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# Huntington's Disease Society of America

SAN FRANCISCO BAY AREA AFFILIATE

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## HDSA VOLUNTEER NEWSLETTER - MAY 2022

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It's time for 2022's first

# HD Education Day!

Online/Virtual session  
**Saturday May 7th at 8:30am**  
Registration is FREE  
Hosted by: Stanford



**MAY IS HD AWARENESS MONTH, AND WE HAVE AN HD EDUCATION DAY AS WELL!**

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It's HD Awareness Month, so be on the look out for lots of great content showing the stories and journeys of people with HD and their families. You can catch up on these great stories on [the national website](#) and [our Facebook page](#).

Locally, we also have a **community educational event** coming up, hosted by the HDSA Center of Excellence at Stanford University.

Stanford University's [Huntington's Disease Virtual Education Day](#) will take place on Saturday, May 7, 2022, from 8:30 a.m to 11:30 a.m. The event kicks off with an Introduction and Welcome from Dr. Sharon J. Sha, MD, MS, followed by Q&A sessions about Social Work and Genetic Counseling, and sessions about Medications and Studies, Palliative Care, Cognitive Problems, Rehab and more!

#### HOW TO JOIN

You can [REGISTER HERE](#), and afterwards you will receive a confirmation email about joining the meeting with all the details about the event Zoom call.

**Don't miss it! Check out our website for more information about all our work and events at [SanFrancisco.HDSA.org](http://SanFrancisco.HDSA.org)**

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## NEW AND NOTEWORTHY IN THE HD COMMUNITY

### RESEARCH NEWS ROUNDUP

Get your science on and check out the latest information from HDSA's Dr. Leora Fox on her blog: [This Week in Huntington's Disease Research](#) - including updates about PTC Therapeutic's PIVOT-HD study and other research news.

### HDSA ONLINE RESOURCES ARE AVAILABLE

HDSA invites you to take advantage of our world-class online support services - FOR FREE! From online support groups to telehealth, you can get the help you need from the comfort and safety of your home. [Learn more and get support here](#).

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## UPCOMING HD EVENTS

### IMPROVING COMMUNICATION WITH YOUR MEDICAL PERSONNEL

Join us for an online workshop on fostering trusting relationships and improved communication with medical personnel. The workshop, led by Dr. Kae Bendixon, is intended for people with Huntington's Disease and their caregivers and support networks. Topics will include preparing for medical visits, addressing communication challenges unique to HD, giving voice to patient and caregiver needs and fostering collaborative relationships with

medical personnel. Structured communication tools designed specifically to meet the needs of people with Huntington's will be provided to attendees and discussed at the workshop.

The workshop will include time for questions and discussion. Space is limited, so sign up now for this free webinar to be held on Tuesday, May 24, from 6.00 to 7.00 PM.

You can [REGISTER HERE](#), and afterwards you will receive a confirmation email about joining the meeting with all the details about the event Zoom call.

### **SIGN UP NOW FOR THE SAN JOSE TEAM HOPE 5K WALK & 10K TIMED RUN**

Form your team and sign up today for our Team Hope 5K Walk & 10K Run in San Jose, CA on June 18, 2022 - starting at 7am for the runners. We will distribute runners bibs at the Sports Basement in Campbell Pruneyard Shopping Center 1875 S Bascom Ave. Suite 240, in Campbell, CA. So form your team and [sign up here for the SJ event](#). We will be following COVID-19 safety recommendations at the event.

Our SF Walk is set for 10am on October 1st, 2022, and you can [register for that event here](#).

### **REGISTER NOW FOR OUR 37TH ANNUAL HDSA CONVENTION**

Join us on June 9-11, 2022 at the Marriott Marquis in Atlanta, Georgia for our 37th annual convention! Following COVID-19 safety recommendations, we will be capping the number of in-person attendees and providing mandatory safety protocols. And if you are not able to make it to Atlanta, you'll be glad to know that every session throughout the HDSA Convention will be live-streamed - FOR FREE! For more information and to register for in-person attendance/hotel/scholarship, please visit [HDSA.ORG/CONVENTION](https://www.hdsa.org/convention).

### **SIGN UP FOR THE RIGHT SUPPORT GROUP FOR YOUR NEEDS**

HDSA online support groups are available to help families affected with HD.

#### **EL CERRITO SUPPORT GROUP**

**Location:** Sycamore Congregational Church - 1111 Navellier St, El Cerrito, CA 94530

**Leader:** Natasha Boissier 415-476-2904 [natashaboissier@berkeley.edu](mailto:natashaboissier@berkeley.edu)

**Schedule:** 4th Monday each month, 7:00 pm – 8:30 pm

#### **TIBURON/MILL VALLEY SUPPORT GROUP**

**Location:** Westminster Presbyterian Church - 240 Tiburon Blvd., 1st Floor, Tiburon CA 94920

**Leader:** Andrea Zanko 415-476-9320 [zankoandrea@gmail.com](mailto:zankoandrea@gmail.com)

**Schedule:** 3rd Thursday of each month, 7:30 pm – 9:30 pm

#### **PALO ALTO HD SUPPORT GROUP**

**Location:** First Baptist Church - 305 N. California Street, Palo Alto, CA 94301

**Leader:** Andrea Kwan 650-725-6571 [andreak@stanford.edu](mailto:andreak@stanford.edu)

**Schedule:** Second Tuesday of each month, 7:00 p.m. – 8:30 p.m.

These support groups are free, but we urge you to register in advance, as space is limited. [Here is the list of the upcoming meetings](#) for this month. Don't see the right one for you? Let us know!

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## 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. HDSA will tow your vehicle at no cost to you. You will receive a donation receipt and help us in our mission. [More information can be found here.](#)

### AMAZON SMILE. YOU SHOP. AMAZON GIVES.

Shoppers who start at <https://smile.amazon.com/> will find the same Amazon they know and love, with the added bonus that Amazon will donate 0.5% of the price of eligible purchases to the charity of your choice. Sign-up today and have your purchases benefit HDSA!

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## VOLUNTEERS NEEDED!

**The Huntington's Disease Society of America is recruiting volunteers for the San Francisco Bay Area Affiliate Team.**

If you have some time to give to a non-profit, please consider us! HD is a rare, fatal, genetic brain disorder with no cure. We can use your expertise, ideas, and creativity. Let us know if you'd like to step up and join a committee!

Volunteer Coordinator & Co-Chair: Uma Thontakudi

Email: [umathont@gmail.com](mailto:umathont@gmail.com)

Phone: (408) 772-7705

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## STAY CONNECTED!

**JOIN OUR NEXT SF BAY AREA AFFILIATE CONFERENCE CALL:**

**The First Wednesday of Each Month @ 7pm**

Contact Therese Crutcher-Marin for meeting information:

[theresecrutchermarin@gmail.com](mailto:theresecrutchermarin@gmail.com)

If you are interested in doing more for our Affiliate, please let us know!

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## WE CAN NEVER LOSE HOPE!

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