



# Huntington's Disease Society of America



**SAN FRANCISCO BAY AREA CHAPTER**

**HDSA Volunteer Newsletter - November 2023**

**DON'T MISS OUR 2023 EDUCATION DAY**



## **2023 FAMILY EDUCATION DAY**

**DECEMBER 2, 2023**  
**STANFORD UNIVERSITY CAMPUS**  
450 JANE STANFORD WAY  
STANFORD, CA 94305

**FROM 9:30AM-2:30PM**

**Registration is FREE!**

**Join us for super-educational sessions, break-out sessions, and some time to visit and network.**



Our two area HDSA Centers of Excellence are combining forces for a blow-out 2023 Family Education Day Event on December 2nd. The day's program will be in person on the Stanford University campus:

Li Ka Shing Center for Learning & Knowledge (LKSC)

291 Campus Drive - Stanford, CA 94305

Scheduled Speakers Include:

Dr. Cameron Dietiker: HD Research Updates

Dr. Julia Kaye: Applying Machine Learning in Cellular Models of HD

Dr. Jocelyn Jiao: Palliative Care

Dr. Sai Folmsbee: Neuropsychiatry and HD

Erica Pitsch: Physical Therapy and HD

[REGISTER HERE](#) and join us for super-educational sessions, break-out sessions, and some time to visit and network. Registration is free and includes a boxed lunch for all attendees.

We'll see you there!

This event is funded by the Huntington's Disease Society of America with support from Genentech, Teva, uniQure, Neurocrine, PicnicHealth, PTC Therapeutics & MassMutual SpecialCare.

**Genentech**  
*A Member of the Roche Group*

 **NEUROCRINE**  
BIOSCIENCES

**teva**  
  
**PTC**   
THERAPEUTICS

**uniQure**

 **PicnicHealth**

 **MassMutual**  
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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!

## NEW AND NOTEWORTHY IN THE HD COMMUNITY

### **SAN FRANCISCO BAY AREA CHAPTER HIRES A SOCIAL WORKER**

When we became an official HDSA Chapter, we were encouraged to hire a part time social worker. Therese Crutcher-Marin, our board President, said 'It's really exciting to now have a part-time social worker to help with inquiries from the broader Bay Area community.' Her name is Michaelia Szarnicki and she works at a local home health/hospice agency. We will let everyone know once we have set her up with a local number and she is ready to start supporting our HD community. Welcome Michaelia!

## 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 information about new HD research studies being conducted by Design Science, Dr. Jody Corey-Bloom from the UC San Diego Center of Excellence provided some advice for the community around overcoming the bumps on the way to HD therapies, and the FDA granted orphan drug designation to SAGE-718.

## 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

### OUR ANNUAL AMARYLLIS SALES HAVE STARTED!

Every year, we offer a final fundraiser in November-December to cap off the year of fighting HD. The amaryllis has long been a symbol of strength and determination for the HD community. [PLACE YOUR ORDERS HERE TODAY](#) and help spread the love this holiday season! For every amaryllis kit you order, \$11 will be generously donated to support HDSA's mission, so make sure to select San Francisco Bay Area Chapter in the designation field.

### GIVING TUESDAY IS ON NOVEMBER 28TH

Please join us for #GivingTuesday - a Global Day of Giving. Mark your calendars now for November 28th and celebrate the biggest celebration of generosity in the world. Last year, over 200 of you joined in the cause and celebration to spread the word about HD and helped to raise over \$100,000 to improve the lives of those with HD and their families! We are so grateful, and we hope you'll include HDSA in your #GivingTuesday plans again this year. [Learn more and donate early here](#).

### HDSA RESEARCH WEBINAR SCHEDULED FOR FRIDAY DECEMBER 8th

On Friday, December 8 at 9:00 AM PT, join HDSA for a research webinar in which Neurocrine Biosciences, Inc. will discuss their new medication recently approved by the U.S. Food and Drug Administration (FDA) for the treatment of chorea associated with HD in adults. [CLICK HERE TO REGISTER](#).

## NOVEMBER SUPPORT GROUPS

## **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**

### **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.](#)

## **STAY CONNECTED**

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

**Wednesday, January 3rd, 2024 @ 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!

### **HDSA'S PROGRAMS & SERVICES**

Get the help you need from the comfort & safety of your home.

Be sure to take advantage of HDSA's world-class HD programs & services - FOR FREE! Learn more at [HDSA.org/support](https://HDSA.org/support).

[Download the new HDSA Programs & Services document here](#)

and click the links below to find support today:

[HDSA Social Workers: HDSA.ORG/SOCIALWORKERS](https://HDSA.ORG/SOCIALWORKERS)

[Online Support Groups: HDSA.ORG/OSG](https://HDSA.ORG/OSG)

[PatientsLikeMe: HDSA.ORG/PLM](https://HDSA.ORG/PLM)

[Telehealth: HDSA.ORG/TELEHEALTH](https://HDSA.ORG/TELEHEALTH)

[HD Trialfinder: HDTRIALFINDER.ORG](https://HDTRIALFINDER.ORG)

[HDSA's National Youth Alliance: HDSA.ORG/NYA](https://HDSA.ORG/NYA)

[Youth Mentorship Program: HDSA.ORG/YMP](https://HDSA.ORG/YMP)

[Disability Resources: HDSA.ORG/DISABILITY](https://HDSA.ORG/DISABILITY)

[Locate Resources in Your Area: HDSA.ORG/LOCATERESOURCES](https://HDSA.ORG/LOCATERESOURCES)

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



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