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# Huntington's Disease Society of America



SAN FRANCISCO BAY AREA AFFILIATE

**HDSA VOLUNTEER NEWSLETTER - AUGUST 2022**



## NOVARTIS SHARES DISSAPPOINTING UPDATES FROM VIBRANT-HD TRIAL

On August 8th, Novartis shared with HD community organizations that dosing in the VIBRANT-HD trial of the huntingtin-lowering drug branaplam has been temporarily suspended. This decision was made based on the recommendation of an independent Data Monitoring Committee (DMC). Their review of the data showed early signs that branaplam may be causing peripheral neuropathy in some study participants.

Given that this news affects not only the early trial participants, but the wider community, HDSA would like to provide some context about the trial, share what we have learned from Novartis, and offer support to those who need it.

"Like all of the HD community, we are surprised and disappointed by this news about the suspension of dosing of branaplam in the VIBRANT-HD study," said Dr. Victor Sung, HDSA Board of Trustees Chair. "We patiently await further announcements from Novartis regarding this decision and news regarding the future of branaplam for HD."

For more information, [check out the article on the HDSA site about the trial](#), as well as [this informative article from HDBuzz](#).

This news is disappointing, and can have an emotional toll. If you or someone you know is having difficulties processing this information, or just need to talk it through, please reach out to us through the HDSA Helpline at (800) 345-4372 or [click here to access any of our community and social support services and programs](#).

### IMPORTANT NOTE

Make sure that [mail@HDSA.org](mailto:mail@HDSA.org) is added to your email list so that you see all of 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 a post where HDSA Center of Excellence Directors discuss biomarkers for HD.

## **IMPROVING COMMUNICATIONS WITH YOUR MEDICAL TEAM**

After a successful first session in May and a second in July, the SF Bay Area Affiliate of HDSA is planning for another online workshop in the near future with Dr. Kae Benedixen, focusing on fostering trusting relationships and improved communication with medical personnel. The workshop is intended for people with HD 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. [Stay tuned to our Facebook page](#) for information about the next workshop date and time.

## **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**

### **SAN FRANCISCO TEAM HOPE 5K FUN RUN AND WALK**

Form your team and [sign up today](#) for our Team Hope 5K Fun Run and Walk in San Francisco on Saturday, October 1. We will be following COVID-19 safety recommendations at the event. Don't miss this amazing IN-PERSON event at at Sports Basement: Presidio - 610 Old Mason Street in San Francisco, California, **starting at 9:00am on Saturday, October 1st, 2022.**

### **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 Monday 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 Kwan](#) 650-725-6571

**Schedule:** Second 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!

[CLICK HERE TO REGISTER OR DONATE FOR THE UPCOMING  
SAN FRANCISCO TEAM HOPE WALK & RUN](#)

## 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! Visit 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!

## VOLUNTEERS NEEDED!



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! Please reach out to:

#### **Uma Thontakudi:**

Volunteer Coordinator & Affiliate Co-Chair

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

Phone: (408)-722-7705

## STAY CONNECTED

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

**Wednesday September 7th @ 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!

***WE CAN NEVER LOSE HOPE...***



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**Our mailing address is:**

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