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Welcome from Sharon F. Terry, MA

President and Chief Executive Officer

Welcome to the 20th anniversary celebration of the most inventive, driven, inspiring community you may ever join! We, advocates all, are celebrating the best of the human spirit: the leap across the threshold (and sometimes the canyon) from dire and devastating diseases and conditions—to the hope and real promise of support, services, and research.

Eleven years ago, when my two children were diagnosed with a genetic condition, I learned from the best: Joan Weiss, Genetic Alliance founder. She linked us to the people and the resources she had brought together. As my husband and I founded our disease-specific advocacy organization, PXE International, the men and women celebrated throughout the Leaders’ Exhibit were our mentors. From ‘mom and pop organizations’ to major foundations—we witnessed Excellence in Advocacy.

What now? We stand on the edge of a revolution—in healthcare, in genetics, in services for those whom we love. Advocates have had a major influence, but the best is yet to come. Genetic Alliance is poised to lead the community to focus on the prize, with single-minded fervor and sharp business acumen. We will engage in transforming disease into health, with the force of the combined passion of this community. We are so glad you are with us—let us go forward together with vision and focus!

Best wishes,

Sharon F. Terry
Welcome from Joan O. Weiss, MSW

Founder, Genetic Alliance

It is incredible to stand at this juncture and look at the phenomenal impact of Genetic Alliance over these 20 years. In thinking about our beginnings, I remember that I convened two conferences, in 1983 and 1985, to identify common concerns of genetic support groups and strengthen partnerships between families and professionals involved with these groups. Some of my colleagues and interested support group leaders joined with me to recommend the formation of a federation of voluntary genetic support organizations. We believed that such a coalition could link advocacy groups to the scientific and research communities, foster public education about genetic conditions, and provide a structure for political action. March of Dimes and the Maternal and Child Health Bureau/HRSA funded our efforts.

Hence, the seed was planted for the Alliance of Genetic Support Groups—now Genetic Alliance.

Now, 20 years later, I feel extremely gratified that those leaders who continued to believe in the original mission of Genetic Alliance—to encourage a true partnership among families, professionals and researchers—have seen this mission fulfilled.

Sincerely,

Joan O. Weiss
20th Anniversary Honorary Committee

Committee Chair
Joan O. Weiss
Genetic Alliance founder

The Honorable Judy Biggert (R-IL)
United States House of Representatives

The Honorable Anna Eshoo (D-CA)
United States House of Representatives

The Honorable James C. Greenwood
President & CEO, Biotechnology Industry Organization

The Honorable Edward Kennedy (D-MA)
United States Senate

Brad Margus
Co-Founder & CEO, Perlegen Sciences, Inc.

Victor McKusick
Professor of Medical Genetics, Johns Hopkins University

The Honorable Barack Obama (D-IL)
United States Senate

Randy Scott
Co-Founder, Chairman & CEO, Genomic Health

The Honorable Louise Slaughter (D-NY)
United States House of Representatives

Henri Termeer
President & CEO, Genzyme

The Honorable Billy Tauzin
President & CEO, Pharmaceutical Research and Manufacturers of America
Genetic Alliance Board of Directors

Sharon F. Terry, MA – President/CEO
Executive Director, PXE International, Washington, DC

Jannine D. Cody, PhD – Chairperson
President, Chromosome 18 Registry & Research Society, Texas

Elliott D. Hillback, Jr., MBA – Treasurer
Senior Vice President, Corporate Affairs, Genzyme, Massachusetts

Scott D. Berns, MD, MPH – Secretary
Chair, Board of Directors, The Progeria Research Foundation, Massachusetts

Donna Jean Appell, RN
President, Hermansky-Pudlak Syndrome Network, New York
Co-founder, Project DOCC, New York

Diane L. Baker, MS
Past President, National Society of Genetic Counselors, Maryland

Kemp Battle
Managing Director, Tucker Capital Corporation, New Jersey
Folklorist and Writer

Nancye W. Buelow
National Director Consumer Advocacy, Coram Healthcare, North Carolina

Patricia Furlong, BSN, MS
President, Parent Project Muscular Dystrophy, Ohio

Wendy R. Uhlmann, MS, CGC
Genetic Counselor/Clinic Coordinator Medical Genetics Clinic, University of Michigan
Past President, National Society of Genetic Counselors
Genetic Alliance Staff

Sharon F. Terry, MA  
President and CEO

Lisa Wise, MA  
Vice President

Cameron Cohen  
Executive Assistant to the President

Donna Foster  
Director of Administration

Karen White, MLS  
Director of Education and Information

Orkideh Malkoc, MS  
Associate Director of Public Policy

Hanaa Rifaey, MA  
Outreach Manager

James C. O’Leary  
Program Manager

Kim Puchir  
Electronic Communications Specialist

Helen Travers, MS, CGC  
Genetics Resource Specialist

Mary Peckiconis, MA  
Office Manager / Bookkeeper

FELLOWS
Kurt Christensen, MPH, Public Health Fellow  
University of Michigan

Nicole Exe, Genetics Fellow  
University of Michigan

Alyson Krokosky, Genetics and Public Health Fellow  
Furman University

David Marshak, Genetics Fellow  
Cornell University
Leaders' Exhibit
Excellence in Advocacy
Families. Heart.
compassion is forever imprinted on our
vitals with SiMS and their families. Ann's
Her greatest gift is her devotion to NiDiT
with other researchers across the world
and she works tirelessly on collaboration
and the works. Her energy is infectious
syndrome and co-founded its support
Ann Smith discovered Smith-Magenis

Ann Smith, PRiSMs

Maggie Miller
commitment;
collaboration, and
founded: compassion,
which PRiSM was
the principles by
Ann Smith exemplifies

Maggie Miller
"Without question, Abbey Meyers and NORD were the driving force behind the Orphan Drug Act."

- Frank J. Sasinowski, NORD

Abbey Meyers, National Organization for Rare Diseases

Abbey Meyers, mother of children with Tourette's Syndrome, started the National Organization for Rare Disorders (NORD), an effective voice for this underserved community. Together, this united grassroots coalition successfully achieved its initial milestones; the Orphan Drug Act and the birth of rare disease awareness.
Betsy Wilson, Let's Face It

"It's a beautiful day because our nation answers the challenge of diversity. People with facial and limb differences live, thrive, and fulfill the lives of others who love them. And because of all you do, Betsy Wilson, magnet to a million people, we are more truly who we are and more truly who we can be."
“Through humor and respect Billy began to change the way people with dwarfism are viewed.”

Billy Barty, Little People of America
Billy Barty founded Little People of America in 1957 with 21 members. Today we have 6000 members and affiliated organizations in 20 countries. Through his celebrity, humor, and grace Billy educated thousands and paved the way for acceptance of physical diversity within a society that values similarity.
Sharon Terry:

"The truth."

Efficient, seeking only
driven, focused and
quintessential advocates.

Brend Mergus, A.T. Children's Project
“Brian Denger runs marathons. With that same drive, he pounds the pavement in Congress.”

-Pat Furlong

Brian Denger,
Parent Project Muscular Dystrophy
Brian is a Duchenne Muscular Dystrophy dad, an unstoppable force. The relationships he has formed both on the Hill and within the NIH has accelerated positive changes in care and increased investment in muscle research. His expertise on Individualized Education Plans has assisted families’ access critical services for their sons.
For Rare Disorders
New Zealand Organisation

Bronwyn Gray, Worldwide

LAM in New Zealand and galvanize research into LAM. Bronwyn Gray helped...
"Reach for the stars and miracles will find you; reach for each other and you will find the STARS!"

- Donna Appell

Candice and Crystal Sipe, HPS Network
Candice and Crystal Sipe are true STARS of the Hermansky-Pudlak Syndrome Network. They light up our souls with their music and shine brightly as our advocates. We are honored to have them as our ambassadors as they continue to educate the world about Hermansky-Pudlak Syndrome through their songs of hope and inspiration.
Cheri Gruverson
Parent Project Muscular Dystrophy

Pat Furong

Heart of Solace and Jacob in her Laurel and missile; her eye on the
Cheri is a heat seeking
“Cindy Prows gave us a foundation for professional standards of practice in genetics nursing.”

Cindy Prows, ISONG
Cindy Prows led the work involved in defining the scope of genetics nursing practice and the standards required of nurses delivering genetic healthcare, published in 1998. This work was key in ensuring provision of quality healthcare for families and is the basis for the system of credentialing for genetics nurses.
"If Connie Lee is a hero, then cavernous angiomias are her nemesis."

-Pat Davis

Connie Lee, Angioma Alliance

After her preschool daughter's third brain surgery, Connie founded Angioma Alliance, a universe of information, support, and researchers who share a common goal: to learn more and do more about cavernous angiomias and other vascular malformations affecting one in every 150 people.
“Diane has an amazing gift for nurturing others to discover their gifts”

-Jannine Cody

Diane Baker, Genetic Alliance
Diane is a Genetic Counselor by training and an advocate by nature. She was a member of the founding Board of Directors of the Genetic Alliance. Diane is again serving on the Alliance Board, bringing strength of character and a vision for advocacy to the organization.
and the rare disease community. Her Kannawati-Fechner Syndrome Network same time is a great gift to her. Her disability and birth anomaly at the tenderness and brutality. Her ability to reach out will have changed all they laugh at. Her ability to reach out with. Her exceptional gift is freely given! Donna Appelli is an expert at surviving. Donna Appelli, HPS Network

Pat Furlong

"Is Donna Appelli, center of that heart has a big heart at the Genetic Alliance"
“Donna patiently but persistently wove family after family into the patchwork that eventually became IDEAS.”

-Brenda Finucane

Donna Bennett, IDEAS
Donna Bennett is a behind-the-scenes kind of leader. Since beginning IDEAS (IsoDicentric I5 Exchange, Advocacy, and Support) in 1992, she has continued to be the first contact person for every new family in IDEAS. Her patience and warmth in these conversations helps many families move forward through grief and acceptance to taking action to help their child.
Earl's dedication and heart-felt leadership has resulted in people living healthier lives with celiac disease.

Cynthia Kappen
Gluten Intolerance Group
of North America
"An entrepreneurial and irrepressibly positive teddy bear, Elliott motivates and challenges us all to overachieve."

Elliott Hillback, Genzyme
Elliott Hillback, Jr., a Senior Vice President of Genzyme Corporation, combines 35 years of healthcare industry management experience with a clear understanding of the patient point of view. An “anthropologist with an MBA” he often serves as a change agent, exuding confidence while helping coalesce ideas into actionable next steps.
Genetic Alliance Board since 2003
Dr. Ervin H. Epstein, Jr.
Lead of the BCCNS Life Support Network

"I understand this syndrome and feel your pain. You are my patient from now on & we do care."
"Soft-spoken and strong of heart, Fran tirelessly continues the work she began 50 years ago."

Fran Berkwits,  
National Tay-Sachs & Allied Diseases Association, Inc.  

Fran Berkwits, a pioneer in community screenings and a genetic counselor to many since 1957, embodies all NTSAD strives to achieve, which is compassion and hope for families worldwide affected by these often cruel and life-changing diseases.
and holds the vision for a cure.

Empowers millions. Advocates unflinchingly.

Leadership. The Foundation educates and

leads. The psoriasis community.

Through her

and compassion, Calli has developed the

advocacy organization. With empathy

Foundation into a leading patient

has shaped the National Psoriasis

Over the past 27 years, Calli Zimmerman

National Psoriasis Foundation

Calli Zimmerman

Mark Lebowitz, M.D.

"Gene discoveries.

stage for psoriasis

tissue bank set the

establishment of a

Calli's vision and

"
"Gene supports and challenges leaders in the advocacy community to lead from the core of their being!"

-Diane Baker

Gene Early
Gene Early catalyzes organizational transformation through his unique orientation to leadership development. He has lovingly challenged the Board of Genetic Alliance to lead from who we are. And, his character, compassion, and competence have modeled a way to raise up a community of leaders taking patient advocacy to entirely new levels of service.
George Preti

Timothy济民基金会

Sandy Gordon

通过服务，奉献精神和倾听

Monell中心的George Preti
"Irene has been the voice of the National Eczema Association since its inception in 1988."

Irene Crosby, National Eczema Association
Irene Crosby has dedicated her personal time to volunteer for the National Eczema Association for 18 years. Her vision, dedication, enthusiasm, follow-through and sacrifices have benefited all who suffer from eczema. Irene is known by medical professionals in several disciplines. Everyone with eczema thanks her for her selflessness.
“The CdLS Family is fortunate to have Ian, dedication and caring.”

Laird Jackson and Ian Krantz.

Cornelia de Lange Syndrome Foundation

Executive Director, Cornelia de Lange Syndrome (CdLS) Foundation

Julie A. Marano.
"As a PWS mother, Janalee's theme of "laughter after tears" resonates with every parent."
-David Wyant

Janalee Heinemann,
Prader-Willi Syndrome Association
Janalee is past President and board member of the Prader-Willi Syndrome Association (USA) and has been Executive Director since 1997. She was co-founder of the MO State Chapter and is known for her writings about the syndrome. Janalee has presented at thirteen national conferences and in ten other nations about the syndrome.
Point of View

health care is from the patient's viewpoint. Health care is about being heard, being respected, and feeling valued. This is where I come in.

Chromosome 18 Registry and Research Society

Jennine is a woman who became a PhD.

"Diane Baker, everyone."
"Jenny Noble's commitment transformed her children's lives and improved the prospects for children with Mucolipidosis."
- John Forman

Jenny Noble,
Lysosomal Diseases New Zealand
Jenny has two children with Mucolipidosis. Her efforts to solve Hayden and Sarah's chronic pain lead to Jenny co-authoring a paper on a treatment that brought significant benefits. Jenny actively shares that knowledge with Mucolipidosis families, and works tirelessly supporting New Zealand families with Lysosomal diseases, and families worldwide with Glycoprotein Storage diseases.
supported the energy legislation.

James C. Greenwood. Biotechnology

The Honorable James C. Greenwood

"Remain confidential."

Genetic information will
when we know our

Providing healthcare

based on individual
"Jo is the quintessential advocate, empowering and supporting all of us in the trenches to go the distance."

Joann Boughman, ACMG
Joann Boughman, Executive VP of American Society of Human Genetics, collaborated with Genetic Alliance to establish the Advocates Partnership Program, bringing advocates to the ASHG's annual meeting to interact, collaborate, and move the field forward with genetics. We are grateful for the dozens of opportunities Jo has created for advocates over the years.
John Forman, NZ Organisation for Rare Disorders

"Policy agenda: New Zealand's health diseases squarely on genetic and rare diseases."

neglected diseases

Disorders. Building the voices of the
services and research in New Zealand. He
ed by his wife Judith, John has worked
bility and holistic and strongly support-
alpha-mannosidosis affecting his lungs
mobilised by the rare genetic disorder

"John Forman, put"
"John and his family were a driving force in raising awareness about Progeria."

-Audrey Gordon,
The Progeria Research Foundation

John Tacket,
The Progeria Research Foundation

John Tacket, The Progeria Research Foundation's first Youth Ambassador, welcomed talking to others about Progeria. One year after speaking at the historic announcement of the Progeria gene finding, he passed away at the age of 15. He continues to inspire us all as we embark on a first-ever drug trial.
including Alpha-1.

hope for those suffering from chronic illness. 

advocate and beacon of.

John W. Walsh is an

John Walsh, Alpha-1 Foundation
"Joyce not only put her money where her mouth is...she also put her kidney!"

- Bruce S. Weinberg, J.D.

Joyce Wilcox Graff, VHL Family Alliance

A founding member and indispensable part of the VHL Family Alliance, she embodies the ideal of leadership and dedication. As founder, member, volunteer, and now staff, she has donated her time, energy, and organ to bring together patients, physicians, and researchers to find, treat, and cure von Hippel Lindau disease.
Julia Holman, PXE International

Julia has Ehlers-Danlos Syndrome type IV (PXE) - a rare genetic condition that causes a myriad of signs and symptoms. Julia is blind as an adult. Though blind, Julia has great vision and is immeasurably generous.

"Patrick Terry"

"Julia embodies leadership in a most fundamental way - she gives herself selflessly."

40
"Julia is one of the most passionate people and volunteers I have ever met."

Julia Roberts, PKD Foundation

Julia Roberts isn’t your average volunteer. She has a husband, two children, and a full-time job. Yet she still finds ways to help end PKD. Julia works tirelessly to raise awareness and funds for PKD research. She has even been a keynote speaker at several national conferences on PKD. Her dedication to the cause is truly inspiring.

She also supports several charities, including the PKD Foundation. She has been a volunteer for several years and has helped raise over $100,000 for PKD research. She is a true role model for all of us.

Julia is an inspiration to all of us. Her hard work and dedication have made a real difference in the lives of those affected by PKD. Thank you, Julia, for all that you do.
gives: "company these technologies must act to protect these technologies and the vocate for genetic and June is a tireless ad.

June Walker, Hadassah

Louise Slaughten (D-NY)

"legislation" non-discrimination furthering genetic in supporting and is a remarkable leader.

Hadassah President, June Walker, National
"Karen's infectious smile and spirit uplift the Sturge-Weber Foundation!"
- Brian J. Fisher

Karen Ball.
The Sturge-Weber Foundation

Karen Ball, founder and CEO of The Sturge-Weber Foundation, was taught to persevere and laugh in the face of adversity. She inspires, creates awareness, supports, and connects research and dialogue. She laughs in hard and
CARERS Foundation to emerge stronger

drive, determination, and humor led
destroyed their offices in 2006. Kelly's
devoted herself to helping families worldwide. When the
lives of her members were turned upside down,
Kelly started CARERS Foundation because

Kelly Lethbridge, CARERS Foundation

Hyperplasia community;

the Congential Adrenal
Lethg is a Champion for
and unwavering, Kelly
Compassionate, Resilient
“A steady player with a ready hand, Kemp enables organizations to realize their deepest capacity.”

-Scott Berns

**Kemp Battle, Genetic Alliance**

As a Genetic Alliance Board member, Kemp contributes an understanding of the emerging model of leadership that blends the best of hierarchy with the dynamism of networks. He recognizes systems and locates pain, energy, and possibility in the way groups move together, empowering Genetic Alliance members to realize their missions.
A seemingly rare condition, Down syndrome is worldwide regarded as a medical and academic challenge, affecting families, as well as medical and academic communities. Providing a wealth of information and support, the Down Syndrome Association has been instrumental in developing resources and education. Kristy Colvin, the founder and president, has championed the need for more information and support for people with Down syndrome. Kristy Colvin, International Mosaic Syndrome Association.

Linda Kunin, Ph.D., CC-SLP

"Syndrome" with Mosaic Down opportunity for people for information and championed the need for more

"Kristy has..."
“Lisa Schoyer—Leader, visionary, advocate, avant-garde—a combination as rare as Costello Syndrome ...1:30,000,000!”

-Tammy Moore

Lisa Schoyer,
Costello Syndrome Family Network
Today, Lisa Schoyer, President of Costello Syndrome Family Network, is probably helping another family with answers that can be hard to come by. And who knows what tomorrow may bring? With possible treatment for Costello Syndrome on the horizon, Lisa, a tireless advocate, is leading families towards a better tomorrow.
Liza Wise, Genetic Alliance

Jannine Cody

and high energy

with wit, intelligence,

serving our members.

Alliance to new heights.

"Lisa has carried Genetic

appreciated and motivated to do more.

The Genetic Alliance family feels
day at her side, Liza makes each person in
growing and learning with a loving
create physical and virtual havens for
entreprenurial strengths of
which to have a part. In building L. She uses her
have a sale home, and be empowered
Liza Wise believes that everyone should
Genetic Alliance"
"With deep understanding of fragile X scenario, Lucia Pimenta gives us confidence to go ahead!"

Lucia Pimenta, AXFRA
Lucia Pimenta is the one who first accepted the challenge of starting our Fragile X Association - AXFRA, in Sao Paulo, Brazil. After six years, we are 145 families strong throughout the country. Lucia's guidance continues to empower us to advocate for those with Fragile X.
Marianne has a strong determination, vision and her passion, and drive. Her commitment has been accomplished by HHT Foundation International, Inc.

Cormie Anderson
“No government official has done more to serve the needs of those with rare disorders.”

-Frank J. Sasinowski, NORD

Marlene Haffner,
National Organization for Rare Diseases
Dr. Marlene Haffner has guided the FDA’s orphan drug program for the past 20 years. Without her enlightened leadership, it is unlikely that FDA would have achieved its sterling record of having approved almost 300 drugs for rare disorders since the 1983 enactment of the Orphan Drug Act.
Strengthen the new organization.
She has developed her energy to build and
our mission in a truly innovative way.
With opportunities to get involved with
and to provide our inspiring members
insights and guidance. From its inception,
formed organizations, the Brazilian Genetic
Alliance has provided insightful
brazilian genetic alliance

"Conditions in Brazil with genetic
c prosecute for those
commitment to
represents our

"Martha Carvalho

Martha Carvalho
“MKR is a force of infinite spirit, empathy, and intelligence without one ounce of egotism.”

-Virginia P. Sybert, M.D.

Mary K. Richter, National Foundation for Ectodermal Dysplasias

Mary K. Richter, founder and executive director of the National Foundation for Ectodermal Dysplasias, has a gift for making things happen. Known for her “down to the bone” no-nonsense approach, she has raised international awareness of the ectodermal dysplasias, reached affected families in 65 countries, and stimulated interest in research.
anywhere in the body at any time.

Neurofibromatosis is a genetic disorder
and can be inherited in several different ways
school and in the research by raising funds
community, his
commited leadership in the
Matthew Freeman, 7 years, has
Matthew Freeman, Neurofibromatosis, Inc.

National Cancer Institute

Brianna Wiedeman, M.D.
Clinical Trial Research

neurofibromatosis

Courageous Pioneer in

A brave and
“Matthew plays an integral, important role on our Board, helping us focus on our mission.”

-Marcia Abbott, Moebius Syndrome Foundation

Matthew Joffe,
Moebius Syndrome Foundation
Matthew S. Joffe has been the vice president of the Moebius Syndrome Foundation for many years. Matthew provides our conferences with nationally known speakers and leads numerous sessions himself. Matthew contributed to our new educational DVD and other publications on Moebius syndrome, and works towards awareness and support of a rare condition.
“Nancye couples unique personal and professional insights with an unwavering determination to achieve real progress”

Nancye Buelow, Genetic Alliance
After Nancye Buelow and her husband were diagnosed with different conditions, she resolved to work in concert with all stakeholders for solutions to earlier detection and treatment for consumers. In both her personal and professional life, Nancye works for those without proper access to education, support, treatment, and quality medical care.
Colorectal cancer advocacy movement

To focus and support the growing

Founded in 1993, Colorectal Cancer Coalition

For people touched by the disease, colorectal
cancer is a silent and pernicious foe,

and increased awareness of colorectal

and head for better research, effective policies

colorectal cancer advocacy. Nancy's push

A cancer survivor and pioneer in

Colorectal Cancer Coalition

Nancy Roach.

Mary N. Wilson Cancer Foundation

Bob Effron

"For patients, effective advocate

Nancy is extremely

and knowledge makes

combination of passion

"A powerful"
"Committed to finding the cause of inflammatory breast cancer, by assisting and facilitating research."

IBC Research Foundation
Mission Statement

Owen Johnson,
IBC Research Foundation

Without the vision, determination and dedication of founder and President, Owen Johnson, the IBC Research Foundation would not likely exist. The untimely death of his wife launched Owen onto the path of research advocate. He has earned the respect of the advocacy community with his altruism, business skills and knowledge.
"I'm excited to help Y-ME ensure that no one—especially diverse populations—face breast cancer alone."

Pat Harris, Y-ME National Breast Cancer Organization

Pat Harris is Y-ME National Breast Cancer Organization’s Board President and Global Chief Diversity Officer. Y-ME has a 24/7 hotline staffed by trained breast cancer survivors with interpreters in 150 languages and a multi-lingual Web site.
"Pal is an inspirational new voice in the patient advocacy community for individualized medicine."

-Randy Scolsi

Patrick Terry, Genomic Health
Pal Terry is a relentless advocate for the best possible individualized medicine and patient outcomes. His ability to translate genomic advances into the public policy arena while always putting the patient first truly inspires and motivates us all.
Glycoprotein Storage Disease
The International Advocate for
Paul Murphy, ISMRD

"Glycoprotein Storage Disease"
A Global Mission of Cures
Gathered 3 led Families in
"The Visionary Who"
“Penny looks at the big picture of public health without forgetting a single face.”

- James O’Leary

Penny Kyler, Genetic Services Branch of HRSA/MCHB

At the Genetic Services Branch of HRSA/MCHB, Penny Kyler paves the way for projects that directly benefit the lives of children with special needs. It is Penny who ensures that breakthroughs in science translate to better health for families.
healthcare worker.

volunteers. Patients whose articles are

seen in the community. She is a role model for

participation in volunteer work.

Vicky Ciccarello is the positive force in

her home and a positive role model. Her

spiritual commitment is a key factor that

National March of Dimes

Priscilla Ciccarello

Priscilla Ciccarello is a parent who looks

Center for Marfan Syndrome Research

Hali Bierz, MD, William S. Smiley

Marfan Foundation

of the National

She is the mother
"Robbie's outstanding leadership, smarts, and sense of humor inspire us daily...."
-Cynthia Wong Hu, EntreMed, Inc.

Robbie Melton, Women in Bio
Robbie Melton, as volunteer and President of Women in Bio, has dedicated herself to helping the entrepreneurial community. She believes passionately in the mission of Women in Bio and continues to encourage and motivate members to excel. Robbie's a fantastic leader and friend to those fortunate to know her.
Dr. Robert White, Jr.

"His patients of HHT is a hero to the leading authority on HHT."

Dr. Robert White, Jr.

HHT Foundation International, Inc.
"If they couldn’t figure it out, they would call Dr. Robert Gorlin."

-Cathy Gorlin, daughter

Dr. Robert J. Gorlin,
BCCNS Life Support Network
Devoted dentist and genetic genius, Dr. Gorlin, described 100 syndromes (six named for him) as Professor at the University of Minnesota. Bob remains a pioneer, cartographer, and explorer; charting new territory in genetics, where few have dared venture. His legacy; his students and thousands of children, who bear the fruit of his courageous work.
Neurofibromatosis, Inc.

Beverly Dobson

"Feel like everyone else. If possible for these kids to Sandy's camps make it!"
“Scott is a rare man—a pragmatic dreamer!”
-Kemp Battle

Scott Berns,
Progeria Research Foundation
Scott Berns, co-founder of The Progeria Research Foundation, tireless builder of coalitions, never accepts “it can’t be done” as an answer. His capacity to bring people of different backgrounds together in search of common ground is evident in his work as a physician, Genetic Alliance board member, colleague, and friend.
Advocacy has advanced research on all novel strategies and confidence in his vision. Willingness to execute on stimulating research on their diseases, advocate groups in their efforts to empower diseases. Empowers diseases, port districts, districts.

Sharon Terry, Director of the Office of Health National Institutes of Health

It is not for Steve Grotta. Where it is today were advocacy would be. One must ask it.
"We continue to reach higher and accomplish more to improve the lives of families affected by MPS."

Steve Holland, National MPS Society
During his term (2003 – 2006) as President of the National MPS Society, Steve accomplished much, including a 25% membership increase, $1.4M dollars raised for MPS research, an MPS Awareness Day senate resolution, and improving the FDA approval process for MPS I and VI therapies.
"Sujeet is a beacon to all who have needed extra light to shine the way!"
-Kristy Colvin
“Suzanne Gauvreau turned her cancer diagnosis into empowering others and we are so grateful.”

Suzanne Gauvreau, Patient’s Best Friend
Vivacious, tenacious, this young woman inspires newly diagnosed, survivors, families, advocates, researchers, clinicians and professional staff with her warmth, strength and knowledge. Suzanne advocates prioritizing quality of life in medical decisions and encourages personal empowerment. She has vast experience with allopathic and natural therapies as cancer patient and practicing therapist.
Newborn screening disorders through comprehensive save babies from the tragedy of brain damage and early death ultimately through national attention and action.

Tera Mize, founder of the Tera’s Resolve to Prevent Foundation. In 1998 inspired by the loss of her infant son, Tera Mize started the Save Babies Through Screening Foundation.

"Tera started something huge!"

Jill Levy-Fisch
“Tiffany House is a leader in the Pompe Community, both in spirit and her participation in disease research.”

Tiffany House

Tiffany's strength of spirit, unwavering courage, and ability to push herself in all aspects of her life sends an inspiring message to all those with rare disorders that giving up is never an option. She is a true pioneer in the journey of finding a treatment.
Together:

Moebius Family

Compassion that holds the leadership, strength, and

Vicki provides the
“Wendy models excellent leadership for all healthcare providers - in service, advocacy and policy.”

- Sharon Terry

Wendy Uhlmann, University of Michigan, Division of Molecular Medicine & Genetics

Wendy Uhlmann has been a genetic counselor since 1988. She has served as a leader within the National Society of Genetic Counselors, including as president. She is committed to compassionate delivery of quality information. Wendy passionately believes in strong public policy to sustain excellent service delivery.
“We've got to find a way to help these kids.”
"Rick Guidotti's images transform both the observer and the participant forever."

-Jannine Cody

**Rick Guidotti, Positive Exposure**

Rick Guidotti's life is dedicated to inspiring us to see that there is indeed outer beauty in everyone. He created an organization called Positive Exposure and travels the world capturing the beauty and magic of people with genetic differences for all to see.
Parent Project Muscular Dystrophy

Pat Furong

Donna Appell

"Hero."

Born, Pat Furong is a

woman, and a hero is

acquires resilience and

been greatly challenged

A beautiful soul that has
“Making a world of difference in a world of facial differences.”

Debbie Oliver, About Face USA
Debbie Oliver understands that patients with craniofacial conditions are not simply service recipients; they are a valuable human resource. Recognizing their strengths, she trains patients and families to enhance outreach services for persons with congenital and acquired facial differences. Debbie is the founder of cleftAdvocate and Executive Director of About Face USA.
Retell syndrome gene

retelling the discovery of the
dichotomous sisters finding funding and
families with retell syndrome forming
Kathy is also responsible for organizing
including the chromosomal register.
several successful organizations
community. She has helped launch
many newcomers to the advocacy
Kathy Hunter has assisted and inspired
Retell Syndrome Association
Kathy Hunter International

Jannine Cody
world of advocacy
retell syndrome, and the
future for people with
Kathy has changed the
“Sue elevated LAM from a rare and forgotten disease to the forefront of pulmonary medicine.”

-Dr. Frank McCormack

Sue Byrnes, LAM Foundation
Sue Byrnes founded The LAM Foundation to bring hope to women with lymphangioleiomyomatosis (LAM), a frequently fatal lung disease. She convinced the NHLBI to form a national LAM Patient Registry and LAM Protocol. Sue’s remarkable efforts raised $8 million, funding groundbreaking research, which resulted in the first-ever LAM treatment trial.
agreement and progress possible that bring people together and make strides for dynamic, innovative solutions. As President & CEO of PhRMA, Taunton in the United States Congress and now leader in the Louisiana State legislature, his reputation on achieving results "is a For over 30 years, Billy Taunton has built PhRMA, PHRIX.

"more productive lives. "longer, healthier and allow patients to live inventing medicines that companies devoted to and biotechnology pharmaceutical research America's leading PhRMA, represents. As President and CEO.
"Kaye was the first person to give me hope in facing this terrifying disease."
-Patty Steinman

Kaye McSpadden,
Lowe Syndrome Association

In 1981, Kaye’s question, “Does anyone know about Lowe syndrome?” led to the creation of a 500-member international organization called Lowe Syndrome Association. The organization emphasizes research and genetic testing, and fosters hope and communication among families affected with Lowe syndrome. Kaye’s belief, “Care today, cure tomorrow,” lives on.
levels of policy, education, and research that seeks to include consumers at all education levels in health professionals. Elizabeth J. Clark, a well-recognized genetics expert in the field of genetic education, has authored a number of research articles in the growing field of genetic research. Elizabeth J. Clark is a leading spokesperson for the role of social work in the advancement of genetic research.
“Sharon lives her convictions—inspiring others to accomplish their dreams and more.”
-Gene Early

“Sharon opens the doors of the world to make sure everyone has a place to survive and thrive.”
-Patricia Furlong, Parent Project Muscular Dystrophy

Sharon Terry, Genetic Alliance
Sharon Terry, President of the Board and CEO of Genetic Alliance, is a born leader. She entered the advocacy community ten years ago as a concerned mother of two; today, she is the matriarch of a community of over 100 million individuals worldwide affected by genetic conditions. In all that she does, Sharon embodies inspiration, commitment, and execution. She mobilizes and energizes. Her compassion and competence combine to produce phenomenal results—raising the genetics advocacy community to higher levels with each passing day. Above all, she loves us, and she is loved.
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*to The Genetic Alliance*
scientific enterprise access to all scientific information, so that discovery and innovation are transformed."

Congratulations on 20 Years of Excellence in Advocacy.
It is a privilege to support and partner with Genetic Alliance in its tireless efforts to advance the awareness, education and treatment of genetic conditions.

Congratulations on 20 years of excellence in advocacy!
Congratulations

Congratulations to the Genetics Alliance and your Member Organizations.

You are making a difference:
• In the battle for Genetic Nondiscrimination Legislation…
• In the regulation of genetic testing…
• In the battle to open access to government research…
• As patient experts with practical knowledge of the intersection of science, health care and privacy.

We are pleased to support the Genetic Alliance in many of these key issues.

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Thank you, Genetic Alliance, for sharing your address and being our "incubator."

Our Goals:

» **Connect** with people touched by colorectal cancer

» **Empower** them with resources

» **Inspire** them to promote research, policy and awareness to help us end the suffering and death due to colorectal cancer
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Genomic Health is pleased to partner with the Genetic Alliance and support its work to build capacity of genetic advocacy organizations to achieve their missions.

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GlaxoSmithKline celebrates Genetic Alliance's Twenty Years of Excellence in Advocacy.

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The International Society of Nurses in Genetics recognizes, congratulates & supports the Genetic Alliance on 20 Years of Excellence in Advocacy

ISONG Mission
To foster the scientific, professional and personal development of health care professionals in the management of genomic information.

Those interested in learning more about ISONG, please visit our website at www.isong.org.
Congratulations to the Genetic Alliance on 20 years of excellence in advocacy.

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Congratulations
to the Genetic Alliance
for 20 years of
Excellence in Advocacy.

We at the National Marfan Foundation share your commitment to making a difference in the lives of people with genetic conditions and their families through EDUCATION - RESEARCH - SUPPORT

NMF

22 Manhasset Avenue, Port Washington, NY 11050 - (800)8-MARFAN - www.marfan.org
The National Association of Social Workers congratulates the Genetic Alliance and Gala Chair Joan O. Weiss, ACSW, Genetic Alliance Founding Director and NASW Social Work Pioneer® on 20 years of excellence in advocacy.

NASW is committed to equipping social workers with knowledge and resources in the growing field of genetic education, research, policy and practice.

- “NASW Standards for Integrating Genetics in Social Work Practice”
- “Understanding Genetics: The Social Worker’s Role,” a free web-based continuing education course for social workers and consumers (coming soon)
- www.HelpStartsHere.org, a free web resource on social work topics for consumers and social workers.
For twenty years, the
Genetic Alliance
has educated the public about genetics
and made a difference in the lives of
those affected by genetic disease. For
that, and for the difference they'll
continue to make, Perlegen is pleased to
join those gathered tonight to honor
them. Tomorrow, we continue our quest,

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Congratulations
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on its

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Anyone who suffers from a rare or genetic disease — or knows someone who does — understands the importance of new medicines and continued research into their cause, treatment and cure. The Genetic Alliance is a leader in the effort to treat, cure and raise public awareness about rare diseases. And, the Pharmaceutical Research and Manufacturers of America (PhRMA) and our member companies are proud to support the Genetic Alliance in these efforts.

Through collaborations such as the publication of “A Decade of Innovation: Advances in the Treatment of Rare Diseases,” America’s pharmaceutical research companies look forward to many more successful efforts with the Genetic Alliance in the fight to combat rare diseases.

Each advancement in the treatment of rare diseases provides patients with a precious gift: hope for the future. PhRMA joins with countless other organizations and individuals in saluting the Genetic Alliance on their energy and commitment to rare diseases. And, most importantly, for providing patients with hope.

PhRMA

The Pharmaceutical Research and Manufacturers of America represents the country's leading pharmaceutical research and biotechnology companies, which are devoted to inventing medicines that allow patients to live longer, healthier, and more productive lives.
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Congratulations Genetic Alliance on 20 years!

The American College of Medical Genetics is proud to partner with the Genetic Alliance for the Consumer Advocate Program at the ACMG Annual Clinical Genetics Meeting, March 21-25, 2007 in Nashville, TN. For more information on the program, visit www.geneticalliance.org.

American College of Medical Genetics

Visit www.acmg.net for detailed program information and online abstract submission, registration and hotel reservations.
Congratulations to the Genetic Alliance

on setting the standard

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NexGenix Pharmaceuticals is a US-based biotechnology company focused on drug development for Neurofibromatosis Types 1 and 2. Neurofibromatosis, or NF, is a genetic disorder characterized by the development of tumors along nerves. These slow growing tumors are resistant to radiation and chemotherapy and the only current treatment is repeated surgical removal. NexGenix has assembled a team of top NF clinicians and researchers on its Scientific Advisory Board and has developed a proprietary screening platform for both Neurofibromatosis Type 1 and 2. NexGenix will soon seek an IND for a unique treatment for NF1. A targeted treatment for NF2 is in early stage development.

For more information, please visit the NexGenix website at www.nexgenixpharm.com
NSGC Congratulates the Genetic Alliance on 20 Years of Excellence!

The National Society of Genetic Counselors would like to thank the Genetic Alliance for the strong relationship we have built over the past 20 years. We look forward to working together for many years to come.

The leading voice, authority and advocate for the genetic counseling profession.

For more information on the National Society of Genetic Counselors (NSGC) visit our Web site at www.nsgc.org.

Is proud to honor the Genetic Alliance for 20 years in Advocacy Excellence

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Greetings

It is a tremendous disappointment to me not to be able to join you in person for the 20th anniversary celebration, honoring the leadership of the Genetic Alliance and its component parts. It was my privilege to watch the formation of the Genetic Alliance 20 years ago. I greatly admire Joan Weiss and so many of the leaders of the individual components such as Priscilla Ciccariello.

I salute all of you on this celebratory occasion.
My heartiest congratulations on your achievements. My best wishes to all of you as you face the challenges of the future.

Victor A. McKusick, M.D. | University Professor of Medical Genetics
McKusick-Nathans Institute of Genetic Medicine | Johns Hopkins University

Congratulations
to Genetic Alliance on
20 Years of Excellence in Advocacy!

The Alpha-1 Foundation
Congratulates the Genetic Alliance for
20 Years of Leadership and Excellence in Advocacy,
Including Raising Awareness of Alpha-1 and Other Genetic Diseases.
The American Medical Association CONGRATULATES Genetic Alliance on its 20th anniversary.

Congratulations to Sharon and the Genetic Alliance!!
Thank you for always bringing HOPE into our lives. CODON!!

Donna and Richard Appell Hermansky-Pudlak Syndrome Network

Congratulations on your 20th Anniversary!
Thank you for all you do for the Genetics Community!

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May this be the year we also pass Genetic Information Nondiscrimination Legislation!

Honoring Jannine Cody, PhD

For her many years of service to Genetic Alliance, as it celebrates its 20 years of service to children, adults and families affected by genetic conditions.

The Department of Pediatrics at the University of Texas Health Science Center at San Antonio

We would like to thank and remember the early work of Sylvia Schild MSW, Rita Beek Black MS and Joan Weiss ACSW who paved the way for the emergence of genetic support groups.

We thank the Genetic Alliance for their vision and commitment.

Congratulations to Genetic Alliance

For Twenty Years of Excellence in Advocacy

Hereditary Disease Foundation

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GENETIC ALLIANCE ON 20 YEARS

OF EXCELLENCE IN ADVOCACY

Thank you for your wise counsel, educational resources, and networking opportunities that have benefited our foundation through the years. Our appreciation to Genetic Alliance for joining our many individual voices so that we can all be heard.

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To wrest from nature the secrets which have perplexed philosophers in all ages, to track to their source the causes of disease, to correlate the vast stores of knowledge, that they may be quickly available for the prevention and cure of diseases—these are our ambitions.

—Sir William Osler

International Mosaic
Down Syndrome
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Congratulations Genetic Alliance
On 20 Years of Excellence!
IMDSA is a non-profit organization dedicated in assisting families and individuals affected by mosaic Down syndrome. We strive to increase awareness in the medical, educational, and public communities throughout the world.

Want to know more about mosaic Down syndrome? Make plans to attend our Research & Awareness Conference to be held Summer 2007 at VCU’s Medical College of Virginia in Richmond!

To learn more about our outreach programs, research goals and family support network, just visit our website or give us a call!

www.imdsa.com

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Genetic Alliance

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20 Years of Excellence in Advocacy!

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Genetic Alliance on your 20th Anniversary

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The Moebius Syndrome Foundation
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The Board and Staff of Genetic Alliance thank all of the leaders, our friends and family who helped us to celebrate our first 20 years of excellence in advocacy

Congratulation to Genetic Alliance for 20 Years of Excellence in Advocacy

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The staff of PreventionGenetics congratulates the Genetic Alliance on twenty years of unparalleled advocacy for the rare disease community.

PreventionGenetics is proud to be able to support the Genetic Alliance and its mission.

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20th Anniversary
Congratulations to the Genetic Alliance!

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American Clinical Laboratory Association

"ACLA Congratulates the Genetic Alliance on 20 Years of Excellence in Advocacy"

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What Else Happened in 1986?

- Eric Thomas, invented LISTSERV, the first email list management program, representing a major milestone in Internet history
- NEC succeeded in developing the world’s first 4-Mb DRAM
- Super Bowl XX: Chicago Bears won 46-10 over the New England Patriots
- Kodak scientists invented the world’s first megapixel sensor, capable of recording 1.4 million pixels that could produce a 5x7-inch digital photo-quality print

The Generic Universal Role Playing system, commonly known as GURPS, a role-playing game system, was designed to adapt to any imaginary gaming environment

World Series: New York Mets won 4 games to 3 over the Boston Red Sox

Delphi, the innermost satellite of Pallas, discovered by Voyager 2

Roaring film: Top Gun, starring Tom Cruise, Kelly McGillis, Val Kilmer

Weg Bednorz and Karl A. Müller discovered a high-temperature superconductor

- Rock and Roll Hall of Fame opened
- NCAA Finals: Louisville won 72-69 over Duke
- Grammy: Quincy Jones (producer) won Record of the Year for “We Are the World” performed by USA for Africa
- NASA’s Space Shuttle Challenger spacecraft disaster
- Bobby Ewing was revealed alive and showering in his wife Pam’s bathroom in the season finale of Dallas, in which it was shown that the entire 1985–86 season was a dream

- First reported methods for constructing a monoclonal antibody containing parts from mouse and human antibodies, a required first step toward the development of humanized antibodies used later as medical therapeutics

- IBM unveiled the PC Convertible, the first laptop computer.
- NBA Finals: Boston Celtics won 4 games to 2 over the Houston Rockets
Genetic Alliance increases the capacity of advocacy organizations to achieve their missions and leverages the voices of millions of individuals and families living with genetic conditions. Genetic Alliance provides leadership and infrastructure development for more than 600 disease-specific advocacy organizations, representing over 1000 diseases, affecting over 25 million Americans.

We are committed to building capacity in all communities. The technical assistance we provide to advocacy organizations results in measurable growth: increased funding for research, access to services, and support for emerging technologies.

Genetic Alliance was founded in 1986—four years before the Human Genome Project was launched. More than twenty years later, in partnership with health providers, industry and academia, Genetic Alliance leads the cutting edge of advocacy and consumer interests in public policy relevant to genetics and genomics.

*Genetic Alliance programs and initiatives are made possible with funding from government agencies, foundations, private donations and industry contributions.*

*For more information, visit geneticalliance.org.*