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# Huntington's Disease Society of America



## SAN FRANCISCO BAY AREA CHAPTER



### HDSA VOLUNTEER NEWSLETTER

## 2025 San Jose Team Hope 5k Timed Run & Walk



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

**May 17th, 2025**

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

SAVE THE DATE



The 2025 San Jose Team Hope event is NEXT month. **SIGN UP NOW!**

[Sign up here](#)

### IMPORTANT NOTE:

Make sure that [mail@HDSA.org](mailto: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



**SATVE ILANGO, MSW**

### Coping with HD: Emotional Support for Families

Receiving a diagnosis of Huntington's disease can feel like a heavy weight on the shoulders of both the person diagnosed and their loved ones. As a social worker, I've witnessed firsthand the profound emotional toll this diagnosis can take. It's important to recognize that the emotional response to HD can be complex and multifaceted, ranging from shock and disbelief to grief and fear for the future. For families navigating this uncertain journey, it's crucial to have the right emotional support to help them through this challenging time.

One of the first steps in coping with an HD diagnosis is simply acknowledging the emotions that arise. It's normal for families to feel overwhelmed, anxious, and even angry. I encourage families to talk openly about what they're feeling. Sometimes, just expressing these emotions in a safe and non-judgmental space can be incredibly healing. I often suggest counseling or support groups

where family members can connect with others who truly understand what they're going through. These groups not only provide comfort but also offer practical coping strategies that can help families adjust. Please contact me for information regarding support groups and assistance in finding therapy resources.

Grief is another emotion that many families experience, even if their loved one isn't at an advanced stage of HD. The progressive nature of the disease means that family members might begin grieving the gradual loss of their loved one, even while they're still physically present. It's okay to grieve, and it's okay to seek support for that grief. Working through these feelings is an important part of maintaining emotional well-being.

Lastly, families often feel helpless when facing the future. I encourage them to focus on what they can control—whether that's legal planning, financial preparation, or finding local resources for caregiving support. Having these conversations early on can give families peace of mind, knowing they've set up practical steps for what lies ahead.

No one should face this journey alone, and as a social worker, I am always here to offer support and guidance. Together, we can help families build resilience and cope with the emotional complexities of a HD diagnosis.

**SATVE ILANGO, MSW, CHAPTER SOCIAL WORKER**

Phone: 650-587-0988 | Email: [silango@hdsa.org](mailto:silango@hdsa.org)

**NEW AND NOTEWORTHY IN THE HD COMMUNITY**



**WEBINAR RECORDING  
NOW AVAILABLE!**

## **2025 RESULTS OF THE HDSA HD SYMPTOMS TREATMENT IMPACT SURVEY**

**LEARN WHAT THE  
RESPONDENTS TO THE  
HDSA HD SYMPTOMS AND  
TREATMENT IMPACT  
SURVEY SHARED ABOUT  
IMPACTS TO DAILY LIVING  
AND THEIR PREFERRED  
TREATMENT OUTCOMES  
FOR NEW THERAPIES TO  
TREAT HD.**

**WHERE:  
HDSA YOUTUBE PAGE**

**WATCH  
NOW!**



**PHYLLIS FOXWORTH**  
Senior Manager of  
Advocacy

### **HDSA HD SYMPTOMS & TREATMENT IMPACT STUDY RESULTS**

Phyllis Foxworth, Senior Manager of Advocacy at HDSA presents the results of the HDSA HD Symptoms and Treatment Impact Survey in a YouTube video (link below). This important discussion sheds light on how Huntington's disease symptoms affect daily life and the impact of available treatments.

**What you'll learn:** Key Findings from the survey; How symptoms impact individuals and families; The role of current treatments and areas for improvement.



[View Results Here](#)

## VOLUNTEER SPOTLIGHT



**REBEKAH GRANLUND**

Rebekah was born and raised in San Jose and her dad was her best friend. They shared the same dark humor to color any difficulties that life threw their way. Her dad worked as an accountant for the county and was known in the family as the human calculator. As Rebekah entered middle school, she started noticing mistakes in his calculations, which was unlike him. There came a day when her mom took her out for lunch and somberly explained her dad's shift in behavior and budding mental symptoms. Rebekah's dad had tested positive for Huntington's Disease back in 1996 and they were beginning to see the symptoms.

Rebekah's family began attending HD support groups and the Team Hope Walks very shortly after her dad's symptoms began in 2010 and that is where they made many of their connections to the community that continue to this day. Their family has been very transparent about HD. Rebekah's grandfather, and uncles all have HD. In 2016, Rebekah became involved in the HDSA National Youth Alliance which offered support groups for teens affected by HD. In these types of support groups and camps, she had the opportunity to meet lifelong friends who understood the process of grieving sick parents multiple times over, and the complexities that come with getting or not getting tested for HD. In 2024, Rebekah became a HDSA San Francisco Bay Area Chapter board member and the board Vice President and wishes to help spread hope among generations affected by HD.

**VOLUNTEERS NEEDED - PLEASE CONSIDER JOINING US!**



**April is Volunteer Appreciation Month!** As we kick off the month, we want to take a moment to recognize and thank all of our amazing volunteers in the San Francisco chapter. Your dedication, hard work, and passion have a lasting impact, and we are deeply grateful for everything you do to support our community.

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

[VOLUNTEER HERE](#)

## UPCOMING HD EVENTS



# HD FAMILY EDUCATION DAY EMPOWER HD

*Unites, Educate and Inspire*



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



**Saturday, May 3rd from 9:00am - 4:00pm** - We are excited to announce this year's HD Family Education Day is a collaboration of compassion between our 2 local HDSA Chapters (Northern California and San Francisco Bay Area) AND 4 HDSA Centers of Excellence (Stanford, Kaiser, UC San Francisco and UC Davis). The only thing we need to make this event the best ever is YOU and YOUR FAMILY. [Please click here to learn more.](#)

[Click here to register](#)

## 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:**

**MAY 7th @7pm**

Contact Therese Crutcher-Marin for meeting information:

[theresecrutchermarin@gmail.com](mailto: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](mailto: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!**







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DONORVIEW