

# NEWS & VIEWS

JUNE 2013

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## Meet A Client Advisory Committee Member



**Karen S.**

### How long have you been a client of Open Door?

I have been accessing HIV testing and services at Open Door since the 80s. I was diagnosed with HIV in 1986 and transferred my primary HIV care to Open Door in 2002.

### How long have you been a member of the CAC?

I have been part of the CAC almost from the beginning and have been an active member for at least 5 years.

### What type of things do you want to see done on the CAC?

I think the CAC has done a lot and come along way since I first joined. I am currently the only member from the Elgin clinic and I would like to see more members and participation from Elgin clients. I would also like to see the CAC continue to advocate for client rights to help them become more self empowered.

### Describe your family (however you describe

### family)

I come from a large family I have 10 siblings and loads of cousins, nieces and nephews. I think my mother and her sister were in a competition to see who could have the most kids. I am the mother of 6 children and have 4 grandchildren. We are all very close and I like to spend as much time with them as I can. Family is very important to me.

### What do you enjoy doing in your free time?

I like to spend as much time with family as possible. I love to take walks and enjoy nature. Armature photography is another one of my interests, I'm always the one with the camera at family gatherings; nature is another one of my favorite photography subjects. I love putting puzzles together, as well as watching Net Flix and socializing on Facebook. One the most important things I like to do with my free time is to attend support groups and other activities at Open Door Clinic. Open Door is like a second home to me I like to seeing my friends, meeting new ones and being able to give each other support and talk about issues with other people who are HIV. The people I know from Open Door are like a second family to me, their love and support is what gives me

strength, hope and reason to keep on keeping on.

### Where is the farthest you've been away from home?

The farthest I've been is Huston Texas. I was visiting my brother who was living there temporarily. That was all the way back in 1981. The only other places are 2 small towns in down state Illinois. Newman and Newton Il. At age of 12- 15 I lived in Newman, that 'is where my great grandmother lived.

### One thing that you want to do that you haven't done yet.

I have never been on a plane. I would like to take a plane ride somewhere to see the ocean.

### Who was the most impactful person in your life?

The most impactful person in my life would have to be my mother. I have realized as I've grown older how much I am like her and how many attributes we share. My mother always kept here children close to her and instilled in me the sense of the importance of family.

### What have you learned on the CAC

I have learned how to be a role model for others living with HIV/AIDS as well as have respect for others and to work as a team to help and support each other.

## DON'T BE LEFT OUT!

The Client Participation Cards have been circulating for almost 2 months now and we are getting a good response. Cards have started to come back in. Don't miss out on your chance to be a winner! Research shows that people who take an active role in their own healthcare have better health outcomes. We are hoping that the participation cards help remind clients to take care of themselves. Healthcare is not only getting your blood drawn and seeing the doctor, it's also about your mental and overall physical well being. Meeting with mental health provider, attending support groups, speaking with a Peer, can help a person manage stress and navigate the host of other non

medical related issues that people living with HIV face. By participating in your own healthcare you are a winner!!

Client Participation Cards are available at reception area, through case managers, peers, or at support groups. To fill the card you must attend at least 3 HIV related medical visits, i.e. doctor, nurse visit, blood draw, and 3 other activities i.e. Keeping mental health appointments, meeting with case manager or peer, completing assessments and surveys, attending support or focus groups, or seeing the dentist. After each appointment or activity have a staff member sign the card and indicate the type of activity participated in. When you have all 6 spaces on your card filled turn it in to an

Open Door staff member and your name will be entered into a drawing to take place in the last week in November. We will be picking 5 cards from each clinic for a total of 10 winners. Winners will be invited to an Appreciation Dinner where they will meet the other winners for food, fun, and help provide Open Door with valuable feedback to help improve services. Each winner will also receive a \$50 gift card

The program is open to anyone who receives at least one of the services offered at Open Door Clinic. If you only receive services from Open Door you can have your own primary care doctor, mental health provider, or dentist sign the card also. Remember your



card must have at least 3 HIV related medical visits to qualify. The other 3 can be any combination of services offered. If there are any questions or problems about qualification please direct them to a Peer Advocate available at either clinic.

## GEL SAFE AND ACCEPTABLE AS APPROACH TO PREVENTING HIV FROM ANAL SEX

From U.S. Centers for Disease Control and Prevention

U.S. National Institutes of Health (NIH) researchers report that a reduced-glycerin formulation of tenofovir gel was safe and acceptable to HIV-negative women and men who used the anti-HIV gel rectally in a phase I clinical trial (MTN-007). NIH is studying rectal microbicides inserted rectally via an applicator as a means of preventing sexual transmission of HIV. In addition

to developing rectal-specific products, researchers reformulated a vaginal product, tenofovir gel, for rectal use. The original vaginal formulation caused gastrointestinal side effects when it was used rectally.

The 2010 MTN-007 study divided 65 men and women into four groups for the one-week trial. One group used a reduced glycerin formulation of tenofovir gel daily; one used a placebo gel daily; one used the spermicide nonoxonyl-9

daily; and one group used no gel. All study participants underwent the same "study-related procedures and tests." The three groups using gels reported no significant differences in side effects. Eighty percent had minor side effects, and only 18 percent reported moderate side effects. Compliance with daily use was high (94 percent), and 87 percent stated they would use the product again.

NIH plans a phase II multi-site trial (MTN-017) of

the reformulated tenofovir gel in the United States, Thailand, South Africa, and Peru. The study will include 186 men who have sex with men and transgender women, all of whom will cycle through three regimens: daily use of tenofovir, use of tenofovir used before and after sex, and use of a daily antiretroviral pill (Truvada). The study will compare the reformulated tenofovir to Truvada and provide additional information about tenofovir gel safety.



## PAT L HONORED AT CINCO DE MAYO / SPRING FLING SOCIAL

The Client Advisory Committee put on a Cinco de Mayo/Spring Fling Party on May 4<sup>th</sup>. Pat Lev (Director of Case Management and Continuous Quality Improvement at Open Door) was one of 2 people who received awards from the advisory committee. Pat was a part of the Client Advisory Committee from the very beginning. She opened up her heart and home as well as providing her guidance and wisdom to the committee for 7 years. In December of 2012 she stepped down as the guiding light and passed the reins onto Perry Maier (Assistant Director) who will be helping to guide the committee moving forward.

Pat has been with Open Door for 23 years and currently directs case management services and works tirelessly behind the scenes to ensure the quality of care at both clinics. Her dedication, com-

passion and commitment to the clients of Open Door have helped improve the lives of many people.

Also honored was Mary Freeman. Mary is a mother of a client who has been there at every opportunity to help with client centered events. Everything from baking cookies to making candy bags for the kids. Her spirit of volunteerism and the things she provides are that little extra touch that make our outings special.

Thank you Mary for your love and support! Since 2012 Cermak Fresh Market has donated most or all the food for every event we've had.

This time was no

different, Cermak catered the meat and donated the fixings.

Joanna Ruiz from the Aurora clinic made the rice and beans and Deloris Gon-

zalez brought delicious taco salad.

La Chincantia and La Central Bakery provided pastries and all 3 of the La Dulceria provided candy for our piñata.

Of course we

can't say enough about the First Congregational Church of Geneva. Not only do they let us use their space for our events, they also give ongoing support to Open Door and clients through out the whole year. We are lucky that they have made us a part of their mission.

It wouldn't be a party without a DJ and we love ours! DJ Tom Warner has provided the awesome atmosphere at our last 3 events. Tom gives generously of his time and talent while playing to the audience. He has what it takes to get the dance floor moving.

Clients, family, friends and staff all came together for a couple hours of fun, music and food. The kids had a great time running around dancing and taking swings at a piñata shaped like a watermelon. The piñata was made by Diane Henning and her support group they did a fantastic job and the kids loved it! Thanks Diane and group!

The Client Advisory Committee (CAC) works very hard to plan and organize these events. As a committee we believe events like

these help increase socialization and decrease isolation and stigma for people living with HIV/AIDS.

Our next big event is August 10, the Open Door Family Picnic hosted by the Men's Group at The First Congregational Church in Geneva. Look for the flyer with all the details coming soon.

Thank you  
Members of the CAC



## Open Door's Annual Picnic to Be Held in August. 10, 2013

**Come and join in on all the fun and great food**

**More Details to Come in**

**Up Coming Issues**



## AFC ADVOCATES TRAVEL TO SPRINGFIELD FOR LOBBY DAY

by [Daniel Cameron \(profile\)](#)

**Springfield, IL** — Springfield was abuzz Wednesday with lobby groups, including a group of about 40 Chicago-based advocates, who traveled by bus to Illinois' capital for the second tour of the AIDS Foundation of Chicago's (AFC) Lobby



Days.

Lobby Days is an annual political advocacy event attempting to bring personal faces and stories about HIV/AIDS directly to lawmakers who will be redrafting as part of a normal budgetary process, Governor Pat Quinn's FY2014 budget.

The proposed budget, released March 6, includes \$4.27M in spending cuts from the Illinois AIDS Drug Assistance Program (ADAP), the third time in as many years the budget has been slashed for that particular program, a total of 30%.

"Human services providers in Illinois have taken the brunt of all the budget cuts in the past few years, said Ramon Gardenhire, Director of Government Relations for the AFC. "We can't take any more cuts, and it's time to say 'enough is enough.'"

Gardenhire said Lutheran Family Services organized the event that formed the heart of the lobbying-on-steroids day at the capitol, Rally for Human Care, and it

happened to coincide with AFC's second day of lobbying. Joining AFC informally were the March of Dimes, Family Crisis Intervention Unit, and many more.

AFC used to travel to Springfield one time each year, but according to Gardenhire this year increased to three days to maximize participation and due to the increasing funding cuts.

"Illinois used to be one of the best ADAP states," stated Will Wilson of the Illinois Alliance for a Sound AIDS Policy (IL-ASAP), "but we've fallen off."

The group also had a secondary mission of lobbying for HB61, a bill which would repeal a 1987 law that requires Illinois health authorities to notify school principals of the names of HIV-positive students.

Illinois is the only state in the union that has this requirement, which was created over 25 years ago, when knowledge and practices in the world were very different regarding reaction to HIV/AIDS.

Wearing matching baby-blue T-shirts with "Just Advocate," a play on Nike's "Just Do It" slogan in red emblazoned on the front, and grouped into six teams organized by their status as constituents of their respective congresspersons, advocates attempted to track them down, either in their offices or at other locations within the various political buildings.

They stopped to attend the Rally for Human Care, which took place in the rotunda of the Capitol Building and was packed with lobbyist groups, congresspersons

and bystanders. Several groups made rousing speeches on behalf of their individual cause. Representing AFC was Chris Wade of IL-ASAP, who made a rousing speech about HIV/AIDS needs.

The approximately 40 senators and representatives who will have a say in redrafting the budget included Thaddeus Jones (D-29), a supporter of the AFC cause and who also spoke at a question-and-answer portion of the Lobby Day, along with Rita Mayfield (D-60). Congresspersons also included Linda Chapa LaVia (D-83), another representative who reportedly supports the cause,



and Representative Greg Harris (D-13) and Senator Heather Steans (D-7), two among the sponsors of both HB61 and SB10, the well-known so-called "gay marriage" bill that would equalize marriage rights in Illinois.

Although the Capitol Building and Stratton Building was busy, almost frenzied, and often lawmakers were in session and unavailable, many aides and secretaries were given strong personal messages to give to their bosses, along with handwritten notes and sheets listing HIV/AIDS and ADAP statistics for Illinois. Over 40,000 live with HIV/AIDS in the state.

At least some of the advocates were able to track down and speak with their congresspersons about the budget cuts.



Lucy Baglin, AFC Policy Coordinator and one of the leaders of the Lobby Days event, said although the advent of the Affordable Healthcare Act in 2014 will mean more persons in need of care will be covered by Medicaid, many individuals and groups, such as persons who make over a certain amount of income, minorities, low-income persons, persons without access to transitional assistance, and undocumented immigrants will find themselves suddenly cut off from the funding they so desperately need, which would mean a step backward in the fight against HIV/AIDS in Illinois.

"We are on the brink of an AIDS-free generation and these cuts are a huge setback," said Baglin, addressing the group before the lobbying began. "If you are going to make cuts, don't make them from this program."

In addition to the AFC, among the sponsors of this year's Lobby Days were Bristol-Myers Squibb, Pfizer, and Boehringer Ingelheim. A final Lobby Day for 2013 will take place on May 22 when supporters from Southern Illinois will meet with lawmakers.

## TREATMENT AS PREVENTION: WHAT YOU NEED TO KNOW

From Black AIDS Institute

For years we've known that with effective treatment, HIV becomes a chronic illness rather than a fatal one. However, there have been different schools of thought about when a person living with HIV/AIDS should begin treatment.

In the past, many HIV/AIDS specialists recommended that people with HIV delay treatment if their immune systems were strong. However, new developments have caused the HIV/AIDS community to rethink that previous wisdom.

### Understanding the Logic

The question about when to begin treatment has largely centered on the number of CD4 cells a person with HIV has in his or her body. CD4 cells, also known as T cells, are white blood cells that fight infections, such as HIV. The higher your CD4 count, the healthier you are.

In the past, many HIV/AIDS specialists believed that if a person had a CD4 count of 500 or higher, he or she was healthy enough to put off treatment. Some of

the earlier medications prescribed during antiretroviral therapy produced serious adverse effects, such as liver damage, hyperglycemia and skin rashes. The school of thought was that someone with a CD4 count of 500 or higher could wait to begin treatment and delay or perhaps even avoid these possible effects. On the other hand, a person with a CD4 count of 200 or below needed to start treatment as soon as possible.

But times have changed for three major reasons: Medications are much more effective, so those who are in treatment are taking fewer pills and suffering fewer side effects.

Some studies suggest that earlier treatment may lessen an HIV patient's risk of later acquiring AIDS-defining illnesses, such as HIV-associated nephropathy, HIV dementia and peripheral neuropathy.

A clinical trial in 2011 found that people with HIV who started taking medications while they had a high CD4 count saw their risk of transmitting HIV to their HIV-negative sexual partners

decrease by 96 percent.

### A New School of Thought

The realization that treatment could also be prevention was a landmark scientific breakthrough, giving the HIV/AIDS community a reason to believe that the end to the epidemic was in reach. Not only does treatment help the person with HIV remain healthy, but it also provides another layer of protection to those in the community who are HIV negative.

The Department of Health and Human Services recommends treatment for all PLWHA, and it has identified dual goals for treating the disease:

Destroy the virus and reduce the risk of disease progression;

Decrease the person's risk of transmitting HIV -- in effect, preventing new infections.

While it's now recommended that all people with HIV begin ARV treatment even if they have a high CD4 count, it's ultimately the decision of the patient. If you do have a high CD4 count and decide you'd rather not go on ARV drugs, make sure you stay in care so that your CD4 count

can be monitored and you can begin treatment if it begins to decline.

### Other Precautions Still Necessary

If you decide to begin ARV treatment, you must still take precautions. Treatment with ARVs is one form of prevention, but it's not a foolproof method for preventing the spread of HIV. Antiretroviral treatment lowers your risk of transmitting HIV to others, but it doesn't eliminate the risk entirely. A person who is on ARVs should continue to use condoms whenever he or she has sex.

If an HIV-negative male or female has sexual intercourse without a condom or the condom breaks, he or she should go to a doctor or an emergency room to begin a PEP (postexposure prophylaxis) protocol, which may prevent HIV infection.

Treatment goes a long way toward keeping you and your sexual partners healthy, but having unprotected sex increases your risk of HIV infection every time.

## GIVE US YOUR OPINIONS

**Open Door's staff and Client Advisory Committee want to hear from YOU.**

**We want to hear the good, the bad and any ideas you have about for the clinics, the staff, or anything else you want to say.**

**Please take a minute and write it down.**

**THE ONLY WAY WE CAN IMPROVE  
IS TO HEAR FROM YOU.**

**The SUGGESTION BOXES are  
located in each clinic in the waiting room area.**



## JUNE EVENTS

- 05 - Making Stress Work  
12:30p - 1:30p (W)
- 06 - Positive Mental Health  
Support Group 3:30p -  
4:30p (A)
- 07 - Happy Birthday  
Sharon M (E)
- 07 - Positive Group HIV Ed  
4p-6p (A)
- 07 - Positive Group HIV Ed  
4p-6p (E)
- 08 - Happy Birthday Shirley  
(CAC - Aurora)
- 10 - Game Night  
4pm - 6pm (W)
- 11 - Happy Birthday  
Carol W (E)
- 13 - Happy Birthday  
David R (E)
- 13 - Happy Birthday  
Pat L (E)
- 13 - Positive Mental Health  
Support Group 3:30p -  
4:30p (A)
- 14 - Peer to Peer Support  
Group 4p-6p (A)
- 14 - Peer to Peer Support  
Group 4p-6p (E)
- 20 - CAC Meeting 5:30p -  
7p (G)
- 20 - Positive Mental Health  
Support Group 3:30p -  
4:30p (A)
- 21 - Game Night Positive  
Support Group 4p-6p (A)
- 21 - Bingo Positive Support  
Group 4p-6p (E)
- 24 - Newsletter Available at  
the Clinics
- 24 - Game Night  
4pm - 6pm (W)
- 27 - Positive Mental Health  
Support Group 3:30p -  
4:30p (A)
- 28 - Combined Positive  
Support Group 4p - 6p (G)

(A) Aurora  
(E) Elgin  
(LA) Love & Action  
(G) Geneva -1st Cong.  
Church  
(W) Wheaton - Canticle Place

Dates are subject to  
Change  
Please call to verify dates



## PEOPLE MORE LIKELY TO KEEP HIV CLINIC APPOINTMENTS IF THEY BELIEVE THEIR CARE PROVIDERS KNOW THEM AS A PERSON

From U.S. Centers for Disease Control and Prevention

Researchers at Johns Hopkins University in Baltimore investigated whether the quality of patients' relationships with their HIV care providers helped patients keep routine care appointments. They were looking for potential targets for future interventions to improve providers' interactions with patients, promote retention in care, and help patients have better outcomes in HIV care. The researchers studied 1,363 of their clinic patients between 2004 and 2009. Participants were mostly male (65 percent), non-white (85 percent), and with a mean age of 46 years. Two-thirds were on antiretroviral therapy and 49 percent had undetectable viral load.

Each participant completed a computer-assisted questionnaire rating the quality of communication and relationship with their care providers in the follow-

ing five areas: being treated with dignity and respect; being involved in decisions about care; feeling listened to; having information explained in a way that could be understood; and feeling known as a person. Researchers hypothesized that high ratings for doctors and healthcare providers would be associated with higher attendance levels at routine clinic appointments.

Participants rated their healthcare providers highly in all five areas, with 85-94 percent of patients giving the highest possible ratings. Results indicated that patients who believed that their healthcare providers really knew them as a person kept 6 percent more appointments than those who did not share that level of belief. Participants who gave highest ratings in terms of being treated with dignity and respect and always having information explained in a way that was understandable, and careful listening were 7, 7, and

6 percent more likely to keep their appointments, respectively, than those who gave lower ratings in these areas. High rating for involvement in decision making was not associated with higher levels of attendance at appointments.

The results surprised researchers. When they included all communication and relationship variables into a single model, which they adjusted for demographic factors and substance use, "feeling known as a person" was the only factor associated with significantly higher rates of clinic attendance. Researchers concluded that the study suggests that healthcare providers could enhance appointment adherence by improving the quality of relationships, so that patients feel known and respected as persons by them. Also, provider communication behaviors such as listening and carefully explaining could make a difference in retaining patients in care.

IF YOU ARE INTERESTED IN  
GETTING THE OPEN DOOR  
CLINIC'S MONTHLY NEWS-  
LETTER VIA E-MAIL OR  
HAVE ANY TOPICS THAT  
YOU WOULD LIKE TO SEE  
IN THE NEWSLETTER.

PLEASE EMAIL ME AT  
[deanb@opendoorclinic.org](mailto:deanb@opendoorclinic.org)

### ELGIN

164 DIVISION STREET  
SUITE # 600  
ELGIN, IL 60120

PHONE (847) 695-1093  
FAX (847) 695-0501

### AURORA

157 S. LINCOLN AVE.  
ROOM K  
AURORA, IL 60505

PHONE (630) 264-1819  
FAX (630) 229-0182

[www.opendoorclinic.org](http://www.opendoorclinic.org)