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Welcome

Dear Friends,

Twenty-five years is an important anniversary for any organization; it is a milestone of stability, a testament to perseverance. And yet, in this age of accelerating change, longevity does not guarantee relevance, and perseverance is wasted without a commitment to grow and develop. That is why our 25th Anniversary Annual Conference will celebrate the power and promise of innovation.

We live in an age in which innovation abounds. We experience its promise in the vast array of products that we use daily. It influences our travel, health, education, and even entertainment. It must also revolutionize translational research, information, and services.

Our determination to transform our health system is at once communal, corporate, and individual. We will succeed because we will marshal within our community the formidable intuition, creativity, and imagination that sustains true innovation.

Our 25th year is not about us—it is about you. We invite you to reflect on your own personal experience of innovation. Explore how it is that you are an innovator. What dreams do you have for bettering the systems around you? What are you willing to risk to bring your idea to fruition? This weekend, we recognize many who have made innovation an expression of their essential identities. You will recognize the passion for innovation in our presenters, awardees, and all of your colleagues. See yourself in them!

Join us to explore innovation within you and beyond. Let’s celebrate and explore how we can and must transform healthcare together!

Enjoy the meeting,
Genetic Alliance Council and Staff
**THURSDAY, JUNE 23, 2011**

8:00 AM – 5:00 PM  
Genetics Day on the Hill  
ROA Association, Washington DC

7:30 PM – 9:00 PM  
Gene Screen: A Night of Film on Health and Genetics  
Bethesda North Marriott, Salons H-G

**FRIDAY, JUNE 24, 2011**

7:00 AM – 6:00 PM  
Registration  
Lower Level Registration Desk

7:00 AM – 8:00 AM  
Welcome Breakfast  
Salon A-C

8:00 AM – 8:30 AM  
Opening Session: A Charge for Innovation  
Salon A-C

8:30 AM – 6:00 PM  
Daylong Symposium

- Research  
  Innovation: What Is My Responsibility?  
  Salan D

- Organizational Development  
  How Can I Get a Treatment for My Disease?  
  White Flint

- Services  
  Collaborating Across Conditions and Communities  
  Brookside A-B

- Leadership  
  How Do I Increase My Leadership Effectiveness?  
  Glen Echo

12:00 PM – 1:30 PM  
Lunch  
Salon A-C

6:00 PM – 7:00 PM  
Cocktail Reception and Exhibits  
Salon A-C Foyer

7:00 PM – 10:00 PM  
Dinner Debate  
Salon A-C

10:00 PM – 12:00 AM  
After Hours Social  
Forest Glen

**SATURDAY, JUNE 25 CONTINUED**

11:00 AM – 12:30 PM  
Workshops: Session II  
Forest Glen

- Beyond De-Identification: The Care and Feeding of Trust Relationships in Biobanking
- Genetic TMI: Ways to Think about and Use Massive Amounts of Sequence Information
- Should Social Media Be Used as a Means to Reduce Loss to Follow-up for Newborn Screening Programs?
- Approaches to Clinical Decision Support in Genomics: Family Health History as an Exemplar

12:30 PM – 1:30 PM  
Lunch  
Salon A-C

3:00 PM – 5:30 PM  
Workshops: Session III  
Forest Glen

- Genotype-Driven Research Recruitment and the Return of Individual Genetic Results
- Public Health Approach to Rare Disorders
- Emergency Preparedness and Transition Activities within the Regional Collaboratives
- Gene Screen

3:30 PM – 5:30 PM  
Workshops: Session IV  
Brookside B

- Evolving Models of Biobank Governance
- Family Medical Data Sharing and Ethical Norms
- Newborn Screening: Innovative Approaches to Collaboration
- Walking in My Shoes

6:00 PM – 7:00 PM  
Cocktail Reception and Exhibits  
Salon A-C Foyer

**SUNDAY, JUNE 26, 2011**

7:00 AM – 9:00 AM  
Registration  
Lower Level Registration Desk

8:00 AM – 9:00 AM  
Breakfast  
Salon A-C

9:00 AM – 12:00 PM  
Building Better Biobanks: An Interactive Stakeholder Workshop  
Brookside A-B

9:00 AM – 3:00 PM  
Genetic Alliance Registry and Biobank Boot Camp  
Forest Glen

9:00 AM – 3:00 PM  
Leadership Symposium  
Glen Echo

12:00 PM – 1:00 PM  
Lunch  
Salon A-C
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8:00 AM – 8:30 AM  | Opening Session: A Charge for Innovation  | Salan A-C

8:30 AM – 6:00 PM  | Daylong Symposia  |
  - Organizational Development: How Can I Get a Treatment for My Disease?  | White Flint
  - Services: Collaborating Across Conditions and Communities  | Brookside A-B
  - Leadership: How Do I Increase My Leadership Effectiveness?  | Glen Echo

12:00 PM – 1:30 PM  | Lunch  | Salan A-C

6:00 PM – 7:00 PM  | Cocktail Reception and Exhibits  | Salan A-C Foyer

7:00 PM – 10:00 PM  | Dinner Debate  | Salan A-C

10:00 PM – 12:00 AM  | After Hours Social  | Forest Glen

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  - Genetic TMI: Ways to Think about and Use Massive Amounts of Sequence Information  | Brookside A
  - Should Social Media Be Used as a Means to Reduce Loss to Follow-up for Newborn Screening Programs?  | Brookside B
  - Approaches to Clinical Decision Support in Genomics: Family Health History as an Exemplar  | Glen Echo

12:30 PM – 1:30 PM  | Lunch  | Salan A-C

3:30 PM – 5:30 PM  | Workshops: Session III  |
  - Genotype-Driven Research Recruitment and the Return of Individual Genetic Results  | Forest Glen
  - Public Health Approach to Rare Disorders  | Brookside A
  - Emergency Preparedness and Transition Activities within the Regional Collaboratives  | Brookside B
  - Gene Screen  | Glen Echo

3:00 PM – 6:00 PM  | Afternoon Coffee Break  | Salan A-C Foyer

3:30 PM – 5:30 PM  | Workshops: Session IV  |
  - Evolving Models of Biobank Governance  | Forest Glen
  - Family Medical Data Sharing and Ethical Norms  | Brookside A
  - Newborn Screening: Innovative Approaches to Collaboration  | Brookside B
  - Walking in My Shoes  | Glen Echo

6:00 PM – 7:00 PM  | Cocktail Reception and Exhibits  | Salan A-C Foyer

7:00 PM – 10:00 PM  | Annual Awards Dinner  | Salan A-C

10:00 PM – 12:00 AM  | After Hours Social  | Forest Glen

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8:00 AM – 9:00 AM  | Breakfast  | Salan A-C

9:00 AM – 12:00 PM  | Building Better Biobanks: An Interactive Stakeholder Workshop  | Brookside A-B

9:00 AM – 3:00 PM  | Genetic Alliance Registry and Biobank Boot Camp  | Forest Glen

9:00 AM – 3:00 PM  | Leadership Symposium  | Glen Echo

12:00 PM – 1:00 PM  | Lunch  | Salan A-C
Innovation: What Is My Responsibility?

Forty years ago, John F. Kennedy made this famous declaration at his Inauguration: "... ask not what your country can do for you - ask what you can do for your country." It is incumbent on us to ask, "What is my responsibility in this quest to accelerate diagnostic and therapy development?"

Innovation. Easy to say. Sounds modern, even trendy: President Obama used the word ten times in his State of the Union address and has launched a couple of programs focused on it since then.

Innovation rides the edge between the selflessness of the Kennedy statement and the competitiveness in Obama’s directive that Americans “out-innovate” everyone else. This year we will take a deep dive into this space, and ask, “How is it my responsibility to live in dynamic tension with these two poles? How can I liberate energy in systems bound in one direction or the other, to accelerate translational research and implementation science?”

Steve Jobs said, “Innovation has nothing to do with how many R&D dollars you have . . . It’s not about money. It’s about the people you have, how you’re led, and how much you get it.” We get it. We need to get it, we need to lead. Join us if you want to take this leap together.

We’ve all been in meetings and conversations where the problem is “them.” We come to the resolution together that we don’t have the diagnostics and treatments we need because [fill in the blank: companies, academics, regulators, investors, the public, patients, etc.] don’t do their part, are greedy, are selfish, have the wrong motivations . . . It’s time to get over this and get to work. This requires that we are each responsible for the whole, and we step into each other’s roles. In this workshop, we will roll up our sleeves and create cooperative teams that will develop viable solutions.

Check out the agenda and become part of it.

FRIDAY, JUNE 24, 2011

7:00 AM – 6:00 PM Registration
7:30 AM – 8:00 AM Welcome Breakfast
8:00 AM – 8:30 AM Opening Session: A Charge for Innovation
8:30 AM – 6:00 PM Daylong Symposium

RESEARCH DAYLONG SYMPOSIUM


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8:30 AM Welcome and Framing the Day
   Stephen Friend, Sage Bionetworks
   Sharon Terry, Genetic Alliance

8:45 AM How to Fundamentally Change Drug Discovery: Sharing Data and Arch2POCM
   Stephen Friend, Sage Bionetworks

9:15 AM Data Sharing as a Means to a Revolution
   John Wilbanks, Creative Commons

9:30 AM THAT’S MY DATA: A Campaign to Empower the Citizen Scientist
   Sharon Terry, Genetic Alliance

10:00 AM Evidence, Outcomes, and Coverage Decisions for Diagnostics, Treatments and Access
   to Services
   Patrick Terry, Scientia Advisors

10:30 AM Activating Citizen Scientists: Accelerating Health Discoveries Through Participant-driven Science
   Greg Biggers, Genomera

10:45 AM Break

11:00 AM An Experiment in Shifting Incentives
   Scott Sacane, Catalytic IP

11:30 AM Engagement Exercise with Participants
   Consider the difficult questions each speaker posed and then reflect on our usual behavior. How can we:
   • Think beyond our current structures?
   • Freely share data and ideas?
   • See ourselves as citizen, scientist, and patient?
   • Allow our piece of the healthcare enterprise to grow beyond stale legacy systems?
   • Understand that we are THE engineers for innovation and solutions?

12:00 PM Lunch

1:00 PM Workgroups
   Each workgroup will enable stakeholders from the advocacy, research, clinical, and policy communities to innovatively redesign the specific topic area. Facilitators expect participants to relinquish their intellectual property, to let go of the fears that immobilize, and to find the drive that emanates from what truly matters. Then – design the new world on the microcosmic and macro level.

   Possible breakouts – we will go where the energy amasses that day. We’ll decide together as we go.
   • Data sharing to revolutionize therapy development
   • Evidence, outcomes, and coverage decisions
   • Empowering citizen scientists
   • Aligning/shifting incentives
   • Participant/speaker- initiated breakouts

4:00 PM Return and Share Plans

5:30 PM Conclusions, Mandates and Marching Orders

Just as energy is the basis of life itself, and ideas the source of innovation, so is innovation the vital spark of all human change, improvement and progress.
— Ted Levitt

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8:30 AM – 6:00 PM Daylong Symposia

Friday, June 23
9:45 AM How to Help Science Pay More Attention to Your Disease
Aled Edwards, Structural Genomics Consortium
10:00 AM Evidence, Outcomes, and Coverage Decisions for Diagnostics, Treatments and Access to Services
Patrick Terry, Scientia Advisors
10:35 AM Activating Citizen Scientists: Accelerating Health Discoveries Through Participant-driven Science
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ORGANIZATIONAL DEVELOPMENT DAYLONG SYMPOSIUM
How Can I Get a Treatment for My Disease?
Fundamentals of Drug Development for Advocates: A Basic Primer

“In order to change an existing paradigm you do not struggle to try and change the problematic
model. You create a new model and make the old one obsolete.” — Buckminster Fuller

There is no deli line in treatment development. You can’t take a number and wait for someone to call
your disease to the front of the line for a treatment.

Despite the enormous amount of time, money, blood, sweat, and tears that have gone into treatment
development for genetic diseases, only a few hundred have treatments. The successes and the
problems have been described over and over. It is time now to forge the solutions.

Some of the answers will come from retooling drug development as it stands today. Some will come
from changing the paradigm completely.

How have some advocacy organizations successfully moved through the drug development pipeline,
resulting in new treatments for their disease? Some have conducted successful natural history studies,
and many have robust registries and biobanks — how is that possible? How did they make it happen?

In this session we will discuss the fundamentals of drug development for advocacy organizations.
We will hear from experts about the drug development process and how advocacy organizations can
influence it by developing much needed tools and resources. We will examine the drug development
map and show case studies of organizations who are leading the way through gene identification,
diagnostics, disease characterization, clinical endpoints/biomarkers, clinical trials, outreach efforts,
registries, and biobanks.

The day will conclude with each organization developing an action plan to move research forward. Join
us for this unique opportunity to learn about the drug development process and how your organization
can lead the way in developing new treatments for your condition.

11:00 AM Models on the Map
10 minutes each: Describe where you are on the map, describe what you did, what it cost, what
you learned, what you would do different next time, how you would franchise or industrialize it.

Gene and Mutation Identification – Martin Naley, Life Technologies
Diagnostics – Sherri Bale, GeneDx
Clinical Endpoints/Biomarkers – Pat Furlong, Parent Project Muscular Dystrophy
Clinical Trials – Donna Appell, Hermansky-Pudlak Syndrome Network

12:00 PM Lunch

1:00 PM How to Get There from Here: Building the Shared Infrastructure
Nuts and bolts
Outreach – Brian Loew, Inspire
Registries – Liz Horn, Genetic Alliance Registry and BioBank
Biobanks – Suzanne Vernon, CFIDS Association of America

2:00 PM Dive In: Create Your Plan of Attack
Completely interactive — newbies, novices and advanced! The goal is a plan — or at least the
questions that one needs to answer to create a plan. Get it done!

4:30 PM Return and Share Plans and Challenges
Find resources in the room and determine what shared resources and infrastructures
should be created.

5:30 PM Conclusions, Mandates, and Marching Orders

SERVICES DAYLONG SYMPOSIUM
Collaborating Across Conditions and Communities

This year, Genetic Alliance places the family at the center of Services Day by integrating genetics into
larger systems of care. We will step into the shoes of the individuals with a newly diagnosed child
or family member. Then we will walk with them through the experiences of not only responding and
coping to the news of the diagnosis, but also navigating the complexities of healthcare, education,
support, and advocacy within the context of the services and networks available in their communities.
We will build bridges between national policy, regional activities, and community-based programs and
services to brainstorm ways in which the groups can learn from one another to make smart services
more accessible and sustainable.

The day will be framed by Healthy People 2020 and its science-based, 10-year national objectives
for improving the health of all Americans. As we consider together the programs and services
offered on a state and community level, this framework will enable us to weave high impact policy
recommendations from a common language and shared goals. Participants will come away from the
event with concrete action items for how to collaborate and advocate across communities, conditions,
and state lines, prepared to forge the future for services centered on the health and wellbeing of
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**LEADERSHIP DAYLONG SYMPOSIUM**

**How Do I Increase My Leadership Effectiveness?**
Creating a Safe Context for the Full Expression of Passion, Creativity, and Productivity in Our Organizations

We understand the direct connection between leaders and the systems of which they are an expression. As a leader goes, so go their family, team, organization, and community.

Genetic Alliance is committed to innovation in all spheres, and in this, our 25th year, we celebrate the sphere that is you. We offer you the opportunity to explore your own leadership with a particular emphasis on what it means to be a transformational leader.

Our community is full of such leaders. Transformational leaders don’t just achieve their goal; they actually change the mindsets, culture, and practices of those around them, primarily by the example of their own passion and responsibility applied to the tasks at hand.

This year, Genetic Alliance has added new dimensions to its understanding of why openness produces such an innovative culture. It is because we have created a safe and secure environment within which individuals are finding their own expressions of the gifts and talents they have that support the vision and mission of Genetic Alliance.

In this workshop, we will address the personal, organizational, and communal bases of this safety and innovation. When leaders transform themselves with substantive changes in how they understand themselves, their purpose, and their strategies for success, those around them are changed as well.

Our invitation is for you to come prepared for transformational opportunities. Discover how you can take your leadership to new levels and create the space for those around you to do the same.

Gene Early will join you on your journey, along with many others who desire personal transformation.
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<th>Speaker/Organizer</th>
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<td>Welcome and Framing the Day</td>
<td>Joe Valenzano, Exceptional Parent</td>
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<td>Andria Cornell, Genetic Alliance</td>
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<td>8:40</td>
<td>Healthy People 2020</td>
<td>Reem Ghandour, Maternal and Child Health Bureau, HRSA</td>
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<td>9:00</td>
<td>The Significance of the Family Story</td>
<td>Moderator: Margaret Kruesi, American Folklife Center</td>
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<td>A Parent’s Letter Project</td>
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<td>Sarah Wagoner, Children’s National Medical Center</td>
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<td>Putting Policy Issues on the Table</td>
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<td>Ellen Ficklen, Narrative Matters - Health Affairs</td>
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<td>The Healing Art of Storytelling</td>
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<td>Andre Heuer, The Art of Storytelling for the Loft Literary Center and Storyfront:</td>
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<td>A Place to Learn Storytelling</td>
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<td>Break</td>
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<td>11:00</td>
<td>Patient and Family Navigation: Sustainability and Outcomes</td>
<td>Brad Thompson, Mountain States Regional Genetics Collaborative Center</td>
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<td>NCI Patient Navigator Research Program</td>
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<td>Martha Hare, Center to Reduce Cancer Health Disparities, National Cancer Institute</td>
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<td>Individualized Education Program (IEP) Checklist iPhon Application</td>
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<td>Catherine Burzio, Parent Educational Advocacy Training Center (PEATC)</td>
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<td>12:30</td>
<td>Lunch</td>
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<td>Community Collaborations</td>
<td>Vicki Park, University of Tennessee Health Science Center</td>
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<td>Serving Those Who Serve</td>
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<td>Joe Valenzano, Exceptional Parent</td>
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<td>Engaging Stakeholders in Outcomes-Based Collaboration</td>
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<td>Sally Hiner, Region 4 Genetics Collaborative</td>
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<td>3:15</td>
<td>Break</td>
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<td>3:45</td>
<td>Best Outcomes Through the Lens of the Congenital Conditions Program</td>
<td>Alyson Krokosky, Genetic Alliance</td>
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<td>4:05</td>
<td>Policy Outcomes: Incentivizing Communication and Support</td>
<td>Moderator: Jerry Hulick, The Washington Group Special Care Team</td>
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<td>Christy Blakey, Family Voices of Colorado</td>
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<td>Karin Dent, University of Utah Health Sciences Center</td>
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<td>TJ Sutcliffe, Policy Advocate, The Arc</td>
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<td>Outcomes of the Day &amp; Maintaining the Momentum</td>
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**LEADERSHIP DAYLONG SYMPOSIUM**

**How Do I Increase My Leadership Effectiveness?**

Creating a Safe Context for the Full Expression of Passion, Creativity, and Productivity in Our Organizations

We understand the direct connection between leaders and the systems of which they are an expression. As a leader goes, so go their family, team, organization, and community.

Genetic Alliance is committed to innovation in all spheres, and in this, our 25th year, we celebrate the sphere that is you. We offer you the opportunity to explore your own leadership with a particular emphasis on what it means to be a transformational leader.

Our community is full of such leaders. Transformational leaders don’t just achieve their goal; they actually change the mindsets, culture, and practices of those around them, primarily by the example of their own passion and responsibility applied to the tasks at hand.

This year, Genetic Alliance has added new dimensions to its understanding of why openness produces such an innovative culture. It is because we have created a safe and secure environment within which individuals are finding their own expressions of the gifts and talents they have that support the vision and mission of Genetic Alliance.

In this workshop, we will address the personal, organizational, and communal bases of this safety and innovation. When leaders transform themselves with substantive changes in how they understand themselves, their purpose, and their strategies for success, those around them are changed as well.

Our invitation is for you to come prepared for transformational opportunities. Discover how you can take your leadership to new levels and create the space for those around you to do the same.

Gene Early will join you on your journey, along with many others who desire personal transformation.
Workshops: Session I

**Relationships Between Biobanks and Their Specimen Contributors: How Organizational Approach Might Matter**

*Keywords: biobank*

Biobank creators must choose how to frame the relationship between the biobank and its specimen contributors, a decision with enormous impact on the biobank’s work and products. This presentation will describe and compare four models demonstrating a range of perspectives on the proper relationship between biobanks and their specimen contributors: trade secret, population-based, and member-model approaches as well as the Personal Genome Project.

Jean Cadigan, Research Associate in Social Medicine, University of North Carolina School of Medicine

John Conley, William Rand Kenan Jr. Professor of Law, University of North Carolina at Chapel Hill

Wendell Fortson, Post-doctoral Fellow, Center for Genomics and Society, University of North Carolina at Chapel Hill

Dan Vorhaus, Attorney, Robinson Bradshaw & Hinson

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**Beyond “Celebrity Genomics”: The Current Status of Whole Genome Sequencing for Clinical Care**

*Keywords: research, clinical care, genomics, sequencing*

Advances in genome science and technology have provided unparalleled access to the human genome. The ability to sequence the human genome in its entirety (whole genome sequencing) or focus on protein coding regions (whole exome sequencing) holds tremendous potential for clinical care, provoking consideration of how these technologies can be used best. Highlighting examples from research and clinical practice, this session will present scientific concepts and challenges of clinical genome sequencing.

Julie Chevalier Sapp, Genetic Counselor, National Human Genome Research Institute, NIH

Flavia Facie, National Human Genome Research Institute, NIH

Julianne O’Daniel, Clinical Genomics Liaison, Illumina, Inc.

Brian Richards, Proteus Syndrome Foundation

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**Lawsuits and Dried Bloodspots Retention**

*Keywords: newborn screening, research, elsi*

The storage of residual bloodspot samples from newborn screening is an emerging issue in both the United States and Canada. It is increasingly important to understand the public’s evolving, and sometimes differing, perceptions about newborn screening in general compared to storage of samples. This presentation will emphasize how the issue of retention of dried bloodspots must not be discussed separately from the impact of any lawsuits on the goals of newborn screening programs generally.

Denise Avard, Research Director, Centre of Genomics and Policy, McGill University

Bartha Maria Knoppers, Director, Centre of Genomics and Policy, McGill University

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**Accelerating Adoption of Medical Genetics Innovations**

*Keywords: clinical care, innovation, genetic testing, regulation*

Structured as an interactive panel discussion, this workshop will focus on emerging and converging technology platforms, regulatory pathways, and accelerating adoption of high-value tests for both common and rare conditions. Industry, academic genetics laboratory, regulatory, and patient advocacy experts will discuss challenges to and opportunities for creating safe, high quality, and affordable genetic, information-based tests.

Madhuri Hegde, Senior Director, Emory Genetics Laboratory

Thane Kreiner, Executive Director, Center for Science, Technology, and Society

Darren Link, Vice President of Research & Development, Raindance Technologies

Jana Monaco, Patient Advocate, Children’s National Medical Center

Mya Thomae, Founder and CEO, MyRAQA, Inc.

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12:00 PM – 1:30 PM  
Lunch

6:00 PM – 7:00 PM  
Cocktail Reception and Exhibits

7:00 PM – 10:00 PM  
Dinner Debate

We hear the claim over and over: genetics is the magic bullet, personalized medicine will save the day. Is it fact or fiction? Hype or hope? There are no easy answers, but we’ll debate the issues with passion and precision. This witty and knowledgeable panel will tell it like it is. Dinner debates are an enjoyable after-dinner repartee between intelligent and quick-witted experts in the field. Add in audience participation, and the evening is both fun and educational.

Reed Tuckson, United Healthcare (moderator)

Misha Angrist, Duke University

Mary Carmichael, Newsweek

Marc Williams, Intermountain Healthcare

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10:00 PM – 12:00 AM  
After Hours Social

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SATURDAY, JUNE 25, 2011

7:00 AM – 6:00 PM  
Registration

7:30 AM – 8:00 AM  
Morning Walk

8:00 AM – 9:00 AM  
Networking Breakfast

9:00 AM – 10:30 AM  
Workshops: Session I

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10:30 AM – 11:00 AM  
Morning Coffee Break

11:00 AM – 12:30 PM  
Workshops: Session II

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— Woody Allen
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**WORKSHOPS: SESSION II**

- **Beyond De-Identification: The Care and Feeding of Trust Relationships in Biobanking**
  
  The research value of biobanks grows exponentially when participants’ involvement is deep and ongoing — for example, when they are willing to contribute multiple biospecimens, fill out surveys, and allow researchers to contact their physicians over time. De-identification of participants’ contributions has been used to protect their privacy, but it isn’t a guarantee. More importantly, de-identification means that some things that are important to participants – like getting individual research results, or receiving information about the studies they’ve contributed to – can’t be carried out. Science suffers too, as researchers can’t gather additional data. As we move beyond de-identification, what should be the relationship between biobank managers and those who contribute?
  
  Joann Boughman, Executive Vice President, American Society of Human Genetics (moderator)
  Liz Horn, Director, Genetic Alliance Registry and BioBank
  Barbara Koenig, Professor of Biomedical Ethics & Medicine, Mayo Clinic College of Medicine
  P. Pearl O’Rourke, Director of Human Research Affairs, Partners HealthCare Systems
  
  **KEYWORDS: BIODATA, ELSI, RESEARCH**

- **Approaches to Clinical Decision Support in Genomics: Family Health History as an Exemplar**

  Family history remains the single best genomic tool for assessing risk for both common and rare heritable conditions. This session will explore four different approaches to the development of automated risk assessment capabilities that make use of family history information. Issues to be explored include disease selection, risk algorithm development, tool construction, and strategies for validation including determination of utility for improving health outcomes.

  Wendy Cohn, Associate Professor, Clinical Informatics, University of Virginia
  Greg Feero, Senior Advisor to the Director for Genomic Medicine, National Human Genome Research Institute, NIH
  Maki Moussavi, Senior Strategist for Genomics, Cerner Corporation
  Marc Williams, Director, Intermountain Healthcare Clinical Genetics Institute
  
  **KEYWORDS: FAMILY HEALTH HISTORY, CLINICAL CARE, RISK ASSESSMENT**

- **Should Social Media Be Used as a Means to Reduce Loss to Follow-up for Newborn Screening Programs?**

  This workshop will explore whether any resources available through social media sites can be used to decrease the rate of children lost to follow-up in newborn screening programs. It will also examine parental and program perceptions of using social media resources. Through presentation and discussion, participants will be able to comment on social media as it impacts infant and child health and parental communication policies.

  Natasha Bonhomme, Vice President of Strategic Development, Genetic Alliance
  Emily Berry, Program Coordinator, OZ Systems
  Lura Daussat, Program Coordinator, OZ Systems
  
  **KEYWORDS: NEWBORN SCREENING, SOCIAL MEDIA**

**WORKSHOPS: SESSION III**

- **Genotype-Driven Research Recruitment and the Return of Individual Genetic Results**

  This workshop will address three questions: (1) What ethical issues arise during genotype-driven research recruitment? (2) In what situations do participants feel researchers should offer individual genetic research results? (3) What do participants see as the benefits and concerns of receiving individual research results? A fundamental tension exists between avoiding the disclosure of potentially unwanted and uncertain information and avoiding deception when explaining to prospective participants the purpose of the research and why they are eligible.

  Marsha Michie, Postdoctoral Research Fellow, Center for Genomics and Society, University of North Carolina at Chapel Hill
  Emily Namey, Clinical Research Coordinator, Institute for Genome Sciences & Policy, Duke University
  Tracey Braze, Assistant Professor of Pediatrics, Treuman Katz Center for Pediatric Bioethics, University of Washington School of Medicine
  
  **KEYWORDS: RESEARCH, ELSI**

- **Public Health Approach to Rare Disorders**

  The public health system encompasses governments, healthcare providers, and others working to improve population health, but people with rare disorders may feel left out. Presenters will discuss how the Centers for Disease Control and Prevention (CDC), Health Services and Resources Administration, and state health departments work together to assess and improve the health of people with rare disorders, using sickle cell disease and hemophilia as examples.

  Hani Atrash, Director, Division of Blood Disorders, National Center on Birth Defects and Developmental Disabilities, CDC
  Scott Grosse, Associate Director, Health Services Research and Evaluation, Division of Blood Disorders, CDC
  Maxine Hayes, State Health Officer, Washington State Department of Health
  Michele Puryear, Chief, Genetic Services Branch, Maternal and Child Health Bureau, HRSA

  **KEYWORDS: PUBLIC HEALTH, RARE DISEASES**
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  Maxine Hayes, State Health Officer, Washington State Department of Health
  Michele Puryear, Chief, Genetic Services Branch, Maternal and Child Health Bureau, HRSA
Emergency Preparedness and Transition Activities within the Regional Collaboratives

**KEYWORDS:** RARE DISEASES, NEWBORN SCREENING, ELECTRONIC HEALTH RECORDS, INNOVATION

Presenters will discuss tools developed by three HRSA Regional Collaboratives to aid families and providers in emergency preparedness or transition activities. The Region 4 Genetics Collaborative will present information on MyEIF.org, a web-based tool used to summarize and communicate critical personalized information during a medical emergency; the New York-Mid-Atlantic Consortium will discuss Emergency Cards for conditions identified through newborn screening and evaluation of the Minerva Health Record, which can be carried on a flash drive; and the Western States Genetic Services Collaborative will present a portable health record designed for individuals with genetic and metabolic conditions.

Kristi Bentler, Newborn Metabolic Screening Coordinator, University of Minnesota Amplatz Children’s Hospital
Jacquie Stock, Research Associate, Seattle Children’s Hospital
Kathryn Tullis, New York-Mid-Atlantic Consortium Project Coordinator, A.I. duPont Hospital for Children

Gene Screen

**KEYWORDS:** GENETIC CONDITIONS, ADVOCACY, EDUCATION

If you missed Gene Screen on Thursday night, here is your chance to watch and discuss several engaging short films, which explore various issues that affect individuals and families with genetic conditions:

- Me and Antoine B.
- Broken Dreams
- No More Hand-Me-Downs: Research Designed for Children
- Aiden’s Journey: Awareness and Hope
- If I Can’t Dance
- One Little Difference
- Epigenetic Landscapes

WORKSHOPS: SESSION IV

Evolving Models of Biobank Governance

**KEYWORDS:** BIOBANK, ELSI

Ethical, legal, and social issues are at the forefront of biobanking. This session will provide case studies of several biobanking governance models found in for-profit, academic, and nonprofit biobanks. The presentation will also tackle important governance questions: Who has access to data and samples? Who should have access? How are results reported to participants? A lively panel discussion will address issues including data sharing, stewardship, privacy, and transparency in biobanking.

Susan Brown Trinidad, Research Scientist, University of Washington
Kelly Edwards, Associate Professor, University of Washington School of Medicine
Liz Horr, Director, Genetic Alliance Registry and BioBank
Helen Moore, Biospecimen Research Network Program Manager, Office of Biorepositories and Biospecimen Research, National Cancer Institute, NIH
Suzanne Vernon, Scientific Director, CFIDS Association of America

Family Medical Data Sharing and Ethical Norms

**KEYWORDS:** FAMILY HISTORY, ELECTRONIC HEALTH RECORDS, ELSI

Patients will increasingly have access to their medical information in electronic form. The ability to share this data among family members could make construction of essential family medical history data easier and more accurate. Presenters will report on public attitudes regarding such data sharing and lead discussion about how the new possibilities of electronic medical records and genomic information may challenge our current ethical norms.

Vernal Branch, Consumer Advocate
Margaret Foster Riley, Professor, University of Virginia School of Law
Ruth Gaare Bernheim, Chairman, Department of Public Health Sciences, University of Virginia School of Medicine
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Newborn Screening: Innovative Approaches to Collaboration

**KEYWORDS:** NEWBORN SCREENING, SOCIAL MEDIA

The profile of newborn screening is on the rise due to continuous media coverage, which has been both positive and negative. This increased attention has led to and made visible some common challenges throughout the newborn screening community. This roundtable-style session will discuss how these challenges affect existing networks and how to overcome common obstacles through innovative collaborations that maximize existing values.

Natasha Bonhomme, Vice President of Strategic Development, Genetic Alliance
Constanze Coon, Manager, Deloitte Consulting
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“Security is mostly a superstition. It does not exist in nature, nor do the children of men as a whole experience it. Avoiding danger is no safer in the long run than outright exposure. Life is either a daring adventure, or nothing.” — Helen Keller
Walking in My Shoes

KEYWORDS: ADVOCACY, EDUCATION

As personalized medicine becomes reality, it is important to learn from those utilizing genomic information in personal healthcare. This presentation will provide insights from projects collecting consumer stories using a variety of media that illustrate the relevancy of learning from others’ experiences and how individuals’ experiences can help identify areas for systems change. It is essential to capture the stories of those most impacted by this radical transformation in healthcare.

Marcy Brenner, Musician, Writer, Advocate
Jean Jenkins, Nurse Consultant and Cancer Survivor
Alyson Krokosky, Assistant Director of Genetics Resources and Services, Genetic Alliance

Building Better Biobanks: An Interactive Stakeholder Workshop

Building on Saturday’s workshop presentations, participants in this session will work together to define the concrete principles, approaches, and processes that make for trustworthy biobank governance. As the number and range of biobanks continues to grow, questions arise about how they should be managed. Who “owns” the biobank? How are biobank participants included in governance. As the number and range of biobanks continues to grow, questions arise about how they should be managed. Who “owns” the biobank? How are biobank participants included in governance. As the number and range of biobanks continues to grow, questions arise about how they should be managed. Who “owns” the biobank? How are biobank participants included in governance.

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Genetic Alliance Registry and Biobank Boot Camp

This interactive training includes a comprehensive overview of what is needed to establish and maintain a registry or biobank, including best practices for working with advisors, an introduction to questionnaire design, an introduction to sample collection, tools to assess registry vendors, a review of organizational operations and resources, strategies for good governance, and tips for recruitment and retention. The day will conclude with participants developing an action plan for making their registry or biobank a reality. This training is available to leadership of disease advocacy organizations for both common and rare diseases.

Liz Horn, Director, Genetic Alliance Registry and BioBank

Leadership: How Do I Increase My Effectiveness?
Creating a Safe Context for the Full Expression of Passion, Creativity, and Productivity in Our Organization

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This year, Genetic Alliance has added new dimensions to its understanding of why openness produces such an innovative culture. It is because we have created a safe and secure environment within which individuals are finding their own expressions of the gifts and talents they have that support the vision and mission of Genetic Alliance.

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Discovery consists of seeing what everybody has seen and thinking what nobody has thought.

— Albert von Szent-Gyorgi
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Our community is full of such leaders. Transformational leaders don’t just achieve their goal, they actually change the mindsets, culture, and practices of those around them, primarily by the example of their own passion and responsibility applied to the tasks at hand.

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In this workshop, we will address the personal, organizational, and communal bases of this safety and innovation. When leaders transform themselves with substantive changes in how they understand themselves, their purpose, and their strategies for success, those around them are changed as well.

Our invitation is for you to come prepared for transformational opportunities. Discover how you can take your leadership to new levels and create the space for those around you to do the same.

Gene Early will join you on your journey, along with many others who desire personal transformation.

Gene Early
PAYING TRIBUTE TO TRAILBLAZERS IN GENETICS, HEALTH, AND ADVOCACY

2011 Genetic Alliance Annual Awards Dinner
SATURDAY, JUNE 25, 2011 7:00 PM - 10:00 PM

Art of Advocacy Award – Dennis Pollock

The Art of Advocacy Award pays tribute to a visionary advocate who advances research, information, and/or support services to benefit both organizations and health.

In this, our 25th anniversary year, Genetic Alliance honors Dennis Pollock with the annual Art of Advocacy Award. Pollock was a great advocate and leader in the Alpha-1 antitrypsin deficiency community who lost his battle with Alpha-1 on October 4, 2010.

“Dennis was a petite man who walked tall; a quiet man you crowded close to for his gentle wisdom; and a healing presence who would smile, duck his head and speak unvarnished truth,” said Diane Baker, Genetic Alliance Council. “He had a natural ability to open your heart to ideas, reason, and laughter.”

Pollock was a tireless champion within the Alpha-1 community and wore many hats as part of the Alpha-1 Association: peer guide, fundraiser, support group leader, board member, and advocate. The latter was his greatest passion. He stressed to others that “every single person can make a difference” and proved this when he played a critical role in the passage of the Genetic Information Nondiscrimination Act (GINA) of 2008.

Though Pollock was a double lung transplant recipient in 2004, he would jump on a plane to Washington, DC, whenever needed to advocate for legislation affecting Alphas. On one day’s notice, he traveled to DC from Oklahoma, learned quickly about GINA, and marched to Capitol Hill with a heart as big as his state, a steady gaze, and a frank story of living with a genetic disorder.

Pollock trained countless others on how to be effective advocates. “He will always be remembered in the Alpha-1 community as a gentle man, who respectfully listened to others, cared immensely, and strongly advocated for all Alphas and future generations to have access to medical coverage for Alpha-1,” said Cathey Horsak, Director of Community Programs from the Alpha-1 Association who nominated Pollock for the Art of Advocacy Award.

Art of Listening Award – Robin Bennett

The Art of Listening Award celebrates a health professional who goes beyond what is required, taking the time to listen and understand, and contributing to the acceleration of research and treatment for a particular disease.

“The Art of Listening Award celebrates great service to men, women and children affected by genetic conditions,” said Sharon Terry. “I am delighted that in our 25th anniversary year, Robin Bennett, a longtime colleague of Genetic Alliance, stands out as the clear choice for the Art of Listening Award.”

Bennett, MS, CGC, PhD Hon, is Senior Genetic Counselor and Co-Director of the Genetic Medicine Clinic at the University of Washington. In addition to her clinical work, she has been a pioneer in the development of genetic counseling practice guidelines, including developing criteria for pedigree nomenclature that are now the world standard. She has also taught high school, undergraduate, graduate, and medical students about genetics issues.

Furthermore, she gives her time and expertise to advocacy organizations because she values their contributions to science and public policy as well as to the lives of individuals and families with genetic conditions.

“Robin’s listening extends to support groups, colleagues, and aspirants,” said Virginia Sybert, MD, her nominator for this award. “She pays attention both to the text and subtext of the clinic visit, responds to both explicit and implicit needs, respects and values the individual, and honors the contract that we have with our patients to serve them according to their individual agenda as well as our own.”

Founder’s Service Award – Betsy Anderson

The Founder’s Service Award is reserved for very special individuals. It recognizes an individual who has served patients and families deeply, consistently, and over a long period of time in partnership with Genetic Alliance, its sister organizations, and the wider health community.

Genetic Alliance pays tribute to its past and looks forward to the future of genetics and advocacy by honoring Betsy Anderson of Family Voices with the Founder’s Service Award. “Betsy exemplifies the dedication and enthusiasm of Genetic Alliance’s founder,” said Sharon Terry. “Like Joan, she is the mother of a child with a congenital condition. And like Joan, she has used her passion, intelligence, and talent as an advocate and professional to improve the lives of not just her own children, but all individuals and families with special healthcare needs.”

Anderson’s interest in family-professional collaboration is longstanding and well recognized. On the family side, she has three adult children, one of whom was born with spina bifida. Professionally, she directs the Family Voices IMPACT Project, which focuses on maternal and child health policies and programs that promote and improve the health and well-being of all children and families.

She has been active regionally and nationally in areas relating to Bright Futures, healthcare reform, genetics, ethics, Title V, special education, and more. She has written articles for both family magazines and professional journals and has received numerous distinctions, including awards from the Maternal and Child Health Bureau, HRSA; the New England Regional Genetics Group; Children’s Hospital, Boston; and the Federation for Children with Special Needs.

“Genetic Alliance does not offer a Founder’s Service Award every year; it is awarded only to individuals who have served patients and families deeply, consistently, and over a long period of time,” said Joan Weiss. “I am excited and honored that this special woman who has made such immense contributions to our community will receive this award.”

Art of Reporting Award – John Seng

The Art of Reporting Award acknowledges a media professional whose reporting contributes to public awareness and understanding about genetic advancements or advocacy organizations and their impact on real people’s lives.

Genetic Alliance celebrates innovation, as well as dedication and expertise, and honors John Seng, founder and president of Spectrum, with the Art of Reporting Award. With more than 30 years of public relations experience, Seng leads one of the nation’s top healthcare public relations firms, creating innovative campaigns for health and science organizations both large and small. “There is more to his innovation than marketing,” said Sharon Terry, “John embodies the human dimension of the science and the cause.”

What started as a one-time pro bono service for The Progeria Research Foundation (PRF) in 2003 developed into a multi-year partnership to raise awareness of Progeria around the world. Seng receives this year’s Award in recognition of his work with PRF on the “Find the Other 150” campaign, which seeks to identify undiagnosed children around the world with the rare, rapid-aging disease Progeria.

“Not a day goes by that PRF’s Executive Director doesn’t email or speak to someone on the Spectrum team. And while all of Spectrum’s services to PRF are pro bono, PRF is treated like an A-list client,” said Scott Bennis, a member of the PRF board of directors. “It is generous people like John Seng that will get us to a cure for my son and the other children with Progeria.”

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GENETIC ALLIANCE COUNCIL AND STAFF

COUNCIL
Sharon Terry, MA - President
Executive Director, PXE International, Inc.
Diane Baker, MS, CGC - Secretary
Past President, National Society of Genetic Counselors
Kemp Battle - Treasurer
Managing Director, Tucker Capital Corporation
Folklorist and Writer
Greg Biggers
CEO, Genomera
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Vice President of Strategic Development
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Stephen Friend, MD, PhD
President, Sage Bionetworks
Shantanu Gaur
Harvard Medical School Class of 2012 Co-founder, SGL Medical

STAFF
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Assistant Director of Translational Research and Policy
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Maternal and Child Health Program Coordinator
Natasha Bonhomme
Vice President of Strategic Development
Molly Brenner
Executive/Network Coordinator
Rhianna Campbell
Associate Director of Finance and Administration
Amelia Chappelle, MA, MS
Genetics Resources and Services Specialist
Andia Cornell
Advocacy and Health Policy Manager
Vaughn Edelson
Programs Manager
Kate Halbruner
Human Resources and Grants Administrator
Liz Horn, PhD, MBA
Director of Genetic Alliance Registry and BioBank
Alyson Krokosky, MS, CGC
Assistant Director of Genetics Resources and Services
James Lightner
Bookkeeper
Scott McDaniel
Web Projects Director
Tetyana Murza, MES
Assistant Director
Tam Nguyen
Web Technologies Specialist
James O’Leary
Chief Innovation Officer
Mary Peckiconis, MA
Office Manager
Mark Petruniak
New Media Coordinator
Lisa Wise, MA
Chief Operating Officer

ABOUT GENETIC ALLIANCE

Genetic Alliance improves health through the authentic engagement of communities and individuals. In this, our 25th year, we celebrate innovation on our journey toward novel partnerships, connected consumers and smart services.

NOVEL PARTNERSHIPS
Genetic Alliance brings together diverse stakeholders to create novel partnerships in advocacy. Over the past 25 years, Genetic Alliance transformed from a basic advocacy organization to a leading network of key stakeholders determined to transform health through genetics. Today, our network includes more than 1,000 disease advocacy groups and 10,000 organizations that serve some aspect of our national health.

CONNECTED CONSUMERS
Genetic Alliance integrates individual, family, and community perspectives to improve health systems. We engage an array of stakeholders in national and international presentations, webinars, coalition building initiatives, the creation of research repositories, film festivals, listservs, peer-reviewed publications, wikis, multi-day conferences with dedicated sessions, and more. Whether fostering intense, open dialogue between adversaries, convening meetings where disparate stakeholders identify common purpose, or sharing resources typically considered proprietary, we are committed to helping systems identify new solutions and pathways for the common good.

SMART SERVICES
Genetic Alliance revolutionizes access to information to enable translation of research into services and individualized decision-making. We believe that system transformation demands innovation, disruption, and collaboration.

Innovation is the ability to see change as an opportunity, not a threat.
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Newborn Screening Newsletter – This quarterly newsletter provides updates on the advancement of Genetic Alliance newborn screening initiatives, current newborn screening news, and new opportunities to engage in newborn screening dialogues on a community, state, and national level.

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Registry and Biorepository Bulletin – Genetic Alliance BioBank sends a monthly update to keep you informed of developments in the field of registries and biorepositories. This newsletter highlights relevant funding announcements, training opportunities, scientific meetings, and recent updates from the literature.

Weekly Bulletin – This weekly update features upcoming events, partner organizations, calls for proposals, new tools and resources, relevant opportunities in health and genetics, and more.

ENGAGE AND PARTICIPATE

Accelerating Translational Research – Genetic Alliance and Sage Bionetworks are accelerating drug development through community engagement and advocacy leadership in translational research. Our goal is to revolutionize the translational research paradigm through consumer activism. We do this by providing consumers and advocacy leaders with the tools and information needed to empower informed participation in research. Learn more at www.geneticalliance.org/accelerating-research.

Advocates Partnership Program – This program allows for a number of leaders from the advocacy community to attend the annual conferences of national organizations (such as American Society of Human Genetics, American College of Medical Genetics, and the National Society of Genetic Counselors) with partial scholarships that include waived registration fees and, occasionally, a moderate stipend. For more information, visit www.geneticalliance.org/advocates-partnership.

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Baby’s First Test – In September 2011, Baby’s First Test will launch as the nation’s clearinghouse for newborn screening information. As a one-stop shop for recent and expectant parents, health professionals, researchers and the public, Baby’sFirstTest.org will have a dynamic, innovative design and architecture that engages visitors, provides easy access to recent information, and enhances individual knowledge and awareness of key aspects of the newborn screening process and system. Since September 2009, Genetic Alliance has worked with newborn screening stakeholders to integrate all the positive work currently taking place into this new clearinghouse of information.

Trust It or Trash It? – This online tool serves two purposes: to encourage critical thinking as people encounter health information and to add to the existing volume of high quality genetics materials. There are two versions of the tool, one for people who are developing educational materials and one for people assessing the quality of health information. Use the tools now at www.trustitortrash.org.

WikiAdvocacy – A compilation of the wisdom of the advocacy community, WikiAdvocacy contains regular updates from key leaders. It also holds the Interactive Guide to Advocacy, a manual that uses articles, templates, and stories to describe the issues, skills, and other elements of advocacy organizations and their activities. Members of the advocacy community continually add and refine the tips and tools offered through this resource at www.wikiaadvocacy.org.

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EXHIBITORS

AMERICAN SOCIETY OF HUMAN GENETICS (ASHG)
9650 Rockville Pike
Bethesda, MD 20814
Phone: 866.HUM.GENE, Email: society@ashg.org

The American Society of Human Genetics (ASHG) is the primary professional membership organization for human genetics specialists worldwide. ASHG's mission is to share research results through the Annual Meeting and in the American Journal of Human Genetics; provide genetics education resources; and advocate for research funding and scientific policy support. For more information, visit http://www.ashg.org

GENEDX
207 Perry Parkway
Gaithersburg, MD 20877
Phone: 301.519.2100, Email: genedx@genedx.com

GeneDx tests for more than 350 Mendelian disorders using DNA sequencing and deletion/duplication analysis of the associated gene(s). GeneDx also offers oligonucleotide microarray-based testing for chromosomal abnormalities, prenatal diagnosis, and testing for cardiac disorders. Services include mutation analysis, carrier testing, and mutation confirmations.

MSUD FAMILY SUPPORT GROUP
9517 Big Bear Ave
Powell, OH 43065
Phone: 614.389.2738, Email: dbulcher@aol.com

The Maple Syrup Urine Disease Family Support Group is dedicated to providing opportunities for support and personal contact for those with MSUD and their families, distributing information and raising public awareness of MSUD, and strengthening the liaison between families and professionals.

NATIONAL COORDINATING CENTER FOR THE REGIONAL GENETICS AND NEWBORN SCREENING COLLABORATIVES (NCCRC); NEWBORN SCREENING TRANSLATIONAL RESEARCH NETWORK (NBSTRN)
7220 Wisconsin Ave, STE 300
Bethesda, MD 20814
Phone: 301.778.9603, Email: acmg@acmg.net

As part of the Newborn Screening Saves Lives Act, the National Institute for Child Health and Human Development (NICHD) awarded a 5-year contract to the American College of Medical Genetics (ACMG) to create the Newborn Screening Translational Research Network (NBSTRN) in October 2008. The basic goals of the NBSTRN focus on the development of resources that facilitate the ability of researchers to become involved in newborn screening. Key resources include the Virtual Repository of Dried Blood Spots (VRDBS), the Long-Term Follow-Up (LTFU) data sets, an electronic data collection tool for the collection and storage of (LTFU) data, model informed consent modules, and IRB information aimed at assisting new investigators.

OFFICE OF RARE DISEASES RESEARCH (ORDR)
6100 Executive Boulevard
Rockville, MD 20852
Phone: 301.402.4336, Email: ordr@od.nih.gov

Office of Rare Diseases Research (ORDR) was established in 1993 within the Office of the Director of the National Institutes of Health, the federal focal point for biomedical research. ORDR coordinates and supports rare diseases research, responds to research opportunities for rare diseases, and provides information on rare diseases. Public Law 107-286, the Rare Diseases Act of 2002, established the ORDR by statute.

SANFORD RESEARCH - COORDINATION OF RARE DISEASE
2301 E 60th Street N
Sioux Falls, SD 57104
Phone: 605.312.6413, Email: liz.donohue@sanfordhealth.org

CoRDS is a rare disease registry that aims to include all rare diseases. Through the establishment of a central registry of persons with a confirmed diagnosis of any rare disease, the CoRDS registry will help accelerate research by providing a resource for the identification and recruitment of research participants.

THERAPEUTICS FOR RARE & NEGLECTED DISEASES PROGRAM, NIH
6101 Executive Boulevard
Rockville, MD 20852
Phone: 301.627.2536, Email: tmd@nih.gov

Therapeutics for Rare and Neglected Diseases (TRND) is part of a congressionally mandated effort to discover and develop therapies for rare and neglected diseases. NIH Rapid Access to Interventional Development (NIH-RAID) makes available late-stage preclinical resources for therapies for all diseases. Both programs generate data in support of Investigational New Drug Applications (IND) by awarding access to in-house and contract therapy development resources. Regulatory affairs assistance is also available.
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9650 Rockville Pike
Bethesda, MD 20814
Phone: 866.HUM.GENE, Email: society@ashg.org
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Powell, OH 43065
Phone: 614.389.2738, Email: dbulcher@aol.com
The Maple Syrup Urine Disease Family Support Group is dedicated to providing opportunities for support and personal contact for those with MSUD and their families, distributing information and raising public awareness of MSUD, and strengthening the liaison between families and professionals.

NATIONAL COORDINATING CENTER FOR THE REGIONAL GENETICS AND NEWBORN SCREENING COLLABORATIVES (NCCRC); NEWBORN SCREENING TRANSLATIONAL RESEARCH NETWORK (NBSTRN)
7220 Wisconsin Ave, STE 300
Bethesda, MD 20814
Phone: 301.718.9603, Email: acmg@acmg.net
As part of the Newborn Screening Saves Lives Act, the National Institute for Child Health and Human Development (NICHD) awarded a 5-year contract to the American College of Medical Genetics (ACMG) to create the Newborn Screening Translational Research Network (NBSTRN) in October 2008. The basic goals of the NBSTRN focus on the development of resources that facilitate the ability of researchers to become involved in newborn screening. Key resources include the Virtual Repository of Dried Blood Spots (VRDBS), the Long-Term Follow-Up (LTFU) data sets, an electronic data collection tool for the collection and storage of (LTFU) data, model informed consent modules, and IRB information aimed at assisting new investigators.

OFFICE OF RARE DISEASES RESEARCH (ORDR)
6100 Executive Boulevard
Room 3801, MSC 7518
Bethesda, MD 20892
Phone: 301.402.4336, Email: ordr@od.nih.gov
Office of Rare Diseases Research (ORDR) was established in 1993 within the Office of the Director of the National Institutes of Health, the federal focal point for biomedical research. ORDR coordinates and supports rare diseases research, responds to research opportunities for rare diseases, and provides information on rare diseases. Public Law 107-280, the Rare Diseases Act of 2002, established the ORDR by statute.

SANFORD RESEARCH - COORDINATION OF RARE DISEASE
2301 E 60th Street N
Sioux Falls, SD 57104
Phone: 605.312.6413, Email: liz.donohue@sanfordhealth.org
CoRDS is a rare disease registry that aims to include all rare diseases. Through the establishment of a central registry of persons with a confirmed diagnosis of any rare disease, the CoRDS registry will help accelerate research by providing a resource for the identification and recruitment of research participants.

THERAPEUTICS FOR RARE & NEGLECTED DISEASES PROGRAM, NIH
6101 Executive Boulevard
Rockville, MD 20852
Phone: 301.627.2536, Email: tmd@nih.gov
Therapeutics for Rare and Neglected Diseases (TRND) is part of a congressionally mandated effort to discover and develop therapies for rare and neglected diseases. NIH Rapid Access to Interventional Development (NIH-RAID) makes available late-stage preclinical resources for therapies for all diseases. Both programs generate data in support of Investigational New Drug Applications (IND) by awarding access to in-house and contract therapy development resources. Regulatory affairs assistance is also available.
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GeneDx
Genomic Health
Goldbug Strategies, LLC
Life Technologies Corporation
National Human Genome Research Institute, NIH
Novartis
Oracle
Oz Systems
Palo Alto Institute
PTC Therapeutics
Sigma Tau Pharmaceuticals
Spectrum Science Communications
Vertex Pharmaceuticals
United Health Group

SPECIAL THANKS

The Greg Adams Trio

2011 Summer Interns
Catherine Dokurno, Georgetown University
Alexandra Ellerbeck, Wesleyan University
Julie Frank, St. Mary’s College of Maryland
Nina Grossman, Tufts University
Lauren James, Ohio State University Moritz College of Law
Jessica King, University of Virginia
Peter Lyu, University of North Carolina at Chapel Hill
Dana Mariani, Johns Hopkins University
Amber Mills, Centre College
Aileen Palmer, University of Pennsylvania
Courtney Pendray, George Washington University

“Innovation distinguishes between a leader and a follower.”  
— Steve Jobs

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EARLIER THIS WEEK

On Thursday, June 23, 2011 . . .

. . . a cross-section of the genetics community—disease advocacy organizations, health professionals, researchers, industry representatives, families, students, and more—came together as a collective voice for the sixth annual Genetics Day on the Hill. This event gave an unparalleled opportunity to experience the power of advocacy in action. Each year, we select issues to bring to the Hill based upon the input and needs communicated by members of our diverse network. This year, we addressed three important topics:

• Incentivizing translational research through the National Center for Accelerating Translational Science, a new Center at the NIH;
• Protecting the role of the Maternal and Child Health Bureau, Health Resources and Services Administration—particularly the Title V Block Grant program—in supporting our nation’s most vulnerable populations; and
• Providing crucial initiatives through the CDC that support the health and well-being of individuals and families affected by chronic medical conditions and disabilities.

. . . immediately following Genetics Day on the Hill, Genetic Alliance hosted the third annual Gene Screen: A Night of Film and Genetics. The mini-film festival brought together Genetic Alliance conference participants, including genetics and health professionals, advocates, policymakers, and community leaders, as well as filmmakers who have taken on genetics as a subject for exploration and interested members of the DC metro community. Seven short films were screened:

Me and Antoine B.
Broken Dreams
No More Hand-Me-Downs: Research Designed for Children
Aiden’s Journey: Awareness and Hope
If I Can’t Dance
One Little Difference
Epigenetic Landscapes

A question and answer session with available filmmakers took place after the screening, allowing viewers to further their understanding of the films and their genetics and health knowledge.