



WHO IS THE CLIENT ADVISORY COMMITTEE CHAIRPERSON?

MARCH 2013

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OPINION

YOU

since 2007

Name: Bryan G

How long have vou been a client of ODC? I have been a client at Open Door Clinic

How long have

you been on the CAC?

I have been on the Client Advisory Committee for four years and I am currently the Chair per-

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

I think our Client Advisory Committee has come a long way in the time I've been participating on it. The members are committed to improving the lives of people living with HIV. We have planned many successful social events helping to deal with some issues of stigma and isolation. We have developed relationships my big fat cat Bob. My parents with local business community leaders and churches in order to support our activities. As we move forward we are going to be coming up with ideas and strategies to keep people engaged in their care, while also providing Open Door client based feedback to improve services where they get care.

We have also done a lot change and strengthen the structure of the committee such as electing officers and coming up

with bylaws, laying a strong ground work for the continuing future of the CAC. Membership has really set the bar high over the course of the last couple years and keep surpassing it . I would love to see some younger members on the committee or transgender. We are sorely in need of representatives from the Elgin clinic. I encourage anyone receiving services at Open Door to apply for open seats on CAC, right now we have 2 spaces open. It's a lot a fun with some wonderful committed people. You also get a great sense of personal satisfaction and empowerment by improving your life along with the lives of others. Describe your family (define

family however you want)?

I am very close with my family, most of which live here in Illinois. I share a home in Aurora with my beautiful 25 year old niece and live in Sycamore. My brother and sister in-law along with my other niece live in St.Charles. If you ask my nieces who their favorite uncle is they both will say Uncle Bryan !!

What do you enjoy doing in your free time?

I love to cook for family and friends. Movies and shopping, Flea markets, are always fun. In the spring and summer I love decorating my porch with loads of flowers. I read every night

before bed. My favorites being German or Russian literature, fantasy and historical fiction.

Where is the farthest place from home you have ever been?

I've been all over Europe. Would like to travel more. My dream trip right now would be to India What is your favorite food? Love all kinds of food. Love eating and making it.

What one thing do you want to do that you haven't done yet? I would like to continue traveling all over the world. I've never been on a cruise, so maybe that

Who is the most impactful person in your life or most impactful person on humanity (dead or alive)?

I believe everyone you meet has an impact on your life

What have you learned since being on the CAC?

I have learned a lot about how a committee is put together and ran, and how to work with others in a deliberative process. I have also learned to be a better advocate for myself and others. Being on the CAC is about being a voice to Open Door for the people you are trying to represent, and improving their lives and the lives of the community at large. I can say my whole experience with the CAC has been a continuing learning process.

Join our Host, Brad Edwards for All Things Chocolate 2013

April 20, 2013 St. Andrew's Country Club **West Chicago** Tickets available online



GIVE US YOUR OPINION

Open Door Clinic staff and Client Advisory Committee

want to hear from YOU.



I WANT TO GIVE AN OVERDUE THANK YOU

Phyllis Stephens, Patient Coordinator

I want to give a very overdue Thank You to Dean B. and Tom B. for their help in giving the Aurora Open Door facility such a great new look. It was so exciting when we discovered we have continued to be could move into the additional space in Aurora. If it wasn't for Dean and Tom, we may of which the staff and

have had the new space, but it would the depressing, old look. Now, because of them, we have an office they did.

clients can all be proud. Please, if you see Dean or Tom in the offices, give them a big Thank You for all the work

PREDICTING SURVIVAL AMONG THOSE AGING WITH HIV INFECTION

TheBody.com

Even with the use of antiretroviral therapy (ART), which can lead to viral suppression and reductions in AIDS-related deaths, researchers maintain that people with HIV infection have a higher mortality rate because chronic HIV infection intensifies age-related organ system injury.

The Veterans Aging Cohort Study (VACS) Index funded by the National Institutes of Health used older indices that measured HIV biomarkers,

including CD4 cell count, HIV-1 RNA levels, and patient age, were from more than 5,000 to ascertain mortality risk. The newer VACS Index uses other critical factors, including the increasing role of multi-organ system injury and hepatitis C infection as well as the decreasing role of other factors such as CD4 count.

In a collaborative study by Yale University, the VA Healthcare System, and the North American Cohort Collaboration, the researchers compared the accuracy of the VACS Index with that of the

newer VACS. Data reviewed veterans and more than 10,000 non-veterans, representing 14 separate cohorts of HIV-infected persons from around the country who had at least one year of ART. The researchers followed up with patients for a little more than three years.

Researchers found the new VACS Index was much more accurate and effective than the previous index, which used CD 4 count, HIV-1 RNA, and age. Dr. Amy Justice,

professor of internal medicine at Yale School of Medicine. stated that the VACS Index accurately estimated risk of mortality among persons aging with HIV infection whether they live in Canada or the United States. She also found that the index was accurate among men and women, older or younger individuals, and white people or people of color. The team has created an app for use by patients and their providers. It is available at http://vacs.med.yale.edu/.

CLIENT PARTICIPATION PROGRAM

The staff and Client Advisory Committee (CAC) of Open Door Clinic (ODC) want to acknowledge and thank attend at least 3 HIV clients for actively participating in their own healthcare and well being by, keeping their medical. mental health, case management, peer appointments, attending support or focus groups, or seeing the dentist. The CAC has created the Client Participation Program.

Starting in March 2013 and continuing through November 2013 clients will have surveys, attending the opportunity to track and be rewarded for taking care of themselves. The Client Participation Cards will be

available at reception indicate the type of area, case managers, peers, or at support groups. To fill the card you must related medical visits: doctor, nurse

visit. blood draw. and 3 other activities like keeping mental health ap-

pointments, meeting with case manager or peer, completing assessments and support or focus groups, or seeing the last week in Novemdentist. After each appointment or activity have a staff member sign the card and

activity participated in.

When you have all 6 spaces on your card filled turn it in to an ODC staff member and your name

> will be entered into a drawing to win a fabulous prize. In addition you will have the opportunity a focus

group to help ODC improve or enhance clinic services. You may fill and enter up to 2 cards. The draw-fered. If there are ing will take place the any questions about ber and we will be picking 5 cards from each clinic for a total of 10 winners. Prizes

may include debit cards, free local trips, entertainment packages and more.

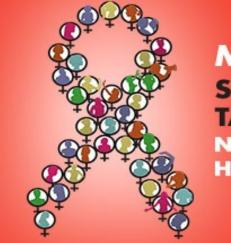
The program is open to anyone who receives at least one of the services offered at Open Door Clinic. If you just get supportive services from Open Door you can have your own primary care doctor, mental health provider, or dentist sign the card. Please to be part of note, your card must have at least 3 HIV related medical visits to qualify. The other 3 can be any combination of services ofthis service please contact the Peer Advocate located at either clinic.







Open Door will be participating in National Women and Girls **HIV/AIDS** Awareness Day. On Monday, March 11, the Aurora



MARCH 10 SHARE KNOWLEDGE TAKE ACTION

National Women and Girls HIV/AIDS Awareness Day

office will have free HIV testing and on Friday, March 15, the Elgin office will have free HIV testina.

National Women and Girls HIV/AIDS Awareness Day is a day to "Share Knowledge. Take Action."

The nationwide observance held each March 10 sheds light on the disease's often overlooked impact on women and girls and empowers people to make a difference.

Women of all ages can get HIV/AIDS, and they account for approximately 24 percent of all HIV diagnoses. Today, women represent a larger share of new HIV infections than they did earlier in the

epidemic. with nearly 280.000 women living with HIV/AIDS in the United States. Women of color are particularly affected, as they accounted for

two-thirds (64%) of new AIDS diagnoses among women in 2010.

If you know any Women and Girls who need or want to get tested for HIV please refer them to the Open Door.

TIPS FOR FINDING YOUR VALENTINE

TheBody.com

Being HIV positive complicates the dating game. Disclosing your status can be stressful since there is always a good possibility that you can get rejected. I think taking medications daily is not as big of an issue as is dating while being HIV positive. That is what I tell HIV-negative young people who think that HIV is a chronic manageable disease and do not see what the big deal is about wearing condoms. I tell them that taking pills is the easiest thing, but dating can be terribly complicated and stressful after you find out you are HIV positive.

Luckily, many people are meeting online and can disclose other poz people to date than to early during email exchanges, before emotional ties are established and more headaches can occur. But many choose not to disclose and put themselves in awkward situations in which they wait too long to tell the person they have been dating

for weeks, which can potentially result in resentment from those people.

However we choose to meet a potential person to date, we know one requirement has to be met first: that person has to be HIV friendly and educated about HIV. But how do you meet peo-



ple that have a better chance at meeting that requirement?

I tell my single friends that there is no better way

volunteer in nonprofit organizations, fundraisers, AIDS rides or walks, or to serve on Boards of Directors of AIDS organizations and other community-related work. In my 18 years of nonprofit work, I have met many a single man with a great heart

and a desire to help others, which are two of the things I find your profile online on the differthe most attractive. Also, these people tend to be more HIV friendly (regardless of their HIV status). If you volunteer for a group or event, chances are that you will be seeing those people frequently. That can give you a great opportunity to get to know them better before you even ask them out on a date. Take a look at this listing of organizations.

Another very good way to meet other poz people is to go on retreats and trips that cater to HIV-positive people. I usually go to the yearly Poz Cruise in October, where 300 or so men and women hang out for a week of fun and relaxation. We have dinner together every night and get to know each other. And we have a rare opportunity to hang out with someone for seven days! Many couples have met on that cruise. For more information go to

www.cruisedesignstravel.com/.

You can also choose to post ent websites created for HIVpositive people to meet each other:

Poz Singles **HIVPoz.net** GayHIVPoz.com PozMatch.com

Last but not least, meeting new people through your friends and network gives you a unique opportunity to meet someone after you can get some input from others about that person. I know there is nothing worse than when a friend tries to set you up with someone who is not a match for you, but at least you get to meet people with some prior background information before meeting them.

It is not easy to meet other poz or poz-friendly people to date, especially if you live in a small town. Luckily, the online world has brought many people together that would not have met otherwise due to their worlds being so far apart.

QUESTIONS AND ANSWERS



Testosterone therapy Feb 5, 2013

Q. hi doctor, I just turned 42 and been positive for little over 2 years. My energy levels have been horrible so i had my HIV doc do a testosterone test about a year ago and he said the normal's were quite normal. My question is what is the downfall of taking a small dose of androgel even-though my numbers are not low. I also heard that the number depends on the type of test. I know that here in Texas there are quite a few Testosterone clinics that seem to have no issues with prescribing this therapy. I just want more energy and feel that it would help me. Any thought would be appreciated.

Α. The studies of testosterone therapy that have lead FDA approval and then to the avalanche of use/advertising enrolled patients with low testosterone (can look at total testosterone or free testosterone) so there is very little safety/efficacy data when normal testosterone levels are boosted to high normal or supernormal. There is concern about increased risk for heart disease, prostate problems, and other conditions but credible data is limited. There has been no data

that patients actually live longer in the general population when given testosterone supplements-it is a matter of possible improvements in quality of life. There are a number of studies going on that hopefully will provide useful data. In women, estrogen supplements, once widely used for post menopausal symptoms to improve quality of life, were shown in large studies to have some harmful side effects leading to a large drop in use and now many studies trying to identify who can safely take hormone replacement (very complicated situation). Data for men and hormone supplementation is lagging behind women so lots of opinions and claims-little long term data.

Pain in leg

Feb 12, 2013

Q. I have been positive since 1994 but have taken Atripla since 2007. I recently had a UTI and was prescribed Cipro. Two days on the Cipro I began to experience pain in my muscles in my right calf. I stayed on the Cipro for 6 days of the 10 day regimen experiencing muscle pain each day. Since going off Cipro, I have experienced peripheral neuropathy constantly in my left leg with pain radiating from my buttocks to my calf with burning and tingling on the sole of my left foot. Since the pain is constant (every day), is it related to my HIV (undetectable viral load and CD4 of 855)? My

job requires me to sit which is hard to do. My muscles in my left leg (especially calf) are so tight it hurts to bend my leg. What can I do to stop the pain?

Ciprofloxcin can sometimes cause tendonitis and less often some muscle problems. The discomfort in right leg and then left leg would rarely be due to the Atripla or HIV infection given the scenario you described. I recommend getting having a full clinical examination includingneurological assessmen t to try to pin down whether a nerve, muscle, or tendon problem seem more likely and what management options area available to you.

Memory loss

Feb 13, 2013

Q. I've been Atripla for just over 3 years the first several months was scary. I didn't know what was real or fake I thought my mother was her sister. But now I have very bad memory loss, and can not gain weight. I stay tired is this normal?

Α. No-severe memory loss and the other problems you describe is not normal. I recommend a thorough neurologic exam and possibly brain imaging to look for HIV related, drug related (efavirenz in the Atripla can occasionally cause long term central nervous system problems), or non HIV related factors causing the memory problems and fatigue (such as hormone, vitamin deficiency, or sleep abnormality).

35 years of medication toll on my body?

Feb 13, 2013

I'm a 56 yr. old male and have been on hiv med's for 30 years. I'm lucky, my number are still very high in the 800's to 1000 with 0 viral load. My concern is with age I reguire less food, less activity ect...I am wondering if my Dr. should reduce medication amounts. I have been feeling excessively tired or over medicated. I know that with ageing some of tiredness is normal, but the feeling of over medication is what I'm feeling, your thoughts?

A. You raise several important points. Some studies have suggested that HIV+ patients, including those doing well on treatment based on good CD4 counts and low viral levels, may be at increased risk for premature frailty (weakness). Cause is not yet clear. Another point your situation makes is whether drug metabolism may change with aging. Renal function typically declines modestly with age as can

change with aging. Renal function typically declines modestly with age as can lean body mass do there is a concern about whether there may be some increased risk for toxicity though good data is lacking and is needed. Levels of some HIV drugs can be checked as can renal and liver function in order to determine if there are any clues to increased toxicity.

MARCH EVENTS

SAVE THE DATE FOR THE NEXT CAC SOCIAL EVENT

01- Positive Support Group HIV Ed 4p-6p (A)

- 01- Positive Support Group HIV Ed 4p-6p (E)
- 05- Positive MH Support Group 4p-5:30p (A)
- 06- Positive MH Support Group 12:30p-1:30p (E)
- 06- Making Stress Work For You 12:30p-1:30p (W) Group 12:30p-1:30p (E)
- 08- Peer to Peer Support 4p-6p (A)
- 08- Peer to Peer Support Group 4p-6p (E)
- 11- Game Night Canticle Place 4p-6p (W)
- 12- Positive MH Support Group 4p-5:30p (A)
- 13- Positive MH Support Group 12:30p-1:30p (E)
- 15- Positive Support Group 4p-6p (A)
- 15- Bingo Support Group 4p-6p (E)
- 15- HAPPY ST. PATRICKS DAY
- 19- Positive MH Support Group 4p-5:30p (A)
- 20-SARAH C BIRTHDAY (E)
- 20- Positive MH Support Group 12:30p-1:30p (E)
- 21-CAC Meeting 5p (G)
- 22- Pos Support Group Combined 4p-6p (G)
- 25- Game Night 4p-6p (W)
- 26- Positive MH Support Group 4p-5:30p (A)
- 27- Positive MH Support Group 12:30p-1:30p (E)
- 27- Drug & HIV Ed Group 2p-3p (E)
- 29- DEE BIRTHDAY (A)

(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



Open Door Clinic's

Client Advisory Committee

is Hosting

De Mayo Spring Fling

for Clients, Family and Friends

May 04, 2013 4p-8p

More information to come...

ALL THINGS CHOCOLATE NEXT MONTH



OPEN DOOR CLINIC'S **ALL THINGS CHOCOLATE** APRIL 20, 2013 TICKETS CAN BE



PURCHASED ONLINE AT OPENDOORCLINIC.ORG







IF YOU ARE INTERESTED IN **GETTING 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

ELGIN

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