

Genetic Alliance Honors Advocate and Industry Leaders in Genetics

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WASHINGTON, D.C. – July 23, 2008 – Five leaders in the genetics community – both prominent trailblazers and unsung advocates – were honored recently at the [Genetic Alliance](#) Annual Conference, *Transformational Leadership*.

Genetic Alliance presents the Art of Listening, Art of Advocacy, and Art of Industry Partnership Awards annually. The Art of Listening award celebrates an individual who has listened attentively to organizations representing the millions of individuals and families living with genetic conditions. Joann Bodurtha, Virginia Commonwealth University, makes communities more welcoming to those with genetic disabilities. “Every single one of us wants to be heard, however varied our voices, difficult our stories, or joyous our discoveries,” she said. Dr. Bodurtha has founded several programs to help those with genetic diseases and currently leads the clinical genetics program at VCU, seeing about 500 patients and families with genetic conditions each year. Elaine Ogburn of the Virginia Leadership and Education in Neurodevelopmental Disabilities program (VaLEND) presented Dr. Bodurtha’s award, remarking, “Whenever she listens, real people’s lives change for the better.”

The Art of Advocacy Award honors individuals who demonstrate novel, voluntary, long-standing forms of leadership in advocacy. The award is made in honor of Joan Weiss, founder of Genetic Alliance. Sharon Terry, current CEO of Genetic Alliance, presented this year’s award to Clare Dunsford, author of *Spelling Love With an X: A Mother, A Son, and the Gene That Binds Them*, for her grassroots leadership through literature. In a review of the book for *Nature*, Terry remarked, “She teaches us to read the misspelled genome with new eyes.” Published last fall, the memoir explores Dr. Dunsford’s life as the mother of a boy with fragile X syndrome, a genetic form of mental retardation caused by a mutation that is carried by several members of her family. “I’ve been an advocate since the day my son was born, and I’ll be one for the rest of my life.”

The Art of Industry Partnership Award honors a for-profit company that models the benefits of creative partnerships between consumer advocates and industry in advancing understanding and treatment of genetic conditions. Patricia Furlong, founding president & CEO of Parent Project Muscular Dystrophy, presented the award to PTC Therapeutics: “This is one company that opened their hearts, minds, and intellectual capabilities to address a number of genetic diseases, which will be able to utilize their technology to develop treatments.” Theresa Nataliccio, Senior Vice President for Marketing and Sales, accepted the award, saying, “PTC was fortunate to establish strong partnerships with many advocacy groups,” which have been essential in establishing clinical endpoints and facilitating communication with the patient community.

Genetic Alliance introduced two new awards this year, the Founder's Service Award and the Art of Transformational Leadership Award, to recognize important figures in the history of both Genetic Alliance and the field of genetics as a whole, respectively. The Founder's Service Award recognizes an individual who has given deeply, consistently, and over a long period to Genetic Alliance. This year's inaugural recipient was Jannine Cody, who has served in a variety of Board of Directors positions for Genetic Alliance from 1992 to 2007. Dr. Cody developed and is now the leader of the multidisciplinary Chromosome 18 Clinical Research Center at the University of Texas Health Science Center in San Antonio. In a statement read by Diane Baker of the Genetic Alliance Board, Joan Weiss, founder of Genetic Alliance, said, "Members of the Genetic Alliance community could not have a more impressive role model than Jannine." Dr. Cody's award was accepted by Kemp Battle, another member of the Genetic Alliance Board.

The Art of Transformational Leadership Award was presented to Francis Collins by Sharon Terry to honor his compassionate, visionary leadership. As Dr. Collins prepares to leave his position at National Human Genome Research Institute (NHGRI), Genetic Alliance celebrated his constant focus on health, his creation of novel partnerships, and his commitment to the research commons. Dr. Collins is noted for his landmark discoveries of disease genes and his leadership of the Human Genome Project. "I've had this enormous privilege of standing at the helm of a project that has changed the world, but it's only been possible because of all these people, from all these walks of life, that got together to make it so. If you're honoring me for transformation, you're really honoring all those partnerships that I've had the privilege of being a part of."

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Genetic Alliance transforms health through genetics, using an environment of openness centered on the health of individuals, families, and communities. Genetic Alliance brings together diverse stakeholders that create novel partnerships in advocacy; integrates individual, family, and community perspectives to improve health systems; and revolutionizes access to information to enable translation of research into services and individualized decision making.