



HDSA VOLUNTEER NEWSLETTER – JULY 2026



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!

2026 SAN FRANCISCO BAY AREA CHAPTER UPDATES

Thank you for being part of the HDSA community. Here's a look at what's happening later this year—from important updates and resources to ways you can stay connected and make an impact.

- [Team Hope Walk & Timed 5k Run](#) - October 3, 2026 - San Francisco, CA
- [Golden Gate Half Marathon](#) - November 1, 2026 - San Francisco, CA
- [Celebration of Hope](#) - November 8, 2026 - Danville, CA

UPCOMING EVENTS



20TH ANNUAL TEAM HOPE WALK & TIMED 5K - SAN FRANCISCO, CA

Join us on **Saturday, October 3rd** at **Sports Basement Presidio!**
Location: 610 Old Mason St,
San Francisco, CA
Check-in: 9:00 AM

REGISTRATION IS FREE!

How to Register? [Click Here](#)

[Register/Donate Here](#)



GOLDEN GATE HALF MARATHON

Join us on **Sunday, November 1st** at **Ghirardelli Square!**

Location: 900 North Point St.,
San Francisco, CA 94109

Check-in: 8:00 AM

Event Time: 9:00 AM

[Register/Donate Here](#)



CELEBRATION OF HOPE - CALIFORNIA

Join us for special Gala on **Sunday, November 8th** at **Blackhawk Museum!**

Location: 3700 Blackhawk Plaza
Cir., Danville, CA 94506

Event Time: 12:00 PM

[Register/Donate Here](#)



Volunteers are the heart of Huntington's Disease Society of America, fulfilling our mission– To improve the lives of everyone affected by Huntington's disease and their families. If you are looking to put your passion for helping others to meaningful use, expand your network, learn new skills, and make a difference; we are looking for you!

[Please complete the Volunteer Application](#)



HOW TO REGISTER FOR A TEAM HOPE WALK:

1

VISIT THE WEBSITE:

Go to www.teamhopewalk.org and find the Team Hope Walk location you would like to attend.

2

CLICK THE “REGISTER” BUTTON

Click the yellow “register” button found next to the location name. Clicking this button will take you to that specific location’s registration page. Once there, click the yellow “register” button again.

3

SPECIFY YOUR REGISTRATION TYPE:

You will be given 3 options to choose from upon clicking “register”: register as an individual, join an existing team, or create a new team.

AS AN INDIVIDUAL

You will have the option to select the amount (and type) of tickets you are reserving.

JOIN A TEAM

If you are looking to join someone else’s team that has already been created, search for it using the search bar.

CREATE A TEAM

If you would like to start a new team, fill in your team name and details.

4

FILL IN YOUR INFORMATION & CONFIRM

Once you have filled in your information, you will receive a confirmation email from HDSA. Once you are registered, you can begin your fundraising efforts!

Questions? Email teamhope@hdsa.org or call 1-800-345-4372

[View More](#)

2026 HDSA Convention Recap



The HDSA Convention did not disappoint the HD community again this year. The sessions will become available on the HDSA YouTube channel soon. A few key topics were:

- UniQure presenting on exciting updates regarding the FDA (see below)
- Recognition of the Impact of Participation in Clinical Research
- Turning Advocacy into Action: How the HD Community is Driving Change
- Support groups were available for all demographics of the HD community
- Parenting a Child with JHD: Emotional Resilience for Caregiving Parents

[HDSA YouTube Channel](#)
[UniQure Press Release, 6.17.26](#)

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**The SF Bay Area Chapter received
the #LetsTalkAboutHD Award**
for the promotion the Chapter does for HD
Awareness Month in May



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Moment of Hope: Many companies are working on or interested in HD (PowerPoint slide from convention)



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Volunteer Spotlight: Rebekah Granlund
She received the HDSA Youth/JHD (NYA) Award. Click on the photo to read more about Rebekah



[Read more](#)

Research Updates

Check out the 22 HDSA-Funded Researchers

[Click here](#)

[Latus Bio Updates](#)

Scientists believe that the damage in HD compounds over time because the disease-causing gene keeps expanding inside neurons throughout a patient's life, in a process called "somatic instability". While the other gene therapies in trials (UniQure's AMT-130 and Roche's SPK-10001) aim to silence the harmful huntingtin protein, Latus is targeting MSH3, the molecular engine driving somatic instability, and its modeling suggests that doing so early could significantly delay symptom onset. Their engineered virus delivers a low dose precisely to the right neurons, injected into a brain region that remains healthy longer in the disease, allowing them to treat a broader population and avoid potential trial design complications that other approaches have faced. The company expects to seek FDA approval to begin human trials this summer. Read more at link above.

[Skyhawk Therapeutics Updates](#)

Skyhawk Therapeutics has released new 12-month data from the ongoing Phase 1/2 trial of SKY-0515, its HTT-lowering oral therapy for Huntington's disease (HD). The update builds on topline results announced on June 1, showing sustained reductions in huntingtin (up to 69%) and PMS1 (up to 26%) in blood, along with encouraging trends on the composite Unified Huntington's Disease Rating Scale (cUHDRS). While these findings are promising, it remains unclear whether the observed reduction in PMS1 is enough to translate into meaningful clinical benefit. Read more at link above.

[Roche Drug Trail Update](#)

Roche announced it is stopping development of two of its huntingtin-lowering ASO drugs, tominersen and RG6496. This marks a disappointing end to an important chapter in HD clinical research. Read more at link above.

Support Groups

SIGN UP FOR THE RIGHT SUPPORT GROUP FOR YOUR NEEDS.

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

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

[HEY PEERS! Link](#)

Social Worker Corner

SATVE ILANGO, MSW, CHAPTER SOCIAL WORKER

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

Read this edition's Social Work Corner



Stay Connected

**JOIN OUR NEXT SF BAY
AREA CHAPTER BOARD
MEETING:**

September 2nd at 7pm

If you are interested in doing more for our Chapter, contact Therese Crutcher-Marin for more information:
thersecrutchermarin@gmail.com



[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.



[HDSA'S Programs & Services](#)



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).

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New HDSA Programs & Services Document

[DOWNLOAD HERE](#)

Review the links below to find support today:

Local (San Fran) HDSA Social Worker:

Satve Ilango, HDSA Social Worker

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

Online Support Groups: [HDSA.ORG/OSG](https://hdsa.org/OSG)

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

HD Trialfinder: [HDTRIALFINDER.ORG](https://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!