OPEN DOOR

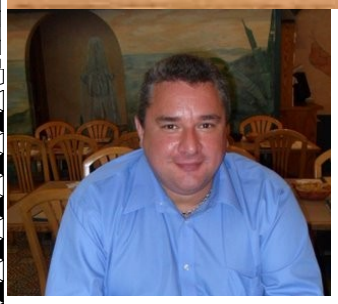
VOLUME 7 ISSUE 4

ODC NEWS & VIEWS

APRIL 2013 ALL THINGS CHOCOLATE

INSIDE THIS ISSUE

WHO IS THE CLIENT ADVISORY COMMITTEE SECRETARY ?



Name: *Dean B.*

How long have you been a client of ODC*? I came to ODC in 2000. I have been a client since than except for about a year when I move to Chicago and received my care somewhere else and when I moved back to the suburbs I went back to Open Door and realized that ODC is the best clinic to get your care. The staff treats you like family and not just another number/client. They treat you like you are the only one they are treating they CARE about you.*

How long have you been on the CAC*? Going on eight years now. I remember when it was just a few people and over the last eight years I have seen it fade to a couple of people and grow to the number now. For the last three years there have been a strong group of eight clients serving on the committee and giving dedication so that the committee keeps strong.*

What types of things do you want to see done on the CAC? *That more clients come to the functions that we plan for them and for the clients to interact with each other so they have the support that they might need.*

Describe your family (define family however you want)? *I am in a civil union with a wonderful man (my soul mate) for just over a year. We have a three year old Min Pin named Dante and a Chihuahua named Cooper that just gives us so much love all the time.*

What do you enjoy doing in your free time? *I do the newsletter for the clinic have been doing that for about seven years. I work around the house and I volunteer at the Aurora clinic when they need something done.*

Where is the farthest place from home you have ever been? *Albert Canada I have family up there.*

What is your favorite food? *I would have to say beef stroganoff, My mom makes the best and she had shared her recipe with me and I just can't make it as good as mom.*

What one thing do you want to do that you haven't done yet? *Taken a cruse but hopeful we can do that soon in the future.*

Who is the most impactful person in your life or most impactful person on humanity (dead or alive)? *My father, He is such a strong, loving and smart man.*

What have you learned since being on the CAC? *That having HIV I am still alive and I still able to do anything that I put my mind to. I have HIV, HIV does not have me.*

You Can Participate in the Client Participation Program

The staff and Client Advisory Committee (CAC) of Open Door Clinic (ODC) want to acknowledge and thank 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 the opportunity to track and be rewarded for taking care of themselves. The Client Participation Cards will be available at reception area, case managers, peers, or at support groups. To fill the card you must attend

at least 3 HIV related medical visits; doctor, nurse visit, blood draw, and 3 other activities like 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 ODC staff member and your name will be entered into a drawing to win a fabulous prize. In addition you will have the opportunity to be part of a focus group to help ODC improve or enhance clinic services. You may fill and enter up to 2 cards. The drawing will take place the last week in November 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 note, 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 about this service please contact the Peer Advocate located at either clinic.

Sleeping Soundly When You Are HIV Positive

Thebody.com

Before starting HIV medication, flight attendant Terry Wong never had a problem with jet lag or sleeping. "I could sleep just about anywhere anytime," he recalls. "If I was tired and there was a bed, I would pass out and be snoring in minutes." Diagnosed with HIV 15 years ago, Terry's health took a nosedive seven years later -- his weight dropped from 175 to 109 pounds and his CD4 count plummeted to zero. He was hospitalized for a week and started HIV treatmentimmediately. The meds saved his life but when combined with flying, they made getting some shut-eye a thing of the past.

Once on treatment, Terry started to gain weight and his health steadily improved, al-

lowing him to return to work shortly afterwards. That's when the insomnia hit: "When you're switching time zones regularly, juggling your sleep and medication schedule without missing a dose becomes very complicated." At first, he took his meds with lunch when in Vancouver. That meant that from his regular destination, Hong Kong, he had to take them at 3 am. He would call the hotel front desk to order a wakeup call and room service for that time, so he could take his pills with food. This threw his whole sleep schedule into a state of disarray. "My sleep was terrible," he says. "I couldn't sleep at all. It was the darkest period of my life." In addition to the headaches and diarrhea he experienced as side effects from the medication, Terry constantly felt groggy, irritable, weak and depressed. After several years of this, he suffered a nervous breakdown.

Like Terry, many people living with HIV experience sleep problems. These can occur at any stage of HIV infection. Upwards of 75 percent of people report sleep issues on a regular basis. Some have difficulty falling asleep, some have trouble staying asleep (due to poor-quality sleep or frequent nightmares) and others wake up too early. Then there are people, like Jasmine, who have the misfortune of experiencing many or all of the above.

For years, when Jasmine went to bed at night she found herself wide awake, staring at the clock for hours on end. "If I fall asleep now," she would calculate, "I'll get only five hours of sleep ... now only four hours ..." -- a vicious circle of insomnia and anxiety. Once she finally nodded off, she had problems staying asleep and achieving a deep sleep. As a result, she awoke each morning feeling sluggish. "It was very frustrating because it took a long time to get my engine up and running, ready to start the day." When she started working night shifts, the problem only got worse. "When I'm sleep-deprived, I'm not as quick with my thinking or speech. I'm off my game and have to push myself to get stuff done."

NOT BY OURSELVES: THE ESSENTIAL ROLE OF FAMILY AND COMMUNITY IN MAINTAINING HEALTH

Thebody.com

In the modern world it can be remarkably easy to discover where you are. A simple tap on the screen of a smart phone or consultation with a car's GPS device instantly reports our location on the planet with almost absurd precision. Such effortless ability to locate ourselves in time and space can shroud the complications of maintaining emotional bearings in the more ambiguous, upside-down world of living with HIV. Those who are newly diagnosed, as well as long-term survivors, are buffeted by the powerful forces unleashed by living with or around HIV, and frequently find it challenging to maneuver this emotional realm.

Researchers are increasingly documenting the importance of social support in maintaining healthy resilience. While medications have altered the landscape of living and dying from the virus, it is increasingly clear that pharmacological interventions alone are not sufficient to achieve acceptable levels of linkage, entry and retention in care.

Psychosocial stressors, including inadequate support, can take a toll on those living with or affected by HIV. They result in denial and avoidance of testing, they affect treatment adherence, and they can push an emotional low point into a crushing depression. Perhaps most harmful, whether from stigma or other factors, individuals may be shunned by their families and communities and thus lose their vital support system. HIV can be characterized by social isolation. Those who cannot find a way to successfully develop a meaningful support network may find their health severely impacted.

I know from my interactions with countless patients that being seen and heard -- simply being socially connected -- can have a profound healing effect. Therefore, it is noteworthy that research findings reported at the 19th International AIDS Conference in July 2012 documented the significant healing role played by one's social context. Health is enhanced when we are surrounded by people who love us and when we, in turn, feel part of something larger than ourselves.

One such study, *Collaborative HIV/AIDS Mental Health Project (CHAMP)*, presented by Susan Reif of the Center for Health Policies Inequalities and Research, looked at treatment barriers for co-occurring mental illness among persons living with HIV. Such disorders are highly prevalent, are associated with negative health outcomes and are often untreated (based on access to health care, stigma and a variety of other factors). This study of a population in North Carolina used a combination of in-home and community-based counseling. There were significant improvements over time in a number of standardized assessments, underscoring the benefit of mental health care that is both accessible and culturally appropriate. Further research will determine the relative effectiveness of the two interventions in this study: in-home versus community based care.

The power of supportive psychosocial care expressed in the family unit was the focus of a presentation by Lucia Knight *(Care and support by households and extended families in the era of HIV treatment: Responses to HIV and AIDS in rural South Africa)* about HIV care and support by households and families in rural South Africa. The aim was to assess the ability of black South African families to respond to HIV/AIDS and to determine the dynamics which support or inhibit this response. The findings documented the overall resilience of the families and their importance in providing an important safety net for those affected. Social norms such as family obligation and reciprocity enabled those needing assistance to acquire it while at the same time building social capital for the family. The study found, however, that such norms were frequently limited by conflicting obligations or lack of resources and should, therefore, not be taken for granted. Clearly, support of family systems, both in the U.S. and abroad, is a beneficial way to improve the care of those living with HIV.

Families were also the focus of a study on black MSM, a population with the highest incidence of HIV in the United States, reported by John Schneider *(Family network proportion and HIV risk among Black men who have sex with men [BMSM])*. Utilizing an egocentric network approach, these researchers determined the proportion of close social network members who were also family members. About 45% of respondents reported at least one close member of their network as family. Greater family involvement, especially of males, was associated with reduced risk behaviors. The study highlighted the need to better understand the role of brothers, fathers and other male family members of BMSM in HIV prevention efforts. Research is also underway to assess the role of family ("of origin" or "of choice") in supporting primary HIV care and treatment adherence of young BMSM.

The essential support of families and communities can benefit not just those living with the virus but those affected by it, as well. A study reported by REPSSI, the Regional Psychosocial Support Initiative *(When time doesn't heal: childhood traumatic grief among orphans in rural Zambia)*, investigated factors that sustain or inhibit ongoing traumatic grief among orphans in sub-Saharan Africa. Factors one presumes might have a great impact, such as circumstances of the parent's (or parents') death, were not highly significant. What was most important was how the children were cared for in their families and communities following the death of their parent. Multiple sequential losses of a primary caregiver, within-household discrimination, a negative relationship with current caregiver, and daily stress and bullying were all found to be significant in predicting ongoing traumatic grief among children orphaned because of HIV. The study found that community-based initiatives played a critical role in allaying some of the debilitating mental health complications among these orphans.

Whether in the United States or abroad, among those living with the virus or those affected by it, the health-promoting effects of family and community are enormous. The healing potential of these connections is beginning to be documented and should be an essential component of ongoing HIV prevention and treatment interventions. In the end, self-esteem, self-respect and resilience can only be achieved when our efforts to stay physically and emotionally

QUESTIONS AND ANSWERS

low T

Nov 2, 2011

I am taking combivir kaletra and viread f or HIV I have been on this regiment for 7 years with no problems. My viral load is currently undetectable and my T cell count fluctuates somewhere between 550 and 800.lately I have had some weight loss and a lot of fatigue. I have been diagnosed with low testosterone and have been given injections of 100mg testosterone cypionate once a week. I have been gaining weight and feel great. Im in the best shape Ive been in in ten years. Is this a safe combination and if so for how long.

Response from Mr. Vergel

When you are diagnosed with testosterone deficiency and start testosterone replacement therapy, assume it is for life much like you take your HIV meds forever. Your body is not producing the levels of testosterone considered "normal" for your age. Stopping testosterone will make you feel just like you did before you started it. Testosterone replacement is not to be "cycled" like anabolics such as nandrolone or oxandrolone used for increasing lean body mass in those who have unintentional weight loss. It is a therapy to normalize your testosterone

Life expectancy

Jun 27, 2012

Dear Doctor, I was HIV diagnosed two months ago. My CD4 were 158 (without OIs). The doctor told me to start ARV treatment immediately. I have one month taking Atripla and I feel better. However, I am worried about life expectancy because I started ARV treatment with a low CD4 count. Please, could you tell me about this? On the other way, could it be possible that stress had worsened my CD4 initial test? Thanks a lot for your support.

Response from Dr. Henry

Life expectancy varies widely. Age is of course a major factor as is presence of life style factors (smoking, obesity, activity levels),family history, other conditions (liver, renal, diabetes). A useful approach to determining 5 year mortality risk us using the VACS index (ask your physician about that-available at http://vacs.med.yale.edu/). With effective treatment the life expectancy is steadily improving with the goal to acheive near normal life expectancy for patients with good viral suppression and CD4 recovery after a while on treatment.

Relationship and HIV test

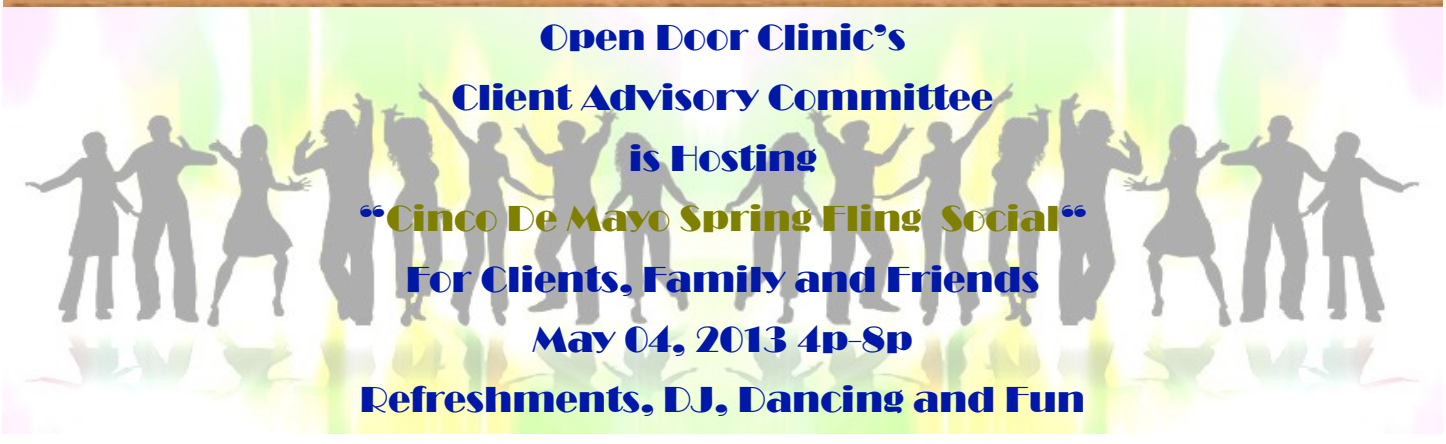
Feb 8, 2013

Dear Doc Many thanks for your very informative forum which i visit weekly. After 6 months onAtripla, my cd4 count is gone up to 400+ from 300 and my viral load is undetectable. I have been on treatment since March 2012, no major side effects. Doc says im responding well to treatment. Will my HIV results be + or - if i were to take a test?. Secondly, will kissing pass on the virus to my partner? Will definitely use condom for sex. Havent garnered courage to tell him yet but he is really pushing for the intimacy and fear if i keep avoiding the subject i will lose him. At the same time i do not want expose him. Im 45, we havent kissed or had sex and we do not see each other often but he wants a shift from that - its a long-distance relationship but he plans on moving closer to home. I know disclosure is the right way to go, but its so difficult and im honestly not ready. Stigma here in most parts of Africa is rife and there are no real and effective support groups in my country. For good HIV treatment like Atripla I have to travel to South Africa to access. Please assist.

Response from Dr. Young

Hi and thanks for posting from Africa.
Sounds like your doing very well on your HIV treatment. Despite having an undetectable HIV viral load, your HIV antibody test will always be positive.
Kissing is not a risky behavior, so your partner isn't at risk from this. Indeed, there is compelling scientific evidence that if you have an undetectable HIV viral load, your risk of transmission of HIV, by any means, is dramatically reduced even with the use of condoms- we call this premise "treatment as prevention", or TasP.
Disclosure to a new partner can be very challenging, but I'd certainly encourage you to find the words to tell your partner. Our blogs on TheBody.com or perhaps searching the interviews at The Positive Project may give you a good vocabulary to have the discussion

COME TO THE NEXT CAC SOCIAL EVENT



MANAGING LIPIDS LEVELS

The Lowdown on Lipids
Our bodies contain thousands of different kinds of fat, known as lipids. When you have your "cholesterol checked," three of these fats are measured:
HDL cholesterol (high-density lipoprotein, also known as "good" cholesterol), which removes bad cholesterol from the blood
LDL cholesterol (low-density lipoprotein, also known as "bad" cholesterol), which can build up in the arteries and lead to heart disease and other health problems
triglycerides, which can also increase your risk for heart disease if levels are too high

Marek Smieja

Infectious Diseases Specialist, McMaster University
Hamilton, Ontario

Most experts agree that HIV infection can cause abnormal lipid levels and heart disease. We're also fairly certain that the main reasons more people with HIV suffer from heart disease are smoking,high cholesterol and some HIV medications that can affect cholesterol levels.

If someone is a smoker and has abnormal lipid levels, I first try to help them quit smoking, or at least cut back. Next, a dietitian helps them find ways to lower their bad cholesterol and overall risk for heart disease through diet and regular exercise. Keep in mind that cholesterol is just one risk factor of heart disease. Even if these changes don't improve a person's cholesterol levels, there are still effective ways to reduce overall risk of heart disease.

The HIV meds known to increase bad cholesterol and triglycerides include some protease inhibitors and some older nukes, such as d4T and probably AZT and ddI. Every person starting HIV treatment should have a blood test to measure their lipid levels. I give my patients the same test six months later. If the latter reveals high bad cholesterol or triglycerides despite healthy lifestyle choices, we may change their HIV meds or start them on cholesterol-lowering drugs. While seeking to lower cholesterol, I recommend frequent testing. Once a person's level is considered safe, I recommend that they continue to test regularly though less frequently -- generally once a year.

Sometimes the body outsmarts our attempts to reduce cholesterol by producing extra bad cholesterol, even when people exercise and are diligent about their diet. When this happens, medications from a class of drugs known as statins can help. Major studies show that these drugs dramatically reduce a person's risk of heart disease-related death.

Taking both a statin and a protease inhibitor can produce various side effects -- some minor and some more serious though rare. In my opinion, too many people stop their statins because of minor side effects. It's important to remember that suffering a heart attack or stroke is a serious consequence of not taking these drugs. In the same way that millions of people remain alive because of HIV drugs, many people are still around today because of statins.

There's a lot of interest in natural treatments. Such approaches can be somewhat helpful, but changes in lipid levels generally occur as a result of a combination of lifestyle changes and drug therapy.

James Snowdon

Pharmacist, Snowdon Guardian Pharmacy
Toronto

Treatment of abnormal lipid levels is integral to improving the heart health of people living with HIV. It should start with a healthy diet, exercise, smoking cessation, managing hypertension and diabetes. These are the cornerstone of any treatment do's and don'ts.

HIV medication combos frequently include drugs that elevate cholesterol and triglyceride levels. One option for people on HIV treatment is to switch from the presumed offending agent to another antiretroviral medication. The recent introduction of more lipid-friendly drugs within existing classes (such as the protease inhibitor darunavir (Prezista) and the non-nukes etravirine (Intelence) andrilpivirine (Edurant)) broaden the options. In addition, new classes of drugs (integrase inhibitors such as raltegravir (Isentress) and CCR5 inhibitors such as maraviroc (Celsentri)) offer more options for people starting therapy and for those who need to switch drugs.

Lipid-lowering therapies that have been investigated in people with HIV include fish oils (see interview with Cheryl Collier, below), statins, fibrates, ezetimide, niacin and combinations of these therapies.

Statins can significantly reduce bad cholesterol and triglycerides. Drug interactions between statins and antiretrovirals are very common. For example, some protease inhibitors can raise the concentration of statins and can lead to statin toxicity. However, atorvastatin (Lipitor) and pravastatin (Pravachol) are less likely to interact. The newer rosuvastatin (Crestor) does not interact with many drugs.

Fibrates are a class of drugs that can reduce triglycerides significantly in people living with HIV. It is unclear if this triglyceride reduction alone is significant enough to alter cardiovascular risk. Fibrates are generally well tolerated; gastrointestinal upset is the most commonly reported side effect.

Ezetimide (Ezetrol) appears to have minor cholesterol-lowering effects when taken alone. According to one study, when taken with pravastatin, it lowered levels of bad cholesterol more effectively.

Niacin appears to be well tolerated and reduces triglyceride levels significantly and bad cholesterol to a lesser degree. A concern is the increase in insulin resistance that it can cause.

There is little information available on the efficacy or safety of people with HIV using a combination of therapies, so this should only be done with strict caution.

APRIL EVENTS

01- APRIL FOOLS DAY
02- Making Stress Work For You 12:30p-1:30p (W)
03- BARB BIRTHDAY (E)
04- Positive MH Support Group 3:30p-4:30p (A)
05- Pos Group HIV ED 4p-6p (A)
05- Pos Group Ed Night 4p-6p (E)
06- PHYLLIS BIRTHDAY (A)
06- LYNN BIRTHDAY (E)
08- Game Night 4p-6p (W)
11- Positive MH Support Group 3:30p-4:30p (A)
12- Peer to Peer Support 4p-6p (A)
12- Peer to Peer Support 4p-6p (E)
15- TAX DAY
18- Positive MH Support Group 3:30p-4:30p (A)
19- Positive Group Game Night 4p-6p (A)
19- Bingo Group 4p-5:30p (E)
20- ALL THINGS CHOCOLATE
22- Game Night 4p-6p (W)
22- EARTH DAY
25- Positive MH Support Group 3:30p-4:30p (A)
26- Pos Group Combined 4p-6p (G)
30- MIKE L BIRTHDAY CAC (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

GIVE US YOUR OPINION

Open Door Clinic 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 clinic, 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.

ALL THINGS CHOCOLATE IS THIS 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 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

ELGIN	AURORA
164 DIVISION STREET	157 S. LINCOLN AVE.
SUITE # 600	ROOM K
ELGIN, IL 60120	AURORA, IL 60505
PHONE (847) 695-1094	PHONE (630) 264-1819
FAX (847) 695-0501	FAX (630) 229-0182

www.opendoorclinic.org