



FROM OUR CAB CHAIR



Megan, De` Angelo and Delia at the Fall 2012 Network Meeting

I am proud to serve as your PHACS CAB Chair. Being the PHACS Chair is not only an honor, but indeed, a privilege. This position allows me to continue working alongside and to lead a great team!

The knowledge, education, and most of all, self-esteem I gained while I served as Vice Chair gave me the ability to make our CAB more successful. I have learned so much. I did not realize that I had it in me, but apparently my fellow CAB members recognized my abilities.

I have come a long way because of the CAB, and I am prepared to work even harder on behalf of the community we represent.

The Fall 2012 Network Meeting was held in Bethesda, Maryland on November 8-9, 2012. It had a different flavor because other study representatives were invited from the United Kingdom, Canada, Thailand and France. They spoke about the different research that they are involved in, and about future research. In addition, the PHACS Working Groups presented updates.

I am very proud of my CAB because we have grown and accomplished so much. The PHACS Community Concerns and Priorities list is completed. We are always busy planning for the CAB sessions. Right now, we have a lot of topics for discussion for our PHACS CAB calls because of the monthly Evaluation Survey. The survey was a great idea. It works because it is confidential and CAB members can ask about the topics that they would like to have featured on the upcoming PHACS CAB calls. We get ideas on how to improve our PHACS CAB, local CABs, clinics, and other topics. The CAB was also very much involved in writing two PHACS CAB Disclosure Fact Sheets.

We had a few invited guest speakers come on our PHACS CAB calls. All the discussions from our guest speakers are always educational. The topic that was most interesting was on ARV medications. We learned that there are so many kinds of medications, how they work in our bodies, and about understanding CD4 counts and viral loads.

Thank you once again for giving me this opportunity. I am very excited, willing, ready and able to lead our CAB team!

Delia, PHACS CAB Chair

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CAB MEMBER EXPERIENCES AT THE FALL 2012 NETWORK MEETING

The PHACS Community Advisory Board (CAB) serves as the voice of the PHACS community and its study participants. The Fall Network Meeting provides a face-to-face opportunity for researchers and community members to work together on the PHACS project.

The PHACS Fall Network Meeting was held on November 8-9, 2012 in Bethesda, MD. CAB members from each site were invited to attend.

"My experience at the PHACS conference was a new, as well as a knowledgeable one," said Rosetta. "I met people from different places and got to go meet the other PHACS CAB members who are on the PHACS CAB calls."



Several CAB members gathered for an informal dinner at La Madeleine the night before the meeting. Many CAB members saw the dinner as an opportunity to break the ice before the start of the meeting.

"We reserved a table for 15," said Delia, PHACS CAB Chair. "The dinner was wonderful, the discussion was educational, and best of all, I was in the presence of delightful people."

CAB members participated in all sessions at the meeting. "There were so

"HIV is still affecting people in different ways, good and bad."



many people from everywhere and I learned so much about different topics concerning HIV from other states and countries like France, England, and Asia," Rosetta said. "HIV is still affecting people in different ways, good and bad."

"In my eyes, [CAB members] are the experts who can teach us a thing or two about commitment, dedication, and growth."

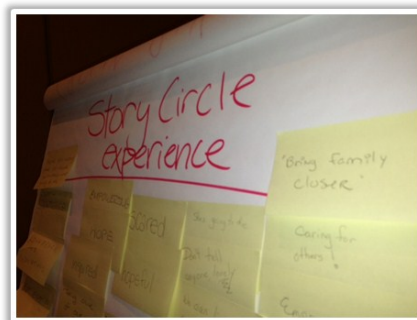
In addition to the regular meeting sessions, there were two CAB-specific sessions. The first CAB session was on the topic of "Helping Children and Teens Cope with Loss." PHACS Neuropsychologists Kay Malee, Claude Mellins and Renee Smith presented the topic to the CAB. The discussion following the presentation served as a forum for CAB members to not only ask questions, but to learn from one another about situations having to do with loss that specifically apply to HIV-affected families.

At the second CAB session, CAB members participated in story circle exercises. This was an opportunity for CAB

members to share personal experiences in small groups without expecting or providing feedback.

"There were some intimate and personal moments at the conference with the PHACS CAB members who shared their stories," Rosetta said. "I was fortunate to be a part of this conference."

During this exercise, CAB members were encouraged to write post-it notes about how each individual story made them feel. Claire Berman, PHACS Director of Health Education and Communication, helped CAB members learn the exercise so that they will be able to lead story circle exercises in their local CABs.



The PHACS Network Meetings provide opportunities for CAB members to give feedback on the study from the community perspective. The meetings are also a learning experience for CAB members. CAB members have to opportunity to share ideas and resources with each other.

"As the site staff liaison and a consumer, I always have twice the learning experience when I attend the network meetings," said Yuri. I get to share my success stories with other site staff and am able to network. In addition, I interact with CAB members and learn from their experience at their sites. It is always a pleasure and a privilege to spend time with CAB members who really care about their community and research. In my eyes, they are the experts who can teach us a thing or two about commitment, dedication and growth."

SPOTLIGHT ON DR. LYNNE MOFENSON

At the 2012 International AIDS Conference, Secretary of State Hilary Clinton set a revolutionary goal, an AIDS-free generation. She stated that “part of the reason we’ve come as far as we have is because so many people all over the world have not been satisfied that we have done enough.” Secretary Clinton may have been talking about people like Lynne Mofenson, who has dedicated her career to pediatric HIV/AIDS research.

Lynne Mofenson, M.D., is the Branch Chief of the Maternal and Pediatric Infectious Disease Branch at the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD). NICHD is the main sponsor/funding agency for the PHACS project.

In 1989, Dr. Mofenson started working at NICHD in the midst of an epidemic. At the time, the HIV transmission rate from mother to child was 25% in the US.

In 1994, Dr. Mofenson was part of a research team that designed a ground-breaking and controversial clinical trial. The researchers gave Zidovudine (AZT) to HIV-infected women during pregnancy and during labor. They also gave AZT to the baby for a short time after birth. The researchers found that this treatment lowered HIV transmission by 70% in this study. By prescribing this treatment, mother-to-child HIV transmission rates in the US fell from 25% to 5-8% in a single year.

During this time, Dr. Mofenson was serving as the Chair of the US Public Health Service Task Force. The task force came up with national recommendations on pediatric AIDS prevention. She worked with the CDC to recommend HIV testing for all pregnant women. She also collaborated with the FDA to get approval for the use of AZT in pregnant women. Finally, Dr. Mofenson worked with Medicaid to guarantee that health insurance covered the use of AZT during pregnancy. As a result of these policies, by 1996, 80% of HIV-infected pregnant women were taking AZT. The number of babies born with HIV has dropped from over 1600 per year to less than 150 per year.

Dr. Mofenson was also part of the group of researchers that formed the Pediatric AIDS Clinical Trials Group (PACTG). PACTG was a team of researchers that designed many successful studies. These studies were created to improve ways to stop mother-to-child transmission of HIV as well as treatment of HIV in children and pregnant women.

This year, Dr. Mofenson received the 2012 Federal Employee of the Year medal. She earned this award for her continued efforts in preventing HIV infections in children by researching ways to prevent mother-to-child transmission. Today, in the US, fewer than 150 babies are born with HIV per year. Dr. Mofenson is now working on the UNICEF and World Health Organization (WHO) 2015 elimination plan. This plan has a goal of reducing the number of babies born with HIV by 90 percent globally. The plan also aims to lower the number of AIDS-related maternal deaths.

In addition to her work at the NICHD, Dr. Mofenson advises the WHO in the development of guidelines for prevention of mother to child HIV transmission and treatment of infected children in developing countries. She attends WHO meetings internationally. She continues to work with other researchers on ways to limit transmission of HIV and optimize treatment for HIV-infected children.

Lynne Mofenson has dedicated her career to pediatric HIV/AIDS research. She continues to work tirelessly to influence national policy in the field of HIV/AIDS. The goal of reaching an AIDS-free generation looks much more attainable with researchers like Dr. Mofenson leading the way.



Dr. Lynne Mofenson at the Samuel J. Heyman Service to America Medals Ceremony receiving the 2012 Federal Employee of the Year Award

PHACS MEMBER PROFILES

William T. Shearer, M.D., Ph.D.

Dr. Shearer is Professor of Pediatrics and Immunology at Baylor College of Medicine. He is also the former Chief of the Allergy and Immunology Service at Texas Children's Hospital. Dr. Shearer graduated from Washington University School of Medicine in St. Louis in 1970. He got his clinical training in pediatrics, allergy, and immunology at St. Louis Children's Hospital and Barnes Hospital. He received a Research Scholar Award from the Cystic Fibrosis Foundation for his early work. He also got a Faculty Research Award from the American Cancer Society. He joined the faculty of Washington University in 1974. In 1978, he was promoted to professor. He later moved to work at Baylor College of Medicine. In 1981, he was elected to membership in the American Society for Clinical Investigation. He also received the Distinguished Teacher Award in 1984 from Baylor College of Medicine. Washington University has also recognized Dr. Shearer with several awards. These included the Alumni Achievement Award in 2000 and the Houston Regional Cabinet Award in 2003. In 2008, they also appointed him an Ethan A.H. Shepley Trustee of the Washington University Board of Trustees. He also became a member of the School of Medicine National Council at Washington University. In 2008, he was elected to the Association of American Physicians.



Dr. Shearer has been active in professional and clinical immunology organizations at the national level for many years. He served as Director and Chair of the American Board of Allergy and Immunology from 1990 to 1995. He was Director of the American Academy of Allergy, Asthma, and Immunology from 1992 to 2002. He was also Chair of their Clinical and Laboratory Immunology Committee. This group published the Core Content Outline for Clinical and Laboratory Immunology and the Practice Parameters for the Diagnosis and Management of Immunodeficiency. He was Councilor of the Clinical Immunology Society from 1997 to 2001. He then served as the Society's President from 2001 to 2002. Dr. Shearer was given the Special Recognition Award of the Academy in 2004 for editing the 5th edition of the book *Primer on Allergy and Immunologic Diseases*. In 2005, he got the Arnold J. Rudolph - Baylor Pediatric Award for Lifetime Excellence in Teaching.

Dr. Shearer's basic research looks at how HIV disrupts the immune system. His clinical research involves directing the Pediatric HIV/AIDS Research Center at Baylor College of Medicine and Texas Children's Hospital. This center currently has over 100 professionals. It gets funding from four National Institutes of Health (NIH) grants. He has served as a Vice Chair and as a Member of the Leadership Group of the Pediatric AIDS Clinical Trials Group. This group is a multi-center national research group that studies therapies for HIV-infected children. It is funded by the National Institute of Allergy and Infectious Diseases. He directs the NIH 7-year International Maternal Pediatric Adolescent Clinical Trials Group (IMPAACT) and the Pediatrics HIV/AIDS Cohort Study (PHACS) research programs at Baylor College of Medicine.

Dr. Shearer also directs the David Center at Texas Children's Hospital. This center was established in 1984. It was named after the Houston "Bubble Boy," whose immune system was very weak. The David Center treats children from all over the world who have problems with their immune systems. The Center works to fix their immune systems with therapies such as bone-marrow stem-cell therapy. In 1998, he became involved in space immunology research. This research was with the National Space Biomedical Research Institute at NASA (the National Aeronautics Space Administration). He helped research whether long-term space travel would harm the human immune system. Dr. Shearer's research has led to 335 peer-reviewed publications and 78 book chapters. He has made 247 presentations at national and international meetings.



PHACS MEMBER PROFILES (CONTINUED)



Claire Berman, M.S.

Anyone who knows me will tell you that I love stories. They will tell you that I love narrative and will talk your ear off about the power of both telling and hearing stories. So I was delighted when I was invited to share my own story with you for the CAB newsletter this month!

I spent my childhood in St. Louis, Missouri, eating lots of gooey butter cake (if you haven't tried it before, please do). I returned there after college to work at Big Brothers Big Sisters as a "mentor matchmaker." My job was to pair vulnerable children with adult mentors. I spent a lot of my free time during those years volunteering at organizations with a focus on HIV. One was a drop-in center for LGBT youth. I did 1:1 counseling and HIV prevention with a support group for young men who identified as gay, bisexual, and/or transgender. The other was St. Louis Effort for AIDS. They offer HIV testing, prevention, and a sense of community for people affected by HIV. Both helped shape my understanding of how different communities experience HIV.

I was also learning more about the impact of HIV around the world. I decided I wanted to volunteer abroad. The Peace Corps wasn't an option for me for medical reasons. Instead, I found myself an independent volunteer position with Save the Children in the tiny country of Swaziland. I quit my job, raised the money for the trip, and traveled for 30 hours to the southern corner of Africa. Swaziland has the highest rate of HIV in the entire world. There, one out of every five people in the country is an orphaned child. It's a full-blown crisis. Because of this, the majority of programs in the country focus on HIV/AIDS. Many children in Swaziland are very vulnerable to HIV infection, to abuse, to hunger, and to sexual exploitation, to name a few. I worked with others at Save the Children to form networks of protection for vulnerable children all over the country. We also helped them with the psychosocial challenges of HIV. I had originally gone to volunteer for only 2 months. But I found that I couldn't bear to leave when the time came! I ended up staying for over 14 months to oversee the program we started.

I also had the chance to volunteer at the Baylor Pediatric AIDS Clinic while I was in Swaziland. Helping with a monthly Teen Club for perinatally infected HIV-positive Swazi youth changed my life. It was in that space every month that these youth got to feel like normal kids. At Teen Club, having HIV wasn't the thing that defined them. I was able to see firsthand the difference that having a community of peers can make.

From there, I moved to Boston to pursue a Master's in Health Communication at Tufts University School of Medicine. I became fascinated with what motivates us to change our health behaviors and how we find information about health. I have worked on many different projects since then. I've worked on LGBT health, mental illness, HIV/AIDS, homelessness, health literacy, and digital storytelling for LGBT youth, among others. I am also a freelance writer. I write health narratives and have led story circles on mental illness and HIV. At the center of much of my work are narrative and stories. I love finding ways for them to create better understanding of health and health behavior.

I love everything about health communication and am thrilled to have joined PHACS as a health educator and communicator. Finding creative ways to create lasting behavior change is one of my passions. I believe that you can learn the most from listening to people and responding to what they tell you. And I will be looking to the many voices of PHACS to guide the new Health Education and Communication Committee. We will find creative and responsive ways to communicate with participants, the CAB, and the public about PHACS.

In my free time, I love to swim laps, read, and cook and bake gluten-free things for my food blog (which my colleagues often benefit from!). I am also a social justice activist and can be found attending events, reading, and talking about racial justice and LGBT rights.

POSTPARTUM DEPRESSION THROUGH THE EYES OF A CAB MEMBER

"I thought I was a super mom and that I could take over the world. I found out that I was positive when I was three months pregnant, and was knocked for a loop."

I was the eldest of 13. I worked at a bank and not only took care of myself but was able to send money home to my mom to help her care for my younger siblings. When I found out I was expecting my first child at 24, I was ready. At my first appointment I found out that I had HIV. I told the doctor that he was lying. I was a good girl and I did not hang with those kind people – you know, druggies or people who sleep around. Little did I know that the love of my life, my first love, was bisexual.

"I can't even remember holding my baby or feeding him a bottle because I was in robot mode."

From day one, I went into super mom/robot mode. I took my medications, I ate right and did any and everything to make sure that my baby would be fine, and he was! I had a support system at home, but when you are used to having all the control your world will come crashing down

like a ton of bricks until your mind deals with the shock and reality that you are facing.

The problems started after birth. I had a bad case of postpartum depression that was not caught until my baby was 6 months old. I went through a long black tunnel with no light in sight. You see, even though I was in a living hell to the rest of the world, I was ok in my mind because I made sure my son took all his medication and that he made it to all his study appointments. To this day, I can't even remember holding my baby or feeding him a bottle because I was in robot mode. I would sit in the shower, watch my long beautiful hair fall with the water, and cry my eyes out. In my mind, as long as my baby was okay, I was still doing it.

During this time, my T-cells dropped and my viral load grew, but because I was in that gap of no insurance, no one ever knew. One day, my grandmother saw me coughing up blood and asked if I was ok; I guess the look that I gave her said it all. She asked me why I was doing this to myself. I told her that my life was over and I could no longer feel my body – it was numb. I was half of myself at this time and steadily going down. My life changed not because of me, but because of others who took me into their hands like the baby I had given birth to, not long ago.

My sister found a female doctor in Houston. She told me that 95% of her

employees are women. She told my family that I was depressed about the HIV, and that I had postpartum depression. No one caught it because everyone was looking at the baby's well-being and forgot about my health like in most cases of new moms.

"My life changed not because of me, but because of others who took me into their hands like the baby I had given birth to, not long ago."

I am telling my story because so many of us in this day and age are taught to be strong no matter what happens. We are told that when the real storms come, we should suck it up because we are moms. I got through it with medication for depression, care by my doctor and family support. Please don't ever think that you are alone in this fight because a strong wall will fall hard, but a strong wall with three other sides will stand! I hope my story helps you or even helps you to look out for us super moms!

Submitted by: K

UPCOMING EVENTS



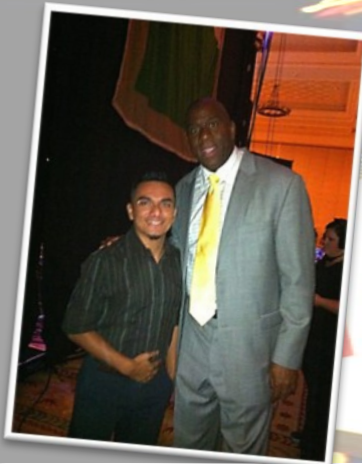
December 2012

- 📅 **February 7:** National Black HIV/AIDS Awareness Day
- 📅 **March 10:** National Women and Girls HIV/AIDS Awareness Day
- 📅 **March 20:** National Native HIV/AIDS Awareness Day
- 📅 **May 18:** HIV Vaccine Awareness Day
- 📅 **May 19:** National Asian & Pacific Islander HIV/AIDS Awareness Day
- 📅 **June 8:** Caribbean American HIV/AIDS Awareness Day

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UNITED STATES CONFERENCE ON AIDS (USCA) 2012



Nominated for the opportunity by a former patient at the University of Miami, Department of Pediatrics, Yuri served as a panelist at the 2012 United States Conference on AIDS (USCA) in Las Vegas, Nevada. As a Patient Advocacy Representative, Yuri works tirelessly with HIV prevention campaigns and fights to end HIV stigma.

Sure it's easy to pose for a camera man and answer questions about your life and HIV diagnosis, but the hard part is allowing them to utilize your image, name and reputation for the entire world. I am so proud of the Greater Than AIDS (GTA) campaign and I think that it opens many other doors in your career and gives you the ability to reach out to a broader community.

As a result of appearing in different HIV prevention campaigns, and the

recommendation from one of my patients, I was recruited by Prochilo Health Inc, (and Gilead) to participate as a panelist on a special edition of the Wendy Williams show during the 2012 USCA in Las Vegas. Although the show won't air, it was a great pleasure and so much fun to



work with this colorful celebrity. I also shared the stage with the amazing Irvin "Magic" Johnson, Phill Wilson (Black AIDS Institute) and other community leaders while discussing how can we end the AIDS epidemic.

In a nutshell, my message focused on battling stigma face-front (so to speak). I believe that people give HIV so much power over them and allow IT to run their lives, when it should be the other way around. We need to keep HIV under control, live normal lives and be proud to be enduring & surviving while living with HIV. I understand it is not easy to live with the virus and take medications with side-effects daily, but if we show the world that we still live normal lives (family, dating, school, work... sex!), I think that we can eradicate HIV stigma. Before you decide to step into the spotlight of the media you need to be emotionally, mentally and spiritually ready. I invite you to seek the support needed to step into that spotlight, and when you're ready, tell the world, "I'm HIV positive, and I live a normal life."

Submitted by Yuri

LIVING HEALTHY WITH HIV—FOLLOW UP

In the last newsletter, I wrote a little article about disclosing to my daughter about her HIV status. So far, there are no changes. Our day to day routine is still the same. From time to time, I explain to her about the importance of taking her medications on time. She is still in charge of preparing the medications in the pill boxes, and she is still the time keeper. She loves that role! I guess, having her in charge of the medication, being the time keeper, patience and understanding helps. I pray to God, that when she gets to be a teenager, that she does not change her habit and routine when it comes to her health care.

Anonymous

FACING FEAR AND MAKING PLANS

It was a program called FACE that helped Sherry and her children talk about one of the hardest things of all: what would happen if one of them passed away.

The fear of talking about death is very real, says Sherry. "But," she adds, "the FACE program gave me this huge sense of relief that we would be able to get through it. I felt that the choices we were talking about were planted inside of us and would resurface if they needed to."

Sherry, a CAB member from Memphis, TN, participated in the three-session program called FACE at St. Jude Children's Research Hospital with her daughter, who was 16 at the time. FACE, which stands for FAMILY-CENTERED, is the first study of a program that helps teens with serious medical conditions and their families talk about death, dying, and living wills.

"[FACE] put us in different scenarios," Sherry says. "It really got us thinking about what would happen if one of us were to die – who would the caregiver [for my children] be? How would we want our death to be handled? And how would we handle other situations that would come up?"

Sherry says many of the scenarios were very detailed. Both she and her daughter were asked to think about what they would each want their loved ones to do if they were unable to talk or move, for instance. They were even asked to think about what kind of clothes or color coffin they would want to be buried in.

A therapist helped guide the conversations with Sherry and her kids. He spoke to them individually, then together, and helped them explore their emotions in a sensitive way – something that Sherry feels is especially important when discussing death with children.

"At first, I was worried because I didn't want the program to hint to my

children that I was going to die," says Sherry. "I didn't want to make them afraid. But once I started to understand what [FACE] was about, I realized that it was really a way to open the door for me to talk to them about what our wishes would be."

And, she adds, these are important things to think about now. Everything can become confused and overwhelming while actually dealing with the crisis of a loved one's death. Writing it down ahead of time makes things so much simpler, she says.

At first, Sherry discussed advance planning with both of her HIV-positive children, who were 16 and 12 at the time. But she also found that the program allowed her to have a conversation about death with her oldest daughter, who was 20 at the time and is HIV-negative.

"Everyone needs to prepare for death. Especially if you have children, you want to make sure you have some simple things in place."

Before Sherry participated in the FACE program, her oldest daughter avoided talking about death or anything related to HIV. But talking about Sherry's living will opened a door and brought them closer together. Her daughter felt more like she was a part of an important conversation that she had been left out of before. FACE helped them communicate with each other in a new way.

For Sherry, the program was about empowerment. "It made me feel more in control, and like I had a voice," she says. "As a mother who is HIV-positive, it really made me feel reassured that I was getting everything in place for the event that something

should happen. [My kids] won't have to worry about finances, the house, burial arrangements – none of that."

For Sherry, making these arrangements ahead of time will allow her kids to focus on being present with their emotions if something should happen to her, instead of worrying about some of these details.

But, Sherry adds, "everyone needs to prepare for death. Especially if you have children, you want to make sure you have some simple things in place. You want to make sure that both you and your children are ok with who you're leaving them with. You want to be sure that person can take care of them in the way you need them to – financially, emotionally, and otherwise." For her, preparing for death is something that everyone should consider – even if they don't live with a long-term illness.

Sherry adds that the process of creating a living will is much easier than people think. You don't need to get a lawyer and spend a lot of money to create a living will, she says. There are plenty of resources online that can help people start the process.

When Sherry thinks about the program's name, FACE, she thinks about teens and caregivers putting a face to the difficult topic of death together. She thinks about giving teens a voice. And she thinks about herself and her own kids, and how they are now prepared to face whatever comes.

For more information about living wills and advance directives, see these resources:

FACE Program:
<http://clinicaltrials.gov/show/NCT01289444>

Five Wishes Guidelines:
<http://www.agingwithdignity.org/five-wishes.php>

Submitted by Claire Berman

THE WORLD'S GREATEST



From 2009 – 2010, I lived in the tiny African Kingdom of Swaziland and volunteered with Save the Children as a grants manager. In my free time, I also volunteered at the Baylor Pediatric AIDS Clinic in the capitol city, Mbabane. HIV-positive youth from all over the country were able to get medical care there, and many also participated in a monthly teen club. Teen Club was wonderful – it gave the youth a chance to be around people who understood them and to just feel like normal kids for a while. At the end of my year there, I wrote this blog entry about the way I'd seen Teen Club – and the youth – change and grow.

"I am a mountain! I am a tall tree! O-o-oh, I am a vision; I can see clearly!"

Tiny arms and hands waved all around me as two hundred voices sang – practically shouted – the lyrics to "The World's Greatest," arguably the most coveted and joyous part of every Teen Club meeting. For those three minutes – or rather, 6, or 9 minutes, depending on how many times we hit "repeat" – those children soar. They *are* a mountain, and a tall tree. For those brief moments, they *can* see clearly.

The potential of Teen Club had always been obvious to me, ever since I first started attending as a volunteer in August 2009. I arrived on that first chilly, sunny Saturday morning to find a huge number of children outside Baylor clinic spilling onto the lawn, playing games, shouting, and laughing with each other. There were some

clusters of children who seemed to be inseparable, and others who floated without direction around the yard, some observing and some taking part in the games, but not seeming to truly belong to any one group. They seemed to be having fun, but the structure was not quite there yet. It was like having all the ingredients to a wonderful recipe, but leaving them unassembled and unorganized on the kitchen counter.

Since that time, a lot has changed. With each Teen Club meeting, there is more structure; more empowerment of the children who come; more meaningful interaction between volunteers and participants; and a specific learning goal for each meeting. There are more volunteers, and everyone knows what he or she is supposed to be doing. Everyone has a role to fill, and the details of the day are never overlooked. There are orderly lines. Spreadsheets. A picture ID card for each child. Things seem to flow more and more seamlessly each time I attend.



But as much as these improvements have helped maintain the sanity of the volunteers and administrators, the true impact can be seen at a much more important level: that of the children who make up the Teen Club.

"Who are your biggest supporters?" I asked a group of eight or so children who were huddled around me for a discussion. The theme of the day was the importance of building meaningful and supportive relationships, and we



stood outside in the soft breeze after completing a larger group activity.

"My mother," offered one soft-spoken young girl, gazing up at me with serious eyes. "Friends," whispered another girl as she tugged the sleeves of her shirt over her hands, her eyes darting around the circle and then to the ground. "Teachers," said a little boy after shyly raising his hand to speak.

"It's *you*," said one of the older boys, looking at me and then around the courtyard at the other volunteers. "It's our aunts. *You* are our biggest supporters."

During another session, we had gone around in a circle to discuss different emotions. The children took turns rolling "emotion dice," and they told the group about a time when they had experienced the emotion that they rolled. Unfailingly, every child who rolled "happy" said that they are happiest when they are at Teen Club, their faces lighting up as they spoke. Some even described their "sad" times as the time they spent *not* in Teen Club.

These children are not merely experiencing positive emotional gains from attending Teen Club; they are also learning. They are learning about supportive relationships, good nutrition, the importance of drug adherence, disclosing their HIV status, and peer pressure, to name a few. And beyond that, they are discovering how to express themselves creatively. *(Continued on page 10)*

THE WORLD'S GREATEST (CONTINUED)

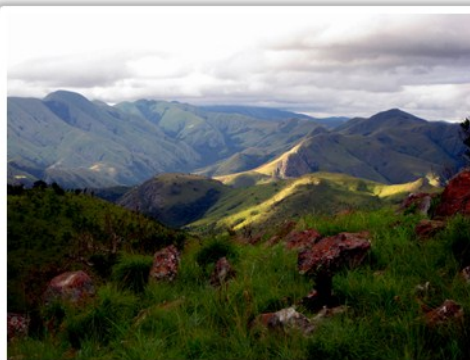
"I am Dr. Garlic!" shouted one girl as she strutted down the makeshift runway of our Nutrition Fashion Show. I looked at her, slightly shocked at the transformation. In our smaller group session for the older youth just an hour earlier, she had been shy and soft-spoken, barely audible. Now, her voice rang out clearly, even over the murmur of the crowd of children. "If you eat me, you will stay very healthy. And by the way, if you are HIV positive, eat two cloves of me per day to help fight off new sicknesses!" The applause from the crowd almost pre-empted her big finish and she sailed back to her place in the crowd, her grin practically taking off from her face. Incidentally, she was crowned Ms. Nutrition later that day, defeating Hot Meat, Perfect Pizza, and Awesome Apples by a narrow margin.

While walking to town from work one day, I ran into one of the girls who attends Teen Club every month on her way home after school. We caught each other's eyes as she walked towards me, and I smiled at her and waved. I held out my hand,

and she grasped it with hers, pressing my thumb with her own in the Swazi style as we greeted each other. "I'll see you on June 19?" she said with a hint of question in her voice, peering up at me.

"Absolutely," I said. "I will see you then." She gave me another shy smile and then continued on her way down the hill. I watched her retreat. June 19 was still weeks away, but the date was etched into her mind.

And *that* is what Teen Club means to these children.



"I'm that star up in the sky; I'm that mountain way up high; hey I made it! I'm the World's Greatest. I'm that little bit of hope, when my back's against the ropes. Hey I made it - I'm the World's Greatest."

Every month, the voices swell around me as they sing, and *feel*, the lyrics. Every single adult sings – and dances – along with the kids. The song ends, and the split second of silence that followed is immediately drowned out with hundreds of desperate pleas to play the song just one more time.

It is difficult to describe just how that song makes us feel. But the beauty of Teen Club is that there, every single person, whether adult or child, can be the world's greatest, and can soar out of themselves for those minutes and hours and experience true, unmitigated joy, no matter how brief or fleeting it may be.

Submitted by Claire Berman

RESOURCES

Growing Up Positive:

<http://www.thebody.com/content/art31161.html>

Children, HIV and AIDS:

<http://www.avert.org/children.htm>

Parenting a Child with HIV:

<http://www.womenshealth.gov/hiv-aids/living-with-hiv-aids/parenting-a-child-with-hiv.cfm>

Helping My Child Stay Healthy: For Carers of HIV Positive Children:

http://www.fhi360.org/en/HIVAIDS/pub/guide/res_HealthyChildGuide_and_WhattodoHIV.htm



Crisco for Dry Skin

People living with HIV/AIDS are not the only ones who suffer from dry skin, or have skin conditions. You will be amazed to see what you can find in your kitchen to help eliminate some of these problems. I found an incredible website—<http://www.livestrong.com>. It is a website that tells you not only about skin care, but also about the different foods that make you healthy, vitamins, fitness, cooking and much more.



Submitted by Delia

RESOURCES (CONTINUED)—THE MEDIA PROJECT

I came across this interesting website about a project called "The Media Project." The Media Project is a program of Advocates for Youth. They are a great organization that works with youth of all sorts including HIV+ youth for over 20 years. They are the only national non-profit organization focusing exclusively on adolescent reproductive health in both the United States and developing countries.

They have also worked with the entertainment industry to place sexual health information and responsible sexual health images on television. They have had a significant impact on popular television shows such as ER, Boston Public, Strong Medicine and many others.

To learn more about this interesting organization, please go to <http://www.themediaproject.com>

Submitted by Delia

PARTICIPANT SUMMARY

Title: The long-term impact of HIV disease severity on cognitive and adaptive functioning during childhood and adolescence

Authors: Renee Smith, Miriam Chernoff, Rick Rutstein, Kay Malee, Patricia Garvie, Betsy Kammerer, Sharon Nichols, Patricia A. Sirois, Ann Usitalo, and Megan Wilkins for the Pediatric HIV/AIDS Cohort Study (PHACS).

Background: Some children with HIV have problems learning, solving problems and/or doing everyday activities. These problems can make it harder to have a good quality of life as they get older. This study compared the learning and everyday functioning skills of youth with HIV to youth who were exposed but not infected to HIV. It also examined whether having HIV or an early AIDS diagnosis made a difference in how well youth learned those skills.

Methods: We studied 461 youth who were enrolled in PHACS. They were between 7 and 16 yrs of age and completed a test that measured their thinking and problem solving skills. Their parents or primary caregivers completed a questionnaire about how their youth did in social settings and in activities of daily living (e.g. daily activities such as feeding, bathing, dressing, grooming, school, household chores, and relaxation/fun). The youth were divided into three groups: 153 were exposed to but did not have HIV; 223 youth had HIV but never AIDS; and 75 with HIV who had an AIDS-illness at some point in their lives. We compared their information with their scores on the problem-solving test and on the questions about daily living skills. Our comparisons took into account differences in age, gender, ethnicity, language, income, education and primary caregiver.

Results: The average age of the youth in this study was 11yrs, 6mths; 71% were African-American; 28% Hispanic; 57% lived with their biological parent; 87% of the youth with AIDS got that diagnosis before they reached age 5. The groups did not differ from one another on most of the areas tested, including overall thinking skills, language, memory, visual-perceptual skills, and activities of daily living. The area that did show differences was a test of how quickly youth can work with visual information. The youth who had an AIDS diagnosis completed tasks much more slowly than youth in the other two groups. Lastly, even though the youth with AIDS did about as well as the others in thinking skills, more youth in this group (20%) had scores in the very delayed range compared to the other two groups. The number of youth in that range in the HIV+/no-AIDS group was 8%, and in the HIV- group, 13%.

Conclusions: We looked at the learning of youth who have lived with HIV for a long time. They did as well on problem solving and other learning tasks as youth who were exposed to HIV but not infected. They also did as well in activities of daily living. However, youth who had an AIDS diagnosis early in life may be more likely to have very specific and severe problems as they grow older. Anti-HIV medications may keep a child with HIV from getting AIDS and this could be very important for their well-being later on in life. Also youth who had an AIDS illness should be followed closely in school to make sure they are getting the right help.

Support: This study was supported by NICHD with co-funding from NIDA, NIAID, NIMH, NINDS, NIDCD, NHLBI, and NIAAA.

Note: Participant summaries are available on the PHACS website at: <https://phacs.nichdclinicalstudies.org>


5 TIPS FOR PARENTING PRE/TEENS

Parenting is a tough job. Parenting a teen or pre-teen is even harder because our youth are going through so many changes and challenges during this period. Remember, this is their time to learn independence, and they WILL make mistakes along the way. This means it can be a trying time for us and them. Here are a few tips to keep in mind...

1. **Take time to ask about your teen's interests, classes, and friends.** When we ask them about their friends and activities it lets them know we care about what they're doing, and it also lets us know who they're hanging out with, and/or if there are problems that may need more attention. The more you talk with your teen about everyday stuff, the more likely they will come to you if they need your help.
2. **Pay attention to the small stuff that your youth says is bothering them.** They may not seem like big problems to us, but things like friendships and fitting in are big deals in your youth's life. Sometimes the stress caused by problems that may seem small to us can lead to depression or risky behaviors like drinking in your teen. You don't always have to solve the problem. Sometimes just listening is enough.
3. **Pick your battles.** Teens can really try our patience, but if we're correcting them for a list of things, they will tune us out. Pick the most important things to you, like safety or respect or grades, and focus on that. Let the little stuff go. When it is time to pick the battle, try not to "yell." Yelling usually just leads to both of you yelling, then very little gets done.
4. **Watch for changes in your teen's behavior.** Watch for big or lasting changes in mood, grades, eating, sleeping, activities, or friends may be warning signs. Changes at this age are pretty normal but if you sense that there is something really not right, spend some time asking your teen how things are going. Teens like privacy at this age but it is important for them to know you are paying attention.
5. **Remind your teen you love them.** Teens may act like they don't need to hear that, but sometimes that's when they need to hear it the most. Some families don't share feelings openly in that way but every teen needs to know (and be reminded) they're loved. So, if saying it isn't comfortable, text them or leave them a note in their backpack.

Submitted by Renee Smith, PhD

CAB MEMBER POEM—HOPE



*WHEN I THINK OF MY CAB
IT FILLS ME WITH HOPE.
I GET PEACE OF MIND
AND THE STRENGTH TO COPE.*

*LOCAL AND NETWORK MEETINGS
HELPS TO OPEN OUR EYES.
WE ALL GET TOGETHER
AND OUR STORIES WE SHARE.*

*I SHARE WITH ALL OF YOU,
MY EXTENDED FAMILY AND FRIENDS,
ABOUT THE HOPE THAT YOU GIVE ME
THAT THE SEARCH FOR A CURE
WILL COME TO AN END!*

PHACS 18+

An exciting new study is in the works for PHACS! We know that some of our adolescents in AMP are becoming busy young adults (YAs). And sometimes, it can be hard for them to get to clinic for a study visit. That's why our new project, "PHACS 18+", will give YAs the option to do many of their study surveys on the internet instead of in the clinic.

We want this new study to be something that is useful for our YAs. We want to create a new website that is fun, youth-friendly, and informative. And we want it to be something that YAs will actually use. So, we are going to work *with* PHACS YAs to create a website just for them. The website will link them to their study surveys. We don't know yet what it will look like, but it will have lots of information – about PHACS, HIV/AIDS, transitioning to adulthood, and other topics that youth tell us they want to know more about.

So how are we doing this? Our main goal is to listen to as many voices as possible. This will help us understand how to do this study in a way that makes sense for our YAs. It means listening to feedback from CAB members and study coordinators. And it also means meeting directly with some PHACS YAs at the clinical sites to hear more of their ideas. PHACS YAs are also responding to a technology survey right now. Their responses are helping us figure out the best way to do the study and website to meet their needs. So far, the technology survey has told us a lot! It shows that YAs have internet access, use the internet regularly, and like the idea of being able to do surveys through a website.

We also want to learn from others who have done similar studies with youth. The PHACS team held a kick-off meeting in September in Boston to do just that. We learned from experts who do research on sensitive topics on the internet. This is helping us make sure that we are thinking about how to keep our YAs safe while we collect information from them online.

PHACS 18+ will study many of the same things as AMP and SMARTT. But there are a few changes. For instance, new topics that affect YAs will also be added, such as reproductive health and employment.

YAs who are 18 years or older will have the option to join PHACS 18+ starting sometime in 2013. We will send more information to the families in PHACS as it becomes available.

HEALTH EDUCATION & COMMUNICATION COMMITTEE

Have you heard about the Health Education and Communication Committee (HECC)? It's a new PHACS working group that will work to find creative ways to communicate with PHACS youth, the CAB, and the general public. The members are people from many different parts of PHACS. They include CAB members, youth participants, study coordinators, research scientists, and other staff. Everyone's perspective is very important, and it's not too late to join!

The HECC met for the first time in early December. Everyone shared wonderful ideas for health education! We talked about how to use technology to reach our participants. We thought about how to retain young adults in PHACS. We discussed creating materials for the CAB. And we talked about how to hear from our participants to about what kind of information they want from PHACS. Our projects are going to be very exciting and fun to work on! I encourage you to get involved if you share a passion for health education and creative communication. For more info and/or join the group by emailing Claire Berman at cberman@sdac.harvard.edu.

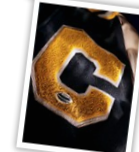
What you need to know:

HECC meeting time: First Thursday of every month at 1 pm EST

Who can join: Anyone involved with PHACS interested in health education

Chair: Claire Berman

Vice Chair: Megan Lukschander



PUBLICATIONS IN THE NEWS!



Since the last PHACS CAB Newsletter in June 2012, PHACS has had six manuscripts accepted to scientific journals and five abstracts will be presented at scientific conferences.

Publications

“Sexual risk behavior among youth with perinatal HIV infection in the US: Predictors and implications for intervention development.” This manuscript is in the *Clinical Infectious Diseases* Journal. Kathy Tassiopoulos, DSc, is a Research Scientist in the Epidemiology department at the Harvard School of Public Health and the Chair of the Adolescent Behaviors Working Group.

“Combination antiretroviral use and preterm birth.” This manuscript is in the *Journal of Infectious Diseases*. Heather Watts, MD, lead author, is a Medical Officer for PHACS from the Maternal and Pediatric Infectious Disease Branch at the Eunice Kennedy Shriver National Institute of Child Health and Human Development and a member of the Executive Committee and Scientific Leadership Group.

“Bone Mineral Density in Children and Adolescents with Perinatal HIV Infection.” This manuscript is in the *AIDS* Journal. Linda DiMeglio, MD, MPH, lead author, is an Associate Professor in the Section of Pediatric Endocrinology and Diabetology at the Indiana University School of Medicine and a member of the Scientific Leadership Group.

“Cardiac status of HIV-infected children treated with long-term combination antiretroviral therapy: results from the Adolescent Master Protocol of the NIH multicentre Pediatric HIV/AIDS Cohort Study.” This manuscript is in *JAMA Pediatrics*. Steven Lipshultz, MD, lead author, is a Professor and Chair in the Department of Pediatrics at the Leonard M. Miller School of Medicine and a member of the Scientific Leadership Group.

“Tenofovir treatment duration predicts proteinuria in a multi-ethnic United States cohort of children and adolescents with perinatal HIV-1 infection.” This manuscript is in the *Pediatric Infectious Disease Journal*. Murlu Purswani, MBChB, lead author, is a PHACS Principal Investigator in the Pediatric Infectious Disease department at the Bronx-Lebanon Hospital Center and a member of the Clinical Investigator Group.

“Cardiac biomarkers in HIV-exposed uninfected children: The Pediatric HIV/AIDS Cohort Study (PHACS) Surveillance Monitoring for Antiretroviral Therapy Toxicities (SMARTT) Protocol.” This manuscript is in the *AIDS* Journal. Jay Wilkinson, MD, MPH, is an Investigator in the Pediatrics department at the University of Miami and a member of the Cardiopulmonary Working Group.

Abstracts

This abstract will be presented at the 3rd International Workshop on HIV & Women in Toronto, Canada on January 14, 2013:

“Prevalence and Persistence of Psychiatric and Substance Abuse Disorders Among Mothers Living with HIV.”

These four abstracts will be presented at the Conference on Retroviruses and Opportunistic Infections (CROI 2013) in Atlanta, Georgia, on March 3-6, 2013:

“Pubertal Onset in HIV-infected Children in the Era of Combination Antiretroviral Treatment.”

“Severe immunodeficiency in children starting ART in low-, middle- and high-income countries.”

“Characteristics and Management of Highly Active Antiretroviral Treatment Failure among Perinatally HIV-Infected Children and Adolescents in the US.”

“Safety of In Utero and Neonatal ARV Exposure: Effects on Cognitive and Academic Outcomes in HIV-exposed, Uninfected Children Age 5-13 Years.”

CAB MEMBERS CELEBRATE THE HOLIDAYS

Christmas Celebrations in My Beautiful Country—Saint Lucia!

Submitted by Delia



"One of the Christmas time traditions is "bursting the bamboo." From late November, one can hear the sounds of bamboo bursting during the night. Men make cannons out of hollowed-out bamboo."



"We play Christmas music on the steel drums!"

"We have the Festival of Lights. It begins on December 13. It features a lantern-making competition and the decoration of towns and villages with lights. The celebration honors the patron saint of light, St. Lucy."



"As part of the Festival of Lights, we have a switching on of Christmas lights and a lantern-making competition."



You and Your Family are Invited To the WINTER HOLIDAY PARTY

Full of Fun and Surprises!

Texas Children's Hospital (TCH) Departments of Immunology, Allergy and Rheumatology and Retrovirology and Global Health held the 2012 Holiday Celebration for children and adolescents with HIV and HIV exposure on Friday, December 7, 2012 6:30 - 8:30 pm at the TCH Meyer Building. This special annual event started over 20 years ago as a way to provide support for families and offer an opportunity for them to network with other families living with HIV. The children and their families are also encouraged to invite their family members and friends.

During the event, the staff and volunteers at the party are fully aware that strict confidentiality will be upheld during and after the event. It is wonderful to see high school students, active sorority members and hospital and community staff and their family members provide support, good tidings and joy to all the beautiful children, adolescents and their families.

This year we had JJ Downz-DJ, Santa, Ms. Santa, and many volunteers to bring cheer to the children. They facilitated a bingo game, art and crafts table, face painting, polishing finger nails, fishing, ring toss and of course, basketball. Fun was had by all and we are thankful that once again everyone enjoyed the celebration. The children went home with a stocking full of candy and stickers, their picture with Santa and plenty of trinkets they won playing games during the fun filled evening.



**Special Guest
Santa Claus**

Special Treats
DJ JJDOWNZ
Holiday Arts and Crafts
Holiday Games and Prizes
Pictures with Santa
Holiday Cookies and
Punch
Sandwiches and Chips

CAB GLOSSARY

Baseline Data: Information gathered about the participant before study treatment begins. To study the effect of a treatment, baseline information is compared with information gathered later in the trial.

Efficacy: Usefulness in treating or preventing a medical problem.

Highly Active Antiretroviral Therapy (HAART): Treatment for HIV infection using a combination of ARVs from at least two different classes .

Incidence: HIV incidence is the rate at which new cases of HIV occur in a population during a specified period of time. For example, the incidence of HIV in country X was 500/100,000 per year.

Liaison: Person serving as a link or connection between individuals or groups.

Mother-to-child transmission (MTCT): Transmission of HIV infection from mother to infant during pregnancy, labor and delivery, or breastfeeding. Also called vertical transmission.

Toxicity: Ability to poison or otherwise harm the body.

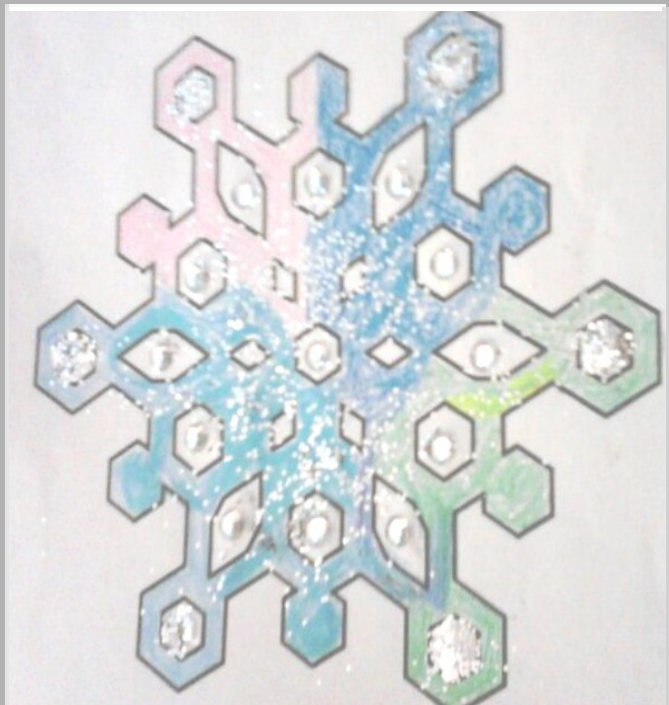
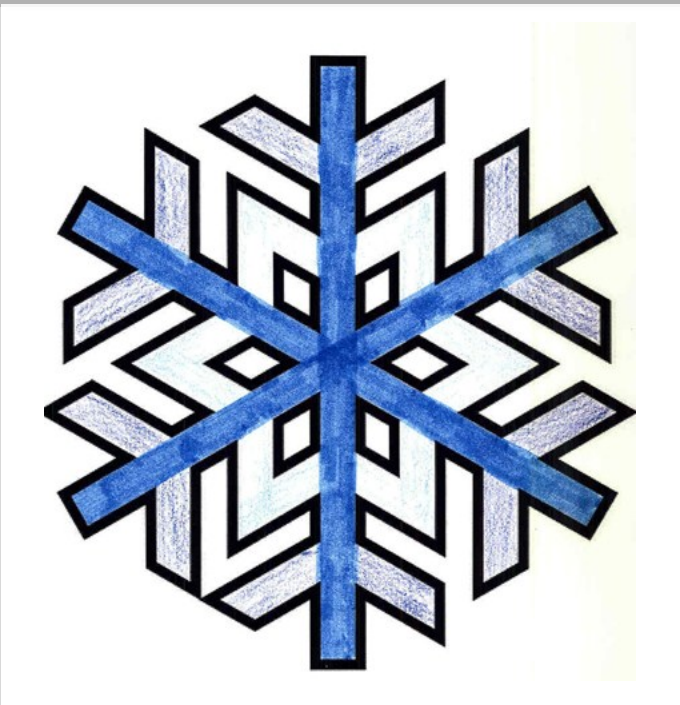
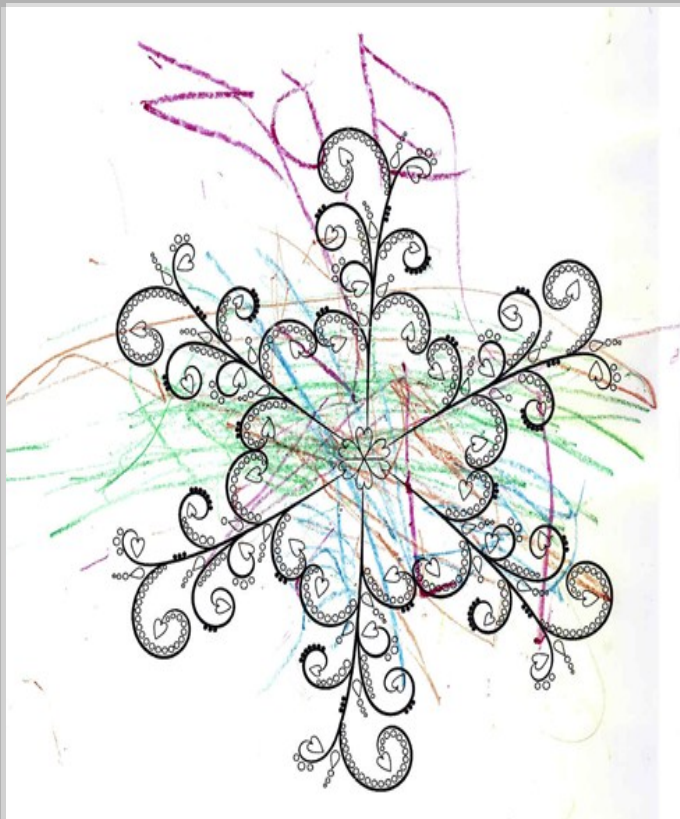


QUIZ YOURSELF!

Directions: Circle the correct answer. Answer Key on page 19.

- HIV infects the cells of what body system?
 - Circulatory
 - Digestive
 - Immune
 - Skeletal
- According to 2011 figures, approximately how many children in the world are living with HIV?
 - 24 million
 - 34 million
 - 44 million
 - 54 million
- Approximately how many people were newly infected with HIV in 2011?
 - 2.5 million
 - 3.2 million
 - 3.5 million
 - 4.5 million
- What helps prevent HIV from multiplying in the body?
 - Condoms
 - Flax Seed
 - Vitamin C
 - Combination ARV therapy
- How is HIV transmitted from mother to child?
 - Pregnancy
 - Child Birth
 - Breastfeeding
 - All of the above
- Approximately how many people had access to ARV therapy in low- and middle-income countries at the end of 2011?
 - 2 million
 - 5 million
 - 8 million
 - 10 million
- As of 2011, what percentage of adults aged 15-49 are living with HIV?
 - 0.8%
 - 3.5%
 - 6.2%
 - 10%
- More than 90% of children who acquired HIV in 2011 live in _____.
 - Sub-Saharan Africa
 - United States of America
 - Central Asia

CAB Kids



CAB COOKS!

Caribbean Christmas Cake

Submitted by Delia

Soak fruits (dried fruits in the packet, raisins, peach, whatever you like), up to one month in a glass closed jar with sweet wine, fruit wine, or Sangria—whichever you prefer, but it must be red wine.

Prep Time: 30 minutes

Cook Time: 1 hour, 30 minutes

Total Time: 2 hours

1 (10-inch) round cake pan

Ingredients:

8 ounces unsalted butter
1 cup sugar
6 eggs
2 teaspoons vanilla extract or vanilla essence
4 cups wine-soaked fruits
1/2 teaspoons ground cinnamon
2 teaspoons baking powder
2 cups all-purpose flour

Preparation:

1. Preheat oven to 350 degrees F.
2. Grease cake pan - rub butter all around the insides of the pan, sprinkle with flour and swirl pan to coat with flour.
3. Cream butter and sugar.
4. Sift together flour, baking powder and cinnamon into a large bowl and set aside.
5. Whisk eggs in a large bowl.
6. Add extract or essence to eggs and continue to whisk until about a minute.
7. Pour whisked eggs into bowl with creamed butter and sugar mixture and stir gently using a rubber spatula. Keep stirring until the mixture will look curdled.
8. Add the wine-soaked fruits to the egg-butter-sugar mixture and stir.
9. Add the flour-baking powder-cinnamon mixture gradually to the wet ingredients and mix gently.
10. Pour batter into prepared pan.
11. Bake for 90 minutes.
12. Remove pan from oven and let cool on wire rack in pan for 10 minutes. At the end of the 10 minutes, carefully, gently and quickly invert the pan, removing the cake. Let the cake continue to cool on the wire rack until completely cool.
13. Slice and serve at room temperature.



CAB COOKS! (CONTINUED)

Holiday Sweet Bread

Submitted by Angel

Ingredients:

3 cups of puree (can be sweet potatoes, pumpkin or carrots)
4 cups of sugar
3 cups of self-rising flour
½ cup of sweet condensed milk
1 cup of oil
1 teaspoon baking powder
2 teaspoons vanilla
6 large eggs
Cinnamon (to taste)
Nutmeg (to taste)
Pineapple (optional)
Raisin (optional)

Preparation:

1. Pre-heat oven 350°F.
2. Grease a flute pan.
3. Add sugar to puree; and beat well, adding 1 egg at a time.
4. Mix in vanilla and spices.
5. Alternate flour with milk and oil; fold in desired options (if any).
6. Bake for 30 minutes.



QUIZ ANSWERS

1. C—Immune
2. B—34 million
3. A—2.5 million
4. D—Combination ARV therapy

5. D—All of the above
6. C—8 million
7. A—0.8%
8. A—Sub-Saharan Africa

Quiz questions and answers provided by:

UNAIDS Report on the Global AIDS Epidemic 2012:

http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/gr2012/20121120_UNAIDS_Global_Report_2012_en.pdf

World Health Organization 10 Facts on HIV/AIDS:

<http://www.who.int/features/factfiles/hiv/en/index.html#>

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