CELEBRATING
20 years of EXCELLENCE IN ADVOCACY
GENETIC ALLIANCE
2006 ANNUAL CONFERENCE
WELCOME to the 2006 Annual Conference, *Celebrating 20 Years of Excellence in Advocacy*. This powerful meeting marks the start of another decade of advocacy in genetics. It’s a time for us all to build bridges, develop partnerships, and applaud each other and ourselves for the inspirational leadership we offer our communities and families. I hope you enjoy the meeting this year and for many years to come.

Warmly,

Sharon Terry
President and CEO
**GENETIC ALLIANCE INSTITUTE FOR ADVOCACY**

8:30 AM – 5:00 PM

**Leadership in Action**  Glen Echo
An intensive day to focus on strategic planning, communications, and fundraising. Individuals from organizations of all sizes are encouraged to attend. Coordinated by Lisa Wise and Hanaa Rifaey, Genetic Alliance Facilitated by Elizabeth Burden, and featuring Jill Levy-Fisch, Save Babies Through Screening Foundation Audrey Gordon, Progeria Research Foundation Cynthia Le Mons, National Urea Cycle Disorders Foundation

**Governance in Action**  Forest Glen
A daylong workshop on developing strong boards. Board members and executives are invited. Coordinated by Gene Early, Sharon Terry, and Genetic Alliance Board of Directors

**Research in Action**  White Flint Amphitheatre
Sponsored by Office of Rare Diseases
Learn how to set research in motion, and keep its focus and intensity alive in the face of many challenges. Coordinated by the Office of Rare Diseases Chaired by Steve Groft, Office of Rare Diseases, and Claire Driscoll, National Human Genome Research Institute

**Industry Advocates and Liaisons in Action**  Oakley
Enhance your capacity to build collaborative alliances with the patient and consumer advocacy communities. Sara Collins, Genzyme Corporation Patrick Terry, Genomic Health

5:00 PM – 6:00 PM

**Conference Orientation**  White Flint Amphitheatre

6:00 PM – 7:00 PM

**Poster Reception and Exhibits Gallery**  Grand Ballroom
Open to All – Cash Bar

7:30 PM – 9:30 PM

**State of the Alliance—Opening Dinner**  Grand Ballroom
Welcome—Sharon Terry, Genetic Alliance Rick Guidotti, Positive Exposure

10:00 PM

**Genetic Alliance ‘After Hours’**  Linden Oak

* Accepted from submitted abstracts

KEY:  
- Information Track
- Policy Track
- Research Track
- Service Track
**Saturday, July 29th**

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>8:00 AM – 10:00 PM</td>
<td><strong>Posters and Exhibits Open</strong>  Grand Ballroom</td>
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<tr>
<td>8:00 AM – 9:00 AM</td>
<td><strong>Networking Breakfast</strong>  Grand Ballroom</td>
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| 9:00 AM – 9:45 AM | **Keynote Address**  Grand Ballroom  
Joann Boughman, American Society of Human Genetics                      |
| 9:45 AM – 10:15 AM | **Coffee Break**                                                        |
| 10:15 AM – 11:45 AM | **WORKSHOPS: Session I**  
**How Do I Get the Word Out about My Disease?**  Forest Glen  
Patricia Furlong, Parent Project Muscular Dystrophy  
Katie Clapp, FRAXA  
**Understanding the Oversight of Genetic Testing**  Glen Echo  
Steve Gutman, Food and Drug Administration  
David Mongillo, American Clinical Laboratory Association  
Juli Murphy, Genetics and Public Policy Center  
**Personalized Medicine Landscape**  Timberlawn  
Challenges and opportunities for consumers.  
Patricia Deverka, Duke University  
Rick Carlson, University of Washington  
**Of Mice and Men (and Women)**  Middlebrook  
Erich Dagnal, Jackson Laboratory  
**Parents as Advocates in the Medical Insurance Context**  * Oakley  
Marla Kraus, Special Needs Advocate for Parents (SNAPS)  
**From Family Tree to Family Health**  Linden Oak  
Janet Williams & Marc Williams, Intermountain Healthcare |
| 12:00 PM – 1:00 PM | **Buffet Lunch**  
Opportunity for Regional and Issue-based Networking (optional) |
| 1:15 PM – 2:45 PM | **WORKSHOPS: Session II**  
**Telling Your Personal Story**  Linden Oak  
Hanaa Rifaey, Genetic Alliance  
Marcia Rosenberger, Science writer/editor  
**Quality Information**  Glen Echo  
Meredith Weaver, University of Maryland  
Kate Reed, National Coalition of Health Professional Education in Genetics  
Patricia Furlong, Parent Project Muscular Dystrophy |
Maximizing Effectiveness of Voluntary Health Organizations (VHO) through Coalitions:

*Using Old Wine in New Bottles*  
**Oakley**

Heller an Shapiro, Osteogenesis Imperfecta (OI) Foundation  
Fran Berkwits & Marion Yanovsky, National Tay-Sachs and Allied Diseases Association  
Priscilla Ciccariello, International Federation of Marfan Syndrome Organizations (IFMSO)

**Preterm Birth and Birth Defects**  
**Middlebrook**

Siobhan Dolan, March of Dimes

**Registries and Databases**  
**Forest Glen**

Liz Horn, National Psoriasis Foundation

**Planning for the Future of Your Child With Special Needs**  
**Timberlawn**

Louis Doroba & Alan Becke, Special Needs Advocates for Parents in Relationship with MetDESK (Metlife's Division of Estate Planning for Special Kids)

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**WORKSHOPS: Session III**

**Brazilian Genetic Alliance**  
**Timberlawn**

Martha Carvalho, Brazilian Genetic Alliance, Associacao X Fragil do Brasil  
Tania Levy, Brazilian Genetic Alliance, Brazilian Gaucher Association

**A Community-Based Approach to Public Health**  
**Glen Echo**

Alejandra Gepp, National Council of La Raza, Institute for Hispanic Health  
Claudia Petruccio, Institute for Cultural Partnerships

**Power Up! Raise the Profile of Your Organization Through Advocacy**  
**Lindenbrook**

Orkideh Malkoc, Genetic Alliance

**Genetic Alliance BioBank**  
**Oakley**

Sharon Terry, Genetic Alliance & other members of Genetic Alliance BioBank

**Advocacy in Action**  
**Forest Glen**

Penny Kyler, Genetic Services Branch, Maternal Child Health Bureau, HRSA  
Jill Levy-Fisch, Save Babies Through Screening Foundation  
Jana Monaco, Organic Acidemia Association  
Micki Gartzke, Hunter's Hope Foundation

**Ensuring the Quality of Genetic Testing**  
**Middlebrook**

Lisa Kalman, Andy Faucett, & Ira Lubin, Centers for Disease Control and Prevention

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* Accepted from submitted abstracts
Saturday, July 29th (continued)

6:00 PM – 7:00 PM  
**Reception with Cash Bar**  
Grand Ballroom  
Featuring live music by Mark Puryear and Paul Watson

7:00 PM – 10:00 PM  
**Awards Banquet**  
Grand Ballroom  
Paying Tribute to Our Heroes

**GENETIC ALLIANCE 2006 AWARDS**

Art of Advocacy: **Priscilla Cicariello**, National Marfan Foundation and International Federation of Marfan Syndrome Organizations

Art of Listening: **Dr. Edwin Kolodny**, New York University School of Medicine

**Dr. Alan Rabson**, National Cancer Institute

Art of Reporting: **Paula Zahn**, CNN

Art of Industry: **Baxter**

10:00 PM – midnight  
**Genetic Alliance ‘After Hours’**  
Linden Oak

Sunday, July 30th

7:30 AM – 9:00 AM  
**Breakfast Network**  
Grand Ballroom

8:30 AM – 10:00 AM  
**WORKSHOPS: Session IV**

**Genetic Alliance Information Tools**  
Oakley

**Karen White & Helen Travers**, Genetic Alliance

**Informed Decision Making and Rare Disorders**  
Great Falls

**Joe McInerney & Kate Reed**, National Coalition of Health Professional Education in Genetics

**It’s in the Genes!**  *  
Linden Oak

**Marla Gilson & Dale Mintz**, Hadassah

**The Interrelation of Genes, Diseases, and Public Health**  
Board Room

**Apryl Brown**, Detroit Medical Reserve Corps

**Deborah Bowen**, University of Washington

**Increasing Research Through Collaboration**  
Middlebrook

**Jannine Cody**, Chromosome 18 Research & Registry Society

**Peggy Devine**, Cancer Information and Support Network

**How Do We Serve Ourselves in the Midst of Serving?**  
Timberlawn

**Brigid Guttmacher**, Licensed Professional Counselor, private practice
Sunday, July 30th (continued)

10:15 AM – 11:45 AM

WORKSHOPS: Session V

Hidden Treasures  Great Falls
Lisa Forman, National Library of Medicine

Outreach to Teach  Board Room
Joann Boughman & Kenna Mills Shaw, American Society of Human Genetics

When Cultural Values Clash  *  Lindenbrook
Wendy Jones & Suzanne Bronheim, National Center for Cultural Competence, Georgetown University Center for Child and Human Development
Isabella Lorenzo-Hubert, Georgetown University Center for Child and Human Development

How Does Newborn Screening Work?  Great Falls
Donna Williams, National Newborn Screening and Genetics Resource Center
Susan Panny, Maryland Department of Health and Mental Hygiene
Marcia Valbracht, Iowa Newborn Screening Laboratory
Sandy LaPrad, Michigan PKU and Associated Disorders

Opportunities for Partnerships:
Advocacy Groups and Genetic Counselors  *  Oakley
Diane Baker, Genetic Alliance
Nancy Callanan, National Society of Genetic Counselors and University of North Carolina at Greensboro
Misti Williams, University of Cincinnati

Clinical and Laboratory Issues in Genetic Testing of Rare Hereditary Disorders  Timberlawn
Sherri Bale, GeneDx
Wayne Grody, UCLA School of Medicine
Soma Das, University of Chicago
Andy Faucett, Emory University, CDC

11:45 AM – 12:15 pM

Coffee Break and Snack

12:15 PM – 2:00 PM

Project DOCC, Delivery of Chronic Care  White Flint Amphitheater
Maggie Hoffman, Project DOCC
Donna Appell, Project DOCC and Hermansky-Pudlak Syndrome Network

2:00 PM

The Year Ahead  White Flint Amphitheater
Sharon Terry, Genetic Alliance

2:30 PM – 9:00 PM

Member Board Meetings

* Accepted from submitted abstracts

KEY:  Information Track  Policy Track  Research Track  Service Track
Workshop Descriptions

SESSION I
Understanding the Oversight of Genetic Testing
As genetic tests become standard in quality care and test results are used as the basis for profound medical decisions, it is important to look at current regulatory oversight and consider any areas where new public policy might be needed. This expert panel will describe the development and genesis of genetic tests, the important role they serve in quality healthcare, and the sources and extent of current regulatory oversight.

Of Mice and Men (and Women)
Mice are a very valuable research tool. The mouse genome, and many of its genes and their functions, is similar to the human genome and genes. In many instances, the gene of interest can be “knocked out” and its effect on mice without the functioning gene can be studied. But not all mice are created equal, nor is this work simple. This workshop will discuss the importance of transgenic mice, and their relevance to genetic disease research.

How Do I Get the Word Out About My Disease?
Often, when faced with a genetic diagnosis, an advocate's first thought is to educate the world about every aspect of the disease. We will discuss what we want people to understand about our diseases, and we will develop strategies to deliver crisp, pertinent information to families, providers, and the community.

Personalized Medicine Landscape
“Personalized Medicine” is a relatively new buzzword intended to capture both the strategy of tailoring health care interventions on the basis of risk stratification, as well as translating the knowledge gained from mapping the human genome to clinical practice. This workshop will explore the concept as it arises in health care delivery, including a discussion of genomics as the science that facilitates its development, but will emphasize what the concept is likely to mean to the Genetic Alliance community.

Parents as Advocates in the Medical Insurance Context
Appropriate and often specialized treatment is needed for children with special needs. Obtaining medical insurance authorization or reimbursement for specialized services such as therapy or medical equipment is not always a simple process. This presentation will show you how to more easily navigate through your medical insurance policy and get much needed benefits authorized or paid.

From Family Tree to Family Health
In the demands of focused healthcare for the family member(s) with an identified health diagnosis, attention to basic family health information can be forgotten. This session will outline how to collect family health history, how to communicate family history, and how to talk with your primary care provider about other important topics such as guardianship, living arrangements and social/behavioral issues.

SESSION II
Maximizing Effectiveness of Voluntary Health Organizations (VHO) Through Coalitions: Using old wine in a new bottle
With competing needs, limited financial resources, and waning federal interest in rare genetic diseases, it is time to “recreate” creative initiatives with a view to increasing and facilitating research resources. The concept of “coalition-forming” and collaboration is as old as civilization itself, but it is an “art” that can be improved to increase effectiveness. This session will focus on two genetic disease coalitions demonstrating the educational and policy implications and benefits of coalition-building, exploring the increased use of the computer and Internet as a resource to simplify communication between similar disorders, conference organizing, and legislative advocacy.

Quality Information
This session discusses what happens when genetic disease information is not evidence-
based or conflicts with other information. The presenters will offer a draft metric developed for the Access to Credible Genetics Resource Network (ATcGRN) project that ranks the quality of evidence-based information about single gene disorders. Participants will discuss the utility of the metric and how they make decisions about conflicting information.

**Registries and Databases**
A registry is a standardized collection of information about patients with a specific condition. Registries are organized so the information collected can be easily studied. This session will provide an overview of registries, examples and practical information about creating a registry. This is a companion session to the Genetic Alliance BioBank.

**Telling Your Personal Story**
Your personal story explains your relationship to the condition you represent and is probably the most compelling outreach activity you can share daily. In this workshop you will learn how to reach your audience with a story that is human, warm, and integrated with the scientific facts. You will leave the workshop with an outline of leading sentences to use in creating your story.

**Preterm Birth and Birth Defects**
The relationship between birth defects and prematurity is complex, with both increasingly appreciated to result from the interaction of genetic and environmental factors. Addressing prematurity and birth defects simultaneously provides the impetus to help reduce underlying, shared risk factors. It sheds new light on familiar issues of fostering healthy pregnancies by providing high-quality preconception, prenatal and interconception care. Further research into the genetic and environmental factors that contribute to both birth defects and prematurity is needed.

**Planning for the Future of Your Child With Special Needs**
Planning for the future of your child is hard enough. If your child has a disability, it is even more difficult. How will they be cared for after you're gone? Special needs estate planning, or “estate creation” for those without any personal estate already will be discussed. Our experienced presenters know first hand the maze of legal and financial information a parent must work through to feel confident that the future of their child is secure. If proper planning is not done, the child could lose all eligibility for governmental benefits.

**SESSION III**

**Power Up! Raise the Profile of Your Organization Through Advocacy**
This session will introduce participants to the value of advocacy and provide guidance on initiating advocacy activities. Participants will also learn about current policy issues affecting the genetics community.

**Genetic Alliance BioBank**
Leaders in the research advocacy field founded the Genetic Alliance BioBank in 2003. It is a centralized biological and data (consent/clinical/environmental) repository to enable translational genomic research on rare genetic diseases. The BioBank works in partnership with academic and industrial collaborators to develop novel diagnostics and therapeutics to better understand and treat these diseases. This workshop will describe state-of-the-art, web-based informatics core, and the centralized management and infrastructure. Participants can explore this relatively cost-effective mechanism by which individual advocacy organizations can pursue sophisticated, novel research collaborations.

**How Do We Serve Ourselves in the Midst of Serving?**
John Lennon said, “Life is what happens to you while you're busy making other plans.” This workshop provides an opportunity to share and learn different ways to balance taking care of yourself while taking care of family, work, advocacy and life.

**Advocacy in Action**
As relationships between the human service professionals and the people they serve continue to change, consumers remain advocates for their personal and their children's health care. This session will demonstrate how advocacy expands beyond the clinical setting and develops into a voice on the state and federal level.
Workshop Descriptions (continued)

Brazilian Genetic Alliance
In recent years, there has been a positive trend towards grouping together advocacy organizations to better support those with genetic conditions and their families. This session will provide salient features and challenges of building an umbrella organization outside the United States of America. Are we efficient in advocating? Do we maximize our resources?

A Community-Based Approach to Genetics and Health Education: Using Family Health History to Increase Awareness
Genetics, cloning, and DNA are commonplace words in our society. However, not all segments of society are familiar with these words and the impact genetics has, or can have, in their lives. This workshop will examine how two community-based approaches have used family health history to increase awareness about health education. Workshop leaders and participants will work together to explore how these ideas can be incorporated into effective advocacy.

Ensuring the Quality of Genetic Testing
Obtaining accurate and meaningful test results requires ensuring the quality of each step of the genetic testing process. This session will explore ways in which the patient community, government, researchers, clinical laboratories, and health professionals can work together to ensure the quality of genetic testing.

SESSION IV
The Interrelations of Genes, Diseases, and Public Health
Pertinent matters of public health reflect the interrelation of genes, disease manifestations, and multifactorial social and behavioral determinants. We need models of genetics and genomics applications that interweave the individual medicine of genetic variation with public health practice in order to change health at the population level. We will present a model for this integration and then present the epidemic of prominent occurring disorders seen among residents of the Detroit Metropolitan area as one example.

It's in the Genes!
Since BRCA1 and 2 results first appeared in 1996, Hadassah has understood that fear of genetic discrimination might keep individuals from undergoing genetic testing to gain personal health information. An educational model will be presented that can be used by any organization to educate their constituency about the science, ethics and legislative importance of learning about the complex issues of genetics.

Genetic Alliance Information Tools
Learn how to easily find definitive information on a wide variety of genetic conditions. This workshop will teach you how to use Disease InfoSearch, the Genetic Alliance online tool that lets you quickly access expert information from a wide variety of sources. We'll also explore how to use the online Resource Repository, a treasury of best practices, to improve advocacy efforts.

Informed Decision Making and Rare Disorders
Educational materials can help families make informed decisions about management of rare disorders, if the necessary information is included. We will present a draft toolkit designed to help users assess the comprehensiveness of materials. This session will elicit discussion about the toolkit's content and usability for a broad range of disorders.

Increasing Research Through Collaboration
The core of each of our missions is to find a cure. Since this may take a long time, different conditions and different organizations take different roads to achieve their mission. Each step along the research path to a cure holds opportunities for meaningful input from various stakeholders. This workshop will highlight two very different examples of advocacy organizations that are taking the lead, influencing research and thereby creating answers for their members.
SESSION V
How Does Newborn Screening Work?
This session will focus on how the system works with respect to its basic elements. Representatives from the National Newborn Screening and Genetics Resource Center (NNSGRC) and several newborn screening programs will provide information on national screening trends, laboratory and follow-up functions, and related parent/consumer activities. The audience is encouraged to ask questions so that a thorough understanding of newborn screening is obtained.

Hidden Treasures
“Be careful what you ask for – you might get it!” can haunt you as you search technical biomedical data on some specific aspect of your disorder. We will explore some of the often overlooked but wonderfully helpful features that resources like PubMed contain that can help you to work smarter, not harder. Let your tax dollars work for you for a change!

Outreach to Teach
Genetics knowledge and technologies have brought attention to many ethical, legal and social issues. It is imperative that scientists and advocates increase public awareness and appreciation of genetics in our daily lives. This workshop will explain how various organizations are engaged in this public education effort and how your organization can join in.

When Cultural Values Clash
Families from diverse cultural backgrounds may have values and beliefs that lead them to distrust, fear and reject genetic screening. This workshop will address key cultural considerations in planning, implementing and assuring the quality of screening services. Examples of successful models and ways to engage diverse communities will be presented.

Opportunities for Partnerships: Advocacy Groups and Genetic Counselors
Explore opportunities for collaborations between genetic counselors and advocates that can promote and enhance the mission of advocacy organizations. The workshop will include examples of current advocacy organization/ genetic counselor collaborations. Participants will examine case examples of potential collaborations, explore opportunities available through partnering with genetic counselors, and develop strategies that can create such partnerships.

Clinical and Laboratory Issues In Genetic Testing of Rare Hereditary Disorders
Clinical availability of testing for rare disorders is falling behind the needs of patients and families. A national effort to make all rare disorder testing available through clinical laboratories in the U.S. is being made. In this workshop, we will discuss the clinical and laboratory issues around DNA testing for rare disorders that concern both the patient and their medical caregivers. Practical issues involved in developing a rare disorder testing program and the clinical and laboratory implications of custom clinical testing for patients whose mutations have been identified in a research study will be presented.

FINALE
Project DOCC, Delivery of Chronic Care
Project DOCC is an award winning medical education program to teach about the day-to-day lives of individuals and families living with chronic conditions. Project DOCC trains family caregivers to be faculty at their medical centers —parents are the teachers. Since 1994, parents have educated doctors through the three pediatric program components: Grand Rounds Panel Presentations, Home Visits, and Chronic Illness History Interviews.

Project DOCC has included family faculty who live with a variety of genetic disorders, illustrating the challenges of living with these chronic conditions.

Genetic Alliance is proud to present this new focus for Project DOCC: Genetics. Five panelists from families affected by Duchenne Becker Muscular Dystrophy will describe their experiences living with the disease. The purpose of the session is to educate healthcare providers and others about the impact of a chronic illness on family members.
Genetic Alliance 2006 Annual Conference
Sponsor List

Major Underwriting  
Glaxo SmithKline 
March of Dimes

Awards Dinner  
PhRMA

Art of Advocacy Award  
Genomic Health

Art of Industry Award  
BioTechnology Institute

Keynote Speaker  
DC Department of Health

Breakfast Network  
Perlegen Sciences

Poster Session  
American Society of Human Genetics

Leadership in Action  
Genzyme

Research Track  
United Health Care

Online Program  
Kennonsoft

Tote Bags  
Affymetrix

Workshops  
DNA Direct; National Human Genome Research Institute; Polidais, LLC; Biotechnology Industry Organization

Conference Fellows  
National Newborn Screening Program, March of Dimes

Conference materials designed by Melissa Allen Design