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Huntington's Disease
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SAN FRANCISCO BAY AFFILIATE

HDSA VOLUNTEER NEWSLETTER - MARCH 2022

MARCH MADNESS BRACKET CHALLENGE

HOOPS 4 HOPE



Huntington's Disease
Society of America

2022 MARCH MADNESS FUNDRAISER IS UNDERWAY

THIS IS YOUR LAST CHANCE TO PARTICIPATE!!!

The HDSA March Madness Bracket Challenge is underway! Will you pick the underdog? Your college alma mater? Absolutely random teams?

EVERYONE loves picking brackets for the NCAA tournament. Show off your selection skills, donate to a great cause, AND have the chance to win a \$100 Gift Card at the same time!

[Visit the website now and make a \\$25 Donation.](#) Then watch for an email with a link to join the CBS Sports Bracket Challenge group. Teams will be announced and your brackets will go live on Selection Sunday, March 13, 2022. You will have until 12:00pm (ET) on Thursday, March 17, 2022 to pick your bracket, but don't wait until the last minute – you don't want to miss it.

DON'T FORGET TO SELECT OUR AFFILIATE WHEN YOU REGISTER!

Instead of selecting from the list of Chapters above the registration form, be sure to scroll down to below the form to select our Affiliate from the additional list at the bottom of the form. It's weird, we know, but PLEASE make sure to register with us, the San Francisco Bay Area Affiliate!

There will also be a SILENT AUCTION which opens on Selection Sunday, 3/13/22, with some amazing Gift Cards, sports memorabilia, sporting event tickets and much, much more! More details to come!

Check out the website for more information at [HDSA.org](https://www.hdsa.org).

NEW AND NOTEWORTHY IN THE HD COMMUNITY

MESSAGE FROM OUR AREA HDSA CENTERS OF EXCELLENCE:

Have you been staying away from clinic? Consider coming back!

At our last volunteer meeting on March 2nd, both the UCSF HDSA Center of Excellence and the Stanford HDSA Center of Excellence emphasized the importance of staying in touch with the care teams at your local HD clinic.

Although COVID-19 hit our community hard, both sites have moved to offer more telehealth services, and over the last months have been able to start seeing patients in clinic again safely. Some new studies have started enrolling patients, looking for pre-symptomatic or early symptomatic individuals to help them learn about the progression of HD. And more trials are likely coming down the pipeline, investigating new methods of action for treatments to fight against the disease.

And don't forget the ongoing need for participation in observational trials like [Enroll HD](#), which not only bring information to researchers about the natural history of HD, but are also often used to help find patients for interventional trials. So please be encouraged to consider enrolling in an observational trial if you are able.

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 HDBuzz and their coverage of news coming out of the CHDI Conference.

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

SAVE THE DATE 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).

SAVE THE DATES FOR OUR LOCAL 2022 TEAM HOPE WALKS

We have the dates set for our 2022 Team Hope Walks in San Jose and San Francisco! We will be following COVID-19 safety recommendations, but currently we plan for the **Team Hope Walk 5K & 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 mark your calendar and [sign up here](#) for the SJ event.

Our **San Francisco Team Hope Walk and Fun Run** is set to kick off at 10am on October 1st, 2022. We will gather, again, following COVID-19 safety protocols, at the Sports Basement at the Presidio (610 Old Mason Street, San Francisco, CA 94129). It's still a ways off, but [get it on your calendar now and don't forget to register!](#)

STANFORD EDUCATION DAY MOVING TO MAY 2022

Stanford University will be hosting an HD Education Day/Session in May 2022 (Yes, we know this one has moved around a bit - it happens!). This educational event will contain valuable information about Huntington's disease, its progression and clinical presentation. The final date of the event is not yet decided, but is currently planned to be a virtual event. So [stay tuned to our Facebook page](#) to hear more information about the content and how to register closer to the event.

SIGN UP FOR THE RIGHT SUPPORT GROUP FOR YOUR NEEDS

HDSA online support groups are available to help families affected with HD. [Here is the list of the upcoming meetings](#) for this month. These support groups are free, but we urge you to register in advance, as space is limited. 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:

The First Wednesday of Each Month @ 7pm

Contact Therese Crutcher-Marin for meeting information:

theresecrutchermarin@gmail.com

If you are interested in doing more volunteering, please let us know!

WE CAN NEVER LOSE HOPE!



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