



Huntington's Disease
Society of America



SAN FRANCISCO BAY AREA CHAPTER

HDSA VOLUNTEER NEWSLETTER - SEPTEMBER 2025

**HDSA Team Hope Timed 5k Run & Walk -
San Francisco on October 4th**
SPORTS BASEMENT PRESIDIO



Huntington's Disease
Society of America

SAN FRANCISCO BAY AREA CHAPTER



SAN FRANCISCO
TEAM HOPE
TIMED 5K
RUN & WALK

Saturday, October 4th, 2025



SCAN ME



Sports Basement Presidio

610 Old Mason St

San Francisco, CA 94129

For additional information contact

Therese Crutcher-Marin

theresecrutchermarin@gmail.com

www.hdsa.org/thwsanfrancisco

JOIN US AT THE SAN FRANCISCO TEAM HOPE WALK ON OCTOBER 4th.

Please join us on October 4th for our 2025 San Francisco Team Hope Walk fundraiser! Share this information with friends, family, co-workers, neighbors, and your community. This year's event will feature a timed run.

Registration Opens at 9:00 AM - Walk and Run Begin at 10:00 AM

Follow the link below to register.

[Click Here To Register](#)

[Click Here To Make General Donation](#)

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- Part 1

When living with Huntington's disease, it's natural to focus on the "now"—managing symptoms, adjusting routines, and finding ways to enjoy meaningful moments with family. But one of the most empowering steps you can take for yourself and your loved ones is **advance care planning**.

Advance care planning means thinking about and communicating your wishes for future care if there comes a time when you're unable to speak for yourself. For many families, this feels uncomfortable to bring up. Talking about "what if" scenarios can stir up fear, sadness, or resistance. Yet advance care planning is not about giving up, it's about making sure your voice is heard in every stage of the HD journey.

HD is progressive, and over time, changes in memory, communication, and decision-making can make it harder to express your wishes. Having conversations early gives you control over your care and provides your family with the gift of clarity.

What advance care planning covers:

Many people think advance care planning only deals with end-of-life care, but it actually addresses a wide range of decisions, including:

- **Health Care Preferences** – The treatments you would or would not want (such as life support, feeding tubes, or resuscitation).
- **Advance Directives** – Legal documents like a Living Will and a Health Care Proxy or Durable Power of Attorney for Health Care.
- **Financial Planning** – Naming someone to help manage finances and bills if needed.
- **Living Arrangements** – Deciding whether you would prefer to remain at home, move to assisted living, or consider nursing care at certain stages.

In Part 2, we'll walk through practical ways to begin the conversation, how to complete documents, and where to find resources.

SATVE ILANGO, MSW, CHAPTER SOCIAL WORKER

Phone: 650-587-0988

Email: silango@hdsa.org

NEW AND NOTEWORTHY IN THE HD COMMUNITY



40th Annual HDSA Convention Workshop & Highlights!

Don't worry if you could not attend the HDSA convention in Indianapolis. You can still experience the magic! Catch the powerful moments, inspiring stories, and unforgettable sessions from the 40th Annual HDSA Convention — now available to watch online. Reconnect. Relive. Be inspired. Click the link below to view the videos.

[Check Here](#)

HDSA Publishes 2024 Year In Review Magazine

Take a look back on HDSA's achievements and top stories from 2024 in the latest Year In Review Magazine.

[Check Here to View](#)



University of California San Francisco Medical Center is enrolling participants in a Huntington's disease (HD) observational study, Enroll-HD, and recruiting those who would like to participate/get involved with research. Currently they are enrolling those who are at risk for HD, and not enrolling healthy controls/partners, and/or spouses of folks with HD.

Partners/spouses/caregivers are more than welcome and are encouraged to attend the visit, however. We are enrolling folks who are not tested but are at risk for HD, those who have pre-manifest or manifest HD, and those who tested negative for expanded CAG repeats but were at risk.

Zachary Lamson, CCRP

UCSF Medical Center Clinical Research Coordinator

Phone: 415-502-0670

Fax: 415-502-7936

Email: zach.lamson@ucsf.edu

Click on the link below to for additional information on Enroll-HD.

[Enroll-HD](#)

CONSIDER JOINING OUR BOARD!

If your family is challenged by Huntington's Disease, and you'd like to make a difference to other HD families in the SF Bay Area, please consider joining the Board. The next San Francisco Bay Area Chapter Board Meeting is September 10th, 2025 at 7 P.M. via RingCentral. The Chapter committees are working behind the scenes, during the summer, on the San Francisco Team Hope 5K Timed Run and 5K Walk, San Jose Giants fundraiser, outreach, and the 2026 HD Family Education Day. The Board is made up of folks who have HD in their family and

others who want to help our nonprofit be successful in the mission we aspire to. *"The Chapter is dedicated to improving the lives of everyone affected by HD and their families."* Email Therese at theresecrutchermarin@gmail.com

SEPTEMBER'S VOLUNTEER SPOTLIGHT - CANCELMO FAMILY



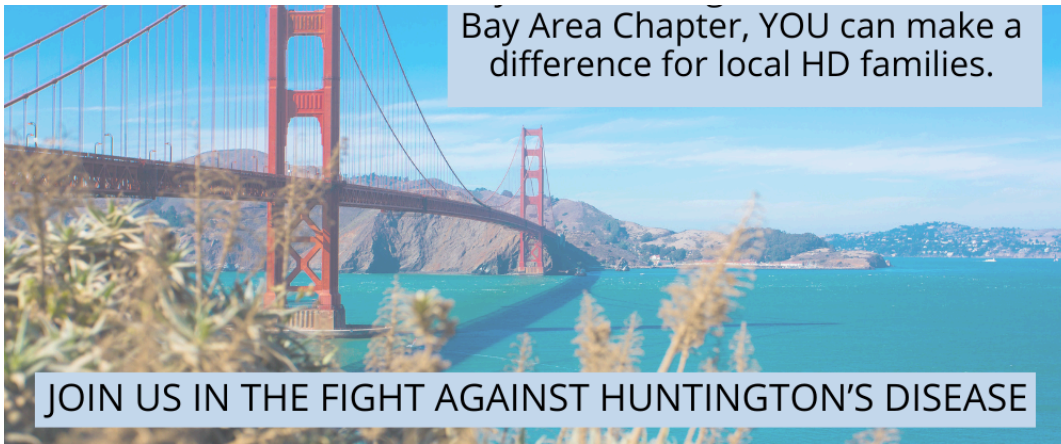
The San Francisco residents of the Cancelmo family have been supporting the annual HD walk since 2008. Soon after attending the first walks in SF, we began providing coffee and treats to keep the walkers energized. Because of the impact of the disease on our family members, we have been happy to ensure that the walkers supporting HDSA are well fed and “coffee’d up”! We do our best to ask local vendors for donations, but usually shop and donate most of the food we provide for our fellow walkers. We enjoy setting up and sharing stories with the volunteers each year, meeting and greeting the walkers, and being part of the HDSA SF community.

Mary is a retired San Francisco Unified special education teacher and continues to work with students needing reading intervention. Mary’s son, Steven, is a freelance comic artist and animator. Sally is a professional dog walker who has owned her own business for 35 years. You may see her walking her pack at Crissy Field. Amy is a current San Francisco Unified special education teacher, and loves being with kids, especially her amazing son, Mundo, who you may recognize as he was the winner of the costume contest for 2 years standing :).

As a family, we are honored to get to support HDSA. Family is everything, and the community is so beautiful to be a part of year after year. We walk and work in memory of Ned Cancelmo, Sr., John Cancelmo, Meaghan Cancelmo, Karen Cancelmo, Mia Cancelmo, cousin Michael, and all of our family currently living with HD. Come and say hi as you grab your bagel this year! Or, if you would like to help solicit donations, feel free to reach out!

VOLUNTEERS NEEDED - PLEASE CONSIDER JOINING US!

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

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

VOLUNTEER HERE

UPCOMING HD EVENTS



SAN FRANCISCO TEAM HOPE TIMED 5K RUN & WALK

Saturday, October 4th, 2025



Sports Basement Presidio
610 Old Mason St
San Francisco, CA 94129

For additional information contact
Therese Crutcher-Marin
theresecrutchermarin@gmail.com



SCAN ME

www.hdsa.org/thwsanfrancisco

Join us on Saturday, October 4 and *help us fight Huntington's Disease!*

Registration Opens - 9:00 AM
Walk and Run Begins - 9:30 AM

River Walk Park

651 2nd St
West Sacramento, CA, 956

For additional information please contact Dawn Green at northernca@hdsavolunteer.org

Sign Up Here For Team Hope!

Click Here To Make A General Donation

If your company is interested in sponsoring the walk, please email teamhope@hdsa.org!

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 10 @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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