



PRESS RELEASE

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GENETIC ALLIANCE CONFERENCE STRENGTHENS ADVOCATES

Washington, DC, August 18, 2004:

Several giants in the genetics community were honored recently at the Genetic Alliance Annual Conference, *Joining our Journeys*. The Genetic Alliance bestows these coveted awards – the Art of Listening, Art of Reporting, Art of Advocacy and Art of Industry Partnership – 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. This year's award went to Stephen Groft, Director of the Office of Rare Diseases. Wendy Chaite, founding president of the Lymphatic Research Foundation, presented the award to Dr. Groft, reminding us all that, *"...Steve brings great honor and grace to his Government post as a "public servant" – he approaches each and every day with an open heart and an open mind – enthusiastically wanting to help and serve his constituents. The NIH is fortunate to have such an individual within its ranks."*

The Art of Reporting acknowledges professionals in the media who understand the difference between education and exploitation, and are able to build awareness of genetic conditions through compassionate reporting. Elizabeth Weil received this award for her article in Time Magazine: Savior Parents. In this article, she described the advocacy work of Scott Berns and Leslie Gordon founders of the Progeria Research Foundation, Jannine Cody, founder of the Chromosome 18 Registry and Research Society and Brad Margus, founder of the AT Children's Project. Ms. Weil spoke with passion about the stories of these parents who have become heroes. Her own profound appreciation for the parent advocate was obvious through her enthusiastic acceptance of the award.

The Art of Advocacy Award honors the giants in the advocacy field – individuals who create novel and long-standing models of leadership. The award is made in honor of Joan Weiss, the founder of the Genetic Alliance. Francis Collins nominated Nancy Wexler, founding president of the Hereditary Disease Foundation. He described her efforts as a stunning example of compassionate, rigorous, groundbreaking clinical research, established through her efforts to forge an effective consortium. In accepting her award, Nancy described the line all families cross when a disease touches their lives, to after. She gave voice to the struggle, the hope and the courage of all the advocates present. *"All of you at the Genetic Alliance are the bridge of DNA spanning the globe - erasing our differences and bringing together our commonalities to ease the world from pain and*

suffering. I love you and thank you and hope your - our - dreams will all be realized soon."

The Art of Industry Partnership was awarded to Genzyme Corporation for its support of the Fabry Support & Information Group, National MPS Society, National Gaucher Foundation and the National Tay-Sachs & Allied Diseases Association. Jack Johnson of the Fabry Support & Information Group presented the award to David Meeker, MD, President, LSD Therapeutics, accepting for Genzyme. He eloquently described their partnership with these advocacy groups and the critical role advocates have in helping Genzyme in making important advances: *"Relationship building exists years before something might ever reach the marketplace. The commitment does not waiver. Genzyme searches for new ways to build upon success to make a difference in the lives of people struggling with rare, genetic diseases. This is the art that complements their science."* Dr. Meeker said, *"The Genetic Alliance is a remarkable organization empowering individuals and patient organizations in their mission to improve the lives of individuals with genetic diseases. Genzyme is privileged to play a part in that mission. The "Art of Industry Partnership" award is wonderfully named in its recognition of the many challenges which must be overcome together to successfully bring a new therapy to individual patients in need."*

The Genetic Alliance is an international coalition of over 600 genetic advocacy organizations, academic and industry professionals. Its mission is to increase capacity in genetic advocacy organizations to achieve their missions and to leverage the voices of the millions of individuals and families affected by genetic conditions.