

HDSA Volunteer Newsletter - January 2023



THE MARKER: 2022 HDSA RESEARCH REPORT

All throughout 2022, HDSA has supported fantastic Huntington's disease science, shared research news with the community, and amplified family voices in drug development **in the latest issue of The Marker**, you can read about all this amazing work and the people who are doing so much for our community.

You will note that both HDSA Centers of Excellence in our area are featured in the issue as being renewed in their accreditation as Centers of Excellence for this year. We recommend that HD families seek out support and services from either of these HD clinics in the Bay area: [University of California San Francisco](#) and [Stanford University](#).

[Download your copy of the report today](#) and learn about all the great work being done to bring about an end to Huntington's Disease.

DO YOU WANT TO GET MORE INVOLVED?

The San Francisco Bay Area Affiliate currently has openings on its board. Our Board Meetings are virtual and occur in the evening on the first Wednesday of almost every month. The time commitment for these roles is flexible, and we would love to work with you if you are open to taking on a larger volunteer role with us.

If you are interested, please email [Uma Thontakudi](#) or give her a call at (408) 772-7705.

Additionally, feel free to apply on our [LinkedIn profile](#), [VolunteerMatch.org](#) or our [Facebook page](#)

Make sure that mail@hdsa.org is added to your email list so that you see all the updates and events in your area!

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 an update from the Huntington's Study Group's 2022 Annual Meeting.

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.](#)

UPCOMING HD EVENTS

UPCOMING HDSA DISABILITY CHAT WEBINAR!

Join us on **January 31st at 9am (PT)** when we discuss **Navigating the Social Security Appeal Process**. Each month, HDSA's Disability Chats feature a topic of interest for either HD families or HD social workers. Each segment includes a 45-minute presentation followed by 15 minutes for discussion with the audience. All webinars are recorded and can be found on the HDSA YouTube channel for later viewing and to serve as an enduring resource. The chats are hosted by Allison Bartlett, HDSA's Manager of Disability Programs and a disability attorney who specialized in representing clients with rare, chronic conditions, like Huntington's Disease. [Register today](#) to join this exciting series of educational talks.

REGISTRATION IS OPEN FOR OUR ANNUAL CONVENTION

Join us **June 1-3, 2023** in New Orleans, Louisiana for the **38th Annual HDSA Convention!** Register today to be a part of the magic of the HDSA Convention at the beautiful Sheraton New Orleans. [More information, rates, and registration is available at \[HDSA.org/convention\]\(https://www.hdsa.org/convention\)](#) - we hope to see you there!

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

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

Leader: [Natasha Boissier](#) 415-476-2904

Schedule: 4th Tuesday of each month, 7:00 pm – 8:30 pm

PALO ALTO HD SUPPORT GROUP

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

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

Schedule: 2nd Tuesday of each month, 7:00 pm – 8:30 pm

STAY CONNECTED

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?

JOIN OUR NEXT SF BAY AREA AFFILIATE CONFERENCE CALL:

Let us know!

, February 1st, 2023 @ 7pm

OTHER WAYS TO HELP THE HD COMMUNITY

Contact Therese Crutcher-Marin for meeting

information: theresecrutchermarin@gmail.com

PARTICIPATE IN HD RESEARCH FROM YOUR HOME

Researchers all over the world are seeking participants from the HD community to participate in

survey-based studies on HD. Whether you have HD, are a care partner to someone with HD, a

member of an HD family, or at risk for the disease, there is a study for you! [Click here](#) to see what

survey studies are available and learn more about how you can get involved.

WE CAN NEVER LOSE HOPE...

HDSA VEHICLE DONATION PROGRAM

Avoid the hassles of selling or repairing your vehicle together 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.](#)



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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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