

WELL INFORMED

CREATED BY THE SPOKANE HIV/AIDS ADVOCACY GROUP TO INFORM, CONNECT AND INSPIRE OUR COMMUNITY

Spring 2016



Strength for the Journey (SFTJ) is a five day spiritual retreat that began as a gift from the United Methodist Churches in Washington and North Idaho, to persons living with HIV/AIDS. The retreat seeks to provide a tranquil, safe place and a caring, supportive community.

This years SFTJ retreat will take place from **August 22 thru 26** at Camp N-Sid-Sen located in Harrison Idaho on beautiful Lake Coeur d'Alene.

Applications to register for SFTJ retreat will be available May 23rd at their website:

www.Inlandnwstrengthforthejourney.com, SAN & SRHD and other locations around Eastern Washington and Northern Idaho including HIV medical providers.

Applications will not be mailed directly to past participants.

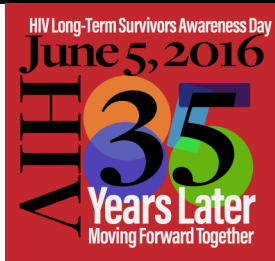
To provide a retreat experience for as many as possible, a fair process will be used to fill all available spaces. Applications must include Provider Release for Participation signatures from your doctor and your mental health provider if you have one.

Applications with \$25 fee to help cover retreat costs must be received by July 20th.

Bus transportation is being arranged to and from the camp for those who need it. Bus pickup will be in Spokane and Coeur d'Alene.

Confirmation letters and more detailed SFTJ retreat information will be mailed out by August 1, 2016.

WE LOOK FORWARD TO SEEING OLD FRIENDS AND MEETING NEW.



SPOKANE BEGINS TO TALK ABOUT HIV LONG TERM SURVIVORS ISSUES

by Mark Garrett, SAN Peer Advocate

On a beautiful Spring evening March 30th in Spokane an amazing thing happened. Nearly 40 Long Term Survivors both infected and affected by HIV/AIDS gathered at Spokane Regional Health District auditorium. The Let's Kick A.S.S. (AIDS Survivors Syndrome) Eat & Learn dinner presentation was originally scheduled on November 17, but had to be cancelled at the last minute due of the devastating windstorm that left thousands in our area without power and worse.

It has been 35 years since the U.S. Centers for Disease Control and Prevention (CDC) first released a report about a mysterious illness that would come to be known as HIV. For the next 20 years, AIDS would hit the gay male community unrelentingly hard. As a community, we would care for and bury hundreds of thousands of our loved ones. Without effective treatments to offer hope, thousands of us became caretakers while preparing to die ourselves. Even for those who remained uninfected, it was a traumatizing time that required extraordinary resilience and ingenuity to survive. Many of our fellow survivors feel invisible and forgotten by even their own community. We are simply not in the zeitgeist or **spirit of the time**.

We are into the fourth decade of the HIV epidemic and half the people living with HIV are 50 or older. By 2020 that number will be 70%. This is a wakeup call to focus on the needs and reality of older individuals aging with HIV. Because we had the audacity to survive we now face a host of challenges few of us could have predicted.

Long-term survivors face a myriad of interconnected psychosocial, practical, and medical challenges rooted in HIV-stigma, aging, ageism, and economic distress that impacts functional health-related quality of life (HRQoL) See article about quality of life study pg. 2.

The AIDS epidemic has been a series of traumatic events. We now know that surviving can also have trauma-related implications. The legacy of our past is having an effect on our lives now, and too many survivors are unaware of what may be happening to them.

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- Spokane Begins to Talk About Long Term Needs
- Spokane Participates in International Study Measuring Quality of Life for HIV Patients in Treatment
- Aden's Advice: Exercise
- Mental Health Therapist Joins SAN Team
- Joe Ready Joins State HIV Planning Group
- State Cannabis Patient Protection Act of 2016
- April - June Calendar



There has been a lot of discussion lately about expanding HIV group support and education in Spokane and Wenatchee areas.

To better understand the unmet need in this area, SAN and SRHD are working together to help address the psychosocial wishes of our diverse HIV community as quickly as possible.

Men's and Women's Support Groups are being developed by SRHD and SAN. Some groups will be focused and intentional, with topics determined by the support group members and facilitated by a licensed counselor free of charge.

Space may be limited so please contact your HIV Case Manager for more information.

Well Informed will share more details in the Summer issue.

Spokane Participates in International Study to Measure Quality of Life for HIV Patients on Treatment

STUDY UPDATE PENDING FINAL REPORT: By Jackie Romaine, Janet Bayfield and Clare Bradley, Health Psychology Research Unit, Royal Holloway, University of London, Egham, UK

Existing symptom measures were outdated and there was no quality of life measure designed for people with HIV. New measures were needed for use in clinical trials and other studies of treatments for HIV and the work has been supported, in part, by ViiV Healthcare (a specialist HIV company dedicated to delivering advances in the treatment and care of individuals living with HIV). We set out to design two new measures, the HIV-dependent Quality of Life (HIVDQoL) measure and the HIV Symptom Rating Questionnaire (HIVSRQ), each in UK and US English. As is the case with other questionnaires we have designed for people with other medical conditions, we have a patient-centred approach to the design of the measures, including patient input throughout the design stage and ensuring that the questionnaires provide an individualised assessment of the patients' Quality of Life (QoL) and symptoms.

Draft questionnaires were produced using templates for—HIV Quality of Life and -Symptom Related measures developed in previous work by Dr Bradley. Items were selected from existing item banks, a review of relevant research and transcript analysis of 68 interviews with people living with HIV conducted in Europe. Twenty-five participants with HIV, recruited by Opinion Health, took part in telephone interviews. The questionnaires were revised as needed between interviews, until no new content/changes were required. On completion of the design interviews the HIVDQoL included 26 items including 10 existing, 12 modified and 5 new items. The HIVSRQ included 64 items including 31 existing, 24 modified and 9 new items. The questionnaire design work was presented at the International Society for Quality of Life Research (ISOQOL) conference in Vancouver Canada in October 2015.

In order to assess the reliability and validity of the questionnaires and determine the optimal scoring we collected data from 128 participants from the UK and 127 participants from the US who completed a questionnaire pack including the newly designed HIVDQoL and HIVSRQ and four other questionnaires for comparison purposes. At the time of writing, analyses are underway. There are already plans for the questionnaires to be used in clinical trials and large scale studies and linguistic validation work is underway to produce Italian and French versions of the questionnaires. It is anticipated that the new quality of life and symptom measures, together with our existing HIV Treatment Satisfaction Questionnaire (HIVTSQ), which is already in more than 40 languages, will help to improve the evaluation of the quality of life of people living with HIV, and better inform their health-care providers about the pros and cons of treatments available.

Participation involved completing a questionnaire package which took about 20-30 minutes. As a token of appreciation, participants received a \$40 Amazon Gift Card after completing and submitting the survey. If you participated and did not receive your Amazon Gift Card please contact Mark Garrett, Peer Advocate at (509) 455-8993 or markg@san-nw.org.

WELL INFORMED WILL REPORT RESULTS OF THIS STUDY WHEN AVAILABLE.

Continued from page 1 - HIV Long Term Survivors

The effects of sustained trauma now present in combinations of depression, anxiety, emotional numbness, anger, survivor guilt, insomnia, nightmares, hypervigilance, hopelessness, substance abuse, sexual risk-taking, low self esteem, avoidance, social withdrawal and isolation, and/or lack of future orientation.

If history teaches us anything, it is that when we come together we can make a difference in peoples lives. With courage and compassion, we strive not only to survive HIV but also to thrive into full, meaningful, productive, independent and connected lives. We want to continue a respectful conversation among peers and educate the world about the existence and power of survivors. The power of a grassroots movement is that it is from the bottom up not the top down.

As a result of our March 30th "Let's Kick ASS (AIDS Survivors Syndrome)" chat, several individuals volunteered to meet to plan next steps in this conversation here in Spokane. Their hope is that we can develop greater awareness within our HIV community about "AIDS Survivor Syndrome" and aging with HIV/AIDS.

PLEASE JOIN US IN CELEBRATION AT
SPOKANE'S FIRST HIV LONG-TERM
SURVIVORS AWARENESS DAY:

Saturday, June 4th 10am - Noon
Shadle Park Public Library
2111 W Wellesley Ave., Spokane
99205

Refreshments provided. This gathering will be a celebration of our successes, sharing of challenges and an important conversation about our future

For more information contact:
Mark Garrett @ markg@san-nw.org
509 455-8993 x230

2016 National HLTS Awareness Day
Theme: Moving Forward Together



Aiden's Advice



Are you getting the recommended amount of daily exercise to help you stay healthy?

Doing regular physical activity can make you and your canine companion feel good and it can have a number of health benefits for both of you. For example, it reduces the risk of developing heart disease, stroke, high blood pressure, some cancers, type 2 diabetes and 'thinning' of the bones (osteoporosis). Regular physical activity also helps to control weight and may help to ease stress.

For most adults, the Department of Health and Human Services recommends these exercise guidelines:

- **Aerobic activity.** Get at least 150 minutes a week of moderate aerobic activity or 75 minutes a week of vigorous aerobic activity. You also can do a combination of moderate and vigorous activity. The guidelines suggest that you spread out this exercise during the course of a week.
- **Strength training.** Do strength training exercises at least twice a week. No specific amount of time for each strength training session is included in the guidelines.

Moderate aerobic exercise includes such activities as brisk walking, swimming and mowing the lawn. Vigorous aerobic exercise includes such activities as running and aerobic dancing. Strength training can include use of weight machines or activities such as hiking or heavy gardening.

As a general goal, aim for at least 30 minutes of physical activity every day. If you want to lose weight or meet specific fitness goals, you may need to exercise more. Want to aim even higher? You can achieve more health benefits, including increased weight loss, if you ramp up your exercise to 300 minutes a week. **Always check with your doctor before starting or increasing an exercise program.**

Short on long chunks of time or tire easily? Even brief bouts of activity offer benefits. For instance, if you can't do one 30-minute walk, try three 10-minute walks instead. What's most important is making regular physical activity part of your lifestyle.

Don't forget to include your dog and please stay well hydrated.



MENTAL HEALTH THERAPIST JOINS SAN TEAM

Spokane AIDS Network (SAN) took a major step forward in its goal to help provide comprehensive and accessible support services for their HIV clients. In February Jessica Garry, a Licensed Mental Health Therapist was invited to provide individual and couple counseling to SAN clients. Jessica has over 15 years experience in the field of mental health that includes a wide variety of areas including depression/anxiety and addiction. This is a pilot program and only accessible to clients of SAN at this time.

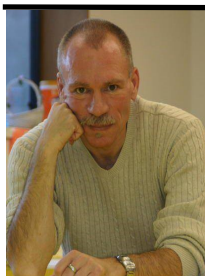
Jessica believes that a person's thoughts impact their emotions, that the past impacts the present. And that we only have here and now, at any given moment. Her commitment to honor diversity and spirituality and truly enjoy being with people are some of the many reasons SAN chose Jessica. She has an optimistic nature and believes in looking for possibilities and building upon ones strengths.

"I enjoy and cherish people and their stories. And that I get to be a part of a persons process of discovery, growth or healing is a great honor to me. I believe in the ability for people to heal, grow and change. I bring myself into the counseling relationship, first and foremost. I draw from techniques that are uniquely tailored to each individual client and what they identify as wanting to be better in their lives."

Individual and couple counseling sessions are offered to all SAN clients on-site at SAN and over phone & Skype. There are resources for transportation to sessions, if needed. **Please contact your case manager at SAN for more information and referral to Jessica.** It's important to utilize this new mental health resource to help SAN assess the benefit of the program for 2017.



New SAN MH Therapist
Jessica M Garry, LMHT



Joseph Ready

Joe Ready Accepts Position on Washington State HIV Planning Steering Group (HPSG)

Many of us know Joe as the Volunteer Coordinator at SAN who always welcomes new SAN volunteers. What you may not know is Joe's commitment to represent Person's Living with HIV/AIDS (PLWH/A) in HIV planning for over a decade.

Joe was an active member of our local and regional HIV care and prevention planning group until those groups ended in 2011. He served on the Client Caucus Committee a consumer member of the EIP Steering Committee for 7 years until that transitioned in 2014.

In 2015, Joe worked tirelessly to represent PLWH/A by serving on the End AIDS Washington special committee of the new State HIV Planning Steering Group (HPSG). Joe with others around the state helped draft the states plan to reduce new HIV infections by 50% by 2020. Joe has proven his dedication and passion to serve our community and we congratulate him on his recent appointment to the new State HIV Planning Steering Group (HPSG).

SO THANK YOU JOE FOR YOUR MANY YEARS OF SELFLESS SERVICE.

Joe welcomes input from PLWH/A and providers to help him represent your needs and concerns. Email him at JosephR@san-nw.org.

Washington State Medical Marijuana Law - What's New Cannabis Patient Protection Act

The new [medical marijuana regulation bill \(PDF\)](#) goes into full effect July 1, 2016, integrating the medical market with the current regulated market.

Primary Goals

- Clarify what is meant by the medical use of marijuana.
- Better protect qualifying patients by regulating medical marijuana products to ensure a safe, adequate and consistent supply.
- Allow for tax breaks for medical marijuana patients who are entered into the authorization database.

Provide protection from arrest and prosecution for patients who are entered into the authorization database.

Department of Health's Role <http://www.doh.wa.gov/YouandYourFamily/Marijuana/MedicalMarijuana>

The department is writing rules for three main components of the law:

- ⇒ [Consultant Certification Program](#) - New Permanent Rules
- ⇒ [Authorization Database](#)
- ⇒ [Product Compliance](#)

In addition, the department is directed to:

- Consult with the Liquor and Cannabis Board about medical marijuana endorsement requirements for retail stores.
- Develop and approve continuing education for healthcare professionals who authorize the medical use of marijuana.
- Make recommendations to the legislature about:
- [Establishing medical marijuana specialty clinics](#); and [Rescheduling marijuana](#)

Contact Us

Well Informed appreciates your comments and suggestions and welcomes your support.

Well Informed Newsletter
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(509) 455-8993 x230

markg@san-nw.org

Visit us on the web at
www.spokaneaids.org

The information contained in this newsletter is offered for the purpose of educating people with HIV/AIDS. Nothing contained in this newsletter should be construed nor is intended to be used for medical diagnosis or treatment. It should not be used in place of the advice of your physician or other qualified health care provider.

Spokane Activities and Events for April through June 2016

- **SAN Food Pantry - 2nd & 4th Thursday monthly 11:00 am - 3:00 pm (lunch 12-2:30 PM) @ SAN - 905 S Monroe Street, Spokane.**
Contact your HIV Medical Case Manager or Assistant Case Manager for information and referral. **Thank you to our pantry volunteers!**
- **Living Positive Peer Support Dinner 2nd Monday monthly 5-7pm @ SAN - 905 S Monroe Street, Spokane, WA 99204**
Persons Living with HIV/AIDS meet in a safe place to share peer support and friendship-**You are not alone.**
Call Mark Garrett, Peer Support Facilitator @ 509.455.8993 or email markg@san-nw.org for more information and ridesharing.
- **Hepatitis AIDS Substance Abuse Program (HASAP) Support Group meets weekdays @ SRHD 1101 W. College Ave.**
For more info and referral contact your case manager or Marie Phillipson at 509.838.6092 mphillipson@nhccspokane.org

~ Upcoming Events ~

- **June 4- 1st Annual Spokane HIV Long-Term Survivors Awareness Day Event** "Moving Forward Together"
10 AM to Noon at Shadle Park Library, 2111 W Wellesley Ave., Spokane 99205. Refreshments provided.
- **June 11 - Annual Spokane Pride Parade and Rainbow Festival** - Theme is Pride 25: Silence to Celebration
Pride Parade begins at Noon and Rainbow festival from Noon to 10pm fireworks display. Riverfront Park in downtown.
- **June 15 - Patient Eat and Learn Dinner Presentation:** 5:30 to 7pm @ SRHD - 1101 W. College Ave, Spokane.
"Aging with HIV" sponsored by Gilead Pharmaceuticals. Free to Person's with HIV.

For more information and volunteer opportunities contact

Spokane AIDS Network (SAN) 509.455.8993
905 S. Monroe Street, Spokane WA 99204

Spokane Regional Health District (SRHD) 509.324.1542
1101 W. College Avenue, Spokane WA 99201

Remember to Register and Vote

Washington State encourages every eligible person to register to vote and participate fully in all elections. Each of us is responsible for protecting the integrity of the electoral process by providing equal access, and guarding against fraud and discrimination. You must be a citizen of US and legal resident of WA State, 18 by election day and not under supervision by Corrections for felony.

Deadline to register, make address change or other updates is October 10th. Registration forms are available at SAN

Spokane County Elections Office 1033 W Gardner Ave Spokane, WA 00260 509.477.2320