



STEVE'S JOURNAL.

Key thoughts:

You must be positive, if you are positive .

Yes, I have AIDS and HIV is always with you.

You should never go around others when you are ill and you should never go around anyone who is ill either.

AIDS or HIV is still a death sentence, if you are run down and catch a bug.

Being alone is one of the worst things that can happen to anyone.

When you miss your meds and take drug holidays, you may become resistant to your HIV meds. We only have so many combinations to fight HIV.

If you have had sex with one person, you need to be tested for HIV, whether you are gay or straight.

Education is the key to understanding and stopping HIV.

10.1.11

The day starts as every day, with a hand full of pills. Since starting meds in 1996, I have NOT missed taking my meds. Not missing even one pill. Wow, wonder how many thousands of pills I have taken since January 8, 1996? Sue and Paul (sister and brother-in-law) come out again today to help with getting the yard ready for planting all my trees, flowers and cacti. It's another long day. Tried to keep going and helping to do things, but had to take several breaks. Had to rest my ankle and use my cane the last part of the day, for my hip is trying to give out from under me. My hip and shoulder are really hurting! This damn medicine! Yes, it has kept me alive, but the side effects are hell to deal with. The pain in my ankle is one thing, I deal with and accept it, for I broke the ankle in 2007. It is the shoulder and hip hurting that aggravates me so. The meds, that I have taken every day since 1996, have created the problem of aseptic necrosis. Blood clots have caused the socket of both my hip and shoulder to die and start grinding to pieces. The grinding of the socket causes me pain and makes my hip feel like it's giving out and not going to hold me. The same thing happened back in 2004, when I had to have my right hip replaced and the core decompression on the left hip. The medicine to fight HIV has caused all of this to happen. I guess the pain and hip giving out on me are reminders that I have AIDS. This is all with me and on my mind every day.

Note to diary: I write AIDS, as Aids. For I will not let Aids control my life!

10.2.11

My pills first thing. A reminder every day that, "Yes, I have Aids!" I have been dealing with this for so long that having Aids is just part of my life. HIV is always there! Sue and Paul came out to work on the yard again. Getting old and having problems with this body sure slows me down. Sue keeps telling me to sit down and rest. The family does not get bent out of shape, because I cannot do things and have to take breaks. All of the family gripes at me, but I know they all do love me! There may not be any of the family to come to my house for quite a while, but then they find time to come and help with things that I cannot do any longer. The not being able to do things, really bothers me. Before I got sick with toxoplasmosis on 1-8-1996, I had a good job that paid well, rental properties, and new horizons ceramics, that mom took care of and earned her some extra money. I did plumbing, electrical work and was a jack-of-all-trades. Now I am dependent on others for help. I have always helped others and been independent, but after getting sick, becoming a PWA, [Person With Aids] Aids has made me become dependent in many ways. Asking for help is something that I could not do, because I have always felt I had to take care of my own things. So I would rather let things that I cannot do, go. I would rather the family see something that needs done and come help do it when they find some time from their own jobs. I am getting better at letting them know I have something that I cannot do.

I have always felt to ask for help is the same as begging. I will not beg for any reason, especially because of Aids.

10.3.11

Ron's birthday – road trip planned, but a sore throat and earache wake me early. Have to get my blood work drawn for I see Dr. Pierone in a few days. Have gotten blood drawn every three months for the last 15 years. I am a hard stick, but got seven tubes of blood with the first stick. Coughing starting, so I call Ron and tell him I will not be able to go to Fort Lauderdale with him today, for am I starting some kind of bug. Make a rain check on the road trip. You should never go around others, when you have a bug or anything and you should not go around anyone who is ill either! Since I am fasting for the blood work, I get a good breakfast at the diner next to Quest Labs. Then I head home to rest and start fighting this bug.

10.4.11

This bug woke me a couple of times in the night. I called Dr. Pierone's office and leave a message for him that I have a sore throat, earache, am wheezing and have a temperature. Knowing that any bug you come down with can end up killing you, when you have HIV or Aids, I know I must get in tune with everything in my body and what the bug is causing.

Start taking the medicine that Dr. Pierone faxed in. Now to keep positive thoughts and know this medicine is going to stop this bug and keep me out of the hospital. Feeling bad, so going to bed to rest more.

10.7.11

I have been sick in bed and did not write in my diary. The following is how I felt and what I was thinking about this bug and HIV.

I got my blood drawn and now what has the bug done to my T-cells? Something else to worry about. This medicine is going to work and stop this bug and everything will be better. Feel really bad and staying in bed. Wake up and feel like I am going to die! I know I have to think about positive things for I am positive; to help my T-cells to fight HIV and this bug. I must do everything I can if I'm going to survive. I have to miss going to my Reiki group. Reiki is what I need. It would help me stop this bug. Aids is still a death sentence, if you are run down and catch a bug. I hope that since my T's were very good, that there are enough T's to fight this bug and HIV, so I can

keep living.

I keep reminding myself that, "You must be positive, if you are positive."

Each time I wake up I still feel like I'm going to die. This damn Aids! It already tries to rule my life, but I have not and cannot let Aids control anything.

Aids is a vicious varmint that wants to rob me of my life. Be positive – think positive. My mind kicks in gear about my partner, John, and hundreds of friends I have lost, since the beginning of Aids. They died with the help of Aids, but I had to face these deaths, every one, and then find a way to movement on. I have all the memories of each person. Aids made what they went through a horror story, filled with many bad things. I cannot go back to those bad memories, for they will just pull me down and my T-cells down. When I lie in bed feeling like I am going to die, I feel so close to John and love him as much as I did 21 years ago. We had more than 15 wonderful years together before John was diagnosed with PCP and with Aids. Those memories have helped me keep going and fighting HIV. I don't want to die. I have so much more that I have to do. I can't die, because I do not know if my nieces and nephews would understand. I would never hurt anything in the family or anyone and I will not let Aids hurt them either.

Still feeling real bad and knowing what having Aids with any bug can do to you, brings me to the reality of what is going to happen if the virus has killed too many of my T-cells. If I let this kill me, what then, I make myself have the strength to write down my "Last Request," so my family and friends will have things taken care of and know that I love them!

Starting to feel better! I am going to make it. I have beat Aids again! My positive thoughts and good memories have helped keep me here for another day and many, many more. Still have to take it easy, because even though I am feeling somewhat better does not mean I am out of the woods yet.

Still reminding myself that, "You have to be positive, if you are positive!"

My Tigre knows that I am sick and she stays as close as she can. Pets always know what is going on and when you are feeling bad. Tigre has been with me for 22 years, so we have been through the good and the bad.

10.8.11

Still feeling better. Haven't given in to let HIV take over. I have beat Aids one more time!

10.9.11

Another day of feeling better. My sister called wanting to know why I am not at Railyn's birthday party. I have not been out of the house, since I got the medicine that helps take care of this bug I had. I do not want to give this to anyone either, but Sue tells me that everyone at the party already has the bug. Railyn is three. I go to the party and stay to see Railyn open her gifts and eat her piece of cake. Feeling tired and tell everyone I am going home and take a nap. Sue tells me to be sure to be at her house for the dinner she and Paul are fixing for me. When I tell her I better just stay home and rest. Sue said I have beat "it" and go take a nap and be at her house at 6:30 p.m.

Bad storm wakes me, so get dressed. Storm seems to have stopped, so head into Vero. Lightning has struck a power transformer and fire and sparks are all over the road. I have beat HIV/Aids and I am not taking any chances otherwise. Call Sue to tell her why going to be late and water high in canals, so may have to take more detours.

When I arrive at my sister's home, the family surprises me with a birthday party. They know this is another milestone in my life of fighting Aids. It is so good to have everyone of the family together and my favorites – German chocolate cake and coconut cream pie. I feel so close to each

one and I am thankful that I have the understanding family that I do have. It is so good to have everyone together and know that they care about me. I am very lucky, for many friends back in the 1980s were disowned, when their parents learned that they were gay and had Aids. In the 80s we took care of each other and the gay community had to come together to help everyone deal with what Aids was doing to us. Today this helping each other is not happening here.

I have said many times that being alone is one of the worse things that can happen to anyone. I guess that really I have never been alone for I have had my three girls (cats) and all my friends back home in southern Indiana and Louisville, Kentucky. I feel my friends are with me always. Having this helps me to fight HIV every day.

10.10.11

Have an appointment with Stephanie, my counselor. She has helped me deal with many issues. Dr. Pierone sent me to see Stephanie the next day after I told him that I had planned to drive to China and had to take my three girls with me, because no one would take care of them, if I were gone. Until I was alone and had this driving to China come to me, I had never been depressed, as far as I know. Stephanie and I talked about everything. I am the president of our Area 15 Aids Consortia and the representative for several groups and a local and statewide advocate. Stephanie knows how I am always concerned about our clients and all the cuts in the area. I owe everything to Stephanie for she helps me keep on track and deal with issues as they arrive.

10.11.11

(PWA – Person With Aids) – Today is my birthday. I made it to 60. Making it another year is a great thing, but being 60 tells me that I have been HIV positive for one-half of my life and a PWA the last quarter of my life.

HIV has guided my life in the many ways I fight it. Educating myself about Aids, when John got sick, started a never ending process of education. My entire life I have been one to help others. HIV has made helping others an important part of my life, from support groups to working in our Aids Consortia and advocacy work. I feel that I have helped someone along the way.

10.12.11

Feeling better, but not totally over the bug. Have to take it easy, rest and nap for HIV is holding me from getting over this as quickly as others that do not have HIV would.

10.13.11

One of our HIV prevention planning groups today. Have to miss another one of our Aids service organization meetings. I have to take care of myself and get this bug out of my body, so I can feel better and get myself back in good shape.

Have to fight HIV.

10.14.11

Taking it easy and trying to get my strength back. I go out to help Paul, my brother-in-law, with landscaping my yard. Cannot do much, so have to go rest.

Having HIV and Aids is bad enough, but when you catch anything it becomes major and if you aren't as lucky as I have been again, well we really have to work to fight HIV and Aids.

10.15.11

Rest. Being 60 and having Aids demands so much from your body.

10.16.11

Feeling better. Over this bug, but I know HIV is always there.

10.17.11

Call CVS pharmacy to order refills of my HIV meds. Intelence and Isentress.

10.18.11

Pickup HIV meds. Intelence and Isentress from CVS pharmacy.

This combination of HIV meds has helped boost my T-cells from 476 to 1006. Hope they keep working for me!

10.19.11

Put all my medicines and vitamins in my pillboxes.

With my pillboxes, I have not missed one pill since I started taking HIV meds, plus many other meds since starting to take meds 15 years ago.

10.20.11

A very busy day! Appointment with Dr. Pierone, my infectious disease doctor. I know my T-cells were going to drop, because of this bug I have had. They only dropped 192, which is 550 in October 2011 from 742 in July of 2011. My T-cells had never been over 475, until we switched meds to Intelence and Isentress. I would have been in the hospital again, if my T-cells had only been around 475.

Now this 192 drop means I have to get my health back to a better level, so my T-cells will go back up. Plus mainly because with my immune system compromise by this bug...is something else, another bug or "???" I may not be lucky enough to survive being pulled down again. The Aids would rear its ugly head again and take advantage of my system being compromised. Also I must keep my T-cells in health and good shape, because I have to have my left hip replaced, when the pain becomes constant and unbearable. Plus, heaven forbid, that I might fall, then there would be no putting off the surgery to replace the hip. This damn medicine! The medicine has kept me alive but it also has caused the side effects.

Next, to the HIV prevention planning group's "meet and greet" luncheon where I am a host. I am the group's treasurer and also represent the Care Network of the Treasure Coast – Area 15, the Aids Consortia. I introduced myself to attendees and told them I am positive. Being a CAG, Consumer Advocacy Group member under the state DOH bureau of HIV/Aids, I agreed to tell people that I am HIV positive, so we can fight stigma and get people to ask questions about HIV and Aids. Also by disclosing my HIV status, I hope to break the ice for someone that is unsure about being tested or someone who is HIV positive to feel that they are not alone. You have someone that you can talk to. Ask questions and learn how HIV has been dealt with in my life. I am still alive after dealing with HIV for 30 years. So HIV/Aids is not the death sentence that it was back in the 80s – if you take care of yourself and take your medicine. I have not missed one pill since starting meds in 1996. When you miss pills and take "drug holidays," you may become resistant to your HIV drugs, when you start them again. There are only so many combinations of our HIV meds, then nothing will help you. So taking your meds as prescribed will help keep you alive and going forward.

I am the president of the Care Network of the Treasure Coast, our Area 15 Aids Consortia and I give my time in all the committees, groups, and anything else to help our clients. I am glad that I can do things to help our clients. The luncheon was good for I talked to people who know about HIV/Aids, but now they know someone with Aids and how HIV is affecting my life. Education is the key to understanding HIV/Aids. And then hopefully they will realize that they need to be tested. If you have had sex with one person, you need to be tested for HIV, whether you are gay or straight.

On my feet all day and the neuropathy is making my feet and legs throb. Again, my HIV meds have caused this neuropathy problem. Also my hurting, because the HIV meds that I was on for years saved my life, but has also caused a blood clot to form just below the socket. To stop the pain in my hip and shoulder, I must have both replaced. I am not looking forward to two more surgeries, because I have coded twice while under anesthesia. It does not do any good to blame HIV or Aids because the meds to fight the HIV has saved my life and given me these extra years. Sixty years. My fear of anesthesia has lessened because I have talked with my counselor and she is helping me deal with the fear of dying while under anesthesia. HIV messes with every part of your life, your body and your mind.

End the day by going to my Reiki group. Again, I am fighting HIV, for Aids is responsible for my neuropathy. Reiki is helping and I have more feeling and less pain in my feet and legs. Since 1996 the neuropathy has caused me to not have any feeling below my kneecaps. The only thing I feel is the constant pain.

10.21.11

Please, shoulder, don't start hurting NOW!

10.22.11

Why doesn't everyone practice safe sex? If they did and everyone, yes, everyone gay, straight, bisexual, MSM, WSW, etc., that has ever had unprotected sex with anyone would get tested, then we would be able to slow the spread of HIV.

10.23.11

Alvin called to see how I am doing and tell me that he and David were going to the planning group meeting in Wheeling, West V. Alvin cannot get anyone to get him any facts or figures on HIV/Aids in West Virginia. Alvin has a list of questions he plans to ask those at the conference.

Talked to Ron about this project, "Faces of HIV" and appointment in Ft. Lauderdale October 27, 2011. We plan a road trip to Ft. Lauderdale on the 27th for the photo for "Faces of HIV."

10.24.11

Left leg keeps giving out on me. Will have to have the hip replacement soon, if this keeps giving out. Walking with my cane. If I should fall, then would probably have hip replacement immediately. Marty, my brother, calls to see if I have gone to Tampa for meetings. He always calls after the meetings are over to make sure I made it home okay.

New cell phone, so since I have Aids anything can happen at any time, I set up my ICE. Emergency contact of Marty and Ardith and Sue and Paul. Found where I can put ICE information. Put that I am allergic to Demerol, Tetracycline and Bactrim. Call Dr. Pierone at 772-257-5785.

10.26.11

PCPG, Patient Care Planning Group in Tampa.

Get up early and have to wear long pants. This is Florida and I wear shorts year round and long pants for meetings in church. Wearing shorts has not affected my T-cell or caused problems with my system and Aids. Drive to Tampa for the PCPG meeting. The Aids institute has our rooms reserved, so I can put some of my medicines in the refrigerator. This meeting is one way I can help others. We get a lot of good information, facts and figures. Tom Liberti gives us good news that with the Ryan White funds, we received extra funds for ADAP. The ADAP wait list will be going down by 1500 clients in the next two weeks. Aids and life give me enough stress. If I were one of the over 4000 clients on the waiting list waiting to receive my HIV meds – I just do not know how anyone can be under that constant stress and keep healthy and also keep a positive

attitude. Stress will kill you! When you add HIV to stress, well, the equation is a bad situation. In my Area 15, we have been able to get HIV meds for those on the ADAP wait list with help from organizations and pharmaceutical companies. Networked with other attendees on things that they are doing for their HIV clients and ways to deal with stigma and adherence to medications to help prevent resistance to our HIV drugs. Have a lot of information to bring back to our Area 15 Consortia, ASO's and our clients.

Arrived home at 6:30 p.m. Long two days, but worth being tired, because have learned a lot of information about HIV/Aids in Florida and our Area 15.

Area 15 is Indian River County, Martin County, Okeechobee County, and St. Lucie County. The Area 15 Aids Consortia is a Care Network of the Treasure Coast.

10.27.11

Road trip for Ron and I to Ft. Lauderdale. Appointment from 12:00 to 2:00 p.m. for a photo session for "Faces of HIV."

With not knowing the details of this appointment, I just go into it with an open mind. This is one of the best days of my life. Everyone involved with this is very professional in their role and gave me a feeling of being at ease. Like Ron and I were getting together with a group of friends. The young men setting up for the interview were very easy to work with and explained everything and helped me to relax. I am several years older than all that were at the studio and we did a good job with the entire session. The questions were answered with ease for they were questions about my everyday life. Everyone, the questions, and photos made me feel very proud to be part of "Faces of HIV."

10.28.11

Feeling very good about being a part of "Faces of HIV."

Raining today and my hip is hurting even more. I guess that the HIV virus is going to make me have every joint replaced. I am not looking forward to any of that.

Have dinner with family and tell them everything about this project and how I feel that this is going to help people to think about HIV, being tested and taking care of themselves if they are positive.

10.29.11

Called a client that my counselor, Stephanie linked us for. He wants to be active with our Area 15 Aids Consortia and support groups. We need more clients to attend our Consortium meetings, so those HIV positive have a voice in the workings of services, etc., in Area 15.

10.30.11

Reflecting on how HIV has played a part in my life. Being positive and a person living with Aids is both good and bad. I have learned so much about all to do with HIV. Learned to keep in tune with everything going on with my body. Things to do and things not to do.

10.31.11

Alvin calls with a report that he was only able to get a very few questions answered at the patient care planning group for the state of West Virginia. Seems that they do not want clients in West Virginia to know anything about Ryan White funding and services.

Leg giving out on me, but I keep going, for I have so much more to do.

I thank "Faces of HIV" for this experience and making me even more aware of HIV and Aids every single day. I am proud to be part of this campaign to help with education about HIV.



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