



Huntington's Disease Society of America



SAN FRANCISCO BAY AREA CHAPTER

HDSA VOLUNTEER NEWSLETTER - NOVEMBER 2025



As Autumn settles in, we're reflecting on the incredible support and spirit of our community. Your engagement and encouragement mean so much to us, and we're grateful for each and every one of you.

During this season of gratitude, we want to take a moment to thank you for being part of our journey and for the impact you continue to make.

From all of us at the HDSA San Francisco Bay Area Chapter, thank you for being a vital part of our community.

**A BIG THANK YOU to Sponsors, Donors, Volunteers,
Walkers and Runners!**

Walkers, and Runners of our San Jose and San Francisco Team Hope Walk!

This year, the HDSA SF Team Hope Run/Walk had a record number of TEAMS formed to raise dollars to provide local HD families and patients with programs / services that will allow them to have the highest quality to their lives on their HD journey.

Thank you so much to these Teams from the San Francisco Team Hope Walk: **Team Daisy 2025, Team Louis, Team Cancelmo, Stop HD, Team Tom Terrific, Heidi Ramos, Mercado Family Team, Marin Family Team, Dehard-Lillard Family Team, Ortega Family, Hudson Family Team, Carolyn's Crew, Team UCSF, Faith, Hope, Love, Team Antje, Team Townley, Team Harold, Team Beautiful, Cooper Family, Team Werby.**

Thank you so much to these Teams from the San Jose Team Hope Walk: **Peep's Party People, The Penguin Pacers and Waddle Warriors, Team Harold, Ferguson Family, UCSF Team For Hope, Denhart-Lillard Team, and Marin Family Team.**

Message From the Chapter President Mrs. Therese Crutcher-Marin

Thank you so much for your generous donation to the HDSA San Francisco Bay Area Chapter. Your support means the world to us and the HD community in the San Francisco Bay Area. The SF Bay Area Chapter is dedicated to improving the lives of everyone affected by HD and their families. We are incredibly grateful for your kindness and commitment to our cause whether it be in a dollar amount, a sponsor for an event, participating in an event or volunteering.

This year the San Jose and the SF Team Hope Run/Walk grossed \$53,000.00.



[View San Jose Team Hope Walk Photos HERE!](#)





[View San Francisco Team Hope Walk Photos HERE!](#)



Many employers have matching gifts programs where the company will match the tax-deductible contribution you make to HDSA. Your gift doubles (or more) when your company belongs to HDSA's Matching Gift Program.

[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

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

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NEW AND NOTEWORTHY IN THE HD COMMUNITY



UniQure has announced positive top-line results from its Phase I/II trial of AMT-130, a one-time gene therapy being tested in people with Huntington's disease (HD). Topline data is a summary of the key results from a study that is released quickly after data becomes available to the company at a specified timepoint. In this update, uniQure reports that symptom progression is being significantly slowed by the drug, and the primary endpoint of the trial was met. This is the first time any drug has been shown to alter the course of HD in people in a clinical trial.

[Read The Details Here!](#)



Huntington Study Group® (HSG) and Teva Branded Pharmaceutical Products R&D LLC are pleased to announce a new study available on the myHDstory® platform.

Patient & Caregiver Reported Burden of Huntington's Disease (HD) Chorea and Effect of Deutetrabenazine (DTBZ) on Symptom Management and Quality of Life (QoL), is an online study for individuals who have self-reported movements related to HD chorea, and for care partners who are providing caring for an individual living with HD chorea.

We invite you to participate in a one-time online survey (approximately 30-45 minutes) asking about movements related to HD chorea. Study participants will be compensated for participation.

To register on the myHDstory® platform and find out if you qualify to participate in the study.

[Check Here](#)

VOLUNTEER SPOTLIGHT - THANK YOU VOLUNTEERS



Our volunteers are the heart of our Chapter.

They bring our mission to life — improving the lives of everyone affected by Huntington’s disease and their families.

A heartfelt THANK YOU to our incredible volunteers who dedicated their heart, energy, and time to raise funds, set up events, cheer on participants on the trails, and help clean up. Their energy and dedication make our events a great success!

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

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Get ready to spread hope this fall! With every purchase of beautiful amaryllis bulbs, you'll be supporting the Huntington's Disease Society of America (HDSA), as 50% of the sales go directly to our mission. Share the joy of blooming flowers with friends and family! Plus, each purchase can be credited to a chapter, affiliate, or region of your choice, ensuring your support makes an even greater impact.

Help us make a difference and watch hope blossom! Visit our online store to explore the amaryllis here:

[Click Here](#)

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. Email: natashaboissier@berkeley.edu

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. Email: silango@hdsa.org

HDSA SUPPORT GROUP FOR YOUNG ADULT CAREGIVERS

Schedule: Monthly Group Meetings - 1st Monday of each month 10am PST/11am MST/12pm CST/1pm EST.

Location: Zoom Meeting

Leader: Brianne Heimbuch, LCSW, Phone: 518-557-8103. Email: bheimbuch@hdsa.org

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](#)