April 1, 2004

The Honorable J. Dennis Hastert
Speaker
US House of Representatives
Washington, DC  20515

Dear Speaker Hastert,

We urge you to consider and pass the Genetic Information Nondiscrimination Act [S. 1053], to prohibit discrimination on the basis of genetic information with respect to health insurance and employment. This bill was passed unanimously (95-0) in the Senate last year, is strongly supported by the President and currently sits at the desk in the House.

We believe that all genetic information, including family history, deserves strong and enforceable protections against misuse in health insurance and employment. Such safeguards will protect the rights, privacy and confidentiality of the individual and their family.

This is an exciting and hopeful time for genetic medicine. It is imperative, however, that we, the public, can take full advantage of new medical advances that could help prevent disease before it develops. Genetic nondiscrimination legislation will reduce the likelihood of genetic information being misused in health insurance or employment decision-making. Genetic information is merely predictive information. Simply having a positive genetic test does not mean one will develop a disease -- thus this information should not be used to make decisions about insurance coverage or employment.

As biomedical research advances, genetic testing will become a critical tool in the provision of healthcare. As a result, many more people will know about their own genetic makeup, putting them at risk of genetic discrimination. These issues will affect you, your family members, neighbors and colleagues. We urgently request that you pass a genetic nondiscrimination bill that truly protects all of us from that risk now and into the future.

Thank you for all your hard work and efforts on this critical issue. We look forward to continuing to work with you to ensure that the Genetic Information Nondiscrimination Act passes and can be signed by the President this year.

Sincerely,

Sharon F. Terry, MA
President/CEO, Genetic Alliance

cc: Congressman Barton, Congressman Bilirakis, Congressman Boehner, Congressman Delay, Congressman Johnson, Congressman Ney, Congressman Wamp
Affymetrix, Inc. – Santa Clara, CA
American Academy of Pediatrics – Chicago, IL
American Association for the Advancement of Science – Washington, DC
American Association on Mental Retardation – Washington, DC
American Autoimmune Related Diseases Association (AARDA) – Eastpointe, MI
American Cancer Society
American College of Medical Genetics – Bethesda, MD
American College of Preventive Medicine – Washington, DC
American Health Information Management Association (AHIMA) – Washington, DC
American Osteopathic Association – Washington, DC
American Psychiatric Association – Washington, DC
American Society of Clinical Oncology – Alexandria, VA
American Society of Human Genetics – Bethesda, MD
Angioma Alliance – Williamsburg, VA
The Arc of the United States – Washington, DC
Association of American Medical Colleges – Washington, DC
The Association of Women’s Health, Obstetric and Neonatal Nurses – Washington, DC
The Barth Syndrome Foundation, Inc. – Perry, FL
B'nai B'rith International – Washington, DC
BCCNS Life Support Network – Burton, OH
Boston Cure Project for Multiple Sclerosis – Arlington, MA
BPEI Family Network – Pullman, WA
Building Resources Corp. – Minneapolis, MN
CARES Foundation, Inc. – Short Hills, NJ
Caring Voice Coalition – Meridian, ID
Chromosome 18 Registry & Research Society – San Antonio, TX
Citizens for Quality Sickle Cell Care, Inc. – New Britain, CT
The Coalition for Heritable Disorders of Connective Tissue – Washington, DC
Colorectal Cancer Network – Kensington, MD
Commission on Social Action of Reform Judaism – Washington, DC
Cornelia de Lange Syndrome (CdLS) Foundation, Inc. – Avon, CT
Cystic Fibrosis Foundation – Bethesda, MD
The Digestive Disease National Coalition – Washington, DC
Duke University Medical Center – Durham, NC
Dysautonomia Foundation, Inc. – Washington, DC
The Dystonia Medical Research Foundation – Chicago, IL
Ehlers-Danlos National Foundation – Los Angeles, CA
Familial Dysautonomia Hope Foundation – New York, NY
Family Voices – Albuquerque, NM
FORCE: Facing Our Risk of Cancer Empowered – Coral Springs, FL
Foundation for Ichthyosis & Related Skin Types, Inc. – Lansdale, PA
GeneDx, Inc. – Gaithersburg, MD
Genetic Alliance – Washington, DC
Genetic Alliance BioBank – Washington, DC
Global Health Initiatives, Inc. – Potomac, MD
Gluten Intolerance Group of North America – Seattle, WA
Hadassah, the Women's Zionist Organization of America – Washington, DC
The Hemophilia Federation of America – Lafayette, LA
Hemophilia Association of the Capital Area – Falls Church, VA
Hunter's Hope Foundation – Orchard Park, NY
Huntington's Disease Society of America - Michigan Chapter – Detroit, MI
IEEE-USA – Washington, DC
IMDSA – Franklin, TX
Incontinentia Pigmenti International Foundation – Washington, DC
International Myeloma Foundation – North Hollywood, CA
International Rett Syndrome Association – Clinton, MD
International Society for Mannosidosis & Related Diseases – Baltimore, MD
International Society of Nurses in Genetics, Inc. (ISONG) – Newton, IA
IsoDicentric 15 Exchange, Advocacy & Support – Portland, OR
Jewish Women's Coalition on Breast Cancer – Boston, MA
Joanne Silverman Memorial Fund – Chicago, IL
Lymphatic Research Foundation – Roslyn, NY
March of Dimes – White Plains, NY
Mid Atlantic Region, Minority Intervention and Kidney Education (MIKE) Program – Rockville, MD
Mycosis Fungoides Foundation – Birmingham, MI
National Association of Catholic Chaplains – Milwaukee, WI
National Association of Social Workers, Inc. – Washington, DC
National Ataxia Foundation – Minneapolis, MN
National Alopecia Areata Foundation – San Rafael, CA
National Coalition of Health Professional Education in Genetics – Lutherville, MD
National Eczema Association for Science & Education – San Rafael, CA
National Endowment for Alzheimer’s Research (NEAR) – Philadelphia, PA
National Gaucher Foundation – Rockville, MD
National Marfan Foundation – Port Washington, NY
National Organization for Rare Disorders – New Fairfield, CT
National Organization on Fetal Alcohol Syndrome – Washington, DC
National Ovarian Cancer Coalition – Boca Raton, FL
National Psoriasis Foundation – Portland, OR
National Partnership for Women & Families – Washington, DC
National Society of Genetic Counselors – Wallingford, PA
National Tay-Sachs & Allied Diseases Assoc., Inc. (NTSAD) – Boston, MA
National Workrights Institute – Princeton, NJ
NBIA Disorders Association – El Cajon, CA
NERGG, Inc. – Needham, MA
Ovarian Cancer National Alliance – Washington, DC
The Progeria Research Foundation, Inc. – Peabody, MA
Psychiatric Service Dog Society – Arlington, VA
PRISMS, Inc (Parents and Researchers Interested in Smith-Magenis Syndrome) – Dallas TX
Pulmonary Hypertension Association – Silver Spring, MD
Purine Research Society – Bethesda, MD
PXE International, Inc. – Washington, DC
Osteogenesis Imperfecta Foundation – Gaithersburg, MD
Sjogren's Syndrome Foundation – Bethesda, MD
Society for Research in Child Development – Ann Arbor, MI
Society for Women's Health Research – Washington, DC
Society of General Internal Medicine – Washington, DC
Spina Bifida Association of America – Washington, DC
Sturge-Weber Foundation – Mt. Freedom, NJ
Texas Central Hemophilia Association – Dallas, TX
Tourette Syndrome Association – Washington, DC
United Cerebral Palsy – Washington, DC
Urban League of Flint – Flint, MI
USCSFN (United States Costello Syndrome Family Network) – St. Louis, MO
VHL Family Alliance – Brookline, MA
Wilson's Disease Association – Wooster, OH

Rochelle K. Abrams
Lantana, FL

Dianne Abuelo, M.D.
Director, Genetic Counseling Center
Rhode Island Hospital
Providence, RI 02902

Pat Allinson, M.S., C.G.C.
Genetic Counselor
University of Virginia Medical Center

Jean Anderson, MA, RN, CPNP
Executive Director, ISONG
Newton, Iowa

Lyn Applebee
SPF Foundation
Sterling Heights, MI

Kira Apse, ScM
Genetic Counselor
Beth Israel Deaconess Medical Center
Boston, MA

Leslie Aptekar, MS CGC
Department of Genetics
Yale University School of Medicine
New Haven, CT

Mary Ann Aronson
San Francisco, CA

don Asmonga, MBA
Director, Government Relations
AHIMA
Washington, DC

Mary Castro Aten
Newton, MA

Jan R. Atwood, PhD, RN, FAAN
Endowed Professor
Major Midwest Health Sciences Center

Sharon Aufox, MS, CGC
Northwestern University
Chicago, IL

Ronald Bachman
Chief of the Department of Genetics at the Kaiser Permanente Hospital
Oakland, CA

Martha V. Backstrom, MSW, MPH, RN
Richmond, CA

Patricia I. Bader, MD
Northeast Indiana
Genetic Counseling Center
Ft. Wayne, IN

Jennifer Bailey
Baraboo, WI
Sherri J. Bale, Ph.D., F.A.C.M.G.
Chevy Chase, MD
President and Clinical Director
GeneDx, Inc. Gaithersburg, MD

Karen Ball
Sturge-Weber Foundation
Mt. Freedom, NJ

Nancy Barilani
Committee Member ISMRD
Shillington, PA

Shannon N. Barringer, MS, CGC
Interim Director, Genetic Counseling Program
College of Health Related Professions
Dept. Of OB/GYN
University of Arkansas for Medical Sciences
Little Rock, AR

Michael A. Barry
Deputy Director
American College of Preventive Medicine
Washington, DC

Krysta Barton
Genomics Program Consultant
Indiana State Department of Health
Indianapolis, IN

Bonnie Jeanne Baty, MS, CGC
Associate Professor, Pediatrics
Division of Medical Genetics
Salt Lake City, UT

Barbara Baum
Montvale, NJ

Randy Beall
Richardson, TX

Cathy Beaudoin
FORCE
O'Fallon, MO

John Beaudoin
O'Fallon, MO
Bobbi Bedinghaus
Columbus, OH

Carly Bedinghaus
Columbus, OH

Cary Bedinghaus
Columbus, OH

Theresa Beery PhD, RN, ACNP
Associate Professor
Institute for Nursing Research
University of Cincinnati - College of Nursing
Cincinnati, OH

Marjorie Benditt
Seattle, WA

Judith Benkendorf, MS, CGC
Certified Genetic Counselor
Gaithersburg, MD

Karin Bennett
Positive for BRCA1
Shelter Island, NY

Robin L. Bennett, MS, CGC
Certified Genetic Counselor
Bellevue, Washington

Linda Bennington
Old Dominion University
Norfolk, VA

John Benwell
Member of PLS friends
ALS Society
St. Louis, MO

Michelle Berkovitz
Vice President, Research
Familial Dysautonomia Hope Foundation
Mother of Eli, age 3, who suffers from
Familial Dysautonomia
Bethesda, Maryland

Ann Berube
Lewiston, ME

Robert G. Best, Ph.D.
Professor and Director, Division of Genetics
University of South Carolina
School of Medicine
Department of Obstetrics & Gynecology
Columbia, SC

Jane E. Bethel
Virginia Beach, VA
<table>
<thead>
<tr>
<th>Name</th>
<th>Position / Organization</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Melissa Bitter</td>
<td>Republican</td>
<td>Arlington, VA</td>
</tr>
<tr>
<td>Mary Pat Bland, MS, CGC</td>
<td>Kaiser Permanente Genetics</td>
<td>San Jose, CA</td>
</tr>
<tr>
<td>Stephen Blanton</td>
<td>Alpha-1 Advocacy Alliance</td>
<td>Bluffton, SC</td>
</tr>
<tr>
<td>Jessica Blasko, MS, CGC</td>
<td>Children's Hospital Boston</td>
<td>Boston, MA</td>
</tr>
<tr>
<td>Kaeta Blessing</td>
<td></td>
<td>Columbus, OH</td>
</tr>
<tr>
<td>Ida Blocker</td>
<td></td>
<td>Brentwood, TN</td>
</tr>
<tr>
<td>Patricia S. Blumenthal</td>
<td>FORCE</td>
<td>Brentwood, TN</td>
</tr>
<tr>
<td>Ann Bogle Ph.D.</td>
<td>Phoenix Perinatal Associates</td>
<td>Mesa, AZ</td>
</tr>
<tr>
<td>Richard G. Boles, M.D.</td>
<td>Director, CCS Center for Metabolic and Mitochondrial Disorders</td>
<td>Los Angeles</td>
</tr>
<tr>
<td>Allan T. Bombard, MD</td>
<td>Chair and Program Director, Division of Medical Genetics</td>
<td>Los Angeles</td>
</tr>
<tr>
<td>Erin Bonacquisti</td>
<td>LeRoy, NY</td>
<td></td>
</tr>
<tr>
<td>Bobbie Bonhage</td>
<td>Director of Community and Patient Services</td>
<td>Towson, MD</td>
</tr>
<tr>
<td>Joann A. Boughman, Ph.D.</td>
<td>Executive Vice President American Society of Human Genetics</td>
<td></td>
</tr>
<tr>
<td>Judith H. Bowen</td>
<td>Member of WDA</td>
<td>Clayton, NC</td>
</tr>
<tr>
<td>Maureen Braun</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mary Anne Brazeal</td>
<td>Prairie Village, KS</td>
<td></td>
</tr>
<tr>
<td>Maureen E. Brewer, RN, MSN</td>
<td>Genetic Services Coordinator San Diego Regional Center</td>
<td></td>
</tr>
<tr>
<td>Kerry Brooks</td>
<td>President of the Texas Central Hemophilia Association</td>
<td>Dallas, TX</td>
</tr>
<tr>
<td>Jeffrey P. Brosco MD PhD</td>
<td>University of Miami Mailman Center for Child Development</td>
<td>Miami, FL</td>
</tr>
<tr>
<td>Nicholas M. Brown Ph.D., CFACMG, MT.CLSp (CG)</td>
<td>Associate Technical Director, Molecular Genetics Chantilly, VA</td>
<td></td>
</tr>
<tr>
<td>Susan Taylor-Brown, PhD, MPH, ACSW</td>
<td>Greater Rochester Collaborative MSW Program Rochester, NY</td>
<td></td>
</tr>
<tr>
<td>Cynthia Browning</td>
<td>Frankford Middle School</td>
<td>Dallas, TX</td>
</tr>
<tr>
<td>Marita Burmeister</td>
<td>Barth Syndrome Foundation</td>
<td>Lincoln NE</td>
</tr>
<tr>
<td>Erica Burner, M.S., C.G.C.</td>
<td>Genetic Counselor University of Arkansas for Medical Sciences/Prenatal Diagnosis Program</td>
<td>Little Rock, AR</td>
</tr>
</tbody>
</table>
Kristi Schmitt Burr  
Executive Director  
BCCNS Life Support Network  
Burton, Ohio

Becky Butler, MSSW, LCSW  
Director, Genetic Counseling Education Consortium  
College of Health Related Professions  
University of Arkansas for Medical Sciences  
Little Rock, AR

Rhonda P. Buyers  
Executive Director  
National Gaucher Foundation  
Rockville, MD

Nancy Callanan  
Director, Genetic Counseling Program  
UNC Greensboro  
Greensboro, NC

Brandi Campbell  
Friend of a family with two children with Cystinosis.  
Aurora, IL

Marjorie Campbell  
Basal Cell Carcinoma Nevi Syndrome (BCCNS)  
Cookeville, TN

Traci Cantrell  
Democrat  
Warrenton, VA

Lorraine Carlino  
RIPIN Parent Consultant  
RI Department of Health  
Newborn Screening Program  
Providence, RI

Diane Carr  
Registered Democrat  
New York, NY

Christi Carter  
Special Education Teacher  
Plano, TX

Debra & Mitchell Case  
four family members with IDIC15  
Machesney Park, IL

Wendy Chaite, Esq.  
Founder and President  
Lymphatic Research Foundation  
Roslyn, NY

Kathy Chamberlain  
R. Chamberlain  
Solon, OH

Shirley Chan, Ph.D.  
Multimedia Producer  
Dolan DNA Learning Center  
Cold Spring Harbor Laboratory  
Cold Spring Harbor, NY

Sarla Chand, Ph.D.  
Professor & Director, Human Services Administration  
Anna Maria College  
Paxton, MA

Ruth Ann Chappell  
Rochester, WA

Nancy Charpentier  
Seattle, WA

Nicole Chauche M.D.  
F.O.R.C.E.  
San Diego, CA

Philip Clancey  
New York, NY

Lana L. Christensen  
Member, CEDA Support List  
Omaha, NE

Megan Clancy  
Geneticist  
ASHG  
Aliso Viejo, CA

Kimberly Clark  
New England Volunteer Coordinator for Force  
Durham NH

Nicole Cleary, M.S.S.  
Executive Director  
IsoDicentric 15 Exchange, Advocacy & Support
Jannine Cody  
Chromosome 18 Registry & Research Society

Monica Coenraads  
Director of Research, Rett Syndrome Research Foundation  
Trumbull, CT

Mitchell Cohen

Carol Cherry, RNC, BSN, OCN  
Project Manager  
Family Risk Assessment Program  
Fox Chase Cancer Center  
Philadelphia, PA

Andrea Cohen  
Cherry Hill, NJ

Jessica Collins  
Yonkers, NY

Linda E. Collins BSN, RNC  
Deale, MD

Sheri Collins  
I have Ehlers-Danlos Syndrome, as do my 2 children  
Brookeville, MD

Kristy Colvin  
International Mosaic Down Syndrome Association  
Franklin, TX

Berni Coleman PhD ACNP-BC  
Cedars Sinai Medical Center  
Los Angeles, CA

John G. Compton, PhD.  
Scientific Director and CEO  
GeneDx Inc.  
Gaithersburg, MD

Janis Lambert Connallon  
Policy Coordinator  
Family Voices  
Washington, DC

Heidi Cope  
Genetic Counselor  
Duke University Medical Center  
Durham, NC

Sandra Corbett  
Fox Chase Cancer Center  
Philadelphia, PA

Peggy Cottrell, MS, CGC  
Board Certified Genetic Counselor  
Cancer Risk Assessment Program  
Albert Einstein College of Medicine  
Teaneck, NJ

John A Coxwell  
Bountstown, Fl

Michelle Craig MEd, RD  
Aurora, OH

Bob Crants  
DC Investment Partners  
Nashville, TN

Shannon Crants  
Nashville, TN

Hewlette S. Crawford, PhD  
USDA, retired  
Eddington, ME

Kimberly G. Crawford  
Family Services Coordinator  
National Tay-Sachs & Allied Diseases Association  
Boston, MA

Maria Cristallo  
Client Development  
RISK MANAGEMENT SOLUTIONS  
Newark, NJ

M. Doreen Croser  
Executive Director  
American Association on Mental Retardation  
Washington, DC

Lori Crossley  
United States Costello Syndrome Family Network  
Bloomington, IN
Pamela Croswell  
Boise, ID

Camille Culbertson  
Graphic Designer, The Heritage Foundation  
Washington, DC

Heather Curran  
New York, NY

Hailey Curtner  
Parent with HSP Robert Curtner  
San Francisco, CA

Sandy Daack-Hirsch RN, MSN  
Clinical Nurse Specialist in Genetics  
University of Iowa  
Iowa City, IA

Therese A. Dannels, RN, MPH  
Wyckoff, NJ

Mary Davidson, MSW  
Executive Director  
KS&A Associates  
Washington, DC

Joie Davis APRN, BC, APNG  
NIH/NHGRI  
Silver Spring, MD

Mary Davis  
Rays of Hope  
Glens Falls, NY

Sheryl Day  
Nashville, TN

Robert Cook-Deegan, MD  
Director, Center for Genome Ethics, Law, and Policy  
Institute for Genome Sciences and Policy  
Duke University  
Durham, NC

Leah DeGuire  
Dearborn, MI

Mary B. Deloe  
Sylvania, OH

Christopher M. Deloe  
Sylvania, OH

Cathryn M. Delude  
Science Writer and Affiliate of The Writing Company  
Andover, MA

David J. Dempsey, ACSW, Manager  
Government Relations/Political Action  
National Association of Social Workers, Inc.  
Washington, DC

Patricia A. Dibble  
Livermore, CA

Lori Dickerson-Odoms  
Washington, DC

Susan L-J Dickinson, MS  
Certified Genetic Counselor  
Devault, PA

M. Joyce Dienger, DNSc, RN  
University of Cincinnati College of Nursing  
Cincinnati, OH

Chris and Ashley DiLorenzo  
Duluth, GA

Patrick Dirlam  
Jonathan D. Moreno, Ph.D.  
Emily Davie and Joseph S. Kornfeld Professor and Director,  
Center for Biomedical Ethics  
University of Virginia Health System  
Charlottesville, VA

Sheila M. Dobin, Ph.D.  
Clinical genetics/Dir. Cytogenetics  
Scott and White Clinic  
Assoc Professor Texas A&M health Science Center  
Temple, TX

Diane E. Dorman, Vice President for Public Policy  
National Organization for Rare Disorders, DC Office  
Washington, DC

Sue Dorsey  
Chromosome 18 Registry and Research Institute  
Evergreen, CO
Jessica Douglas
Brandeis University
Worcester, MA

Carolyn Driscoll RN MSN FNP-C
University of Tennessee Health Science Center
Memphis, TN

Brian J. Dudgeon, Ph.D., OTR
Assistant Professor
Department of Rehabilitation Medicine
University of Washington
Seattle, WA

Ann M. Dylis, PhD, RN
Assistant Professor, Northeastern University
Boston, MA 02115

Chad Edwards
Chromosome 18 Registry & Research Society
Jacksonville, AR

Marla Edwards
Chromosome 18 Registry & Research Society
Jacksonville, AR

Roland C. Einhorn, M.D.
Baltimore, MD

Louise J. Elbaum, MS
Madison, WI

Sarah CR Elgin
Professor of Biology, of Genetics, and of Education
Washington University in St Louis
St. Louis, MO

Eric Ellwanger
Chromosome 18 Registry & Research Society
Flower Mound, TX

Gloria Ellwanger
Chromosome 18 Registry & Research Society
San Antonio, TX

Jim Ellwanger
Chromosome 18 Registry & Research Society
San Antonio, TX

Tara Ellwanger
Chromosome 18 Registry & Research Society
Flower Mound, TX

Susanne Bross Emmerich
Founder and Executive Director
Incontinentia Pigmenti International Foundation
New York, NY

Joan Esnayra, Ph.D., President
Psychiatric Service Dog Society
Arlington, VA

Charles J. Epstein, MD
Division of Medical Genetics and Program in Human Genetics
University of California,
San Francisco, CA

Sara Estes
Government Relations Coordinator
Society for Women's Health Research
Washington, DC

Rena Ellen Falk, M.D.
Associate Director, Cytogenetics Lab
Director, Prenatal Diagnosis Center
Cedars-Sinai Medical Center
Los Angeles, CA

Debra Farrell
Parent - two boys (ages 7 & 13) with Phenylketonuria (PKU)
Arlington, MA

Julie C. Faucheux, MS, CGC
Instructor of Pediatrics, LSUHSC
Genetic Counselor, Children's Hospital
New Orleans, LA

Michelle Fedewa RNC, MSN
Clinical Nurse Manager/Nurse Practitioner
Michigan State University
Department of Obstetrics, Gynecology, and Reproductive Biology
Lansing, MI

Jennie Feiger, MS, MA, CGC
Certified Genetic Counselor
Adult Medical Genetics Program
University of Colorado Health Sciences Center
Aurora, CO
Micki Gartzke  
Hunter's Hope Foundation  
Director of Education and Awareness  
Orchard Park, NY

Robert Gasparini, M.S., CLSp(CG)  
Trabuco Canyon, CA

Thomas D. Gelehrter, M.D.  
Professor and Chair  
Department of Human Genetics  
University of Michigan Medical School  
Ann Arbor, MI

Katy George  
Member of the Ehlers- Danlos National Foundation  
Canton, OH

Pam Gerrol, MS  
Certified Genetic Counselor  
Brigham and Women's Hospital  
Boston, MA

Jayne Gershkowitz  
Executive Director  
National Tay-Sachs & Allied Diseases Assoc., Inc. (NTSAD)  
Boston, MA

Susan Ghanbarpour  
Washington, DC

Ellen Giarelli, EdD, RN  
Research Assistant Professor  
University of Pennsylvania  
School of Nursing  
Philadelphia, PA

Randy Yudenfriend Glaser  
Brooklyn, NY

Audrey Glickson  
Cathleen M. Goetsch, MSN, ARNP, AOCN  
Hereditary Cancer Risk Consultant  
Virginia Mason Medical Center  
Cancer Prevention Research Coordinator  
Community Clinical Oncology Program

William D. Ginn  
Board of Trustees, BCCNS Life Support Network  
Chesterland, OH

Emily Glogowski, M.S., M.Sc., C.G.C.  
Genetic Counselor  
Memorial Sloan-Kettering Cancer Center  
New York, NY

Rachel E. Goldberg, Ph.D.  
Director of Senior Advocacy and Service Development  
Center for Senior Services  
B'nai B'rith International  
Washington, DC

Sima Golden  
Project Administrative Assistant  
National Coalition for Health Professional Education in Genetics (NCHPEG)  
Lutherville, MD

Michael A. Goldman, Ph.D.  
Professor  
Department of Biology  
San Francisco State University  
San Francisco, CA

Ellen & Steven Goldstein  
New York, NY

Audrey Gordon, Esq. President  
The Progeria Research Foundation, Inc.  
Peabody, MA

Ora Karp Gordon, MD, MS  
Director, GenRisk Adult Genetics Program  
Cedars Sinai Medical Center  
Assistant Professor of Medicine  
UCLA School of Medicine  
Medical Director, Graduate Program in Genetic Counseling  
California State University, Northridge  
Los Angeles, CA

Theresa Jaworski Gosselin  
Licensed Clinical Psychologist  
Williamsville, NY

Marguerite Goulet, RN, BSN  
Mount Carmel Cancer Risk Program Manager  
Columbus, OH
Irwin and Sybil Grace
supporters of a family whose child has 18q-syndrome, mosaic.
Hillsdale, NJ

Suzanne P. Graf, Director
Premature Ovarian Failure Support Group (POFSG),
Alexandria, VA

Joyce Graff, Executive Director
VHL Family Alliance
Brookline, MA

Leonard E. Graham
Minister Sugar Grove Presbyterian Church
Morgantown, WV

Patti Graham, R.N.
Lantana, FL

Sharron Graham
Genetic Nurse Specialist
Health Sciences Center
West Virginia University
Morgantown, WV

Dr. Joseph L. Graves, Jr.
Evolutionary Biologist
University Core Director and Professor of Biological Sciences
Farleigh Dickinson University
Fellow, American Assoc. for the Advancement of Science
Glendale, AZ

Mindy Greenberg
California State University, Northridge Genetic Counseling Student
Los Angeles, CA

Carrie Greeson, MS, CGC
Certified Genetic Counselor
Kaiser Permanente- Santa Teresa
San Jose, CA

Adriane K. Griffen, MPH, CHES
Director, Public Health Programs
Spina Bifida Association of America
Washington, DC

Josephine Grima, Ph.D.
Director of Research and Legislative Affairs
National Marfan Foundation
Port Washington, NY

Diana Groome
Wilson’s Disease

Barbara Grossman
grandparent to a little girl with 18q-syndrome mosaic
Hillsdale, NJ

Richard Grossman
grandparent to a little girl with 18q-syndrome mosaic
Hillsdale, NJ

Robin Grossman, LCSW
San Diego, CA

Jeremy Gruber, Legal Director
National Workrights Institute

Donna Gruetzmacher
Executive Director
National Ataxia Foundation
Minneapolis, MN

Margaret L. Gulley, MD
Associate Professor
Dept of Pathology
University of North Carolina
Chapel Hill, NC

Michelle Gwin
Mullica Hill, NJ

Howard Gwin
Mullica Hill, NJ

Diane Hageman
Columbus, OH

Karen Hall
Dobbs Ferry, NY

Kristi Hall
Lemoore, CA
Rebekah Hamilton PhD RN  
Post Doctoral Clinical Genetics Fellow  
College of Nursing  
University of Iowa  
Galena, IL

Lori Hamby, ScM, CGC  
Project Director  
The Genetic Counseling Video Project  
The Johns Hopkins Bloomberg School of Public Health  
Baltimore, MD

Katherine M. Hammitt  
Director of Research Development and Public Policy  
Sjogren's Syndrome Foundation  
Bethesda, MD

Colleen Hammond  
Executive Director  
Cystinosis Research Network  
Burlington, MA

Don Han  
Board of Directors, Hemophilia Federation of  
Chairman of Advocacy Committee, HFA  
Falls Church, VA

Sonja Hardy  
My friends two children have Cystinosis  
Dolton, IL

Heidi Harmon  
Lee's Summit, MO

Asad & Ferda Haroon  
Chromosome 18 Registry group  
Vienna, VA

Betty Harris  
Institute for Nursing Research  
U.C. College of Nursing  
Cincinnati, OH

Jessie Hastings  
Student Brandeis University  
Boston, MA

Shelby Hawthorne  
Contact Person in VA for Mitochondrial Disease  
Williamsburg, VA

Linda Chess Healy, R.N.  
Cedars-Sinai Medical Center  
Los Angeles, CA

Jennifer Heberer  
Affected Parent  
Portland, ME

Stephanie Herbert  
Genetic Counselor  
Dr. Martin Pollak Lab  
Brigham and Women’s Hospital  
Harvard Institute of Medicine  
Boston, MA

Karen Heller  
University of TX Southwestern Medical Center  
Dallas, TX

Ms. A. Merrill Henderson, M.S.  
Genetic Counselor  
Gorham, ME

Hendrix, Ed.D.  
Muncie, IN

Erin K. Herrick, MS  
National Coalition for Health Professional Education in Genetics  
Lutherville, MD

Bonnie Heintskill, MS, CCC/SLP  
Thiensville, WI

Richard Higashi  
OMB Electrical Engineers, Inc.  
Irvine, CA

Ann Hill SPF  
Rego Park, NY

Lori Hill  
GeneDx  
Gaithersburg, MD

Keli Holly  
Barth Syndrome Foundation  
Monahans, TX
Ezra C. Holston, PhD, RN  
Clinical Genetics Fellow and Clinical Research Scholar  
Colleges of Nursing and Medicine  
The University of Iowa  
College of Nursing  
Iowa City, IA

Adrienne M. Hopkins

Shannon Hopkins  
Selah, WA

Melissa Hopp

Rachel Hopp  
Gaithersburg, MD

Sheriann Houtrouw  
Member of CMTTC support group  
Mother of child with M-CMTTC  
Glenn, CA

Emma L. Howser  
Parent & Member NKH Family Network  
Frederick, MD

Karen M. Howser  
Member NKH Family Network  
Walkersville, MD

Kenneth G. Howser, Jr  
Member NKH Family Network  
Walkersville, MD

Ann Hunter  
Member: Wilson's Disease Association  
Boulder, CO

Kathy Hunter  
Parent, Founder and President  
International Rett Syndrome Association  
Clinton, MD

Helene Ince, CPNP  
ISONG, NAPNAP, NYS Assoc of NPs  
Bklyn/Queens Chapter  
Brooklyn, NY

Sarah A. Jackson, MS  
Adult Genetic Counselor  
University of Arkansas for Medical Sciences  
Little Rock, AR

Deborah Jacobs  
Carrier of Lowe Syndrome  
Vice President of Lowe Syndrome Assoc.  
Dallas, TX

Greg Jacobs  
Dad of son with Lowe Syndrome  
Dallas, TX

Christopher Janson, M.D.  
President/CEO  
The National Endowment for Alzheimer's Research (NEAR)

Julie Jodoin, MEd, MA  
Study Coordinator  
Registered voter in Somerset, MA  
Researcher in Providence, RI

Judy Jones  
Mycosis Fungoides Foundation

Jazmine Jung, MS  
Genetic Counselor  
Kaiser, Santa Teresa  
San Jose, CA

Roger and Marti Kalar  
Friends of Wilson’s Disease Parents  
Avon, CT

Rosanne Keep  
Certified Genetic Counselor  
Albert Einstein Medical Center  
Philadelphia, PA

Ruth Kelley  
Hereditary spastic paraparesis  
Byron, GA

Amanda Kennedy, RN, BSN  
Aurora, OH

Nikki Karl  
President- Maryland Division  
National Ovarian Cancer Coalition
Teresa Kim, RN, BSN
Research Nurse
National Cancer Institute
Genetic Epidemiology Branch
Rockville, MD

Rebecca A. Kirch
Deputy Director
Federal Government Relations
American Cancer Society

Angie Kirk
Ehlers Danlos Syndrome Patient
Mother of 2 daughters with Ehlers Danlos Syndrome
Mt. Vernon, IL

Paul Kirk
Spouse of Ehlers Danlos Patient
Father of 2 daughters with Ehlers Danlos Syndrome
Mt. Vernon, IL

Travis Kitchens
father of child with cystinosis
Member, Cystinosis Research Network
Athens, GA

Shelley J. Klein, Esq.
Director, Advocacy
Hadassah
New York, NY

Uli Klingbeil
Belmont, MA

Gail Knapp
Mother with leukemia
Stamford, CT

Joyce A. Kobori, M.D.
The Permanente Medical Group
Genetics Department
San Jose, CA

Dvora Konstant
Person with Wilson's disease
Ambler, PA

Bruce R. Korf, M.D., Ph.D.
Wayne H. and Sara Crews Finley Professor of
Medical Genetics
Chair, Department of Genetics
University of Alabama at Birmingham

Amy Koslosky
FORCE
San Carlos, CA

Dina Kulick, MD
Assistant Professor of Medicine
Clerkship Coordinator, Internal Medicine
Univ of Nevada Reno, NV

Cynthia Kupper, RD, CD
Executive Director
Gluten Intolerance Group
Seattle, WA

Virginia Ladd, President
American Autoimmune Related Diseases
Association (AARDA)
Eastpointe, MI

Nancy Landes
Radford, VA

Kathy Laney
Biology teacher
Hicksville HS
Hicksville, OH

Cynthia L. Lang
Carleton, MI

Eric J. Lang
Carleton, MI

Joanne Langeraar
National Eczema Association for Science &
Education
San Rafael, CA

Mary Langerud
Plymouth, MN
Margie Laramore
Altha, FL
Tim Laramore
Altha, FL

Sheila LaRosa
Administrator
BCCNS Life Support Network
Burton, Ohio

Natalia Tszine Leach, Ph.D.
Pathology Department, BWH/HMS
Boston, MA

Sue Ellen Ledford
Spastic Paraplegia Foundation
Harvey, LA

Brett & Brittney LeBeau
Parents of 2 children with Cystinosis
Aurora, IL

Connie Lee, Psy.D.
Angioma Alliance
Williamsburg, VA

Mejkin Legler
Arlington, VA

Bridget LeGrazie, RN, MSN, AOCN, APN,c.
Fox Chase Virtua Health Family Risk Assessment Program
Voorhees, NJ

Kelly R. Leight, Executive Director
CARES Foundation, Inc.
Short Hills, NJ

(Rev.) Richard M. Leliaert, Ph.D.
Representing the National Association of Catholic Chaplains
Dearborn, MI

Alan I. Leshner, Ph.D.
Chief Executive Officer and Executive Publisher, Science
American Association for the Advancement of Science
Washington, DC

Hal Levine

Shari Levine
Carmel, IN

Jacob Levitt, M.D., Medical Director
Periodic Paralysis Association
New York, NY

Judith A. Lewis, PhD, RNC, FAAN
President, ISONG
Virginia Commonwealth University
Richmond, VA

Cynthia Lim, M.S. - genetic counselor
Arkansas Children's Hospital
Little Rock AR

Angela E. Lin, MD, FAAP, FACMG
Assistant Clinical Professor of Pediatrics
Harvard Medical School
Co-Director Professional Advisory Board,
Costello Syndrome Support Association
Member, NERGG

Martin Lipp
Carmel, IN

Adam Litte
Director of Government Affairs
National Organization on Fetal Alcohol Syndrome
Washington, DC

Cindy M. Little, RNC, MSN, WHNP
Virginia Beach, VA

Sue Livingston
Controller for Infinity Radio Stations in Memphis
Memphis, TN

Lois J. Loescher, Ph.D., RN
Assistant Professor, College of Nursing
Research Assistant Professor, College of Medicine
University of Arizona
Tucson, AZ

Cynthia Lofaso
President Central Virginia Division NOCC

Maileen Lokich
Wayne, PA

Diana A Long
Winter Springs, FL

Mary Ann Lopez
Lodi, CA
Leigh LoPresti, M.D.  
Faculty Physician  
Eastern Maine Medical Center  
Bangor, ME  

Jennie Lou, M.D., M.Sc.  
Associate Professor of Public Health  
College of Osteopathic Medicine  
Nova Southeastern University  
Ft. Lauderdale, FL  

Deborah Lucas  
Suwanee, GA  

Lauren MacArthur, C.P.C.  
Principal Consultant  
Winter, Wyman & Company  
Waltham, MA  

Deborah J. MacDonald, RN, MS, APNG  
Genetics Associate/Assistant Director,  
Cancer Screening & Prevention Program Network  
Duarte, CA  

Mary Jo Macklem, RN  
New Hope, MN  

Anne Maddalena, PhD, FACMG  
Associate Clinical Director  
GeneDx, Inc.  
Gaithersburg, MD  

Julie A. Mairano, M.S.  
Executive Director  
Cornelia de Lange Syndrome (CdLS) Foundation, Inc.  
Avon, CT  

Karen Malina, CSW  
Private Practice  
Chatham, NY  

Susan Manley, MS  
Genetic Counselor  
Clarksville, MD  

Ladislav Matejka  
Professor Emeritus  
University of Michigan  
Hyannis, MA  

Anne Elizabeth Matejka-Grossman and Seth A. Grossman  
Parents to Talia Liana Grossman (age 4 1/2; 18q-mosaic)  
Lantana, FL  

Gudrun I. Matejka  
Retired Law Librarian  
University of Michigan  
Hyannis, MA  

Jane Matlaw  
Chair, Jewish Women’s Coalition on Breast Cancer  
Boston, MA  

Martha Matlaw  
Jamaica Plain, MA  

Anne L Matthews, PhD  
Associate Professor of Genetics  
Director, Genetic Counseling Training Program and Family Studies Core  
Department of Genetics  
Case Western Reserve University  
Cleveland, OH  

Susan E. Mazzoni, MPH  
Health Educator and Network Program Manager  
Fox Chase Cancer Center  
Philadelphia, PA  

Mary Ann McCabe, Ph.D.  
Director, Office for Policy and Communications  
Society for Research in Child Development  
Associate Clinical Professor of Pediatrics  
George Washington University School of Medicine  
Washington, DC  

Andrew McCluskey  
Executive Director  
Ehlers-Danlos National Foundation  
Los Angeles, CA  

Jamie McDonald, MS, CGC  
University of Utah Health Sciences Center  
Salt Lake City, UT  

Hereditary Hemorrhagic Telangiectasia Foundation  
International  
Vice-President, Board  
Member, Medical and Scientific Advisory Board
Michael D. McDonald, Dr.P.H.  
President, Global Health Initiatives, Inc.  
Potomac, MD

Deanne L. McInerney  
Cumberland, OH

Joseph D. McInerney  
Director  
National Coalition for Health Professional Education in Genetics  
Lutherville, MD

Laurie McKee  
FORCE  
Pottstown, PA

Diane McKnight  
Down Syndrome Partnership of Tarrant County  
Birdville ISD Special Education Advisory Committee  
Executive Boards Academy at Carrie F. Thomas PTA and Birdville High PTSA  
North Richland Hills, TX

Lemmietta McNeilly, PhD., CCC-SLP  
ASHA Fellow  
Chair, Communication Sciences and Disorders  
Florida International University  
Miami, FL

M. Dave McVicker  
Basal Cell Carcinoma Nevus Syndrome  
Mountain View, MO

Tracy McVicker  
Basal Cell Carcinoma Nevus Syndrome  
Life Support Network Board of Trustees  
Mountain View, MO

Kim Mecklenburg  
EDS patient  
Gaithersburg, MD

Art Mellor  
Boston Cure Project for Multiple Sclerosis

Debra J Mercy, MS, CRNP  
Saint Alphonsus Regional Medical Center  
Prevention, Early Detection and Genetics Program  
Boise, ID

Christian M. Mericle  
Tucumcari, NM

Jo Merrill  
Director of Public Policy and Government Affairs  
March of Dimes  
Washington, DC

Tahma Metz, Exec. Director  
Purine Research Society  
Bethesda, MD

Aida Metzenberg, M.A., Ph.D., C.G.C.  
Director, Genetic Counseling Program  
Associate Professor  
Department of Biology  
California State University, Northridge  
Northridge, CA

Scott T. Michalski, M.S.  
Genetic Counselor  
Methodist Maternal-Fetal Medicine  
Clarian Health  
Indianapolis, IN

Susan Mickler  
Pinetta, FL

Carol J. Mikols

David Mikols  
Redford, MI

Barnabo S. Mikols  
Gerald & Deborah Mikols  
Howell, MI

Aubrey Milunsky, M.D., D.Sc.  
Center for Human Genetics  
Boston University School of Medicine  
Boston, MA

Jeff Milunsky, M.D.  
Center for Human Genetics  
Boston University School of Medicine  
Boston, MA
Virginia M. Minichiello, M.S., APRN-BC
Adult Nurse Practitioner
Coordinator Direct Entry Nursing Program
Northeastern University
Boston, MA

Mittie Moffett, R.N., M.S.
President, Big Bend Division
National Ovarian Cancer Coalition
Tallahassee, Florida

Rita Black Monsen, DSN, MPH, RN
Member of the International Society of Nurses in Genetics, Immed. Past President and Interim Director of the Genetic Nursing Credentialing Commission,
Member of the American Nurses Assn
Past President of the Arkansas Nurses Assn.,
Current Chair of the Arkansas Genetic Services Advisory Cmte to the AR Dept. of Health.
Hot Springs, AR

Susan Montgomery, BSN
Fox Chase Cancer Center
Philadelphia, PA

Shaun Moran
National Ovarian Cancer Coalition - Philadelphia Division
Philadelphia, PA

Jonathan D. Moreno, Ph.D.
Emily Davie and Joseph S. Kornfeld Professor and
Director, Center for Biomedical Ethics
University of Virginia Health System
Charlottesville, VA

Robin Morhouse
upper motor neuron dominant ALS
Summit, NJ

Cynthia C. Morton, Ph.D.
William Lambert Richardson Professor of Ob/Gyn and Reproductive Biology
and Professor of Pathology, Harvard Medical School
Director of Cytogenetics, Brigham and Women's Hospital
Boston, MA

Paul Murphy
President
International Society for Mannosidosis & Related Diseases
Baltimore, MD

Richard J Murray
Bellingham, WA

Bette Nabi
Great Neck, NY

Scott Nelson
River Falls, WI

Steve Nelson
Wadena, MN

Jamesetta A. Newland, PhD, APRN
ISONG
White Plains, NY

Debbie Watters
Needham, MA

Joyce Newton, President
Vermont Division of the National Ovarian Cancer Coalition
North Fayston, VT

Janice A. Nicklas, Ph.D.
Research Associate Professor of Medicine
University of Vermont
Burlington, VT

Valerie Nobach
FORCE Member
Portland, OR

Rosanne Nuktis
Nashville, TN

Amy O'Connor
Parent of a child with a chromosomal abnormality
Raleigh, NC

Victoria Odesina
Parent of two young adults with sickle cell disease
Member, International Society of Sickle Cell Nurses and Physician Assistants
Member, International Society of Nurses in Genetics
New Britain, CT
Monica and Chuck Odom  
Parents of an 18q- child  
North Augusta, SC

Sue Ogden, R.N., B.S.N.  
Clinical Nurse in Genetics  
University of Arizona  
Department of Pediatrics  
Tucson, AZ

Catherine Ogorzaly  
Washington University in St. Louis

Sandy Olesen  
son with Huntingtons and 2 daughters at risk  
Audubon, IA

Sharon J. Olsen, MS,RN,AOCN  
Assistant Professor, School of Nursing  
Johns Hopkins University  
Baltimore, MD

Kelly E. Ormond, MS, CGC  
Director, Graduate Program in Genetic Counseling  
Northwestern University  
Chicago IL

Ben Oshman  
Columbia, MD

Irving & Deborah Oshman  
Durham, NH

Kelly Ouellet  
Chromosome 18 Registry  
Gardner, MA

Robbin Palmer, Ph.D.  
Certified Genetic Counselor  
Northern Nevada Genetic Counseling  
Reno, NV

Candice L Paolino  
Loveland, OH

Denise Parker  
Chromosome 18 Registry  
Jarrettsville, MD

Suzanne R. Pattee, J.D.  
Vice President of Public Policy and Patient Affairs  
Cystic Fibrosis Foundation  
Bethesda, MD

Trina Paulk  
Niemann-pick  
Atlanta, GA

Linda Pedraza  
West Roxbury, MA

Cynthia E. Perry, RN, CNS, PhD (c)  
University of San Diego  
San Diego, CA

Beth N. Peshkin, MS, CGC  
Georgetown University  
Washington, DC

June Peters  
Rockville, MD

Jan Petty  
Indianapolis, IN

Karen Phillips, PhD  
Cytogenetics Laboratory Director  
GeneCare Medical Genetics  
Rockville, MD

Marcia Phillips, RN, DNSc  
Assistant Professor  
Adult Health Nursing & Health Systems Management  
Rush University  
Coordinator, Section of Genetics  
Rush University Medical Center  
College of Nursing  
Chicago, IL

Jonathan Picker MD, PhD, ABMG  
Depts. Of Genetics and Child and Adolescent Psychiatry  
Children's Hospital Boston  
Boston, MA

Jean Pickford  
Executive Director  
Foundation for Ichthyosis & Related Skin Types, Inc
Janice S. Pielert  
Stamford, CT

Barbara Pober, MD  
MassGeneral Hospital for Children and Children's Hospital, Boston  
Boston, MA

Patricia Poli  
Lansing, Michigan

Kevin Poli  
Lansing, Michigan

Dinel Pond, M.S  
National Society of Genetic Counselors (NSGC)  
Chicago, IL

Victoria M Pratt

Isabel Prescott  
Riverview Orchards  
Rexford, NY

Jennifer Crum Preuss  
North Carolina Marfan Support Group  
Greensboro, NC

Marie A. Primeau  
Enhanced Family Provider for an adult with Tetrasomy 18p  
Board member of SOFT  
Preschool Teacher  
CH 18 member  
New Hampshire

Sheila Prindiville, MD, MPH  
Genetics Branch  
National Cancer Institute  
Bethesda, MD

Cynthia A. Prows, MSN, RN  
Clinical Nurse Specialist, Genetics  
Children's Hospital Medical Center  
Cincinnati, OH

Dee Quinn, MS, CGC  
Clinical Lecturer, Ob/Gyn  
Director, University of Arizona Genetic Counseling Graduate Program  
Director, Arizona Teratology Information Program  
University of Arizona  
Tucson, AZ

Leslie J. Raffel, M.D.  
Associate Director, Common Disease Genetics Program  
Cedars-Sinai Medical Center  
Los Angeles, CA

Kathleen L. Rainen  
Republican  
Mission Hills, Kansas

Lonye Rasch  
Hadassah National Board member  
Short Hills, NJ

Bill Ravalesi MA, MPH  
Boston Campaign Director  
Health Care Without Harm-Boston  
Longmeadow, MA

Luise Reading  
Joubert Syndrome Foundation  
Lititz, Pennsylvania  
Ellen Ann Reagan  
Waleska, GA

James Reardon  
Tax Counsel  
Pfizer, Inc.  
New York, NY

David E Regenstrief  
Indianapolis, IN

Heidi Rehm, PhD  
Harvard Medical School  
Boston, MA

Liesel Reinisch  
Chief Operations Officer  
Adams O'Connell, Inc.  
Los Angeles, CA

Katherine M. Reinleitner, Ph.D.  
Rockaway, NJ
Stephanie Reighart  
Columbus, OH

Sara Reichstein  
Student, Washington University  
St. Louis, MO

Juanita Reynard  
Audubon, IA

Rebecca & Bud Reynolds  
President & Vice President of NOCC Southern Colorado

Pamela Repetz  
Vice President  
Lehigh valley chapter NOCC

P. Preston Reynolds, MD, PhD, FACP  
Chair, Human Rights Cluster, Health Policy Committee, Society of General Internal Medicine  
Fellow, American College of Physicians Member, Board of Directors, National Coalition of Health Professional Education in Genetics.

Suzanne Richard, Artistic Director  
Open Circle Theatre  
Rockville, MD

Leisa Y. Richardson  
President/CEO  
Urban League of Flint  
Flint, MI

Heather Richmond  
Madison, WI

Peter Richter  
San Francisco, CA

David L. Rimoin, MD, PhD.  
Steven Spielberg Chair  
Director, Medical Genetics Institute  
Cedars-Sinai Medical Center  
Professor of Pediatrics, Medicine and Human Genetics  
David Geffen School of Medicine at UCLA  
Los Angeles, CA

Debi Risch  
Springfield, MO

Valerie M Rogers  
Wilson’s Disease  
Billerica, MA

Mary E. Ropka, Ph.D., RN, FAAN  
Associate Professor, Division of Health Services Research & Outcomes Evaluation  
Dept. of Health Evaluation Sciences  
University of Virginia School of Medicine and  
Associate Professor  
School of Nursing  
UVA Health System  
Charlottesville, VA

Traci L. Rorden  
Wallowa, OR

Bonnie Rosalind  
FORCE  
Seattle, WA

Judy Rose, R.D., Director  
Community Nutrition Program  
Indiana State Department of Health  
Indianapolis, IN

Lenore Roseman, Executive Director  
Dysautonomia Foundation, Inc.  
New York, NY

Beth S. Ross  
Project Manager  
Family Risk Assessment Program  
Fox Chase Cancer Center  
Philadelphia, PA

Margo Ross  
Roswell, GA

Shelly Rozenberg  
Boca Raton, FL

David Reusser  
Huntington's Disease Society of America - Michigan Chapter  
Detroit, MI

Mitchell Rubin  
New York, NY
Delia V. Ruiz  
Pismo Beach, CA  
Nikole Rupp  
Wilson’s Disease  
Hans & Ann Ruppel  
Independent  
Santa Fe, NM  
Wendy Ruppel  
Seattle, WA  
Donna Ruppert  
Executive Director  
Familial Dysautonomia Hope Foundation  
Conover, NC  
Cathy Rusyniak  
Rockaway, NJ  
Michelle Schwartz  
Chicago, IL  
Florence Schweitzer  
Member of FORCE  
Weston, FL  
Jeremy R. Scott  
Director of Public Policy  
Tourette Syndrome Association  
Washington, DC  
E. Michael D. Scott  
Chairman, Advocacy Sub-Committee  
International Myeloma Foundation  
North Hollywood, CA  
Dr. James H. Scully, Jr., MD  
Medical Director, American Psychiatric Association  
Cecelia Seltzer  
Crystal River, FL  
Heller An Shapiro  
Executive Director  
Osteogenesis Imperfecta Foundation  
Gaithersburg, MD  
Cindy Shelley  
Board of Trustee  
Basal Cell Carcinoma Nevus Syndrome Life Support Network  
Creston, IA  
John Shepperd  
Cystinosis Research Network  
San Antonio, TX  
Cathy Sherman  
Founder, Birt Hogg Dube Family Alliance  
York, PA  
Bill and Dawn Shilling  
Farwell, MI  
Carol Shooter  
Member of FORCE  
Alpharetta, GA  
Mark & Susan Shuter  
Hilliard, OH  
Dale C. Rutschow  
Spastic Paraplegia Foundation  
Colorado Springs, CO  
Tharini Sathiamoorthy, MHS  
Medical Advocacy Services, Inc.  
Washington, DC  
Priscilla A. Savary, Executive Director  
Colorectal Cancer Network  
Kensington, MD  
Steve and Lynne Schauble  
BPEI Family Network  
Pullman, WA  
Helen and Carmine Schepis  
Grandparents of 2 Wilson’s Disease Children, Pt. St. Lucie, FL  
Lisa Schoyer, President  
USCSFN (United States Costello Syndrome Family Network)  
Altadena, CA  
Kirstin Schwandt, M.S., C.G.C.  
Genomics Program Director  
Indiana State Department of Health  
Indianapolis, IN
Lisa S. Steinberg, M.S., C.G.C.  
Director, Master's in Genetic Counseling Program  
University of Maryland School of Medicine  
Baltimore, MD

Jessica Stevens  
Portland, OR

Susan Stewart  
Bedford, MA

Shelley M. Stiles  
St. Clair Shores, MI

Tara Stockwell, RN, BSN, OCN  
St. Alphonsus Cancer Care Center  
Boise, ID

Joan C. Stoner, Ed.D.  
Roca, NE

Ed Strobel, Ph.D.  
Departments of Molecular Genetics and Molecular Diagnostics  
City of Hope National Medical Center  
Duarte, CA

Laura Struhl, Ph.D.  
San Diego, CA

Rebecca Surmont  
Building Resources Corp.  
Minneapolis, MN

Millard Susman  
Interim Director, Institute for Cross-campus Biology Education  
Professor Emeritus, Laboratory of Genetics  
Director Emeritus, Center for Biology Education  
University of Wisconsin-Madison  
Madison, WI

Vicki T. Sweet, RN, MS, PNP  
Nurse Practitioner  
Division of Medical Genetics  
Stanford Univ. Medical Center  
Stanford, CA

Heather Sylvester, M.S. Cancer Genetic Counselor  
Maine Center for Cancer Medicine and Maine Medical Center  
Scarborough, ME

Kimberly Symonds  
Executive Director  
Wilson's Disease Association  
Wooster, OH

Eric A. and Judith E. Talla  
Broken Arrow, OK

Gary and Linda Taylor  
Gold Coast Dows Syndrome  
Loxahatchee, FL

Julie Taylor, CAE  
Director, Cancer Policy  
ASCO  
Alexandria, VA

Susan Taylor-Brown, PhD, MPH, ACSW  
University of Rochester Medical School and Nazareth College  
Rochester, NY

Michael & Michelle Telles  
Members of the Barth Foundation  
Kyle, TX

Nathania tenWolde  
St. Louis, MO

Patrick F. Terry  
PXE International, Inc.  
Potomac, MD

Lisa Thomson  
Savage MN

Kecia Thompson  
Wison's Disease  
Soldotna, AK

Kelly Tinnon  
Member of Ehlers-Danlos National Foundation  
Gadsden, AL

Cynthia J. Tifft, M.D., Ph.D.  
Chief, Division of Genetics and Metabolism  
Center for Hospital-Based Specialties  
Children's National Medical Center  
Ellicott City, MD
Susan Tinley
Council Bluffs, IA

Helen Travers, MS, CGC
Genetics Consultant
Miami Shores, FL

Norma Tulloch
Coordinator Breast Care Center
Saint Alphonsus Regional Medical Center
Boise, ID

Drea Thew
Marshfield, VT

Cara Ugolini
Advocacy and Awareness Manager
Pulmonary Hypertension Association
Silver Spring, MD

Wendy R. Uhlmann, MS, CGC
Genetic Counselor/Clinic Coordinator
University of Michigan
Ann Arbor, MI

Catherine Valenti
Caring Voice Coalition
Meridian, ID

Shelley Vaughn, MS
Indianapolis, IN
Ms Virginia Vaughn, President
DE National Ovarian Cancer Coalition
Newark, DE

Christine Vocke
PXE International
Germantown, MD

Rosalind Vogelbaum
Hillsdale, New Jersey

Rita R. Vosters, RN,MS
Clinical Associate Professor
School of Nursing, University of Wisconsin-
Madison

Ann P. Walker, MA, CGC
Professor and Director, Genetic Counseling Program
Division of Human Genetics
Department of Pediatrics
University of California Irvine Medical Center
Orange, CA

Linda Ward, MN, ARNP
Spokane, WA

Janet A. Warrington, Ph.D.
Vice President Clinical and Applied Genomics R&D
AFFYMETRIX, INC
Santa Clara, CA

Michael S. Watson, PhD, FACMG
Executive Director
American College of Medical Genetics
Bethesda, MD

Danille Watters
Needham, MA

Lori Watts
Social Worker at a cancer care center
Boise, ID

Karen Wcislo, MS, CGC
Kaiser Permanente
San Jose, CA

Angie Weaver
Mechanicsville, VA

James L. Weber, Ph.D., President
Prevention Genetics LLC
Marshfield, WI

Berta Weiner
White Plains, NY

Madeline Weiner
DebRA of America
Chapel Hill, NC

Joan O. Weiss, MSW
Founding Director, Genetic Alliance
Vice Chair, National Association of Social Workers
Foundation
Marina L. Weiss  
Senior VP for Public Policy and Government Affairs  
March of Dimes  
Washington, DC

Mary Wells RN, MA  
Member of ISONG  
Research Nurse National Cancer Institute  
Bethesda, MD

Frances M. Corda-Whitehead  
Member Wilson's Disease Association  
Bronx, NY

C. Edward Whitney  
Republican  
San Diego, CA

Vicky Holets Whittemore, Ph.D.  
Senior Science Advisor  
Tuberous Sclerosis Alliance  
Crofton, MD

Susan Wilkins  
Barth Syndrome Foundation  
Lincoln, NE

Janet K. Williams, PhD, RN, FAAN  
Professor of Nursing  
The University of Iowa  
Iowa City, IA

Lori Wills  
Pharmaceutical Representative  
Radford, VA

Daynna J. Wolff, Ph.D.  
Director, Clinical Cytogenetics and Molecular Pathology  
Associate Professor, Department of Pathology and Laboratory Medicine  
Medical University of South Carolina  
Charleston, SC

Jacqueline Wolff, CRRN, CHPC, M.ED  
Newton, MA

Patricia Wood, President  
NBIA Disorders Association  
El Cajon, CA

Sarah Wright  
Sr. Project Specialist  
Marriott International  
Arlington, VA

Huiying Yang, M.D., Ph.D.  
Director, Genetic Epidemiology Program  
Cedars-Sinai Medical Center  
Associate Professor of Pediatrics and Epidemiology, UCLA  
Los Angeles, CA

Colleen Yinger  
Thousand Oaks, CA

Joan Young  
Platelet Disorder Support Association  
Potomac, MD

S. Robert Young, PhD, FACMG  
Professor, Obstetrics & Gynecology  
Director, Cancer and Research Genetics  
Founding Director, M.S. Genetic Counseling Program  
Univ. of South Carolina School of Medicine  
Columbia, SC

Jonathan Youse  
Nashville, TN

Kathleen Zeitz  
breast cancer survivor  
Omaha, NE

Katherine Crotty Zuback  
Woodbine, MD

Audra Zuckerman  
Democrat  
New York, NY

Janice Zunich, M.D.  
Director, Genetics Center  
Indiana University School of Medicine  
Northwest Center for Medical Education  
Gary, IN
International Signers

Yann Joly, lawyer
Research Associate
Centre de recherche en droit public
Université de Montréal
Montreal, Quebec, Canada

Dalia Mikha
Melbourne, Victoria
Australia

Loraine Oman-Ganes MD, FACMG
Clinical Geneticist
American Society of Human Genetics affiliate
Toronto, Ontario, Canada

Patricia Pearsell
Canadian Representative of the Basal Cell Carcinoma Neviod Syndrome Life Support Network.
Whitby, Ontario, Canada

John Sulston
Human Genome Project member
Vice-Chair of the UK Human Genetics Commission
Cambridge England