



Huntington's Disease
Society of America



SAN FRANCISCO BAY AREA CHAPTER

HDSA Volunteer Newsletter - August 2024



LOUISE VETTER SAYS GOODBYE

Louise Vetter has announced her departure as President and Chief Executive Officer of HDSA after serving for 15 years. During her tenure she led the expansion of the Society's reach with new programs and initiatives to strengthen the web of support for the HD community. Prior to coming to HDSA, she spent nearly 10 years leading the American Lung Association of New York. We thank Louise for her leadership and dedication and wish her well in her all her future endeavors.

IMPORTANT NOTE:

Make sure that mail@HDSA.org is added to your email list so that you can see all of the updates and events in your area!

NEW AND NOTEWORTHY IN THE HD COMMUNITY



DR. ARIK JOHNSON, PsyD NAMED INTERIM HDSA CEO

The HDSA Board of Trustees has announced Erik Johnson, PsyD, Chief Mission Officer, as the interim CEO while the search for a new permanent CEO is underway. Dr. Johnson joined HDSA in 2021 and brings a wealth of experience to the role. Dr. Johnson earned his masters and Doctor of Psychology degrees at the California School of Professional Psychology at Alliant

International University and received his Bachelors of Science degree at the University of Minnesota.

VIDEOS FROM THE 2024 CONFERENCE NOW AVAILABLE ON YOUTUBE

Several videos from the 2024 HDSA Conference in Spokane have now been posted on YouTube. Please take some time to listen to them at the links provided below:

[FULL PLAYLIST](#)

[Self Care for Caregivers](#)

[Staying Connected: Isolation and HD](#)

[Long Term Care Options in HD](#)

[Optimizing Sleep](#)

2024 BERMAN-TOPPER FAMILY HD CAREER DEVELOPMENT FELLOWSHIPS

HDSA has awarded Dr. Thai Bao Nguyen (University of California, Irvine) and Dr. Sonia Vazquez-Sanchez (University of California, San Diego) the HDSA Berman-Topper Family HD Career Development Fellowships for 2024. The fellowship provides up to \$100,000 of funding per year for three years to postdoctoral scientists and clinicians who desire to make HD part of their long-term career plan.

[Read the announcement in its entirety here](#)

HDSA HD SYMPTOMS AND TREATMENT IMPACT SURVEY

Have you taken the HDSA HD Symptoms and Treatment Impact Survey yet? If not, please follow the link below. The survey will be the foundation for an HDSA externally-led patient-focused drug development meeting for pre-symptomatic and early to mid-stage adult onset HD. Both the survey results and the meeting comments can inform the FDA's decisions and oversight during the development of new therapies and during the agency's review and approval of new therapies.

[Take the survey here](#)

UPCOMING HD EVENTS

JOIN US FOR OUR 18TH ANNUAL
heroes & villains
TEAM HOPE 5K WALK & FUN RUN

OCTOBER 5, 2024 **SPORTS BASEMENT PRESIDIO**

REGISTER NOW: [HDSA.ORG/THWSANFRANCISCO](https://hdsa.org/thwsanfrancisco)



SAN FRANCISCO TEAM HOPE WALK SCHEDULED FOR
SATURDAY, OCTOBER 5th!

Be sure to join us for the 2024 San Francisco Hope Walk on Saturday, October 5 at the Presidio Sports Basement. To register, or to find out more information, please click below.

[2024 San Francisco Team Hope Walk Info](#)

SAN JOSE WALK FOR 2025 - DATE CHANGE

The HDSA [SF Bay Area Chapter](#) leadership decided to move the date of the San Jose Walk because of the heat, graduations, and HDSA Awareness Month. We hope to capture a higher number of HD families/patients who can attend the fundraiser.

New Date: Saturday May 17, 2025 at Campbell Park

SAVE THE DATE

Our 2024 Family Education Day will be held on **Saturday, October 19th**. This will be a free, in-person event hosted by our Chapter and two HDSA Centers of Excellences - Stanford Medicine and UCSF Medical Center. Location, agenda, and registration link will be announced soon, but please make sure to mark it on your calendars!

JULY SUPPORT GROUPS

SIGN UP FOR THE RIGHT SUPPORT GROUP FOR YOUR NEEDS

Local HDSA online support groups are available to help families affected with HD.

EL CERRITO SUPPORT GROUP

Schedule: 4th Tuesday each month, 7:00 pm - 8:30 pm

Location: Sycamore Congregational Church - 1111 Navellier Street, El Cerrito, CA 94530

Leader - Natasha Boissier Phone: 415-476-2904

PALO ALTO HD SUPPORT GROUP

Schedule: Second Tuesday of each month, 7:00 p.m. - 8:30 p.m.

Location: First Baptist Church - 305 N. California Street, Palo Alto, CA 94301

Leader- Satve Ilango Phone: 650-587-0988

These support groups are free, but we urge you to register in advance, as space is limited. All our chapter support groups are hosted on Hey Peers. Once you sign up, you can go in and register for any groups you are interested in. Join Hey Peers by clicking the link below and sign up for each group to get email reminders right to your inbox.

Click Here for *HEY PEERS!* Link

OTHER WAYS TO HELP THE HD COMMUNITY

HDSA VEHICLE DONATION PROGRAM

Avoid the hassles of selling or repairing your vehicle altogether when you donate it! All vehicle types are accepted. Call **888-HDSA-151 (888-437-2151)**. HDSA will tow your vehicle at no cost to you. You will receive a donation receipt and help us in our mission.

More Information on Vehicle Donation Here

STAY CONNECTED

JOIN OUR NEXT SF BAY AREA CHAPTER CONFERENCE CALL:

September 4th, 2024 @7pm

Contact Therese Crutcher-Marin for meeting information:

theresecrutchermarin@gmail.com

If you are interested in doing more for our Chapter, please let us know!

HDSA'S PROGRAMS & SERVICES

Get the help you need from the comfort & safety of your home.

Be sure to take advantage of HDSA's world-class HD programs & services - FOR FREE!

Learn more at HDSA.org/support.

New HDSA Programs & Services Document

[DOWNLOAD HERE](#)

Click the links below to find support today:

Local (San Fran) HDSA Social Worker:

Satve Ilango, HDSA Social Worker

silango@hdsa.org | (650)-587-0988

Online Support Groups: HDSA.ORG/OSG

PatientsLikeMe: HDSA.ORG/PLM

Telehealth: HDSA.ORG/TELEHEALTH

HD Trialfinder: HDTRIALFINDER.ORG

HDSA's National Youth Alliance: HDSA.ORG/NYA

Youth Mentorship Program: HDSA.ORG/YMP

Disability Resources: HDSA.ORG/DISABILITY

Locate Resources in Your Area: HDSA.ORG/LOCATERESOURCES

WE CAN NEVER LOSE HOPE...



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