

Genetic Alliance Introduces New Web Resource for Accessing Information on Genetic Diseases

April 30, 2007 - Genetic Alliance today announced a new feature on its website designed to help patients, care givers, health professionals, and others easily locate and navigate through the vast array of information on genetic disorders that is available from the National Library of Medicine (NLM), a part of the National Institutes of Health (NIH). The “portal” into NLM resources brings together, on one webpage, links to a wide range of information that patients and caregivers might want – from basic descriptions of a disease and its symptoms to the most current scientific research. It is designed to serve the needs of a broad spectrum of users, ranging from those who are just beginning to learn about a disorder to those who understand complex scientific information. This valuable new resource was developed in collaboration with the National Center for Biotechnology Information (NCBI), a division of NLM that creates and maintains public databases of biomedical information.

What Can One Find Through the Genetic Alliance/NCBI Resource?

- Disease descriptions from NCBI’s Genes & Disease online book
- Disease and genetic information from Genetics Home Reference (www.ghr.nlm.nih.gov)
- NLM Medline Plus web pages, which provide extensive links to information on diagnosis and treatment of diseases, physicians in the field, relevant health organizations, and more (www.medlineplus.gov)
- A guide to genetic testing, and directories of geneticists and gene testing laboratories, from GeneTests (www.genetests.org), a University of Washington service funded by NIH
- Clinical trials that may be available to those with genetic diseases, via www.clinicaltrials.gov
- Medical dictionaries and encyclopedias
- Primers and tutorials on DNA, genetics, genome mapping, and other scientific subjects
- The latest research published in scientific journals, via PubMed (www.pubmed.gov) and PubMed Central (www.pubmedcentral.gov)
- Technical information about the genes, DNA sequences, chromosomes and protein structures associated with genetic diseases

How Does it Work?

The Genetic Alliance/NCBI Resource is accessed through the “Disease InfoSearch” function on Genetic Alliance’s website, www.GeneticAlliance.org. After selecting a genetic disorder from an alphabetic list, users see links for various information sources, including “Research and Genetic Information” from the National Library of Medicine. Clicking on the link brings users to a customized page where an automatic search for their disorder has already been conducted within the NLM resources.

“Compiling all these sources of information together in a single location, and in an automated format with pre-computed search results, will make it significantly easier for patients and others to find the information they need about genetic disorders,” said Sharon Terry, M.A., President and CEO of Genetic Alliance. “Information is a vital component of our vision – a world in which those affected by genetic disorders have everything they need to live fully – and this joint project with NCBI brings us one step closer to achieving that vision,” she said.

“We are pleased to collaborate with Genetic Alliance on this project,” said David Lipman, M.D., Director of NCBI. “Genetic Alliance is dedicated to improving the lives of those with genetic disorders, and we share their goal of improving public access to information.”

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Genetic Alliance increases the capacity of advocacy organizations to achieve their missions and leverages the voices of millions of individuals and families living with genetic conditions. We build communication and mentoring networks, design and sponsor rigorous training courses, and provide infrastructure that strengthens and empowers our 600 member organizations. The technical assistance we provide to advocacy organizations results in measurable growth: increased funding for research, access to services and support for emerging technologies. For more information: [/www.geneticalliance.org](http://www.geneticalliance.org).

Established in 1988 as a national resource for molecular biology information, NCBI creates public databases, conducts research in computational biology, develops software tools for analyzing molecular and genomic data, and disseminates biomedical information, all for the better understanding of processes affecting human health and disease. NCBI (www.ncbi.nlm.nih.gov) is a division of the National Library of Medicine (www.nlm.nih.gov) at the NIH.