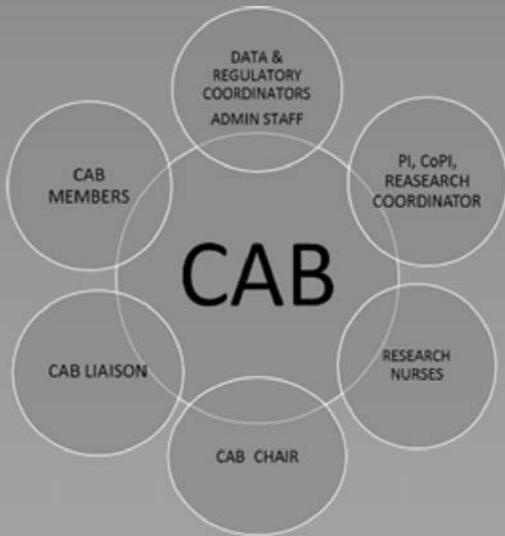
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COMMUNITY INVOLVEMENT: SITE 19

EDUCATION

With more CAB members this year, trainings have focused on ethics and protocol reviews. The CAB has also focused on logistics, recruitment, and retention. The CAB reviewed clinical trials and submitted their input in a timely manner to researchers. Our CAB members actively participated in the Health Education and Communication Committee (HECC). The HECC created two comics for caregivers to use if they choose to disclose their HIV status to their children. CAB members helped create the whiteboard video and Photovoice project. CAB members also helped edit the research summaries.



SPECIAL EVENTS

All patients and their families are invited to the annual Fall Festival and Holiday Party. These events are for families living with HIV. AIDS Awareness Day is recognized every year on the TCH Auxiliary Bridge. We remember all who have lost their battle to AIDS. We also bring awareness to the public about the need for continual support for HIV care and research. Youth with HIV attend Camp You Only Live Once (YOLO) by the Periwinkle Foundation. Youth also attend Camp Hope by the AIDS Foundation, Houston. TCH also participates in the annual AIDS Walk, Houston event.

In summary, the CAB members at TCH/BCM continue to have a strong working relationship with HIV/AIDS research team members. They continue to provide education, advocacy, and outreach in Houston and in the nearby cities. This model has helped to successfully create a network of caregivers in our community affected by food allergies. The main principles are the same for making successful CABs across all healthcare settings.

ACKNOWLEDGEMENT

Support from NIAID-IMPAACT, NICHD-PHACS, ATN and HRSA-Ryan White Part D.

Many thanks to the past and current CAB members for the time they have devoted to CAB over the years.

With great gratitude to William T. Shearer, M.D., Ph.D. for his continual leadership and support of the community.



UPCOMING EVENTS



- September 18: National HIV/AIDS and Aging Awareness Day
- September 19 & 20: PHACS Fall 2016 Network Meeting
- September 21: PHACS Fall 2016 CAB Retreat
- September 27: National Gay Men's HIV/AIDS Awareness Day
- October 15: National Latino AIDS Awareness Day
- December 1: World AIDS Day

STRENGTH IN MY CAB

The place I feel the most love and strength is definitely at my CAB meetings. The reason is because anyone that knows me knows that I come from a large family of 13 sisters and brothers, including myself. It's not always easy for me to talk to or confide in them when I have a problem going on; whether it's about my kids, my personal life, or any problem in general.

I DONT KNOW WHY BUT EVERY TIME I SAY IM GOING TO. I GET AFRAID.

But what my family doesn't know, is that I'm HIV positive. I've been positive for almost 10 years this October, and I haven't disclosed my status to them. I don't know why, but every time I say I'm going to I get afraid. Maybe it's because I feel like they will reject me or don't want me

to be around them. Whatever the reason may be, I won't talk to them about my health.

This is where my extended family comes in, the Texas Children's Hospital (TCH) CAB. Anytime I have a problem, I can pick up the phone, make a call, and I will always get an answer. Whether I call Mrs. Theresa, Mrs. Gloria, Mrs. Shelly, Mrs. Carlis, Mrs. Felicia or even Mrs. Terri, I will always get an answer. If for any reason I can't reach anyone of them, I can always count on one of the beautiful women of the CAB whether it's Kimbrae, Lesley, Dominique, or any of the ladies because I can tell them anything. I trust that I won't hear it again, and I always get the answer that I'm looking for because they've been there through the highs and lows in my life.

That's why my CAB members are not just members, they're my family. So you want to know why

IF I NEVER KNEW THE MEANING OF FRIENDSHIP. I DO NOW.

I feel love and strength in the community? It's because TCH is the Community. They've been there since the beginning of my journey and it's because of them I've made it this far. So, again I want to say, "thank you" to my CAB and my TCH family. If I never knew the meaning of friendship, I do now. That is why I love my TCH community.

Submitted by: KRM

RESOURCES

CONNECT

INFORM

ENGAGE

CDC: Let's Stop HIV Together:

<http://www.cdc.gov/actagainstaids/campaigns/lsht/index.html>

United States HIV/AIDS Organizations:

<http://www.thebody.com/index/hotlines/other.html>

Project Inform:

<http://www.projectinform.org>

POZ Community Forums:

<http://forums.poz.com>

American Civil Liberties Union AIDS Project:

<https://www.aclu.org/issues/hiv?redirect=hiv>

THE GREATEST GIFT

Hello, to all the CAB families. Allow me to take advantage of the space in the newsletter to tell you that there is no better gift that we can give our children than our time. Time to spend with them; to play, talk, laugh, cry, eat together as a family, go to the park, to the beach, even shopping at the super market, we can make each moment an adventure. They don't need grand expensive luxuries, not money, not the iPad, not a cellphone; they need us, their mothers.

In order to make it into the memories of our children, we should be present in their lives today. Have good communication with them and be happy. During this summer, we should take an outing with them. We need to put on our swimsuits and go to the beach. They won't remember if we are fat, skinny, or the little veins in our legs; they will remember their strong, smiling moms happily playing with them. So, we must enjoy the summer with our families. Greetings to you all!

Submitted by: MR



AMP UP METHODS PAPER

The first paper from the AMP Up study, "Following young people with perinatal HIV infection from adolescence into adulthood: the protocol for PHACS AMP Up, a prospective cohort study" has been published! The paper appeared in June in the online journal BMJ Open. The writing team was led by Katherine Tassiopoulos, an epidemiologist at Harvard University.

Keeping young adults involved in research is challenging given the important changes that happen in their lives during this time. In this paper we highlight how the design of AMP Up accommodates young adults' lifestyles and priorities, which can make it easier for them to participate in research. AMP Up offers flexibility in how study visits are completed. It includes online surveys, which can be done at home, work, or anywhere with an internet connection. Some of the laboratory specimens can even be collected at home and mailed to the clinic.

In the paper we discuss the steps we took to prepare for AMP Up. First, we asked clinic patients questions about their use of computers, cell phones, and the internet. These questions showed that most patients use the internet more than once a day and are willing to do online research. We also looked at whether AMP participants were able to complete the ACASI, which is a computer survey used in AMP. Almost all AMP participants were able. This information made us feel that using online surveys in AMP Up was a good choice.

We also spoke with the PHACS Youth CAB to get their ideas on the best way to organize the surveys.

The paper describes how the study is set up, what we've done so far, and some early feedback from participants. Some of the main points are:

305

305 participants enrolled as of the date the paper was sent to the journal in April.



AMP Up looks at a wide range of topics, including: transition to adult HIV clinical care, employment and education, use of health care, health and well-being, adherence to HIV medications, quality of life, and sexual behavior and substance use. Participants complete online surveys and provide laboratory samples yearly and have a clinic visit every three years. Clinic staff does a chart review every year.



Participants are enrolled through their AMP study clinic. Even though they are older now, they tend to still have a strong connection with the clinic staff. This connection may help keep participants engaged in the study, which is sometimes a problem for other studies that do surveys online.



As participants age, they may no longer attend visit at their clinic. We will need to encourage direct connections between participants and the study itself to keep their interest. We are reaching out to the youth CAB for their support, and we set up a study website was developed just for participants. The website gives participants direct access to their surveys, providing important information that is useful to young adults, and allows them to connect with other youth with HIV.



To ensure continued success, we will begin to look at enrollment trends and reasons for not enrolling. We will also explore doing more parts of the study online to reduce the time burden even more, such as online informed consent forms, enrollment and medical record release authorizations.

By sharing our experiences in this paper, other researchers may benefit from and build on what we've learned. This may allow them to learn more through their own research. It could also help them to provide a better experience for people who give their time and effort to participate in research studies.

Submitted by: Julie Alperen and the Data and Operations Center (DOC)

WHY I LOVE

The reason why I love can be viewed in so many ways.
Maybe some may say I use the word too lightly, and full heartedly – but isn't that part of being human?
So, when I say I love you
It means it's something in you that I admire
And know you

It's because of what I found in you.

And the good I see in you.
It's because of what I found in you.
It's reasons I know your heart is great.
I love the sky
It's because I know waking up seeing it somehow, someway
Life will be okay.
The reason I say I love my family and friends is because it takes a village
Not only to raise a child,
But to help keep them grounded.
I know that I am never alone
And even in my darkest hour I know that I am loved.
So, next time you feel alone in this fight
Think about the last time someone said hello
Gave you a hug
Said thank you.
On some form or level they're telling you,
Hey, thanks for being you,
and by the way
I love you.

Submitted by: Kim

"I'VE NEVER FELT LIKE A PATIENT. I'VE ALWAYS FELT PART OF A FAMILY. THEY HAVE BEEN MY ROCK AND MY SUPPORT SYSTEM IN WAYS THEY WOULD NEVER KNOW. I FEEL LIKE THE PATIENTS AND STAFF ARE MY MOTHERS, FATHERS, BROTHERS, AND SISTERS. THEY HAVE BEEN THERE FOR ME EVEN IN TIMES I DIDN'T WANT TO BE THERE FOR MYSELF."

COMMUNICATION IS KEY

This article refers to CAB members' roles in recruiting and retaining participants at PHACS sites.

Communication plays the most important role in keeping participants engaged. Communication is more than an appointment reminder or saying hello at study visit. Always acknowledge the participants when you see them, whether it's at a study visit or a regular medical visit. If you are inside of your facility, get to know the participants' families – not just the participants. In other words, get to know caregivers of participants, aunts, uncles, cousins, or even friends that might be a help in participants' lives. Always ask or address concerns, if any. Try not to only ask about medical issues. This is because some families have more than medical issues and these issues may prevent them from being able to attend visits. Some participants may only need you to be a listening ear. Some families need support to be able to complete a visit. This means that you may need to accompany them to appointments, in and out of facilities. Babysitting children can play a great part in participation efforts.



You can also consider providing food while attending a study visit.

Always share what you have learned on a call or in a meeting, even if you aren't able to participate in a CAB regularly. Invite them to outside events that will provide them information or resources that would be beneficial to them. For new PHACS participants, do the same thing that you would do with any other participant. Remember that they are new, and might be nervous. If you are comfortable, it may help to share your experience as a participant. This could help someone to overcome some fears or stress that they deal with.

My daily activities with participants flow okay because I have been interacting with some of them for years. I share my status, when needed, for new comers. My greatest support for our participants comes from our center through our Principal Investigator (PI), research team, the social workers, and medical staff; it's a team effort. We pretty much meet them where they are and start from there. The greatest thing that I love about providing all these services to our participants, is that I am able to see the outcome of some of their lives. We take care of them and their families so they know that their lives matter.

Our center at Children's Diagnostic and Treatment Center is set up so that families can utilize more than one service while at their appointment. We provide them with a living area that is known as a **safe haven**. While here, most participants wash clothing, use computers, and let their children play in the children's play area.

Submitted by: Exzavia

SMART AND AMP/AMP UP PRIORITIES

The goal of the PHACS Leadership Retreat is for PHACS leaders to come together to make decisions about the future scientific direction of the PHACS project. This year, the retreat followed a slightly different format. Instead of splitting Working Group (WG) presentations up across two

days, each day focused on one of the protocols. The group considered SMARTT on the first day and AMP/AMP Up on the second day. WG leaders first presented their thoughts about the future of PHACS from their WG's point of view. The team then broke out into small groups to explore topics related to each

WG. The small groups brainstormed ideas about future PHACS research priorities. After the brainstorming sessions, the group had an informal vote on the top research priorities for PHACS.

(Continued on [page 18](#))

SMARTT AND AMP/AMP UP PRIORITIES

Drs. Russ Van Dyke, MD and Ellen Chadwick, MD presented the new research priorities to the PHACS CAB and solicited the CAB's valuable feedback and insight during the April and May CAB conference calls. Dr. Chadwick reviewed the new SMARTT research priorities, and Dr. Van Dyke reviewed the new priorities for AMP/AMP Up. These priorities will steer the PHACS scientific agenda for the next few years:

SMARTT



Pregnancy outcomes in mothers born with HIV

Outcomes may include preterm birth, baby's growth in the womb, and pregnancy complications. The team has already analyzed moms born with HIV. The next step is to compare pregnancy outcomes between moms who got HIV during their life and moms born with HIV, as well as compare the outcomes for babies born to each group of mothers.



Establishment of a PHACS women's cohort

The team will study moms of babies in the SMARTT Dynamic Cohort. The women's cohort will help the researchers study factors that may influence outcomes of babies born to moms living with HIV. The team will also look at inflammation during pregnancy and how it can contribute to baby outcomes and/or pregnancy outcomes.



Exploration of neurodevelopmental outcomes in 5-year-olds as they relate to HIV medication exposure

The team will look at different tests for all children in PHACS. Tests will focus on domains like hearing, language, and behaviors. This will help the team gain a better understanding of the brain issues across all children in PHACS.

AMP/AMP UP



Relationship of DNA with the outcomes of HIV and HIV treatment

Many characteristics are passed down in DNA. There are genes in our DNA that can protect people from certain diseases. There are also genes in DNA that can make people more susceptible to certain diseases. The team will look at whether there are any genetic factors that influence outcomes of PHACS participants. Outcomes may include behavioral, medical, and developmental. The team will explore the genetic factors that may influence how people respond to HIV treatment. The team already has DNA available from consenting AMP participants.



Screening for heart disease with a cardiac Magnetic Resonance Imaging (MRI) exam

During an MRI exam, doctors can see inside the body to look at organs, blood vessels, and other body functions. A specialized MRI allows us to look at the structure and function of the heart. This will allow us to look for early evidence of heart and blood vessel disease long before it is symptomatic.



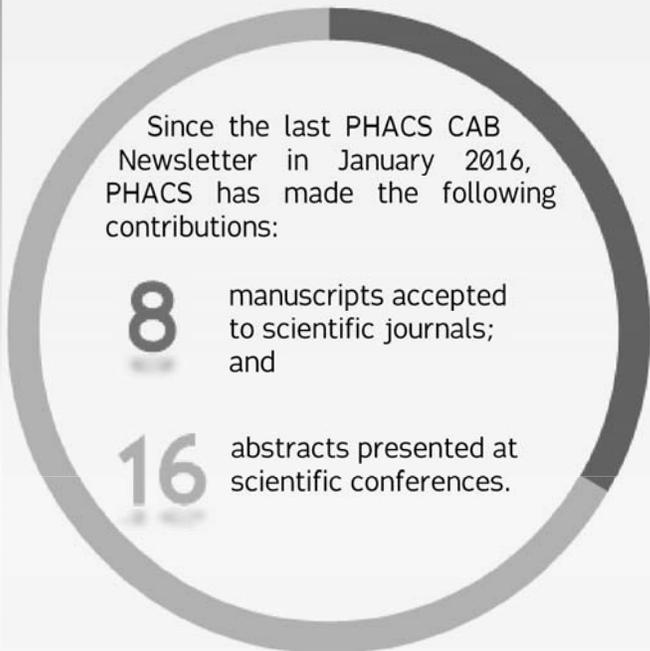
Exploration of neurodevelopmental outcomes in 5-year-olds as they relate to HIV medication exposure

The team will look at different tests for all children in PHACS. Tests will focus on domains like hearing, language, and behaviors. This will help the team gain a better understanding of the brain issues across all children in PHACS.

The WGs will help figure out the best ways to move ahead with these high priority ideas. We will review our progress during the Spring 2017 Leadership Retreat.

Submitted by: Drs. Russ Van Dyke and Ellen Chadwick.

PUBLICATIONS IN THE NEWS



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

8

manuscripts accepted to scientific journals; and

16

abstracts presented at scientific conferences.

Publications

“Long-term effects of in utero antiretroviral exposure: systolic and diastolic function in HIV-exposed uninfected youth.” This manuscript is in *AIDS Research and Human Retroviruses*. Lead author is Vitor Guerra, MD.

“Atazanavir exposure in utero and neurodevelopment in infants: A comparative safety study.” This manuscript is in *AIDS*. Lead author Ellen Caniglia, is a Doctoral Candidate at the Harvard T.H. Chan School of Public Health and is a member of the Maternal Exposures Working Group (WG).

“Exposure to violence and virologic and immunological outcomes among youth with perinatal HIV in the Pediatric HIV/AIDS Cohort Study.” This manuscript is in the *Journal of Adolescent Health*. Lead author Deb Kacanek, ScD, is a Research Scientist at the Harvard T.H. Chan School of Public Health and is the Co-Chair of the Maternal Exposures WG.

“APOL1 renal risk variants are associated with chronic kidney disease in children and youth with perinatal HIV infection.” This manuscript is in the *Journal of Acquired Immune Deficiency Syndromes*. Lead author Murli Purswani, MBChB, is the Principal Investigator at Bronx-Lebanon Hospital Center and is a member of the Scientific Leadership Group (SLG).

“Antiretroviral drug resistance among children and youth in the U.S. with perinatal HIV.” This manuscript is in *Clinical Infectious Diseases*. Lead author Russ Van Dyke, MD, is the AMP Protocol Chair and AMP Up Protocol Co-Chair. He is also the Principal Investigator of the PHACS Coordinating Center at Tulane University.

“Following young people with perinatal HIV infection from adolescence into adulthood: the protocol for PHACS AMP Up, a prospective cohort study.” This manuscript is in *BMJ Open*. Lead author Kathy Tassiopoulos, DSc, is the AMP Up Protocol Co-Chair and Co-Chair of the Adolescents and Young Adults WG.

“The PHACS SMARTT study: assessment of the safety of in utero exposure to antiretroviral drugs.” This manuscript is in *Frontiers in Immunology*. Lead author Russ Van Dyke, MD, is the AMP Protocol Chair and AMP Up Protocol Co-Chair. He is also the Principal Investigator of the PHACS Coordinating Center at Tulane University.

“Growth at age two in HIV-exposed uninfected children in the US by trimester of maternal antiretroviral initiation.” This manuscript is in the *Pediatric Infectious Disease Journal*. Lead author Denise Jacobson, PhD, is a Senior Research Scientist at the Harvard T.H. Chan School of Public Health, and is the Co-Chair of the Nutrition, Growth, and Metabolism WG.

Abstracts

This abstract was presented at the International Neuropsychological Society in Boston, Massachusetts, February 3-6, 2016:

“Associations of memory and executive functioning with academic and adaptive functioning among youth with perinatal HIV exposure and/or infection.”

(Continued on [page 20](#))

PUBLICATIONS IN THE NEWS

Abstracts (Continued)

These abstracts were presented at The 23rd Conference on Retroviruses and Opportunistic Infections (CROI 2016) in Boston, Massachusetts, February 22-25, 2016:

- “Longitudinal evaluation of language impairment in perinatally HIV exposed adolescents.”
- “Brain volumes, HIV disease severity, and substance use in perinatally-infected youth.”
- “ARV risk for speech and language impairments in HEU children at 3 and 5 years.”
- “Long-term effects on the basal ganglia in youth with perinatally-acquired HIV infection.”
- “HIV-1-DNA dynamics over a decade or more of viral suppression in perinatal infection.”

This abstract was presented at the 2016 Eastern North American Region (ENAR) International Biometric Society Spring Meeting in Austin, Texas, March 6-9, 2016:

- “A cautionary tale: mediation analysis applied to censored survival data.”

This abstract was presented at The 2nd Workshop on Adolescent Transition, Collaborative Initiative for Pediatric HIV Education and Research in Budapest, Hungary, April 6, 2016:

- “Older perinatally HIV infected youth have lower CD4 counts, more viremia and clinical events.”

These abstracts were presented at the 20th International Workshop on HIV observational Databases (IWHOD) in Budapest, Hungary, April 7-9, 2016:

- “Older perinatally HIV infected youth have lower CD4 counts, more viremia and clinical events.”
- “Is there a higher risk of mother-to-child transmission among women with perinatal HIV infection?”
- “Mediation analysis for censored survival data: applications for HIV Research.”
- “Following young people with perinatal HIV infection through the transition from adolescence into adulthood.”

This abstract was presented at the Institute for Healthcare Advancement (IHA) Health Literacy Conference in Irvine, California, May 4-6, 2016:

- “The Humble Blood Droplet: Developing whiteboard videos for retention in the Pediatric HIV/AIDS Cohort Study.”

This abstract was presented at the International Association of Providers of AIDS Care (IAPAC) 11th International Conference on HIV Treatment and Prevention Adherence in Fort Lauderdale, Florida, May 9-11, 2016:

- “Nonadherence and unsuppressed viral load across stages of adolescent development in US youth with perinatally acquired HIV in the Pediatric HIV/AIDS Cohort Study: A longitudinal analysis.”

This abstract was presented at Comics Art Conference in San Diego, California, July 20-24, 2016:

- “Comics and Health: Saving Lives and Preventing Disease.”

PARTICIPANT SUMMARY



OUTCOMES OF CHANGES IN TREATMENT AFTER TREATMENT FAILURE IN YOUTH LIVING WITH HIV

Most children with HIV are treated with combination antiretroviral therapy (cART). cART treatment failure can happen when the HIV medications are not controlling the virus well enough. We wanted to see how children who failed treatment were taken care of and how they responded to treatment.

WHO PARTICIPATED



We looked at 2,373 youth living with HIV receiving cART. All youth were in the Pediatric AIDS Clinical Trials Group 219C study or in PHACS between 1993 and 2012.

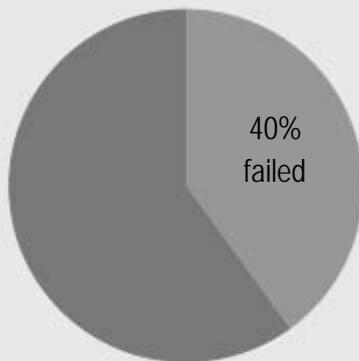
WHAT WE DID



HIV medications can help to control HIV.

HIV viral load is the amount of HIV in the blood. CD4 cells are a type of cell that help protect the body from infection. When HIV medications work well, CD4 cells go up and viral load goes down. Treatment failure can happen when HIV medications are not controlling HIV. Youth who fail treatment may need new medications. We wanted to know how they responded to treatment, so we looked at the medications and management of youth who failed treatment.

WHAT WE FOUND



About 40% of youth in the study failed cART. We found that of those youth who failed treatment:

- About 84% were kept on their first medication treatment when the medications no longer controlled their HIV;
- Most had treatment failure before the year 2007;
- One year after failing cART, youth who had changed to a new medication treatment were doing the best;
- Youth who stopped all ARVs had the largest drop in their CD4 cells. This means that these youth were the most at risk for worsening disease.

WHAT WE LEARNED



We found that if youth fail cART, it is best to change to new medications. However, if they are not ready to change treatment or need to get better at taking their medications, then it is safe to temporarily continue their current treatment or change to simpler treatment as long as we watch them closely. This study gave us valuable information about youth whose medications are no longer controlling their HIV.

C051. Fairlie L, et al. CD4+ and viral load outcomes of antiretroviral therapy switch strategies after virologic failure of combination antiretroviral therapy in perinatally HIV-infected youth in the United States. AIDS 2015;

<http://www.ncbi.nlm.nih.gov/pubmed/26182197>

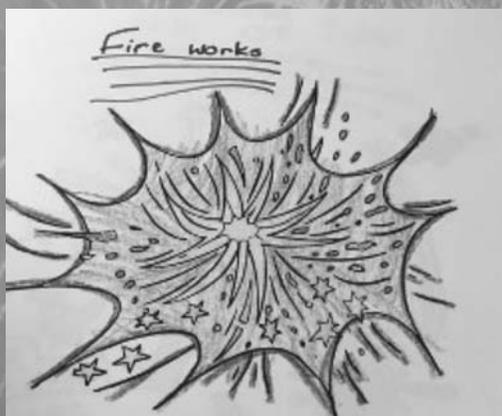
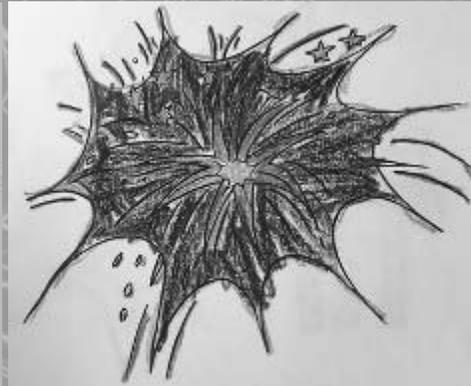
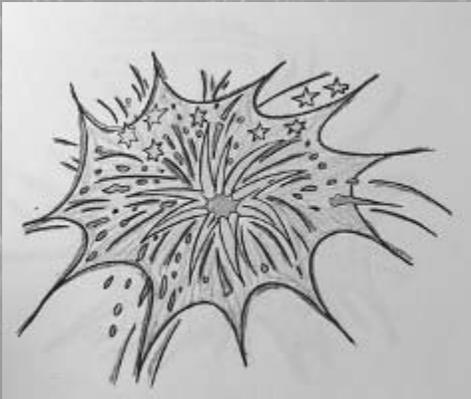
For more information, contact:

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CAB KIDS

CAB KIDS CELEBRATED THE FOURTH OF JULY WITH FIREWORKS!



CAB GLOSSARY



Confounding Factor: Any characteristic or factor other than the treatment that might affect the results of a clinical trial.

Control Group: In most comparison clinical trials, one group of participants receives the experimental medicine while another group (the control group) of participants receives the standard treatment.

Discrimination: Unfair treatment of a person or group based on prejudice.

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

Study Arm: The treatment or placebo group in a clinical trial may be referred to as an “arm” of the study.

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 the laboratory. An undetectable viral load usually shows that treatment is effective and/or that the person is at low risk of disease progression.

QUIZ

Instructions: Quiz yourself using the articles in this newsletter! Answer key on [page 24](#).

- Which site is putting together a three-part HIV-stigma reduction intervention to healthcare workers?
 - Site 5, Los Angeles
 - Site 12, Fort Lauderdale
 - Site 14, Jacksonville
 - Site 19, Houston
- According to a CAB member, what is the greatest gift moms can give their children?
 - School
 - Time
 - Cheese
 - Music
- One of the new SMARTT priorities is to create a _____ cohort.
 - Mystery
 - Men’s
 - Elderly person’s
 - Women’s
- From the participant summary featured in the newsletter, if youth fail cART, it is best to change to what?
 - New house
 - Old medications
 - New foods
 - New medications
- One of the new AMP/AMP Up priorities is to screen for what kind of disease using an MRI?
 - Heart
 - Brain
 - Breast
 - Ovary
- Since the last newsletter, how many manuscripts were accepted to scientific journals?
 - 16
 - 10
 - 8
 - 156

RECIPES

FISH DIP

This is one of my favorites. You can use it with a salad, to make sandwiches, or it is best served as an appetizer with tortilla chips or club crackers. I don't measure the ingredients. Add the ingredients to your satisfied taste and depending on the number of people who will be enjoying the fish dip. I prefer to use a white fish, but you can use any fish you prefer as long as you remove any bones. You can use whatever seasonings you like to your desired taste. I use everything that I have in my cupboard that I know will put some flavor into the dip.



Ingredients (Measure to Taste):

- Black pepper
- Worcestershire sauce
- Onions (chopped)
- All-purpose seasoning
- Mayonnaise
- Sour cream

Preparation:

- Boil the fish with any seasonings (i.e., salt, pepper, garlic powder, etc.). Time depends on the size and type of fish.
- Drain the water and take out the fish.
- Blend the fish using a fork or food processor. Mix the fish until it is spreadable.
- Combine with all remaining ingredients.

Submitted by: Delia

CHOCOLATE CHIP COOKIES

Ingredients:

- ¼ Cups of all-purpose flour
- 1 Teaspoon of baking soda
- 1 Teaspoon of salt
- 2 Sticks of butter
- ¾ Cups of sugar
- 3 Cups of packed light brown sugar
- 1 Teaspoon of vanilla extract
- 1 Teaspoon of almond extract
- 2 Large eggs (optional)
- 2 ½ Cups of semi-sweet chocolate chips
- 1 Cup of shaved almonds
- 1 Cup of shaved pecans

Preparation:

- Spray a cookie sheet with butter or oil.
- Preheat the oven to 350 degrees.
- Microwave butter for 1 minute.
- Mix flour, baking soda, and salt.
- In another bowl, beat the warm butter, sugar, brown sugar, vanilla, and almond extract until creamy.
- Slowly blend one egg at a time into the butter mixture.
- Mix one scoop of the flour mixture at a time into the butter mixture until all ingredients are combined, and then mix chocolate chips into the mixture.
- Spoon mixture onto the oiled cookie sheet, making sure to space out the cookies.
- Sprinkle the almonds and pecans onto each cookie.
- Bake in the oven for 8 minutes or until golden brown.



Submitted by: Kim

QUIZ KEY

1) A, 2) B, 3) D, 4) D, 5) A, and 6) C

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