



Huntington's Disease
Society of America



SAN FRANCISCO BAY AREA CHAPTER



MAY IS HD AWARENESS MONTH



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#LetsTalkAboutHD

HD



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#LetsTalkAboutHD is a social media initiative during Huntington's Disease Awareness Month to encourage families to share their experiences with HD throughout the month of May.

Attention HD San Francisco Bay Area HD Families:

Please post on your social media platforms to heighten awareness of Huntington's Disease.

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!

Social Worker Corner



Advance Care Planning

When facing a diagnosis like HD, conversations about the future can feel overwhelming. Many families understandably want to focus on the “now,” staying present and savoring the good days.

But part of caring for ourselves and each other means also making room for some of the harder, future-oriented conversations.

Advance care planning is not about giving up. It's about making sure that your voice, wishes, values, and goals continue to guide your care, even if there comes a time when you can't speak for yourself. It's a powerful way to take back a sense of control in a situation that can often feel uncertain.

So, what does advance care planning involve? It includes choosing a healthcare proxy or power of attorney, creating a living will, and talking with your loved ones.

These are not always easy conversations—but they are loving ones. When families have a clear understanding of a person's wishes, it can reduce anxiety, prevent conflict, and help everyone feel more at peace with the care decisions that arise.

As a social worker, part of my role is to support families in these discussions. I can help you understand your options, guide you through the paperwork, and offer tools and conversation starters for talking with your family.

SATVE ILANGO, MSW, CHAPTER SOCIAL WORKER

Phone: 650-587-0988 | Email: silango@hdsa.org

NEW AND NOTEWORTHY IN THE HD COMMUNITY



HDSA AWARDS MORE THAN \$1.8 MILLION TO EXPAND HDSA CENTERS OF EXCELLENCE NETWORK TO SIXTY-NINE SITES

The Huntington's Disease Society of America (HDSA) is expanding its HDSA Centers of Excellence network of comprehensive care clinics with 69 grants totaling \$1,810,400. HDSA recognized 60 HDSA Centers of Excellence and nine Partner Sites, ensuring expert HD in 37 states across the nation and Washington, DC.

HDSA Centers of Excellence are multi-disciplinary care teams with expertise in Huntington's disease that share an exemplary commitment to providing family-focused care and enabling clinical research for this complex, rare, neurodegenerative disease. The expansion from 68 HDSA Centers of Excellence grants in 2024 to 69 grants in 2025 comes from the addition of the Central Florida

Center for Huntington's Disease, the University of Tennessee Erlanger Neurology, and the Cole Center for Parkinson's and Movement Disorders at the University of Tennessee Medical Center. In addition, Cedars-Sinai Medical Center was named as a Partner Site to the HDSA Center of Excellence at University of California, Los Angeles. Launched in 1998, the HDSA Centers of Excellence network has grown from just 20 sites as recently as 2015. ***Grantees include our local COE's Stanford and UCSF.***

[Read More Here](#)

GENENTECH/ROCHE GENERATION HD2 STUDY UPDATE: COMMUNITY LETTER

Genentech/Roche has released an update on their HD2 Study with a letter to the HD community. Read the letter in its entirety below. The study is testing the investigational drug tominersen in people with early or very subtle signs of Huntington's disease (HD).

[Full Details Here](#)

VOLUNTEER SPOTLIGHT



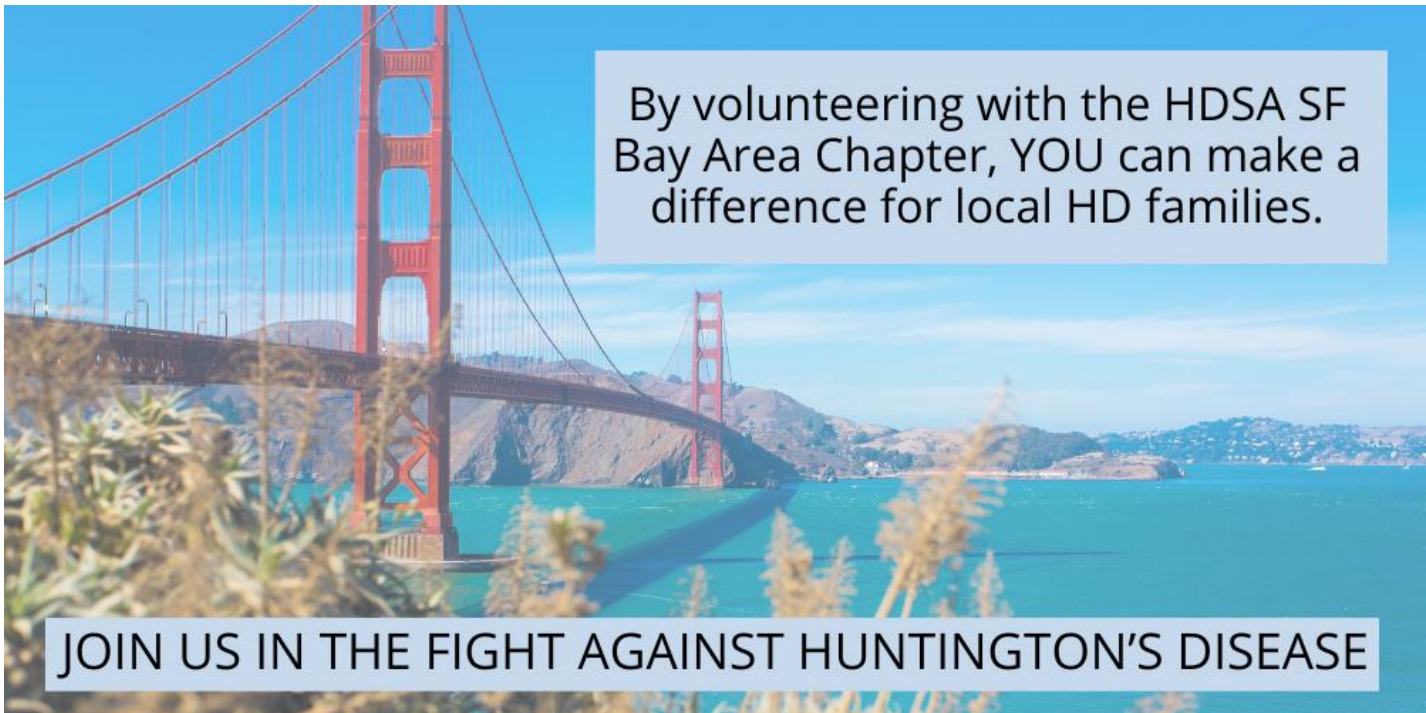
Daniel Denhart-Lillard

Daniel Denhart-Lillard is originally from Indiana, but came to the Bay area from Atlanta, where he worked at Piedmont Hospital in Risk Management. He feels passionate about the fight to find a cure for Huntington's disease, which is in his family via his uncle's wife and their children, his aunt dying from the disease in 1978. HD also claimed the lives of his aunt's sister and 4 of her 8 children, all of whom were his childhood friends and classmates. He has been volunteering with the San Francisco Bay Area chapter for several years, helping to set up the San Jose and San Francisco Hope Walks, and became a Board member of the chapter 2 years ago. Daniel lives with his husband Jay in San Mateo.

VOLUNTEERS NEEDED - PLEASE CONSIDER JOINING US!

"Volunteers do not necessarily have the time; they just have the heart." - Elizabeth Andrew

[VOLUNTEER HERE](#)



By volunteering with the HDSA SF Bay Area Chapter, YOU can make a difference for local HD families.

JOIN US IN THE FIGHT AGAINST HUNTINGTON'S DISEASE

UPCOMING HD EVENTS



TEAM HOPE 5K TIMED RUN & 5K WALK SAN JOSE

Saturday, May 17th, 2025

Campbell Park
E Campbell Ave & Gilman Ave
Campbell, CA, 95008

For additional information contact
Uma Thontakudi
sanfrancisco@HDSAvolunteer.org

www.hdsa.org/thwsanjose



SCAN ME

Sign Up Here!



Sponsorship Opportunity for Santa Clara County Businesses

- A local Huntington's Disease Society of America (HDSA) San Francisco Bay Area Chapter Team Hope Run/Walk **sponsorship** at any level is an excellent opportunity for you to support a great cause and to take advantage of a wonderful marketing opportunity
- As a **local sponsor**, you will be increasing your brand recognition, visibility and demonstrating your commitment to the local community your employees and customers live and work in
- May 17th at Campbell Park
- Example of two (2) Sponsorship Opportunities ***San Jose Team Hope Run/Walk Sponsorship Packet Attached***

BRONZE \$1,000	<ul style="list-style-type: none">• Company name and logo on t-shirt• Acknowledgement during speech & on social media• 2 free registrations
EVENT \$500	<ul style="list-style-type: none">• Company name and logo on t-shirt• Acknowledgement during speech & on social media

Call Therese Crutcher-Marin with Questions 530 906-8415/theresecrutchermarin@gmail.com

[Click Here for Sponsorship Form](#)

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:

JUNE 4th @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](https://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](https://hdsa.org/OSG)

PatientsLikeMe: [HDSA.ORG/PLM](https://hdsa.org/PLM)

Telehealth: [HDSA.ORG/TELEHEALTH](https://hdsa.org/TELEHEALTH)

HD Trialfinder: [HDTRIALFINDER.ORG](https://hdsa.org/HDTRIALFINDER.ORG)

HDSA's National Youth Alliance: [HDSA.ORG/NYA](https://hdsa.org/NYA)

Youth Mentorship Program: [HDSA.ORG/YMP](https://hdsa.org/YMP)

Disability Resources: [HDSA.ORG/DISABILITY](https://hdsa.org/DISABILITY)

Locate Resources in Your Area: [HDSA.ORG/LOCATERESOURCES](https://hdsa.org/LOCATERESOURCES)



We Can Never Lose Hope!



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