



Huntington's Disease
Society of America



SAN FRANCISCO BAY AREA CHAPTER



HDSA VOLUNTEER NEWSLETTER

HDSA VOLUNTEER NEWSLETTER - JUNE 2025

2025 SAN JOSE HOPE WALK



The 2025 San Jose Hope Walk for Huntington's Disease was a success. Held on Saturday, May 17 at Campbell Park, the Walk had 65 participants and raised a total of \$17,185!

Sponsors of the event were were: National sponsors: Teva, Genentech; Local Sponsors: Mirror Senior Living, Stanford Medicine, San Jose Water Company, NuMotion Foundation, UA Local 393, The Denhart-Lillard Trust, Marin Family, and Bray Firm.

Thanks to all the volunteers, participants, sponsors, and families that helped make our Team Hope Walk a success!

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



Caring for the Caregiver- Part 1

When someone is diagnosed with a chronic or progressive illness, the focus often—and understandably—shifts to the needs of the person with the diagnosis. But what about the person standing beside them? The spouse who quietly handles the medications. The adult child juggling appointments and their own family. The friend who checks in every day. These caregivers are the unsung heroes of the story—and they need care, too.

As a social worker, I've seen caregivers give everything they have and more: time, energy, emotional bandwidth, and often their own health. And I've also seen what can happen when caregiving becomes a one-way street. That's why it's crucial to talk openly about what it means to care *for* the caregiver.

Caregiving is not just about tasks—it's about emotional labor. Watching a loved one decline can bring waves of grief, stress, guilt, and helplessness. You may feel like you have to be strong all the time, never show your sadness, never admit you're tired. But that's not sustainable—or fair.

Unacknowledged stress can turn into burnout, and burnout affects everything: your relationships, your physical health, your ability to provide care, and your overall well-being. You deserve support too. In our next newsletter, we will go over ways you can support yourself as a caregiver.

SATVE ILANGO, MSW, CHAPTER SOCIAL WORKER

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

NEW AND NOTEWORTHY IN THE HD COMMUNITY



JOINT EDUCATION DAY HELD IN NAPA ON MAY 3

The first ever joint Education Day held by both the Northern California Chapter and the San Francisco Bay Area Chapter was held May 3 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. Gray spoke of the challenges ahead for the Society in an environment of funding changes and highlighted her vision for the future of the organization. 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. Thanks to all who organized the event, and, especially, to those who attended!

WELCOME NEW BOARD MEMBER IAN FERRY

We are pleased to welcome Ian Ferry as a Board Member of the San Francisco Bay Area Chapter of the Huntington's Disease Society of America. Ian noticed our organization while looking for a volunteer position in rare diseases and contacted us. We look forward to working with Ian and benefiting from his expertise in fundraising.

If you'd like to volunteer as well, please follow the volunteer link below.

Visit the HDSA Podcast

The HDSA Podcast gives listeners an opportunity to meet members of the Huntington's disease community and get a behind-the-scenes look at the Huntington's Disease Society of America. A new episode will be released every month and please visit www.HDSA.org to learn more about HD and how to get involved.

Visit the Podcast Here



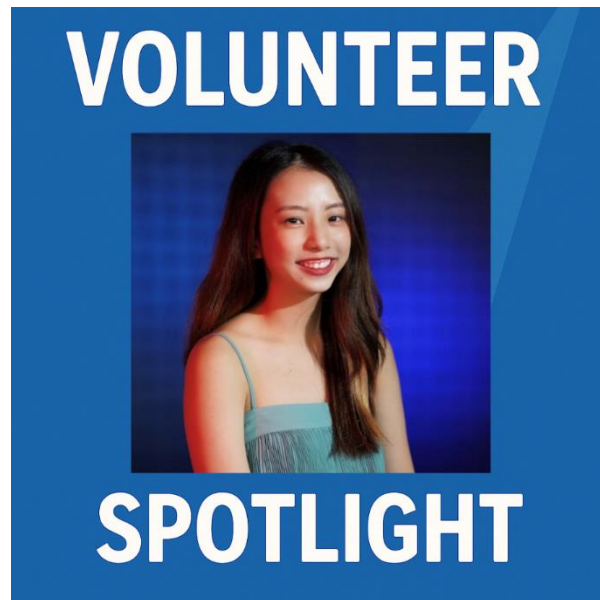
HDSA Centers of Excellence Expanding

The Huntington's Disease Society of America is expanding its HDSA Centers of Excellence network of comprehensive care clinics with 57 grants totaling \$2,100,557. In addition to the 57 grant funded facilities, eleven regional partner sites were also named, ensuring expert HD care at 68 distinct medical facilities in 37 states across the nation and Washington, DC. Visit our local centers at the links below.

UCSF HD Clinic

Huntington's Disease Center of Excellence at Stanford

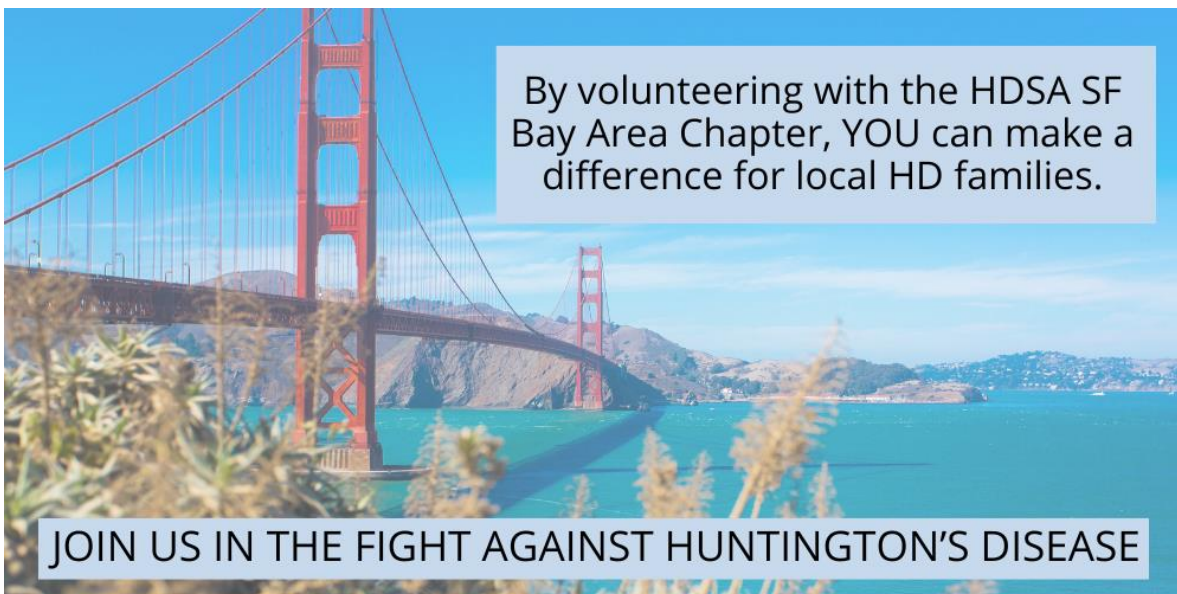
JUNE'S VOLUNTEER SPOTLIGHT- HAYLEY WONG



As a San Francisco Bay Area Chapter Board member Hayley Wong is grateful for the opportunity to volunteer with HDSA. After relocating from Singapore to the Bay Area in 2023, she sought out a meaningful way to connect with her new community and to give back. Volunteering has always been close to her heart and a way to show appreciation for the opportunities she's been given as well as to help make a positive impact. Discovering more about the HD, Hayley immediately felt drawn to the cause and realized the importance of shining a light on the families and individuals affected by it. Through volunteering, Hayley hopes to not only support the mission but also to help spread greater awareness and compassion. For Hayley, one of the most rewarding parts of the volunteer experience has been the incredible community of volunteers she's met along the way and their commitment and enthusiasm have inspired her. Being part of this community made her transition to life in the Bay Area even more meaningful.

Besides volunteering, Hayley lives with her spouse and their beloved dog, who brings endless joy to their lives. In her free time, she loves exploring the outdoors through hiking, working on crochet projects, and she recently started experimenting with a new hobby: hand-building ceramics.

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

PLAY

HDSA SF FUNDRAISER!

BALL!



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SAN FRANCISCO BAY AREA CHAPTER

AUGUST 9TH, 2025

**SAN JOSE GIANTS
VS VISALIA
RAWHIDE**



- JOIN US AS WE RAISE AWARENESS AND ENJOY A BALL GAME!
- 5 PM GAME TIME [A*] EXCITE BALLPARK IN SAN JOSE!
- TICKETS: \$21
- FIREWORKS SHOW AFTER THE GAME!



More Information or Accommodations

joshjacobs@sjgiants.com 

(408) 297-1435 



JOIN US AT THE SAN JOSE GIANTS GAME ON AUGUST 9

Please join us at on August 9th for our San Jose Giants Park Packer fundraiser! Share this information with your people, and let them know to use promo code **HDSA**! Can't wait to see everyone at the park! Follow the link below for more details.

[More Details Here](#)



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

www.hdsa.org/thwsanfrancisco



Sign Up Here For Team Hope!

NEW THIS YEAR!

The SF Team Hope fundraiser is offering a Timed 5K Run on Chrissy field.

Runners are \$60. *The top 3 runners will receive a medal.*



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:

therese.crutchermarin@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://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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