Huntington's Disease Society of America

SAN FRANCISCO BAY AREA CHAPTER

HDSA VOLUNTEER NEWSLETTER - OCTOBER 2025

HDSA Team Hope Timed 5k Run & Walk - San Francisco THIS SATURDAY!

SPORTS BASEMENT PRESIDIO

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

JOIN US AT THE SAN FRANCISCO TEAM HOPE WALK THIS SATURDAY!

Join the fun this Saturday at Sports Basement Presidio at 610 Mason Street, San Francisco. You can walk in to register for a 5K Walk or a 5K Timed-Run at the beautiful Crissy Field. We have breakfast and coffee to get you started, as well as lots of Auction and Raffle Items to bid on!

Registration Opens at 9:00 AM - Walk and Run Begin at 10:00 AM

Follow the link below to register.

Click Here To Register

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 the updates and events in your area!

Social Worker Corner

Advance Care Planning- Part 2

In Part 1, we explored what advance care planning is and why it matters for families navigating Huntington's Disease. Now, let's turn to the practical side: how to start the conversation, what documents are most important, and where you can find support.
It's common for families to avoid advance care planning because they're unsure how to bring it up. You don't need to sit down for a long, serious meeting right away. In fact, small conversations over time can feel more natural. You might ask:

- "If you were very sick, what would matter most to you?"
- "Who do you trust to make decisions if you couldn't?"
- "Would you want to stay at home or be in a hospital if you needed more care?"

Putting It in Writing
Talking is important—but writing things down ensures your wishes are honored. Key documents include:

- Living Will – Outlines which medical treatments you do or don't want.
- Health Care Proxy (Durable Power of Attorney for Health Care) – Names a person you trust to make health decisions on your behalf.
- Financial Power of Attorney – Authorizes someone to handle financial matters if needed.

You don't always need a lawyer—many states have free, downloadable forms. Once completed, share copies with your family, your doctor, and your local hospital. Keep an extra copy in an easy-to-find place at home.

Finding Support
You don't have to navigate this alone. Helpful resources include:

- Your HD Center of Excellence or clinic social worker. · The Conversation Project (theconversationproject.org) – Tools for starting conversations. · National Institute on Aging (nia.nih.gov) – Guides on legal and medical planning.
- HD support groups – where families often share their personal experiences with advance care planning

SATVE ILANGO, MSW, CHAPTER SOCIAL WORKER
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Email: silango@hdsa.org

NEW AND NOTEWORTHY IN THE HD COMMUNITY

Huntington's Disease Society of America

HDSA STRATEGIC PLAN COMMUNITY SURVEY

HDSA is developing a new Strategic Plan to guide our mission, and they need your input. The survey takes just a few minutes, and your feedback will help shape the mission, vision, and goals to better serve families impacted by Huntington's disease. Click the button below to participate.

Check Here

PARTICIPATE IN A RESEARCH STUDY!

CHDI Foundation, Inc., invites you to participate in an online research study designed to evaluate the Functional Rating Scale 2.0 (FuRST 2.0). The FuRST 2.0 is a new measure that is being developed to improve the assessment of Huntington's disease's (HD) impact on people's functional abilities. Any person who is 18 years of age or older and self-identifies as having HD (e.g., gene positive pre- or post-clinical motor diagnosis) is invited to participate. The study involves responding to the FuRST 2.0 and two other short questionnaires. The study will take approximately 20 minutes to complete. No compensation is provided for participation. If you are interested in participating, please click on the weblink below or copy and paste the weblink into your browser.
If you have any questions about this study, please contact FOCUSOnlineStudy@chdifoundation.org

Check Here

OCTOBER'S VOLUNTEER SPOTLIGHT - COOPER FAMILY

My family's journey with Huntington's disease is deeply personal and has shaped the work I do. My grandfather, Jack Christensen, lived with Huntington's disease and, tragically, lost his life in a way connected to the struggles of the disease. My mother, Carrie Cooper, was diagnosed at the age of 33 and showed incredible strength throughout her battle until she passed away in March 2022 at the age of 52.

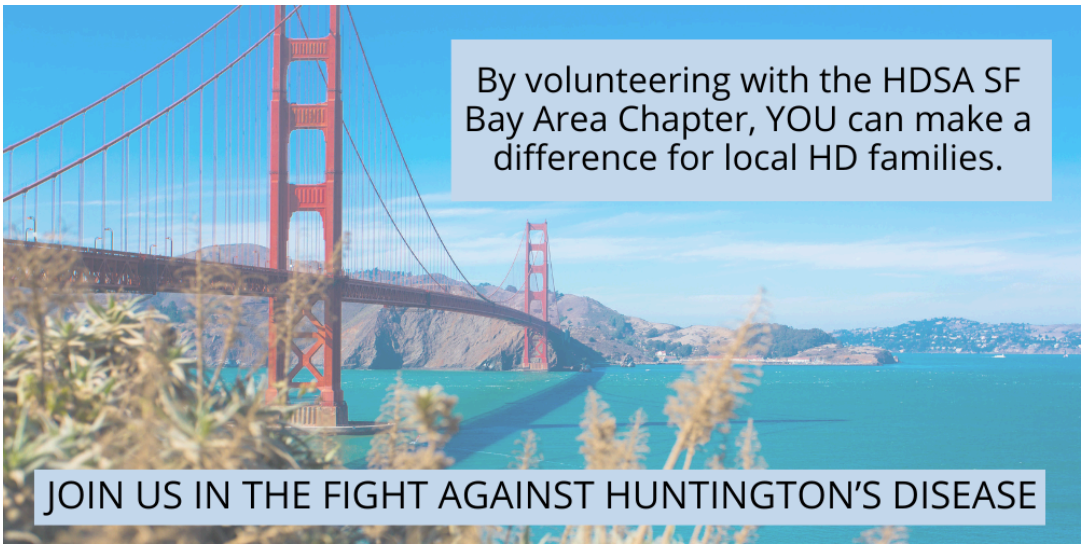
In 2023, my brother Jack began hosting Huntington's Disease Awareness Nights with his hockey team at King's College, and he even created custom HD awareness jerseys that were auctioned off to support the cause. When he moved to Trine University, he continued this tradition, using these events to honor other families and bring more visibility to Huntington's Disease Society of America.

That same year, I held my first HIIT HD Back event in Eugene, Oregon. In 2024, I continued the

event and ran the Eugene Half Marathon for HD. By 2025, I expanded it into Movement for Huntington's, a week-long series of events with local studios. I also had the honor of speaking at Alpha Phi's Red Dress Gala for the third time.

I founded the Huntington's Sports Club to create a space for young people to come together, celebrate movement, and support HD families. In everything we do, we are honoring our loved ones and building a hopeful, resilient community

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

Please join us for our Northern California Regional Celebration of Hope: Together We Shine!

SUNDAY, OCTOBER 26TH, 2025
11:30-2:00PM
BOUNDARY OAK GOLF COURSE

3800 Valley Vista Rd, Walnut Creek, CA 94598

Appetizers, plated meal, dessert, and open bar + drinks included with ticket purchase!
Questions or looking to sponsor? Please contact Christine Greve: cgreve@hdsa.org

Sign Up Here For Celebration of Hope!

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:

OCTOBER 1ST @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!

Our mailing address is:

HDSA San Francisco Bay Area Chapter

P.O. Box 1599

Cupertino, CA 95015