

Mission Statement: To improve the lives of the large and growing population of long-term HIV and AIDS survivors by studying the impacts of long-term HIV disease and its treatments on the natural aging process.

Issue #: 3, Fall 2018/ Winter 2019

PCORI

The Patient-Centered Outcomes Research Institute is a non-partisan, independent research sponsor federally funded through the Affordable Care Act. PCORI helps people make informed healthcare decisions, improving healthcare delivery and outcomes. They fund and promote evidence-based information from research guided by patients, caregivers, and the broader healthcare community. PCORI strives to make science accessible.

UC Riverside

The University of California Riverside School of Medicine was founded in 2013 as the first new public medical school west of the Mississippi in 50 years. Through its Center for Healthy Communities, UCR promotes research to improve the health of the culturally and economically diverse communities in Inland Southern California, especially those that are medically underserved.

Citizen Panels

After completing our focus groups to determine our community research priorities, we then conducted a series of "citizens panels" with more community stakeholders. The top-ranked research concerns that emerged from the focus groups were: isolation & depression, co-morbidities & underlying inflammation, and neurocognitive dysfunction & memory loss. Members from five broadly-defined community subgroups were identified and invited to discuss and rank 3 proposals to address each research area. The research proposals came from a scientific retreat with our key clinician researchers & academic partners, and then vetted with our Stakeholders Steering Committee and Patient Partner Advisory Board. The groups were patients, caregivers, providers, academics, and community-based organizations. The top ranked proposals are highlighted in the chart below.

HARP-PS will co-host a meeting on December 15 with researchers from throughout Southern California to learn about HIV & aging related research at academic centers throughout the region, and then re-convene our clinician researchers afterwards to finalize a comprehensive research proposal for our upcoming PCORI research grant proposal in Spring 2019.

Final Results of Citizens Panels Rankings

Inflammation:

- 1. Cohort Study
- 2. NAC- Glycine supplement study
- 3. Metformin Study

Cognitive Function

- 1. Microbiome Study
- 2. Methamphetamine Study
- 3. Diet & exercise Study

Isolation & Depression:

- 1. Program comparative effectiveness
- 2. Cannabis use survey
- 3. Psilocybin study

AIDS WALK 2018

HARP-PS created its own "Team Thrive" to participate in AIDS Walk 2018 on Saturday, Oct 20. Our team placed 5th overall, and was the top-earning community group this year—beat out only by 4 large corporate businesses. We raised over \$17,000—about 1/3 of which will go directly to HARP-PS to fund our activities not covered by our PCORI capacity building grant. A special thanks to our Team Thrive co-captains Jill Langham and Ted Guice who spearheaded our fundraising efforts at Oscars' and at Chill Bar, as well as new HARP-PS board member Jeff Denean

Jones who took our social media promotion to new heights for this event. Kudos to all!



Ethics Training

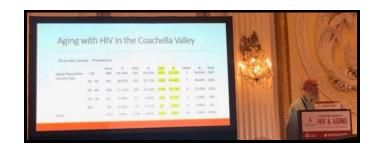


On October 25, Dr Dario Kuzmanovic, from the UC Riverside Office of Research Integrity, joined members of our Patient Partner Advisory Board, Stakeholders' Steering Committee, and other interested community stakeholders to provide a training on ethical research conduct. Dr Kuzmanovic gave a fascinating history of past examples of unethical research—including the "Tearoom

Trade", and described how current protections like Institutional Review Boards and federal laws protect human research participants.

International Workshop on HIV and Aging

Chris Christensen & Jeff Taylor attended the 9th Annual Workshop on HIV & Aging in NYC on Sept 13 & 14. Jeff was asked to present on the work HARP-PS has done locally, and to provide a community perspective on what further research is.



PCORI Annual Conference

Jeff Taylor and administrative coordinator Chris Christensen attended the annual PCORI conference in Washington, DC October 31-November 2. This was the first time for both to attend this meeting, and they found the various presentations extremely informative, and learned much from other PCORI-funded projects being conducted around the country. They also had an opportunity to meet with our PCORI program officer Yasmeen Long to discuss our progress on our current PCORI capacity building grant, and got some excellent advice on which avenues to pursue for a research grant in 2019



HARP-PS & PCORI at APHA

HARP-PS collaborator Alejandra Cabral presented the poster she authored on the results of our focus groups at the American Public Health Association annual meeting in San Diego. Dr Cabral (pictured below at APHA with Chris Christensen) identified exercise, community involvement, and pursuing hobbies as behaviors that participants identified as contributing to resiliency. In addition, a supportive community, including friends and competent medical care and other forms of social support and resources were common themes that allowed long-term survivors in the Coachella Valley to continue to age healthily.

Resiliency Survey Project

HAPP-PS partnered with Dr Michael Plankey from Georgetown University to assess the resiliencies of long-term survivors in our community. This arose from the initial survey he & collaborator Ron Stall from University of Pittsburgh conducted in the Multicenter AIDS Cohort Study (MACS) at study sites around the country. MACS was formed in 1984 to study the emerging epidemic in gay men who were the primarily affected project at the time. Drs Plankey & Stall sought to understand why—despite the many medical & mental health challenges, and incalculable losses experienced by this cohort over the years—most of these men continued to thrive as they got older with HIV.

Here in Palm Springs, we worked with Dr Plankey to ask the same question in our MSM community. We administered a shortened 15 minute version of this survey at our Pride Festival booth November 3 & 4, at the Modern Men's Chorus rehearsal on Nov 5, and at the Nov 6 Positive Life program. Results are currently being evaluated, and we hope to be able to report those back to the community in Q1 of 2019.

HARP-PS and UC Riverside are now working to make this survey available in an online format so that we can broaden this survey to the entire Coachella Valley HIV community. Once we demonstrate the feasibility of conducting the survey online, this could prove to be a valuable tool to assess resiliencies in long-term survivors nationally, and even globally—helping us to identify new ways to help people to continue to age healthily with HIV



Alternative & Complementary Medicine Research at Desert AIDS Project: Grounding

Grounding, or earthing, refers to connecting electrically with the Earth. A growing body of research is finding numerous health benefits as a result of the physical body being grounded. Unfortunately, with our modern rubber or plastic soled shoes and insulated sleeping arrangements, we no longer have a natural electrical connection to the Earth, unless walking barefoot. Desert AIDS Project has teamed up with the Chopra Center in Carlsbad to offer grounding to its staff.

The most immediately noticeable effect people report from being grounded is that they 'feel better'. This has been described as a feeling of greater peace within themselves, feeling calmer with reduced stress levels. If there is pain present then often this is reduced or disappears completely.

With regular grounding, numerous health benefits have been observed, such as:

- * Improved immune function
- * Improved digestion
- * Improved sleep
- * Rapid healing of injuries
- * Improved blood circulation
- * Harmonization and stabilization of the body's basic biological rhythms

- * Accelerated recovery from intense athletic activity
- * Reduction of inflammation
- * Reduced stress / anxiety / irritability
- * Reduced electro sensitivity

Scientific research over more than a decade indicates that your body can be protected and helped-and that you feel better-when you electrically reconnect to the Earth. That is, when you are grounded. Here are three examples of potential benefits that have been reported in these studies:

- * Decreased Levels of Inflammation and Pain
- * Reduced Stress Levels

When grounded, the diurnal rhythm of the stress hormone, cortisol, begins to normalize. Cortisol is connected to your body's stress response and helps control blood sugar levels, regulates metabolism, helps reduce inflammation, and assists with memory formulation.

* Improved Circulation

When you are grounded, your circulation improves, aiding in the delivery of oxygen and nutrients to the tissues in your body, including better blood flow to your face

Sources:

https://bit.ly/2GOtqfv (Grounding the Human Body)

https://bit.ly/2ELRHnh (What is Grounding?)

Here's a link to Clint Ober's video that explains grounding both in layman's terms and goes into some of the science. https://youtu.be/CSNnIg2cVjc