

# Site CAB Updates

**What activities has your site CAB participated in during the last year? Tell us why these activities were important to you and your site CAB?**

- CAMP KEY Women's retreat, LYFE leadership for our young adults, and PHACS appreciation dinner. Because of these events we have seen changes in their attendance and participation with being involved in their health care and also sharing with others their own achievements.
- Besides our normal monthly meetings, there have not been CAB additional activities. As a group we try to make a few meetings a year focus on "fun" time together, so we will have a game night, we had meeting at the park, and had someone come in to talk about self-care, wellness.
- We participated in the following:
  - Reviewed proposed research studies and offered feedback to study investigators and coordinators;
  - Planned a patient appreciation conference for research participants and did a short talk about their responsibilities, accomplishments, and goals;
  - Helped plan an HIV-stigma reduction curriculum for healthcare providers;
  - Participated in national research network meetings;
  - Established a framework for the second issue of the MCA Clinic Newsletter; and
  - Contributed to national newsletters (PHACS).

These projects have helped improve MCA clinical care and research, created stronger relationships among MCA consumers, increased MCA clinic visibility and highlighted the need for women- and youth-specific HIV/AIDS services and funding in Los Angeles County and nationally, and fostered empowerment and reduced stigma.

- On October The Medical School of Rutgers University had "A Pretty in Pink Brunch" in Breast Cancer Month. We also walked in the Making Strides Against Breast Cancer Walk
- CAB members attended the IMPAACT CAB retreat and Scientific Meeting in June 2015. Four of the CAB members will also attend the PHACS CAB Retreat and Scientific meeting in October. The CAB members learn and share experiences at the meeting. They also have the opportunity to network with other CAB members. They return to the site and share the information they learned with the local site CAB members. Several CAB members participated in the AIDS Walk 2015 in Houston. Our site is able to show their support for this important community event.

We are able to give all participants an opportunity to learn about children, adolescents and mother with HIV/AIDS. Several CAB leaders are active participants on the HECC CAB Subcommittee/CAB Retreat. Planning Committee Conference Calls. All participants share their knowledge and experience to improve the annual CAB retreat and other PHACS educational projects. The CAB leadership was invited to Dr. Shearer's Recognition Luncheon in September. He was recently awarded high honors for his dedication to clinical and research at Baylor College of Medicine. The CAB members were able to interface with all the research staff and especially Dr. Shearer.

- Christmas party and workshop, school supplies, Tulane Hospital, local case management, STATE TROOPERS, bake sale. Provide services to clients and our community to fight the epidemic against HIV and AIDS.



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- As part of our goal to increase community involvement in research we've organized several Family Advisory Board (FAB) events throughout the year. These activities are important to our site because our goal is to increase community involvement in research. It is our belief that community involvement can improve health, assist families in staying connected to their health care providers, and make both research and our program better. Our site has found that meeting participation can be sustained by hosting social events and training opportunities.
  - October 2014 Lessons Learned from Recent Health Conferences
  - December 2014 Holiday Party (theme: Frozen)
  - January 2015 Better Understanding Healthcare & Research
  - February 2015 Immigration Law Changes & Research Updates
  - March 2015 How can Free Legal Services Help You?
  - April 2015 A Woman's Voice – Women's HIV Conference
  - May 2015 Health Communication & Mobile Treatment Adherence Program
  - June 2015 Mental Health Services
  - July 2015 Family Summer Picnic
  - September 2015 AIDS Walk San Diego
  - October 2015 New Studies & Key Findings

## **What topics did you cover during your CAB meetings this year? Which were the most important to you and why?**

- Comic book, Stigma & Disclosure, White board video, and Photo voice. We have also share research findings and updates.
- Topics for 2015 were Recruitment/Retention, Roles & Goals of the cab. Medication discussion with MD. Community Input, feedback, and need. Nutrition guidance, Stigma and advocacy. Criminalization of HIV. Women prevention programs.
- We covered the following topics:
  - Stigma
  - Disclosure
  - CAB's role within the MCA family
  - Representing the needs of MCA patients
  - Representing MCA at PHACS meetings
  - Reviewing of MCA research protocols

While all of the above topics were important in different ways, the ones that resonated most with me were meeting other patients at the SMARTT event and introducing our CAB as a resource for patients, and working on a stigma reduction project for healthcare workers.

- Protocols P112, P1026, IMPAACT 2002, SMARTT, AMP and AMP UP were reviewed monthly. We also discussed disclosure, privacy, and ethics in research, outreach and advocacy. What are the best ways your site CAB has worked to keep CAB members involved in your site CAB in the past year? The CAB members receive an email, US mail invitation and a phone call to remind them of the upcoming meetings at TCH. A small raffle is done at each meeting. The items are usually a small gift or movie tickets donated by generous staff donors.

We celebrate birthdays and special events. We will have a Fall Festival on October 23, 2015, a Holiday Festival in December, 2015. All the HIV research patients and clinic patients are invited to attend. This year we are planning for 75 children/50 adults. We had a 4th of July Celebration, Start of Summer, Back to School Bash and will also have a Thanksgiving Luncheon/Meeting in November.

- Disclosure, retention, and study appreciation. Why retention? It helps to keep us in care and education, and to maintain rapport beautiful, wonderful relationship with staff.

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- Every meeting included updates on perinatal, pediatric or adolescent HIV research which was usually presented by a registered nurse who is a study coordinator at our site. Some of the topics covered were updates from health conferences, healthcare changes and enrollment information, immigration and healthcare, how legal services may affect wellbeing, using technology to improve health and adherence, mental health services for youth and families, new studies, PrEP and key findings from research studies.

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

- Support is our most popular strategy to keep our CAB committed to being involved, and to remain healthy.
- Communication: flyers and emails. Feeling comfortable at meetings.
- Our CAB is very active and all members have a vested interest in representing the MCA Clinic and patients. What maintains our group cohesiveness is working on projects that are meaningful and challenging. It is also helpful that we receive incentives and reimbursements for our efforts.
- Our site is pleased to have so many direct stakeholders involved at our meetings and the best ways we are able to maintain this involvement is by conducting the meetings in both English and Spanish, providing childcare, a light dinner and assisting with transportation. In addition, we believe meeting participation can be increased by hosting social events and training opportunities. Our site has been successful in encouraging community representatives to contribute at scientific meetings, and they share their experience with the group upon their return. We hope that PHACS will provide opportunities for community involvement in the future in both English and other languages. We were told that PHACS did not budget to make interpretation services available at their Fall meeting this year. Our CAB is active and in order to keep Spanish-speaking CAB members involved it is important that they have equal opportunity to contribute to PHACS.
- Communication, planning, providing transportation, providing meals

## **Tell us about your site CAB Leadership. Do you have leaders in your site CAB? How has Leadership been important to you and your CAB?**

- Yes! I consider all CAB members leaders, because they are all willing to do their part when it comes to education, sharing info with others and they all are always willing to show Support.
- We have our staff patient advocate and retention to care specialist lead the cab. We have leaders within our local cab that attends network calls.
- Our CAB doesn't have a hierarchy. It is an egalitarian group and all members share equal responsibilities.
- The CAB chair at our site is Leslie Raneri. She is also the Vice Chair of the ICAB for IMPAACT. Ki brae Sanders is an active CAB member and is also the Chair of the USA PHACS CAB. The Vice Chair of the Domestic PHACS CAB is also one of TCH/BCM CAB members. We have a new PHACS representative from our site and she will be attending her first PHACS CAB retreat in Arlington, Virginia. We also have 3-4 teens/young adults who attend the local CAB meetings. One of the teens will also attend the PHACS conference in October of 2015. They will all be traveling to the conference with Ms. Sanders and Ms. Williams. The CAB liaison and the entire PHACS staff are available and active in mentoring and supporting all the local CAB members. The CAB leaders also address issues requiring advocacy and education. They lend their voice to important issues related to pediatric and maternal HIV and research. They are addressing the issues in our community that are unjust, unfair or discriminatory in any way toward people with HIV.

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- There are several community leaders who are part of our CAB, their experiences and accomplishments range from public speaking at conferences and schools, serving on the local HIV planning council, multiple hours of HIV trainings, and volunteers that generously share their time at programs that serve families living with HIV. Staff assistance is provided by multiple individuals at our meetings and our PI's support of the CAB events has been essential for our site's success. CAB members have submitted ideas during meetings and introduced guest speakers to share their expertise with the group. An important component of the meetings is the input of the community.
- CAB leadership: Joint effort between staff and participants, work together, all decisions are a shared effort



## **What barriers, if any, has did your site CAB face this year? What strategies, if any, did you use to overcome these barriers?**

- Getting more youth involved. The only barrier that I see we face is when a CAB member has personal issues outside of their health that pushes their priority and focus to what's happen right at that moment and it will make them say everything else can wait.
- Having difficulty recruiting new members, we developed a flyer to hand out in clinic. We have lost a couple long time members-
- Some CAB members experienced significant personal hardships and the group provided social support to one another to assist with coping. This support helped members maintain their CAB membership and responsibilities.
- At our site, a lot of our youth CAB members had either started school or working we really didn't do many things this year. Our main problem we seems to continue to have at our site is retention.
- Funding, bake sales, outside assistance (money), limited access to technology, overcame this barrier by teaching others how to use email, fax information.
- Our CAB meeting is held at our site's conference room, due to space and budget limitations, as well as privacy concerns, we are unable to invite guests to attend unless they are part of our program. A strategy that may be helpful is checking in with attendees before the meetings so expectations are clear and no one feels they were turned away.
- The barriers are minimal and are addressed by the CAB Liaison or CAB Leadership. We continue to recruit new members to join CAB. Several parents have agreed to join us but have not attended a meeting. So, the CAB liaison and research nurses continue to reach out to them. It generally take a few months to interest and engage a new member to attend the monthly meetings.

Several of our members are now working and are unable to be at the meetings but they do call into the meetings and are conferenced in every month. This has been a successful approach to the meeting the needs of CAB members.

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**How did you site CAB review PHACS materials or information? For example, did you review minutes or notes from PHACS CAB calls? Did you look at any of the HECC projects (comic books, Photo voice, whiteboard videos, etc.) together? Did you review any PHACS studies or participant summaries? If not, what would you like to learn from other CABs about how they review PHACS materials or information?**

- CAB members participated by viewing HECC comic book and white board video by sharing their thoughts and ideas. Photo voice was a great way for CAB members to express their feeling and to also show support of one another when it comes to stigma, disclosure and everyday challenges that we may face.
- We have a study coordinator come to meetings and provide study updates and education. They present new studies and new information. The PHACS cab representative share the monthly call information with the group.
- The CAB reviewed the HIV Disclosure Comics the Reclaiming Identity PhotoVoice projects.
- PHACS is always on our agenda. The minutes and whatever HECC has going on we always send our input.
- At our site every community meeting includes updates on perinatal, pediatric or adolescent HIV research which is usually presented by the registered nurse who is a study coordinator at our site. Our site reviewed comic books use for disclosure and stills from whiteboard videos. Our FAB group enjoyed the cartoon format (whiteboard videos) for health communication.

We were able to watch both videos during the meeting. At our site it would be important to have a version in Spanish too. A notebook at our site has been created to hold participant summaries and participant summaries are emailed to staff.

- Lack of knowledge/access HECC presentations, whiteboard video, HIV comics etc. How others CABs deal with the same issues?
- Notes are taken and the PHACS CAB representatives on the IMPAACT ICAB or PHACS conference calls present at the monthly CAB meetings. The CAB liaison make copies of documents for all the members to have and take home. The overhead projector was also used this year to showcase the educational materials and newsletters. The artwork from our youngest CAB members is also shown at the CAB meetings.

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

- Our CAB pretty much piggy back from my monthly calls within PHACS, HECC, and what's new from the research prospective. PI, and research staff will most definitely be involved with Topics for future CAB discussion or findings from Studies as usual.
- This may be year of change for our site cab. Not sure exactly how it is going to change, but change will be good. Our CAB leader is developing a survey to go out to all past and present cab members to assess the needs of the cab and how they would like to grow in the next year.
- Future goals: Christmas party/meetings, topics like healthy eating, calendar of events, planning for youth CAB joining with ATN, possible picnic, recruitment of new CAB members.

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- We plan to do the following:
  - Finish the MCA Clinic Newsletter
  - Implement a stigma reduction program for healthcare workers
  - Continue to represent the MCA clinic in community organization
  - Provide input for stigma and disclosure questionnaire
  - Submit an article to POZ
- Our hope for the new year is that we can find a way to get new members to get involved in CAB. Hopefully while at the retreat we can hear some ideas from other sites that could help us in that area.
- We continue to recruit new members to join CAB. We will start to handout the PHACS educational materials completed in 2015. They can be shared with families during their annual PHACS visit at TCH. Several of the TCH/BCM CAB members are also members of the Prevention, Education, Advocacy and Research CAB started in 2015. This CFAR CAB was started by Dr. Grimes at UT. Theresa Aldape, LMSW, is available to help with logistics and invite local HIV agency representative and individuals affected by HIV.

Our primary goal for 2015-2016 is to ensure that every CAB member is fully knowledgeable regarding current protocols, legislative issues, new medications, upcoming research studies at BCM/TCH and also address new and ongoing evaluation guidelines for IMPAACT and PHACS.

- This December we will be hosting our annual holiday party. At this celebration families feel inspired, hopeful, and a part of a community. Last year, 250 patients and their immediate family members attended. We are currently collecting gifts, raffle prizes, and donations to help fund the party. Our program is a recipient of toys from The Toys for Tots program donates many gifts to qualifying children under 12 at our site. Families enjoy the holiday meal, arts and crafts and have the opportunity to take family photos. Our goal for 2016 is to host at least 8 meetings, we are especially looking forward to a meeting focusing on HIV cure research.

## **Written Contributions from a couple of attendees at Site 21 CAB meetings:**

### **What did you learn during FAB today?**

- Teenagers try to hide the fact that they take medication and have HIV.
- I learned barriers to care for women.
- About medications to help for depression.
- At all of the meetings I always learn more about the problems with HIV and many other things that are important for my family. All of the topics that we go over are very interesting for everyone in the Hispanic community. Thank you.
- I learned about the meetings that some people went to and I learned about the messages at other conferences.
- I learned thank God that we are moving forward and advancing in terms of the medicines and that the housing has improved a lot, and this was the first time I visited this group and I really enjoyed it.



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- I learned about information from the conferences, the things that were shared about those who attended and the statistics.
- HIV conferences and new studies.
- About topics covered at the conference.
- The medicine to prevent HIV. The HIV campaigns and what you can learn from doctors, youth and parents.

## **What have you gained by being a part of Family Advisory Board (FAB)?**

- I've learned a lot more. I feel more informed and confident.
- Being in the FAB group helps me understand more. It gives us the support we need, my mom and I. We learn a lot of things.
- Yes, I learned about all the studies about adolescents and how to talk to them about substance use and STIs.
- I have gained a lot and yes I feel stronger. Well, the support that is given here is very important and yes, I've learned a lot touching the problem that I have. I am happy with the program. In terms of my diagnosis I can't talk to people because despite everything they are not prepared to understand my diagnosis and that is very important. To the program thank you for all your support.
- In my opinion, I think that this has helped get over many concerns about medications and I also feel a lot of support like I am at home and I like listening to everything and more information.
- This is my first time and I hope it's not the last.
- I like all of the meetings that are done, they are very interesting all the information is very important, and I learn a lot for myself and I share the message with my friends in support groups or workshops.
- More information about resources in the community for people with HIV. More self-confidence and it helps my family.
- I feel more supported by people who have the same condition that I do. I learned how to take care of my health.
- I feel more positive and I know that I am important for myself not for others.



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## **Share an idea on how studies can best support families?**

- 12% more deficiencies from adverse effect of infants born with calcium deficiencies from prophylaxis treatment-counteract with calcium supplement.
- Have many more conferences touching the problems about HIV/AIDS so that many people have more information about this illness. That's why I'd like to see more conferences about the medications and the consequences of taking the medications.
- I think it's all pretty good as is - glad to get information on the results.
- Share more information with other people about this illness and be able to support others with their self-esteem
- The studies can support us by keeping us informed if our babies have any illnesses that is a result of HIV exposure.
- The studies know if HIV is still in the body or when the children are negative follow their growth to see if the medicines have affected them or not. Just the fact that you keep monitoring out children's health makes us feel supported as mothers.
- We can learn at the class.
- We want a positive experience. We want happy kids! And Healthy kids!