

March 27, 2020 Community Update

Dear Friends of HDSA,

As we continue to navigate through the unknown future with COVID-19, there is one thing that we know for certain - **our fight against HD does not stop.** In the face of adversity, we must continue our mission work to provide families with much-needed resources and support meaningful HD research.

Like everyone, we have had to adjust to many things, but our team is committed to supporting HD families and I wanted to provide an update on our recent activities:

HD & COVID-19: HDSA's National Board of Trustees Chair-Elect, Dr. Victor Sung, provided some insight into COVID-19 & Huntington's disease.

**ONLINE RESOURCES:** We have ramped up HDSA's FREE online resources, such as <u>TELEHEALTH</u> & <u>ONLINE</u> <u>SUPPORT GROUPS</u>. HDSA's Helpline (800-345-HDSA) is also available on weekdays between 9am-5pm (eastern time). Additionally, HDSA's network of Chapter and Regional social workers and support groups nationwide has increased their access through phone and web platforms. Check out HDSA.org to find these resources near you. They remain available to help guide you through HD during this pandemic.

**EVENTS PLANNING:** Due to social distancing requirements, all of HDSA's in-person events and fundraisers through April 30<sup>th</sup> are postponed. Additionally, many May events are also being rescheduled. We encourage you to visit the event calendar at HDSA.org for the most up-to-date information about events in your community.

**ONLINE ENGAGEMENT**: In order for our mission work to continue during this time of crisis and beyond, we're counting on our HD community to be a part of new activities for giving and keeping HDSA alive in your home and virtual community. Stay tuned for the launch of our new *Virtual Team Hope* program on April 1<sup>st</sup> and please tag us on social media to showcase the creative ways that you're supporting the fight against HD from the safety of your home. (Creativity is encouraged!)

**HERE'S THE DEAL ... WITH DISABILITY**: Speaking of creativity, HDSA's staff team is trying new things to bring expertise and support to our families. This week Jennifer Simpson chatted with Allison Bartlett about the Social Security disability program in the latest episode of HDSA's popular online series, <u>Here's the Deal.</u> Utilizing Zoom and other platforms, HDSA will continue to produce meaningful content online.

Oh, and got more questions about SSDI? Introducing <u>ASK ALLISON. Submit your questions to HDSA's</u> <u>disability expert Allison Bartlett.</u>

And of course, planning is underway for the <u>Virtual HDSA Annual Convention</u>! More to come on that event as June nears.

We know this is a stressful time so please, remember you have the support of the entire HDSA family. Most importantly, work with your personal clinician and continue to follow the guidance of our friends at the Centers of Disease Control & Prevention (CDC), World Health Organization (WHO) and your state and local health departments to keep your family safe and healthy.

If you have additional questions or concerns related to HDSA's work during this public health crisis, please contact your HDSA team member or write to us at <u>info@hdsa.org</u>. Thank you for all your hard work and concern during this difficult time.

Please take care of one another, and be safe.

Sincerely,

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Louise Vetter President & CEO Huntington's Disease Society of America