

Sharon Terry Receives the American Society of Human Genetics Advocacy Award

Genetic Alliance Welcomes Two New Council Members

DAMASCUS, MD, USA, November 10, 2022 /EINPresswire.com/ -- The American Society of Human Genetics (ASHG) honored Sharon Terry with the Advocacy Award at the ASHG 2022 Annual Meeting. This prestigious award honors individuals or groups who have exhibited excellence and achievement in applications of human genetics for the common good.

In nominating Sharon, Robin L. Bennett, MS, CGC; Director, University of Washington Genetic Counseling Graduate Program; said, "Sharon Terry is the epitome of advocacy for human genetics and genomics on an international stage. She has led [Genetic Alliance](#) to advance global genetic research agendas toward health benefits for all by engaging a broad range of stakeholders, including healthcare providers, researchers, industry professionals, public policy leaders as well as individuals, families, and communities. Her expertise and guidance has been sought by many prestigious policy organizations, e.g., The Institute of Medicine. She is a tireless advocate for biorepositories, registries, translational research, patient rights to their genomic information, orphan drugs, and open access to genetic research information. If I picked one word to describe Sharon, it would be luminary. She is an inspiration to anyone she touches, and her reach has been into almost every new area of genetics and genomics research, policy and health."



Sharon Terry, President & CEO, Genetic Alliance

The Advocacy Award was granted to Sharon in 2021 but formally recognized in 2022 at the first in-person American Society of Human Genetics meeting since the pandemic's start. ASHG President, Charles Rotimi congratulated Sharon during the ceremony. Sharon also participated in the annual meeting with a poster on Genetic Alliance's new program, [iHope Genetic Health](#) (iGH). iGH seeks to diagnose undiagnosed individuals in low to middle income countries and

communities, using generous in-kind donations from Illumina, ASW, and Luna.

New Council Members

Genetic Alliance is also delighted to announce two new board members, both of whom have expertise key to iHope Genetic Health.

Julia Ortega brings over thirty years of experience in the biotech, diagnostics and healthcare industry. She describes herself as a patient advocate skilled in Operational Leadership, Clinical Translational Research, and Patient Care. Her interest is in developing large-scale effective multi-systems in healthcare to improve the daily lives of people. Julia was honored to receive a

Bureau of Primary Care scholarship that enabled her to earn Physician Assistant and Masters in Health Science degrees from Duke University School of Medicine. She then practiced in internal medicine and geriatrics at a federally qualified health center and in skilled nursing facilities for

over 15 years. Her baccalaureate degree is from the phenomenal Spelman College, whose mission is to empower the whole person to engage the many cultures of the world and inspire a commitment to positive social change.

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Robin L. Bennett, Director, UW Genetic Counseling Graduate Program

Prior to her current position at C2N Diagnostics, Julia initiated the iHope Genetic Health philanthropic program at Genetic Alliance, where she focused on the global expansion of genetic testing to undiagnosed communities. Julia was a Director of Scientific Research at Illumina, Inc, where she ran the daily operational activities of the

Illumina iHope Program as well as a portfolio of several clinical research genomic projects that utilized whole genome sequencing and multi-omic technologies. Her background also includes working for United Health Group, Aetna, and Blue Shield of California, where she developed Clinical Programs for populations in need based on medical and prescription aggregate claims data. Julia currently sits on the Scientific Advisory Board of the Augustana-Sanford Genetic Counseling Graduate Program and runs a STEM Mentoring Program for high school students in



Julia Ortega, Genetic Alliance Council

under-resourced communities.

Julia brings a combination of people-centric skills and experience that are critical to Genetic Alliance's expansion with the iHope Genetic Health Program. You can [hear Julia](#) speak about this with Natasha Bonhomme, our Chief Strategy Officer.

Ryan J. Taft, PhD, is Vice President, Scientific Research at Illumina Inc, where he leads a portfolio focused on deploying genomic technologies for patients worldwide, especially the use of whole genome sequencing as a platform for genetic testing. At Illumina, his activities include oversight of the Illumina Clinical Services Laboratory's clinical whole genome sequencing test, pediatric and adult clinical trials, bioinformatic innovation, and novel application development.

Dr. Taft has helped describe more than a dozen novel genetic disorders, published more than 100 peer-reviewed scientific manuscripts, and is credited with being one of the first to use short-read whole genome sequencing of a family to resolve an undiagnosed disease. He is an advisor to half a dozen rare genetic disease focused technology companies and non-profits. His work has been featured in WIRED, Forbes, Science, Scientific American, Nature Biotechnology, the television series Chasing The Cure, and the documentary series Australian Story.



Ryan Taft, Genetic Alliance Council

Previously Ryan was a Group Leader at the Institute of Molecular Bioscience at the University of Queensland, focusing on the discovery and function of novel regulatory RNAs and the role of non-coding DNA in animal evolution. He obtained his PhD in Genomics and Computational Biology, which received a Deans' Commendation for Academic Excellence, from the University of Queensland on a US National Science Foundation Graduate Research Fellowship and Bachelor of Science in Biochemistry and Molecular Biology from the University of California, Davis on a Regent's Scholarship. Among other awards, Ryan received the Biocom Life Science Catalyst Award for innovation in the life sciences and the 2021 International Alumnus of the Year award from the University of Queensland.

Ryan leads the Illumina iHope program providing free clinical whole genome sequencing for over 1000 undiagnosed individuals in the past 7+ years. He brings this passion for supporting genetic disease patients to Genetic Alliance as we dive into the iHope Genetic Health program.

About Genetic Alliance

Genetic Alliance is a 501 (c) (3) that engages individuals, families, and communities to transform health. For more than three decades, we have empowered advocacy organizations and other

communities to collaborate with policy, service, research institutions at the international, national, state, and local levels.

Genetic Alliance has provided registry and biobanking services since 2003 to any nonprofit or disease community. We also support studies with our partner Luna (lunadna.com). Our iHope Genetic Health program provides free clinical whole genome sequencing to anyone in need of a diagnosis.

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