



Huntington's Disease
Society of America



SAN FRANCISCO BAY AREA CHAPTER



HDSA VOLUNTEER NEWSLETTER

HDSA VOLUNTEER NEWSLETTER - AUGUST 2025

HDSA SF FUNDRAISER ON AUGUST 9 SAN JOSE GIANTS VS VISALIA RAWHIDE

PLAY
HDSA SF FUNDRAISER!
BALL!



San Jose Giants

 Huntington's Disease
Society of America

 SAN FRANCISCO BAY AREA CHAPTER

AUGUST 9TH, 2025

**SAN JOSE GIANTS
VS VISALIA
RAWHIDE**

- JOIN US AS WE RAISE AWARENESS AND ENJOY A BALL GAME!
- 5 PM GAME TIME [A+] EXCITE BALLPARK IN SAN JOSE!
- TICKETS: \$21
- FIREWORKS SHOW AFTER THE GAME!



More Information or
Accommodations
joshjacobs@sjgiants.com 
(408) 297-1435 

JOIN US AT THE SAN JOSE GIANTS GAME ON AUGUST 9

Please join us at on August 9th for our San Jose Giants Park Packer fundraiser! Share this information with your people, and let them know to use promo code **HDSA**! Can't wait to see everyone at the park! Follow the link below for more details.

[More Details Here](#)



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



New Medicaid/Medi-Cal Proposals: What They Mean for the HD Community

This year, Medi-Cal/Medicaid faces major policy shifts that will affect thousands

of families.

Asset Limits Are Back: Individuals with more than **\$130,000 in assets** may now lose Medi-Cal eligibility. This reverses recent progress toward eliminating asset tests for older adults and people with disabilities—many of whom may now face tough choices about their savings, homes, or family inheritances.

Work Requirements Could Leave Families Uninsured: One of the most concerning proposals is the implementation of work requirements for Medicaid enrollees. For people with HD, maintaining full-time work becomes increasingly difficult—if not impossible—as symptoms progress. Many rely on SSDI, but there’s a 29-month wait from the time a person stops working to when Medicare coverage begins. During that gap, Medi-Cal is the only safety net. Imposing work requirements would unjustly penalize those who cannot work due to HD symptoms—leaving them without access to critical medications, home health aides, and therapies.

Eligibility Checks: The proposal also increases the frequency of Medi-Cal eligibility checks, adding administrative burdens that disproportionately impact families already juggling caregiving, financial strain, and progressive illness. People may lose coverage not because they’re no longer eligible, but because of missed deadlines, lost paperwork, or system errors.

Worse yet, if someone is disenrolled and later deemed still eligible, Medi-Cal will only backdate coverage **30 days**. Any expenses outside that window would fall to the individual.

Home Equity Limit: A new federal cap on home equity for long-term care eligibility—set at \$1 million—would eliminate state flexibility to account for regional housing costs or individual family circumstances. For many, their home is both a sanctuary and their only substantial asset. Restricting eligibility based on home equity risks forcing families to sell homes or forgo care.

Please reach out if you have any questions or concerns about Medi-Cal/Medicaid and I would be happy to assist.

SATVE ILANGO, MSW, CHAPTER SOCIAL WORKER

Phone: 650-587-0988 | Email: silango@hdsa.org

NEW AND NOTEWORTHY IN THE HD COMMUNITY



NEW RETREAT FOR YOUNG PEOPLE

HDYO is excited to host a new program, #HDCONNECT, an interactive two-day retreat held in conjunction with the [Help4HD Symposium](#) on **September 5-6 in Ft. Lauderdale, Florida**.

This retreat will offer young people (14-30) in the US the chance to meet others impacted by HD to learn about HD through educational workshops and shared experiences. **This retreat will combine traditional conference-style sessions with summer camp-inspired community building.** For those selected to attend, HDYO will cover the travel and hotel costs.

The hope is to analyze how this type of retreat could be utilized in many different countries in the future.

[Check Here for Details](#)



Stanford
MEDICINE

STANFORD

Stanford Health Care Neurosciences Wellness Classes provides personalized consultations & connects patients to wellness resources. These wellness classes help patients and caregivers care with their mind and body and it is a way to connect with others who have similar experiences.

Classes are free and open to the community. Patients and caregivers of all ability levels are welcome.

Telephone: 650-736-2234

Email: wellnessclasses@stanfordhealthcare.org

Hours: Monday-Friday, 9:00 a.m.-5:00 p.m. PST

[Check Here for Details](#)

CONSIDER JOINING OUR BOARD!

If your family is challenged by Huntington's Disease, and you'd like to make a difference to other HD families in the SF Bay Area, please consider joining the Board. The next San Francisco Bay Area Chapter Board Meeting is September 10th, 2025 at 7 P.M. via RingCentral. The Chapter committees are working behind the scenes, during the summer, on the San Francisco Team Hope 5K Timed Run and 5K Walk, San Jose Giants fundraiser, outreach, and the 2026 HD Family Education Day. The Board is made up of folks who have HD in their family and others who want to help our nonprofit be successful in the mission we aspire to. *"The Chapter is dedicated to improving the lives of everyone affected by HD and*

their families." Email Therese at therese@crutchermarin@gmail.com

AUGUST VOLUNTEER SPOTLIGHT- PENNY LAI

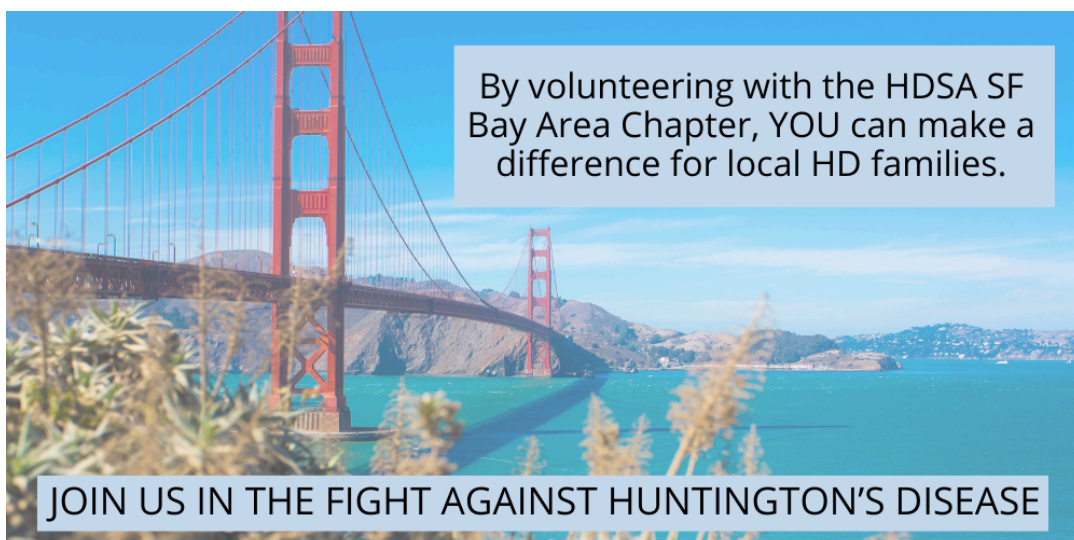


Penny grew up in Taiwan and the United States. After she graduated from university, she worked at nonprofit organizations in Taiwan for 3 years. In 2022, she decided to move to San Francisco to be with her sister.

In 2024, she saw a fundraising volunteer opportunity for HDSA SF Bay Area Chapter on Indeed and applied. From attending biweekly meetings and participating in the 2024 San Jose walk, she saw firsthand the amount of time and effort the other volunteers, such as Therese and Uma, put into HDSA. She was touched by their dedication and hopes to help out by securing in-kind donations for the annual fundraising events.

During her free time, she likes to volunteer, play jigsaw puzzles, and read fantasy books.

VOLUNTEERS NEEDED - PLEASE CONSIDER JOINING US!



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

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VOLUNTEER HERE

UPCOMING HD EVENTS



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

TEAM HOPE
WALK • RUN • RIDE

SAN FRANCISCO TEAM HOPE TIMED 5K RUN & WALK

Saturday, October 4th, 2025

 **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



SCAN ME

**Join us on Saturday, October 4
and help us fight Huntington's Disease!**

Registration Opens - 9:00 AM

Walk and Run Begins - 10:00 AM

NEW THIS YEAR: Get ready to race the clock! This year's event will feature a timed run.

Sports Basement Presidio

610 Old Mason St

San Francisco, CA, 95008

If your company is interested in sponsoring the walk, please email teamhope@hdsa.org!

Sign Up Here For Team Hope!

Click Here To Make A General Donation

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 10 @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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