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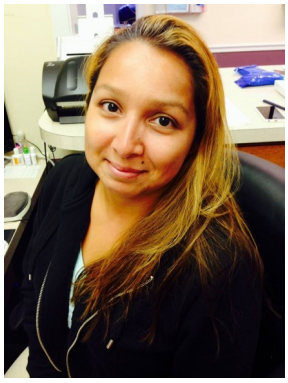
VOLUME 8 ISSUE 10

OCTOBER

NEWS & VIEWS

HAVE YOU MET ESTER YET?



Name: Esther Hancock
Title: Receptionist
What did you do before coming to Open Door? I worked at Rush Copley Medical Group as a receptionist for Gastroenterology department for 3yrs.
How long have you been with Open Door? 4 months
What types of things do you do or would like to do with Open Door? I'm the receptionist here at ODC and I hope in the future I can move up or go back to school for billing.
Describe your family (define family however you want)? My family is very small I have a daughter that is 14 years old and my son that is 10 years old.
What do you enjoy doing in your free time? I love to read on my nook as much as I can.
Where is the furthest-place from home you have ever been? I went to Hawaii.
What is your favorite food? I love pizza
What one thing do you want to do that you haven't done yet: I would love to skydive one of these days.
Who is the most impactful person in your life or most impactful person on humanity (dead or alive)? I would have to say my cousin Eddy Lopez he died in Iraq in 2006 but before he left he told me hay cuz I do this for your family and all the families in America to fight for their

INSIDE THIS ISSUE

COME AND BOWL WITH US ON 10/05/14

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THIS BOWLING OUTING IS SPONSORED BY THE OPEN DOOR CLINIC CAC

THE ONLY THING MISSING IS YOU!

PLWHA & THEIR ALLIES—A TOWN HALL

Bryan Gooding & Chris Wade

As part of the 23rd Annual Illinois HIV/STD Conference, People living with HIV/AIDS and their Allies are invited to attend a town hall meeting, October 29 at 3:45-5:00 p.m. at the Hilton downtown Springfield IL.

The conference is being held October 28- 30, featuring 3 days of workshops, presentations and speakers. Bryan Gooding of Aurora and Chris Wade of Peoria will be facilitating a town hall meeting.

Bryan Gooding has been living with HIV/AIDS for 15+ years, and is an advocate/activist for PLWHA. He has served as the past chair of Open Door's CAB (CAC), and is the current Co -chair of the Ryan White CAB at the AIDS Foundation of Chicago (AFC). Bryan is a new member of Illinois Alliance for Sound AIDS Policy (IL-ASAP) and has been involved in advocacy on both the state and national levels. As you might know, Bryan, is currently employed at Open Door were he is spread over 3 programs. Working as an Early Intervention Specialist and CAPUS Advocate, he provides support and services to newly diagnosed, and clients that have been lost to care. Bryan integrates EIS, linkage to care, with outreach and prevention, doing counseling, testing and education in the clinic and community. He also plays a role in the implementation of Part B services.

Chris Wade studied Health Care Management and Administration at Southern Illinois University –Carbondale. In 1992, Mr. Wade tested positive for HIV while residing in Los Angeles. In 2009 Wade returned to Illinois, and is currently active in his regional Client Advisory Board; the Prevention Coordinator for Central Illinois FRIENDS of People with AIDS, Inc. in Peoria, Il.; an independent contractor with the Illinois Public Health Association (IPHA) - HIV Care Connect Program Outreach; Parliamentarian of the Illinois HIV Planning Group (ILHPG); and Co-Chair of the Illinois Alliance for Sound AIDS Policy (ILASAP), an advocacy program of AIDS Foundation of Chicago.

PLWHA's and their allies are encouraged to take part in this roundtable session to discuss the formation of a Statewide Network of PLWHA's in Illinois. The goal is to provide a unified voice by, for and about PLWHA's.

An Illinois Statewide Network of PLWHA's would allow for an exchange of information, networking and opportunities to work collaboratively on larger identified statewide initiatives (stigma reduction, engagement, retention). Input from PLWHA about the communities in which they live, work and play, is a valuable tool in outreach, prevention/ education, care & treatment within those communities. Barriers to addressing health care disparities, achieving viral suppression and reduction of new infections can vary from region to region, as do the solutions. The network could share capacity building and skills to strengthen existing Client Advisory Boards and support the creation of new CABs in areas without. With the creation of a National & Illinois HIV/AIDS Strategy input from PLWHA's is essential as we implement that strategy. In turn the network can partner with the Federal, State, and Local stakeholders to ensure a unified voice, quality and continuity of care across Illinois.

The objectives of the session will be to provide the ground work and gather information to explore the possibility of creating a Statewide Client Advisory Network. We will examine capacity and skills building opportunities in order to strengthen existing Client Advisory Boards (CAB) and support the creation CABs in all Regions across the state, as well as try to identify the role PLWHA play in implementing the National and Illinois HIV/AIDS Strategy.

Please join us in this exciting opportunity.

RESILIENCY

By Diane, Christine and Bryan

When Mike was little he loved Disney's Winnie the Pooh Movie. If you recall, at one point in the movie Tigger gets stuck in a tree and looses his bounce. Despite the fact that he had seen that movie 100 times, Mike would get big crocodile tears and say "Tigger no bounce." In life, sometimes we all loose our bounce.

Most simply, resiliency is the ability to bounce back like Tigger, the bouncing Tiger, or a ball, when it hits a hard surface and returns to you! We use our resiliency to manage many types of stress from breaking up with a partner to being diagnosed with HIV/AIDS or trying to cope with the stress of living with HIV/AIDS.

You know, the opposite of bouncing back is remaining motionless, or stuck, like a deflated ball, that hits the pavement. A deflated ball remains motionless or stuck when it hits the pavement, "Tigger no bounce." We all experience periods in life when we feel deflated and stuck because something distressing has happened. But it's our response to these events that's important. If we begin to take a deep breath and let the fresh air in, we will start to bounce back much like an air filled ball, or the wonderfully bouncy cartoon character from Winnie the Pooh, Tigger.

According to Dr. Donald Meichenbaum (2006), the Director of Research at the Melissa Research Institute for Violence Prevention and Treatment, "Resilience is the process of adapting well in the face of adversity, trauma, threats or significant sources of stress…Resilience involves behaviors, thoughts and accompanying feelings that can be nurtured, developed and learned."

One hopeful take-away from Dr. Meichenbaums' definition of resilience is that we can choose to *grow* resilience. It's not the nature of the painful event that determines our ability to bounce back, but how we choose to handle it. So, we may not have control over the painful events that occur in our lives, but we do have control over the way we chose to respond to these events. Research on resiliency shows us that connecting with supportive people and avoiding isolation may help to bring some of the bounce, back into our step.

Open Door's Support Groups, provide a safe and confidential forum that allows clients to connect with other HIV/AIDS survivors. The Positive Group meets Tuesdays in Aurora at 4pm and Wednesdays in Elgin at noon. Open Door also has a Substance Use Recovery Group (Clients in Aurora please ask us about our ***New Recovery Rewards Program*** you may qualify to win more than your sobriety by signing up) that meets Tuesdays in Aurora at 11am and Thursdays in Elgin at 3pm. Lastly, there is a social-educational Group that meets weekly – every Friday in Aurora at 5pm. There are no requirements to be part of any of the Open Door Support Groups. Please consider yourself invited – you are welcome to participate!

Self-care is another skill we can practice to help ourselves become more resilient. Self-care means getting enough sleep (at least 8 hours), eating nutritious foods, taking our medications as prescribed and making sure we do at least one pleasurable thing each day. Open Door's Behavioral Health department has individual counselors and a Psychiatrist, Dr. Jessie Mabaquiao, who are available to assist you in developing your self-care plan and provide support as you learn how to use it.

Finally, the things we tell ourselves about painful or stressful events impacts our ability to bounce back. Research tells us that having confidence in our ability to manage stress is helpful as well as trying to balance the negative thoughts with positive thoughts, but there are many other skills we can develop to build resiliency. Make an appointment with one of the Behavioral Health Specialists at Open Door to get the support you need and deserve when life leaves you feeling deflated and stressed.

Please call the **Aurora** office at (630)264-1819, ext 311 (ask for Diane) or ext 316 (ask for Shannon), or the **Elgin** office at (847) 695-1093, ext 227 (ask for Shannon) or ext 226 (ask for Diane).

Meichenbaum, D. (2006). Resilience and posttraumatic growth: A constructive narrative perspective. In L.G. Calhoun & R.

THE FUTURE OF HIV PREVENTION, TREATMENT AND CARE

By Terri Wilder
From TheBodyPRO.com

TheBodyPRO.com recently interviewed longtime activist Mark Harrington, the executive director of Treatment Action Group. Harrington talks about the ramifications of the PARTNER study results, as well as what to expect from HIV treatment and care in the next five years.

How is HIV prevention changing today?

One of the really interesting things about the renewed discussion and debate about prevention in the gay community is that a lot of people are explicitly beginning to say one of the goals of ending the epidemic is to be able to have condomless sex without being worried about HIV transmission. And there are some people who can do that today, right? If you're in a seroconcordant relationship and you both got tested yesterday, and you've been totally faithful since then, you probably could have sex without a condom today. And if you're in a serodiscordant relationship and one person's got an undetectable viral load, or their partner's on PrEP [pre-exposure prophylaxis], or both, you can probably have condomless sex without risk of transmission.

Even from the PARTNER study recently -- even just one partner being virally suppressed, and the other being negative, it seems like the rate of transmission was low, was very low, in the first two years of the study. It was so low that nobody got infected, which implies that a controlled viral load is pretty safe, safer than what we used to call unsafe sex. And so we need to rebrand; we need to rethink safer sex. We can't just keep on using the same old messages from the '80s and '90s, because they're obviously not working.

We need to add new tools to the arsenal of sexual health. That includes PEP [post-exposure prophylaxis], PrEP and fourth-generation testing, with more frequent testing if you're in a high-risk group. Most people don't know about these new tools and how to use them. It's been very exciting to see in ACT UP a real hunger and awareness, interest in the emerging new science around testing incidence, transmission and epidemiology. If there were more places where those conversations were going on, I think we could have a new generation of activism to really stop the epidemic.

In terms of the PARTNER study, what should medical providers be saying to their clients?

They should say it's really early days yet, and the sample size is small, and the error bars are large. So far, there have been no transmissions observed. But if we run it out longer and with enough people, eventually there's going to be some.

How much longer, and how many more people?

Well, you can see what Jens Lundgren said about the confidence interval. He was very clear that it's really early days in the study. And the study is not saying it's 100 percent fail-safe; they were very careful about that.

On the other hand, I think it's undoubtedly good news, for that number of people followed for that length of time, that nobody's been infected. That would appear to concord with the 052 study, where there was really zero infections after treatment started. The one infection that happened in the treatment arm was already underway at the enrollment period of the study, which, remember, nobody could believe it when it came out.

What it also shows you, which is unlike the PrEP studies, the adherence to treatment in 052 was incredibly high, or there would have been more infections. There were no infections in the treatment group, except for that one at baseline. In most of the PrEP studies, adherence was all over the map. That's one of the valid issues that people had about the PrEP studies, is that adherence is all over the map. But on the other hand, now that we know PrEP works, adherence might be better, at least, in some groups. Theoretically, you could do tests for adherence with blood levels.

Furthermore, in a few years, when tenofovir [Viread] comes off patent, you'll be able to get PrEP for about 200 bucks a year.

When's that going to happen?

In about 2017. And the long-acting injectables will come around. There will be no adherence for them, unless you just don't get your shot.

So the outlook for chemoprophylaxis is just going to get better. There are going to be more options available for more delivery mechanisms. Even on some of the lists that I've been on, you can see the discussion is shifting from a discussion about condom Nazis or people who are condemning barebacking to much more of a discussion about people saying, "Well, I've started it." "I'm starting it." "I'm thinking of starting it." "Why did my doctor send me to a specialist just to get a prescription?"

People are at least willing to say that they are considering doing it. I think that's a really good sign. People were absolutely desperate for stuff. They were even willing to do stuff that *didn't* work for a long time, because there was nothing that worked or because there was nothing that they knew worked. And then, as the years went on, some of us asked for higher standards of data. Because some stuff worked for a little bit, but it didn't work for very long. And we wanted it to work longer.

We need to have standards for data and high-quality data in prevention, just like we do in treatment. People shouldn't be still putting crap in our bodies, and people should be able to use any tool that can help them not become HIV infected, whether that means more frequent testing, chemoprophylaxis, barrier methods, legal clean needles or [circumcision].

Let's talk about care and treatment for the person with HIV. Anything exciting that you think is going to be coming down within the next five years?

Well, I think dolutegravir [Tivicay, DTG] is very exciting. It's probably more exciting from the global standpoint, because it will enable us to have a cheaper second-line and maybe even first-line therapy than what we have now because it's going to be cheap to manufacture. It seems to be very potent. It's really the first drug that's come along that's really clearly more potent than efavirenz [Sustiva, Stocrin] and either more potent or equipotent with the protease inhibitors, darunavir [Prezista] and atazanavir [Reyataz]. So we really have an integrase inhibitor that's as good, or more potent than any of our other drugs. And it's a small molecule, once daily, without a booster. It's a huge breakthrough. It also happens to treat raltegravir [Isentress]-resistant [virus].

Are we concerned about resistance?

Anytime you have an antimicrobial drug, there is going to be resistance. The only way to prevent it is to not ever give the drug out at all. So we're going to have resistance to anything.

What's interesting is that, since the advent of HAART [highly active antiretroviral therapy], the incidence of transmitted drug resistance has actually gone down, because most of the people in the '90s that were on partially suppressive therapy, they got resistant to everything they were on. After HAART, most people don't become resistant at all if they're adherent -- or they might become resistant to one thing, and then they switch. So incidence of transmitted drug resistance is under 10%. And we've had HAART for 18 years now. It was higher in '94 than it is now.

I'm not terribly worried about resistance. I'm worried about people not being able to get treatment that they need, because of price, costs or health system barriers.

There are other drugs. But we're at the point where, in HIV therapy, things are pretty good, and getting better. I think where a lot of action is going to be is in trying to figure out how to improve our game and other aspects, like in chemoprophylaxis and vaccines. We're very, very far from having a vaccine.

Do you think we're going to see a vaccine in our lifetime?

I don't know. I hope so. I think they have a better understanding of what kind of antibodies they would like to elicit. I don't think they know how to elicit them.

What about a cure?

Well, apparently, two people have been cured: one baby and one adult.

We may have a third.

I know. That's what people said last year about the Massachusetts patients. We shouldn't count that third person until the second baby goes off therapy. All we know about is two cures right now: one baby, and one adult. Neither one has been confirmed with another case. At this point, they are exalted and exciting medical anecdotes.

We don't know how to repeat them. We haven't been able to reproduce what happens in them yet. So there's nothing that's scalable about it. We can't even do it in a second bone marrow transplant patient yet. We might have a second baby, or we might not. But we won't even know for a long time, because I think they're going to wait until that baby's been on therapy at least two years, or something. And I can't remember how old the baby is.

I think the baby is 9 months, from California.

We might as well not talk about it being cured until we find out when it goes off therapy. We have no idea. We don't know how to measure the reservoir. And the only way to find out is by taking the poor kid off therapy. It's not worth the risk until they're probably at least 2 years old.

What was the one thing at CROI 2014 that you were excited about?

The use of molecular phylogeny to interrupt ongoing chains of active HIV transmission among MSM [men who have sex with men] in San Diego, as presented by Susan Little from UCSD [University of California - San Diego], using the *pol* gene sequences and showing how they were assessing people's risk. Really, their risk had more to do with how many people they were connected to in their network than safety per act. And the people who are more connected in networks are more in a

situation to be part of a transmission chain.

What she said, in answer to a question, was that they have data that treating people early, like within 12 weeks of infection, and within those clusters could break ongoing chains of transmission. Now, she said it, but she didn't show data to show it. We assume it's an ongoing project that is either in submission or that they're waiting for more data.

What she did show was very beautiful molecular epidemiology using those data. It solicited some interesting discussions about community participation in prevention science. Because those individuals in the study have to consent. Now the state has our *pol* gene, for anyone that's been diagnosed. But Susan is getting their *pol*gene; and she's got data, I guess, before the state has it, or is outside of the state surveillance. Because she said their identifiers are being protected by a 13-key algorithm -- which means that nobody, "not even the NSA [National Security Agency]" can crack their ID. Now, of course, once it goes up to the state, anyone with the password to the state database can get it.

So they're concerned about the issues of community consent. They're addressing them in a prospective way. I think there's an obvious concern about if you document the relatedness of various strains of HIV, that if there's a criminalization law in your jurisdiction, those data could be used in a very, very harmful way.

But so far as we know, that hasn't been the case with these datasets up to now. And we need to make sure they're protected. But we do have the molecular tools to start interrupted ongoing chains of transmission if we can get community buy-in and willingness.

Really, it's almost like thinking about partner notification and contact tracing before you get infected, instead of after. Like, what if we did the New York Chemoprophylaxis Registry, where everyone who got PEP or PrEP was in a registry? And then, by definition, they're in an intervention cohort where you could start getting data on their networks, and then could potentially reach out to people in their network and say, "Hey, do you want to join this cohort? It's a chemoprophylaxis cohort. It's designed to help people stay negative."

And we could build on that -- just the way we have transmission networks -- to have non-transmission networks. Wouldn't that be cool? To me, that was the most exciting paper of the meeting.

What advice do you have for a young activist who's just starting out?

People ask me that kind of thing all the time. People have to find their own mission in life, their own issue, their own target, their own strategy and their own way of doing it. The one thing that older activists can do and more experienced activists can do is we can help; we can answer questions. We can help people learn. We can talk about our experiences. We can mentor people.

But you can't really mentor somebody if they don't want to be mentored. And so I think, really, it's a matter of, where are they coming from, and what do they want to do? What are the issues that really are most meaningful to them?

It's really not for me to say what a person should do with their life. This epidemic touches on almost everything that's unjust about our world. And yet, at the same time, in this one space, humanity has made more progress and shown more solidarity with some of our most excluded and despised brothers and sisters than we have in many other cases. And so, out of great suffering, some great human work has been done.

And we're far from finished, so there's plenty of work for everyone. I think we should all try to figure out how to end the epidemic as quickly as possible. But there's not one way to do it.

DONT FORGET THE NEW SOCAIL ACTIVITIES PROGRAM STARTS IN JUST A COUPLE OF MONTHS

ALL YOU HAVE TO DO IS … PICK UP A CARD AT ONE OF THE CLINICS OR AT ONE OF THE SOCIAL EVENTS, THEN ATTEND THE CAC EVENTS DURING THE PROGRAM YEAR AND GET YOUR CARD STAMPED AT EACH EVENT

THEN ALL YOU NEED TO DO IS… AT THE END OF THE PROGRAM YEAR TURN IN YOUR CARDS AND YOU JUST MIGHT BE ONE OF THE LUCKY FOUR WHO WILL BE CHOOSEN TO ATTEND A VERY SPECIAL VIP EVENT IN YOUR HONOR

COPD MAY BE COMMON AND UNDERDIAGNOSED IN PEOPLE LIVING WITH HIV

From TheBodyPRO.com
September 12, 2014

Chronic obstructive pulmonary disease (COPD) was found in 9% of people living with HIV in a large French cohort -- and most (77%) of the cases were previously undiagnosed, according to the results of a study at ICAAC 2014 in Wpresented ashington, D.C., by Karine Risso, M.D., of Nice University Hospital in France.

The study also evaluated risk factors for COPD, and found that in addition to already known risks, such as smoking and age, low CD4 cell counts were independently predictive of COPD. Given the low rates of diagnosis, and the serious progressive nature of COPD, Risso recommended a screening algorithm with six simple parameters to identify high -risk patients (see below).

Background

COPD is a progressive lung disorder, which is associated with airway inflammation, fibrosis and the destruction of lung tissue that limits airway elasticity. Upon exertion, the lungs may become hyper-inflated due to air trapping, limiting airflow and ultimately making physical activity difficult.

In industrialized countries, 95% of the cases are linked to smoking, although aging is also a clear risk factor. Although there are preventive measures (including, obviously, smoking cessation) and treatments that can slow the progression of COPD and ameliorate symptoms, they cannot completely reverse the condition once it is established.

Other studies in a population of older French adults (45 years and older) found the prevalence to be 7.5%, while the global estimates in older adults ranged from 9%-10%. Consequently, COPD is now believed to be the third most common cause of death globally.

Despite effective highly active antiretroviral therapy (HAART), a growing number of studies have begun to propose that COPD may be an emerging issue in people living with HIV for a number of reasons:

- Despite immune recovery, respiratory complaints are more common and there are more lower respiratory tract infections among people living with HIV than in the general population.
- People living with HIV are two to three times more likely to smoke.
- Studies have estimated that as many as 15% - 23.4% of people living with HIV are at risk of COPD. Some studies have suggested that HIV itself may have a role in the development of COPD, while others have questioned whether antiretroviral treatment (ART) or specific antiretrovirals might be associated with a greater risk of developing COPD.

The Nice University Hospital Study

Risso and her colleagues conducted a cross-sectional study in a large cohort of HIV-infected outpatients who visited the Nice University Hospital from Jan. 1 to Dec. 31, 2012, evaluating the prevalence of COPD with strict spirometry (a breath test measuring lung function), potential risk factors for COPD, and whether there were factors that could help predict which patients to screen for COPD. Patients were excluded if they were under the age of 18, had had a lower respiratory infection within the last two months, or were physically or mentally unable to perform spirometry.

Of the 623 patients who were screened, 42 (6.7%) were excluded for meeting one of the exclusion criteria, leaving 581 for the analysis. The median age was 48.3 years and 73.8% were male. The mean CD4 count was 622 and about 85% had an undetectable viral load. Fifty percent were current smokers and about 72% were current or past smokers. Additionally, about 23% had reported respiratory symptoms in the past.

Results

The prevalence of COPD among these patients was 9% (52/581). Approximately three quarters were unaware of their diagnosis. Only 9% had ever performed spirometry before, and only 9% were receiving any respiratory therapy.

COPD had gone undiagnosed despite the frequency of smoking in the cohort, the frequency of respiratory complaints and the existence of international guidelines on COPD screening.

A number of factors were significantly associated with COPD in univariate analyses, including: older age, lower BMI (body mass index), ever smoking, ever having used cannabis, injecting drugs, HCV (hepatitis C virus) coinfection, depression, longer duration of HIV infection, lower CD4 count, lower viral load and lower nadir CD4 count. Most of the cohort was on treatment so ART exposure was not significantly associated with COPD risk, nor was exposure to specific classes of antiretrovirals associated with COPD risk.

The following factors were independently related to COPD risk, according to the multivariate analysis:

- Age (OR [odds ratio]: 1.61; *P* = .007)
- BMI (OR: .78; *P* < .001)
- Pack-year history (OR: 1.28; *P* = .003)

CD4 count (OR: .77; *P* < .001)

Risso and colleagues also found that the following factors were strong predictors of two-to-four times more COPD risk:

- Age > 50 years (OR 2.37; *P* = .017)
- BMI < 21 kg/m^2 (OR 4.07; *P* < .001)
- Current/past smoking (OR 3.40; *P* = .031)
- Respiratory symptoms (OR 3.49; *P* < .001)
- Previous lower respiratory infection (OR 2.37; *P* = .006)

CD4 count < 500 (OR 2.19; *P* = .027)

The take-home message, according to Risso, is that clinicians should be alert to the possibility of COPD in people living with HIV who smoke and have respiratory complaints. COPD is common and frequently goes undiagnosed. Clinicians should strive to improve their smoking cessation strategies and screen for COPD, particularly in their patients who have the predictive risk factors.

OCTOBER EVENTS

01 - Positive MH Group (E) 12p - 1:30p
03 - HIV/AIDS Activity Education Group (A) 4p -6p
06 - Substance Use Group (A) 11a - 12p
07 - Positive MH (A) 4p - 5:30p
08 - Positive MH Group (E) 12p - 1:30p
10 - HIV/AIDS Activity Education Group (A) 4p - 6p
15 - Newsletter Articles Due
20 - Substance Use Group (A) 11a - 12p
21 - Positive MH Group (A) 12p - 1p
22 - Positive MH Group (E) 12p - 1:30p
24 - HIV/AIDS Activity Education Group (A) 4p - 6p
24 - Bingo Night (E) 4p - 6pm
27 - Newsletter to Clinics
27 - Substance Use Group (A) 11a - 12p
28 - Positive MH Group (A) 12p - 1p
29 - Positive MH Group (E) 12p - 1:30p
30 - Pain Management Group (A)1p - 2p
31 - HIV/AIDS Activity Education Group (A) 4p - 6p

(A) Aurora Clinic
157 S. Lincoln Ave Rm K
Aurora, IL 60505
(E) Elgin Clinic
164 Division St, Suite 607
Elgin, IL 60120
(G) First Congregational Church
321 Hamilton
Geneva IL 60134

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 AT

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