HUNTINGTON'S DISEASE YOUTH ORGANIZATION

Biographies

February 18, 2022

HDYO has more information about HD available for young people, parents and professionals on our site:

www.hdyo.org

Jenna Heilman - Executive Director

Over the past 15 years, I have enjoyed leadership roles in both the non-profit and for-profit sectors, developing a reputation for strategic thinking and planning. I quickly found out that my heart belongs to non-profit life. I recently left the Executive Director position at the Head for the Cure Foundation whose mission is to build awareness, raise funds and ignite hope for the brain tumor community. When I started in 2017, HFTC had hit a plateau for fundraising and staff bandwidth. Over my four-year tenure, we restructured the foundation to allow for maximized growth, re-tooled the financial reporting to allow for more grant opportunities, nearly doubled the dollars raised from $1.6 to $3 million annually between 2017 and 2019, strategized our marketing platforms including new websites and social media presence, created new programs to help provide education and support to patients and caregivers of all ages, started a national podcast to bring awareness to brain cancer and lifted HFTC's reputation nationally and internationally as a force within the advocacy community.

I truly believe that the best way to make an impact is through building and solidifying each relationship to truly understand how we can make a difference together. I'm so honored to join the amazing team as the Executive Director at HDYO. I have an unwavering passion to help all who have faced the most difficult of challenges to bring hope and inspiration throughout their journey.

Email me at jenna@hdyo.org

Matt Ellison, Project Coordinator and Founder

Hi! My role at HDYO includes developing all the educational project work we do for our website, including video projects, overseeing the youth camps and events HDYO hosts globally, planning future global projects to expand our reach, keeping the website up-to-date, responding to any messages we are sent for support/advice/questions and coordinating our volunteer translation team.

I am the founder of HDYO and come from a HD family. I started working voluntarily on the idea of HDYO in 2010 and it launched in 2012, I have been a staff person since 2013. I also have a degree in Childhood and Youth Studies. I am fortunate to work on something that is a passion for me. Contact details are below!

Email: matt@hdyo.org

Jacky Tse, Social Worker

Hi HDYO friends! My name is Jacky Tse. I was born and raised in Hong Kong and immigrated to California in the United States in 2017. I received Bachelor's degree in Humanities from Hong Kong Baptist University, Master of Philosophy (MPhil) degree from University of Cambridge and Master of Social Work (MSW) degree from California State University, San Bernardino. I am native in Cantonese and can speak fluent Mandarin and English.

I have more than 8 years of social service experience in Hong Kong and the United States. I started working as Program and Communications Officer in The Women's Foundation advocating for gender equality education in Hong Kong and later joined the Hong Kong Jockey Club Charities Trust as Management Trainee to collaborate with local non-profit organizations to implement innovative community-based projects to support the underserved and minority groups in Hong Kong. After immigrating to the United States, I started my career in California as Service Coordinator at San Gabriel/Pomona Regional Center serving the developmentally-disabled populations for almost 3 years. I

later joined Planned Parenthood for 2 years and assumed the positions of Education Specialist, Public Affairs Community Organizer and Patient Programs Specialist in which I was engaged in community health education, reproductive justice advocacy and patient care. I am also passionate to serve the youth populations and completed my MSW research on school-based suicide prevention programs for high school students. Most currently, I am working as a mental health therapist providing mental health counseling services for K-12 school-aged populations as well as marginalized communities in California.

In my free time, I enjoy traveling and I visited more than 25 countries in 5 continents through backpacking and Couchsurfing. I am a fan of reality TV and love to sing karaoke to relieve my stress. I am also a foodie and love to try out new restaurants.

Jenna Shea, North American Project Coordinator

Jenna, a teacher in the GTA, is a mother to two little girls and a member of a family deeply affected by Huntington's Disease. Over the last several years, Jenna has taken on a fairly active role as a patient advocate for those affected by HD. She is currently a mentor for the Youth Mentorship Program through the Huntington Society of Canada (HSC) and has supported HSC's efforts to raise awareness by sharing her story of HD at conferences and other educational forums within the Canadian community and internationally. In 2018, Jenna became a member of HD-COPE, a coalition for patient engagement that seeks to incorporate the patient-voice in global therapeutic development efforts for HD. Since joining HD-COPE, she has shared the experiences and needs of those affected by HD with regulators, researchers and industry professionals through her role on various advisory boards with Roche-Genentech, Wave Life Sciences, UniQure, Azevan, Novartis, Triplet Therapeutics and CHDI. In 2018, Jenna was presented with the "Change-Makers Award" by the Neurological Health Charities of Canada for the care she provides to her mother who lives with HD. In 2019, she joined Clinical Trials Ontario's 'College of Lived Experience' and most recently, has become a member of the Ontario Drug Policy Research Network's Citizens' Panel.

Prior to her involvement with HD, Jenna worked with Canada's leading national youth organization as a project support leader. During her role with that organization, she supported young people from various socio-economic and cultural backgrounds. It is her passion for working with young people and her desire to make a difference in the lives of people affected by HD that makes her excited to work with HDYO as the Project Coordinator for the Mentorship Program. Growing up in a family affected by HD, Jenna understands that isolation and lack of peer understanding can present challenges for young people affected by HD and knows the value and importance of the support of positive role models. If you have any questions about the Mentorship Program or would like to get involved, please contact Jenna via email at jen@hdyo.org

Marisa Pecoraro, In-Person Program Coordinator

Marisa Pecoraro (she/her) is a dynamic program coordinator with experience in a variety of industries, from higher education to retail, tech, and non-profit. Marisa is adept at managing people, communicating effectively, and making sure operations run smoothly. While attending university she realized she loved people, places, and cultures and has dedicated her time to educating herself and connecting communities. With an MA in Conflict Resolution and Mediterranean Security and an MS in Conflict Analysis, Marisa has made it a priority in her life to bridge the gap between resources and people and works every day to make the spaces she is in better for others. She does not shy away from the spotlight; however, she believes her true strengths lie in helping others shine and grow. Her personal and professional experiences solidified that being behind the scenes is foundational to a successful organization and she jumped at the opportunity to help support HDYO's in-person programs across the globe.

Marisa believes in the power of people and understands the strength communities, storytelling, and platforms can provide. She plans to carry on HDYO's mission through her role as the In-Person Program Coordinator. In her free time she hangs out with her two cats and her twin sister's dog, goes on runs and hikes, and plays D&D and other games. You can reach her at marisa@hdyo.org.

Kelly Atkins – Vice Chair

I'm Kelly and I'm from Melbourne, Australia! I first became involved in the HD community during my doctoral degree in 2016. My research helped to understand how best to measure the mood and personality changes that occur in HD, especially apathy. My neuropsychology training specialised in progressive neurological diseases, including HD and I'm a registered Clinical Neuropsychologist in Australia.

Since finishing my doctorate, I have continued to work as a researcher. I am especially interested in finding ways to measure changes in thinking or mood, as well as understanding the non-pharmacological strategies that can prevent changes in thinking and memory. I now live in New York City where I am completing a Fulbright postdoctoral fellowship looking at changes in the blood (called biomarkers) that may be associated with changes in thinking.

I am so excited to be a part of the HDYO Research Committee and for the opportunity to work with brilliant HD scientists and an empowered HD community alike. Outside of work I am an enthusiastic, albeit amateur tennis player and when time permits, I love anything outdoors, especially camping and hiking with my partner Sam.

Emily Machiela-Leestma – Secretary

Emily Machiela-Leestma is a scientist and longtime advocate for the Huntington's disease (HD) community. She earned her PhD in molecular genetics, with most of her graduate and postdoctoral work focused specifically on HD. Over the years, she's stayed involved in both research and patient support, including serving on the Florida HDSA board in 2019 and working with HD groups in Michigan.

After leaving the lab to pursue a few business ventures, Emily now owns and operates two small businesses in Michigan. Even though her day-to-day work has shifted, her passion for HD research and supporting young people and families affected by the disease has never changed. She's excited to be part of HDYO and help however she can.

Jacose Bell - General Board Member

Jacose Bell has always been motivated by the solidarity of ensuring that those directly affected by systems are in the conversation and shaping their outcomes. This work started in her teens and 20's where she saw firsthand the impact of giving a voice to people who traditionally would be talked about, but not talked with, or truly listened to. This has taken her on quite a road and that road eventually took her to HD in 2022. Jacose had the immense privilege of working with HDYO in her previous role at Spark Therapeutics, and when life transitioned her career in a different direction, she was determined to stay and work with the HD community.

In addition to advocacy, Jacose is passionate about education, and wild about the importance of younger people in both those arenas. The unique skills, concerns, perspectives, and priorities of young adulthood offer so much to a community, and in advocacy and education, they are critical for ensuring that we create a care system, including medicines that works for everyone.

Jacose holds a Masters in Bioethics and Health Policy from the University of Pennsylvania Perelman School of Medicine and is currently the Global Head of Public Affairs for Hemophilia at Sanofi. She lives in Philadelphia with an incredible partner and two hilarious dogs.

Paul Conn - Marketing & Fundraising Co-Chair

Paul began his early career as a Registered General Nurse working in Emergency Medicine and Ophthalmology. Working with patients with various conditions as a professional, he then became a Specialist Nurse in Multiple Sclerosis before moving into pharmaceutical sales. Spending time with several companies across a range of therapeutic areas, he then moved to Elsevier where he sells digital health platforms to NHS Trusts in the UK.

He is happily married to Elaine and has a son, Adam and two daughters, Charlotte and Hannah.

He's an avid runner and loves football, particularly his team, Sunderland. To relax, Paul loves walking their 4 dogs near their North East England home. He became a passionate HD advocate when his wife Elaine, was diagnosed with Huntington's disease and his daughter Charlotte recently tested positive. Using his professional and personal experiences, he's excited to see positive change for all those impacted by HD.

Dr. Katherine McDonell- Education Committee Co-Chair

I'm a neurologist at Vanderbilt in Nashville, TN and have been working with the Huntington disease community for the past 10 years. I lead the genetic testing program at Vanderbilt and am passionate about helping young people and their families as they navigate this disease.

I am also a researcher studying early cognitive and behavioral changes in children and adolescents at risk for HD. I think it's critically important to involve young people in research so that we can learn from their experiences and understand how best to support them. We also still don't know enough about how the earliest stages of HD might impact young people, so my work is focused on trying to identify early symptoms long before traditional disease onset so that we can better target potential new therapies.

I am very excited to be joining the HDYO board and leading the education committee. I have found HDYO resources to be extremely helpful in my clinical practice to support our families and look forward to helping grow and develop these programs.

Outside of work, I'm a mom to two daughters, ages 3 and 6, and have a dog and four chickens. In my spare time I'm also involved in walking and biking advocacy work in Nashville and can usually be found riding around town with my kids on our cargo bike.

Corey Janke – Education Committee Co-chair

Corey lives in London, Ontario, Canada and has been working with the Huntington community for 33 years as an employee of the Huntington Society of Canada. During his time with the HSC, he has held the roles of Family Service Worker, Resource Center Director for Southwestern Ontario and most recently National Social Worker.

In addition to offering individual support to families living with HD, Corey has also developed and implemented support groups, both in-person and virtually and worked with the local genetics and the movement disorder clinics. He has been the co-ordinator of the Youth and Young Adult Mentorship Program, supported the Young People

Affected by Huntington Disease (YPAHD) community and has presented at the Huntington Society of Canada's National Conference as well as the HDYO Congress in Glasgow. Lastly, Corey has worked with HDYO to support North American Youth at their amazing youth camps. His passion and commitment for the HD community has grown to be a huge part of his professional career and he is so grateful and excited for the opportunity to join the HDYO Board of Directors to continue to serve this beloved community.

Corey has been practicing social work since 1991, after obtaining his Bachelor of Social Work. In 2003, he graduated with his Master of Counselling Psychology. In addition to his work with the Huntington Society of Canada, Corey has focused his career within the health care sector, working in both a hospital and a community-based rehabilitation setting. He currently has a private practice, with a focus on trauma informed psychotherapy. He has extensive training in various trauma psychotherapy models including Eye Movement Desensitization and Reprocessing, (EMDR), Sensorimotor Psychotherapy and Deep Brain Reorienting Psychotherapy.
When not working, Corey loves to travel, play in his garden, cook spend time with family and friends.

Dr Bonnie Hennig-Trestman – Research Committee Co-chair

I have over 30 years of experience as a clinical therapist and have worked with people who have HD and their families since 1999. Currently I am the Director of the Carilion Clinic HD Program in Roanoke, VA. I am also an Assistant Professor at Virginia Tech

Carilion School of Medicine in the Department of Basic Science Education. In addition, I am the Special Programs Director for HD Reach in Raleigh, NC. I am the president and owner of HTA Consulting, PLLC where I provide tele-therapy to people at-risk for HD, people affected by HD, and to families. I also conduct behavioral research.

I provide educational lectures on various topics related to HD to healthcare professionals and to the public throughout the USA and internationally. I have been involved in HD research, conducting both observational and clinical trials. I am a member of the Huntington's Study Group (HSG) and the European HD Network (EHDN).

In 2003, I began to lecture on the topic of talking to kids about HD and in 2005 wrote a book called, "Talking to Kids About Huntington's Disease: a book for people who know children with HD in their family". The book was revised in 2017 and it has been translated into multiple languages. You can purchase a copy through Amazon Kindle via this link.

I have attended the North America HDYO camps as a staff member since 2015 and I am honored and thrilled to serve as a member of the HDYO Board of Directors, Chair of Research.

My passion to support the HD community is matched by the enthusiasm of the staff and volunteers at HDYO. I believe that HDYO is an excellent resource for kids, teens and young adults to obtain education, support, motivation and friendship. HDYO is a place where you never need to explain what HD is and there is always someone who will listen and support you. All you need to do is reach out. We are here for you!

Please connect with me through email DrBonnie@hdyo.org

Dr Lauren Byrne JOIN-HD Chief Investigator

My HD story started before I was even born with my grandmother who died from HD. I grew up with my uncle and aunt both affected by HD and in wheelchairs. In my early teens I learned that my dad had the HD gene. In the years to follow I was aware of the subtle changes and in his behaviour and eventually his movements and cognition. There are currently over 30 people at risk in my extended family… a constant motivator for the work that I do.

I was always interested in science and was naturally drawn to the brain and neurodegenerative disease. Whilst completing my Bachelor's degree in Biology at Imperial College London, I was inspired by Dr Jeff Carroll to pursue a research career in HD. I graduated my undergrad in June 2014, tested negative for HD in July 2014 and started a masters in Translational Neurology at UCL Institute of Neurology, September 2014 – with the sole purpose of getting a project working in Prof Sarah Tabrizi's research group (Our HD research Kahleesi!). During my masters, I serendipitously met Dr Ed Wild at a time when he needed a research assistant and I needed a job. I haven't looked back since.

I am now a HDSA Berman-Topper Postdoctoral fellow and feel so privileged that my research work on biofluid biomarkers might help with the development of drugs for HD. I am so excited to be a member of the HDYO board and co-chair the Research Committee with Dr Bonnie. It is a privilege to be a part of the efforts to support, educate, and empower the next generation of people affected by HD.

Clare Braithwaite – Marketing & Fundraising Committee Co-chair

Hi I'm Clare. I live in Manchester in the United Kingdom.

I come from a family affected by HD. My Mum has it and is still doing amazingly well in her 70s. She is my inspiration and my Dad who looks after her at home still along with some amazing carers . We were brought up knowing all about HD and being involved with the disease in a positive way, including being members of the HDA in England for many years.

I was diagnosed gene positive in 2018. I've no symptoms at the moment. It was a tough time but I dealt with it pretty well which was a result of the amazing support of family, friends and the HD family. Fortunately my sister Jo tested gene negative a few years ago. She was an incredible support to me through my testing process and continues to be for me and the family.

As a family we've done lots of fundraising for the HDA and been involved with the support groups and branches. I love running (slowly!) and have run the Great North Run (a big half marathon in England) four times to raise money. My sister Jo, brother in law, Matt, and I also run quizzes as fundraisers which are great fun and raise lots of money and awareness. We fight HD as a family in a positive way and make sure even in tough times there's lots of laughter! When I'm not running with my fantastic club Chorlton Runners in Manchester I love spending time with friends and family and travelling.

I've over 20 years' experience in marketing, working for companies like Kellogg's and

Nestlé and a marketing agency ATOM. I'm now starting a business as a life coach. I've got lots of experience that I can bring to help HDYO and young people and I'm passionate about doing that.

My aim is to help HDYO over the next few years in all areas but especially from a marketing point of view. Please get in touch if you need anything via email clare@hdyo.org

Ashley Clarke - Education Committee Co-chair

With over ten years of experience within the Huntington's Disease community, I have enjoyed getting to know the members around the world through a variety of roles. I am currently an HDYO board member and chair of the education committee. Creator of #imnotdrunk lifestyle blog and employed by Huntington's Disease Association Northern Ireland (HDANI) as their Youth Awareness and Events Office and recently joined HD-CAB as an advisory team member. In previous years I have attended HDYO summer camp, volunteered with HDANI at their youth events, medical training events and annual conference, spoken publicly about what it is like growing up in an HD family, attended

the HDSA convention and heard many medical professionals and what I call HD celebrities speak about Huntington's Disease.

I have truly enjoyed getting involved with the HD community and look forward to what the future brings. My father was diagnosed with Huntington's when I was 15 and from the age of 17, I was responsible for his care. I successfully graduated from University with a Hons Degree in Leisure and Events management and look forward to using that to help educate and empower people about Huntington's Disease.

Jenny Harte - Board Member

Myself, husband and two grown up children live in Buckinghamshire, England. As a family we have been rewarded and challenged by the hurdles faced for children with physical disabilities and neurodiversity. I am a vocal advocate for access to education for children with special needs having been a School Governor, chair and Board member at primary and tertiary educational institutions. Currently I am Non-Executive Director at a Leading University Technical College; Silverstone in the UK. My background is in

Economics and Medical Physics, having held a clinical role for 6 years in the UK National Health Service.

I now run my own boutique consultancy for Life Science building on my roles as global commercial leader and marketer with 20+ year' experience in specialty branded pharmaceuticals, including rare diseases such as Huntington's at local market and Global levels (Lundbeck, Teva, Genzyme and Sanofi). Additionally, I have global leadership experience in medical devices & Med Tech, including genomics for over 10 years. Regardless of my commercial objectives I have always been recognised as the leader who grows a service offering improving patient empowerment, access to diagnosis and therapy and establishing innovative patient programmes that improve lives. I am privileged to join the Board with HDYO