NEWS & VIEWS

SEPTEMBER

opendoor
www.opendoorclinic.org

VOLUME 9
ISSUE 08

WHAT IS THE (CAC) CLIENT ADVISORY COMMITTEE?

The Open Door (CAC) Client Advisory Committee is made up of clients from Aurora and Elgin . CAC's objective is to be the liaisons to all clients. They also plan events for clients throughout the year at little or no cost to the clients. CAC plans these events to create a client community, friendships and support amongst clients.

The clients that are on the CAC are dedicated and committed to helping, and to be the voice for all Open Door clients. There are clients in this committee that have been a part of it CAC since its conception about 11 years ago and there are other clients who have bee with CAC for less than a year. Every member is focused on getting the best results possible for clients of Open Door in regards to any concerns, support and the opportunity to building new friendships through CAC events. The members of the CAC ask local businesses for donations to help fund these events, they also do the planning, setup, clean up and hosting for four out of the five events that are put on each year.

The Participation Program is a program that the CAC organizes and sponsors to help the clients of Open Door be more involved in their physical and mental health. By completing a maximum of two cards a year your name will go in a drawing to win a great dinner out with the other winners and an additional prize. There are a total of 10 winners, five from each clinic. This program goes from December 1st to November 30th of each year. So you still have time get your cards at the health centers (Clinics) and get them filled out and drop them in the Communication box at each health center by November 30th.

The CAC is also sponsoring a New Program that started this year it is the Social Activity Program. This program is based around clients attending the social events the committee puts on. This program starts at the Holiday Party in the beginning of December and ending at the fall Bowling event the following October. You get the cards at the Social events and your name goes into a drawing as many times that you attended. You will win a free VIP attended event for the 10 winners again 5 clients from each location. So when you attend an event don't forget to ask for a card and get it stamped.

The CAC ask if you plan to attend an event please RSVP to that event one of three ways: Call Aurora Center at 630-264-1819 Ext 375 OR Elgin Center at 847-695-1093 Ext. 375 (All you need to do is leave a message) OR You can email your RSVP to rsvp.odcac@outlook.com OR Drop your RSVP in the Communication & Suggestion Box at either center. We ask you to RSVP so we have enough food and provisions for everyone that attends.

Hope to see new and old faces at the Bowling event in October.

RSVP

Please RSVP For CAC Events Here's How

RSVP

There are three ways to RSVP :
Call Aurora Center at 630-264-1819 Ext 375 OR Elgin Center at 847-695-1093 Ext. 375
(All you need to do is leave a message) OR
You can email your RSVP to rsvp.odcac@outlook.com OR
Drop your RSVP in the Communication & Suggestion Box at either center
When your RSVP, we can ensure there is enough food for everyone

INSIDE SEPTEMBER'S ISSUE

IT'S TIME TO RETIRE THE MEDICAL CATEGORY OF AIDS

From TheBody.com

"Cancer is first of all a disease of the body's geography, in contrast to syphilis and AIDS, whose definition depends on constructing a temporal sequence of stages," wrote Susan Sontag in her 1987 essay "AIDS and Its Metaphors."

And while much has changed about AIDS in the intervening decades, the construction of those time-related sequences remains. AIDS is not, and has never been, a label of precise definition. It has been a soft-moving target, used to classify people with certain symptoms, but it has no relevance to living with HIV infection today.

We know that a person with HIV can look completely healthy and harbor a CD4 count of 50 cells/mm^3, or a person can look sickly and wasted and harbor a more robust number like 199. But both, by definition, have AIDS because their CD4 counts are under 200. The cause of their CD4 count decline does not matter; the presence of HIV combined with the decline is the defining factor.

I am exceedingly aware of the import of an AIDS diagnosis for many of my friends who have overcome the darkest days of this epidemic. It is a badge of honor. But it is time to retire the AIDS label altogether as medical category.

A Cavalier Label

In mid-April, I began feeling like death warmed over -- and that was on my better days. I was in and out of the ER, and no one could quite figure out what was wrong. Then a lab screw up sent me back to the ER. Within hours I was admitted to the hospital -- not for the "blood infection" the lab results showed, but PCP pneumonia (pneumocystis pneumonia) and a partially collapsed lung. The next day, I had thrush. My CD4s, maintained at a fairly respectable average of 400 since I started meds in 2010, had crashed to 110.

The initial assumption was that I had failed to adhere to my treatment. Three days later, that was shown to be untrue. My viral load was undetectable. Another, still unidentified, infection had suppressed my bone marrow activity -- crashing my immune system and my general red blood cell populations.

Despite that medical reality -- that my PCP and suppressed immune system were *not* caused by HIV, but by some other infection -- I was diagnosed and labeled with "AIDS."

I don't care about that; but I do care about the cavalier way medical terminology applies that label when there is only partial evidence. It is a box in which I shall remain beyond the grave. Because once you are diagnosed with AIDS, or HIV stage 3, you are always a person with AIDS or HIV stage 3. That is not science, it is medieval mysticism.

It's HIV Disease

It is time to retire the ill-fated staging of HIV disease. It should be called, quite simply, HIV disease. The same perspective should be taken on it as on heart disease, which represents a host of diagnoses related to the heart, or on diabetes that involves a failed pancreas.

From "Terms, Definitions and Calculations Used in CDC HIV Surveillance Publications":

A confirmed case can be classified in one of five HIV infection stages (0, 1, 2, 3, or unknown):

If there was a negative HIV test within 6 months of the first HIV infection diagnosis, the stage is 0, and remains 0 until 6 months after diagnosis.

Otherwise, if a stage-3-defining opportunistic illness has been diagnosed, the stage is 3.

Otherwise, the stage is determined by the CD4 test immunologic criteria shown in the following table: (See Table Below

If none of the above apply (e.g., because of missing information on CD4 test results), the stage is U (unknown).

As HIV infects and affects the immune system, there is no corporeal geography to which to attach the infection; there is also no one way HIV progresses. Trying to label it is an act of control that is both hubristic and futile. HIV will do what HIV will do in a body, tracking its own course.

Creating false categories to define the virus in our body creates classes of haves and have nots in our community. In reality, if we have an AIDS diagnosis, an HIV stage 3 diagnosis or an HIV stage 1 diagnosis, we all have HIV disease. We are all on our own unique uncharted journey with this virus.

Words will not and cannot control, contain, limit, minimize or stop the story that the virus will unfold with replicated viral RNA strains. Just as each of us has our own story of how we became HIV positive, we also have our own HIV disease story. Each is unique to our DNA, and pretending otherwise erases our unique experiences and our unique realities.

HIV Infection Stage, Based on Age-Specific CD4+ T-Lymphocyte Count or CD4+ T-Lymphocyte Percentage of Total Lymphocytes*

Stage*	Age on date of CD4 T-lymphocyte test					
	< 1 year		1-5 years		6 years through adult	
	Cells/µL	%	Cells/µL	%	Cells/µL	%
1	≥1,500	≥34	≥1,000	≥30	≥500	≥26
2	750-1,499	26-33	500-999	22-29	200-499	14-25
3	<750	<26	<500	<22	<200	<14

* The stage is based primarily on the CD4+ T-lymphocyte count; the CD4+ T-lymphocyte count takes precedence over the CD4 T-lymphocyte percentage, and the percentage is considered only if the count is missing.

ANNUAL BOWLING OUTING 10/4/15

Food
2 Hours Bowling & shoes
Clients and their children under 12 free

CAC Hosting Bowling Party
Sunday October 4, 2015
Registration 11:30am / Bowling & Fun Noon to 2pm
St. Charles Bowl
2520 W. Main Street, St. Charles

Please RSVP To The Party

Come and Join in on the Fun

MORTALITY GREATER, CD4 COUNT GAINS SLOWER IN HIV/HCV– COINFECTED PATIENTS

From TheBodyPRO.com

Adults coinfected with hepatitis C (HCV) and HIV gained CD4+ cells more slowly after starting antiretroviral therapy than people infected only with HIV, according to results of a large cohort study in California. Coinfected patients also had greater all-cause mortality over the study period.

HCV coinfection is highly prevalent in certain HIV populations because the viruses share transmission routes. Research indicates that both HCV and biological sex may affect response to antiretroviral therapy, but no work has addressed treatment outcomes by both HCV status and sex. To address that research gap, investigators from Kaiser Permanente California analyzed response to antiretroviral therapy and progression to AIDS or death in HIV-positive men and women with or without HCV coinfection.

The analysis involved HIV-positive adults who started antiretroviral therapy in the Kaiser Permanente health care system at some point from 1996 through 2011 and had their CD4+ cell count and viral load measured within six months before starting treatment. Researchers recorded four outcomes: CD4+ cell count in the first five years of treatment; attainment of viral load below 500 copies/mL in the first year of treatment; clinical AIDS diagnosis through 2011; and death through 2010.

The study cohort of 12,865 people starting antiretroviral therapy included 1,088 HIV-monoinfected women, 10,623 HIV-monoinfected men, 154 HIV/HCV-coinfected women and 1,000 HIV/HCV-coinfected men. Respectively in those four groups, age averaged 39, 42, 45 and 45 years; and 40%, 14%, 39% and 17% were African American.

In the first year of antiretroviral therapy, CD4+ cell count rose more slowly in HIV/HCV coinfected women (75 cells/mm^3) and men (70 cells/mm^3) than in HIV-monoinfected women (145 cells/mm^3) and men (120 cells/mm^3). After the first year of antiretroviral therapy, CD4+ cell gains were greatest in HIV-monoinfected women (30 cells/mm^3 per year), followed by HIV/HCV-coinfected women (27 cells/mm^3 per year), HIV/HCV-coinfected men (23 cells/mm^3 per year) and HIV-monoinfected men (22 cells/mm^3 per year). After five years of antiretroviral therapy, women had significantly higher CD4+ cell counts than men whether HIV-monoinfected (598 versus 562 cells/mm^3, $P = .003$) or HIV/HCV-coinfected (567 versus 509 cells/mm^3, $P = .003$).

Cox regression analysis found no link between HIV/HCV coinfection and reaching an HIV load below 500 copies/mL or risk of AIDS through 2011. But Cox regression tied coinfection to a 40% higher risk of death (adjusted hazard ratio [aHR] 1.4, 95% confidence interval [CI] 1.2 to 1.6), regardless of sex. Liver-related death largely drove the association between coinfection and all-cause mortality (aHR 6.0, 95% CI 3.9 to 9.0), but coinfected people did not have a higher AIDS death risk.

The association between HIV/HCV coinfection and diminished CD4+ response in the first year of antiretroviral therapy, but not later, reflects results of a recent meta-analysis. The Kaiser Permanente researchers proposed that differences in behavioral factors (such as substance use), biological factors (such as pharmacokinetics) or sex hormones could explain the better CD4+-cell response in women than men regardless of HCV status. Women may also have higher CD4+ cell counts than men regardless of HIV status.

Because HIV/HCV coinfection may raise the risk of all-cause mortality, the authors suggested, "HCV infection should be aggressively treated among HIV-infected individuals as recommended, regardless of sex."

THE CAC IS LOOKING FOR A FEW GOOD CLIENTS

IF YOU ARE INTERESTED PLEASE CONTACT DEAN B AT deanb.odcac@outlook.com OR CALL EITHER CENTER AND ASK FOR EXT. 375 AND LEAVE YOUR INFORMATION OR CONTACT PERRY M. OR A STAFF MEMBER FOR MORE INFORMATION

WHEN TUMMY TROUBLES STRIKE, SHOULD YOU TREAT AT HOME OR CALL YOUR PROVIDER?

When to Get Help: The Experts Weigh In

Stomach woes are an annoying fact of life. Why else would we have whole aisles in pharmacies dedicated to remedies for heartburn, acid reflux, diarrhea and nausea?

Sometimes it can be hard to distinguish between bothersome pains that may require a few extra trips to the bathroom and more serious issues for which we should seek professional medical help. This can be even trickier for those living with HIV and on antiretroviral drug regimens.

TheBody.com asked two experts -- Benjamin Young, M.D., Ph.D., and Howard Grossman, M.D. -- some basic questions to help our readers figure out when to hit the drug store for the pink stuff and when to call their health care provider instead.

Are people living with HIV more likely to have gastrointestinal issues?

They can be. Gastrointestinal (GI) symptoms are common for everyone, but can be more common among people living with HIV -- either as a consequence of immune suppression and secondary infections (among people with lower than normal CD4 counts) or as a side effect of medications.

SHOULD PEOPLE WITH HIV BE MORE CONCERNED ABOUT STOMACH ISSUES?

Not necessarily. People living with HIV who are on drug therapy, and who have both a low viral load and normal CD4 count (over 500), are essentially normal with regard to their health risks. For such people, GI symptoms are likely to be caused by acute infections, such as food poisoning or parasites like *Giardia*. They may also be a side effect of medication or another medical condition, such as a general food intolerance. Those are factors that could apply to anyone.

However, people who are not yet on HIV treatment and people with a lower CD4 count (especially below 200) are at greater risk for GI complications, some of which can be serious. They should pay close attention to their symptoms, which could be signs of serious issues such as colitis or even cancer.

IS MY SYMPTOM DUE TO ILLNESS OR A SIDE EFFECT OF MEDICATION?

Unfortunately, stomach upset is a common side effect of many medications, especially protease inhibitors. The best clue to whether it's the medication is timing. Did you just change medications or dosage? Does your stomach hurt more shortly after you take a medicine?

If you suspect that one of your medications may be the cause of your troubles, talk to your provider about the best way to address the problem. If you find that stomach upset, nausea or vomiting happens with meds and makes you miss or lose a dose, let your provider know right away. There may be a way to adjust the dosing, or (if worse comes to worst) even switch to another medicine that would be easier on your stomach. Try your best to speak with your provider before skipping doses of any of your HIV medications, to help ensure you don't begin to develop drug resistance.

IF IT'S NOT A SIDE EFFECT OF MEDICATION, SHOULD I JUST TREAT IT MYSELF?

Maybe. It really depends on what the symptoms are, how bad they are and how long they last. If you have nausea or vomiting that won't stop and you can't keep fluids down, you need to have yourself checked out right away. Blood in your stool -- whether it's bright red or black and tar-like -- also needs immediate attention.

Diarrhea, general nausea and heartburn may be things you can treat using home remedies or over-the-counter (OTC) medications unless they become persistent and last for more than a few days.

IF I DO HAVE DIARRHEA, WHAT SHOULD I DO?

As long as there's no blood in your stool, it's OK to try to manage diarrhea at home for a few days.

Start by changing your diet. Avoid all spicy foods and dairy products. Or, try the BRATT diet, which limits you to bananas, rice, apples or applesauce, weak tea and toast. It may be boring, but it can put your stomach on the right track after just a day or two.

WHAT ABOUT THE OVER-THE-COUNTER MEDICINES FOR DIARRHEA? DO THEY WORK?

Yes. These pharmacy treatments are OK in the short run, and generally don't have any drug interactions with HIV medications. But they should not be used for more than a week without medical evaluation or consultation. So, if the diarrhea continues for more than five days, definitely see your provider.

WHAT ABOUT HEARTBURN OR REFLUX? CAN I TREAT THESE BY MYSELF?

Heartburn is common in many people. If you are having these symptoms frequently, start by trying to change your diet and habits. Some people do better avoiding garlic, spicy foods, tomatoes and other acidic foods like coffee and chocolate. And, both smoking and alcohol make symptoms worse.

AND OVER-THE-COUNTER MEDICINES FOR REFLUX, CAN I TAKE THEM?

OTC medications such as H2 blockers (like Pepcid) and proton pump inhibitors (like Prilosec or Nexium) do help many. The problem is that these medications may have very significant interactions with many commonly prescribed HIV medications.

So it's not a good idea just to pick one off the shelf and start taking it. At a minimum, our experts suggest that people on HIV medications use online tools like HIV-druginteractions.org to check interactions.

Better still, work with your provider or pharmacist to pick the best medication that fits both your symptoms and the other medication you're taking.

BUT IF IT'S JUST HEARTBURN, IS IT OK TO IGNORE IT?

Heartburn may actually be a symptom of reflux disease, which can be serious. If symptoms are persistent, they really do need to be checked out.

SO, WHAT'S THE BOTTOM LINE ON WHEN TO CALL MY MEDICAL PROVIDER?

Apart from the set rules we mentioned earlier (blood in stool, inability to keep liquids down, etc.), it all comes down to gut instinct (pun completely intended).

If your symptoms are troubling you, call your provider. If your provider says they don't sound worrisome yet, ask for advice on what you should eat or take to get some relief. And then get a firm timeline for when you should call back if you don't feel better.

The most important thing, according to our experts, is having a relationship with your care provider in which you feel comfortable calling when things are troubling you, even if you don't meet a strict set of criteria for urgency.

Patient Portal is NOW Available to Clients.

Clients will now have instant access to their Medical Records and have appointment reminders if wanted. If you are interested ask the receptionist for more information to get signed up.

KEY QUESTIONS ON HIV PERSISTENCE AND CURE RESEARCH

TheBody.com

You recently became chair of amfAR's Scientific Advisory Committee. What do you think you can bring to the role of chairman?

I've got almost 20 years of experience in research, most of that in HIV, all of it in immunology, mostly in human immunology. I think that's all particularly important for the future, which really looks toward translating basic research into clinical trials in people. That's what I've been doing over the last 20 years. Given that background -- as a translational scientist in the truest form of the term -- I think that puts me in a good position to help guide the kind of research that amfAR might want to champion.

Has amfAR ever played a role in supporting your own research?

Well, the first grant I ever got as an independent investigator was an amfAR grant. It was to study a certain aspect of the immune response to HIV. And I'm still doing it; I'm still doing that project. It's much more advanced, using new technologies. But that's what set me off as an independent investigator. So I have a lot of thank amfAR for [and] I will be forever grateful.

Can you tell us more about your work?

I'm interested in HIV disease pathogenesis and prevention. I want to know why some people get infected when they're exposed, and other people don't. And why some people progress rapidly, while other people progress less rapidly. And I'm trying to understand virus factors and host factors.

In terms of my involvement in the cure field, I'm really trying to understand which cells are infected; which cells carry latent virus -- which subsets, which anatomical sites -- what is it about a cell that makes it susceptible to infection, where another cell is resistant. These types of questions are important, so that we can target our cure approaches to particular cell subsets. There might be a common theme between those cells -- a set of genes that are turned on or turned off or something that makes them the prime cells that harbor latent live virus.

Let's say you're a betting man. If we divide cure research into three basic approaches -- pharmacologic, immunologic, and cell therapy -- where would you put your money?

Well, I never bet because, remember, betting is rigged to make money for the casino! But, if I were to say which one is the best option ... it's probably going to be a combination of all three, and that's the approach we need to take. The reason there is persistence of virus in people is multifactorial. So the therapeutic approach, I bet, is going to be multifactorial.

There you go, I just bet!

In your opinion, what are the biggest challenges standing in the way of a cure?

They are the reasons why HIV becomes a persistent infection. One of them is, it infects CD4+ T cells and kills them, so you've lost your immune system, or are severely immunocompromised. Number two, the virus escapes from the immune system rapidly, so immune therapies are at a disadvantage. And number three, the virus integrates. So basically, it becomes a host gene.

You mentioned that HIV weakens the immune system by quickly killing off the body's CD4+ T cells. So even if someone is cured, aren't they still immune compromised, despite being free of HIV?

I think they would remain immune compromised. The longer I spend in this field, I think I'm coming to the realization that immune reconstitution needs to be more robust, and it should be part of the actual cure approach itself. Not just getting rid of the virus, but repairing the immune system too.

I think that's something we really need to think about, because if you look at the lifespan of people who are infected with HIV, even if they are on antiretroviral therapies, and particularly if they've started on antiretroviral therapies when they have a low CD4+ count, their lifespan is reduced. And I think that's intimately linked to the immune compromised state.

What prompted you to pursue a career in AIDS research?

I always wanted to do research. I've always been an immunologist, since before going to medical school. And I really became interested in human immunology during my

Continued on page 6

KEY QUESTIONS ON HIV PERSISTENCE AND CURE RESEARCH

Continued From Pg 5

Ph.D. Human immunology is a newish subject, in a sense. It's different from the old-style mouse immunology. With human immunology, you have to approach it completely differently. You have the people who are infected with something, and you have to design your experiment around that. You can't cause the infection in people. So you have to deal with what you've got. You have to be a little bit more inventive. The advent of HIV has really helped the field of human immunology come to the fore, because we had to do something quickly. So that whole arena was very attractive. Also at the end of the day, it sounds kind of trite, but I do what I do because the goal is to make sick people better. That's it. It's no more complicated than that. We learn a lot of stuff, and that's all very nice. But the goal is to make sick people better. It's a fantastic challenge. It's difficult, but I can see the light at the end of the tunnel. It's there.

So you are optimistic we will find a cure for HIV?

I am optimistic by nature. I look at it like this: Before the spring of 1922 if you had a diagnosis of diabetes, they sent you to a sanatorium to die. A few months later, that same year, enough insulin was being produced in laboratories, and then you lived. It's as simple as that. So, for me, that is the light at the end of the tunnel. We know that we're going to succeed. We just have to find a way to do it. But I have total confidence we will. It's going to be difficult and it may take some years, but we will.

Join Team Open Door on September 26 at the Chicago AIDS Walk! Visit our website for more info.

THE CAC HAS A NEW SOCIAL ACTIVITIES PROGRAM IN PROGRESS. WHEN YOU ATTEND AN CAC EVENTS YOU COULD WIN A CHANCE TO BE A VIP WINNER FOR A VERY SPECIAL VIP ONLY EVENT. JUST TO RMIND YOU THAT THE CAC NEEDS THE CARDS THAT ARE FILLED OUT WITH YOUR INFORMATION AND THE EVENTS THAT YOU ATTENDED HANDED IN BY NOVEMBER 30 2015.

SAVE THE DATE
CAC Holiday Party
December 12, 2015

ELGIN CENTER
1665 LARKIN AVE
ELGIN, IL 60123

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

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

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

www.opendoorclinic.org

IF YOU ARE INTERESTED IN RECEIVING OPEN DOOR'S MONTHLY NEWSLETTER VIA E-MAIL OR HAVE ANY SUGGESTIONS YOU WOULD LIKE TO SEE IN THE NEWSLETTER. PLEASE EMAIL DEAN B AT

deanb.odcac@outlook.com

SEPTEMBER EVENTS

01 - Positive Support Group (A)
4p - 5p
02 - Positive Support Group (E)
12p - 1p
03 - Recovery Support Group (E)
12p - 1p
04 - Support Group (A)
4p - 6p
07 - Labor Day
CLINICS CLOSED (A) & (E)
08 - Positive Support Group (A)
4p - 5p
09 - Positive Support Group (E)
12p - 1p
10 - Recovery Support Group (E)
12p - 1p
11 - Support Group (A)
4p - 6p
14 - Health & Wellness Group (A)
10a - 12p
14 - Pain Management Group (E)
12p
14 - Latino Support Group (E)
3p - 4p
15 - Positive Support Group (A)
4p - 5p
16 - Positive Support Group (E)
12p - 1p
17 - Recovery Support Group (E)
12p - 1p
18 - Support Group (A)
4p - 6p
21 - CAC Meeting
5:30p - 7p
21 - Health & Wellness Group (A)
10a - 12p
21 - Latino Support Group (E)
3p - 4p
24 - Recovery Support Group (E)
12p - 1p
25 - Support Group (A)
4p - 6p
28 - Health & Wellness Group (A)
10a - 12p
28 - Latino Support Group (E)
3p - 4p
28 - Pain Management Group (E)
12p
29 - Positive Support Group (A)
4p - 5p
30 - Positive Support Group (E)
12p - 1p

(A) Aurora Center
157 S. Lincoln Ave STE K
Aurora, IL 60505

(E) Elgin Center
1665 Larkin Ave. Elgin, IL 60123

(G) First Congregational Church
321 Hamilton Geneva IL 60134