

Genetic Alliance

A Bilateral Approach to Outreach and Advocacy in Genetics

Strengthening Newborn Screening in North Africa and the Middle East
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Genetic Alliance

Founded in 1986, we are a coalition of more than 600 advocacy organizations representing over 1,000 genetic conditions.

Our mission is to increase the capacity of advocacy organizations so they can achieve their missions and leverage the voices of millions of individuals affected by genetic conditions.

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Where We Focus

- Screening
- Detection
- Diagnosis
- Prognosis
- Treatment Selection
- Monitoring Therapy
- Early Relapse

- Prolonged, or disease-free survival
- Improved Quality of Life
- Avoidance of ineffective and/or toxic treatment
- Reduction in cost

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Genetic Condition Search

Genetic Alliance
Advocacy, Education & Empowerment

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Disease InfoSearch Results

35 Results found for "breast cancer"

EXPAND ALL | CLOSE ALL

Select: Keyword [breast cancer] [v]

breast cancer

Directory Inclusion Guidelines
What is a Genetic Disease?

Support Groups	(10 results)
Clinical Description	(9 results)
Genetic Information	(8 results)
Research	(1 results)
Insurance Issues	(3 results)
Arts & Literature	(3 results)
Other References	(9 results)
Public Databases	(2 results)

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Examples of Member Organizations

- Children's PKU Network
- American Foundation of Thyroid Patients
- Thyroid Foundation of America
- Iron Disorders Institute
- Autism Speaks
- American Diabetes Association
- Sickle Cell Disease Association of America
- FRAXA Research Foundation [Fragile X]
- Children with Spinal Muscular Atrophy
- Chromosome 18 Registry & Research Society

Information about each organization is available in Disease InfoSearch at www.geneticalliance.org

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Resource Repository

This section provides resources for running a nonprofit 501 (c)(3), such as board and staff development, organizational toolkits, templates for doing benchmarks and human resources documents.

Document	Date	Action
Best Practices for Creating Best Practices Author: Genetic Alliance This document outlines how to begin creating your Best Practices document, what to keep in mind while creating your Best Practices, and what to do after you've created your Best Practices.	7/8/10	Download
Conference Planning Presentation Author: Lisa Wiles This includes sample contracts, agreements, timelines, and budgets related to conference planning. It is from the 2004 Genetic Alliance Conference.	1/22/09	Download
"Rising Up" a diverse group of Effective Author: Luke Compton, Executive Director, Faria Institute, Inc. As organizations grow, they need advisors who can challenge them, and support what is truly best for their mission. This is a presentation from the 2008 Genetic Alliance Conference.	7/28/10	Download

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- Genetic Information Nondiscrimination
- Genetic Testing
- Open access to National Institutes of Health funded research
- Newborn Screening Tests
- Stem Cell Research

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Advocacy

Advocacy is an umbrella term for organized action related to a particular set of issues.

Outreach

Outreach is an effort by an organization or group to connect its ideas or practices to the efforts of a specific audience or the general public.

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How do advocacy and outreach relate to newborn screening?

Translation
↓
Communication
↓
Engagement
↓
Understanding

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How do we create a system that encourages empowerment through advocacy and outreach?

By engaging both the grasstops and the grassroots



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Approach #1: Engaging the Grasstops

Establish the Genetic Alliance of North Africa and the Middle East (GANAME)

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Established in 2001 to promote research, technologies, genetic services, and access to information, which alleviate the burden of genetic disease for patients, families, and communities.

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Members

- Australasian Alliance of Genetic Support Groups
- Brazilian Genetic Alliance
- Dutch Genetic Alliance
- European Genetic Alliance
- Genetic Alliance
- Genetic Interest Group (UK)
- Indian Genetic Alliance
- Japanese Genetic Alliance
- South American Genetic Alliance

- Other representatives without coalition organization:
 - China - (Chinese Genetic Alliance in formation)
 - South Africa
 - Russia

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GANAME

Goals:

- Act as a voice for patients, families, and communities living with genetic conditions in North Africa and the Middle East to policy makers, industry, research, and media
- Compile and create culturally competent, relevant means of education
- Serve as a representative at the international table

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GANAME

Needs:

- Unifying leadership
- Funding source
- Home base
- Diverse members and supporters throughout North Africa and the Middle East

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Approach #2: Engaging the Grassroots

Develop a system of Health Promoters



Health Promoters

- Come from the community in which they work
- Are defined by their active stance within the community and health care setting
- Are well trained and expected to perform health promotion, education, and service delivery within a limited scope
- Respond creatively to local and national realities
- Use “popular education” in their work

<http://community.gorge.net/ncs/background/promoters.htm>



Health Promoters in North Africa and the Middle East

Goals:

- Disseminate culturally competent, community-tailored information concerning issues and/or programs
- Increase awareness and understanding for individuals and communities
- Provide accessibility to complicated or daunting matters
- Reach a wider audience in rural and urban populations in a more personalized fashion

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Health Promoters in North Africa and the Middle East

Needs:

- Organizing Body: GANAME, individual governments, or combination?
- Funding
- Recruiting
- Training and Materials
- Method of Evaluation and Follow-Up

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Conclusion:

Provide health care, services, information, and support to three-thirds of the population.

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Genetic Alliance

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