

[View this email in a browser](#)



Huntington's Disease Society of America

SAN FRANCISCO BAY AREA AFFILIATE

HDSA VOLUNTEER NEWSLETTER - JUNE 2022

TEAM HOPE WALK



National Team Hope Sponsors



HAVE YOU SIGNED UP FOR THE SAN JOSE TEAM HOPE 10K TIMED RUN & 5K WALK YET?

It's time! The first of our premiere fundraising events of the year is almost here! We've been busy preparing and organizing and posting our excitement on [our Facebook page](#). This event (alongside our SF walk in October) is the crowning jewel in our calendar and the focus for our Affiliate because they generate so much of the fuel we need to reach our mission - to improve the lives of everyone affected by Huntington's disease and their families through our local support.

[CLICK HERE TO REGISTER OR DONATE](#)

This amazing IN-PERSON event will be held at Campbell Park in Campbell CA (E Campbell Ave & Gilman Ave) on **Saturday, June 18th, 2022**. Runners can pick up their bibs at Campbell sports basement from 5-7pm on the 17th.

REGISTRATION OPENS: 7:00am on the 18th

10K TIMED RUN STARTS: 7:30am

5K WALK STARTS: 8:00am

Note: each of the top three runners will receive a medal.

We'll have a fun auction going on during the event as well, and If you can't make the Team Hope Run/Walk, or if exercise is just not your thing, please make a donation on the event link above. But if you can make it, we look forward to seeing you and your loved ones there! For any questions, please reach out to [Christine Greve](#), especially if you'd like to volunteer!

Don't miss it! Check out our website for more information about all our work and events at SanFrancisco.HDSA.org

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 HD in the Media and other research news.

HEALTHCARE PROVIDER OUTREACH

The Healthcare Provider Outreach Committee recently completed a major outreach activity, with a 1,200-piece mailing that dropped on May 7th. The mailing was addressed to CA Department of Public Health Licensed and Certified Healthcare Facilities and members of the California Association of Health Facilities (CAHF). Last year the committee had sent around informational resource emails to a similar

list of Healthcare Professionals across the area, and this year they decided to expand the effort to a mailing containing trackable QR codes that lead to information. This mailing contained flyers about HD educational resources, information about our Bay Area Centers of Excellence, and a flyer for our educational seminar with Dr Bendixon (which we spoke about in last month's newsletter). We would like to thank these committee members for their contributions to our outreach efforts in the Bay Area - so thank you to: Scott Song, Stephen McConoughey, Tanvir Kaur, Jung Hyun Yoo, Kelsee Furagganan and Jay Denhart-Lillard. The printing and mailing cost about \$1,300, and if you'd like to help provide funds to cover it, you're welcome to [reach out to Jay](#).

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](#).

Last month the HDSA Center of Excellence at Stanford University held a Virtual Education Day on May 7th. Topics included the treatment and care for people with HD, research and study progress, support for the community and a question and answer session with a social worker and genetic counsellor. The session was very well received and attended by 40 users (it's not always possible to know if more than one person is watching per user login for these sessions, so it is possible that more people were in attendance). The Affiliate congratulates Stanford for all their work to create another great day of education for our Bay Area HD families. This event was funded by the Huntington's Disease Society of America with support from Genentech, Neurocrine Biosciences, Sage Therapeutics and uniQure.

Things continue to move forward at the HDSA Center of Excellence at The University of California, San Francisco. Our great partner and star Research Coordinator, Julia Glueck will be moving on to grad school, so she has been training her replacement, Zach Lamson. We welcomed Zach to the community in our last volunteer meeting and wish Julia the best of luck in the next phase of her journey!

As a reminder, all HDSA Center of Excellence clinics must have an expert clinical director (typically either a neurologist or psychiatrist) that understands HD - which is not always the case in any given clinic, even larger centers. HDSA Centers of Excellence are also connected with the collaborative global HD research community that is working together to develop effective treatments for HD. The unique structure of the HDSA Centers of Excellence program helps to enhance outreach to beyond just the patient, to the family/caregiver and local health professionals.

[Learn more about the HDSA Centers of Excellence program here](#)

UPCOMING HD EVENTS

37TH ANNUAL HDSA CONVENTION

We hope you were able to join us June 9th -11th, 2022 at the Marriott Marquis in Atlanta, Georgia, for our 37th Annual Convention!

And if you were not able to make it to Atlanta, you'll be glad to know that every session throughout the HDSA Convention was live-streamed - FOR FREE! The recorded sessions will be available soon. For more information, please visit

[HDSA.ORG/CONVENTION](https://www.hdsa.org/convention).

SAN JOSE TEAM HOPE 5K WALK AND 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. We will be following COVID-19 safety recommendations at the event. We will distribute runners bibs the night before the event at the Sports Basement in Campbell Pruneyard Shopping Center in Campbell, CA. Don't miss this amazing IN-PERSON event at Campbell Park in **Campbell CA on Saturday, June 18th, 2022.**

SIGN UP FOR THE RIGHT SUPPORT GROUP FOR YOUR NEEDS

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

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

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

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

Location: First Baptist Church - 303 N. California Street, Palo Alto, CA 94301

Leader: [Andrea Kwan](#) 650-725-6571

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!

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!

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

Phone: (408) 772-7705

STAY CONNECTED!

JOIN OUR NEXT SF BAY AREA AFFILIATE CONFERENCE CALL:

Wednesday, August 3rd @ 7pm (we're taking July off!)

Contact Therese Crutcher-Marin for meeting information:

theresecrutchermarin@gmail.com

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

WE CAN NEVER LOSE HOPE!



Copyright © 2022 HDSA San Francisco Bay Area Affiliate, All rights reserved.

You are receiving this email because you opted in via our website.

Our mailing address is:

HDSA San Francisco Bay Area Affiliate

P.O. Box 853

Carnelian, CA 9610

[Add us to your address book](#)

[Unsubscribe](#) | [Manage Subscriptions](#)

DONORVIEW