TRANSFORMATIONAL LEADERSHIP
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11 July, 2008

Dear Friends,

**THIS IS OUR MOMENT!** We are transforming leadership in a new age. The change is palpable! The old paradigms are tired, and they are unable to move us forward in this age of connectivity and openness. Every one of us must be authentically open—to partnership, to change, and to all the risks this sea change will bring. Gandhi taught that we must be the change we want to see in the world. If we are truly committed to improved health, to transforming systems, then each of us is an advocate.

In our major events this year, we both celebrate and challenge leadership. We applaud the passage of the Genetic Information Nondiscrimination Act. GINA is only the first milestone on the long road to the transformation of health through genetics. We have released a powerful energy by transforming a stagnant bill into an empowering law, and now we must learn as a community how to sustain and amplify that energy. We know that genetics is a wonderfully disruptive innovation, and we can make it a vibrant catalyst in the creation of a health system that faithfully serves all of us.

We eagerly delved into the nuances of genetic testing in Joanna Rudnick’s film, *In The Family*. Hundreds of us pounded the pavement once again for Genetics Day on the Hill. Our daylong courses on Friday afford both the neophyte and the veteran new opportunities to interact with experts in policy, research, organizational development, and leadership. Saturday provides a wide array of workshops, all seeking to equip us, leaders transforming our selves and our world. We’re particularly excited to celebrate these transformational leaders on Saturday night: Joann Bodurtha, Jannine Cody, Francis Collins, Clare Dunsford, and PTC Therapeutics. Sunday, our panel discussions will explore the thorny issues inherent in this time of tumultuous change, and seek to find the ‘commons’ we all share in true openness.

We will dance, sing, play, and simply be present this weekend. Join in as deeply as you can, set aside your agendas, don’t worry about turf—**OPEN YOURSELF TO TRANSFORMATION.**

Sincerely,

Sharon F. Terry, President and CEO
## Friday, July 11th

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<td>8:30 AM - 5:30 PM</td>
<td><strong>DAYLONG SYMPOSIA</strong></td>
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11:00 AM - 12:30 PM  WORKSHOPS: Session II

Using Family History to Improve Your Health: A School-Based Approach for Reaching Students and Families  Brookside A
Rebecca Giles, Utah Department of Health Chronic Disease Genomics Program
Louisa Stark, Genetic Science Learning Center

Newborn Screening: Joint Responsibilities  Brookside B
J.Gerard Loeber, International Society for Neonatal Screening
Hanaa Rifaey, Genetic Alliance
Judi Tuerck, Oregon Health & Science University

Making the Most of Your Educational Materials  Glen Echo
Mimi Blitzer, University of Maryland School of Medicine
Kate Reed, National Coalition of Health Professional Education in Genetics
Christine Vocke, PXE International

The Power of Youth: Nurturing Next Generation Leaders  Oakley
Teresa Davis, Sickle Cell/Thalassemia Patients Network
Cindy Hahn, Alagille Syndrome Alliance

Crossing All the T’s: Translating Human Genomics Discoveries into Population Health Benefits  Forest Glen
Ralph Coates, National Office of Public Health Genomics, CDC
Siobhan Dolan, Albert Einstein College of Medicine

12:30 PM - 1:30 PM  Lunch  Salon F-H
State of the Alliance, Sharon Terry, President & CEO

1:30 PM - 5:00 PM  Curbside Consults  Linden Oak
Sign up for a 20-minute, personal consultation at the Registration Table

1. Collaboration in Research on Genetic Conditions  Steve Groft
2. Graphic design and communications  Melissa Allen
3. Fundraising and Friendraising  Elizabeth Burden
4. Taking Care of Yourself in the Caregiving  Bridgid Guttmacher
1:30 PM - 3:00 PM  WORKSHOPS: Session III

Family History for Communities: Creating a Unique Tool  Brookside B
Vaughn Edelson, Genetic Alliance
James O’Leary, Genetic Alliance

Assuring Quality in Parent to Parent Support Services  Oakley
Kathy Brill, Parent to Parent USA
Dana Yarbrough, Parent to Parent USA

Patient Empowerment: Research and Experience  Glen Echo
Cathy Cantilena, The LAM Foundation
Symma Finn, University of Florida/Alpha-1 Foundation
John Walsh, Alpha-1 Foundation

Coverage and Reimbursement: The Ultimate Hurdles  Forest Glen
Bruce Quinn, Foley Hoag
Patrick Terry, Genomic Health

After the Screening: Assuring Long-Term Follow-Up After Diagnosis Through Newborn Screening  Brookside A
Coleen Boyle, National Center on Birth Defects and Developmental Disabilities, CDC
Alex Kemper, Duke University
Michael McConnell, Jones Day

3:00 PM - 3:30 PM  Afternoon Coffee Break

3:30 PM - 5:00 PM  WORKSHOPS: Session IV

Nutrition and Genetics: Translating Science to Practice  Glen Echo
Kathryn Camp, Walter Reed Army Medical Center
Judith Gilbride, New York University
Steven Yannicelli, Nutricia North America

Electronic Health Records: What’s Happening and Why You Should Be Involved  Brookside B
Wendy Benz, Raising Special Kids
Grant Wood, Intermountain Healthcare
Saturday, July 12th continued

1:30 PM - 3:00 PM WORKSHOPS: Session IV continued

**Family Networking and Leadership** Brookside A
Terri Bruns, Hope’s Hope
Michael Cohn, Hope’s Hope
Rachele LaCount, Hope’s Hope
Cheri McDonald, Hope’s Hope

**De-Identified Samples: The Humanity of it All** Oakley
Paul Cusenza, Entrepreneur
Ivor Pritchard, Office of Human Research Protections
Laura Rodriguez, National Human Genome Research Institute, NIH

**Education and Resources for the Public about Rare and Common Genetic Disorders: A Trans-NIH Approach** Forest Glen
May Cheh, National Library of Medicine, NIH
Lisa Kaeser, National Institute of Child Health Development, NIH
Dale Lea, National Human Genome Research Institute, NIH
Janine Lewis, Genetic and Rare Diseases Information Center
Alicia Santiago, Self Reliance Foundation

6:00 PM - 7:00 PM Reception

7:00 PM - 10:00 PM Awards Banquet Salon F-H
Clare Dunsford, *Art of Advocacy Award*
Joann Bodurtha, *Art of Listening Award*
Jannine Cody, *Founder’s Service Award*
PTC Therapeutics, *Art of Industry Award*
Francis Collins, *Art of Transformational Leadership Award*

10:00 PM - 12:00 AM After Hours Reception Linden Oak
Sunday, July 13th

7:15 AM - 8:00 AM  Morning Service (all faiths welcome) Oakley
Led by Francis Collins

7:15 AM - 8:00 AM  Morning Walk Meet at Registration

8:00 AM - 9:00 AM  Networking Breakfast Salon E

9:00 AM - 10:30 AM  PANELS: Session I

Novel Partnerships: Gateway to Success Salon F
Moderator: Kemp Battle, Tucker Capital Corporation
Panelists: Patricia Furlong, Parent Project Muscular Dystrophy;
Kelly Longo, Pfizer; Theresa Natalicchio, PTC Therapeutics;
Laura Rodriguez, National Human Genome Research Institute, NIH

Race, Ethnicity, Gender, and Genetics Salon H
Moderator: Vivian Ota Wang, National Human Genome Research Institute, NIH
Panelists: Marsha Tyson Darling, Adelphi University;
Perry Payne, Department of Health Policy, George Washington University;
Ron Whitener, University of Washington Native American Law Center

10:30 AM - 11:00 AM  Light Fare Salon E

11:00 AM - 1:00 PM  PANELS: Session II

Direct to Consumer Genetic Testing: Revolution or Risk? Salon F
Moderator: Francis Collins, National Human Genome Research Institute
Panelists: Mari Baker, Navigenics;
Trish Brown, DNA Direct;
Sue Friedman, Facing Our Risk of Cancer Empowered;
Joanna Mountain, 23andMe

Moderator: Rick Carlson, University of Washington
Panelists: John Adams, Canadian Organization for Rare Disorders;
James Evans, University of North Carolina;
William Pewen, Office of Senator Olympia Snowe (R-ME)

1:00 PM - 1:30 PM  Closing Debrief & Comments Salon E
Led by Sharon Terry
*Leadership*
Friday, July 11th, 2008
9:00 AM - 5:00 PM Forest Glen

**Inside Transformation: The Anatomy of Being a Change-Maker**
We are often anxious for the systems around us to function well, to yield better results, to advance a cause more dynamically. In this daylong workshop, we will experience intimate connection among the many levels of transformation: personal, organizational, communal, and global. We will begin with our own capacity for transformation and understand its power in transforming the systems around us.

Participants will be profoundly challenged to be present to their own personal leadership qualities and the barriers within that limit their expression. This workshop calls participants to open space, asking each one to leave their intellectual property at the door and to move together into working together for the greater good on all levels. You are invited into this experience by the Genetic Alliance Board of Directors.

The Organizational Development workshop will be facilitated by Elizabeth Burden, whose career in nonprofits has given her extensive experience with media relations and marketing, grant writing and fund development, and staff and volunteer development. Additional training and tools will be offered by Lisa Wise, Vice President of Genetic Alliance.

*Research*
Friday, July 11th, 2008
8:30 AM - 5:00 PM White Flint Amphitheater

**From Bench to Bedside to Practice: A Practical Course – Moving Toward Treatment**
Sponsored by the Office of Rare Diseases, NIH, DHHS

8:30 AM
**Welcome, Introductions, and Overview**
Steve Groft, Director, Office of Rare Diseases, NIH and Alan Guttmacher, National Human Genome Research Institute, NIH

9:00 AM
**So You Have the Gene: What Now? Steps in Determining the Best Path and Methods**
Les Biesecker, Genetic Disease Research Branch, National Human Genome Research Institute, NIH

9:30 AM
**Assay Development and the “Valley of Death”**
Christopher Austin, Chemical Genomics Center, National Human Genome Research Institute, NIH

10:00 AM – Break

*Organizational Development*
Friday, July 11th, 2008
9:00 AM - 5:00 PM Glen Echo

This daylong, comprehensive, hands-on training will give advocacy group leaders the skills to grow their organizational capacity. This year’s Organizational Development workshop will focus on assessment, strategic planning, and communication techniques that are effective with all audiences, including providers, members, patients, politicians, and the media.
10:45 AM
**Best Practices in Registries**
Jerome Wilson, Outcome Sciences

11:15 AM
**Data Collection Strategies to Fuel Bioinformatics Breakthroughs**
Lisa Forman Neall, National Center for Biotechnology Information, NLM, NIH

11:45 AM
**Morning Wrap Up**
Alan Guttmacher, NHGRI, NIH

12:00 PM – Lunch and Networking

1:00 PM
**Managing Information in a Registry/Biobank**
Liz Horn, International Psoriasis Foundation and Genetic Alliance BioBank

1:30 PM
**Collaboration, Education, and Test Translation Program**
Andy Faucett, CDC

2:00 PM
**Trial Drift: The Revolution and the Evolution of Clinical Blended Learning**
Al Pacino II, TrainingCampus.com

2:30 PM – Break

3:00 PM
**Rare Disease Clinical Research Network – Challenges and Portability**
Steve Groft, ORD, NIH

3:30 PM
**The Challenges of Social Science Research in Rare Diseases**
Barbara Biesecker, Genetic Counseling Program, National Human Genome Research Institute, NIH

4:00 PM
**Putting It All Together: An Example of Success**
Dennis DeMarinis, HAE Association

4:30 PM
**Wrap Up**
Steve Groft, ORD, NIH and Alan Guttmacher, NHGRI, NIH

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**POLICY**
Friday, July 11th, 2008
8:30 AM - 5:00 PM *Brookside A & B*

8:30 AM
**Welcome and Overview**
Sharon Terry & Andria Cornell, Genetic Alliance

9:00 AM
**The Fight for Genetic Anti-Discrimination Legislation**
Michelle Adams, Office of Congresswoman Louise Slaughter (D-NY)
Susannah Baruch, The Genetics and Public Policy Center
Joann Boughman, American Society of Human Genetics
William Pewen, Office of Senator Olympia Snowe (R-ME)

10:15 AM – Break

10:45 AM
**The Roles of Government, Industry, and Advocates in Genetic Testing Oversight**
Amy Brower, Third Wave Technologies
Gail Javitt, The Genetics and Public Policy Center
Paul Radensky, McDermott Will & Emery

12:00 PM – Lunch
1:30 PM  
**The Need for Health Information Technology**  
Janet Marchibroda, EHealth Initiative  
Nancy Johnson, Baker Donelson  
Andy Mekelburg, Verizon

2:45 PM – Break

3:15 PM  
**The Importance of Public Access for Research**  
Pat Furlong, Parent Project Muscular Dystrophy  
Heather Joseph, Scholarly Publishing and Academic Resources Coalition  
Neil Thakur, National Institutes of Health

4:30 PM  
**Closing Debrief and Comments**

**WORKSHOPS: Session I**  
Saturday, July 12th, 2008  
9:00 AM - 10:30 AM  
Forest Glen

**In the Family: Exploring Issues Related to Predispositional Genetic Testing**  
The National Society of Genetic Counselors and filmmaker Joanna Rudnick of *In the Family* partner to present an interactive workshop addressing issues surrounding genetic testing.  
A viewing of expanded footage from the film, a feature documentary on predictive genetic testing, precedes dynamic discussion about the importance of family history, the benefits and limitations of genetic testing, the genetic counseling process, genetic discrimination, cultural implications, and more.

**Community Screening and Counseling for Sickle Cell Disease Oakley**  
Re-establishing community testing and counseling for hemoglobinopathy risks provides an opportunity for educating diverse groups in genetics and community health. Through the Connecticut Hemoglobinopathy Counselor Course, investigators developed policies and consent processes for a community-wide screening for sickle cell disease. This project conducted five screening offerings and follow-up counseling sessions in various community settings. Summary and discussion include lessons learned, enhanced capacity of the community-based organization, and sustainability after grant funding ends.

**The Challenges and Rewards of Developing, Maintaining, and Translating Disease-Specific Fact Sheets for Parents Glen Echo**  
Although developing, maintaining, and translating family-friendly, disease-specific educational materials is challenging, the benefits are innumerable. The multi-state Screening, Technology, and Research in Genetics (STAR-G) Project developed fact sheets for disorders identified by newborn screening. This workshop presents the following: 1) challenges of developing condition-specific materials; 2) process of maintaining a web-based fact sheet; 3) challenges of translating technical health information into other languages; and 4) lessons learned in developing family-centered, disease-specific educational resources.
Collaborating for Genetics Education: Roadblocks and Rewards  
*Brookside A*

Partnerships across states and specialties are the key to achieving regional health priorities, but bringing multiple perspectives to the table can be difficult. This presentation focuses on the development of the New England Public Health Genetics Education Collaborative and a regional needs assessment. Through the demonstration of model projects, presenters explain how expansion of state projects, tailoring of national materials, and cross-regional collaboration can create successful public health initiatives.

**Bringing Social Justice to Genetic Technologies  
*Brookside B***

This workshop outlines the multi-movement model to ensure the ethical uses of genetic technologies in order to prevent the commodification of human life, exploitation of the financially insecure, augmentation of existing health disparities, and reification of race. Without coalition building, individual social justice movements will respond in isolation and may unintentionally negotiate wins at the expense of others. Panelists detail the challenges presented by the reproductive choice framework in addressing assisted reproductive technologies and how the current dialogue around technologies occurs within the context of a neo-liberal framework shifting responsibilities of health inequities from the state to the individual.

**WORKSHOPS: Session II  
Saturday, July 12th, 2008  
1:30 PM - 3:00 PM**

**Using Family History to Improve Your Health: A School-Based Approach for Reaching Students and Families  
*Brookside A***

This hands-on workshop helps you teach the “Using Family History to Improve Your Health” curriculum module. Developed by the Utah Department of Health, Genetic Science Learning Center, and high school teachers, the curriculum covers topics on chronic diseases, preventive risk factors, and healthy lifestyle choices. The materials address national and state-level Health Education standards and have been evaluated to ensure they are engaging and effective. The materials have also been adapted for Hispanic/Latino and Pacific Islander students.

**Newborn Screening: Joint Responsibilities  
*Brookside B***

In many countries, parent groups are increasingly interested in the possibilities of emerging newborn screening programs. As scientists, politicians, and the public become more excited, it is important for short- and long-term planning to be in place to guarantee the success of these programs. This workshop highlights the various responsibilities of implementing and maintaining a newborn screening program. Presenters speak on examples from both the United States and abroad.
Making the Most of Your Educational Materials Glen Echo

Diagnosis of genetic conditions is often followed by confusing or inappropriate educational material. Providers and consumers need quality information. The Access to Credible Genetics Resources Network (ATCG RN) is a project to create systems and tools for developing, assessing, and disseminating quality information. Presenters discuss experiences with the Quality Assessment Toolbox, a tool developed to determine the quality, content, and usability of educational materials. Learn how to use this tool to assess, develop, or revise educational materials.

The Power of Youth: Nurturing Next Generation Leaders Oakley

Youth often ridicule their peers with genetic conditions, yet these children are capable of educating and advocating in a refreshingly personal and effective way. Transitional leadership isn’t the division of work between adults and youth; it is the stratification of responsibility across generations, nurturing youth’s leadership potential. Capitalizing on youth’s energy and enthusiasm assures the future vitality of our organizations. This workshop looks at successful youth-adult partnerships, ways to engage youth, applicable laws, and the vital role of adult board members in nurturing leaders of the future.

Crossing All the T’s: Translating Human Genomics Discoveries into Population Health Benefits Forest Glen

This workshop provides an overview of the current initiatives of CDC’s National Office of Public Health Genomics (NOPHG) and its new portfolio for genomics translation research and surveillance activities to increase knowledge about the validity, utility, utilization, and population health impact of genetic testing, family history, and other genomic applications. The workshop highlights NOPHG’s Evaluation of Genomic Applications in Practice and Prevention (EGAPP) initiative, which serves as an example of a systematic, evidence-based process for evaluating genetic tests and other applications of genomic technology that are in transition from research to clinical and public health practice.

Workshops: Session III
Saturday, July 12th, 2008
1:30 - 3:00 pm

Family History for Communities: Creating a Unique Tool Brookside B

Family health history is often called the most basic genetic test, yet many remain ignorant of their family’s history of disease. The Community Centered Family Health History (CCFHH) project has shown that the adaptation of family history tools can increase family communication in a variety of community settings. To enhance accessibility, this workshop introduces participants to an online tool for easy, at-home customization of family health history materials. Presenters describe the customization process, followed by discussion.

Assuring Quality in Parent to Parent Support Services Oakley

Parent to Parent support—the matching of experienced, trained Support Parents with families seeking assistance and encouragement—has proven effective in helping the families of children with disabilities or special health care needs cope day to day, connect with community resources, and navigate the healthcare system. Presenters discuss the evidence-based practices
promoted and evaluated by Parent to Parent USA and offer guidance and resources for implementing a successful support program.

**Patient Empowerment: Research and Experience**

*Glen Echo*

The definition of empowerment in the Alpha-1 Antitrypsin Deficiency (Alpha-1) community was studied by gathering input from diagnosed individuals and their healthcare providers. This work led to an understanding of empowerment that includes personal forms (such as disease self-management, networking with other Alphas, and participation in research) and community-wide forms (advocacy, organizational development, and policymaking). This workshop expands on these findings through discussion with Alpha-1 and LAM patients about their experiences and community involvement.

**Coverage and Reimbursement: The Ultimate Hurdles**

*Forest Glen*

Coverage and payment for tests, treatments, and services is problematic for many Americans. With the emergence of genetic tests, therapies, and services, the system is further stressed. This workshop examines these issues and works to pinpoint the opportunities to inject change.

**Assuring Long-Term Follow-Up After Diagnosis Through Newborn Screening**

*Brookside A*

The U.S. Secretary of Health and Human Services Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children approved a statement defining long-term follow-up. This workshop reviews the key details of this statement, describes the current state of long-term follow-up activities, and encourages participants to describe their experience with the delivery and receipt of care. This includes the perspective of the public health system, healthcare providers, and consumers.

**WORKSHOPS: Session IV**

*Saturday, July 12th, 2008*  
*3:30 PM - 5:00 PM*

**Nutrition and Genetics: Translating Science to Practice**

*Glen Echo*

Emerging disciplines of nutrigenetics and nutrigenomics hold promise in treatment and prevention of many genetic disorders. This workshop looks at the relationship between nutrition and genetics and creates awareness of the role of nutrition in genetic disorders. Limitations and promises are explored, including genetic testing for nutrition therapy and disease prevention. Participants evaluate clinical scenarios and participate in a simple experiment that illustrates the impact of genetic inheritance on nutritional status.

**Electronic Health Records: What’s Happening and Why You Should Be Involved**

*Brookside B*

Electronic health records systems have the potential to transform healthcare through better access to information, clinical decision-making, and patient involvement. Find out why you should be paying attention to these rapidly evolving technologies. Learn more about national happenings, technology models, privacy and security issues, integration of genetics and family history, and benefits for patients and their families.

**Family Networking and Leadership**

*Brookside A*

Coping with disabilities evokes mixed emotions. To help patients with disabilities, the medical community can partner with three different but important groups: 1) patients, 2) family members, and 3) support groups and/or organizations that specialize in disabilities and neurological disorders. In this workshop, a person with a disability, the parent of a disabled child, and non-profit support organization representatives facilitate a meaningful discussion on disabilities.
**De-Identified Samples: The Humanity of it All Oakley**

Anonymized, coded, de-identified samples – what does it all mean? How can research in this age of abundant information proceed quickly and at the same time offer appropriate protections for human participants? This workshop examines these issues mindful of the tension to move toward treatments and therapies while avoiding harm to participants.

**Education and Resources for the Public about Rare and Common Genetic Disorders: A Trans-NIH Approach Forest Glen**

The National Institutes of Health (NIH) is translating genetic and genomic discoveries and their applications to genetic conditions to the general public in layman’s language. The panel presents information on and discusses 1) the Trans-NIH Working Group for Genetics Education of the Public, 2) the Genetic and Rare Diseases Information Center (GARD), 3) the Public Trust Initiative of NIH, and 4) the Self Reliance Foundation’s outreach effort with funding from the National Human Genome Research Institute.

**Panels: Session I**

**Sunday, July 13th, 2008**

**9:00 AM - 10:30 AM**

**Novel Partnerships: Gateway to Success Salon F**

This panel examines qualities and characteristics of successful partnerships. The age for working alone or with similar stakeholders has passed. Partnerships are enabling rapid growth and results in areas that would otherwise be stagnant or burdened by inherent challenges. Participants describe the interface between their organizations and principles that are portable to other entities.

**Race, Ethnicity, Gender and Genetics Salon H**

Genetics tells us that we are all 99.9 percent alike. What role do gender and concepts of race and ethnicity play in disparities in healthcare and health status? The panelists explore challenges and opportunities related to these disparities. They address issues related to research and services, including emergence of direct to consumer services.

**Panels: Session II**

**Sunday, July 13th, 2008**

**11:00 AM - 1:00 PM**

**Direct to Consumer Genetic Testing: Revolution or Risk? Salon F**

Genetic testing, from research to clinical services, is available direct to consumer in many forms. Why do individuals choose to receive these services in nontraditional forms? This panel describes and examines several types of testing from both the companies’ and the consumers’ points of view. Is this productive innovation or exploitation of the unsuspecting?

**Healthcare Reform: Is Universal Coverage Enough? Salon H**

As the presidential election draws near, healthcare reform is once again a top news story. With opinions becoming increasingly polarized supporting universal healthcare or reform of the private healthcare system, are rare and genetic conditions getting lost in the shuffle? This panel explores the issues of access to care, genetic services, and coverage.
GINA VICTORY CELEBRATION!

Join us for our celebration of Public Law 110-233: the Genetic Information Nondiscrimination Act of 2008 (GINA!).

Friday, July 11th, 2008  
**Reception** 6:00 PM - 7:00 PM  **Dinner** 7:00 PM - 12:00 AM

**Who can attend:** Full conference registrants & individuals who registered separately for this event

Dress is comfortable, festive, “celebration” attire. No jeans please. DNA ties welcome.

The GINA Band, featuring the musician-scientists of the National Human Genome Research Institute, will be on hand to rock the night away.

We celebrate the passage of a bill that will affect the lives of millions of Americans. Since 1995, sponsors, led by Congresswoman Louise Slaughter (D-NY), and supporters have been working to protect individuals from discrimination by employers and insurance companies. On May 21, 2008, after passing in the U.S. House of Representatives 414-1 and the U.S. Senate 95-0, President George W. Bush signed GINA into law.

GINA provides legal protections for every individual in the nation. With these protections in place, individuals can feel free to avail themselves of genetic testing and use that information to make more robust medical decisions. Researchers can also select from larger pools of clinical trial participants, which will expedite the research and development process for new therapies.

On Friday night, we celebrate not only a milestone in American history, but also a turning point in American civil rights.

CONGRATULATIONS TO ALL.
The Art of Advocacy Award pays tribute to a visionary grassroots leader who is harnessing his or her knowledge and experience to improve the quality of research, healthcare, information and support services for a specific condition or for a coalition of grassroots organizations.

Clare Dunsford is an associate dean in the College of Arts & Sciences at Boston College. After graduating from St. Louis University summa cum laude and Phi Beta Kappa in 1974, she received a PhD in English from Boston University in 1985. She was an adjunct lecturer in English at Harvard University for four years before taking a similar position at Boston College in 1991. She has taught courses in writing, poetry, modern literature, narrative and interpretation, literature and censorship, and literature and illness. After serving for three years as an assistant dean, she was appointed associate dean in the College of Arts and Sciences in 1999.

Last fall she published her first book, a memoir entitled Spelling Love With an X: A Mother, A Son, and the Gene That Binds Them. The book explores her life as a 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.

Chapters from Spelling Love with an X have appeared in the winter 2006 issue of The Kenyon Review, an issue dedicated to the Human Genome Project, and in X Stories: The Personal Side of Fragile X Syndrome (Flying Trout Press). Another chapter from her book appears in Love You to Pieces: Creative Writers on Raising a Child with Special Needs (Beacon Press, 2008), the first literary collection – fiction, essays, and poetry – on raising special-needs children.

Dr. Dunsford has read from her book in bookstores, arts festivals, and university classes as well as academic settings. In 2002 she read from the book-in-progress at a plenary session of parents and scientists at the National Fragile X Foundation international conference. She has given invited talks at the Pacific Center for Technology and Culture at the University of Victoria in 2004, and at the Center for Health Law Studies at St. Louis University School of Law at a symposium on “Disability, Reproduction, and Parenting” this past April. She will also be on a panel with other writers at the Society for Disability Studies conference in New York City this June.
Art of Listening Award

The Art of Listening Award honors a health professional who is a caring, receptive professional in the lives of individuals and families living with genetic conditions.

Joann Bodurtha, MD, MPH, is a Professor of Human and Molecular Genetics at Virginia Commonwealth University with joint faculty appointments in the Departments of Pediatrics, Obstetrics-Gynecology, and Epidemiology and Community Health. Throughout her career, she has worked to make genetics grow to help people and to form communities more welcoming to persons and families with disabilities. She graduated from Swarthmore College with a biology degree in 1974 and received her graduate degrees from Yale University in 1979. Her medical school thesis was based on research she did with boys with muscular dystrophy during a year as a Luce Scholar at the Nagasaki University of Medicine. Excellent mentoring from exemplary geneticists continued during a pediatrics residency at Children’s Hospital of Philadelphia and later a medical genetics fellowship at VCU. She worked as a USPHS physician on the Turtle Mountain Chippewa Reservation in North Dakota from 1982-84. Dr. Bodurtha has survived a copperhead bite, been happily married to Dr. Tom Smith for 26 years, and has a delightful daughter Anna who surpasses her genetic endowment.

Dr. Bodurtha helped start the Masters in Genetic Counseling program at VCU in 1990 and the VaLEND (Leadership Education in Neurodevelopmental Disabilities) program in 1995. Over 200 trainees have completed these programs. She is particularly proud of the family mentorship program at VaLEND that pairs trainees with families in which a member has a neurodevelopmental disability. She served on the American Academy of Pediatrics Committee on Native American Child Health for ten years and has been fortunate to be recognized as the team leader for a number of awards, including the Richmond YMCA Woman of the Year in Science and Medicine in 1997, the VCU School of Medicine’s first Innovation in Teaching award in 1999, a State Council of Higher Education Outstanding Teacher in 2006, and the Virginia Breast Cancer Foundation Sherry Kohlenberg Award in 2006. From 2000-2003, she was the President of the WISDM (Women in Science, Dentistry, and Medicine) organization at VCU. She currently helps lead the clinical genetics program at VCU and sees about 500 patients and families with genetic conditions each year. She has been the director of the VaLEND program since it began, co-director of the BIRCWH (Building Interdisciplinary Research Careers in Women’s Health) program, chair of the Statewide Genetics Advisory Committee, principal investigator of a National Cancer Institute research grant on the effects of incorporating genetic risk assessment in annual clinic visits, and vice chair of the Chickahominy Health Advisory Board. She started two endowments at VCU in memory of two former genetic counselors. She continues to try to help those missing at the table find a voice and work to make communities more welcoming to those with disabilities.
Paying Tribute to Our Heroes

Founder’s Service Award
Sponsored by the Elliott and Marge Hillback Family Foundation

The Founder’s Service Award is a new award in 2008. It recognizes an individual who has given deeply, consistently, and over a long period to Genetic Alliance.

Jannine Cody is the mother of Catherine and Elizabeth Cody. Elizabeth, who is now 23 and attends San Antonio Community College, has a chromosome abnormality called 18q-. When Elizabeth was born, the Codys were told there were 60 other families in the world with this condition. In 1990, she founded the Chromosome 18 Registry and Research Society. To date, the Registry now includes more than 2000 families affected by 18q-.

When Elizabeth was born, they were told that she would lie in a frog-like position in a vegetative state and have a normal lifespan.

Clearly this was not accurate and more research needed to be done, but no one was doing it.

In 1991, Jannine enrolled in a PhD program in Human Genetics. While pursuing her PhD, she developed the multidisciplinary Chromosome 18 Clinical Research Center at the University of Texas Health Science Center at San Antonio. Upon completion of her postdoctoral training, she became the Director of the Center. Jannine is now an Associate Professor and Interim Chief of the Division of Genetics in the Department of Pediatrics at the UT Health Science Center at San Antonio.

The Chromosome 18 Registry families now fund over a half a million dollars a year in research. This research ranges from the molecular biology of the conditions to the clinical consequences to the psychosocial ramifications for the affected individual, the parents, and the siblings. In an effort to ensure support for research into chromosome abnormalities, Jannine has testified twice before the U.S. Congress. Jannine served in a variety of Board of Directors positions for the Genetic Alliance from 1992 to 2007.
**Art of Industry Partnership Award**

*The Art of Industry Partnership Award honors a for-profit biotechnology, pharmaceutical, or genetics company whose track record models the benefits of creative partnerships between consumer advocates and industry to advance understanding and treatment of genetic conditions, disorders, and diseases.*

**PTC Therapeutics** is a biopharmaceutical company focused on the discovery, development, and commercialization of orally administered, proprietary, small-molecule drugs that target post-transcriptional control processes. Post-transcriptional control processes regulate the rate and timing of protein production and are of central importance to proper cellular function. PTC’s internally discovered pipeline addresses multiple therapeutic areas, including genetic disorders, oncology, and infectious diseases. In addition, PTC has developed proprietary technologies and extensive knowledge of post-transcriptional control processes that it applies in its drug discovery and development activities, including the Gene Expression Modulation by Small-molecules (GEMS) technology platform, which has been the basis for collaborations with leading pharmaceutical and biotechnology companies such as Pfizer, Celgene, CV Therapeutics, and Schering-Plough.

PTC has always prioritized its relationships with patients and patient advocacy groups. Early in the development of PTC124, our lead product for the treatment of genetic disorders due to a nonsense mutation, PTC reached out to the advocacy community to better understand the challenges and needs of those affected by genetic disorders. PTC was fortunate to establish solid partnerships with many advocacy groups including Parent Project Muscular Dystrophy, the Muscular Dystrophy Association, the Cystic Fibrosis Foundation, the Spinal Muscular Atrophy Foundation, and Fight SMA. The input and financial support from the advocacy community in the early years was critical in PTC’s efforts to collaborate with key opinion leaders and establish preclinical proof of concept. More recently, PTC’s relationships with the advocacy community have been essential in establishing clinical endpoints and facilitating communication with the patient community. As PTC continues to grow, strong partnerships with our advocacy partners will remain a top priority.
Paying Tribute to Our Heroes

Art of Transformational Leadership Award

As Francis Collins leaves his position at National Human Genome Research Institute (NHGRI), Genetic Alliance honors his compassionate, visionary leadership. His constant focus on health, his creation of novel partnerships, and his commitment to the research commons are only a few of the attributes we will celebrate!

Francis S. Collins, MD, PhD, a physician-geneticist noted for his landmark discoveries of disease genes and his leadership of the Human Genome Project, is Director of the National Human Genome Research Institute (NHGRI) at the National Institutes of Health. With Dr. Collins at the helm, the Human Genome Project consistently met projected milestones ahead of schedule and under budget. This remarkable international project culminated in April 2003 with the completion of a finished sequence of the human DNA instruction book. Building on the foundation laid by the Human Genome Project, Dr. Collins is now leading NHGRI’s effort to ensure that this new trove of sequence data is translated into powerful tools and thoughtful strategies to advance biological knowledge and improve human health. Dr. Collins is also known for his consistent emphasis on the importance of ethical and legal issues in genetics. In addition to his achievements as the NHGRI Director, Dr. Collins’ laboratory has discovered a number of important genes, including those responsible for cystic fibrosis, neurofibromatosis, Huntington’s disease, and most recently, genes for adult onset diabetes and the gene that causes Hutchinson-Gilford progeria syndrome, a dramatic form of premature aging.

Dr. Collins received a BS from the University of Virginia, a PhD in Physical Chemistry from Yale University, and an MD from the University of North Carolina. He has been elected to the Institute of Medicine and the National Academy of Sciences, and was awarded the Presidential Medal of Freedom in November 2007.
Genetic Alliance has radically transformed its governance. We seek to govern out of the new paradigm of openness, as process and product. In that spirit, several individuals have agreed to examine joining the board. They are considering the enormous time commitment, agenda-less process, and the deep personal openness required to move Genetic Alliance to the next level. We expect this process will result in adding three or four people to the board. If you are interested in being a part of this process, please contact Sharon Terry.
About Genetic Alliance
Genetic Alliance transforms health through genetics. We promote an environment of openness centered on the health of individuals, families, and communities. Openness forms both the process and product for Genetic Alliance.

Our goal is to build capacity within the genetics community by being fluid, dynamic, and efficient; we work to eliminate obstacles and limitations through:

Novel Partnerships
Genetic Alliance convenes diverse stakeholders—including disease-specific advocacy organizations, universities, companies, government agencies, and policy organizations—to explore and create novel partnerships in advocacy. Our network of thousands of organizations provides an open space for shared resources, creative tools, and dozens of timely programs.

Informed Decision Making
Genetic Alliance revolutionizes access to information to enable translation of research into services and individualized decision making. We offer technical assistance to organizations, build and sustain robust information systems, and actively work for public policies that promote the advancement of healthcare for the common good.

Individual, Family, and Community Perspectives
Genetic Alliance identifies solutions to emerging problems and reduces obstacles to rapid and effective translation of research into accessible technologies and services that improve human health. In all we do, we integrate individual, family, and community perspectives to improve health systems.

Genetic Alliance Programs
Genetic Alliance programs and initiatives are made possible with funding from government agencies, private donations, and industry contributions. Genetic Alliance empowers our mission through five multi-year awards totaling $2.5 million per year.

Four of these programs are focused on consumer genetics education and family health history with Department of Health and Human Services/Health Resources and Services Administration/Maternal Child Health Bureau/Genetic Services Branch (DHHS/HRSA/MCHB/GSB).

The National Consumer Center for Genetics Resources and Services is growing, developing, and innovating new resources within all of our program areas. All are available free of charge to the public, and many are currently available online. Future resources are being designed with a digital audience in mind. Our goal is to develop quality tools that can be easily accessed by anybody, anywhere in the world.
An abridged list of our current resources:

**Resource Repository** – This open source electronic repository for documents and audio and video files covers all aspects of organizational development: fundraising, incorporation, conference planning, volunteer recruitment, and more. Features include the ability to track new content tailored to your interests; view the most recently uploaded and most often downloaded content; and easily submit your own material.

**Disease InfoSearch** – A trusted means for locating accurate information, this online search and database of advocacy organizations connects you to resources for genetic conditions. The content is vetted for quality and links to clinical descriptions, treatments, and other relevant information.

**WikiAdvocacy** – A compilation of the wisdom of the advocacy community, this ‘wiki’ contains regular updates from key leaders and advisory and editorial board oversight. Members of the advocacy community continually add and refine the tips and tools offered, constantly evolving the knowledge base that we share.

**WikiGenetics** – An open source, user generated encyclopedia for the public, WikiGenetics is a valuable resource for anyone searching for genetics information, including people with no science background. Anyone can contribute and edit information. To ensure credibility, WikiGenetics requires references for all contributions. Advisory and editorial boards comprised of experts in genetics review all additions to the site.

**MemberForum** – This online roundtable allows the more than 250 support group leaders and other genetics and health professionals who are registered to share ideas, inspirations, best practices, and much more.

**Guide to Understanding Genetics** – This straightforward, intuitive, and customizable guide covers basic genetics concepts and in-depth information about receiving a diagnosis of a genetic condition, understanding newborn screening, gathering a family health history, exploring genetic counseling, and considering genetic testing.

**Weekly Bulletin** – This weekly update synthesizes need-to-know information within and around Genetic Alliance.

**Policy Bulletin** – The public policy department at Genetic Alliance keeps a close eye on international, federal, and regional policy news. As debates are conducted and votes are held, we keep our network informed via the weekly Policy Bulletin.

**Genetic Alliance Webinar Series** – Genetic Alliance offers information and a discussion framework to leaders and advocates in three series: Strategies for Success, Meet Your Neighbors, and Hot Topics in Genetics and Advocacy. We hold at least one webinar in each series per month.
Genetic Alliance has two cooperative agreements funded by HRSA called the **Consumer Focused Newborn Screening Projects**. They aim to create models based on consumer and medical home perspectives to minimize harms and maximize the benefits of newborn screening systems for all participants. Our partners in this project are Genetics and Public Policy Center and the University of Maryland Medical School as well as a number of consumer/advocacy groups.

The final HRSA grant supports Genetic Alliance and more than 20 partners in the **Community Centered Family Health History project**. We believe that accessible family health history tools produced by the community, for the community, will promote conversations about health within the family and translate knowledge of family health history into healthy choices. A broad definition of community is the basis of this approach. We work with diverse partners, including community-based organizations, professional societies, healthcare systems, faith groups, universities, and condition-specific organizations.

In 2005, The Centers for Disease Control (CDC) awarded Genetic Alliance a five-year cooperative agreement to develop the **Access to Credible Genetics Resources Network (ATCG RN)**, in partnership with University of Maryland Medical School, National Coalition for Health Professional Education in Genetics, Parent Project Muscular Dystrophy, Fragile X Research Foundation, National Fragile X Foundation, and Genetests. Finding accurate information for genetic disorders can be difficult for families faced with a new diagnosis. Healthcare providers also need quality information that will help them recognize genetic disorders and give appropriate care. The goal of the ATCG RN is to provide accurate information about rare genetic disorders for families and healthcare providers.

Genetic Alliance promotes disruptive innovation. Examples include:

- **Genetic Alliance BioBank**: a cooperative model, providing infrastructure for clinical records and images, research questionnaires, and biological samples (DNA, tissue, cell lines). Disease-specific organizations manage these collections as well as their analysis and distribution.

- **Coalition for Genetic Fairness**: more than 500 organizations came together to educate Congress and the public about the Genetic Information Nondiscrimination Act. The culmination of thirteen years of work, it was signed into law on May 21, 2008.

- **Eyes on the Prize: Truth Telling about Genetic Testing**: a summit that engaged stakeholders in laying aside their turf and focusing on health outcomes as a goal. This resulted in concrete action steps and clear pathways for various aspects of the field of genetic testing.
Exhibitors
The Exhibits Gallery opens on Friday, July 11th at 10:00 AM.

American Academy of Pediatrics
141 Northwest Point Blvd,
Elk Grove Village, IL, 60007
Tel: 847.434.7081
Email: gcchanda@aap.org
Website: www.aap.org/

The AAP is a professional membership organization of 60,000 primary care pediatricians, pediatric medical sub-specialists and pediatric surgical specialists dedicated to the health, safety, and well being of infants, children, adolescents, and young adults. Our members are the pediatricians working in communities and hospitals around the world.

FSIG & Cambridge Group
4100 Horizons Dr., Suite 201
Columbus, OH, 43220
Tel: 614.206.3226
Email: madams@cpgnet.com
Website: www.FSIGConnections.org

FSIG & Cambridge Group introduce FSIGConnections.org, a demonstration of turnkey IBM/Lotus Social Networking applications for Patient Advocacy Organization communication and collaboration, including Profiles, Communities, Wikis, Blogs, Dogear, Activities, Document Management, Sametime Video Chat, Instant Messaging, and Webcasting. These Web 2.0 features are available now for adoption by GA members and organizations.

FORCE: Facing Our Risk of Cancer Empowered
16057 Tampa Palms Blvd W. #373
Tampa, FL, 33647
Tel: 954.255.8732
Email: sueFriedman@Facingourrisk.org
Website: www.Facingourrisk.org

FORCE is a nonprofit organization devoted to improving the lives of people and families affected by hereditary breast and ovarian cancer. We provide support, resources, and information on cancer risk, risk management, treatment, and the latest research regarding hereditary cancer.

GeneDx
207 Perry Parkway, Gaithersburg, MD, 20877
Tel: 301.519.2100
Email: Allison@genedx.com
Website: www.genedx.com

GeneDx provides rapid molecular diagnosis for rare and not-so-rare hereditary disorders, including gene sequencing, Genome-Wide Oligonucleotide Microarray analysis (Genomedx), and AutismDx. We serve the needs of patients, physicians, genetic counselors, and researchers worldwide by offering array services, mutation detection, genotyping, carrier detection, and prenatal diagnosis for more than 150 disorders, as well as custom prenatal diagnosis and carrier testing after confirmation in our CLIA lab of mutations that were identified in the research setting.
Exhibitors

The Exhibits Gallery opens on Friday, July 11th at 10:00 AM.

Howard University Department of Community & Family Medicine National Human Genome Center Community Partnership Program
520 W Street NW, Suite 2400 Washington, DC, 20059
Tel: 202.806.6300
Email: fkhunter@howard.edu
Website: www.myfamilies.org

The Health Resources and Services Administration funded a cooperative agreement with the March of Dimes, who engaged four local partners targeting African Americans, Latinos/Dominicans, Chinese, Korean, and Pacific Islanders. The exhibit displays culturally appropriate consumer genetic education materials developed to increase genetic literacy and promote lifestyle changes to reduce health risks.

Office of Rare Diseases, National Institutes of Health
6100 Executive Blvd, Suite 3B-01 Rockville, MD, 20892-7518
Tel: 301.480.9655
Email: griffinc@od.nih.gov
Website: rarediseases.info.nih.gov/

The Office of Rare Diseases (ORD) was established in 1993 within the Office of the Director of the National Institutes of Health (NIH), the Federal focal point for biomedical research. ORD coordinates and supports rare diseases research, responds to research opportunities for rare diseases, and provides information on rare diseases.

United Mitochondrial Disease Foundation
8085 Saltsburg Road, Suite 201 Pittsburgh, PA, 15239
Tel: 412.793.8077
Email: info@UMDF.org
Website: www.UMDF.org

From simplifying less/non-invasive diagnostic methods to the discovery of a new gene, the United Mitochondrial Disease Foundation (UMDF), founded in 1996, continues to fund cutting edge biogenetic research that could change the way scientists look at many of the more common age related diseases such as Parkinson’s, Alzheimer’s, and even some cancers. The UMDF Mission is to promote research and education for the diagnosis, treatment, and cure of mitochondrial disorders and to provide support to affected individuals and families. Bringing together clinical and basic science researchers sharing an interest in mitochondria, the Foundation’s annual conference will be held June 24-27, 2009 at the Sheraton Premier Tyson’s Corner in the Washington DC area.

StemSave, Inc.
PO Box 15422, Scottsdale, AZ, 85267
Tel: 877.StemSave
E-mail: info@stemsave.com
Website: www.stemsave.com

StemSave is a collaborative effort between stem cell researchers and the dental community to provide families, individuals and stem cell researchers a cost effective, non-invasive methodology for the recovery and cryopreservation of stem cells residing within baby teeth, wisdom teeth, permanent teeth and other oral tissues. StemSave follows GTP guidelines.
Earlier this week ... 

On Thursday, July 10, the largest group of Genetics Day participants in three years came together on behalf of the genetics community to visit Congressional offices. Together, we worked for the transformation of health through genetics. We thanked the champions of the Genetic Information Nondiscrimination Act and educated staff members.

Genetics Day participants discussed the implications of GINA and laid the groundwork for addressing concerns in genetic testing oversight and health information technology, among other topics. We look forward to following up with each of the visited offices, building upon previous relationships, and forging new partnerships.

Also on Thursday, July 10, following Genetics Day on the Hill, Genetic Alliance held back-to-back screenings of In the Family at E St Cinema. Joanna Rudnick – filmmaker, journalist, and BRCA positive woman – was present for a Q&A session after each screening, along with Sharon Terry, to field audience questions and comments about her powerful, poignant film. Almost 250 attendees at each screening shared in her journey through the unpredictable world of predictive genetic testing.

In the Family is a co-production of Joanna Rudnick, Kartemquin Films, and the Independent Television Service (ITVS). Coming to PBS on P.O.V. Fall 2008.
Special Thanks to:

Mark Puryear and Paul Watson
The Greg Adams Trio
Alex Rihm

2008 Summer Interns:
Emanuela Acquafredda, George Washington University
Katie Boundy, Illinois State University
Candice Chambers, University of Tennessee, Chattanooga
Hema Krishna, Case Western Reserve University
Malia McPherson, University of California, Berkeley
Kate Pennington, University of Michigan
Sara Teixeira, University of Virginia
Jamie Van Horne, Yale University
SAVE THE DATE!

Genetic Alliance 2009 Annual Genetics Day on the Hill and Conference

Thursday, July 16th – Sunday, July 19th

Bethesda North Marriott Hotel and Conference Center

Metro Washington, DC
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Centers for Disease Control and Prevention  Major Conference Support
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