

**A COMMUNITY ADVISORY BOARD
NEWSLETTER PUBLISHED BY:
Pediatric HIV/AIDS Cohort Study
(PHACS) Community Advisory
Board**

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FROM OUR CAB CHAIR



*De' Angelo and Delia at the
Spring 2013 Leadership Retreat*

The PHACS CAB Chair position has certainly given me more knowledge, and more self-esteem. I am lucky to be working with great people and we make a really great team!

The CAB has accomplished much more since our last newsletter. We have many topics lined up for discussion because of the PHACS CAB Evaluation Survey. We have had more guest speakers and Participant Summary discussions on our calls. We also work closely with the Health Education and Communication Committee (HECC). The HECC has created a list of goals and is looking to start many potential projects. One project is looking at how to help PHACS sites learn more about how other sites disseminate PHACS study results. The HECC is also assisting in the development of a new PHACS website. The new PHACS website was discussed at the Spring 2013 Leadership Retreat to get input from other people.

The CAB is working with the HECC CAB Subcommittee to develop a CAB Handbook for site CABS. Many CAB members have asked about having a CAB member speak about their CAB on different CAB calls and how to get more participation in their site CAB. The CAB Handbook will give other CAB members ideas about how to improve their CAB.

The PHACS Spring 2013 Leadership Retreat was different than other meetings and was held in Potomac, Maryland on March 21-22, 2013. It was at the Bolger Center which was originally a convent for nuns. It was not close to the shopping malls or restaurants. In a way it was a good thing because after the meeting everyone got together for dinner at the same restaurant which was never done before. Some people played pool and darts. There was also karaoke and dancing. We got to know each other a little better and it was fun.

I was very much interested in the topic presented by Allen Wilcox at the retreat. He spoke about prenatal exposure and long-term health consequences in humans. He also spoke about a drug called Diethylstilbestrol (DES). Also, there were Working Group presentations and other guest speakers.

As you can see, the PHACS CAB has a lot to do. We are very proud of our accomplishments and we are looking forward to our upcoming projects!

Thank you once again.

Delia, PHACS CAB Chair

CAB PERSONAL STORIES ABOUT SUPPORT

I found out I was positive back in 1999 when I was 5 months pregnant. As anyone can imagine this was a very difficult time for me and my family. But the fact that they were there for me to support me and help through those hard times was the most important thing at that moment; along with the great agency, services and staff. So far, I have managed to stay healthy, learned many things, am involved in research and community activities, and participate and facilitate my site's CAB. I feel great, I'm healthy and I plan to stay this way for many years to come. I would not have been able to come this far without all the great support that I have been lucky enough to have.

"I would not have been able to come this far without all the great **SUPPORT** that I have been lucky enough to have."

My son and I have received a lot of support from the community. We no longer have other family in this country. We participate in support groups and clinical studies and have found true friends. I always enjoy being informed and learning about our community. My son and I are very grateful.

In my experience, support comes from communication with the clinic, and the social workers. UCSD asks me what my needs are. For over 20 years, they have assisted and guided me. I feel like it is my second home and my health depends on it.

I have found support with friends and family. I never tried internet support groups. Thank God I always found support. I have learned that sometimes people are not willing to show support.

I have always found support from my older sister. Nonetheless, I was scared to get close to her and disclose my diagnosis. I kept my secret for twelve years. Much to my surprise, when I revealed my problem, she accepted me and supported me like I would have never imagined. For twelve years, I unnecessarily suffered with fear of being rejected. I learned that you can't think or worry about everyone else. Don't worry about the worst that can happen...maybe it will never happen!

Friends and companions have helped me with advice. I've never had trouble finding support. I feel very happy that I have received so much support. Thank you for everything you have offered us.

I have found support with my friend at Christie's Place; I never go online to look for support. I've always had the support of my friends, since I get very little support from my family.

I get support at groups and meetings. I like to listen to my friends share their experiences. They have helped my morale; they motivate me to improve going forward. The people who help me find what I need are my case manager at Christie's Place. It also has been an agency that has helped me, and I've met a lot of people there who are going through the same situations as me.

I feel supported by my family, especially my wife and daughter. They are always on my side and because of them I always come out ahead. I would like to thank my wife and daughter—because of them, I am who I am today. I am always moving ahead thanks to them and to God. I also thank you all for inviting me to these meetings. May God bless you.

"Much to my surprise,

When I revealed my problem, she *accepted me* and **SUPPORTED ME** like I never would have imagined."

CAB PERSONAL STORIES ABOUT SUPPORT (CONTINUED)

I receive great support from my sister and an unconditional friend. After I was diagnosed with HIV, Christie's Place and The UCSD Mother, Child and Adolescent HIV Program was full of people with lovely hearts, the workers. I found resources and support with the help of my social worker, my doctor and my case manager.

"I found resources and support with the help of my social worker, my doctor, and my case manager."

I always get support from the Women's Support Group I attend at Christie's Place and from talking on the phone with my case manager. I've never participated in a support group on the internet.

I am supported by my friends at support groups and meetings. At first it was hard, but all the services have helped me a lot.

My personal story is from the CAB liaison perspective. I would like to thank all of the network staff, site staff, and especially every parent, caregiver, and non-direct caregivers who have been committed to the BCM/TCH CAB. Our CAB is successful because of the dedication from each member involved in our CAB. Have a wonderful summer and CAB carry on!

Fortunately, San Diego has a lot of help available for people living with HIV. Personally, I have never had trouble finding help since I was diagnosed. I found the help I needed at Christie's Place and at the UCSD Mother, Child and Adolescent HIV program.

I feel supported by two agencies. I have also felt supported by a staff member, Tita, my case manager. It hasn't been hard for me to find support from a case manager. I have been in support groups too. I need a lot of help and support for my children. My aunt and my friends all help me.

MY STORY

It's been 20 years since I've been diagnosed with HIV. I'm at the point in my life where I am secure and not ashamed to be living with HIV. I have great support from my family, my fiancé, my clinic, and my church. In the past, I have struggled with a drug addiction to crack, and have been to a few drug rehabs. I thank God for keeping me alive, and for my two children and one on the way. I know God has a purpose for my life. I know I'm not here just for myself, but to help someone else who may be living with HIV and doesn't know how to handle it, or how to deal with a drug addiction problem, or other issues. I can help guide and encourage others. I'm glad that I am healthy, strong, and can live a normal life.

Submitted by Rosetta



RESOURCES

The Voices of Teens Living With HIV: How You Can Support Us

<http://www.thebody.com/content/art47466.html>

HIV/AIDS Tribe: Free Online HIV/AIDS Support Community

<http://www.hivaidstribes.com/>

Emotional Needs and Support

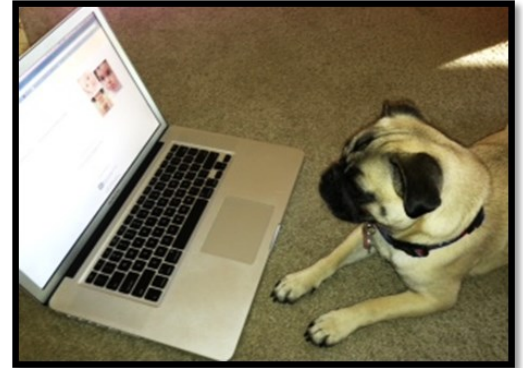
<http://avert.org/emotional-needs-support.htm>

Support Groups: Tools for Living Well

<http://www.thebody.com/content/art32349.html>

The Positive Project: HIV+ Stories for the Greater Good

<http://www.thepositiveproject.org>



PHACS MEMBER PROFILES



Mary Vachon, MSW, MPH

Bronx-Lebanon Hospital is located in a diverse and vibrant Bronx neighborhood three subway stops away from Yankee Stadium. Born and raised in the Boston area, one of my biggest challenges as a member of the PHACS team based at Bronx-Lebanon is being surrounded by so many Yankees fans when baseball season starts. As a lifelong Red Sox fan, even after more than 10 years in New York City, my heart will always be with Boston.

My early experience on the frontlines of the HIV epidemic was, in fact, in Boston. I was a housing advocate with the AIDS Action Committee. I spent one day each week at a shelter for HIV-positive, active drug users on Long Island in Boston Harbor. I witnessed true struggle and transformation. I joined advocacy efforts to support needle exchange

programs and to create more housing options for people living with HIV and AIDS. These experiences influenced me to study social work policy and public health at Columbia University in New York.

In my twenties, I had enjoyed a year-long adventure as a teacher in Ecuador learning Spanish and visiting every corner of the country by backpack and bus. After graduate school, I jumped at another great opportunity to live and volunteer in Uganda. I wanted to learn as much as I could about HIV in Uganda. I spent most of my time with a wonderful project called Reach Out. Reach Out relied on the volunteer support of community members living with HIV to provide testing, treatment, case management, and social services. Alongside these volunteers, I learned so much about the impact of HIV in their communities.

For the past five years, I have coordinated research activities for the PHACS and IMPAACT projects at Bronx-Lebanon Hospital. My travel abroad was, perhaps, some of the best preparation for my role on our team. As a social worker, I usually don't see patients for study visits, but I do many other things, including working closely with our Community Advisory Board. We have a small group of dedicated parents who are eager to learn about research and share their knowledge with the community. Like many other sites, we have tried to be creative in how we keep young people and parents engaged in care. Again this summer, we plan to replicate an arts program available two days each week to adolescent patients. Last year's participants practiced their photography skills, made a short film, and wrote stories with assistance from the writing center at Fordham University. All in all, I am grateful to be surrounded by experienced and hard-working colleagues who are always interested in taking on new projects and finding ways to improve our work.

As a working parent, any free time I have is spent with my daughter (who is 3 ½) and my son (who just turned 5). We have lots of fun exploring the city by bike, scooter, and subway. And if I can wake up early enough, I may get out for a morning run. This coming November will be my second time running the New York City Marathon, and training season has started.

PHACS MEMBER PROFILES (CONTINUED)



Leslie, MSW, MPH

Maybe it's because we moved a lot when I was a child, or maybe it's because I loved reading from a young age, but I've always loved hearing others' stories and experiences. So when Megan asked me to write a member profile about myself, I was a little at a loss. But here goes. :)

When I was in college, I studied sociology and enjoyed being a volunteer helping pregnant women and children. After college, I got a Masters in Social Work, feeling called to serve God through helping others. Providentially, my first position as a social worker was working with women and children with HIV. When I started in the 90s, there was still a lot of ignorance about HIV and few effective treatments. I really loved working with these families, walking with them through difficulties and rejoicing in happy times. I

worked with families with HIV for several years. I obtained a Masters in Public Health and then worked for a few years with federal programs related to adolescent pregnancy and parenting.

I was blessed to become a parent through adopting two daughters. Of all the things I have done, they have changed me the most and made my life so full and fun (and busy)! There is a world of difference between being a social worker and being a family affected by HIV. During the adoptions, I gained support through internet groups and by emailing with families going through the same process. Several families started a group to encourage families to adopt children with HIV. The group assisted caregivers in the process of international adoption immigration. The group also provided support. Private internet and Facebook groups for families affected by HIV and adoptive families have provided invaluable support and education. We also gain support from a camp for families affected by HIV and other chronic illnesses. The girls love attending camp because they feel supported being with others like them.

Having children in clinical trials sensitized me to the importance of the community perspective in research. I became involved with the IMPAACT/ PHACS Community Advisory Board (CAB) at Texas Children's Hospital/ Baylor College of Medicine. Through the CAB, I have enjoyed integrating my personal and professional experiences. CABs are a great source of support and empowerment because we can share our perspectives, advocate for others involved in research, and provide support to one another. By sharing our stories and listening to those of others, we can gain strength and courage, opening ourselves up to new possibilities and experiences. We can be encouraged in knowing we are not alone. Our stories can also make things better for others as we participate in our CABs and let the researchers know what it is like to be in studies. We all have a story to tell.

I still work as a social worker at a children's hospital. When I'm not working, I homeschool my daughters and take them to their various appointments and activities. I still get to learn new things every day. I'm also a member of the Ryan White Planning Council and a support organization for families. Sometimes life is crazy, but I have never felt more blessed.

SURVIVOR STORY

S is for strength. H is for health. A is for AIDS. R is for reality. E is for excelling. L is for love. L is for life.

My name is Sharell. I was born in 1983—that's when the world was unaware of AIDS and HIV. In 1983, people were dying and didn't have a clue why. During this time, crack and heroin took over the world. I was diagnosed at the age of five. I was just a baby girl. I can remember being eight years old and being told I was going to die. I was told that I contracted this horrible disease because of a blood transfusion at birth. I grew up with the ignorance of people afraid to even touch me. I can even remember going to parties as a little girl not being able to bob for apples. I had to have my own plate and spoon at home to eat off of. As years went along, there has been more progress with this disease, and yet, still no cure. I have so many people loved ones that passed—the number of people, I'm not even sure, and yet, still no cure. Over time, doctors and scientists came up with more and more medications so people like myself could live longer. I'm still healthy, and now have two healthy children. I can tell my story to them so they can live through me. I am truly happy about how far AIDS and HIV research has come, and that I am still here to say that I am living a healthy life.

CLOSER LOOKS AT SUPPORT

Although his family is hundreds of miles away, Yuri feels support all around him. Yuri turns to the group he knows will support him without judgment – his medical team.

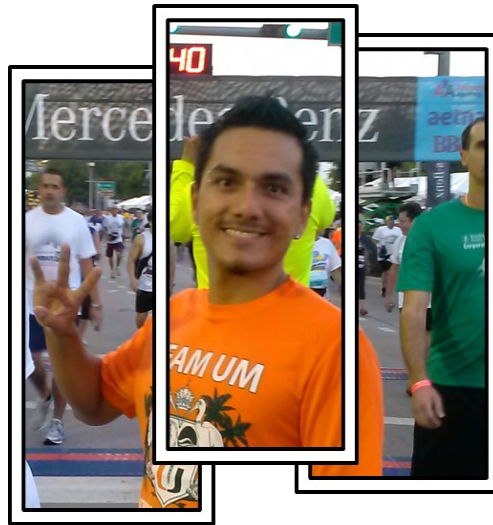
Yuri, Peer Educator at the University of Miami, says that co-workers at the clinic know of his diagnosis. "Therefore," he adds, "it is much easier to vent about mostly anything." Yuri believes that support from family and friends are very important. However, there can be barriers to support. "You'll know who your real friends and family are once they react to you coming out as HIV+," he says. Yuri has never had a problem seeking support because of his clinic. His clinic provides support groups and psychosocial services.

Yuri himself does not attend any support groups. However, he co-runs a support group for youth. "Part of my job as a peer educator is to share my experiences with my patients and their families, so that they don't feel alone," Yuri says. "Ultimately, we can all learn from each other."

For Yuri, face-to-face interaction with people is important when seeking support. "I believe that everyone is conscious, at some level, of body language," says Yuri. Yuri says that for some, it may be more comfortable to join an online support group. "It may be easier to share as much as possible without staring at someone's expression." However, Yuri would rather go to in-person support groups.

"I've always been supported by my co-workers and friends since my immediate family lives hundreds of miles away," says Yuri. That doesn't mean that Yuri has not faced challenges in seeking support from his community. "Stigma and self-confidence were obstacles right after the diagnosis, but with the support of my medical care team I became more vocal and stood up for myself," he says. Yuri now stands as an advocate for the HIV-affected community. In addition to working as a Peer Educator, Yuri is now a spokesman for the Greater than AIDS campaign.

Yuri advises HIV-affected individuals to seek support from their medical community. Clinical staff should be able to link individuals with services like support groups. For Yuri the most important piece of support is feeling a part of a community of people who share the same experience. "I strongly encourage HIV+ patients," Yuri says, "especially [the] newly diagnosed, to attend some type of support group to vent and feel that you're not alone."



Submitted by Yuri and Megan

Hi! How are you? My name is Alexander, I am 30 years old and I am one of the many survivors of the virus so badly judged worldwide: HIV. I was diagnosed when I was 19 years of age. For me, being HIV positive was not a tragic situation, as is for many. On the other hand, I thank God, who transformed my life and made me the person I am today. With the knowledge I now have of this condition and all other STDs, and above all, with those angels on earth that have given me more than support (and even with things from my everyday life), I have been able to cope with this condition.

There is one very special person who is still around me and was my first case manager. We have known each other for over 11 years, which is the amount of time I have lived with HIV. My case manager was the one who invited me to become part of CAB, in which I have been active for six years. I also know of the wonders he has done for many other

people. Well, getting back to me – living with HIV does not undermine me. HIV brings sadness and difficult times, but at least in my case, I can say I don't feel bad for living this way, since I have come to know many people who have given me very precious things in my life.



I have learned to walk through such a difficult path. I love all the beautiful experiences I have lived, such as having worked for an agency dedicated to offer-

ing HIV services. I have lived spectacular moments at this agency, such as being in charge of two support groups. One group is for HIV+ women and the other for HIV+ gay men. Here, the participants' dynamics and even mine, as facilitator, have brought tears as well as laughter. I will always take those memories and participants' spirits with me. I love offering services and being able to help others. In addition, there are times in which I can identify myself with many cases. Now that you know a part of the history of my life, I close with these words: YES, I AM HIV+ AND YOU, DO YOU WANT TO LIVE A POSITIVE LIFE?....

Get information, ask about STDs, and if you are sexually active, get the HIV test every 6 months. I am very happy to know that I have medical, family, and friends' support, and that there are people in my community that understand, accept, and care for me.

Submitted by Alexander

HIV AND HEARING LOSS IN SOUTH AFRICA

After leaving San Diego and traveling approximately 24 hours in planes, we finally arrived in Cape Town, South Africa. The purpose of this research trip was to take what we have learned in PHACS about the relationship between HIV and hearing loss and apply it to children with HIV in Cape Town. There was a slight difference, though. In PHACS, hearing was tested in HIV-exposed but uninfected children. But in Cape Town, we tested hearing in both HIV+ children and HIV-exposed but uninfected children. Our goal was same as in PHACS. We sought to determine hearing characteristics in HIV+ and HIV- children. We also looked to evaluate any relationship between HIV and hearing loss. Together with our colleagues at the Children's Infectious Disease Clinical Unit (KID CRU) at Tygerberg Children's Hospital, we tested the hearing of a group of children over two weeks. Hearing loss was determined using the pure-tone hearing thresholds from audiometric exams. Pure-tone average (PTA) is the average of these thresholds at 500, 1000, 2000, and

4000 hertz (Hz). A PTA was calculated for each ear. Hearing loss was defined as PTA greater than or equal to 16 decibels (dB) hearing level (HL) in the poorer ear.

Forty-five children were tested over two weeks. The participants were an average of 7 years old. Of the participants, 30 children were HIV-infected and 15 were HIV-unexposed and uninfected. Overall, the rate of hearing loss was 21% (n=6) among HIV+ children. The rate of hearing loss was 7% (n=1) in HIV- children. The mean of the poorer ear PTA, however, was higher for HIV+ compared to HIV- children. PTA of the HIV+ participants was 16.5 dB. PTA of the HIV- participants was 8.8 dB. The sample size in the Cape Town database is substantially smaller than the PHACS hearing database. However, the results between the studies are very similar. Specifically, HIV+ children had higher rates of hearing loss and poorer PTAs.

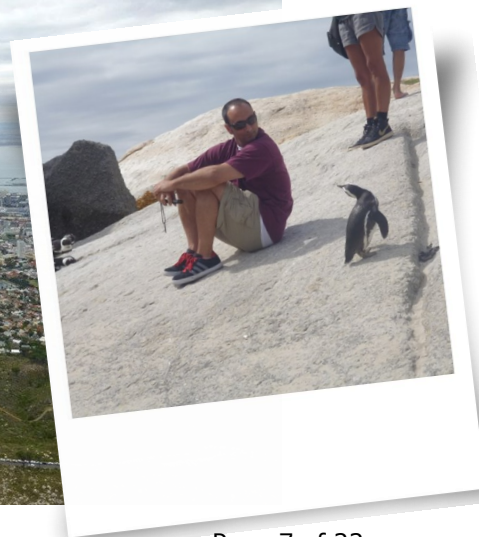
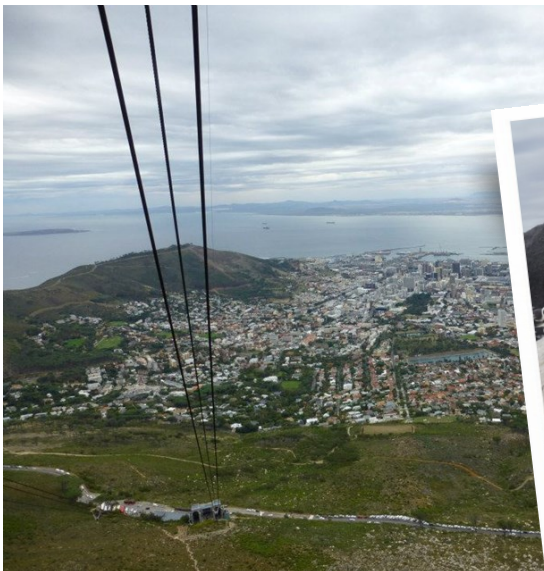
HIV+ children are also more at risk for middle ear infections, so we examined this in the children of Cape Town.

There were two children (both HIV+) who had outer ear infections. There were four HIV+ children and only one HIV- child with a middle ear infection. More HIV+ children had some outer or middle ear problems compared to HIV- children. Regardless of the problem (for example, outer ear, middle ear, or hearing loss) each child was referred for a full diagnostic evaluation in the Audiology Clinic of Tygerberg Children's Hospital.

It was not all research! On the weekend between our hearing tests, we had a chance to explore Cape Town and the surrounding area. Our first stop was Boulders Beach for a visit with African penguins. You can sit on a rock with the chance that a penguin will walk by or take a nap right next to you! We continued to the Cape of Good Hope where we hiked to the lighthouse. We had an amazing view of False Bay on one side and the Atlantic Ocean on the other side. As we were leaving the Cape Point, we encountered a herd of ostriches on the side of the road. And if that was not enough, we had to stop on the road because some baboons were feeding right in the middle of the road. The next day we took the cable car to the top of Table Mountain. It was another amazing view, this time of Cape Town from over 3500 ft.

Overall, this was an incredible research and adventure experience. Our goal is to maintain this collaboration with the researchers at Tygerberg Children's Hospital to further study how hearing loss affects language development in children of Cape Town, South Africa.

Submitted by Peter Torre, PhD



AIDS WALK MIAMI 2013

Yuri, a peer educator at The University of Miami, participated in AIDS Walk Miami 2013. The event benefited the Community AIDS Resource, Inc., dba Care Resource. Care Resource provides HIV/AIDS research, prevention, care and treatment services to over 9,000 clients. This year, AIDS Walk participants helped Care Resource reach its fundraising goal of \$250,000 for AIDS research and care!

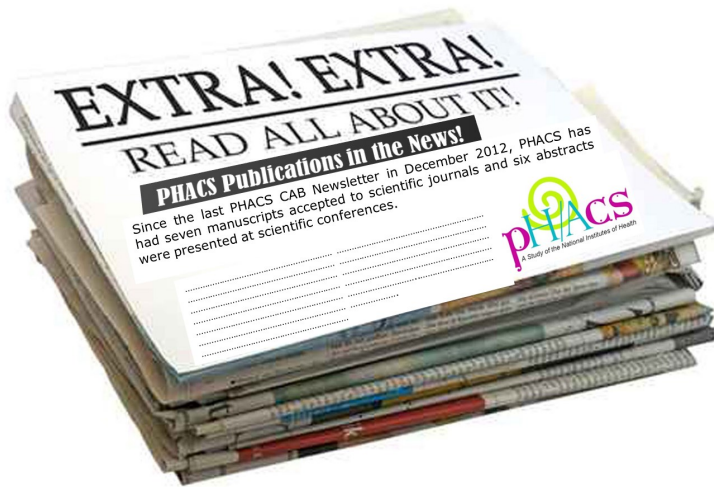


UPCOMING EVENTS



- ✂ **September 18:** National HIV/AIDS and Aging Awareness Day
- ✂ **September 27:** National Gay Men's HIV/AIDS Awareness Day
- ✂ **October 1:** PHACS CAB Retreat
- ✂ **October 2-3:** PHACS Fall 2013 Network Meeting
- ✂ **October 15:** National Latino AIDS Awareness Day
- ✂ **December 1:** World AIDS Day

PUBLICATIONS IN THE NEWS



Since the last PHACS CAB Newsletter in December 2012, PHACS has had seven manuscripts accepted to scientific journals and six abstracts were presented at scientific conferences.

Publications

"Safety of perinatal exposure to antiretroviral medications: developmental outcomes in infants."

This manuscript in the *Pediatric Infectious Disease Journal*. Patricia Sirois, PhD, lead author, is a neuropsychologist at the Tulane University School of Medicine and a member of the ND/Neurology Working Group. She is also a member of the Hearing and Language Working Group.

"Development and validation of the first liquid chromatography-tandem mass spectrometry assay for simultaneous quantification of multiple antiretrovirals in meconium." This manuscript is in the *Analytical Chemistry* journal. Sarah Himes, lead author, is a doctoral candidate, on an intramural research training fellowship at the National Institute on Drug Abuse (NIDA).

"Pubertal onset in perinatally HIV-infected children in the era of combination antiretroviral treatment." This manuscript is in the *AIDS* journal. Paige Williams, PhD, lead author, is a Senior Statistician at the Harvard School of Public Health and is a member of the Scientific Leadership Group and the Executive Committee.

"Evaluation of risk for late language emergence after in utero antiretroviral drug exposure in HIV-exposed uninfected infants." This manuscript is in the *Pediatric Infectious Disease Journal*. Mabel Rice, PhD, lead author, is a distinguished professor at the University of Kansas and a member of the Scientific Leadership Group. She is also co-chair of the Hearing and Language Working Group.

"The relationship between mitochondrial dysfunction and insulin resistance in HIV-infected children receiving antiretroviral therapy." This manuscript is in the *AIDS Research and Human Retroviruses* journal. Tanvi Sharma, MD, lead author, is a Co-Investigator at Boston Children's Hospital and a member of the Nutrition, Growth and Metabolism Working Group.

"Relationship between viral load and self-report measures of adherence among youth with perinatal HIV infection." This manuscript is in the *AIDS Care* journal. Ann Usitalo, PhD, lead author, is a neuropsychologist at the University of Florida Health Sciences Center in Jacksonville and a member of the Adolescent Behaviors Working Group.

Abstracts

This abstract was presented at the Eastern Society for Pediatric Research in Philadelphia, Pennsylvania on March 22-23, 2013:

"Frequency of APOL1 Risk Alleles among a US Cohort of Children with Perinatal HIV-1 Infection and Associations with Renal Phenotypes."

PUBLICATIONS IN THE NEWS (CONTINUED)

Abstracts (Continued)

These two abstracts were presented at the 17th International Workshop of HIV Observational Databases in Cavat, Croatia on April 11-13, 2013:

"Patterns of Childhood Growth in HIV-Exposed Uninfected (HEU) Children in the Pediatric HIV/AIDS Cohort Study (PHACS).

"Clonal expansion, artificial censoring, and inverse probability weighting to compare the effects of multiple treatment management strategies after HAART failure among perinatally HIV-infected children and adolescents.

This abstract was presented at the 2013 National Conference on Pediatric Psychology in New Orleans, Louisiana, April 11-13, 2013:

"Concordance of cognitive and academic achievement outcomes in youth with perinatal HIV exposure."

This abstract was presented at Experimental Biology, in Boston, Massachusetts on April 20-24, 2013:

"Associations of Diet and Supplement Use with Birth Size in HIV-infected Pregnant Women."

This abstract was presented at Pediatric Academic Societies in Washington D.C. on May 4-7, 2013:

"Frequency of APOL1 Risk Alleles among a US Cohort of Children with Perinatal HIV-1 infection and Associations with Renal Phenotypes."

AMP 18+ UPDATE

Many of you have heard about our new study for PHACS participants who are 18 or older. We're excited to announce that this study is almost ready to begin recruiting!

We designed this new study for youth who are aging up into adulthood. Many parts have come together to create it! We listened to CAB members, study coordinators, and the first members of our newly-formed Young Adult CAB (YACAB). These groups advised us on the best ways to keep our young adult participants involved in PHACS. We hope that this feedback will help us create a study that is designed with our young adults' best interests in mind.

All of this feedback is now being used to plan for the study. This includes everything from the design of a new website for young adult participants to the actual name of the study (which will be announced soon). Our YACAB members are helping us create a website that will be just for young adults. This website will have health information and will also link them to their online PHACS surveys.

Most importantly, this new study will give young adults more flexibility. They will be able to decide when and how they give some information to the study. Young adults will visit the clinic when they first enter the new study, and then again after 3 and 6 years. They will then have the option to either go to the clinic or go online to fill out their annual surveys. The online surveys can be filled out on computers, tablets, or even on smartphones. We will keep collecting much of the same information as we do in AMP. However, we added some new questions on topics like reproductive health and employment.

We will send more information to the families in PHACS when we know the start date for this new study. Stay tuned!

PARTICIPANT SUMMARY

Risk Behaviors and HIV in Older Children and Teens

Youth who have HIV or were exposed to HIV at birth may have unique challenges as they become teenagers. We wanted to understand how much these challenges affect youth in PHACS.

What we did

We asked youth and their parents a series of questions. These questions were about their experiences with certain problems.

What kinds of problems did we look at?

We looked at:

- Mental health issues
- Sexual risk behaviors
- Using alcohol and/or drugs
- (for HIV+) Adherence to their HIV medications

Who we studied

349 youth in PHACS AMP ages 10 to 16

- 238 HIV+ youth
- 111 youth without HIV who were born to mothers with HIV

For more info, contact:

Claire Berman
Director, Health Education &
Communication
617-432-1853
cberman@sdac.harvard.edu

What we found

About half of the children and teens were affected by **at least one** of the problems we looked at. Some (11% - 16%) had two or more of these problems. Also:

- 28% had mental health issues. This was the most common problem.
- About 16% said they had used drugs or alcohol (mostly alcohol).
- About 16% said they had started having sex. Of those, more than half said they did not always use a condom.
- More than 33% of youth with HIV said they had missed doses of their HIV medications in the past week.

What we learned

Youth who have HIV or were exposed to HIV may be at risk for mental health problems, risky sexual behaviors, alcohol and/or drug use, and not taking HIV medications the right way.

More services are needed to help youth make healthy decisions about sex and drug & alcohol use as they grow up. Services to provide support for mental health issues are also needed.



Reference Info:

Concept Sheet #C016
*2011. AIDS Patient Care
STDS (25), pp. 385-294*

YOUNG ADULT VOICES IN PHACS



*Inspired. Empowered. Encouraged.
Grateful.*

At the end of every Young Adult CAB (YACAB) call, we each say one word to describe how we feel as we leave the space. The words above were the ones to fill the last minute of our May 2013 call. Although our YACAB is small and we have only met a few times so far, our meetings truly have lived up to these words.

It's a pretty gratifying way to spend an hour every month. The young adults

who have participated so far (who can range from 16 to 25 years of age) are creative, thoughtful, and inspiring. They come from different parts of the country, different backgrounds, and different experiences. But the fact that they all share a commitment to advocacy makes being in this space together very powerful.

The mission of the YACAB has two parts. The first is for young adult participants to provide PHACS with expert guidance around study-related issues. Right now, this is focused on giving feedback on the online surveys for the PHACS study for young adults 18 and older that will open later this year. They are also helping create a plan for the content that will go on the young adult website.

The other half of the YACAB's mission is for us to return the favor by offering the young adults in the YACAB a way to access resources, peer support and to build knowledge and skills. This part of our program is driven directly by feedback from the young adults themselves. For instance, based on a recent request from our YACAB members, the May 2013 YACAB call focused on advocacy.

We invited a prominent HIV advocate, Cristina Peña, to speak on our call about ways to become involved in advocacy (see Cristina's "Advocacy Tips and Advice" on page 14). Eventually, we anticipate that at least part of each call will be run by the young adults themselves.

We're very excited to be building a forum where the voices of our young adult participants can be heard together. Each month, our numbers grow. We are looking forward to seeing the great things that these young adult leaders will do - not just for other youth in the study, but also to help us grow our understanding as researchers and staff on PHACS.

As one young adult on a recent call said, "I'm just very grateful for this group." And we share that feeling.

For more information, to offer suggestions, or to ask about joining the YACAB, please contact Claire Berman (cberman@sdac.harvard.edu) or Megan Lukschander (meganlukschander@westat.com).

Submitted by Claire Berman

PHACS WEBSITE REDESIGN

Get ready for a new PHACS website!

The PHACS website is getting a makeover! We're so grateful for the thoughts and ideas you've shared with us over the last several months about our new PHACS website. Our website design team has been working to create a website that will reflect the needs and preferences we've heard from all of you. This will include a new look and feel of the website. It will also include a special section with lots of resources for CAB members and PHACS caregivers. As a CAB member and/or caregiver, you'll be able to log on to the PHACS website using an email address. You will choose a password for yourself. Once you log in, you will find links to HIV resources, HIV news, and health education materials. We'll have a new layout for participant summaries to make them easier to find. We also heard from many of you that you'd like to be able to communicate more with each other - so we're looking for a way to make that happen through a discussion forum. This will allow you to share CAB-related ideas with each other in a private CAB forum (if you choose to). We're excited to be moving forward with the development of this website. The website should launch by late Fall 2013!

If you have ideas for content to include on the PHACS website for CAB members and caregivers, please send it to Claire Berman (cberman@sdac.harvard.edu) or Megan Lukschander (meganlukschander@westat.com).

Submitted by Claire Berman

FINDING A VOICE IN ADVOCACY



Cristina Jade Peña was a guest speaker on the May 2013 Young Adult CAB call. She shared her experience as an advocate and offered tips and advice for getting involved in advocacy work. Cristina is currently in graduate school to earn a Masters Degree in Public Policy at the University of California Berkeley. She was also recently one of five women who worked with Alicia Keys in her EMPOWERED Campaign with Greater Than AIDS.

To find out more about the EMPOWERED Campaign, visit <http://greaterthan.org/campaign/empowered>.

If you ask Cristina Jade Peña, she'll tell you that there are many different ways to be an advocate. And being part of a national campaign – like her recent EMPOWERED Campaign with musical artist Alicia Keys – is just one of them.

Cristina's experience with advocacy began when she was 10 years old, just a year after she found out she had been living with HIV since birth. "I told my mom then that I wanted to speak out, and that I wanted to help others somehow," she remembers. She felt sharing her story with others was a way to do that. But sharing your story, she explains, can take

many different forms. And it all depends on the comfort level of the person who is sharing. For Cristina, starting small was important. Cristina's mother helped her find opportunities in which she felt very safe at first.

She also did most of her early advocacy work away from the immediate area where she went to school. There, she could speak out while still keeping her HIV status semi-private. This helped her feel safe during her middle school and high school years.

To find opportunities to speak, Cristina talked to people she trusted, like her doctors. She volunteered at fundraisers for HIV-focused organizations. She shared her story anonymously in articles and documentaries. She spoke up when others made incorrect or negative statements about HIV.

After graduating from high school, Cristina started branching out more. She continued to share her experience growing up with HIV. But now, she was more comfortable publicly sharing her full name, using childhood photos, and going on camera. She spoke to live audiences at HIV fundraising events, to medical students at college, and even teenagers at middle and high schools.

Cristina is careful to ask about the event details before agreeing to speak. For instance, she always asks who will be in the audience and whether journalists are planning to report on the event. "This has helped me feel more prepared, but it also gives me a sense for how my story will be used," she says. In other words, it allows her to control her own narrative.

Cristina says it is important to be in a strong place personally before disclosing. Publicly disclosing one's HIV status can feel very vulnerable. It also helps to have a strong support network to rely on, such as family and friends. Cristina adds that she feels more comfortable working through an organization for this reason. "The staff have helped me feel more supported

throughout the process," she explains. "They have also made sure I have a safe space to share my story."

Cristina says her family has been very supportive of her advocacy work. But when she disclosed her status, she says, it had implications for her mother as well. She has kept an open line of communication with her mother to make sure she is comfortable with what Cristina shares publicly.

Today, Cristina's commitment to advocacy is as strong as ever. She speaks publicly in a number of forums about HIV, including the national EMPOWERED campaign with Alicia Keys. In Summer 2013, she will work in Malawi and South Africa with youth infected and affected by HIV. There, she will also have a voice in a UNAIDS meeting with policy leaders. And after finishing her degree, she plans to continue her advocacy work. She has a particular interest in youth needs, holistic sex education, gender equality, and human & health rights.

"Advocacy is not for everyone," Cristina says. "Some people aren't comfortable with it or don't want to do it, and that's completely ok." For her, it helped build confidence in herself and her public speaking abilities. She gained skills in resilience, organization, and writing. She became more connected to others around her and became more empowered.

Cristina believes we are all in a position to define the world we live in. She says her experience growing up with HIV and continuing her education has shaped how she views the world. At the same time, Cristina does not feel that HIV is something that defines her or has made her a victim. In fact, that is part of the message she hopes to communicate to people. And if she has been able to reach someone with her message, she says, then it's all been worth it.

Submitted by Claire Berman

ADVOCACY TIPS AND ADVICE

What are the different kinds of advocacy?

- “Behind-the-scenes” (examples: educating others about HIV/AIDS or participating in the AIDS Walk—you can do this without disclosing your status).
- Sharing your story anonymously (examples: sharing your story in the newspaper, on the radio, on a blog, or on TV).
- Public speaking (examples: speaking openly to an audience about your experience or about an organization, or working with a national campaign).
- It’s often a good idea to try to get involved in behind-the-scenes advocacy first. This is a way for you to promote HIV/AIDS education without having to disclose directly.

- Consider talking to people you trust like your doctors, social workers, and nurses at your clinic about opportunities for advocacy. They might know of ways for you to share your story.
- Consider getting involved with a local nonprofit organization in your community, ideally one that provides HIV/AIDS-related services and education. You may already be aware of organizations that assist with food, transportation, housing and support efforts for people living and affected by HIV/AIDS.
- When you feel comfortable enough to share your story openly, consider approaching national campaigns, television programs, and internet movements.

How can I find opportunities for advocacy?

What are important things to remember when looking for advocacy opportunities?

- It takes time to feel comfortable speaking out about HIV. Listen to yourself. Only participate in events you feel completely comfortable with. It’s okay to start small. It’s also okay to say no to opportunities if you’re not ready.
- If you are interviewed for a story you have the right to remain anonymous by requesting a pseudonym (fake) name be used instead and opting out of using an identifying photo. You can tell your story without giving your real name. If you are ready to speak publicly, make sure you are comfortable with the size of the audience, the purpose of the event, the sponsoring organization, and disclosing your status. Remember, public speaking opportunities may vary a lot in these respects!
- Keep an eye out for red flags so you can make sure that you are not being taken advantage of. Pay attention to things like how well your contact is keeping promises. You should never be afraid to ask direct questions about how your story will be used, how many people you’ll be speaking to, etc.
- You also have the right to know how your story is being used. For example, is your presentation or speaking event being recorded and shared online after the event is over or written up in a blog? It’s important to ask so that you are not surprised and caught off guard after the interview or event is over.
- You should never feel pressured to tell your story. Always make sure that you trust the organization you are working with.
- During a speaking engagement or interview, a question may come up that you are not comfortable answering or that asks about parts of your life you do not want to publicly discuss. You can always politely say, “That’s personal and I’m choosing not to comment on that right now—thank you.”
- Consider how your open disclosure affects your family. By speaking out about being HIV+, you may also indirectly disclose the HIV status of your parents or siblings. Talk to your family about these issues before you move forward.

ADVOCACY TIPS AND ADVICE (CONTINUED)



- You are creative and have important things to say, and remember that you are empowered!
- Advocacy is an important chance to educate the people around you about HIV in whatever way you feel most comfortable.
- Meeting new people can open up opportunities for advocacy. At the same time, advocacy can help you connect with peers.
- Advocacy can help build your skills, such as verbal and communication skills, analytical skills, and improve your writing—all good stuff to have as a young professional. Remember that advocacy can also happen online—look for groups on Facebook or other online platforms. These can be great ways to brainstorm and get support.
- Gain confidence in your voice and with speaking out.
- Most importantly—have fun!

Submitted by Cristina Jade Peña

ADVOCACY RESOURCES

Global Network of Positive People Living with HIV (GNP+) -Youth Programme called the Y+ Programme

New members must apply to join the group but everyone involved is under 30 years old and keeps in contact using Facebook and emails. It's a great resource to learn about new leadership opportunities happening internationally.

<http://www.gnpplus.net/en/programmes/empowerment/young-people-living-with-hiv>

<http://www.hivyoungleadersfund.org/>

Smart Youth—New York, New York

<http://www.smartuniversity.org/annualreport/youth.html>

One Love Project- HIV/AIDS Youth and Young Adult Life Skills Retreat—ages 16-26

This retreat is held in California. Youth and young adults can also join the task force to help plan the agenda and discuss important topics for the conference. It is a great way to build skills. Find the application in the link below.

<http://www.sunburstprojects.org/programs/one-love-conference/>

Speak Positive Blog

This is a new blog launched by Janice, a fantastic youth leader and advocate.

<http://speakpositive.wordpress.com/>

United States Conference on AIDS 2013- USCA Youth Initiative

<http://nmac.org/youth-initiative-to-end-hivaids-in-america/>

Youth and young adults under 26-years-old are encouraged to attend the conference in October/September this year being held in New Orleans. The USCA Youth Initiative aims to help youth develop strong relationships in order to assist them in becoming leaders to end HIV/AIDS in the United States.

Advocates for Youth

The website has advocates on many different platforms, not just HIV/AIDS.

<http://www.advocatesforyouth.org/>

Submitted by Cristina Jade Peña

CAB GLOSSARY



Analyze: To study data (information) to determine clinical trial results.

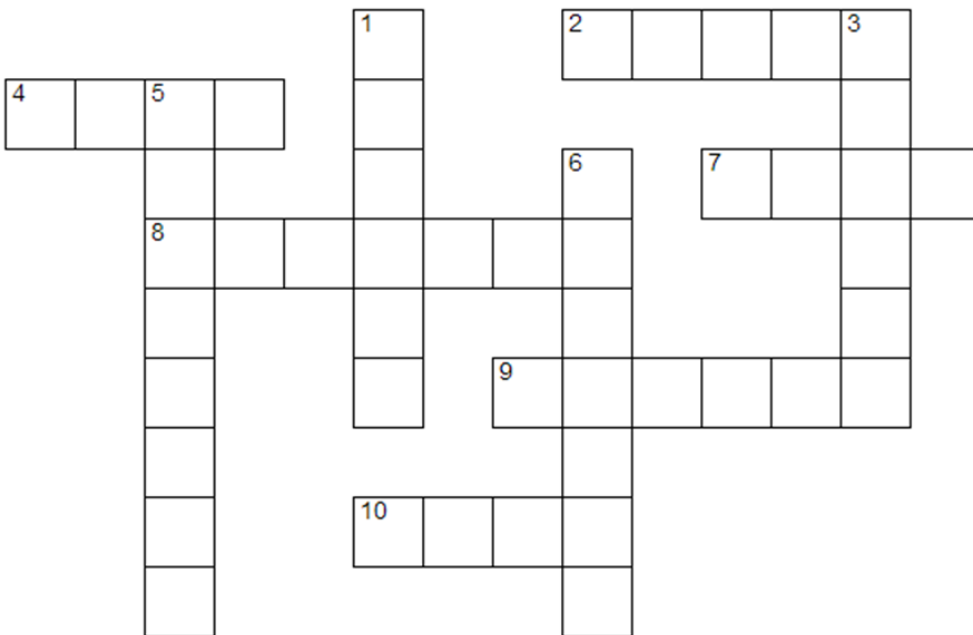
Biostatistician/Epidemiologist: The person responsible for all or a subset of statistical design, statistical monitoring, analysis, and presentation of a study.

Coordinating Center (CC): In PHACS, the institution responsible for funding the participation of scientific consultants, and the administrative management of many PHACS committees as well as any potential substudies. The CC for PHACS is Tulane University.

Drug Resistance: The ability of a virus like HIV (or bacteria) to change so that it can continue to reproduce, even in the presence of medicines that would normally kill it.

Vertical Transmission: Transmission of HIV from mother to infant during pregnancy, labor and delivery, and breastfeeding.

CROSSWORD PUZZLE



ACROSS

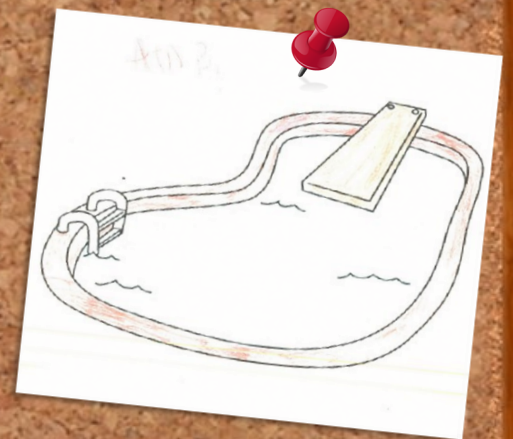
2. NICHD: National Institute of _____ Health and Human Development
4. OAR: Office of _____ Research
7. NHLBI: National Heart, _____ and Blood Institute
8. NIAAA: National Institute on _____ Abuse and Alcoholism
9. NIMH: National Institute of _____ Health
10. NIDA: National Institute on _____ Abuse

DOWN

1. NINDS: National Institute of Neurological Disorders and _____
3. NIDCR: National Institute of _____ and Craniofacial Research
5. NIDCD: National Institute on _____ and Other Communication Disorder
6. NIAID: National Institute of _____ and Infectious Diseases

(Answer Key on page 22)

CAB Kids – Summer Fun



CAB Kids – Summer Fun



CAB COOKS

The Soursop

Submitted by Delia

The soursop, or the fruit from the gasviola tree is native to the Caribbean, Central America, South America and Sub-Saharan Africa. The soursop can grow in areas of high humidity. It tastes like a combination of strawberry and pineapple, with a hint of creaminess and sour citrus. Soursop juice is not particularly difficult to make and offers a range of health benefits. High levels of vitamin C keep the urinary tract clean, and vast amounts of fiber improve digestive health. The fruit juice also contains a number of other nutrients.



Soursop Drink

Ingredients:

1 ripe soursop
1 1/2 cups milk, evaporated milk or water
1 tablespoon vanilla essence (optional)
1 tablespoon sugar (optional)
1 lime, juiced (optional)
Nutmeg (optional)
Ginger (optional)

Preparation:

The skin is very soft and can be peeled by hand. You do not need to use a peeler or any other tools to complete this step. All seeds should be removed.

Pour the soursop in a blender. Add any extra flavorings. Try a combination of vanilla and nutmeg, or a mix of sugar, ginger and lime.

Mix the ingredients together using a medium to high speed setting. Blend for several minutes. The pulpy liquid should be smooth and creamy by the time you finish.

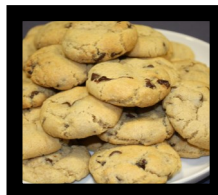
Add more water if the juice is too thick, about 1/2 cup at a time. Blend again. Serve the juice chilled or in glasses with ice. Refrigerate any extra juice for up to a week.

Chocolate Chip Cookies

Submitted by Angel

Ingredients:

2 sticks of butter
1 cup brown sugar
1 cup sugar
2 large eggs
1 tsp. almond extract
1 1/2 cups oats (put in food processor)
2 cups flour
1 teaspoon baking soda
1 teaspoon baking powder
1/2 teaspoon. salt (optional)
2 1/2 cups of "stuff"



Preparation:

"Stuff" is made up of chocolate chips, toffee, walnuts, pecans or marshmallows.

Preheat oven to 350 degrees.

Cream together first five ingredients with the mixer.

In a different bowl mix together the next five ingredients. Fold in the stuff.

Drop by spoonful on baking sheet and bake until golden brown.

CAB COOKS (CONTINUED)



Dulche de Coco (Coconut and Milk Fudge)

Submitted by Carlos

Ingredients:

2 grated coconuts
4 cinnamon sticks
1 1/2 pounds of sugar
1/2 inch piece of fresh ginger
1 can of evaporated milk



Preparation:

Combine grated coconut milk, cinnamon, sugar, and ginger in a pot.

Cook at medium heat without a lid for 1 1/2 hours, stirring regularly to avoid sticking and prevent it from boiling.

The fudge is ready when it reaches a yogurt-like consistency.

Remove from heat and let it cool.

Oatmeal Raisin Cookies

Submitted by Angel

Ingredients:

1/2 cup butter (softened)
3/4 cup brown sugar
1/2 cup sugar
2 large eggs
1 teaspoon vanilla
1 1/2 cup flour (all purpose)
1 teaspoon baking soda
1 teaspoon cinnamon
1/2 teaspoon salt (optional)
3 cups of oats
1 cup raisins
Dash of cream of tartar (optional)

Notes: Trade 1/4 less raisin for 1/2 cup of walnuts or pecans (optional)

Dash of cayenne pepper - Angel's secret ingredient (optional)

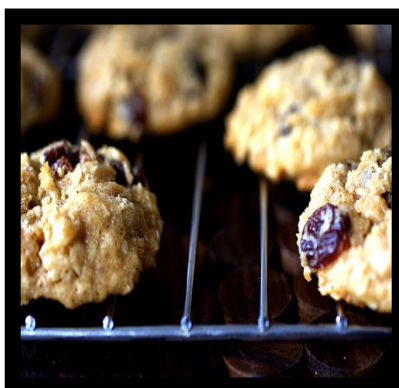
Preparation:

Preheat oven to 350 degrees.

Cream together first five ingredients with the mixer.

Put 1/2 of the oats in food processor before adding to dry mixture. In a different bowl mix together next five ingredients. Fold in raisins and optional nuts.

Drop by spoonful on baking sheet and bake until golden brown.



CAB COOKS (CONTINUED)

Mango Juice

Submitted by Delia

Ingredients:

Two medium size mangos
Sugar (optional)
Ice cubes (optional)

Preparation:

Wash the mangos.

Peel the mangos and chop them into small pieces.

Put the mango pieces into the blender.

Blend with ice and sugar until smooth.



Phata Burger

Submitted by Angel

"I love to bake, but it's now summertime and the barbeque is what it is all about! This burger only needs a bun. It's fun for all ages!"

Ingredients:

1 1/4 pound ground beef
1 small onion
1/2 small bell pepper
1 clove garlic
2 stalks green onions
2 teaspoons Worcestershire sauce
2 teaspoons spicy mustard
3 ounces feta cheese crumbles
1 large egg

Preparation:

Mix together all ingredients.

Mold four, even patties.

Allow the burger patties to rest in refrigerator.

Light up the grill.

Cook burgers on a hot grill.

Serve and enjoy!



WHAT CAMP MEANS TO US



We have each attended camps for kids with HIV for many years. There are many things we love about camp.

We love the pool and the awesome way they greet you when you come on the bus. We love the counselors and the things we do. We love seeing friends at camp. We like camp because we get to meet new people, old friends, and counselors. At camp, we get to go to the pool with friends. We love all the activities like rock climbing, fishing, and the dance.

There are people there to help us feel supported. Others there have HIV like us, and we can make new friends who also have HIV. You're not the only one with HIV. Even if you don't talk about it, you know you're not the only one. You see how other kids take medications, too.

The people at camp are supportive, and so are the counselors. They make you feel like you're at home. If you have other friends with HIV, you don't have to worry about feeling awkward when you talk about it. You can feel supported and comfortable and know that other people are like you.

Kids and teens need support that is positive and encouraging. You can have fun and be with others like you. There are other people there like you so you don't need to worry. It is great to have a place where you don't have to explain yourself and people don't feel sorry for you because you're adopted, because your parents died, or because you have HIV. They understand you and let you be yourself and have lots of fun.

If someone were thinking about going to camp, we'd tell them to come because it is really fun and it feels good to be with other kids like you. We are very thankful to get to go to camp. It is a special place for us.

Submitted by A (12), G (11), and K (10)



CROSSWORD PUZZLE KEY

Across:

2. Child
4. AIDS
7. Lung
8. Alcohol
9. Mental
10. Drug

Down:

1. Stroke
3. Dental
5. Deafness
6. Allergy

Please send all questions, comments, and suggestions for the CAB newsletter to Megan Lukschander at MeganLukschander@westat.com