

WeHaveAFace 2020 Review



In 2020, WeHaveAFace continued to provide education, information, and resources to our global Huntington's and Juvenile Huntington's disease community. Like many, we also struggled financially due to COVID-19, however, we remained focused and aware of the continuing needs of our community.

WeHaveAFace began 2020 with a decision to remain privately funded and did not receive grants from any pharmacological group. We were blessed to receive donations via our products (online store), our community, and from the private sector. Without the support from these gracious individuals, WeHaveAFace would not have been able to remain open in 2020.

WeHaveAFace also received much needed help via the Small Business Administration (SBA) via the [EIDL](#) which enabled us to continue to offer our programs and services to our HD/JHD community.

We wish to acknowledge and thank our private supporters who have placed their trust in WeHaveAFace.org.

Private Supporters

Greene's Quality Construction	Hella Lange
Bruce Vandegriff	Diane Finocchio
The Eastman Family	Doug Head



With the hard work and dedication of our educational partners, Delaware Media Group, WeHaveAFace was able to publish our [Ten-Year Review Magazine](#). We understand that many new community members join us in the trenches each day. I was refreshing to publish this magazine to facilitate a better understand of who and what WeHaveAFace.org is, how we began, and where we are today. It was also a great honor to highlight the many individuals and organizations we have worked with along the way.

We truly thank our friends at Delaware Media Group for their time, dedication, and love.



On October 31, 2020, WeHaveAFace.org held its first [Virtual Convention](#), however there were unfortunate technical difficulties which were beyond our control. Technology can be your friend or foe! WeHaveAFace continued with the day program and then posted the entire video coverage of the convention for our patients and families to view. We wish to thank our guest speakers for their time and amazing presentations.

- Hillary Lange (Licensed Professional Counselor)
- Dr. Thomas Bird (CoE, Washington State)
- Dr. Kelsey Finn (Mayo Clinic)
- Dr. Kyle Fink (UC Davis)
- BJ Viau
- Dr. Herwig Lange (George Huntington Institute)
- Dr. Peg Nopoulos (University of Iowa)
- Jimmy Pollard (CHDI)
- Dr. Travis Cruickshank (Edith Cowen University, Australia)





WeHaveAFace also wishes to thank our educational partners for their participation in our virtual convention.

Louise Vetter (CEO/President, Huntington's Disease Association of America – HDSA)
Frances Saldana (Founder – HDCare.org)
Allison Bartlett (Esq., HDSA Manager of Disability Programs)
Paramjit Oberoi (Sheenams Wish, UK)
Christine Hopkins (Dementia Group, UK)
Joe D'Onofrio (Delaware Media Group)
Donaji Toledo (AMEH – Mexican Huntington's Disease Association)

WeHaveAFace wishes to give a special thanks to our amazing teams – WeHaveAFace Canada, and WeHaveAFace England and Wales for their love, support, and participation!

WeHaveAFace TV

In 2020, [WeHaveAFace TV](#) was launched! It is the first of its kind to offer a mainstream quality production to provide education, information, and resources to our population. We aim to host interviews with outstanding medical professionals across the globe. Our professionals will add value and a voice to subject matter on all aspects of Huntington's and Juvenile Huntington's disease.

WeHaveAFace TV will push the envelope, so our community is delivered accurate and vetted information. We will also continue to discuss subject matter that is still considered taboo. WeHaveAFace TV will also celebrate the uniqueness of our international community - patients, caregivers, and families.

We are pleased to announce that Amazon Fire TV and Roku TV have accepted our TV program, and users of both platforms can access WeHaveAFace TV!



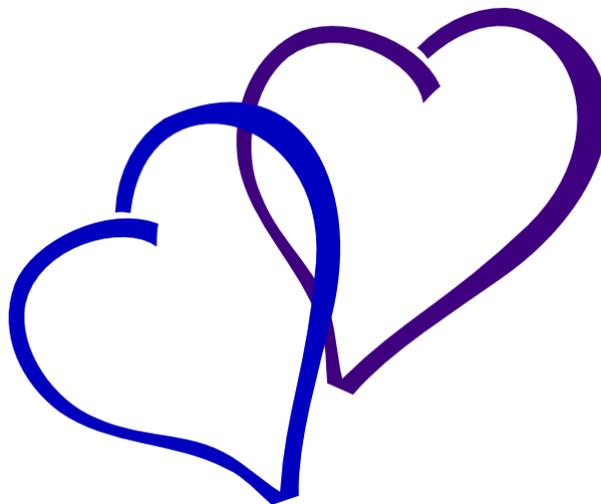
Season 2 is coming soon! Visit our [programs page](#) for additional information.

HD Assistance Fund

In 2020, WeHaveAFace struggled to raise funds to support the HD/JHD community as we had in the past. Although we were unable to surpass our goal, we were able to provide some support in 2020.

- Amazon Wish Lists
- Gift Cards
- Rent/Utilities, etc.

Through donations, and fundraising events, WeHaveAFace has been able to support our community since 2016. As of 2020, we have been able to provide \$80,000.00 of support to patients and families. We truly thank everyone who has donated to this fund (Facebook fundraisers, online donations, convention donations, and through our online store). Because of all of you we were able to help so many throughout the years.



- Adaptive equipment
- Wheelchairs/shower chairs
- Rent/Utilities, etc.
- Holiday Gift Cards
- MyID! Bracelets
- Personal hygiene needs
- Travel to convention
- HD/JHD Cards
- HD Youth Alliance (NY)
- HD Marathon (California)

WeHaveAFace hopes to reinstate the HD Assistance Fund soon. Please be sure to visit our [HD Assistance Program Page](#).

WeHaveAVoice Radio!



With 135 episodes since 2017, WeHaveAFace continues to provide quality content directly encompassing Huntington's and Juvenile Huntington's disease. It is our responsibility to "push the envelope" by hosting shows with sensitive topics such as suicide, sexuality/sexual promiscuity, alcoholism, aggression, behaviors, and so much

more. We must continue to openly talk about all aspects of this disease. Listen to [WeHaveAVoice Radio](#).

We look forward to piloting additional shows in 2021 with incredible special guests! Stay Tuned!

WeHaveAFace Global Times!

Since the release of our "WeHaveAFace" magazine in early 2017, we have received such incredible feedback from our international Huntington's and Juvenile Huntington's families, and from our amazing medical professionals. The publication provided many vital resources for our community and the general public.



In 2020, we continued to publish articles pertaining to all aspects of Huntington's disease. We deeply thank all of you for reading and sharing these publications across all social media platforms. Read our articles on [WeHaveAFace Global Times](#).

WeHaveAFace invites you to review all of our programs and services for Huntington's and Juvenile Huntington's disease. Visit: www.WeHaveAFace.org/programs

Listening to the community!



Since 2009, WeHaveAFace has always listened to the voices of our community. Every single program we have created was built and initiated by the needs of our HD/JHD patients and families. Our two films – “The Huntington’s Disease Project: Removing the Mask” and “The Purple Road” were also productions made by the HD/JHD community, for the HD/JHD community.

We didn’t stop there! Since our inception in 2009, WeHaveAFace continued the fight! In 2020, we began a comprehensive study/survey regarding a specific topic which has been on the minds of thousands in our community – the diagnostic criteria for Huntington’s disease.

With the professional guidance of our Senior Medical Advisor, Dr. Herwig Lange (George Huntington Institute, Germany), we launched an international survey. On October 13, 2020, we asked the community: *“Should the diagnostic criteria for Huntington’s disease be reviewed and updated?”*

By November 2020, we received over 1,400 completed surveys (USA, Canada, Mexico, England, Scotland, Ireland, Germany, Finland, Australia) with resounding results and feedback. It was abundantly clear – The community wanted the diagnostic criteria for Huntington’s disease to be reviewed and updated.

WeHaveAFace wishes to thank all of you who had completed the survey and provided us with feedback. If you have not seen the results of our findings, please review our [survey](#) page for more information.

We hope to provide the international community with additional information in the upcoming months. Stay tuned!

Our Mission has not change...



WeHaveAFace.org aims to broaden global awareness of Huntington's disease and Juvenile Huntington's disease. Our success in increasing awareness and education of this disease will continue to be measured by our ability to embrace and utilize various state-of-the-art technologies: international videos, films, radio shows, mobile applications, electronic publications, accredited training, social media networking, and WeHaveAFace TV. WeHaveAFace will move our mission forward to close gaps in education and services and provide support to our international Huntington's community. It is

also paramount that we educate the general public.

We are proud patients, caregivers, and professionals with years of experience in nonprofit and corporate management, group home management, day-training management, hospice, nursing, hospitals, teaching, training, and technical backgrounds. We have first-hand experience working with individuals with diseases and disabilities.

The Board of Directors, Advisors, and Advocates of WeHaveAFace are unpaid volunteers as per the [National Council of Nonprofits recommendations](#). The decision to remain as an unpaid, volunteer-only organization is to ensure that our priorities remain focused on allocating 100% of donations received to our educational suite of programs. WeHaveAFace.org is a legally registered [IRS 501\(c\)\(3\)](#) nonprofit organization.

WeHaveAFace.org - GuideStar Participant!
Platinum Seal of Transparency
2017 - 2021



WeHaveAFace wishes to thank our private supporters and our educational partners for their ongoing trust, love, support, and willingness to work together to benefit the lives of our Huntington’s and juvenile Huntington’s patients and families.

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Educational Partners



“Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has.” – Margaret Mead

#YouAreLoved