



Huntington's Disease
Society of America



SAN FRANCISCO BAY AREA CHAPTER

HDSA Volunteer Newsletter - November 2024

Huntington's Disease
Society of America

**GIVING
TUESDAY**

A day of
world-wide
generosity

Save the Date
Dec. 3, 2024

GIVING TUESDAY SET FOR DECEMBER 3, 2024

#GivingTuesday is a global generosity movement, unleashing the power of people and organizations to transform their communities and their world. On December 3rd,

2024, HDSA will join thousands of other organizations to raise critical funds in the spirit of collective generosity.

People demonstrate generosity in many ways on GivingTuesday. Whether it's helping a neighbor or stranger out, showing up for an issue or people we care about, or giving to causes we care about, every act of generosity counts.

1. GIVE

Any amount makes a difference! Your gift of any size will have a bigger impact than you think on HDSA's programs, including research, advocacy, disability services and more!

2. FOLLOW

Please follow us on Facebook, Instagram and LinkedIn and invite your friends and family to do the same.

3. SPREAD THE WORD / SHARE YOUR STORY

Encourage everyone you know to join you in creating real impact on #GivingTuesday by sharing what HDSA and our mission means to you and why you support HDSA. Make sure to use the hashtag #HDSAGivingTuesday.

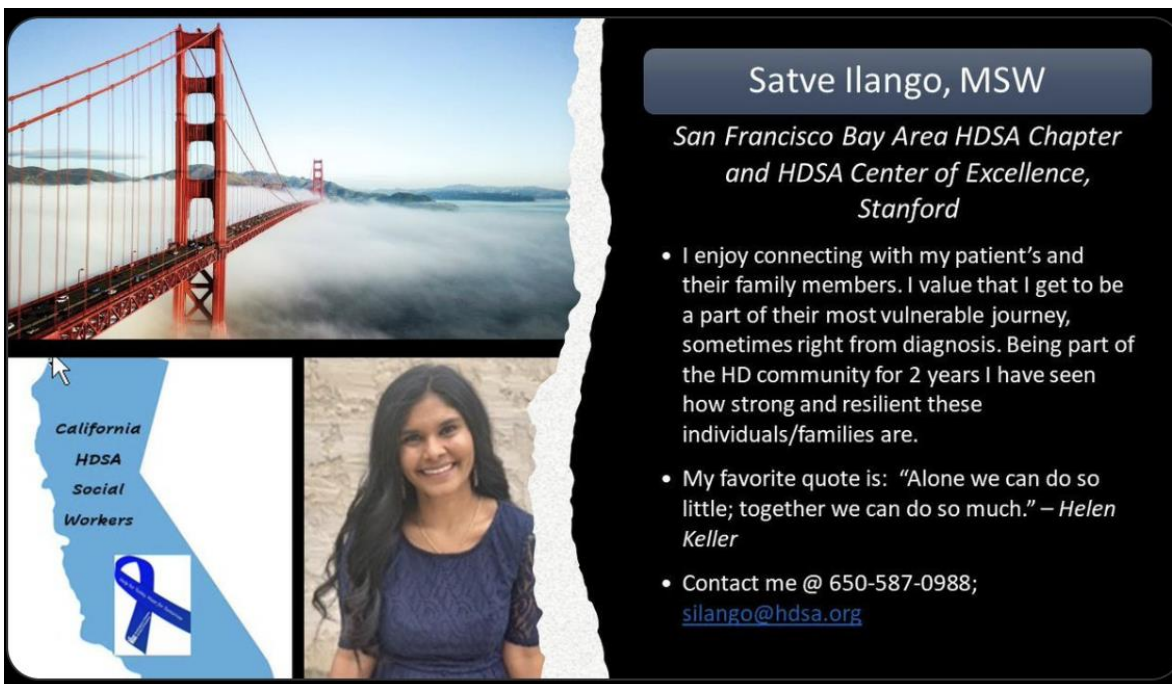
To find out more, click [HERE](#)

THANK YOU FOR YOUR SUPPORT!

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!

NEW AND NOTEWORTHY IN THE HD COMMUNITY



Satve Ilango, MSW

*San Francisco Bay Area HDSA Chapter
and HDSA Center of Excellence,
Stanford*

- I enjoy connecting with my patient's and their family members. I value that I get to be a part of their most vulnerable journey, sometimes right from diagnosis. Being part of the HD community for 2 years I have seen how strong and resilient these individuals/families are.
- My favorite quote is: "Alone we can do so little; together we can do so much." – *Helen Keller*
- Contact me @ 650-587-0988;
silango@hdsa.org

SOCIAL WORKERS PROVIDE CRITICAL SUPPORT

Social workers like Satve play a crucial role in supporting families affected by Huntington's Disease (HD), offering a range of services to address the complex needs associated with this progressive condition. Here's an outline of the primary services they provide, working in conjunction with the services offered by HDSA:

1. Emotional Support and Counseling

Family Counseling: Provides emotional support to both the patient and family members, helping them cope with the emotional challenges of the disease.

Individual Counseling: Offers one-on-one counseling to family members who may need additional emotional support or who are struggling with feelings like guilt, anxiety, or depression.

Support Group Referrals: Connects the family to support groups for individuals affected by HD, where they can share experiences and find comfort in a community.

2. Education and Disease Management

Education on Huntington's Disease: Educates the family about HD's symptoms, progression, and expected challenges, helping them understand what to expect.

Behavior Management Guidance: Helps family members learn how to handle behavioral changes or cognitive decline in the affected person, ensuring more effective communication and daily interaction.

Safety Planning: Advises on ways to modify the home environment to ensure the patient's safety as motor skills and cognitive function decline.

3. Coordination of Care and Medical Referrals

Healthcare Coordination: Helps manage appointments and coordinates between various healthcare providers, such as neurologists, physical therapists, and mental health professionals.

Referral to Specialists: Refers the family to additional specialists as needed, such as genetic counselors, psychiatrists, and occupational therapists.

Medication Management Support: Assists with understanding medication schedules and potential side effects, especially as the condition progresses.

4. Financial and Legal Assistance

Resource Identification: Helps the family locate financial resources, including grants, disability benefits, and insurance assistance programs, which can be critical due to the long-term nature of HD care.

Legal Planning Guidance: While not a lawyer, they can provide information on essential legal documents like power of attorney, advance directives, and guardianship options, encouraging early planning due to the progressive nature of the disease.

5. Long-term Care and Placement Support

Long-term Care Planning: Guides the family in making decisions about future care, including in-home care, assisted living, or nursing home facilities when needed.

Respite Care Referrals: Provides information on respite care services, allowing family caregivers to take breaks and manage caregiver fatigue.

End-of-Life Planning: Assists in discussions and planning for end-of-life care, helping ensure the patient's wishes are respected.

6. Advocacy and Community Resources

Advocacy for Services: They can help the family and individual advocate to secure necessary services from healthcare providers, government agencies, and insurance companies.

Access to Community Resources: Connects the family with local resources, such as transportation services, meal programs, and other community support programs.

Public Awareness and Education: May work with the family to promote public awareness of Huntington's disease, which can help the community better understand and support individuals affected by it.

By offering a range of practical, emotional, and advocacy support, social workers play an integral role in helping families navigate the complexities of Huntington's disease.

HD EDUCATION DAY A SUCCESS

The HD Family Education Day held on October 19 at UCSF was a success with over 30 persons attending either in-person or via Zoom. Sessions included Overview of Palliative Care, Psychiatric Treatment in Huntington's Disease, Navigating Disability and the Workplace with HD, Huntington's Disease Physical Therapy: "Putting the Fun in Functional," Caregiver Self-Care, and A Day in the Clinic. A special thanks to all who attended and participated.

[CLICK HERE](#) to view photos.

UPCOMING HD EVENTS



SAVE THE DATE!

It's not too early to put next year's 40th HDSA Conference on the calendar. The conference will be held in Indianapolis, Indiana from June 26-28, 2025. Registration and other details will be available soon.

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

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:

NOVEMBER 6th, 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.

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

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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