



Huntington's Disease  
Society of America



SAN FRANCISCO BAY AREA CHAPTER

## HDSA Volunteer Newsletter - January 2025



### **HDSA Names Jenne Coler-Dark as New Chair of the Board of Trustees**

The Huntington's Disease Society of America is proud to announce Jenne Coler-Dark as the new Chair of the National Board of Trustees. Jenne brings a wealth of personal experience, professional expertise, and a deep commitment to the Huntington's disease community to her new role.

Jenne's connection to Huntington's disease is deeply personal. In 2014, she learned that HD was in her family. The following year, Jenne, her mother, and her sister tested positive for carrying the HD gene. Her two children remain at risk for the disease. Despite the challenges of her diagnosis, Jenne was determined to make a difference. She became an active advocate for HD awareness, fundraising, and patient support, joining HDSA's National Board of Trustees in 2017. Over the years, she has chaired multiple committees and played a pivotal role in advancing HDSA's mission.

Read more about Jenne [here](#).

#### **IMPORTANT NOTE:**

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

## **NEW AND NOTEWORTHY IN THE HD COMMUNITY**

### **HUNTINGTON'S DISEASE SOCIETY OF AMERICA AWARDS \$523,320**

#### **TO HUNTINGTON'S DISEASE HUMAN BIOLOGY PROJECTS**

The Huntington's Disease Society of America announced that three research grants have been awarded under the Society's largest research initiative, the *HDSA Huntington's Disease Human Biology Project*. These grants represent HDSA's patient-centric research focus which brings basic and clinical researchers together to facilitate Huntington's disease science in the human condition – instead of in animal models – with the direct participation of people affected by HD.

Read more [here](#).

### **uniQure Announces Alignment with FDA on Key Elements of Accelerated Approval Pathway for AMT-130 in Huntington's Disease**

uniQure N.V., a leading gene therapy company advancing transformative therapies for patients with severe medical needs, today announced that the company reached agreement with the U.S. Food and Drug Administration on key elements of an Accelerated Approval pathway for AMT-130. "We are very pleased to reach agreement with the FDA on core components of an Accelerated Approval pathway for AMT-130," said Walid Abi-Saab, M.D., chief medical officer of uniQure. "Our alignment reflects the strength of our data and collaborative discussions with the staff and senior management at FDA's Center for Biologics Evaluation and Research (CBER). This is an important milestone for the Huntington's disease community as it puts us on the most rapid and efficient pathway to deliver a potentially life-changing therapy to people living with this devastating neurodegenerative disorder."

Read the entire announcement [here](#).

***In 2025 Join the HDSA SF Bay Area Chapter Team. There are Many Volunteer Roles to Chose From!***



## UPCOMING HD EVENTS



### **SAVE THE DATE!**

It's not too early to put next year's 40th HDSA Conference on the calendar. The conference will be held in Indianapolis, Indiana from June 26-28, 2025. Registration and other details will be available soon.

### **SAN JOSE WALK FOR 2025 - DATE CHANGE**

The HDSA [SF Bay Area Chapter](#) leadership decided to move the date of the San Jose Walk because of the heat, graduations, and HDSA Awareness Month. We hope to capture a higher number of HD families/patients who can attend the fundraiser.

***New Date: Saturday May 17, 2025 at Campbell Park***

## 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**

**Schedule:** 4th Tuesday each month, 7:00 pm - 8:30 pm

**Location:** Sycamore Congregational Church - 1111 Navellier Street, El Cerrito, CA 94530

**Leader -** [Natasha Boissier](#) Phone: 415-476-2904

#### **PALO ALTO HD SUPPORT GROUP**

**Schedule:** Second Tuesday of each month, 7:00 p.m. - 8:30 p.m.

**Location:** First Baptist Church - 305 N. California Street, Palo Alto, CA 94301

**Leader-** [Satve Ilango](#) Phone: 650-587-0988

These support groups are free, but we urge you to register in advance, as space is limited. All our chapter support groups are hosted on Hey Peers. Once you sign up, you can go in and register for any groups you are interested in. Join Hey Peers by clicking the link below and sign up for each group to get email reminders right to your inbox.

[Click Here for \*HEY PEERS!\* Link](#)

## 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 (888-437-2151)**. HDSA will tow your vehicle at no cost to you. You will receive a donation receipt and help us in our mission.

[More Information on Vehicle Donation Here](#)

## STAY CONNECTED

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

**JANUARY 8th @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://www.hdsa.org/support).

**New HDSA Programs & Services Document**

[DOWNLOAD HERE](#)

Click the links below to find support today:

**Local (San Fran) HDSA Social Worker:**

Satve Ilango, HDSA Social Worker

[silango@hdsa.org](mailto:silango@hdsa.org) | (650)-587-0988

**Online Support Groups:** [HDSA.ORG/OSG](https://www.hdsa.org/OSG)

**PatientsLikeMe:** [HDSA.ORG/PLM](https://www.hdsa.org/PLM)

**Telehealth:** [HDSA.ORG/TELEHEALTH](https://www.hdsa.org/TELEHEALTH)

**HD Trialfinder:** [HDTRIALFINDER.ORG](https://www.hdsa.org/HDTRIALFINDER.ORG)

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

**Youth Mentorship Program:** [HDSA.ORG/YMP](https://www.hdsa.org/YMP)

**Disability Resources:** [HDSA.ORG/DISABILITY](https://www.hdsa.org/DISABILITY)

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

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



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