

Site CAB Updates

What does your CAB usually talk about during site CAB meetings? What activities do you participate in during site CAB meetings?

- Normally, the PI, Dr. Marilyn Crain will give an overview of a specific topic or review participant summaries. She also addresses any questions we might have for her;
- Updates in the community/ resources/ study;
- Updates from the PHACS CAB conference call;
- Issues at hand; and
- Discussions about topics the CAB had requested at an earlier meeting.

- Right now, we are working on our second newsletter, so we're currently talking about what to include in the newsletter;
- Our clinic recently moved, so we've talked a lot about the differences in the clinic and how to get the things we liked back to the best of our abilities;
- We also talk a lot about optimizing experiences for the patients in the clinic;
- We are working with the health care providers to educate them about stigma;
- We also give feedback on new protocols; and
- Finally, we always have an open forum to discuss other issues.

"The CAB is the largest empowerment system in my life."

During the meetings we talk about different studies. If results are available, we discuss those. We also discuss how to keep participants in the study.

Our CAB usually talks about different needs that our members may need. We invite speakers to present on medical care, medication, nutrition and other things along that line. We have different bonding activities that we do. We also do wellness activities such as crafts and wellness activities.

The CAB determines the topics that they would like to discuss for the year. There are quarterly research updates, nutrition, medical treatments/prevention advances, HIV Criminalization and multiple community events.

We have an agenda that we follow during our meetings. We discuss the old minutes and from the last meeting and HIV activities that we are going to be involved in. We also discuss research issues, and questions that make be of concern to our CAB.

CAB members discuss the following:
-Protocol at hand;

- Medication;
- Disclosure;
- Stigma;
- Youth and adherence;
- CURE;
- Mother to child transmission ;and
- Discussion from Annual CAB meeting that give CAB member input or feedback.

At this time we are working diligently to get consumers involved. Upcoming topics of discussion consist of the following:

- Stigma;
- Disclosure; and
- Medication adherence.

At this time Philadelphia site is having some challenges with involvement of consumers. We are strategizing a plan of action moving forward.

Our CAB consists of IMPACCT, PHACS & RYAN WHITE. Each representative (IMPAACT, PHACS and Ryan White) have a report for the conference calls, research and anything that is happening in the community.

I participate in several community meetings and sometimes it's hard to remember which meetings covered what. I represent the community at Christie's Place, the San Diego HIV Health Services Planning Council and at University of California San Diego (UCSD) Mother-Child-Adolescent Program (MCAP) Family Advisory Board (FAB). At UCSD, I have attended meetings that covered keeping children safe online, how to read food labels and buy healthier products, effects of substance use by adolescents, understanding the Affordable Care Act and using storytelling to disclose health status to children. I participate in almost all the activities during the FAB meetings.

Since I've been in the University of Puerto Rico's CAB (2010), we have talked about the IMPAACT network and the PHACS network conference calls. We go through the conversations and review the minutes from the conference calls and then we debate, add up, and react to the information. We also discuss news and information from different magazines like POZ, Positively Aware, and others. Besides magazines, we retrieve and bring more things to discuss from local and international newspapers, clinical investigations, articles from health magazines, and anything related to HIV/AIDS or health is-sues that might impact our CAB's community.

During our CAB meetings, we al-ways provide snacks. Sometimes, this functions as an icebreaker for members to start the meeting. If there are new members, we introduce each member, CAB liaisons, clinic personnel, and the Principal Investigator. We explain the purpose of the CAB, confidentiality, and importance of the CAB. Assign-ing different articles, news, and topics to discuss to different members can be challenging. We do this because we try to encourage every member to participate during the meetings. This is a way to empower them and make them feel that they are working for the community. Some meetings take place through activities outside the clinic, like at health conferences,

conservatories, or community encounters. We also use media relevant to the topics discussed in our CAB.

Our CAB usually talk about a very wide range of issues that deal with not only issues involving our site 19 but any matters that has to do with PHACS protocols and even if CAB members have personal items that they may need to address. As a CAB members I try to participate in everything on our agenda, giving my opinions where it is needed, and listening to guest speakers and sharing what I have learn.

What kinds of activities (outside of site CAB meetings) does your site CAB participate in? Tell us why these activities are important to you and your site CAB.

We can attend the joint cab meeting with the UAB 1917 Clinic once a year. We don't normally do activities outside of the hospital.

“Community involvement is very important because this illness has affected us all in some way or another.”

We participate in speaking engagements at schools and at public events, if we feel comfortable. We also participate in peer education. In order to be a peer educator, we have to attend classes which our site pays for.

Outside meetings, members do volunteer work like helping in the National HIV Testing Day and World AIDS Day. This helps us promote studies in community-based agencies. These activities are important because members gain more experience. They feel more committed to the CAB.

We have quarterly community (fun) activities. This year we have had a picnic, game night and bowling. These activities allow for our CAB to get to know each other, let loose and spend time just being around other participants.

We participate in many activities outside of CAB meetings. Below are some examples:

The Family Place of the Francois-Xavier Bagnoud Center at University of Medicine & Dentistry of NJ in conjunction with the CAB the FXB CAB and network of community agencies hosted a Teen Summit. Spring of 2003-2007. The CAB went to see at Kean University, Union NJ September 24, 2003 the AIDS Memorial Quilt. Kean University hosted the Memorial Quilt

Yolanda Adams Health & Wellness Tour

Believe in Healthy BP (Blood Pressure

Black Issues Convention

Breast Cancer Awareness Luncheon and Lecture.

40 Years and Counting. The International Youth Organization
The Grand opening and ribbon cutting ceremony of IYO's Youth & Family Resource Development Center

NJWAN Confronting the Crisis 2011 Women & HIV Conference

HIV & End of Life Broadway House Care

CAB/support group meeting

12 members attended Newark Public Library exhibit " Dancing "

We have participated in Women's History. We honored Councilperson Mildred Crump by giving her a nursing sash from the School of Nursing. Our theme was "owning our own healthcare."

We participate in World's AIDS Day December 1st every year

Seminar "My Crying in the Dark: Breaking the Vicious Cycle of Domestic Violence". Seminar "My Crying in the Dark: Breaking the Vicious Cycle of Domestic Violence". Support group room. "My Cry in the Dark: Breaking the Vicious Cycles of Domestic Violence".

AIDS Walk in New Jersey, A Day of Fun and Learning About Women's Wellness

Eliminating Mental and Physical Stress.

2nd Annual Lecture and Lunch LGBT Health Awareness Week Lecture, HIV testing at Essex County Community College, Newark NJ

The FXB's Community Advisory Board Big Hat Celebration, all our ladies and staff wore their Big HATS. We have participated in a food drive during the month of November/ December 2013

We are inviting everyone to 2 webinars for National Women and girls HIV/AIDS Awareness Day. At the end of the 2nd webinar, we will launch red balloons in honor and memory of those girls and women who are in living with HIV and those who have lost the battle to the virus.

NJ Statewide Family Centered HIV Care Network Family Day

Robert Wood Johnson Medical School New Brunswick

A Day of Reflection A Caregiver Day to Retreat and Relax

UMDNJ's Young Father Job Fair Medical Science Building

Free Unified Pre-Ramadan Health Fair

We made special get well cards for our former advocate and mentor Vera Holmes who died of colon cancer May 2012. The CAB expressed their feelings for Vera and discussed their own mortality.

The CAB was able to donate baby clothes and toiletries to a local women's shelter May 2012.

We had a webinar discussing update on the state of HIV/AIDS in the US.

Workshop: Write The Vision- Vision Casting! Connecting and committing ideas, inspiration, dreams, goals to writing and creating vision boards. Participants are encouraged to talk, listen, write, create, and accountability.

Healthy Living, Healthy Eating, Making Strides Against breast Cancer every year, we participate in a variety of health fairs throughout the city, county.

CAB members participated in a CAB/POETT Education forum for youth. Every two years our moms have a chance to experience CAMP KEY a three day retreat. CAMP key provides moms a chance to experience some of things that their children get to experience when they go to camp each year. It also gives those moms that have never been away from their children, a chance to be themselves, relax, share who they are without being judged. It helps as a support system for all moms that participate in this event. CAB members are also recipients of Back to School give away, Thanksgiving basket, and Christmas gifts.

At this time we do not have anything in place, however, we are looking forward to future cab meetings with possible. We'd like to have a beauty day. The consumers of the would meet at a nail salon to get manicure and pedicure pampering. In addition we would like to have an outing which could be dinner and theater or show of some type.

Right now, we are working on recruiting more members, and when we are done with recruitment, we will be working on activities outside the CAB.

Some outside activities we have participated in together are AIDS Walk, A Women's Voice Conference, the UCSD Mother-Child-Adolescent Program (MCAP) Holiday Party, and the UCSD MCAP Summer Picnic. It's important because it's a way for me to meet the other women and families.

We invite the members to different health conferences, conservatories, community encounters, and meetings. We have also participated in sport benefits from other institutions, and activities at other HIV/AIDS clinics. These activities are important for me and our site CAB because it diversifies the methods of providing information, running CAB meetings, empowering members, and facilitating community involvement.

Outside activities are an important aspect to keep the CAB members motivated to keep coming to our CAB. It also encourages them to continue providing information and feedback. It helps them continue teaching others about HIV/AIDS and its prevention, and motivating others to come to our CAB meetings.

Our site try's to provide many different activities for not only our CAB members and their families but to help others to know what they could do to show our families how important they are and that they care. We have fall and holiday parties which is paid for by bake sales that are sold to the hospital staff and other donations.

What are the best ways your site CAB has worked to keep CAB members involved in your site CAB?

The CAB has developed a partnership with the research team and the members feel comfortable, welcome and included. They also feel valued and respected. The CAB has an agenda and we follow that. We have meetings that allow the research team to keep the CAB members informed about all PHACS activities. We talk about enrollment, retention of participants or changes to a protocol. The CAB has rules about confidentiality and members feel that all personal information is kept private. The research team recognizes the CAB members' special needs and do their best to meet them. The team

includes a social worker. The social workers is there to help support CAB members for their HIV and non HIV related issues.

We interview potential CAB members before inviting them to join so that we know they will be a good fit. We encourage participation because of the nature of our discussions. We are not a support group, but we listen to each other's issues in the open forum.

We provide snacks and refreshments. We think this is a nice incentive.

We spend a great deal of time creating an atmosphere where people feel safe and supported. We also do email and phone call reminders two weeks ahead of the meetings and again a few day prior to the CAB meeting. The staff is also involved in inviting new members to participate in the CAB meeting. We also provide food and childcare to all participants and transportation assistance when necessary.

We send follow-up letters to all members to keep them abreast of the events that we are participating in. It motivates those who may not come on a regular basis to still stay involved. We have toll free conference call number for those who want to stay involved but may find it hard to attend all the meetings due to their schedules.

Our CAB works by having a chance to be ourselves, and to discuss things that they would not discuss outside of CAB. It helps to know we have a support system. It also helps by being able to give feedback to the CAB, and to know that participating will help others in our situation.

At this time this does not apply. However, some of the ideas that are in the making can be considered to be a small incentive for attendance.

With this question, we will be needing CAB members' input or help at the CAB Retreat.

Well, having topics during the meetings that are important to us like the nutrition workshops or how to talk to children about having a diagnosis.

During the time I've been in our CAB site, I've seen that the empowerment and the information brought from the conference calls are very important aspects to keep CAB members at our site. Another thing that keeps CAB members coming to our meeting is the variety of information provided. Since we bring different health news, articles and information important to our CAB members in addition to HIV/AIDS information, we create a more welcoming meeting.

Even though we are not a support group, indirectly, we are one. Sometimes we discuss matters from our CAB members that can be addressed and helped through the help of other CAB members and other contacts. Finally, the invitations to different activities outside our meeting from different entities also keeps the members motivated to come back for more "benefits" like these.

I believe that some of the best ways that our site has kept our CAB members involved is we make them feel like they are doing something bigger than them and make them feel loved. Our family is

offered lunch transpiration, we sometimes have raffles, but most of all we tried to be there for them outside the CAB meetings.

Do site staff members come to your site CAB meetings? If so, how does this help your CAB meetings?

Yes. Having the representation of a variety of staff present allows us to have varying issues addressed.

Yes, our Study Coordinator comes to all our meetings. She is the facilitator and is very helpful in running our meetings. She bring a lot of opportunities and speaking engagements to our attention. She gives us feedback and we give her feedback on the studies and the goings on of the clinic. We don't have leadership. Our bylaws are different. We chose to just be five strong women that respect each other.

The Principal Investigator and one of the Study Coordinators attend our meetings regularly. It really helps the CAB feel that their opinions are valued.

Yes! We usually have a research nurse, our client retention specialist, and a social worker come to meetings. We also invite our Principal Investigator once a year for updates. If so, how does this help your CAB meetings? It helps keep the members informed about the clinic. It helps the members feel comfortable and personable with the clinic staff.

The staff members that attend our meetings are the research nurse, and the doctors of the FXB Center. Our nutritionist comes in and does seminars for the group as stated before. This lets us know they are interested in work in the community. This also clears up any questions that any CAB members may have regarding the medical treatment.

Yes! Site staff are always joining in on CAB meetings. Their participation means a lot. It helps our CAB members with their comfort zone. If there are questions, they can be answered by the staff. Just being there to show their support of our CAB is awesome.

This does not apply at this time, however, it is possible with moving forward this can be an invitation the CAB may want to consider.

Yes, site staff members do come to our site CAB meetings. The researchers, doctors and staff, come to our CAB meetings. They are there for updates on our CAB, to announce new research, and to give updates on existing research.

Yes, like Patty a case manager gave a class about the affordable care act and insurance, and Dr. Spector came to talk to us about research and Veronica talks about the community and research.

We have staff members from our site at our meetings. Our CAB Liaison, Study Coordinator, and Principal Investigator come to our meetings. It is important to have them at our CAB meetings

because they help us with clinical terms, explain things that we might not completely understand, and give overviews of what's happening in the clinic.

Yes our great site staff members are very active in all our meetings, this is so helpful because when there are times when we may not understand some of the terms use in protocol the help by breaking them down so the CAB members to have better understanding.

How does your site CAB learn about PHACS including study findings?

Participant summaries, press releases, etc. are presented at the CAB meetings. Because our CAB is small, we have been able to participate in the CAB calls and have learned of different events, findings, etc. occurring throughout the country. This year we have tailored our meetings around the PHACS CAB conference call schedule.

Sometimes, our Study Coordinator brings participant summaries to CAB meetings. We incorporate some of them in our newsletter. We also give feedback on protocols.

We discuss PHACS and other ongoing protocols during every meeting.

We do quarterly updates on study information. We share the newsletter from PHACS, talk about new studies, and updates.

We are always kept abreast with PHACS study findings through our research nurse. Linda Bettica. She comes to our meetings regularly to discuss protocols, how many participants are in certain studies and what we need to be involved in.

IRB approved Participant Summaries are distributed, as well as the site staff presentations on the protocols and findings (ie. CAB representatives, Study Coordinators, Principal Investigator, and Liaison).

This does not apply at this time, however, it is in the making.

Our site CAB learns about PHACS through the PHACS CAB representative. She is on PHACS CAB conference calls, CAB Retreats and reports back to our site.

Well, the researchers come to our FAB and give us a class with the computer presentation.

We talk about protocols, participant summaries and press releases. We not only talk about the actual topics from the conference calls, but we also compare them to other protocols and studies. We also mention other studies currently running in and outside our clinic, within and outside PHACS.

Our CAB learn about impending PHACS and IMPAACT issues from emails and our site PI not only gives us well rounded discussions about protocols press releases new laws but help us give each participant summaries the special view that is needed.

What barriers, if any, has your site CAB faced? What strategies, if any, did you use to overcome these barriers?

Active participation and recruitment continues to be a challenge. Life itself tends to challenge our consumer leadership. Stigmatization is still so strong in the south and many of SMARTT participants are afraid of joining the CAB. Citing their fears of their "business getting out in the community" or "recognizing someone at the meeting" tends to be common.

-Transportation has been difficult for many of our members. Cabs are provided for transportation if there is a transportation issue and that has helped get people to the meetings;

-Childcare has been provided so that members can attend and have their children nearby in the family center being supervised by hospital volunteers; and

-The site provides a meal for each meeting and having that time to eat and talk together is just nice.

-We created conflict resolution guidelines in our bylaws. If CAB members have issues, they bring it to the CAB. If they can't bring it to the CAB, they speak with the Study Coordinator who helps mediate the situation. If they can't speak to the Study Coordinator, they bring the issue to the doctors;

-In the past, we've had problems with people being late. We came up with a rule that if you're late more than 30 minutes, you do not receive the full reimbursement; and

-We also have votes to deal with conflicts and decide other matters.

One of the biggest obstacles is transportation. Meetings are held on Saturdays and during the weekends most members work or study. Another obstacle is childcare.

We have a very consistent group of CAB attendees. The biggest barrier that we have is weather (in the winter). When this happens we try to accommodate or reschedule when necessary.

The barriers we have faced are the lunch/postage use to be covered under a grant within the FXB Center. We have had to rely on CAB members, staff donating snacks, lunch beverages to the CAB which is much appreciated. Transportation can also be a barrier. Many CAB members find they may not have any funds to always attend every event that we may have. We ask those that can always afford to attend to contact the state transportation in a timely manner to ensure arrangements for that day.

The only barrier with our CAB is getting more teens involved in our CAB.

"I can honestly say I am no longer the shy woman that stepped into the door."

The current barriers the St Christopher's Hospital site is having is participation. At this time we are striving to create a group of participants.

We still struggle with membership participation. We call and provide lunch and transportation. We also have our meeting in the clinic lobby to include others while they wait on appointments.

We are not allowed to physically talk to people about recruitment. If we were allowed to we would not have this barrier problem. The Liaison is the one who is allowed to physically talk to people about the CAB.

The transportation that is now solved, also the language was a barrier, some of us are monolingual Spanish speakers and now that has a solution too.

What is your favorite part about being involved with your site CAB?

"The genuine concern and interest in my life by the team is encouraging". It is also a place where I can go and talk about HIV and know that I am safe and that things will remain confidential. I feel informed about the study and its findings and I also feel that my participation in the CAB teaches the team how to communicate with those of us that are infected.

The CAB is the largest empowerment system in my life. It gives me strength to move on. I feel like I have such a powerful voice in everything. I have become an advocate. I realize now that I have to embrace what I have to deal with on my own.

Satisfaction from participating in the meetings comes from seeing how members feel useful. This is shown by their commitment to the unity and the clinical staff. Knowing that each member of the CAB is advocating for consumer rights in clinical research is one of the most important aspects.

My favorite part about being involved with CAB is constantly learning new information, being around people of the same situation and reaching out to new people.

I feel that this has been one of the best parts of my job. I get to advocate, network with the CAB members and other agencies with Newark, statewide, nationally and worldwide. I am very supported by other staff and especially the research staff. When I need to bounce an idea or an issue of somebody, they are there for the CAB and me. I am confident and outspoken.

I love being able to share the information that is given to us with others. I appreciate the support of the CAB members and the research staff. The trust levels play a great part.

At this time, I am new to this commitment. What I am currently enjoying is the opportunity to meet and speak with individuals from different locations. I like hearing different ideas, hurdles and accomplishments.

Making sure that members have a good time.

I enjoy learning new information about HIV, new medications and speaking to the community about the CAB.

I like seeing everyone who attends the meetings and the workers too. We know each other those that participate.

My favorite part of being involved in our CAB is that I feel that I'm working for the entire community; not only for the HIV/AIDS community. Bringing information to our CAB members and others is one of my purposes in life.

My personal favorite part of my CAB is the people because when I look into all the faces that are there I know that I'm not in this fight alone and it's not in vain.

What have you gained by being a part of your site CAB?

-Knowledge about HIV;

-Confidence that I AM doing what I can to make things better for those unborn children that are exposed to HIV; and

-Acceptance of the diagnosis and that I can LIVE and LIVE a normal life.

I wouldn't be in the position I am today. It took me out of depression. It took me to a different level of my life of understanding that I can't change anything, but now I realize what I'm in control of. I'm not in control of HIV, it does what it wants. I have to feel good about me and my CAB has helped me do that.

The CAB has helped me to become more confident in who I am be more open with others around me. It has also taught me a lot of information that I did not know prior to attending.

-Education;

-Support;

-Trust;

-Confidence; and

-Not feeling alone knowing that we have a system that works for us.

As a CAB member and now Chairwoman it is an awesome experience of growth with wanting to help this community of individuals.

I'm not shy when it coming to speak in the meeting. Yes, I do feel more supported by the members. I'm starting to come out of my shell.

I have gained confidence. I am now very outspoken and more informed.

Yes, I do feel supported and more confident. I have lost the fear and I've learned a lot, much more than I did.

By being part of our site CAB, I've gained more knowledge, maturity, confidence, friends, tons of information, life experiences, empathy, more ways to look at life and the world, the importance of education and prevention, and many other things. Since I have more information and education, it gives me the power to educate others and talk more securely about the HIV/AIDS and other topics with confidence. I don't think I feel more supported, yet I feel that I support others.

I have gained a lot from being a CAB member at my site. I can honestly say I am no longer the shy woman that stepped into the door. Because of the great leaders at my site and in PHACS I am more outspoken, confident, and not only have I been supported but I will be support to future CAB members to come.

Why is community involvement in the research process so important?

"Without
community support
there wouldn't be
research"

Community feedback is so important when you start a protocol. We had a doctor who came in with a protocol and we said, "Who would do this? Think about it." Sometimes, doctors and researchers think differently than we do.

The importance of community involvement is immense. The CAB serves as a way to spread the word in the community. They also serve to report on what is done in clinical research having to do with HIV.

It important so we can continue to improve the process and the everyday living of people living with HIV.

Community involvement is very important because this illness has affected us all in some way or another. People must become aware that we have to help each other at all times. Our motto for our group is "Each One Teach One".

Our plans for the coming year we are going to have a book series on "A year for Being Well". We will be attending the La Case De don Pedro presents "Bigger & Better" National Latino AIDS Awareness Day held the Robert Treat Hotel. Also we will walk for some many of our sisters who continue to struggle. The American Cancer Society Making Strides against Breast Cancer which is held October 19, 2014 Military Park Newark, NJ.

It helps researchers with helping our community and it gives them a perspective on what will work in a community.

As time continues to move forward making an attempt to educate others and empower others is rewarding.

Without involvement from the community we will never know what know discoveries they have made.

Without community support there wouldn't be research.

Since my daughter is coming in to help with the study, at the visits I know if something is wrong with her or with me and we can get help quickly. Also for the same reason, I come to the FAB meetings sometimes you might not notice that something is wrong especially with children.

It is essential for the research process since community input will let the researchers know in advance if a study might work or not. It also gives the research process validation and specific data before and after the research.

I believe community involvement in the research process is always so important because if there is no community involvement there can be no research process. Unless we have brave community members we could never truly reach our goal of finding the cure.

What plans does your CAB have for the future? Do you have any goals for the coming year?

We are working on a new stigma health provider education study and our second newsletter.

We want to recruit more members and make more and better volunteer activities. We are also developing strategies for retention in the research studies.

We will determine the schedule and goals for the new year at our November and December meetings. These goals and discussion topics are always determined by the CAB with assistance from staff to secure speakers.

Our goals for 2015 is to continue to increase our membership and involve ourselves in activities and events that are HIV related. We will continue to work with team. We will also continue being in the fore front for the cure.

CAB goal for the next year is to get more teens involved in CAB meetings.

At this time if we could have participants this would be able to assist with moving forward. In addition, nothing beats a failure but a try, and this site is definitely working forward to making it happen. As you know, our site is a work in progress. While we do not have a functioning CAB at the moment, we haven't lost hope and are working to make this a reality in the future, of course with the help of others. We are making a stronger effort of involvement with moving forward.

The plans we have is to get more people involved in the CAB. We want to have more members in CAB and to play a big part in our community. Plan to grow in membership and consistency. Provide as much information to clients as possible.

We are working on recruitment, activities (i.e. we will be working on having cake sales, etc), that way the CAB will have their own money for outside CAB activities. We also want to host movies, picnics etc.

Well the Holiday Party is coming up and this year it will be a bigger party because it will be hosted by two organizations. My goal is to keep coming to the FAB meetings.

Fortunately, the incidence of HIV/AIDS in the pediatric community in Puerto Rico has been reduced to not having new cases for many years. Unfortunately, this reduced our opportunity to keep our site working because of different aspects. We do hope that we can continue to have our CAB meetings and members for many years to come.

Even though there's been a reduction in funding across many studies, we would like to have more meetings, activities, and opportunities for the CAB members to be involved. Since every site has different difficulties and needs, maybe the network can work with sites individually. This would help each site and prevent future situations for all CAB sites.

My goal as CAB member will be as followed one I will try to get more new community members to become active CAB members and also become more vocal not only at my site but all the way to the capital.