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**Huntington's Dis
Society of Americ**



SAN FRANCISCO BAY AREA AFF

HDSA Volunteer Newsletter - February 2023



We hope that you've had a wonderful February, and a Happy Valentine's Day where you could tell someone that you love them.

We've started gearing up for a great year, with plans for some serious fun and serious fundraising, and we hope you'll join in and participate to the full!

As a reminder, we encourage you to reach out to us and let us know how you'd like to be a part of our mission to improve the lives of everyone affected by Huntington's disease and their families. Our Monthly Volunteer Meetings are virtual and occur in the evening on the first Wednesday of almost every month.

If you are interested, please email Uma Thontakudi at umathont@gmail.com, or give her a call at (408) 772-7705.

Additionally, feel free to check out our [Facebook page](#) to stay in touch.

Hearts for Huntington's: The love-liest month!



Share the love this month with Heart's for Huntington's - [Pacificwest.hdsa.org/hearts](https://pacificwest.hdsa.org/hearts)! For the whole month of February, send some love to your community while also raising awareness and funds for the HD community & HDSA. We have e-cards and handwritten options available.

All donations will benefit the Pacific West Region. Please reach out to cgreve@hdsa.org with any questions. [Click here to send your card.](#)

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

HDSA PUBLISHES 2022 YEAR IN REVIEW

Last week, HDSA issued the 2022 edition of its Year in Review Magazine, which features highlights from HDSA's Mission-related programs and regional events as well as a recap of our research initiatives and scientific achievements in HD. [Check out this page on the HDSA website](#) for an overview of HDSA's progress in 2022.

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.

INTRODUCING THE HDSA PODCAST

The HDSA Podcast, hosted by Louise Vetter, gives listeners an opportunity to meet members of the Huntington's disease community and get behind-the-scenes look at the Huntington's Disease Society of America. Check it out at [HDSA.org/podcast](https://www.hdsa.org/podcast)

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

INDUSTRY UPDATE: NOVARTIS DISCUSSES THE VIBRANT-HD TRIAL

Join us on **February 22, 2023** at 12PM ET for an update from Novartis concerning their announcement of the ending of development of branaplam, a possible treatment in Huntington's disease (HD). [Register today](#) to hear from the company about their decision and what this means for the community..

WEBINAR FOR IMPROVING COMMUNICATION WITH YOUR MEDICAL PERSONNEL

Join us for another encore workshop on fostering trusting relationships and improved communication with medical personnel. The workshop, led by Dr. Kae Bendixen, 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 will be limited, so watch our Facebook page to hear when the sign up is available for this free webinar. Date and time for the workshop will be communicated on our Facebook page as well - so stay in touch!

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](#) - 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

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

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.

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!

AMAZON SMILE IS SHUTTING DOWN!

You may have heard that after almost a decade of running AmazonSmile, Amazon announced they would be winding down the AmazonSmile program by February 20, 2023. They felt that their ability to have an impact was often spread too thin and so they're going to focus their

philanthropic efforts in the communities where their employees live and work. However, we already have a partner in iGive that has been supporting HDSA and the nonprofit community for more than 20 years and we hope you'll give them a try! iGive is similar to the AmazonSmile program, but rather than being limited to one vendor, you can shop at more than 2,000 stores online that provide 2X LARGER DONATIONS than AmazonSmile to HDSA! Over the next month, we'll reach out and give you the information needed to transition to iGive. In the meantime, [you can get started here](#).

STAY CONNECTED

JOIN OUR NEXT SF BAY AREA AFFILIATE CONFERENCE CALL:

March 1st, 2023 @ 7pm

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...



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