



# Huntington's Disease Society of America



**SAN FRANCISCO BAY AREA CHAPTER**

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## HDSA Volunteer Newsletter - May 2023

# HD AWARENESS MONTH

#LetsTalkAboutHD is a social media initiative during Huntington's Disease Awareness Month in May to encourage families to share their experiences with HD. You can share a video, a photo or a written story to help raise awareness – HD impacts every family differently and it's time the world knows our story.

All stories are welcome – research included! Maybe you have a story about participating in HD research, or want to share resources to learn about the amazing things that are happening in the field today. Maybe you're a researcher who wants to talk about the work you're doing or the things that inspire you to continue.

Post videos, stories, and photos to social media using #LetsTalkAboutHD to educate the world about the devastating impact that HD has on families. [Learn more.](#)

### #LetsTalkAboutHD Resources

[Download & Print the #LetsTalkAboutHD Sign](#)

[View the #LetsTalkAboutHD Toolkit](#)

[Watch & Share Celebrity #LetsTalkAboutHD Videos](#)

[Watch the #LetsTalkAboutHD Promo Video](#)

[Upload the Official #LetsTalkAboutHD Social Media Profile Frame](#)

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**Make sure that [mail@hdsa.org](mailto:mail@hdsa.org) is added to your email list so that you see all the updates and events in your area!**

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## 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 Prilena top-line data from the PROOF-HD study of pridopidine in people with HD.

### NOW IS THE TIME TO REGISTER FOR THE 2023 NYA RETREATS

The National Youth Alliance Retreats are being planned for 2023. You can [find out more on their website and register there](#). There are retreats planned in Louisville, KY, Denver, CO, and one in California (November 10, 2023 - November 12, 2023), but the location of the California retreat is not known at this 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](#). Not sure where to start? Reach out to one of our board members and we'd be happy to listen to your needs and point you in the right direction.

## UPCOMING HD EVENTS



**ARE YOU READY TO RUN OR WALK?** [Registration is AVAILABLE](#) for our 2023 Team Hope Timed Run and Walk in San Jose on Saturday June 17th! So head over there now and start putting together your team today to start raising those much needed funds for our mission. You can also visit our [Facebook page](#) to stay in touch as we prepare to reveal our THEME for this

year's event!!

## Click here to sign up today!

### **WILL WE SEE YOU AT 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 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 THE HDSA DISABILITY/ADVOCACY SURVEY**

We are still looking for MORE family's experiences with Social Security.

IF YOU or someone you know has applied, or IS applying for SSI or SSDI (Disability) we would like to know your experiences [via this survey](#). Anyone can fill it out, even if they did not file for SSDI, but the more people who do, the more data we collect.

This data will be used to convince Congress to help with the administrative process, issues, concerns, challenges, etc. Its hard enough to have HD, love someone with HD, care for someone with HD or be at-risk for HD; that the disability process shouldn't add to that.

Please share with other family or friends that can offer their experience. Thank you in advance for you time and help in advocating for the HD community via this survey.

### **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.](#)

**SUPPORT HDSA WHILE YOU SHOP!**

We 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 allows you to shop at more than 2,000 stores online that provide DONATIONS to HDSA, just for doing your shopping with the iGive plug in on your browser! Later this year, we'll provide you the information needed to set up your donations to our chapter. In the meantime, you can [get started here.](#)

**STAY CONNECTED**

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

**June 7th, 2023 @ 7pm**

Contact Therese Crutcher-Marin for meeting information: [theresecrutchermarin@gmail.com](mailto:theresecrutchermarin@gmail.com)

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

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



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