opendoor
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VOLUME 7 ISSUE 7

NEWS & VIEWS

JULY 2013

INSIDE THIS ISSUE

Meet Maria Client Advisory Committee Member

How long have you been a client of Open Door? In the year 2011 I became a client of Open Door. I learned that Open Door existed when I was first diagnosed in 2010. I began to participate in support groups that same year of my diagnosis. Later after becoming part of support groups I decided to begin my care at Open Door.
How long have you been a member of the CAC? I have the pleasure of being part of the CAC for about a year and a half.
What type of things do you want to see done on the CAC? I think the CAC does an excellent job in intergrading client in social event, however I would like to see that the CAC begins to focus more on Client education such as; what they can do to improve their adherence to medications?, how they can improve their health? And what we can do to help change the laws to make healthcare and education accessible for everyone.
Describe your family? I consider my siblings my best friends, I derived from a tight knit family and they provide a tremendous support for me.
What do you enjoy doing on your free time? I love being by myself, Listening to music relaxing in a bath. I also love to travel and wish I could do this often.
Where is the Farthest you've have been away from home? I would say the farthest I have been from home is here in the United States. I consider Mexico my first home and the United States my second home. I have also been to Canada, California, Texas, Jamaica, and Dominican Republic.
What is one thing that you want to do that you haven't done yet? Skydiving, I always enjoy a good thrill
Who was the most impactful person in your life? I would say mother Teresa she taught me how to be more caring and human she had a great heart and was very loving to all it did not matter to her how much a person was worth she was just willing to help others. She had a great saying "you have to give until it hurts," and magic Johnson, because he created awareness of HIV and he was one of the first to come out openly and speak about this virus.
What have you learned in CAC? To be more tolerant of others

CAC MEET AND GREET!

PIZZA PARTY

Come join the Client Advisory Committee as we recruit new members.

The Client Advisory Committee will be holding 2 open meetings. Come meet the members, learn what we do, and hear about opportunities to join and become part of the team. It will also be a chance for the committee to meet clients and receive valuable input and suggestions that they can take back to help improve or enhance services at Open Door.

July 18, 5:30 Aurora Clinic

August 15, 5:30 Elgin Clinic

Please let us know you plan on attending by contacting Bryan Gooding 847-695-1093 x23

Open to clients only

PICNIC

August 10th First Congregational church of Geneva will be hosting the second annual Open Door Clinic School Supply Picnic Event.

And this year we have a special treat for everyone! We have a Fire Truck that will be giving free rides to those in attendance.

Then men's group at the church will be cooking hot dogs, hamburgers and corn on the cob. All attending can bring sides to share if they like.

We will assemble school supplies lists and have them packed in back packs to pick up during the picnic. So mark your calendars for—

AUGUST 10TH from 4pm - 7pm

HIV Opportunistic Infection Guidelines Updated

From thebody.com

Some very hard-working folks at the NIH, CDC and IDSA have updated the*Guidelines for the Prevention and Treatment of Opportunistic Infections in HIV-Infected Adults and Adolescents*, which are available for review here.

As with the previous versions (the prior iteration is from 2009), the OI Guidelines are comprehensive, exhaustively referenced (184 references for TB alone!), and authoritative. Note that the PDF version weighs in at 416 pages, so I doubt many people will be printing this out and carrying it around in their white coats. Fortunately, for the first time these Guidelines are also available in their entirety online in an HTML version, which is undoubtedly how most will access them, and certainly make them easier to update.

After a quick review (no, I have not read all 416 pages *quite yet*), here are a few of the notable changes, plus a couple of miscellaneous comments:

There is broadened discussion of when to start HIV therapy in the setting of multiple OIs, in particular tuberculosis. This reflects publication of several pivotal clinical trials -- here's a nice discussion of three of them, to refresh your memory.

There are updates on treatment of hepatitis B and C; for the latter, strong consideration of deferring therapy is explicitly mentioned for patients with minimal disease given the rapid pace of drug development. This must be the preferred approach for most patients right now, for obvious reasons.

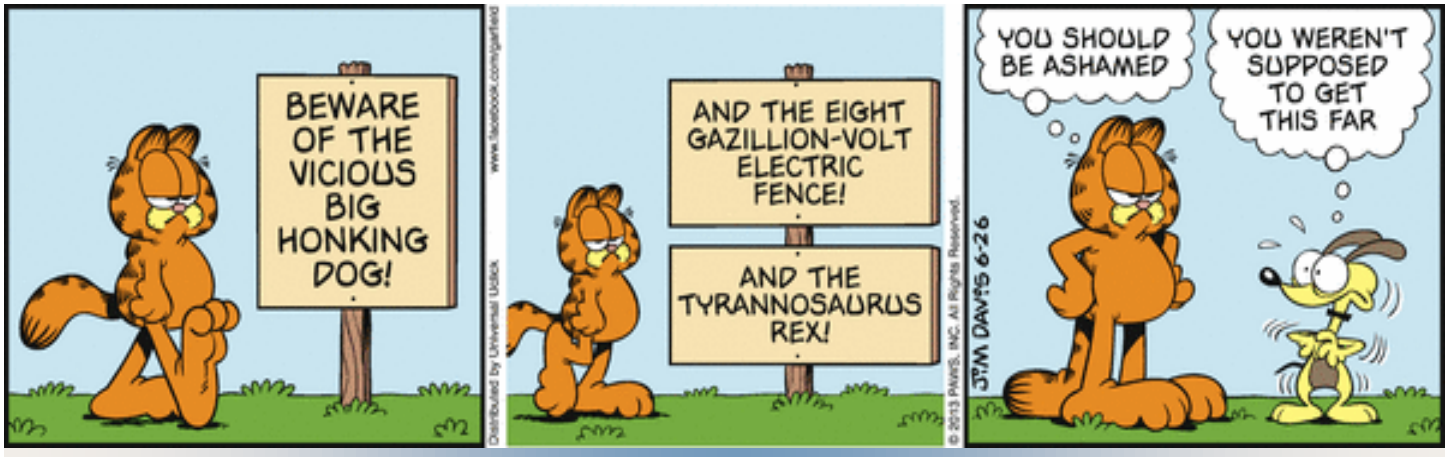
Diagnosis and management of IRIS -- again, in particular for TB -- is covered for each OI.

The structure of the Guidelines is now different, with pathogen-specific tables of recommended prevention and treatment options at the end of each OI section.

Following ACIPs lead, they endorse the three-vaccine approach to preventing pneumococcal disease -- one 13-valent conjugated vaccine and two 23-valent polysaccharide vaccines separated by 5 years; we further discussed it in *Journal Watch* here.

Vaccination for HPV is recommended for men and women through age 26. Related: still no formal recommendation to do anal pap smears on either men or women.

What about the zoster vaccine? Despite this study (presented, not published) showing that vaccination is safe in HIV-infected patients, the Guidelines provide no formal endorsement, only saying it "is contraindicated in persons with CD4 cell counts <200." (For what it's worth, I give it to all my patients older than 60 with cd4 > 200.)



HCV Transmission Rate Higher Among MSM With HIV

From U.S. Centers for Disease Control and Prevention

Researchers at Johns Hopkins University (JHU) prospectively followed 5,310 men who have sex with men (MSM) enrolled in the Multicenter AIDS Cohort Study.

The participants were men with HIV infection and men at risk for HIV. All the participants tested negative for hepatitis C virus (HCV) antibody within two years of enrollment and at follow-up visits through September 30, 2011.

The researchers followed

the group for a median of 7.1 years for a total of 55,343 years of follow-up. During follow-up, researchers documented 115 incidences of HCV infection, with an incidence rate of 2.08 per 1,000 person-years. HIV-positive men had a 4.22 HCV infection rate, approximately 8.5 times higher than the 0.5 rate for men who did not have HIV.

Factors associated with increased HCV risk were older age, HIV infection, being positive for hepatitis B, history of injection drug use, having more than 13 drinks a week, syphilis, and unprotected receptive anal sex with multiple partners in the previous six months. Among HIV-positive MSM, HCV risk decreased as CD4 cell counts increased.

Chloe Thio, M.D., associate professor of medicine at JHU, noted that the data emphasized the importance of screening MSM for HCV regardless of whether they were sexually active as they might have been infected many years ago. Also, she suggested patients should be counseled about the increased risk to receptive partners.

PRAIRIE STATE LEGAL SERVICES
Equal Access to Justice

PRAIRIE STATE LEGAL SERVICES
Equal Access to Justice

HIV/AIDS Legal Services Projects

Understanding Social Security Overpayments

What are Social Security overpayments?

An overpayment is when Social Security Administration (SSA) finds that an individual was provided more benefits than are entitled to him/her.

What are some common reasons that SSDI overpayments happen?

- Client doesn't report income to SSA after returning to work
- Client reports work income, but SSA fails to process it or processes it incorrectly
- Client receives another benefit such as a civil service pension or worker's compensation that affects SSDI benefits
- Client receives benefits pending an appeal of termination and then loses appeal

What are some common reasons that SSI overpayments happen?

- Client's income is more than expected
- Client's living situation or marital status changes
- Client's resources go over the allowable limit
- Client does not report a change in income to SSA
- Client reports income, but SSA does not process the information or does not correctly figure benefits

Other common causes for overpayments:

- Client has an outstanding warrant for flight or escape
- Client is found to be in violation of probation or parole

I received an overpayment notice, what should I do?

Contact Prairie State Legal Services. In appropriate cases, Prairie State Attorneys can investigate whether there actually was an SSA overpayment and, if so, explore remedies. Individuals who have received an overpayment notice may have options, such as waiving the overpayment or negotiating a payment plan with SSA. There are time limits on submitting forms to SSA that request waiver or reconsideration of payment, so it is impor-

Fair Debt Collection: Consumer Rights

I can't pay my bills! Now what?

When people are unable to pay debts for a long period of time, creditors will often use strong debt collection tactics. It is important to understand the consumer rights and protections related to fair debt collection practices.

Under the Fair Debt Collection laws, consumers have three important rights:

- The right not to be harassed
- The right to notice and verification of the debt; and
- The right to stop contact by the debt collector (if the debt collector is not the original creditor)

A debt collector cannot:

- Contact you before 8 a.m. or after 9 p.m.
- Contact you at your place of work once you have informed the collector that you are not allowed to receive calls there
- Call you repeatedly or continuously with the intent to annoy, abuse, or harass any person at the called number
- Threaten to use force or violence to collect the debt
- Communicate by postcard, or put anything on an envelope that looks like it came from a debt collector
- Use profane, obscene or abusive language
- Engage in dishonorable, unethical or unprofessional conduct
- Contact you if you are being represented by an attorney

Creditors are prohibited from taking certain property and income. Creditors cannot take:

- Clothes, bible, school books and family pictures
- Up to $4,000 of other property of consumer's choice
- Interest in one motor vehicle, up to $2,400
- Up to $1,500 value of trade tools
- The right to receive certain government assistance or benefits
- Any disability, illness or unemployment benefit
- Alimony, maintenance or support payments, Weekly pay that is equal to or less than 45 times the State or Federal minimum wage, whichever is higher

If you know someone who is being harassed by debt collectors, facing garnishment or wage deduction, refer him/her to Prairie State Legal Services.

LSC

For more information, contact us by phone at: (800) 690-2130 and ask for the HIV Project, or visit our website at: www.pslegal.org

United Way
LIVE UNITED

We hope this information is helpful; however, we caution people with legal problems to talk with a professional about the specifics of their situations.

Lost and Found: Helping Patients Develop Emotional Resilience

By David Fawcett, Ph.D., L.C.S.W.

From TheBodyPRO.com

Widespread publication of the treatment cascade has heightened the level of concern for engaging and retaining patients in HIV care. A significant percentage of persons living with HIV are unaware of their status, and an astonishingly low number of people have successfully suppressed their viral loads. Despite recent articles that have reported potential variation in these calculations, it is clear that a significant number of people remain out of care, marginally engaged or worse. While the causes for such poor therapeutic achievement are complex, a central factor is certainly the emotional skillset of patients and their ability to manage the negative psychosocial effects of chronic illness. HIV is an unwelcome companion that requires significant and ongoing adjustment and adaptation. Whether when first testing positive, starting medications, being diagnosed with an opportunistic infection or even experiencing HIV-related stigma, strong emotions emerge, which require both knowledge and skills to retain emotional balance. Without them, it is likely that patients will disengage through outright resistance or more subtle and often subconscious strategies, such as avoidance or recreational drug use.

Most patients dealing with HIV at first experience only loss, specifically their potential for good health, a sense of security, hope for the future and sometimes even family and friends. There are patients that can, however, work through these powerful feelings and incorporate acceptance into their lives in ways that can be profound, and which affect their personal health outcomes as well as their ability to impact others. For them, living with HIV has meant not only things lost, but new potential found.

Although this emotional resilience is highly variable among individuals, its development follows a predictable course that can be enhanced by health care professionals. It involves an understanding of change and how people react to it, and most important, guiding people through next steps while providing a sense of empowerment.

Through years of psychotherapeutic work with persons living with HIV, I have been consistently struck by the ability of many long-term survivors to incorporate the virus into their lives so that it is not granted a central role, but rather is an undeniable part of themselves that must be accommodated. This is a form of processing trauma, in which the negative emotional power is felt and expressed, thereby removing overwhelming feelings and leaving a more empowered sense of self.

I witnessed this recently at a group for long-term survivors, some of whom were in good health and others who experienced chronic pain or some other constant reminders of HIV. Each one had evolved to a place of peace with the virus and, more important, each had actually taken the devastation of infection and turned it into a source of strength and empowerment. HIV shifted the life path of nearly everyone in the room in ways they ultimately viewed as beneficial. They had experienced many losses due to HIV but had, unexpectedly, found other rewards. Many attributed the virus with a development of spirituality, an increase of community involvement, a healthier lifestyle or even (as in my own case) entirely new careers. Every person had somehow managed to retain a sense of empowerment through psychological shock, health setbacks, physical ups and downs and an overarching sense of not knowing what tomorrow will bring. Each person experienced, at least to some degree, what some have called "post-traumatic growth."

Many health care professionals are uncomfortable engaging their patients at an effective level, preferring to leave "emotional issues" to support groups or mental health professionals. Addressing or even acknowledging these more elusive processes, however, can greatly assist patients in adapting to their particular situation and achieving a degree of acceptance where they can engage their internal resources and promote their own health.

Here are some methods for improving patients' emotional resilience:

Help patients identify and express feelings

When confronted with drastic change, people typically feel that everything they understand and rely upon has suddenly slipped away. People are triggered to respond as they did at other traumatic times in their lives, often regressing emotionally to a much younger age at which they had far fewer coping skills. Helping them to identify what they are feeling and to express it appropriately is vital to move them in a healthy way beyond this shock. Encouraging them to engage their own inner resources is helpful and calming. It is beneficial to remind them of another time they successfully coped with adversity, or invite them to think about what some strong figure in their life (such as a loving grandmother) might say to comfort them.

Create a safe emotional space

Sometimes the only thing we can do is "hold space" for someone. This simply means taking a few moments to allow them to identify and express their feelings. The intensity of such moments can be extremely difficult because we too become triggered. At such times we need to heighten our own self-awareness and hold our responses in check, conveying psychological safety and giving the patient the space for their own process without rescuing them or cutting them off.

Keep the patient empowered

Once the feelings are expressed, practical steps to address the situation must be identified. Of course, patients rely on physicians to guide them with their medication regimen, but it is crucial to include the patient as a collaborator in this process. Losing a sense of empowerment is a critical factor resulting in patients drifting away from ownership of their health and medical care. Mental health professionals stay tuned in to "where the patient is," that is, keeping information and suggestions relevant to the person's level of knowledge, individual motivation, and other important cultural aspects, all the while keeping an awareness of the patient's psychological, social and even spiritual life in the context of medical care.

Assist in visualizing healthy possibilities

Patients can usually understand how HIV and all its medical consequences will negatively impact their lives. More important, they need to be able to visualize how they can successfully incorporate health and wellness into their routines. Many will catastrophize or jump to overwhelmingly negative conclusions. Building on their strengths, reinforcing existing social connections or suggesting new supports is vital. A referral to a peer navigator or support group is an excellent way to assist the patient in discovering possibilities.

Converting losses into gains is a long process requiring a variety of skills, including self-awareness, the ability to fight resistance, a willingness to put plans into action and the promotion of flexibility and persistence. Co-occurring mental health disorders, including addiction, can easily sidetrack a patient from this path. Some patients are particularly vulnerable to the emotionally numbing effects of addiction when facing the pain of negative emotions. If present, co-occurring addiction and mental health concerns, which no doubt account for a significant portion of the treatment cascade, must be addressed, as they will interrupt the healing process.

When asked what accounts for their resilience, patients describe many things, including the ability to feel and express emotions, being connected to others, a sense of empowerment (if only that they will conduct themselves with grace in the face of any complication), some form of spirituality and outreach to others. With some luck, time and encouragement from providers, most patients can foster a degree of emotional resilience that will significantly contribute to their health and wellness.

JUNE EVENTS

03 - Making Stress Work 12:30p - 1:30p (W)
04 - Happy 4th of July Clinics Closed
05 - Positive Group HIV Ed 4p-6p (A)
05 - Positive Group HIV Ed 4p-6p (E)
08 - Game Night 4pm - 6pm (W)
11 - Positive Mental Health Support Group 3:30p - 4:30p (A)
12 - Peer to Peer Support Group 4p-6p (A)
12 - Peer to Peer Support Group 4p-6p (E)
18 - CAC Meeting 5:30p - 7p (A)
18 - Positive Mental Health Support Group 3:30p - 4:30p (A)
19 - Game Night Positive Support Group 4p-6p (A)
19 - Bingo Positive Support Group 4p-6p (E)
22 - Newsletter Available at the Clinics
22 - Game Night 4pm - 6pm (W)
25 - Positive Mental Health Support Group 3:30p - 4:30p (A)
26 - Happy Birthday Perry M (A & E)
26 - 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

Questions and Answers

From thebody.com

Q WHAT CAN I TAKE TO TRIM AND TONE?

Hello. I am 35 years of age and my CD4 is 350 and my viral load is undetected. My current regimen since 04/2012 is Prezista, Norvir, and Truvada. I workout 4 days a week and I am having trouble trimming off the fat and toning up muscle. I lift weights and do intense cardio each day I workout yet I am still not seeing my mid-section trim-up nor am I seeing any definition in my muscles. I need help. What supplements can i take to help? Of course that will not interfere with my regimen.

A

Nelson Vergel

Program for Wellness Restoration

Concentrate on minimizing your sugar and processed (low fiber) carbohydrate intake. Many HIV+ people, specially those on boosted protease inhibitors with family history of metabolic issues, have insulin resistance which interferes with the proper use of glucose for energy. Signs are elevated lipids, higher than normal fasting glucose and insulin levels, and higher body fat. So we have to be very aware of the intake of foods that can worsen insulin response.

Try to follow a diet high in fiber, protein, good fats and be aware of hidden sugars and processed carbohydrates. You do not and should not be hungry when you increase your fiber intake. I have written an article on this type of diet with details: Outsmarting HIV With Healthy Eating

Keep exercising like you are making sure that you sweat for at least 10 minutes. That will raise your metabolic rate. Also, some studies have shown that those who take 10,000 steps a day tend to lose weight and keep it off more effectively. That usually means 3 miles per day (walking and adding steps at the gym on elliptical trainers or treadmills). I downloaded a free step counter app to my phone for that purpose. It sounds like a lot of steps but you would be surprised to find out how easy it is to reach that goal, specially if you live in a walking city like New York, San Francisco or others (I live in Houston where we hardly walk!).

I am an advocate of having a hormone panel done on those of us who are older at least every two years specially if we have symptoms of fatigue, lack of sex drive, and difficulty losing weight even when we follow a good diet and exercise program. Thyroid function and testosterone (free and total) blood levels are part of that panel. But keep in mind this is not part of standard of care for aging HIV positive people, so some physicians may not be willing to do this specially in public clinic settings where funds are limited.

As far as supplements go, green tea has been shown to increase energy expenditure and may also have some beneficial antioxidants. Just make sure that you do not take green tea capsules after 3 pm or so since they have caffeine that may disrupt sleep. Be careful with all the bogus supplements out there that promise fat burning since they can have cause cardiovascular issues.

I hope this information helps you! As we get older, the key is to be consistent and not fall for our own inner voices that give us excuses not to eat well and exercise. I have those voices in my head frequently even after all these years. The important thing is to be aware of them and not allow them to rule your life. In my case, fear of falling apart and not feeling my best are my greatest motivators!

More on fat loss here: Nelson's Top 10 Trick for Fat Loss

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

PLEASE EMAIL ME AT deanb@opendoorclinic.org

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