



National Genetics Education and Consumer Network

Program Updates

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Genetic Alliance

- Formed in 1986 as the Alliance of Genetic Support Groups by Joan Weiss
- Nonprofit health advocacy organization
 - Transforming health by engaging individuals, families, and communities.
 - Engagement and Education



BioTrust



Genes in Life



Expecting Health

Who do we engage?



Individuals, families, and communities



Advocacy organizations and support groups



Health systems at the national and local level

What do we do?

Engagement

How do we do it?

- Focus Groups
- Data Collection
- Project Advisory Groups
- Consumer Feedback

Education

How do we do it?

- Resource Development
- Customizability
- Outreach



How do we measure success?



Advocacy ATLAS



- Increased knowledge about and access to genetic services and support
- Knowledge to make healthy personal and familial decisions around genetics and genetic services
- Improved quality of genetic services



Building a Network of Partnerships and Tools



- National Genetics Education and Consumer Network (NGECN)
- 3 year grant from HRSA
 - June 2012-May 2015
 - ACMG's National Coordinating Center (NCC)
- Goal:
 - Collaborative network of partnerships/tools
 - Improve consumers' access to, knowledge about and quality of genetic services



Program Objectives

1. **Support consumers** and **engage** consumer groups
2. **Improve access** to **information, services,** and **resources**
3. Promote genetics **education** through **new linkages**
4. Disseminate **resources** and services **information**
5. Ensure activities are **consumer directed**



What is the VALUE of Consumer Engagement?

- “Provides perspective on life after diagnosis”
- “Two-way learning experience that benefits overall care”
 - Medical home partnerships
 - Effectiveness of programs often judged by outcomes; or the benefits to the individual and/or family

Value of Consumer Engagement, cont.

- “Having all the ‘players’ at the table in equal partnership is key to optimal outcomes”
- “Helps remedy shortcomings of ‘top-down’ professionally driven model”
- “No one has the same understanding of the importance of advocacy”

Consumer Engagement Across the Regions

- How do we define/ensure full participation of consumers?
- How can we learn from what works in different regions?
- How can we move forward as a group with common goals?



Learning from Shared Experiences



“My daughter, Alana, was born with a chromosomal difference, Tetrasomy 9p. I wrote a story about Alana’s uniqueness to share with her peers. I used it to share her story with her cousins, classmates, and children at her after school program. The story is only 8 slides long, but it packs a huge message about understanding each person’s individual needs.”



The Advocacy ATLAS

Accessible Tools for Leadership and Advocacy Success

www.geneticalliance.org/advocacy-atlas



Educating Around Genetics and Health

Public Education

Goals:

1. Increase public understanding of the importance genetics plays in individual and family health
2. Empower individuals and families to make healthy decisions

Targeted Education

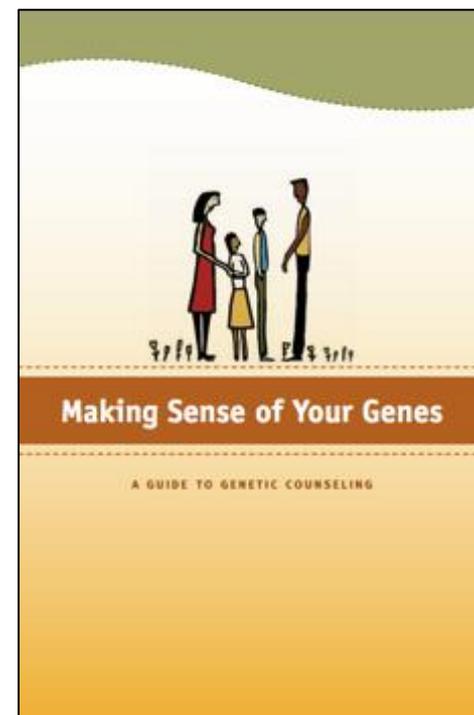
Goals:

1. Alleviate barriers that exist in accessing genetic services for individuals with or at risk for genetic conditions and their families
2. Connect individuals with support
3. Provide educational materials in clinical and public health settings

Educating the Public

- GenesInLife.org
- Genes in Life YouTube playlist
- Family Health History Toolkit (English & Spanish)
- How do I talk to my family about my genetic condition? (English & Spanish)
- Screening and Genetic Testing for Lynch Syndrome
- Making Sense of Your Genes: A Guide to Genetic Counseling (English & Spanish)

Contact: info@genesinlife.org



What is my risk for disease?

Genetic counselors can help you understand your risk for disease and make decisions about genetic testing.

see how



Search

search

Spotlight On Whole Genome Sequencing

What is whole genome sequencing? How is it used, and how does it apply to you? Learn more on the Genes in Life blog, and have your questions answered by our featured experts!



GENES IN LIFE BLOG



ASK THE EXPERTS



Genes in Life Blog

Incidental Findings in Whole Genome Sequencing

December 23, 2013 - 2:53pm

What are incidental findings? Why are they creating such controversy? And how should are standard practices being created?

READ MORE

On Twitter

 **Genes in Life**
@GenesInLife

23 Dec

A new blog post on #incidentalfindings in #WholeGenomeSequencing from @GenesInLife goo.gl/UNWJ4p

Keeping Our Readers Interested

Topical Spotlights In Genetics and Health	Interactive Content
<ul style="list-style-type: none">• Family Health History• Whole Genome Sequencing• Screening throughout the life cycle	<ul style="list-style-type: none">• Genes in Life Blog• Ask the Experts• Twitter @GenesInLife• Family health history outreach

Genes in Life Blog

You can't change your genes, but you can change your behavior. You can take steps to prevent disease, lower your risk, or find problems early when treatments work best.



Meeting Consumers Where They're At



This Holiday Season,
give the gift of
Family Health History!

We'll mail free copies of our
toolkit to share at your
family table.

Request your free booklets today.

Wishing You A Happy Holiday,
The Genes in Life Team



	Family Member
	Organization

Supporting Existing and Novel Programs

Guide to Successful Outreach and Education Programs

www.geneticalliance.org/outreacheducguide

1. Review of literature
2. Catalogue of projects,
collaborating with the RCs
3. Compilation of model
programs



Expanding Outreach and Education

Impact Awards: Building on Successful Outreach and Education Programs to Improve Access to Genetics Services and Support

www.geneticalliance.org/ImpactAwards

- Demonstrate increased impact
- New disease populations
- New geographical area
- 7 awards, up to \$25,000 each
- Awardees will be announced
April 2014



Impact Awards: With and For Consumers

- Impact for individuals and families
- Understanding of the needs of the community
- Stakeholder involvement
- Realistic estimates of impact and limitations
- Strategies fit the preferences of the target audience
- Strong collaboration
- Plans for sustainability, including partnerships and integration into existing services
- Family-centric and culturally sensitive



Improving Systems

- Building upon existing data collection
- Facilitate national level data collection on the needs of consumers
 - Data can be used to demonstrate need for systemic change



Next Steps for NGE CN

- **Partnering with the regions**
 - Disseminate tools developed by regions
 - Develop Learning Collaborative for consumer advocacy workgroups, ACMG 2015
 - Provide support/training for consumers and consumer groups
(grant writing, etc.)



Next Steps for NGEEN, cont.

- **Building upon the network**
 - Facilitate partnerships with and across regions with support and other community-based organizations (Impact Awards)
 - Conduct needs assessment with GPCI, NCC Medical Home Workgroup
 - Work collaboratively with consumers to create resources
- **Amplifying the voices of consumers so that we can improve programs and systems**

Thank You!



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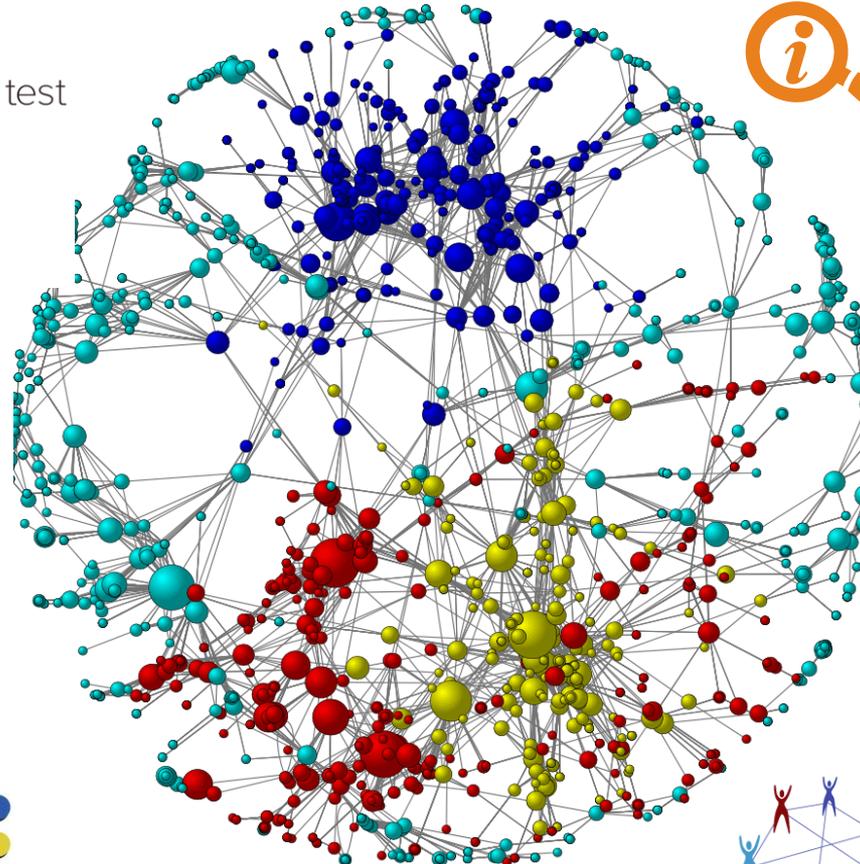


More from Genetic Alliance



Genomics and Medicine: Where Promise Meets Clinical Practice Sharee Terry featured on #GreatChallenges Series TEDMED	Webinar: Resources on Access, Support and Advocacy in the Health and Insurance Worlds TODAY 2-3 PM ET ngv.us/cn	Thanksgiving is Family Health History Day! Resources for Individuals, Families, and Providers
Webinar: Ancestry and Whole Genome Sequencing: Other Privacy Concerns? December 10, 12-3 PM ET	Meet Your Neighbor United Health Foundation United Health Foundation works to improve medical outcomes, expand access to services and support local communities.	Ready, Set, Go! ACA Basics and Outreach & Education Opportunities Watch the Webinar!
November is National Family Caregivers Month! Find Resources and Volunteer Opportunities. CAREGIVER ACTION NETWORK	The Road Ahead for Maternal and Child Health January 25-26, Washington, DC AMCHP Register now for early-bird rate	Reaching and Enrolling the Uninsured Early efforts to implement the Affordable Care Act Robert Wood Johnson Foundation

Weekly Bulletin & Listservs



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www.geneticalliance.org