

Publication: FALSE BAY ECHO Title: Quashing stigmas

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PICTURES: KAREN KOTZE

■ The African Independent Cat Association held its cat show at the Muizenberg community hall on Saturday June 24. Pictured is Carol Middleton as she waits for judging with her Maine Coon, Highlanders Cashmere in her arms.

More pictures on pages 6 and 9

Quashing

A Muizenberg resident hopes to help turn the tide on the negative perception of HIV/Aids...

KAREN KOTZE

an it be true, that in 2017, there is still stigma about testing positive for HIV/Aids? Can it be real, that in this digitally advanced world – this digitally advanced world—where information is but a click away—there is still misunderstanding and fear?

Niles Hemming of Muizenberg is learning that this is indeed, true, and real for many

people. People whose fear of reprisals, whose fear of being shamed, keeps them silent. Ultimately, people who die; rather than admitting they need the medication which can save their lives. Yes, says Niles, stigma and

radical misinformation still exist. So he has launched a campaign to educate people, and uphold the dignity of people living with HIV. He also wants to create support groups for newly diagnosed people which offer new and relevant information at the vertiginous start of their journey. He says every person of the 35 million diagnosed worldwide started this journey with a secret, that being, their diagnosed.

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He wants to help people here move through the five stages that he experienced: in whichever order they occur, from the initial secret of that diagnosis, through truth, cour-

age, shame to resilience.

age, shame to resilience.

Niles also speaks about the vital importance of universal access to PreP – which is a medication which has been designed as a preventative measure to ensure that your body does not contract the virus. A medication which can be taken by anyone.

So what is Prep? PreP stands for pre-exposure prophylaxis. Niles points out statistics which show that PreP medication can reduce the chance of a neerative

reduce the chance of a negative HIV positive person by more than 90%.

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Campaign will be taken across the far south

The next step – which our government is looking at offering – is offering PreP to people who are HIV negative; to keep them that way.

It is not, Niles points out, a cure. "However, it stands to reason that if we treat generations of people with PreP and eradicate the chance of the virus spreading, then that is close enough," he says. "The government here is looking at rolling out PreP and discussions have been taking place as to which groups should be targeted. I believe that this is the wrong approach, though. The high risks approach, though. The high risks groups are men who have sex with men, and sex workers. I think by tar-

men, and sex workers. I think by targeting specific groups we are at risk of stigmatising those groups and stigma is already playing a huge role in the high rate of new infections," he says.

Niles's personal belief is that PreP should be offered to anyone that wants to take it. "And yes we need studies and stats, but let's not stigmatise anymore than we already do. I agree with Professor Quarrasiha Abdool Karim. She is an epidemiologist who is the associate scientific dirgist who is the associate scientific director of The Centre for the Aids Programme of Research in South Africa (CAPRISA). She suggests that aiming right thing to do, in terms of public PreP at particular groups is the wrong approach because it will stigmatise PreP use. She says it may be better to make it available to those who want to use it as part of combination prevention and let those who need to protect

Willies hails from the UK and lived there for seven years with his personal HIV positive status never causing any issues. Then he moved to South Africa, and here, hid his status for 10



■ Niles Hemmina

themselves choose what they want to use. We know that the more options people have the more likely they are to use the option that works best for them at a point in time." The aim, Niles says, is to stop trans-

mission, and he believes all individuals mission, and ne beneves an individuals should have the right to choose to take PreP. He points out that while the cost is a factor to the government, in relation to the cost of treating those with the disease, it's pretty much the

years because of negative comments, disrespect and misunderstanding: in a word, because of stigma.

"How does it feel? I can say for me that it really hurts the core of a person's self-esteem and self-worth. I felt hurt, powerless, and mostly ashamed. The shame came from a sense that I had brought this on myself. I felt dirty. I could almost feel the HIV on my body and it was there for all to see even though I knew this was not the case. I felt small and utterly defeated. I felt a need to hide from myself,

utterly defeated. I felt a need to hide from myself, hide under the duvet, and never come out again. I also felt moments of suicidal thoughts. It would have been easy not to face up to the realities that I needed to face, in order to stay well," he said.

The first person Niles told in South Africa was a nurse whose response was "Oh, how dreadful." This left him a bit stunned. He thought, if somebody in the medical field responds this way, how will the general population, or people less educated on health matters. "I am now coming out HIV positive and devoting my time to fighting this terrible stigma. It's about having negotiated the full gamut of responses to the diagnosis, and growing a resili-

of responses to the diagnosis, and growing a resili-ence – held strong with experience and clear facts. "It is about having the guts to stand up against the hate and say enough. I have had enough," Niles

He has dedicated a Facebook page to his cam-He has dedicated a Facebook page to his campaign and has several celebrities speaking in support of his efforts. He is funding himself and devoting his energy full time, to the campaign. Part of his campaign has been to visit Kalk Bay in person with a sign which says "HIV does not discriminate, and nor do I" and ask people to be photographed with the sign. The next areas he will take his campaign into are Ocean View and Masinhumelele. into are Ocean View and Masiphumelele.

Jenkor

He uses a spoonful of sugar as a visual aid to explain how HIV antibodies are measured and read by doctors in our immune systems, and what that means for treatment and options. "I want to help maintain the dignity of every person who is diagnosed positive. I don't ask them how they got it, that's no one's business. I only want to point them in the direction of help so that they can live well. I have lived with it for 17 years, and I guarantee most people would never have known if I had not said anything about it. "It need not be a death sentence. Medication is

never have known if I had not said anything about it.

"It need not be a death sentence. Medication is available. We just need to allow people access to it by quashing the stigma which prevents them from reaching out for it." Niles says.

Using the sugar as an analogy of a single drop of blood, Niles separates the grains from the pile which represents your CD4 count (which is your healthy immune system) into the pile of grains called the viral load, which represent the virus, and he shows the shift between the two piles of sugar, with and without medication.

Niles was recently able to communicate the correct

Niles was recently able to communicate the correct Niles was recently able to communicate the correct facts to an elderly person who had been too afraid to the HPIV positive family members visit her, use the toilet, or have a cup of tea. "Knowing the truth now allows that whole family to heal," he says. "This is what I want to have happen, on a massive scale."

Niles says that he calls all HIV positive people his heroes. "It's interesting that if someone survives cancer they are called heroes, but not so for HIV," he says. To learn more about what Niles is doing and find helpful resources, visit Niles' Facebook page: https://www.facebook.com/NilesHIV/



