



Regional
HIV/AIDS
Connection

Community Inspired. Courage Driven.

SPEAK OUT

SPRING 2012

SPECIAL POINTS OF INTEREST:

Disclosure

Ontario Accord

Hep C support

PHA input

Evolution

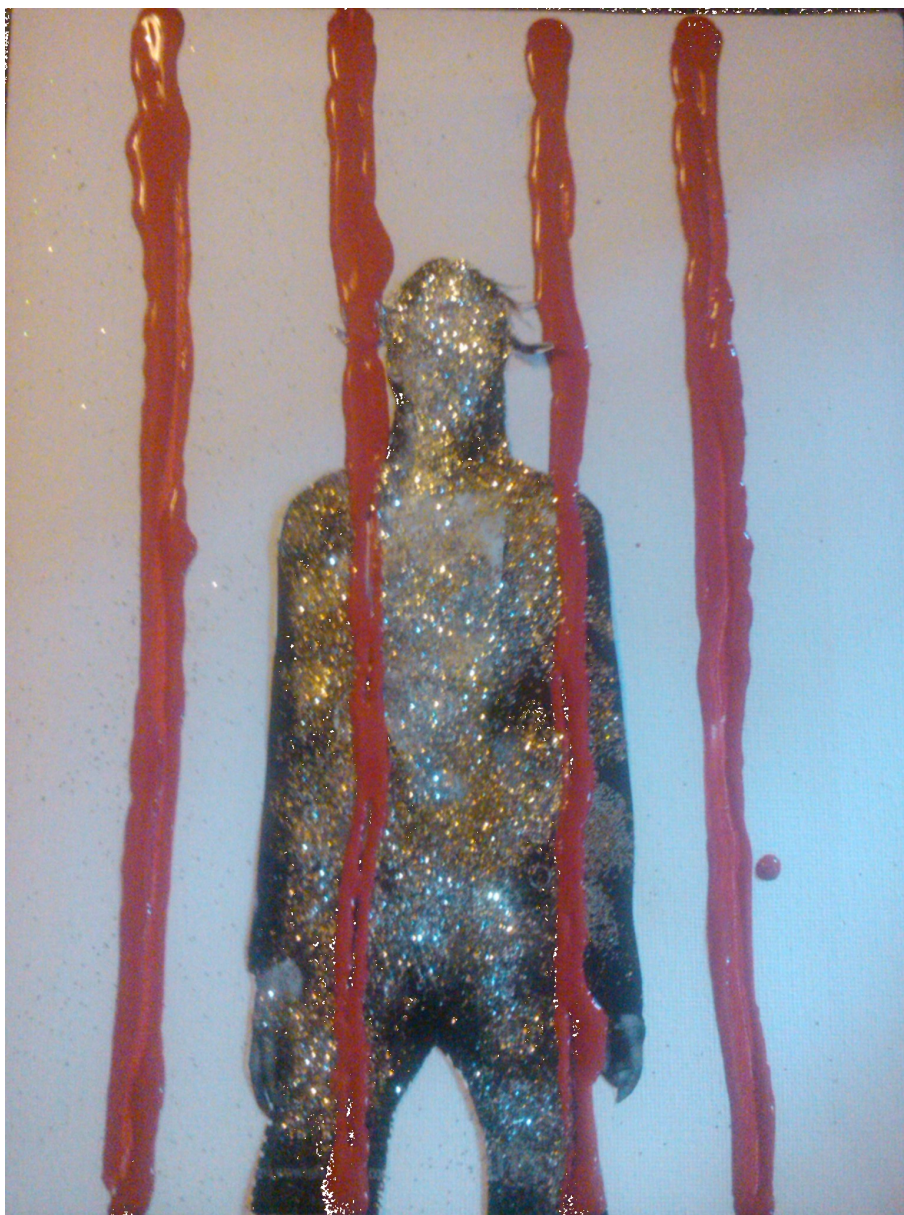
Stigma 2012

Groups

Wendake news

Taste for Life

More ...



CONSTANT CAUTIOUS CONSCIOUS

Over the last few months I have been undergoing a transformation of sorts that trust me when I tell you have had many a bump in the road. The transformation is of course a life process but I am particularly paying attention at this current junction ... which I assure you is no easy task for me as I move forward in this journey of mine. Throughout this latest leg I have been made aware of things that when I look back on I can't help but wonder about Like how long a person may have felt such a way with regard to a rather unconscious almost constant characteristic of mine. Without identifying the person or the characteristic let me assure you that this AH HA moment came with curiosity and at no time was I hurt to learn that actions, my actions, made another pause.

We need to learn these things. Information like this is important for our inner navigation system. These blips that involve another or others are the blips that we know can cause discomfort or concern. These things are more of a human – geographical issue rather than actually something I am doing wrong. This same characteristic that one may find less then appealing another could actually seek out in me But I digress as I so often do. This self awareness is in actuality a constant cautious consciousness that we do all the time in such a way that they become part of how we “operate”.

The most obvious for me is of course my HIV status. In my travels I am certain that everyone that I in one way or another come in contact with are aware of my HIV status But not only is that not true, but yes, today, after all of these years there is still that pocket of people that I have no intention in sharing my status with. For that certain person(to know that about my life would make no difference whatsoever in the dealings I have with that person.

OR I don't need to hear their CRAP..... There I've said it.

I grow weary of the uninformed the ill-informed and the plain ignorant who for whatever reason do not now nor have they ever bothered to learn anything about the pandemic that is going on in the world that they live in; and I resent that the lack of insight on their part has caused this constant cautious consciousness that it has therefore tossed me into. I must remember that I refrain from disclosure because of their ignorance and not my shame. I have no shame, but their ignorance reminds me that according to them I should have shame. That to therefore quench their thirst for details, I must explain myself, my actions, and my life.

I have had to explain a lot of things in my life; as a father, a son, a friend, a peer. For me to be careful in a conversation when I have in fact spent the better part of my adult life coming out of a variety of closets is a difficult chore And the irony of that effort on some stranger who in truth will not make or break my day week month year life is a pisser!!

I do it to keep the peace Not THE peace, just my peace.

Although the constant cautious conscious is an effort, the effort is mine to choose to make at that moment and trust me when I say it again I do it for my peace because at this stage of the game that's what it is all about for me anyway Personal peace.



Robert Newman

THE ONTARIO ACCORD

A statement of solidarity with GIPA/MIPA

We, people living with HIV/AIDS and allies in the community:

Commit to the greater involvement and meaningful engagement of people living with HIV/AIDS (GIPA/MIPA); GIPA/MIPA puts PHAs at the centre and is grounded in human rights and the dignity of the full human being.

Aim to transform all who live with, work in, and are affected by HIV/AIDS in Ontario.

Commit to personal and social transformation.

Value community expertise in embracing the challenge for the betterment of society.

Value inclusion over exclusion, a quest for integrity at all times and the embodiment of self-determination.

Promote the evolution of thought, action and collaboration among us and with our allies.

Because GIPA/MIPA is about human struggles and aspirations, ethics, empowerment and accountability are its foundation

The Regional HIV/AIDS Connection recently held an all day GIPA/MIPA training day attended by all staff and members of the Board of Directors. The day was spent looking at how we can better implement the GIPA principles in the agency. At the end of the day we held a ceremony presenting this plaque that is now proudly displayed in our foyer.

Kevin Murphy & Rob Newman
(pictured)



Man On Board: Jesse Huntus!

Hep-C Outreach Worker

I provide support for anyone living with, or at risk for Hep-C. I can help with things like housing, advocacy, information on Hep-C, accompaniment to medical appointments, or even if you just want to talk. We can meet in the office, or we can meet where you are comfortable. You will also see me around at different agencies in the community. If you are going to be spending time in the Elgin Middlesex Detention Centre (EMDC) you can request to see me. Just ask the Social Worker for the Outreach Worker from RHAC OR if you want to keep your privacy you can ask for the Outreach Worker from Intercommunity Health Centre.



“I can help with things like housing, advocacy, information on Hep-C, accompaniment to medical appointments, or even if you just want to talk.”

*Jesse Huntus
Hep-C Outreach Worker
519-434-1601 x236*

SPEAK OUT**Meet our new Hep C Peer Support Worker: Keri Wheatley!**

I am an Honours Graduate of the Addiction Worker Program at Trios College. I completed my student placement at RHAC and was so excited when I got offered the position of Hep C Peer Support Worker. I have a passion to help those who struggle with issues associated with HIV/AIDS, Hep C and Addiction. I, myself, have struggled with addiction, homelessness and poverty for the past 20 years. Through those years I learned some very valuable survival skills and have been able to transfer those skills to my current position. I identify with my clients and they appreciate that I have experienced many of the same things they are dealing with. I can share with them how I got through my own struggles and offer them the tools that helped me. There are many of our clients who knew me on the street and as they can see the difference in me and where I am at now, they have trust that it can also happen for them.

As the HCV Peer Support Worker I will be providing: Support to Clients who either have, at risk of or affected by Hepatitis C; One-to-one peer support. I will provide assistance for clients to: help them get to appointments, filling out forms, and help with housing issues and concerns. I will advocate on behalf of my clients. I will also be doing outreach and education at various locations across the city. I am available for drop in or by appointment.



“I identify with my clients and they appreciate that I have experienced many of the same things they are dealing with. I can share with them how I got through my own struggles and offer them the tools that helped me.”

Keri Wheatley
HCV Peer Support Worker
519-434-1601 ex261

Artwork and Poems by PHAS



THE WALLS COME TUMBLING DOWN

O SIEM O SIEM have you heard
O SIEM O SIEM a precious word
Open your eyes and open your
heart

For the GIFT of LIFE from "A
PLACE SET APART"

Where there are pastures of
LOVE and meadows of GRACE
Partake of the beauty from this
HOLY PLACE

Where all people are ONE and all
are FAMILY

If you believe in this it will ever
be

Blessed are those who come from
afar

Enlightened with LOVE like a
bright shining STAR

With LOVE and ACCEPTANCE
all around

You will leave your mark on hal-
lowed ground

Be a BEACON of LOVE and not a
SIGN of FEAR

The FIRE of WENDAKE will
blaze again in a year
Neither US or THEM
Just as ONE, O SIEM

These are the words engraved in
your HEART

O SIEM O SIEM from "A PLACE
SET APART"

Frederick Lush



Im lost in a maze I cant seem to escape
Tired of all the bullshit tired of all the games
Stress out and exhausted from all the pain
Slowly burnin out countin down the days
Thinkin to myself why try to change
As I mix another hit to inject Into my vains
It only helps for the moment I cant even control it
Who the fuck am I someone please tell me

My soul has been stolen

By the addict Inside me

The sands of time are runnin out

Im lost whos gonna find me

Creator I need your help from myself

This I ask of you kindly

I just want whats good in life

And leave all this chaos behind me

These pills have me by the balls

To the point im sick and crying

Askin god why me the real me is hiding

My demons walk beside me

I could tell you that I wanna Quit

But I cant so I guess im lying

Theres a war Im tired of fighting

I cant win and now I know

I need all the help that I can get

I cant do this on my own

Right now Im so alone nowhere to call home

I never thought this world could be so fuckin cold

Don't trust anybody is something I was told

Ive should of listened to what was said

Its too late to turn back

I used to love hustling on the streets

But now I feel trapped

That's the here and the now

So hear my story its very real

As a matter of fact

This is my hell my life and that's that

So make no mistake these streets aint no place

They'll chew you up and spit you out within a matter of
days

Theres no room for the weak gotta stand on your own feet

I work hard for my keep to get high and eat

Theres not a goddam thing In this world that comes free to
get what you need

It's a dog eat dog life 24 hour a day Job this is the school
of hard Knocks

Im a full fledge addict hi my names John

A junkie to the max is the way I walk

Ever minute of everyday this shit is nonstop

Tommy Hill

Evolution

They say that the one constant in life is change. I think most of us can attest to the fact that rarely does everything stay the same. Sometimes that can be scary, sometimes that can be embraced, and sometimes it can both. During my time here at RHAC, formerly ACOL, I have certainly have my share of learning curves. I feel during my time here I have developed a strong relationship with our clients and have worked with them to face struggles, challenges, as well as celebrate success.

Recently in my role I have started working more broadly with individuals who are living with hepatitis C, whether they are mono-infected, or co-infected with HIV. So far that has included direct support, connecting clients with other hepatitis C services through our partnership with the London Intercommunity Health Centre, and working with Sarah Wood, hep C educator. We have worked on coordinating lunch and learns which have explored many similar themes to our work with HIV positive individuals; these have included stigma, discrimination, treatment, and a host of other items. I also have begun working one day a week at the John Gordon Home, supporting the residents there through the various transitions which they are experiencing and the challenges that may include.

In learning about hepatitis C in my evolving role, my eyes have been opened to the level of discrimination individuals' face living with this virus. Hepatitis C affects people from all walks of life, and notably a large portion of the IDU population; an already judged and stigmatized group. As is often the case in my work here, I find the individuals who walk through our doors are often in very different places in regard to their hepatitis C status, but all of them bring skills, knowledge, and very often a strength that is admirable. The most powerful moments are those in which I am lucky to witness individuals sharing the wisdom of their experience with their peers. There is an amazing pool of knowledge and advice waiting to be accessed.

I continue to learn in this role, which is a gift I appreciate, as when we stop learning, it can be said that we stop growing as well. I look forward to the continued growth of our agency and embracing new knowledge and opportunities to contribute.



Richard MacDonagh
Case Manager
Regional HIV/AIDS Connection

This story first appeared in the Toronto Star and features a fellow PHA: Shari Margolese. It is a sad but all too honest portrayal of HIV/AIDS 31 years later and the stigma that still so profoundly exists today...



(Shari Margolese)

For four years Shari Margolese has been in phone contact with a woman who lives somewhere in rural Ontario. Margolese doesn't know anything about her — except that she is HIV-positive.

Terrified by her status, the woman has refused to seek proper treatment for her disease.

They talked about disclosure in their first phone conversation, said Margolese, a Toronto community consultant and HIV researcher at Women's College Hospital. The woman was given Margolese's number from a support worker try-

ing to persuade her to seek help.

"She said, 'I can't tell anyone. I can't tell my son because I'm afraid he won't let me see my grandchildren. I can't tell people at work because I'm afraid I'll lose my job and I'm close to getting my pension.'"

The woman wouldn't go to an HIV clinic. She saw her doctor after hours, telephoned AIDS service organizations but never went to one. And any information related to her illness she had delivered to a post-office box.

In a country such as Canada, with decades of readily available treatment for HIV and clinics and programs devoted to the disease, the stigma and shame associated with the virus continues to be a barrier, HIV experts say.

HIV advocates and physicians say they still encounter people with the disease who don't seek treatment, increasing their risk of death and spread of the disease. By the time they go to hospital, they have deeply compromised immune systems, and sometimes full-blown AIDS.

"They don't want to look themselves in the mirror and say 'I'm HIV positive,' " says Dr. Anne Stewart, a family physician and medical director at [Casey House](#), a palliative care hospital in Toronto for people living with HIV or AIDS.

"So they don't test, don't get treat-

ment, avoid dealing and they'll come to you 10 years into their disease with the complication of AIDS which, in this day and age, is a travesty."

An estimated 65,000 people in Canada (26,630 in Ontario) were living with HIV in 2008, the most recent figures available through the Public Health Agency of Canada. It is also estimated that nearly 17,000 of those people are unaware of their status.

What isn't known is how many of those individuals who test positive for HIV do not seek treatment, although an Ontario study last year found one in 10 men and one in 14 women had not gone for viral-load testing a year after being newly diagnosed. The test, which measures the amount of HIV in one's blood, should be done every three to four months to determine the need for anti-retroviral drugs.

Earlier this month, an American study found one in four people with HIV do not stay in care, the first comprehensive nation-wide look at patients and their willingness to seek treatment over time.

"Our findings show too many patients are falling through the cracks," said lead author Baligh Yehia, a fellow at the Perelman School of Medicine at the University of Pennsylvania.

(continued next page)

fear of exposure. “It is such a traumatic diagnosis that people can’t and don’t and won’t face it,” he said. “It’s easier at the time to ignore it and pretend it’s not there.”

Dr. Ahmed M. Bayoumi was lead author of the HIV chapter in the Ontario study, a government-funded report last year that also found one in five people diagnosed with HIV had not had a first viral-load test within three months of testing positive. The Ontario Power study findings, he said, point to a gap between initial diagnosis and accessing proper care.

Stigma, fear, mental health and addiction issues, lack of health-care coverage, and immigration status and the high cost of drugs — it can cost over \$1,000 for a month’s supply of an anti-retroviral regimen — are the most common reasons given to explain this phenomenon.

Bayoumi, a research scientist at St. Michael’s Hospital, says because of the readily available treatment for HIV, there is a general perception that issues around HIV aren’t that prominent anymore.

“I think that really neglects the experience for a whole lot of people for whom saying that you’re HIV-positive would result in ostracism and discrimination within their own communities,” he said.

This month, leading AIDS experts at Johns Hopkins and around the world released new guidelines on how best to encourage HIV-

positive people to seek treatment and stay in care. Among the strategies: assign a “navigator” or personal guide to help each newly diagnosed person through hospital and other services; assign a nurse or case manager to regularly follow up; use automated devices that alert a physician to lapses in care longer than six months; and provide one-on-one, instead of group counseling.

Margolese says there are initiatives like these in place in some parts of Canada, but funding for them remains a challenge.

Dr. Mona Loutfy, an HIV specialist and researcher at Women’s College Hospital, said she has a handful of patients who do not consistently seek care “and they’re dying.” Yet, the disease is completely manageable, she added.

“If someone comes in today, I can start them on one pill once a day and the average life expectancy is 40 years from diagnosis,” said Loutfy. People can live a normal life, she added.

Loutfy can’t say whether it is because of stigma, but adds there is certainly a component of denial.

She recently had a woman come in late and pregnant. Her CD4 count, a measure of immune system strength, was 30. (A healthy person’s CD4 cell count is between 500 and 1,500 cells per cubic millimetre of blood.) Loutfy couldn’t

figure out why she had come in so late because the woman knew her husband was HIV-positive. She ended up very sick and was hospitalized a l i z e d . Meanwhile, Margolese continues to wait for another call from the woman in rural Ontario.

She has spoken to her unknown client about five or six times. “And I still don’t know her name. I worry about her.”

Margolese has referred her to services she can access anonymously, like the [Canadian AIDS Treatment Information Exchange \(CATIE\)](#). But that is all she can do.

“It’s challenging because this is the population that’s not in care, so that means it’s difficult to reach them.”

Dr. Mona Loutfy, an HIV specialist and researcher at Women’s College Hospital, said she has a handful of patients who do not consistently seek care “and they’re dying.” Yet, the disease is completely manageable, she added.

SPEAK OUT

For Your Information...

Groups at the Regional HIV/AIDS Connection

PHA Café: Monthly social support group

Women's Group: Monthly social support group

Winner's Circle: Monthly social support group for long-term survivors

Open closet : Weekly LGBT2Q Youth group for teens aged 14-18

Bathhouse BINGO: Monthly Safer sex education at the Bath house

Hep C Peer Support Group "C" Life: Weekly support group

Volunteer Training: Anyone interested in volunteering-

Ambassador Training: A comprehensive capacity building program for volunteers who are interested in representing the agency at educational Speaks, booth & venue specific outreach.

For more group information contact

Regional HIV/AIDS Connection

519-434-1601 / 1-866-920-1601



Registration for Camp Wendake is May 1, 2012 ... if you are interested in attending camp this year; camp fills up very fast so be here on May 1st to fill out a camp application and RHAC will mail it in for you.

SPEAK OUT

Who we are...

As of January 1st 2011 The AIDS Committee of London will be doing business as The Regional HIV/AIDS Connection. We will be providing the same services and programs for people living with and affected by HIV/Hep C.



Community Inspired. Courage Driven.

Our Mandate is to serve the 5 counties surrounding London and to:

- Improve quality of life for those living with & affected by HIV/AIDS
- Reduce the number of new HIV infections
- Increase community awareness about HIV/AIDS

Our service users include thousands of people: those living with HIV/AIDS, their partners, friends and family, and those who are concerned about HIV/AIDS—anyone at risk for HIV, and anyone who provides services to people with, or at risk for, HIV. All of our services are free and confidential.

We are a registered charitable corporation, #11877 9008 RR0001.

“NOTHING ABOUT US WITHOUT US”

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This newsletter made possible by the generosity of...

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