

SAN FRANCISCO BAY AREA CHAPTER



HDSA VOLUNTEER NEWSLETTER - JULY 2025

HDSA SF FUNDRAISER ON AUGUST 9 SAN JOSE GIANTS VS RISALIA RAWHIDE



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.





IMPORTANT NOTE:

Make sure that <u>mail@HDSA.org</u> 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 2

You Deserve Support, Too

Here's something every caregiver needs to hear: you are not alone, and your well-being matters just as much as the person you're caring for. Here are a few ways to start prioritizing yourself:

1. Emotional Self-Care

Allow yourself to feel. You don't have to "stay strong" all the time. Find someone to talk to—a friend, therapist, spiritual advisor, or support group. Try journaling or quiet time to process your own experience.

2. Ask for Help

Accepting help is not a weakness. It's a necessity. Let others take on tasks—even small ones like picking up groceries or sitting with your loved one for an hour. Look into community resources or home care agencies that offer part-time or respite care.

3. Take Breaks—Without Guilt

Rest is not a luxury. It's part of staying healthy. Schedule time for yourself regularly. Even short breaks can make a difference. Use respite services when you need to recharge. They exist for this exact purpose.

4. Connect With Other Caregivers

Joining a support group can be a lifeline. It reminds you that you're not alone and provides a safe place to share and learn. Please contact me for information on our support groups!

Caring for a loved one is one of the most compassionate and generous things you can do, but you are not a machine. You are a human being with your own needs, emotions, and limits.

So please—check in with yourself. Reach out. Rest. Refill your own cup, so that you can keep showing up with love and strength not just for others, but for yourself.

Because you matter, too.

SATVE ILANGO, MSW, CHAPTER SOCIAL WORKER

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

NEW AND NOTEWORTHY IN THE HD COMMUNITY



Enroll-HD

Want to help in the fight against HD another way. Please look into <u>Enroll-HD</u> which is the world's largest observational study for Huntington's Disease. Families, currently more than 20,000 people, are taking part in Europe, North America, Australia and Latin America. By monitoring how the disease happens in people and how it changes over time in very fine detail with the same test and assessments around the world, researchers can use the huge data and biosample collection to learn more and come up with new ways to effectively treat Huntington's Disease.

EDUCATION DAY 2025 FEEDBACK REVIEWED

Feedback from the 2025 Education Day in Napa has been received and reviewed. This will help to plan the 2026 event more effectively and to ensure all needs are being met. Thank you to all who participated in the survey, which helps us to fine-tune our planning! Some of the findings can be found in the images below.





HDSA Annual Meeting Held June 26-28 in Indy



The 2025 40th Annual HDSA Convention took place in Indianapolis, Indiana on June 26-28th. You can watch the presentations from the Convention in a couple of weeks at the <u>HDSA</u> <u>Youtube channel</u>.

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

JUNE'S VOLUNTEER SPOTLIGHT- IAN FERRY



My interest in volunteering stems from the fact that I have a family member who suffers from chronic and debilitating pain caused by a rare disease. I am interested in helping organizations which have a mission to help those in similar circumstances. I watched a documentary on Huntington's Disease with my daughter several months ago and we both instantly wanted to learn if there was a way to help. I have found that HDSA offers a chance to support groundbreaking research, raise awareness, and provide critical care and community resources for those navigating the challenges of Huntington's Disease. Becoming a volunteer is a way for me to turn empathy into action.

When I am not working I spend most of my time chasing my kids around. I have a 13-year-old son and a 9-year-old daughter and we live in Marin county. When I have extra time I enjoy cycling, hiking, and reading historical biographies.

VOLUNTEERS NEEDED - PLEASE CONSIDER JOINING US!



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

VOLUNTEER HERE

UPCOMING HD EVENTS



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

Registration Opens - 9:00 AM Walk and Run Begins - 10:00 AM

NEW THIS YEAR: Get ready to race the clock! This year's event will feature a timed run.

Sports Basement Presidio

610 Old Mason St San Francisco, CA, 95008

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

Sign Up Here For Team Hope!

Click Here To Make A General Donation

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

<u>Schedule:</u> 4th Tuesday each month, 7:00 pm - 8:30 pm <u>Location:</u> Sycamore Congregational Church - 1111 Navellier Street, El Cerrito, CA 94530 <u>Leader: Natasha Boissier</u> Phone: 415-476-2904

PALO ALTO HD SUPPORT GROUP

<u>Schedule:</u> Second Tuesday of each month, 7:00 p.m. - 8:30 p.m. <u>Location:</u> First Baptist Church - 305 N. California Street, Palo Alto, CA 94301 <u>Leader:</u> <u>Satve Ilango</u> 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 I (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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