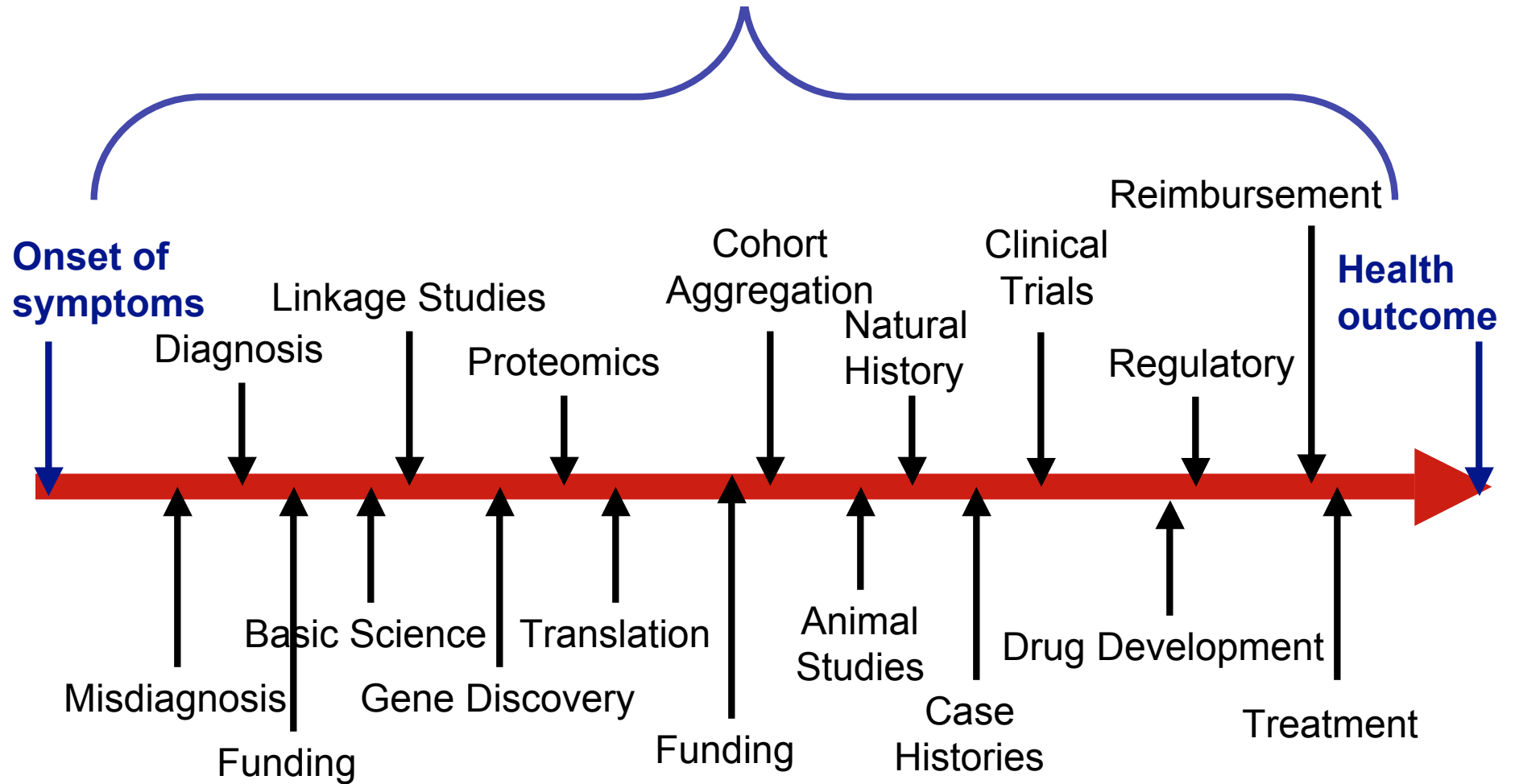




Genetic Alliance

Sharon F. Terry, President & CEO
www.geneticalliance.org

Perspective → Vision



International Organization of Glutaric Acidemia • International Patient Advocacy Association •
 International Rett Syndrome Association • International Society for Mannosidosis and Related
 Diseases • International Tremor Foundation • Intestinal Multiple Polyposis and Colorectal
 Cancer Foundation • Iron Disorders Institute • Johns Hopkins University-Center for Med.
 Genetics • Joubert Syndrome Foundation • Kaiser Permanente - Dept of Genetics •
 Kids with Heart • National Association for Children's Least Disorders • Klinefelter Syndrome
 and Associates • Lippa Tenauna Support Group • Phelan-Smith Syndrome Group • Langer-Giedion
 Syndrome Association • Late Onset Tay-Sachs Foundation • Let's Face It • Little People of
 America • L.I. Program in Regional Genetics & Sickle Cell • Lowe Syndrome Association, Inc.
 • Lutheran General Children's Health Resource Center • MAGIC Foundation for Children's
 Growth • March of Dimes Birth Defects Foundation • Massachusetts Down Syndrome Congress
 • Medical College of Wisconsin • Jersey Medical Airlift • Michigan State University • Mid-
 Atlantic Regional Human Genetics Network • Möbius "Warriors" International • Mommies
 Enduring Neonatal Death • Montgomery Heart Foundation for Cardiomyopathy • Mountain
 States Regional Genetics Services Network • MSL Help • Multiple Sclerosis Association of
 America • MUMS National Parent-to-Parent Network • Mycosis Fungoides Foundation •
 Myotubular Myopathy Resource Group • Myriad Genetic Laboratories • Neuro Lensy Network •
 National Alliance for the Deafblind • National Apoptosis Research Foundation • National
 Association for Pseudoxanthoma Elasticum • National Ataxia Foundation • National Center for
 Chromosome Inversions • National Center for Education in Maternal & Child Health • National
 Coalition for Cancer Survivorship • National Coalition for PKU & Allied Disorders •
 Y-ME National Breast Cancer •

25 Million Affected Individuals

National Deaf Education Network and Clearinghouse • National Down Syndrome Congress •
 National Down Syndrome Society • National Foundation for Ectodermal Dysplasias • National
 Foundation for Facial Reconstruction • National Foundation for Jewish Genetic Diseases •
 National Fragile X Foundation • National Gaucher Foundation • National Genealogical Society
 • National Healthy Mothers, Healthy Babies Coalition • National Hemophilia Foundation •
 National Incontinentia Pigmenti Foundation • National Intellectual Disability Network • National
 Marden-Walker Organization • National Marfan Foundation • National MFL Society • National
 Neurofibromatosis Foundation • National Niemann-Pick Disease Foundation • National Org. for
 Albinism and Hypopigmentation • • National Parent Network on Disabilities • National Parent
 to Parent Support & Information System • National Psoriasis Foundation • National Society of
 Genetic Counselors • National Tay-Sachs & Related Diseases Association • National Tuberosus
 Sclerosis Association • National Urea Cycle Disorders Foundation • National Vitiligo
 Foundation • Nebraska Newborn Screening Genetics • Nephrogenic Diabetes Insipidus
 Foundation • New Jersey Self Help Clearinghouse • NF and Neurogenetics Clinic, MGH •
 Neurofibromatosis Inc. • Neurogenetics Clinic • NKH International Family Network • NYU
 Medical Center - Human Genetics Prgm. • Office of Rare Diseases, NIH • Organic Acidemia
 Association • Oogenesis Imperfecta Foundation • Ovarian Cancer National Alliance •
 Oxalosis and Hyperoxaluria Foundation • Pacific Northwest Regional Genetics Group • Pacific
 Southwes. Regional Genetics Network • Parent Assistance & Connection to a Syndrome •
 Parents and Researchers Interested in Smith-Magenis Syndrome – PRISMS • Parents Helping
 Parents • Parents of Galactosemic Children, Inc. • Ped. Adolescent Gastroesophageal Reflux
 Assoc. • VHL Family Alliance • Virginia Breast Cancer Foundation • Vision World Wide •

All 50 States & International



Pediatric Associates • Pediatric Neurotransmitter Disease Association • Periodic Paralysis
 Association • Peter's Anomaly Online Support Group • PhRMA • Pierre Robin Network • Pilot
 Parent Partnerships • Polycystic Kidney Research Foundation • Prader-Willi Syndrome
 Association • Progressive Osseous Heteroplasia Association • Project DOCC--Delivery of
 Chronic Care • Proteus Syndrome Foundation • Public Response Initiative in Medicine & Research •
 PXE International • Research!America • Restless Legs Syndrome Foundation • Rockford
 Memorial Hospital • Rubinstein-Taybi Parent Group USA • Share and Care Cockayne
 Syndrome Network • Shwachman-Diamond Syndrome International • Sickle Cell Association,
 TX Gulf Coast • Sickle Cell Disease Association of America, East NC • Sjögren Syndrome
 Foundation • SmithKline Beecham Society for Albinism Syndrome Families • Scaps Syndrome
 Support Association • Southeastern Regional Genetics Group • Special Needs Advocate for
 Parents • Spina Bifida Assoc. of Lancaster County • St. Joseph Perinatal Center • Stickler
 Involved People • Sturge-Weber Foundation • Sudden Arrhythmia Death Syndromes
 Foundation • Support Organization for Trisomy 18, 13 and Related Disorders • Tennessee
 Department of Health • Texas Department of Health • Texas Neuromatosis Foundation •
 Texas Regional Genetics Network • The ARC • The Noonan Syndrome Support Group • The
 Prune Belly Syndrome Network • The Queen's Medical Center • Thomas Jefferson University
 Hospital • Tourette Syndrome Association • Treacher Collins Foundation • Trisomy 9
 International Parent Support • Turner's Syndrome Society of the US • Tyler for Life Foundation
 • United Leukodystrophy Foundation • University of Arkansas for Medical Sciences •
 University of Michigan Pediatric Genetics • University of California Health Science Center -
 Department of Pediatrics • Valley Children's Hospital • Velo-Cardio-Facial Syndrome
 Education Foundation • Velo-Cardio-Facial Syndrome Research Institute

Largest Provider of Genetic Services



Examples of Partnerships

**Ad-hoc Committee for Consumer Issues, The American Society of Human Genetics
Advisory Committee on Informed Consent, Centers for Disease Control, Atlanta, GA
American Academy of Dermatology, Consumer representative, Women's Dermatology Committee
American Association for the Advancement of Science
American College of Medical Genetics
American Society of Human Genetics Information and Education Committee
American Society of Matrix Biology Board of Directors
Aneurysm Outreach Inc., Professional Advisory Board
Association for Research in Vision and Ophthalmology
Autosomal Recessive Polycystic Kidney Disease Alliance, Professional Advisory Board
Biotechnology Institute, Board of Directors
Center for Biologics Evaluation and Research Advisory Committee, FDA
Coalition of Advocates for Research on the Eye (CARE)
Coalition of Heritable Disorders of Connective Tissue
Coalition of Patient Advocates for Skin Disease Research
Ethical, Legal and Social Issues Research Advisors, NIH
Genetic Services Research Advisory Board, HRSA
Genetics and Public Policy Center, Johns Hopkins University, Advisory Board
International Genetic Alliance
National Human Genome Research Institute, Liaison to the Advisory Council
National Institute of Arthritis Musculoskeletal and Skin Diseases Council, NIH
Office of Rare Diseases, NIH, Rare Diseases Clinical Research Network, Advisor
PXE France, Scientific Council
Rare Disease Testing Working Group – Office of Rare Diseases, NIH and CDC
Representative to the Research Council, American Academy of Dermatology
Society of Investigative Dermatology Government Liaison Committee**

Government Partnerships

21st Century Medicine Coalition

Ad-hoc Committee for Consumer Issues, The American Society of Human Genetics

Advisory Committee on Informed Consent, Centers for Disease Control, Atlanta, GA

American Association for the Advancement of Science

American College of Medical Genetics

American Society of Human Genetics Information and Education Committee

American Society of Human Genetics Board of Directors

Aneurysm Outreach Inc., Professional Advisory Board

Association for Research in Vision and Ophthalmology

Autosomal Recessive Polycystic Kidney Disease Alliance, Professional Advisory Board

Biotechnology Institute, Board of Directors

Center for Biologics Evaluation and Research Advisory Committee, FDA

Coalition of Advocates for Research on the Eye (CARE)

Coalition of Heritable Disorders of Connective Tissue

Coalition of Patient Advocates for Skin Disease Research

Ethical, Legal and Social Issues Research Advisors, NCI/NIH

Genetic Services Research Advisory Board, HHS

Genetics and Public Policy Center, Johns Hopkins University, Advisory Board

IOM Roundtable on Translational Research

International Genetic Alliance

National Human Genome Research Institute, Liaison to the Advisory Council

National Institute of Arthritis Musculoskeletal and Skin Diseases Council, NIH

Office of Rare Diseases, NIH, Rare Diseases Clinical Research Network, Advisor

Rare Disease Testing Working Group – Office of Rare Diseases, NIH and CDC

Representative to the Research Council, American Academy of Dermatology

Society of Investigative Dermatology Government Liaison Committee

Careful Regulation
Patient Safety
But
Remove Obstacles
Advance Research



Professional Society Partnerships

21st Century Medicine Coalition

Ad-hoc Committee for Consumer Issues, The American Society of Human Genetics

Advisory Committee on Informed Consent, Centers for Disease Control, Atlanta, GA

American Academy of Dermatology, Consumer representative, Women's Dermatology Committee

American Association for the Advancement of Science

American College of Medical Genetics

American Society of Human Genetics

American Society of Matrix Biology Board of Directors

Aneurysm Outreach Inc., Professional Advisory Board

Association for Research in Vision and Ophthalmology

Autosomal Recessive Polycystic Kidney Disease Alliance, Professional Advisory Board

Biotechnology Institute, Board of Directors

Center for Biologics Evaluation and Research Advisory Committee, FDA

Coalition of Advocates for Research on the Eye (CARE)

Coalition of Heritable Disorders of Connective Tissue

Coalition of Patient Advocates for Skin Disease Research

Ethical, Legal and Social Issues Research Advisors, NIH

Genetics and Public Policy Center, Johns Hopkins University, Advisory Board

International Genetic Alliance

National Human Genome Research Institute, Liaison to the Advisory Council

National Coalition for Health Professional Education in Genetics (NCHPEG)

Office of Rare Diseases, NIH, Rare Diseases Clinical Research Network, Advisor

Rare Disease Testing Working Group – Office of Rare Diseases, NIH and CDC

Representative to the Research Council, American Academy of Dermatology

Society of Investigative Dermatology Government Liaison Committee

Provider Education for Early Adoption of New Technologies and Treatments



NGO Partnerships

21st Century Medicine Coalition

Ad-hoc Committee for Consumer Issues, The American Society of Human Genetics
Advisory Committee on Informed Consent, Centers for Disease Control, Atlanta, GA
American Academy of Dermatology, Consumer representative, Women's Dermatology Committee
American Association for the Advancement of Science

American College of Medical Genetics

American Society of Human Genetics Information and Education Committee

American Society of Human Genetics Board of Directors

Aneurysm Outreach Inc., Professional Advisory Board

Association for Research in Vision and Ophthalmology

Autosomal Recessive Polycystic Kidney Disease Alliance, Professional Advisory Board

Biotechnology Institute, Board of Directors

Center for Biologics Evaluation and Research Advisory Committee, FDA

Coalition of Advocates for Research on the Eye (CARE)

Coalition of Heritable Disorder of Connective Tissue

Coalition of Patient Advocates for Skin Disease Research

Ethical, Legal and Social Issues Research Advisors, NIH

Genetic Service Research Advisory Panel, HRSA

Genetics and Public Policy Center, Johns Hopkins University, Advisory Board

IOM Roundtable on Translational Research

International Genetic Alliance

National Human Genome Research Institute, Liaison to the Advisory Council

National Institute of Arthritis Musculoskeletal and Skin Diseases Council, NIH

Office of Rare Diseases, NIH, Rare Diseases Clinical Research Network, Advisor

Rare Disease Testing Working Group – Office of Rare Diseases, NIH and CDC

Representative to the Research Council, American Academy of Dermatology

Society of Investigative Dermatology Government Liaison Committee

**Partnerships to
Leverage
Each Other's Resources
for Common Agenda**

What Matters?

Improved Health Outcome

Diagnostics

Medicines

**Prevention
Strategy**

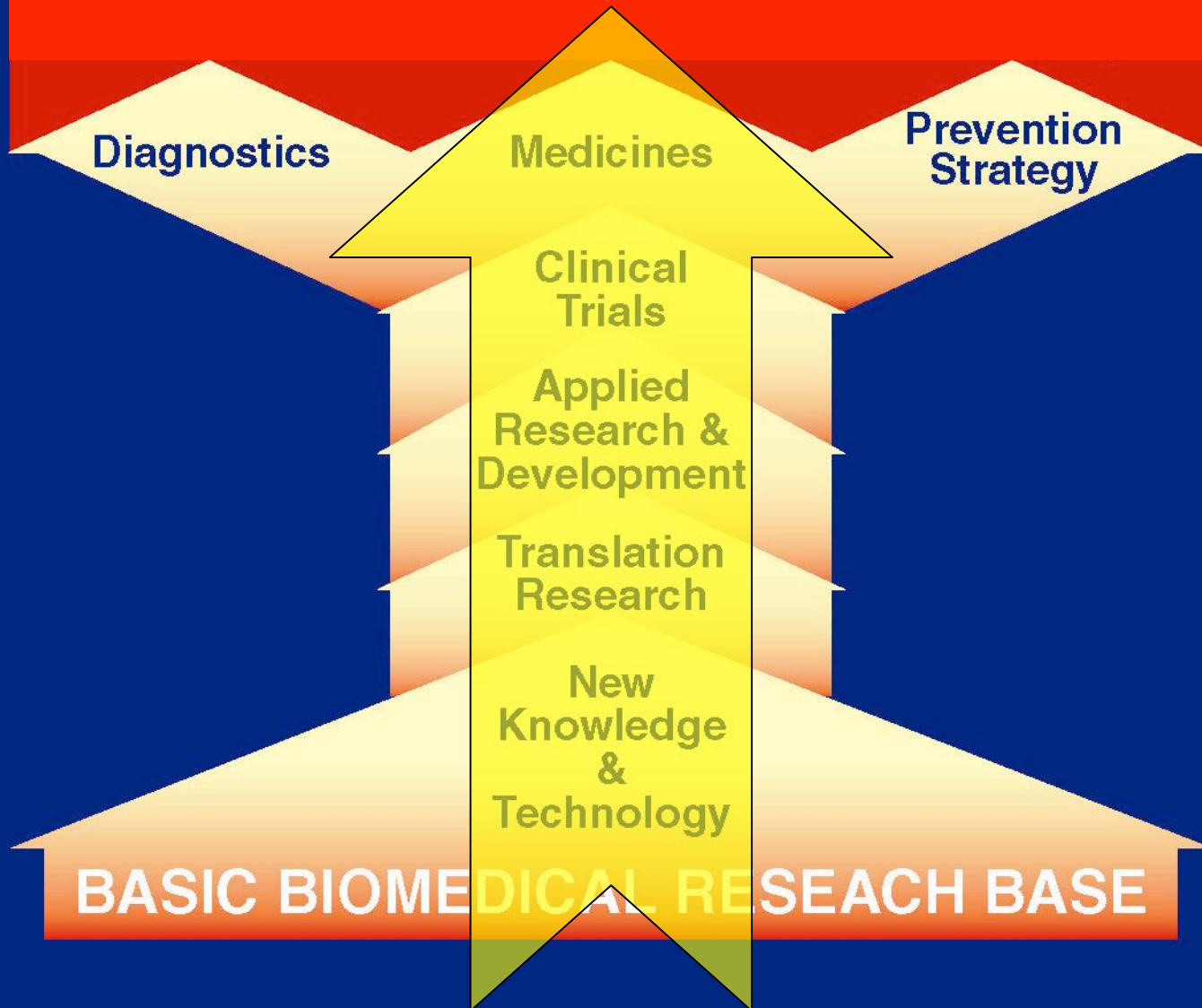
**Clinical
Trials**

**Applied
Research &
Development**

**Translation
Research**

**New
Knowledge
&
Technology**

BASIC BIOMEDICAL RESEARCH BASE



**How do we
transform the
paradigm - beyond
membership to
network?**

Network - dissemination, and resource sharing

SNA

File Edit View

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Drawing Metrics

Select metric

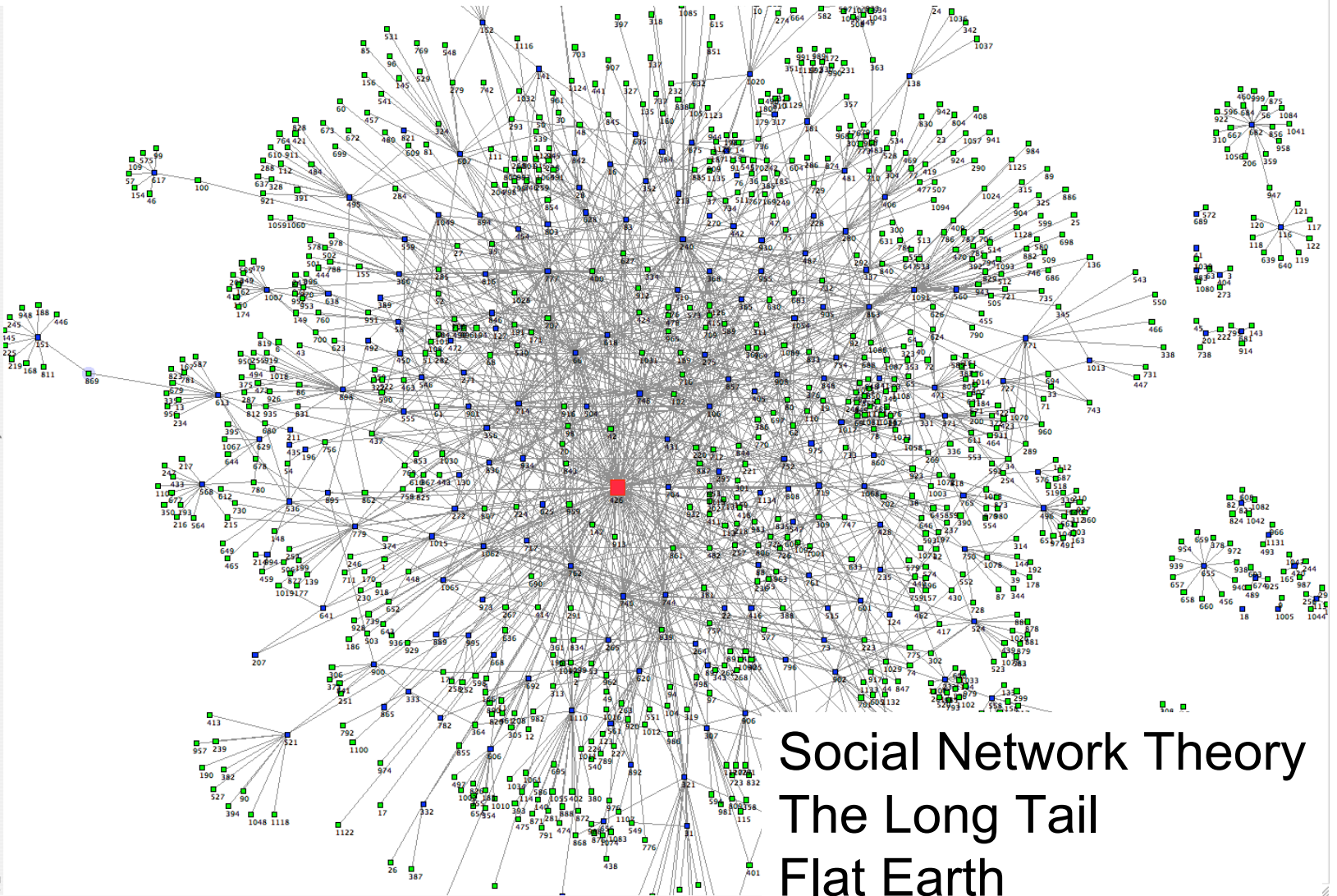
- Awareness
- Connector
- Influence
- Integration**
- Opportunity
- Link similarity
- Key bridges

Run

Results

426	16883
863	3836
240	3658
777	3545
66	3521
106	2668
762	2574
740	2374
714	2263
406	2177
618	1593
83	1552
1062	1529
748	1526
42	1260
744	1246
719	893
555	821
58	654
1065	631
428	555
431	536
141	530
181	485
35	475
450	475
704	473
1049	459
368	446
68	442
1110	384
1068	378
61	373
892	369
1000	260

Save last result... Clear



Social Network Theory
The Long Tail
Flat Earth
Wisdom of Crowds



National Consumer Center
for Genetics Resources and Services

Resources

Phone and in-person guidance

Interactive Guide to Advocacy

MemberForum

Listservs

Website

G. Advocacy

Weekly Bulletin

Policy Bulletin

Guide to Understanding Genetics

Strategies for Success

Annual Conference

Institute for Advocacy

Advocates Partnership Program

Resource Repository

Disease InfoSearch



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Tools

Disease InfoSearch

What is a Genetic Disease?
Disease InfoSearch Inclusion
Guidelines

Resource Repository

Interactive Guide to
Advocacy

Guide to Understanding
Genetics

Family Health History

ATCG

Subscribe to podcasts

Join Listservs

Disease InfoSearch

Select Alphabetical

A B C D E F G H I J K L
M N O P Q R S T U V W X
Y Z

Bardet-Biedel syndrome

Disease InfoSearch

Are you, or someone you know, affected by a genetic disease? Search with the **Disease InfoSearch** box at the left to learn more about the disease.

Are you looking for a genetic advocacy group for a patient or for your own family? Search using the **Organization Search** at the left to find an advocacy group.

Are you interested in learning about a specific genetic condition or genetic conditions in general? **Learn more about what is a Genetic Disease here.**

Within Disease InfoSearch you will find:

- ... advocacy support groups related to specific genetic conditions
- ... information about the clinical features of a wide number of genetic conditions
- ... updates on management, treatment, and more.

This information is provided to you by the advocacy organizations* which form Genetic Alliance. These advocacy organizations provide the tools you may need to cope day to day, find solutions, obtain services, and heal. Our members know first-hand what it means to be faced with a diagnosis and need accurate information. They are highly motivated to keep this information up-to-date and accessible and to share it with you.

*Organizations that are included in Disease InfoSearch meet our **Directory Inclusion Guidelines.**



Disease InfoSearch Results

24 Results found for: Cystic Fibrosis

Links provided by disease-specific organizations.

EXPAND ALL | CLOSE ALL

▼ Support Groups

(7 results)

▶ **Chicago Center for Jewish Genetic Disorders** (last updated on 9/27/04)

<http://www.jewishgeneticscenter.org>

The Center is dedicated to gathering and disseminating knowledge about Jewish genetic disorders. Its mission is to educate and serve health care professionals, clergy and the Jewish community.

▶ **Cochrane Collaboration** (last updated on 5/30/07)

<http://www.liv.ac.uk/cfgd>

A non-profit making international network of health care professionals, researchers and consumers, we prepare, maintain and distribute systematic reviews of randomised control trials of intervent

▶ **Cystic Fibrosis Foundation** (last updated on 1/18/07)

<http://www.cff.org>

Our mission is to improve the quality of life of individuals with CF and to find a cure or control for this disease.

▶ **Cystic Fibrosis Research, Inc.** (last updated on 9/27/04)

<http://www.cfri.org>

To fund cystic fibrosis research and offer education and support to those with cystic fibrosis and their families.

▶ **Jewish Genetic Disease Consortium** (last updated on 2/05/07)

<http://www.JewishGeneticDiseases.org>

The JGDC was created as a means by which a number of smaller, individual organizations could join together to heighten awareness of Jewish genetic diseases with a strong and unified voice. Our strength lies in our ability to pull together resources and experience to best reach our target audience - medical professionals, rabbis, and the Ashkenazi population at large. United, we are better equipped to educate this audience about the existence of carrier screenig which will ultimately prevent the birth of...

▶ **PARENT TO PARENT OF NYS** (last updated on 2/02/07)

<http://www.parenttoparentnys.org/>

- ▶ **PARENT TO PARENT OF NYS** (last updated on 2/02/07)

<http://www.parenttoparentnys.org/>

To connect and support parents of children with special needs.

- ▶ **Parent to Parent of Vermont** (last updated on 4/25/07)

<http://www.partoparvt.org>

Our mission is to nurture and support families whose children have a chronic illness or disability or have been born prematurely; and to encourage the implementation of family-centered policies and practices at all levels.

▼ Clinical Description (2 results)

- ▶ **Cystic Fibrosis Foundation (CFF) - What is CF?** (last updated on 7/16/07)

- ▶ **eMedicine - Cystic Fibrosis**

▼ Treatment (4 results)

- ▶ **Cystic Fibrosis Foundation (CFF) - Find Chapters and Care Centers**

- ▶ **Cystic Fibrosis Foundation (CFF) - Pharmacy Services**

- ▶ **eMedicine - Cystic Fibrosis**

- ▶ **Cystic Fibrosis Foundation (CFF) - Living with CF** (last updated on 7/16/07)

▼ Research (4 results)

- ▶ **Cystic Fibrosis Foundation (CFF) - CF Research in the News** (last updated on 7/16/07)

- ▶ **National Human Genome Research Institute (NHGRI) - Learning About Cystic Fibrosis**

- ▶ **Cystic Fibrosis Foundation (CFF)- The Face of Innovation and Beyond**

- ▶ **Cystic Fibrosis Research, Inc. (CFRI)**

▼ Insurance Issues (3 results)

- ▶ **Cystic Fibrosis Foundation (CFF) - Insurance and Assistance Programs** (last updated on 7/16/07)

- ▶ **Drug Manufacturer Assistance Programs** (last updated on 12/07/06)

- ▶ **Cystic Fibrosis Foundation (CFF) - Patient Assistance Programs** (last updated on 12/07/06)

▼ Insurance Issues (3 results)

▶ [Cystic Fibrosis Foundation \(CFF\) - Insurance and Assistance Programs](#) (last updated on 7/16/07)

▶ [Drug Manufacturer Assistance Programs](#) (last updated on 12/07/06)

▶ [Cystic Fibrosis Foundation \(CFF\) - Patient Assistance Programs](#) (last updated on 12/07/06)

▼ Arts & Literature (2 results)

▶ [Breathing Room - The Art of Living With Cystic Fibrosis](#)

▶ [Blow the House Down: The Story of My Double Lung Transplant, by Charlie Tolchin](#)

▼ General Information (2 results)

▶ [Cystic Fibrosis Foundation \(CFF\) - The Many Faces of Cystic Fibrosis](#) (last updated on 7/16/07)

▶ [Locations of CF Foundation Chapters and Care Centers](#)

See National Library of Medicine Resources for [Cystic Fibrosis](#)

GO

▼ The Latest Research on Cystic Fibrosis

View summaries of articles published in scientific journals that are included in NCBI's PubMed and PubMed Central (PMC) literature databases. PubMed summaries include links to the full text if available on the web; virtually all articles in PMC are freely available in full text. In both PubMed and PMC, the most recent articles appear first. You may want to check back frequently, or sign up for PubMed e-mail updates, as new articles will continually be published.

All Research Categories

- ▶ **PubMed Articles** (27785)
- ▶ **PubMed Reviews** (4171)
- ▶ **PubMed Central Articles** (9331)

Screening and Diagnosis Research

- ▶ **Screening and Diagnosis Literature** (387)
- ▶ **Gene Testing Literature** (6020)

Treatment and Case Studies

- ▶ **Therapies** (10201)
- ▶ **Medication Literature** (3265)
- ▶ **Case Studies** (2234)
- ▶ **Alternative Medicine Literature** (684)

▼ Get Research Updates By E-Mail

Receive the latest research on **Cystic Fibrosis** by e-mail!

Sign up for special searches and e-mail updates with **My NCBI**. You can save searches, set up e-mail alerts for new content, and choose filters that group search results.

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Resource Repository

Indispensable resources for the genetics community.



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- How to Submit
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- Notify Me
- Genetic Alliance

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Results

[Notify Me](#) when future documents match this search request.

Showing 1 through 12 of 12 matches for: Full Text is Cystic Fibrosis:

Author	Year	Title	Publication
New England Public Health Genetics Education Collaborative (NEPHGEC) and Genetic Alliance	2007	Understanding Genetics	Genetics Information
Sharon Terry	2007	Genetics Resources Glossary_Genetics 101	Genetics Information
Sharon Terry	2006	Rare Disease Trial and Drug Date Disclosure and Transparency	Research
Peter Teuber, Candice Teuber, and Debra Lewis	2006	Best Strategies to Obtain Grant Funding for Rare Disease Drug Development	Fundraising
Sharon F. Terry, K Zeitz, M A. Majumder, and Patrick F. Terry	2006	Genomics, Cancer Care and Advocacy	Genetics Information
James C. O'Leary	2006	Why is competency crucial? A Consumer Perspective	Organizational & Community Tools
Bradford Therrell	2006	Status of Newborn Screening Programs in the United States	Genetics Services
Sharon Terry and Abbey Meyers	2006	A Decade of Innovation: Advances in the Treatment of Rare Diseases	Research
Joan Weiss	2006	Genetic Alliance: A History of Advocacy Organizations	Organization Development
Donna Williams	2005	National Newborn Screening and Genetics Resource Center	Genetics Services
National Partnership for Women and Families	2004	Faces of Genetic Discrimination: How Genetic Discrimination Affects Real People	Policy Documents
MT	2004	FIXSM1	Medical/Clinical




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Main Page - WikiAdvocacy

http://wikiadvocacy.org/index.php/Main_Page Google

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WikiADVOCACY

article discussion edit history

Main Page

Welcome to WikiAdvocacy [\[edit\]](#)

WikiAdvocacy is a free, reader-built guide, as well as a community for advocacy. It covers every aspect of founding and growing an advocacy organization—from fundraising to detailed explanations of issues, skills, and the elements of creating a registry and samples repository.

If this is your first time visiting WikiAdvocacy, we recommend reading **About WikiAdvocacy** and **How to Get Started**. We also recommend checking out the **community portal** and **help** pages.

[| About WikiAdvocacy](#) | [How to Get Started](#) | [Community Portal](#) | [Help](#) |

Directory [\[edit\]](#)

Introduction [\[edit\]](#)

[Defining Our Terms -- The Power of Advocacy Organizations -- Why Go There? -- How to Use This Guide --History of Advocacy Organizations and Genetic Alliance -- The Kitchen Table Is a Good Place to Start](#)

Organizational Assessment [\[edit\]](#)

[Determine Goals -- Characterize Condition -- Characterize Resources -- Compare Goals and Resources, with the Characteristics of the Condition](#)

Organization Development [\[edit\]](#)

Organizational Structure [\[edit\]](#)

[Organization's Name -- Governance Board -- Bylaws and Articles -- Tax and Finance -- Finding a Lawyer -- Working with a Lawyer](#)

Resources for Development [\[edit\]](#)

[Helping Your Membership Help Your Group -- Recruiting -- Internet Service Provider -- Maintaining Membership -- Taking Credit Cards on the Web -- Becoming the Organization You Imagine -- Getting Grants -- Donations -- Member Dues -- Events -- Celebrity Spokesperson -- People and Roles -- Harnessing the Resources That Are Hard to Measure](#)

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article discussion edit history

Main Page

Welcome to WikiGenetics

[edit]

WikiGenetics is an open source, user-generated encyclopedia on human genetics for the public. It provides credible and up-to-date information on human genetics.

If this is your first time visiting WikiGenetics, we recommend reading **About WikiGenetics** and **Getting Started**. We also recommend checking out the **community portal** and **help** pages.

| [About WikiGenetics](#) | [Getting Started](#) | [Community Portal](#) | [Help](#) |

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Basic Science

- [Chromosomes in Cells](#)
- [DNA Structure and Gene Expression](#)
- [Genes & Inheritance](#)

Understanding the Human Genome

- [Organization of the Human Genome](#)
- [Human Gene Expression](#)
- [Instability of the Human Genome: Mutation and DNA repair](#)
- [Physical and Transcript Mapping](#)

Understanding Health and Disease

- [Genetic Contributions to Health](#)
- [Identifying Human Disease Genes](#)
- [Genetic Mapping of Single Gene Disorders](#)
- [Genetic Mapping of Complex Conditions](#)
- [Molecular Pathology](#)
- [Cancer Genetics](#)
- [Psychological and Social Implications](#)
- [Patient Stories and Consumer Profiles](#)

Genetic Services

- [Who's Who in Genetics - Professions & Credentials](#)
- [Family History](#)
- [Genetic Counseling](#)
- [Public Health Programs - Newborn Screening](#)
- [How to Find Qualified Services](#)

Genetic Testing

- [How Genetic Tests Work - Molecular \(sequence, target, array\), Biochemical & Cytogenetics](#)

Treatment and Therapies

- [Studying Human Gene Structure, Expression, Control, and Function](#)

Programs

- Access to Credible Genetics Resources Network

(funded by the Centers for Disease Control and Prevention)



- Community Focused Family Health History

(funded by Health Resources and Service Administration)



Community Centered Family Health History

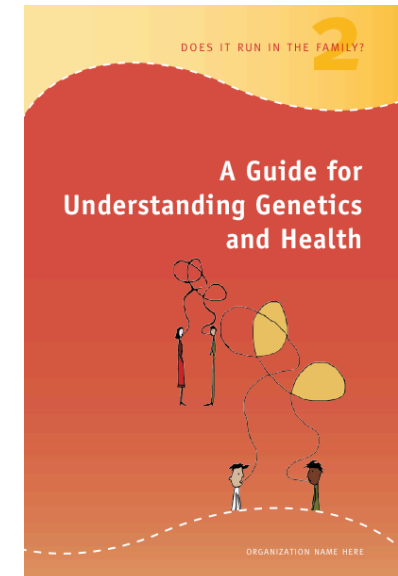
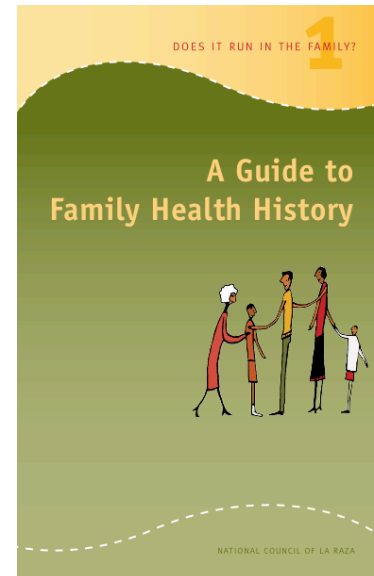
- Family health history
- Folklore
- Genetics



Individuals and families gather health history to make positive health choices.

Does It Run In the Family? Toolkit

- Accessibility
- Community Input
- Sustainability
- Evaluation
- Resource Sharing



Newborn Screening



Two new grants to determine consumer concerns and issues:

- Educational needs
- False positives
- Carrier identification

Policy Issues



**Discrimination in
Insurance and
Employment
Lab Services
Enhanced CLIA
FDA Regulation
Innovation
Access
Medicare Reform
Reimbursement
Newborn Screening
Disease Priorities
Open Access**

Eyes on the Prize: Truth Telling about Genetic Testing

This two-day meeting will bring together a wide variety of stakeholders to examine the current genetic testing landscape and propose solutions to advance the field of quality diagnostics.



Save the Date

Transformational Leadership: Signature Events

Genetics Day on the Hill

- July 10, 2008
- Annual Conference
 - July 11–13, 2008

**We are transforming
ourselves, our issues, our
community**