



*Broadening Global Awareness of Huntington's and Juvenile Huntington's Disease*

**USA - Canada - UK - Germany - México**

## *2018: Programs and Services Year in Review*

---

### **Charity Status:**

- WeHaveAFace is a legally registered 501(c)(3) nonprofit charity organization.

### **Mission:**



WeHaveAFace aims to broaden global awareness of Huntington's disease and Juvenile Huntington's disease. WeHaveAFace is the premier international multimedia advocacy organization for Huntington's disease and Juvenile Huntington's disease. Our continued success in increasing awareness and education of this disease is measured by our ability to embrace and utilize various state-of-the-art technologies: international videos, films, radio show, mobile application, electronic publications, accredited training, and social media networking. WHAF will move our mission forward to close gaps in education and services and provide support to our peers in our international Huntington's community. It is also paramount that we educate the general public.

### **Board of Directors - Advisors - Advocates**

The Board of Directors, Advisors, and Advocates of WeHaveAFace are unpaid volunteers. The decision to remain as an unpaid, volunteer-only organization was to ensure that our priorities remain focused on allocating 100% of donations to our Huntington's and Juvenile Huntington's community via education, resources, and financial needs. It is also our mission to fund Huntington's and Juvenile Huntington's disease research directly.

### 501(c)(3) Transparency - GuideStar

As per the GuideStar website: *"If you care about nonprofits and the work they do, then you're affected by what GuideStar does—even if this is your first visit to [www.guidestar.org](http://www.guidestar.org). Here at GuideStar we gather and disseminate information about every single IRS-registered nonprofit organization. We provide as much information as we can about each nonprofit's mission, legitimacy, impact, reputation, finances, programs, transparency, governance, and so much more. We do that, so you can take the information and make the best decisions possible."*



WeHaveAFace is pleased to have earned the [GuideStar Platinum Participant](#) rating for transparency reporting in 2017 and 2018. Since our inception, we have presented the highest level of transparency to our Huntington's community, investors, and donors. We will continue to report all aspects of WHAF as per the requirements of GuideStar and the IRS.

---

### Huntington Study Group (HSG)



As per the HSG website: *"The Huntington Study Group (HSG) is a proven world leader in facilitating high-quality clinical research trials and studies in Huntington disease (HD). We have the first and largest HD clinical research network of over 400 active and compassionate investigators, coordinators, scientists, and HD experts at over 100 HSG Credentialed Research Sites across the globe dedicated to seeking treatments that make a difference and improving the quality of life and outcomes for families affected by HD. In addition to this vast clinical network we collaborate with industry, government, and foundation sponsors, CROs and HD advocacy and community partners."*

WeHaveAFace has been a friend of the Huntington Study Group since 2009 and has played a proactive role in patient participation in studies and trials for Huntington's disease. WHAF will continue to help our patients and caregivers understand, locate, and participate in studies and trials for Huntington's disease.

## Huntington Study Group Memberships:

- Associate Members: WeHaveAFace USA, Canada, and UK teams are pleased to be Associate Members of the Huntington Study Group.
- HSG Member: Our Chief Medical Advisor, Dr. Herwig Lange (George Huntington Institute, Münster, Germany) is an HSG Member.



- ✓ Dr. Herwig Lange:
  - ❖ George Huntington Institute
  - ❖ European HD network EHDN
  - ❖ HD research group of the World Federation of Neurology

---

## EHDN – European Huntington’s Disease Network:



*Advancing Research, Conducting Trials, Improving Care*

*“The EHDN is a nonprofit research network committed to advancing research, facilitating the conduct of clinical trials, and improving clinical care in HD. Through the EHDN a platform has been created such that basic*

*scientists, clinicians, patients, and families can collaborate on academic and industry studies to fulfil its mission. The EHDN is supported by and collaborates closely with CHDI Foundation, Inc.*

*As a network of stakeholders in HD, the EHDN offers its members the opportunity to take a lead and propose, conduct, and publish studies. Anyone who has an interest in HD, including those affected directly by the disease, may join the EHDN and, in so doing, make a personal contribution to HD events and research.”*

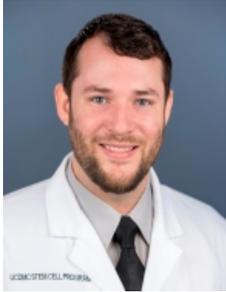
- ❖ In 2017, WeHaveAFace continued to support the mission of EHDN. The team of WHAF (International regions) has broadened awareness of Huntington’s disease as well as providing research support. WHAF has Associate and Regular (voter) Memberships within EHDN.

More information: [www.WeHaveAFace.org/EHDN](http://www.WeHaveAFace.org/EHDN)

## Research Support:

In 2017, WeHaveAFace made the decision to focus 100% of our research funding support for Juvenile Huntington's disease. WeHaveAFace supports the following researchers in their efforts to find viable treatments or the cure for Juvenile Huntington's disease.

WeHaveAFace supports the Juvenile Huntington's disease research of Dr. Kyle Fink – UC Davis Medical Center Institute for Regenerative Cures.



As per Dr. Kyle Fink: *"Dr. Kyle Fink, Department of Neurology, is working on highly exciting and novel approaches in which to treat Juvenile Huntington's disease (JHD) at the DNA level. His team, including talented Graduate Student Peter Deng, works closely with the labs of Dr. David Segal from the Genome Center and Dr. Jan Nolte from the Stem Cell Program at UC Davis to translate exciting gene editing/modifying techniques to hopefully one day treat those suffering from JHD. The team using DNA binding domains such as zinc fingers, TALE, and CRISPR/Cas9 to specifically shut down only the mutant huntingtin gene in the regions of the brain most affected by JHD. A major component of this work is to develop methods in which to safely and efficiently deliver these potent therapeutics to the brain. These ongoing efforts involve national and international collaborations to test the best system in which to move towards clinical trials. The team is focusing on testing these therapeutics in mouse models of the disease and is beginning to see very exciting results."*



WeHaveAFace supports the Juvenile Huntington's disease research of Dr. Peg Nopoulos – The University of Iowa – Kids-HD / Kids-JHD.



As per Dr. Peg Nopoulos: *"The Kids-HD Study and the Kids-JHD Study are both brain imaging studies run by researchers in the Department of Psychiatry at the University of Iowa Hospitals and Clinics. Our research is about kids who have a parent or a grandparent who has Huntington Disease. Huntington Disease (or HD) is a brain disease that is passed through families, so someone with a parent who has it is at risk of having it someday, too. HD causes parts of the brain to stop working like they should. Usually, this happens when a person is already grown up, but some people might have small problems in their brain for a long time before any bigger problems start. This study will try to find those early, small problems and measure them."*

Additional information: [www.WeHaveAFace.org/JHDResearch](http://www.WeHaveAFace.org/JHDResearch)

## Our Programs:



WeHaveAFace unites the international Huntington's and Juvenile Huntington's community via email, online surveys, mobile application responses, private online groups, and through in-person events to gauge educational needs and supports. WHAF does not wish to reinvent the wheel, but to tighten gaps which currently exist in regions lacking supports and services. We understand that a single organization cannot provide education, resources, and supports to an international community of patients and caregivers.

In 2017, WeHaveAFace added additional educational resources to our suite of programs.



### **WeHaveAFace Connect – “eVi”**

In early 2017, WeHaveAFace released “WeHaveAFace Connect” introducing “eVi” – Electronic Visit! We recognize that too many of our caregivers and patients are unable to receive advice and guidance pertaining to the daily challenges with Huntington's and Juvenile Huntington's disease.

With the participation of our Senior Medical Advisor, Dr. Herwig Lange (George Huntington Institute, Münster, Germany), patients and caregivers can now participate in a one-on-one session from the comfort of their homes. Our patients and caregivers are able

to receive vital information and support from medical professionals who actually have experience with this disease-oriented group.

Dr. Lange started his career as HD researcher at the Vogt Institut für Hirnforschung (brain research) in 1969 and as a clinical expert for Huntington's disease in 1980. He is a pioneer of the investigation of the preclinical phase of Huntington's disease, and has decades of experience caring for HD/JHD patients and families in Germany. In 1982 Dr. Lange opened the first specialized HD ward in Europe. Dr. Herwig Lange is one of the world's leading Huntington's Disease clinicians and researchers.

Additional Information: [www.WeHaveAFace.org/Connect](http://www.WeHaveAFace.org/Connect)



### **WeHaveAVoice Radio –**

WeHaveAFace understands the need to discuss sensitive subject matter and topics pertaining to 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 talk openly about all aspects of this disease.

**iHeartRadio:** WeHaveAVoice Radio broadcasts via iHeartRadio, with the potential reach of over 70 million registered users. In 2018, WeHaveAVoice Radio will begin hosting shows in the following languages: English - German - Spanish\*

Additional Information: [www.WeHaveAFace.org/Radio](http://www.WeHaveAFace.org/Radio)



In June 2017, WeHaveAFace began to construct a unique platform to provide education for our international Huntington's and Juvenile Huntington's patients and caregivers, as well as professionals who are unaware of what this disease is. All of us at WeHaveAFace: USA, Canada, UK, and Germany, have decades of experience working in group homes, nursing homes, hospice, day-training facilities, and hospitals. We have first-hand experience working with individuals with diseases and disabilities.

WeHaveAFace has produced a robust, interactive, multimedia-based training for our patients, caregivers, and medical professionals.

### **A 3-Tiered Approach!**

HD1- The Huntington's patient: newly diagnosed, and early-to-mid-stage.

HD2- Caregivers/families

HD3- Nurses, CNA's, social workers, group home and nursing home staff (unfamiliar with Huntington's and Juvenile Huntington's disease).

\*The HD3 Training will launch in the UK - Spring 2018\*

- HD1 & HD2 (Tiers) - Certificate of Completion
- HD3 (Tier) - Accredited (Skills for Care)

Carol Kennedy: (RGN, RDSA, RM, IV.), Vice President of WeHaveAFace England and Wales leads the HD3 Training Package in the UK.

Candice Neblett: (BS of Technical Education and Industry Training at University of Florida – AS of Business Management, Marketing, Administration at Seminole State College) leads the HD3 Training Package in the United States.

Dr. Herwig Lange: (Senior Medical Advisor for WHAF) provides oversight and approval for the training program.

Additional information: [www.WeHaveAFace.org/Programs](http://www.WeHaveAFace.org/Programs)





In 2017, WeHaveAFace launched the international "WeHaveAFace Global Times" newspaper. Since the release of our "WeHaveAFace" magazine in early 2017, we received such incredible feedback from our international Huntington's and Juvenile Huntington's families, and from our amazing medical professionals. This new publication provides many vital resources for our community and the general public.

**This online publication includes:**

- ✓ Current research: Studies and trials
  - ✓ News and insight from our partnering Huntington's organizations
  - ✓ Articles from HD/JHD doctors and researchers
  - ✓ Articles from the HD/JHD community
  - ✓ Video and audio clips pertaining to HD/JHD
- ❖ Currently, the "WeHaveAFace Global Times" online newspaper has been read by more than twenty countries. The newspaper is also embedded within our international mobile application, which reaches over 25,000 daily active users.

WHAF is pleased to have the support and contribution of incredible [writers](#) within this publication. We look forward to expanding this program in 2018 to include additional tools and resources for our international Huntington's and Juvenile Huntington's community.

Additional Information: [www.WeHaveAFaceGlobalTimes.org](http://www.WeHaveAFaceGlobalTimes.org)

WeHaveAFace invites you to review all our programs, resources, and products. Please visit: [www.WeHaveAFace.org/Programs](http://www.WeHaveAFace.org/Programs) for more information.

## Huntington's Disease Assistance Fund



The "Huntington's Disease Assistance Fund" helps those directly affected by Huntington's disease and Juvenile Huntington's disease and their families. Currently, there are very few financial resources for those of us within the Huntington's disease community.

Via community events and private donations, WeHaveAFace provided over \$20,000.00 of assistance to our Huntington's and Juvenile Huntington's disease families in 2017.

WeHaveAFace assisted families struggling with the financial burdens of this disease: Groceries, Clothing, Utilities, Equipment, Holidays, and Wishlist support. WHAF aims to triple the amount of support to our patients and families in 2018.



### 2017: WeHaveAFace Expansion of Services

In 2017, WeHaveAFace expanded its services via legal nonprofit Global HUBS:

- ✓ WeHaveAFace Canada
- ✓ WeHaveAFace England and Wales

In early 2018, WHAF added an additional nonprofit HUB:

- ✓ WeHaveAFace Mexico

WeHaveAFace looks forward to continued expansion in 2018.

\*Note: In 2017 WeHaveAFace UK was dissolved (currently Huntington Disease UK Limited - no affiliation with WHAF).

- ✓ WeHaveAFace Contributions: Hardware/Software/Educational Travel: \$14,305.33

Please review our annual report for the tax year ending [December 31, 2017](#).

## Educational Partnerships

WeHaveAFace is pleased to have educational partnerships with outstanding Huntington's organizations who do their share to better the lives of our HD/JHD patients and families.



**Help 4 HD International**

Educating The World About Huntington's Disease



Community, Advocacy, Research & Education



Asociación Mexicana de la Enfermedad de

**Huntington I. A. P.**

Una enfermedad del cuerpo y de la mente.



HUNTINGTON'S DISEASE  
YOUTH ORGANIZATION



Always remember...

**#YouAreLoved**