



Huntington's Disease Society of America



SAN FRANCISCO BAY AREA CHAPTER

HDSA Volunteer Newsletter - September 2024

Please join us for a very special day of giving.

FOUNDER'S DAY IS SEPTEMBER 18, 2024

Please join us on September 18th, 2024 for a very special 24 hour day of giving dedicated to Marjorie Guthrie, her legacy, and the movement she inspired that led to the establishment of HDSA.

57 years ago, on September 18, 1967, the Committee to Combat Huntington's Disease (CCHD) - which later became Huntington's Disease Society of America (HDSA) - was incorporated in New York state.

At the helm, Marjorie Guthrie, the widow of folk musician Woody Guthrie, began a movement for HD families that continues on today through HDSA's mission: to improve the lives of everyone affected by HD and their families. On Founder's Day, we honor Marjorie and her legacy by raising critical funds, voices, and awareness for the HD community all over the country, and across the world.

[CLICK HERE FOR MORE INFORMATION](#) and please make sure to select **San Francisco Bay Area Chapter** in the donation designation dropdown!

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!

NEXT MONTH IN SAN FRANCISCO

JOIN US FOR OUR 18TH ANNUAL
heroes & villains
TEAM HOPE 5K WALK & FUN RUN

OCTOBER 5, 2024 **SPORTS BASEMENT PRESIDIO**

REGISTER NOW: HDSA.ORG/THWSANFRANCISCO

TEAM HOPE
WALK - RUN - RIDE

SAN FRANCISCO TEAM HOPE WALK SCHEDULED FOR **SATURDAY, OCTOBER 5th!**

Be sure to join us for the 2024 San Francisco Hope Walk on Saturday, October 5 at the Presidio Sports Basement. To register, or to find out more information, please click below.

2024 San Francisco Team Hope Walk Info

The Chapter's joint Family Education Day with the HDSA Center of Excellence Stanford Medicine and HDSA Center of Excellence UCSF Medical Center is **October 19, 2024**. It will be in-person at UCSF Medical Center Campus from 9:30-3:30PM. This is a free educational event and lunch will be provided.

[CLICK HERE TO REGISTER](#)

NEW AND NOTEWORTHY IN THE HD COMMUNITY

HDSA CENTERS OF EXCELLENCE



HDSA CENTERS OF EXCELLENCE

HDSA Centers of Excellence provide a multidisciplinary team approach to Huntington's disease care. Patients benefit from expert neurologists, psychiatrists, social workers, therapists, counselors and other professionals who have extensive experience working with families affected by HD and who work collaboratively to help families plan the best HD care program throughout the course of the disease. Applications to become an HDSA Center of Excellence are open to all clinics in the United States who share HDSA's commitment to high-quality, comprehensive care and access to clinical research. There are currently 56 HDSA Centers of Excellence and 11 Partner Sites covering 36 States plus the District of Columbia.

[STANFORD UNIVERSITY CENTER OF EXCELLENCE](#)

[UNIVERSITY OF SAN FRANCISCO CENTER OF EXCELLENCE](#)

ONLINE SURVEY: INSURANCE FOR PEOPLE WITH HD

Whether you are diagnosed with or are at-risk for Huntington's Disease, the decision to pursue life, long-term care, or disability insurance is a difficult one. Researchers for the UT Health Houston are looking to better understand the experiences of those pursuing these specified insurances, including motivating factors and barriers faced in obtaining these insurances.

This survey is open to any English-speaking individuals, 18 years or older, who are diagnosed with or are at-risk for HD, and who are currently residing in the U.S. If you are interested in participating, check out the flyer [here](#), or click [here](#) to access the anonymous survey. If you have any questions or concerns, please contact karli.livingston@uth.tmc.edu.

HOW YOUTH CAN GET INVOLVED WITH HD RESEARCH

Studies of drugs to treat Huntington's disease have been primarily focused on adults, but the ultimate goal is to treat or even prevent HD symptoms in everyone who carries the gene. In order for trials and treatments to occur earlier and in younger people, it is essential that researchers gain a better understanding of the developing brain in people at risk for HD, and this is where youth from HD families can have a big impact.

Find out how you can get involved [here](#).



HDSA NATIONAL YOUTH ALLIANCE

SAN JOSE WALK FOR 2025 - DATE CHANGE

The HDSA [SF Bay Area Chapter](#) leadership decided to move the date of the San Jose Walk because of the heat, graduations, and HDSA Awareness Month. We hope to capture a higher number of HD families/patients who can attend the fundraiser.

New Date: Saturday May 17, 2025 at Campbell Park

JULY 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:

September 4th, 2024 @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](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...



Our mailing address is:

HDSA San Francisco Bay Area Chapter

P.O. Box 1599

Cupertino, CA 95015

