



Huntington's Disease Society of America



SAN FRANCISCO BAY AREA CHAPTER

HDSA VOLUNTEER NEWSLETTER - DECEMBER 2025



San Francisco Bay Area Chapter 2025 Accomplishments

2025 JOINT EDUCATION DAY: The first-ever joint Education Day held by both the Northern California Chapter and the San Francisco Bay Area Chapter was held on May 3rd at the Hampton Inn and Suites in Napa. Giving the Keynote address was the newly appointed President and CEO of the Huntington's Disease Society of America, Amy Gray. The event was well attended by both area families dealing with HD, as well as Board members of the two chapters, with 110 attendees, including 14 walk-ins.

2025 SAN JOSE TEAM HOPE WALK: The 2025 San Jose Team Hope Walk, held on Saturday, May 17th, at Campbell Park was a success. We had 65 participants, and we raised a total of \$17,185! The 2026 San Jose Team Hope Walk will be held on Saturday, May 16th at Campbell Park.

2025 SAN FRANCISCO TEAM HOPE WALK: The 2025 San Francisco Team Hope Walk was held on October 4th at Crissy Fields, was also a success. We had 180 participants, and we raised a total of \$35,875!

The Chapter grossed **\$53,060** from the 2025 fundraising events.

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



Resources to Know Before the End of the Year

As the year winds down, many families in the Huntington's disease (HD) community are managing not only holiday plans, but also renewals, forms, and care decisions that affect the year ahead. This is a key time to pause, review, and make sure your support stays in place going into 2026.

1. Health Coverage & Open Enrollment

Medicare, Medi-Cal, and many private insurance plans are currently in Open Enrollment. This is the time to confirm that your 2026 plan still covers the medications, specialists, and therapies you rely on. If telehealth has been important for your care, take a moment to verify whether your plan will continue reimbursing for virtual visits — several programs are changing rules as pandemic-era flexibilities end. If comparing plans feels overwhelming, your

state's **SHIP (State Health Insurance Assistance Program)** can provide free, unbiased guidance.

2. Renewal of Public Benefits

Programs like SNAP, SSI/SSDI, and In-Home Supportive Services often require annual reporting. Look out for mail or online notices requesting income updates or re-certification. Delays in responding can lead to benefit interruptions, so try to complete renewals before the holiday rush.

Note: SNAP benefits have been affected due to the government shutdown. If you need additional resources, please contact me or any social worker!

3. End-of-Year Planning for Care

This is also a good moment to check on important documents: advance directives, powers of attorney, medication lists, and emergency contacts. If you rely on respite care, adult day programs, or transportation services, consider scheduling early—January spots fill up fast.

4. Stay Connected

Support groups will still be held every month. These can be a grounding space for both caregivers and individuals living with HD.

A little preparation now can make January feel less stressful. Think of it not as extra work, but as a gift of stability to yourself and your family.

SATVE ILANGO, MSW, CHAPTER SOCIAL WORKER

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

New and Noteworthy in the HD Community

In HDBUZZ.net on October 23, 2025

The past 4 weeks have been a whirlwind in Huntington's disease (HD) community. On [September 25th we had an update from uniQure](#) about a drug they're testing for HD in ongoing clinical trials. The news was positive, and it took the world by storm, producing jaw dropping headlines from news sources around the world, generating global interest in HD, and prompting many people within the HD community to reach out to neurologists and care centers around the world with various questions. Now that the dust has settled, we can take a step back to break down what we know and where the uncertainties lie.

[Click Here to Read Full Article](#)



UniQure Provides Regulatory Update on AMT-130 for Huntington's Disease

Lexington, MA and Amsterdam, the Netherlands, November 3, 2025 — "uniQure N.V. (NASDAQ: QURE), a leading gene therapy company advancing transformative therapies

for patients with severe medical needs, today announced that it received feedback from the U.S. Food and Drug Administration (FDA) during a recent pre-Biologics License Application (BLA) meeting regarding AMT-130, an investigational gene therapy for Huntington's disease (HD)."

[Click Here to Read Full Announcement](#)

A Message from Our Board President

Standing with all those impacted by Huntington's disease, united in hope and support

[Read the Full Letter Here](#)

Ongoing Event



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

Location: Oceanview Congregational Church - 1111 Navillel Street, El Cerrito, CA 94708

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

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:

JANUARY 7th @7pm

Contact Therese Crutcher-Marin for meeting information:

thersecrutchermarin@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://www.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://www.hdsa.org/OSG)

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

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

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

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

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

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

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



We Can Never Lose Hope!



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