

HIV + Aging Research Project | PS

## \*NEWSLETTER\*

VOLUME MMXXIII - ISSUE 3, PAGE - June + July 2023

**PROJECT** 

**INFORMATION &** 

REGISTRATION:

WWW.HARP-PS.ORG/

POSITIVELY-AGING-

## **SAVE THE DATE**

SEPTEMBER 23, 2023 9:00AM - 3:30PM PST



#### **BODY MIND SOUL**

A symposium on living and thriving with HIV, featuring highprofile keynote speakers & other prominent figures from the HIV/AIDS community.

#### PETER STALEY

Long-term AIDS and Gay Rights Activist, first as a member of ACT UP New York, then as the founding director of TAG - the Treatment Action Group. He's the leading subject in the Oscar-nominated documentary "How to Survive a Plague." Staley recently published his memoirs, titled "Never Silent: Act Up and My Life in Activism."

√ 760-760-HARP (4277)

info@harp-ps.org

info@ha

LOCATION:

**MIZELL CENTER** 

480 S SUNRISE WAY

PALM SPRINGS, CA 92262

PETER STALEY

AIDS & GAY RIGHTS

KEYNOTE SPEAKER

**ACTIVIST** 



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Jeff Taylor
Executive Director HARP-PS

## National HIV & Aging Long-Term Survivors Awareness Day

June 5 is National HIV & Aging Long-term Survivors Awareness Day, which commemorates the first report in 1981 of what later became known as AIDS to the CDC, by LA physician Dr. Michael Gottlieb. Fast forward 42 years, and though people with HIV are no longer dying in huge numbers like they were in those awful first fifteen years, they are instead faced with multiple challenges and daily insults as they grow into an older age neither they nor their doctors ever expected them to see.

Beyond the research we do, HARP is committed to ensuring that we remember the legacy of those we've lost, and those who've paved the way for an HIV-free future. One such

pioneer was beloved Palm Springs resident Timothy Ray Brown the so-called "Berlin Patient", who was the first person cured of HIV. Sadly, while Timothy's HIV was successfully cured, his cancer was not, and we lost him to a relapse in 2020. Last year, as part of our partnership with the NIH-funded Delaney Collaboratories for HIV Cure Research, named after notable HIV research activists Martin Delaney, we held the first annual Timothy Ray Brown Community Cure Symposium to honor Timothy's memory, and share the research that's being conducted to eventually cure this disease.

This year we'll be reprising the program on World AIDS Day (December 1) at the Palm Springs Cultural Center. Drs Paula Cannon from USC and Sumit Chanda from the Scripps Institute in La Jolla will speak to the research they're doing in the RID Collaboratory. The state-funded stem cell research initiative, the California Institute for Regenerative Medicine, will present their work in HIV as well. Our featured guest will be "City of Hope Patient" Paul Edmonds--a local man whose own cure from HIV was featured in the news recently.

Earlier that same day, we will honor the memory of Timothy Ray Brown by placing a star on the Palm Springs Walk of Stars on Museum Way directly in front of the location of the future AIDS Memorial Sculpture. We can't think of a more fitting way of honoring the person whose cure gave hope and provided the impetus for the hundreds of millions of dollars now invested in finding a cure for HIV. Of course a star on the Palm Springs Walk of Stars is not free, so we have started a to raise the \$15,000 needed. Please check out the link and consider making a contribution so we can make this tribute to Timothy a reality.

Go Fund Me for Timothy Ray Brown

STAR

on Palm Springs Walk of Stars

**DONATE** 



Our friends at Let's Kick AIDS Survivor Syndrome/Palm Springs are hosting a dinner for National HIV & Aging Long-term Survivors Awareness Day on June 5. Click here for more info and to RSVP



Research and Programs
Director HARP-PS

# ATTENTION! Virtual Village Seeking Volunteers

HARP-PS, is excited to launch a new virtual village program, for people over 50 living with HIV, in the Coachella Valley. we need your help to make this program a success!

This project manifested itself after grew out of a two-year



partnership with UC Riverside, USC, and University of Tampa to explore the efficacy impactof an on-line platform where people with HIV can socialize, learn, and engage with others, as many long-term survivors experience loneliness and isolation.

The virtual village will offer a range of services and activities for people over 50 who are living with HIV, including virtual exercise classes, HIV education resources, online support groups, and more!

We are looking for enthusiastic volunteers who are willing to support this new initiative and help us implement and monitor the Palm Springs Virtual Village. As a volunteer, you will need to be able to navigate the new website, take part in performing weekly administrative task, and assist new members as the program rolls out. We are also seeking candidates to sit on our Advisory Board.

With your help as a team member, we can make a positive impact in the lives of older adults living with HIV.

Please contact Christopher today (<u>Christopher.Christensen@harp-ps.org</u>) if you would like to volunteer for this exciting new program. We look forward to hearing from you!



## The Benefits of Volunteering

Having a reason to get up in the morning contributes to healthy aging and is an essential element of good self-esteem. Researchers at Rush Alzheimer's Disease Center in Chicago found that those who scored high on a purpose-in-life assessment were 2.4 times less likely to develop Alzheimer's. Discovering new opportunities to engage in something meaningful to you is essential to your well-being, and volunteering can help you find that sense of purpose. We know from the Blue Zone research on healthy aging that there are 8 universal lifestyle common denominators that all active, independent centenarians share, and 2 of those are having a sense of purpose and staying social and engaged with others. When you volunteer, you do both.

Many Long-Term Survivors (LTS) aging with HIV suffer from loneliness and isolation. LTS have good reasons for isolating. Many lost an entire social circle of friends to AIDS in their '20's and '30's, a time when it was not developmentally appropriate. For young adults this was very traumatic, and as a result those premature losses now make it tough to reach out to form new meaningful connections. In general, it's more difficult to develop new relationships as we age, but given the history of multiple loss, and unprocessed grief, it's even more of a challenge for LTS.

The Community Research Initiative of America's groundbreaking 2005 Research on Older Adults with HIV (ROAH) study found high levels of isolation and loneliness. In the 2nd ROAH in 2018, 43% reported feeling "lonely" or "very lonely". ROAH 2.0 found that 70% of survivors live alone, compared with only 30% of the general population. Many studies link isolation and loneliness to an increased risk of stroke, heart disease, high blood pressure, and earlier onset of dementia. Isolation increases stress hormones and inflammation. In people with HIV (who already have high levels of inflammation), the risks from these are much greater. One researcher stated, "Feeling isolated may be as bad for a person's health as smoking 15 cigarettes a day." However, the good news is that volunteering is an effective antidote to isolation and loneliness. There is a powerful benefit in intentional socializing through volunteerism.

Healthy aging requires older adults to stay engaged with life, and volunteering is an excellent way to do that. When you volunteer you have an opportunity to meet others with common interests while doing something useful that you enjoy. Regular contact and working together on a shared activity encourages the development of supportive relationships. Working for the benefit of others also tends to take your mind off your own problems and ameliorates loneliness. The more you give, the greater your capacity to receive.

There are many agencies in Coachella Valley that could use your help from traditional volunteer organizations and venues such as churches, schools, hospitals, youth agencies, food banks, the Red Cross, etc., but don't forget the grassroots organizations that organize volunteers for specific projects, political organizing, or event fundraisers. Newspapers also run listings of volunteer opportunities. Volunteering at a local school will help you stay in touch with younger people, and keep you current on trends. Becoming a volunteer C.E.R.T (Certified Emergency Response Team) member will keep you up to date with emergency response procedures. Make a list of volunteer options that appeal to you.Consider the following:hospitals, public service agencies, nonprofit organizations, libraries, school, community programs, Big Brother/Big Sister programs, hospice programs, youth programs, LGBTQ+ organizations, environmental groups, animal shelters, or recreational activities that need volunteers to organize community events.

Volunteering is a win-win for everyone and is a beneficial way of combating loneliness and depression.



Bridgette Picou, LVN, ACLPN, President, Greater Palm Springs ANAC, HARP-PS Board

## Ask, Advocate, Thrive

Going to the doctor has the potential to be a highly frustrating experience in any circumstance, let alone while living with HIV. Anxiety and stigma play into it. The relationship dynamic between patients and providers can make it hard to ask questions to quiet fears and gain understanding. All these things can keep you from having control of your health and from having a therapeutic relationship not only between you and the provider, but also between you and your HIV.

It doesn't have to be that way.

There are some easy steps that you can take to make visits easier, and to encourage a therapeutic relationship. People tend to think of a "therapeutic" environment or relationship

only as it relates to a counselor or psychologist/psychiatry arena. The truth is, it's more than that. Its emotional trust that lets you believe in your care, it's respect and agreement on the goals and

collaboration on the "work" of being healthy.

The question is what does that look like? That is different for everyone and how you get there is different from person to person as well. However. there are some common things you can do to make it a little easier. First, is preparing for your appointment. Remember to make your appointments early and keep them! It's much easier to take and stay ahead of things in a preventative way, as opposed to trying to catch up to an issue or letting something become an emergency. Bring relevant information from referrals or tests and take notes on things that not only you have questions about, but things that make sense that you want to remember.

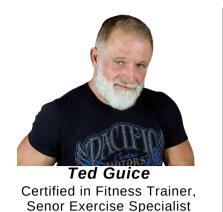


"Your appointment with the doctor is at eleven-fifteen, but his appointment with you is at twelve-fifteen."

Next is to remember that a closed mouth doesn't get fed. What I mean by that is- ask your questions! You'll never know what you don't ask, or you may think you know, but working on incomplete information. In almost all cases, your question is the same question someone else has. Ask. Then ask again. You have the right to understand not only your disease process, but your plan of care as well.

Last but not least, take care of yourself. Be kind to yourself. Take advantage of wellness opportunities that present themselves. Yoga, meditation, walking or painting, whatever moments of peace and feeling good about yourself looks like for you! You should thrive in life not just endure or survive.

You matter. Be well.



HARP-PS Board Member

## **Invest NOW for Amazing Gains**

Invest Just 2% (in yourself) For Incredible Gains!

Do you know what percentage of your day 30 minutes takes up? Just 2%! Heck, I spend at least 10% of my day on Facebook, it seems! Surely, we can invest a mere 2% on exercise - can't we? Let's unwrap that and see what happens.

According to the CDC National Center for Health Statistics, Less than a quarter of Americans are meeting all national physical activity guidelines, according to a new report from the Centers for Disease Control and Prevention's National Center for Health Statistics (NCHS). Federal physical activity guidelines recommend that adults get at least 150 minutes of

moderate or 75 minutes of vigorous exercise each week, in addition to muscle-strengthening activities at least twice a week. But according to the new NCHS report, which drew on five years of data from the National Health Interview Survey, only about 23% of adults ages 18 to 64 are hitting both of those marks. Another 32% met one but not both, and almost 45% did not hit either benchmark.

There are no readily available stats for older people living with HIV.

Please follow this link to learn more: <a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8702781/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8702781/</a>

So, what would happen if we took just 2% out of our day for regular exercise? Well, the results are life changing, especially if you are dealing with HIV and any of the issues cited in the above paper from the NIH.

Taking just 30 minutes a day to exercise, 2%, will deliver the following results for most folks:

| AGE   | % OF ACTIVITY MEN | % OF ACTIVITY WOMEN |
|-------|-------------------|---------------------|
| 18-34 | 41.30%            | 28.70%              |
| 35-49 | 29.70%            | 22.70%              |
| 50-64 | 21.60%            | 17.60%              |
| 65+   | 15.30%            | 10.80%              |

#### **Prevents Bone Loss**

Both men and women lose bone density as they age, with post-menopausal women losing up to 2% each year. Strength training has been shown to counteract this loss and restores bone density. Having stronger bones leads to fewer fractures and can also aid in balance.

Continued on page 7.

Invest now for Amazing Gains -Continued

#### Relieves Osteoarthritis Pain

While it may seem counterintuitive, moving more can help lessen the pain and stiffness of arthritis. Arthritis-friendly exercises includes low-impact cardiovascular activity, strength training, and range-of-motion exercises.

#### **Helps Prevent Chronic Disease**

Start exercising every day. Any way you can! Walking, Resistance Exercises, Body Weight Exercises, Yoga, Pilates, Group Exercise, Aerobics, Swimming, Biking, Chair Exercise – whatever exercise you think you can do and will enjoy does the trick. I promise!

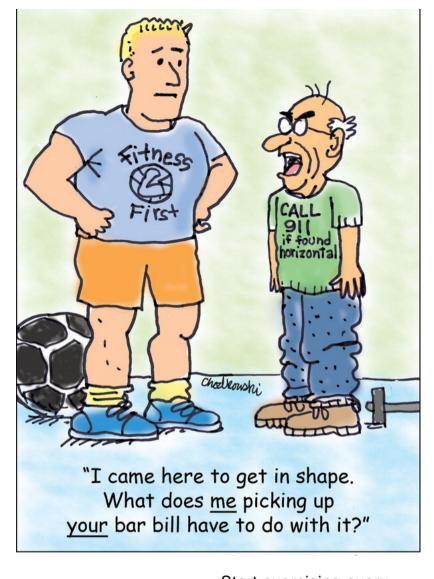
#### **Boosts Immunity**

A 2018 study linked moderate exercise with a lower incidence of acute respiratory illness and fewer sick days off from work. The exact way exercise supports immunity is not known.

#### **Improves Mood**

Simply put, exercise makes us feel good. It can help ease anxiety and depression symptoms, increase relaxation, and create an overall sense of wellbeing.

My best advice if you are over 60 and living with HIV?





Start exercising every day. Any way you can! Walking, Resistance Exercises, Body Weight Exercises, Yoga, Pilates, Group Exercise, Aerobics, Swimming, Biking, Chair Exercise – whatever exercise you think you can do and will enjoy does the trick. I promise!

Keep thriving and don't hesitate to call upon me with any questions or thoughts you may have about all this. I want you to live your best, your happiest, your healthiest I life going forward!

TedGuice.com



## Bend Over and Take it Like a MAN!

Good you are reading now. I'll tell you more about that in a minute. I am 63 years old, a thirty-year HIV+ gay male, and a volunteer with HARP-PS. I want to share with you the importance of not only focusing on your HIV care but also taking care of your *whole* self.

Why is this important? I recently completed my bi-annual labs which included a PSA (Prostate Specific Antigen) test. My results came back with an elevated PSA. I met with my Urologist and scheduled a biopsy which came back positive for cancer.

I have my PSA checked every six months along with other labs which has proven to be to my advantage as we caught the cancer early and I stand a much higher chance of successfully treating it. This makes me hopeful for a complete recovery.

Always working in partnership with my Primary Care Physician and HIV Specialist is how I keep on top of my healthcare. I came across the attached article titled Bend Over and Take it Like a Man, by Dr. Myles Spar, a well-known integrative physician specializing in men's healthcare which outlines the ten



most important things you can do to partner with your healthcare providers and be the healthiest you can be.

It's a great guide and I recommend you copy it, put it on your refrigerator, bathroom mirror, or anywhere that works for you as a constant reminder of <u>what you can do</u> to maintain the best, healthiest you.

## Click the Button to Access the Article



#### By Myles Spar, M.D., Contributor

Myles Spar MD practices Integrative Medicine in Los Angeles, California.

May 29, 2010, 05:12 AM EDT|Updated Nov 17, 2011

This post was published on the now-closed HuffPost Contributor platform.



# <u>Upcoming Events!</u> The Palm Springs Cultural Center

**June 6, 2023** OI Conference Upo

CROI Conference Update Golkoo Morcos, PhD Bios Clinical

July and August 2023 Summer Break No Event

September 5, 2023

STI Update
Phyllis Ritchie, PS Test
Trent Broadus, DAP Health

October 3, 2023
Resistance in HIV
Jim Osburne
Thera

**November 7, 2023** 

HIV Research in Palm Springs Bios Clinical & Palmtree Carlos Martinez & Golkoo Morcos

December 2023

No Event

To register for in person attendance please follow the link for each event at: <a href="https://www.harp-ps.org/upcoming-events">https://www.harp-ps.org/upcoming-events</a>

Or register to attend via Zoom by following the link for each event at: <a href="https://www.harp-ps.org/upcoming-events">https://www.harp-ps.org/upcoming-events</a>

## A Very Special Thank You To Our Volunteers!

Ken Vergonet – Social Media & Webmaster Extraordinaire
Jim Ferguson – Layout of Newsletter, Administration, and all around good guy!
Chad Sain – Volunteer Photographer (Chad Sain Photography) a great person, artist,
and friend to HARP-PS