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Huntington's Disease Society of America

SAN FRANCISCO BAY AREA CHAPTER

HDSA Volunteer Newsletter - March 2025

2025 SAN JOSE TEAM HOPE WALK

SIGN UP NOW!

Sign up here!

Huntington's Disease Society of America

SAN FRANCISCO BAY AREA CHAPTER

TEAM HOPE 5K TIMED RUN & 5K WALK SAN JOSE

Saturday, May 17th, 2025

Campbell Park
E Campbell Ave &, Gilman Ave
Campbell, CA, 95008

For additional information contact
Uma Thontakudi
sanfrancisco@HDSAvolunteer.org

www.hdsa.org/thwsanjose

IMPORTANT NOTE:

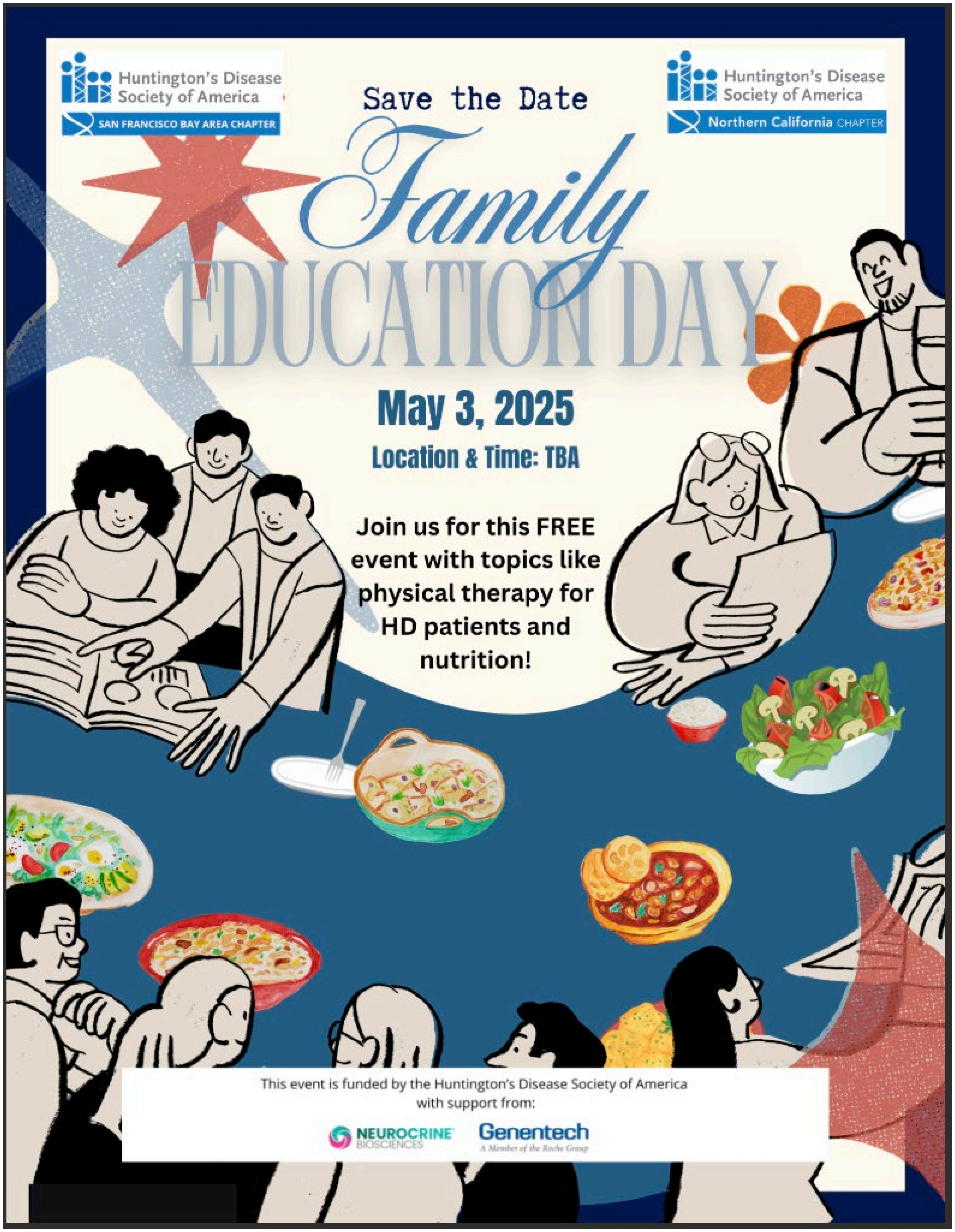
Make sure that mail@HDSA.org is added to your email list so that you can see all of the updates and events in your area!

BOARD CHANGES ANNOUNCED

We are pleased to welcome three new members to the Board of Directors of the San Francisco Bay Area Chapter. Gaurav Kaushik, DPT, MBA, who is in the South Bay area and Jeanette Hrnyak, a long-time volunteer will join as Board members. Rebekah Granlund, who currently works with the HDSA Youth Alliance will join the Board, as well as take over the position of Vice President of the Chapter from current Vice President Uma Thontakudi, who will step down to focus on the San Jose Team Hope Walk. Thank you to Uma for all her hard work and welcome to our two new Board members!

Huntington's Disease Society of America
SAN FRANCISCO BAY AREA CHAPTER

Huntington's Disease Society of America
Northern California CHAPTER



Save the Date

Family EDUCATION DAY

May 3, 2025

Location & Time: TBA

Join us for this FREE event with topics like physical therapy for HD patients and nutrition!

This event is funded by the Huntington's Disease Society of America
with support from:

NEUROCRINE BIOSCIENCES
Genentech
A Member of the Roche Group

Understanding Genetic Testing for Huntington's Disease: A Consultation Journey with a Genetic Counselor at Stanford Health Care

Genetic testing for HD is a significant decision that involves careful consideration and support. The process typically unfolds over three distinct visits with a genetic counselor, each designed to provide education, emotional support, and informed consent.

1st Visit: Educational Foundation

The first appointment mainly focuses on education. Patients learn about Huntington's disease. The genetic counselor discusses the implications of testing, helping patients understand what a positive or negative result could mean for themselves and their families. This visit also provides space for patients to share personal stories and motivations for seeking testing, allowing counselors to identify any specific concerns or reasons for pursuing genetic evaluation.

2nd Visit: Psychosocial Support and Logistics

The second visit shifts to a psychosocial framework. Here, emotional support becomes paramount. If the patient did not have a support person during the initial consultation, this visit offers an opportunity to involve them. Education may be revisited to reinforce understanding. The genetic counselor will also discuss the logistics surrounding the testing process, including how and when the test will be conducted, and what to expect afterward. This visit is crucial in ensuring patients feel emotionally prepared and supported as they contemplate their next steps.

3rd Visit: Result Disclosure

The final appointment is dedicated to disclosing the genetic test results. It is highly encouraged that a support person be present, as this can provide emotional backing during what can be a challenging moment. The genetic counselor reviews the results with the patient. This session aims to provide clarity and resources for coping with the outcomes of the testing.

Another way to get tested is through a small privately funded company called HD Genetics. They provide genetic counseling and testing for individuals in the U.S.A. who are at-risk for HD. They offer anonymous testing as well. They also offer genetic counseling for individuals who have already had HD genetic testing and are looking to connect with an HD specialist to discuss the implications of their test results. Here is their website for more information: HD Genetics Best-In-Class Genetic Testing & Counseling

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

NEW AND NOTEWORTHY IN THE HD COMMUNITY

2025 HDSA Berman/Topper Family HD Career Development Fellowship Application Now Open

The Huntington's Disease Society of America (HDSA) believes we must ensure that the pipeline of passionate and bright HD scientists and clinicians remains full, a vision that is shared by the Berman and Topper families. With their support, HDSA sponsors innovative lines of scientific inquiry into HD biology by young researchers with a desire to make HD research a part of their career plan. This fellowship is open to investigators with a doctoral or medical degree who are within 5 years of obtaining PhD or completing residency/fellowship.

3 Year Grant
Up to $100,000/year

Applications Due by April 14, 2025
Notification by Late May 2025
Fellowships Begin by August 1, 2025

VOLUNTEER SPOTLIGHT - JEANETTE HRNYAK

Hello, I’m Jeanette Hrnyak, and I began volunteering with the HDSA San Francisco Chapter in 2021. After the pandemic, I wanted to get involved and help others again and was moved by Therese Crutcher-Marin’s passion for raising awareness and supporting families affected by Huntington's disease. It’s been such a joy to help with the San Francisco walk each year, and I’m always happy to contribute my ideas and skills whenever I can. The team has been so supportive and values my efforts, which makes it even more rewarding. With my background in hospitality, events, and travel, I find it natural to lend a hand to those in need. Watching the chapter grow and flourish over the years has been amazing—they’re truly an awesome group of people!

VOLUNTEERS NEEDED - PLEASE CONSIDER JOINING US!

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

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:
MARCH 5th @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 l (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:
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