Applauds House for Holding Hearing

Washington – January 30, 2007 – The Coalition for Genetic Fairness, an alliance of advocacy organizations, health professionals and industry leaders working to educate Congressional policymakers and staff about the importance of legal protections for genetic information, and ensure passage of meaningful genetic information non-discrimination legislation, today commended the House Education and the Workforce Subcommittee for its hearing on protecting workers from genetic discrimination.

"We would like to thank the Health, Employment, Labor and Pensions Subcommittee for taking an important first step in the passage of the Genetic Information Nondiscrimination Act (H.R. 493) with today’s hearing on 'Protecting Workers from Genetic Discrimination,' said Robert Wells, Vice President International Markets Groups & Corporate Affairs, of Affymetrix, a genomic research tools company in Santa Clara, California. “For the past six years, Affymetrix has played a leading role in helping to prevent the misuse or abuse of genetic information and ensure that the American people continue to benefit from the tremendous advances in genomic technology.”

The Coalition has worked for twelve years toward the passage of legislation to eliminate the misuse of genetic information. Fear of the misuse of genetic information has been demonstrated to cause many individuals to choose not to take advantage of genetic tests, information from which could be used to manage their health proactively. The potential for discrimination continues to grow as the number of tests available increases and electronic health information proliferates.

Studies have shown that fear of discrimination also causes a large numbers of people to opt out of clinical trials. This lack of participation in research has a negative impact on researchers, clinicians, and industry, slowing the research and development process for targeted drugs and treatments. President Bush has shown his support and in a visit last week to NIH, said, “I really want to make it clear to the Congress that I hope they pass legislation that makes genetic discrimination illegal.”

“We are grateful for bipartisan efforts of our champions in the House of Representatives: Representatives Louise Slaughter, Judy Biggert, Anna Eshoo and Greg Walden. We look forward to the bill’s passage early this year,” said Sharon Terry, President and CEO of Genetic Alliance, and President of the Coalition.

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The Coalition for Genetic Fairness is led by: Genetic Alliance, Affymetrix, American Academy of Pediatrics, American Society of Human Genetics, Hadassah, National Society of Genetic Counselors, and the National Workrights Institute. For more information, contact Sharon Terry, sterry@geneticalliance.org, 202.966.5557 x201