The Alliance

of

Genetic Support Groups

Tenth Anniversary Gala

Honoring

Joan O. Weiss

Founding Executive Director

Saturday
October 12, 1996
Washington, D.C.
Warm greetings to everyone gathered in our nation's capital for the Tenth Anniversary Gala of the Alliance of Genetic Support Groups.

Genetic conditions can strike any family, causing hardship and suffering for everyone involved. But thanks to the members of the Alliance of Genetic Support Groups, individuals and families have access to the information and support services they need to cope with the financial, social, and emotional impact of such disorders.

I salute the Alliance members for a decade of consumer leadership in the genetics community. By educating the American people about genetic conditions and giving voice to the concerns of families affected by these conditions, you are providing a vital public service. On behalf of all those you have helped, I thank you for your compassion and commitment.

Hillary joins me in extending best wishes for a memorable evening and for continued success.
Greetings.

It gives me great pleasure to welcome all participants celebrating the tenth anniversary of the Alliance of Genetic Support Groups.

Since our inception in 1986, the Alliance has grown into a flourishing national coalition of voluntary genetic support groups, consumers, and professionals. Together, we address the needs of individuals and families affected by genetic disorders from a cross disability perspective. We also foster a consumer-professional partnership that advocates for accessible, appropriate, affordable, and culturally sensitive genetic services.

This occasion is a celebration of our many achievements and a time to recognize the outstanding efforts and dedication of our founder, Joan O. Weiss, whose vision and deep commitment to individuals and families affected by genetic disorders led to the creation of the Alliance. We are also pleased to honor all of our member groups which are represented this evening by the nine groups in the Hall of Fame.

Over the years, we have benefited from the involvement of caring individuals too numerous to mention. We are also deeply indebted to the Genetic Services Branch of the Maternal and Child Health Bureau, U.S. Department of Health and Human Services, for continuing financial support. Guidance from Dr. Jane Lin-Fu, GSB Chief, and our federal project officer, John Gallicchio, has been invaluable, and our close working relationship serves as a wonderful example of true partnership in the public interest.

We wish to express our appreciation to all of you for your past support. We wouldn’t be where we are without you, and now we need you more than ever as we begin our second decade of service to our members and the public.

Joan Burns
President
One's destination is never a place but rather a new way of looking at things.

Henry Miller

Joan Weiss, with her engaging smile and embracing manner, is the Pied Piper of genetics. Were she ever to stop her frenzy of activity long enough to look back, she would see a line of followers far too numerous to count. But Joan doesn't stop and look back any more than she rests on her laurels. She focuses on the work still to be done, seeking out the opportunities ahead.

Joan knows everyone in the world of genetics and is responsible for involving a good many of them. How many consumers have been launched by speaking to Joan's course at Georgetown? How many families have found the appropriate services and support by asking Joan? How many programs have been strengthened in response to Joan's question: "Why aren't consumers represented on the agenda?"

Always the advocate and the activist, Joan was a primary mover behind the two national symposia that laid the groundwork for the Alliance. In the proceedings of the first, "Genetic Disorders and Birth Defects in Families and Societies: Toward Interdisciplinary Understanding (1983), Joan summed it up: "...there has evolved a tremendous need for teamwork in this new, dynamic medical arena." At the second conference (1985) entitled "Genetics Support Groups: Volunteers and Professionals as Partners," her call to transform the energies of the over 80 groups present into power was heard and acted upon.

The rest, as they say, is the history of the Alliance of Genetic Support Groups.
Joan O. Weiss
MSW, LCSW

Founding member and Executive Director of the Alliance of Genetic Support Groups... social worker... public speaker... author... mentor... friend... board member... advisor... networker... enabler... first champion of the consumer/professional partnership... natural leader and teacher... inspired and inspiring... internationally recognized consumer advocate... a visionary who continually looks for new and better ways to meet the needs of individuals and families affected by genetic disorders.

Vision is the art of seeing things invisible.
Jonathan Swift
*Honorary Committee*

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The Alliance of Genetic Support Groups' Tenth Anniversary Benefit Gala is under the Honorary Chairmanship of:

The Honorable Nancy Landon Kassebaum
United States Senate

Victor A. McKusick, M.D.
Johns Hopkins Professor of Medical Genetics

Judy Woodruff
CNN's Prime Anchor and Senior Correspondent
Tenth Anniversary Benefit Gala
is under the Co-Chairmanship of Beverly Raff and Geraldine McGrath

Masters of Ceremony
Francis S. Collins, M.D., Ph.D.
Director, National Center for Human Genome Research

Julie Kurnitz
National Marfan Foundation
Actor, creator of the Workshop on Humor, Creativity and Chronic Illness

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Jayne Mackta
Betsy Trombino

The Tenth Anniversary Committee acknowledges with deep appreciation the unstinting efforts of Mary Ann Wilson, Alliance’s Consumer Staff Representative. Her boundless energy and deep commitment to the Alliance contributed greatly to the success of this evening’s Gala.

Well done, Mary Ann, and many thanks.
Tell me, and I’ll forget,
Show me, and I may not remember.
Involve me, and I’ll understand.
Native American Saying

The Honorary Committee of Support Groups is comprised of nine support groups which have played an integral part in the success of the Alliance. Some of these diverse organizations were participants in the historic national conferences where the need for a national coalition was conceived. Others have received assistance and support from the Alliance to nurture their own development. This give-and-take exemplifies the essence of the Alliance, where sharing from strength and experience is the defining bond.

We are pleased to honor these groups as models of voluntary genetic support groups. They reach out to individuals and families, professionals, and the public to provide information, services and support that can not be found elsewhere. A constant over the course of a lifetime, be it short or long, genetic support groups function as a safety net for individuals and families with a genetic diagnosis who need them in so many different ways at so many different times.

*Honorary Committee of Support Groups*

- Cystinosis Foundation
- Human Growth Foundation
- Neurofibromatosis, Inc.
- Treacher Collins Foundation
- National Organization for Rare Disorders
- Little People of America
- Osteogenesis Imperfecta Foundation
- National Marfan Foundation
- Support Group for Trisomy 18, 13, and Related Disorders (S.O.F.T.)
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The Alliance of Genetic Support Groups

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The Alliance is grateful to Eugenia Siegler, bookkeeper, for her devoted services from 1990 - 1996.

The Alliance is funded in part by Project #MCJ-241009-05 from the Maternal & Child Health Bureau (Title V Social Security Act) Health Resources and Services Administration, Department of Health and human Services.
The Kaplun "Art of Listening" Award

The "Art of Listening" Award encourages service providers to address the psycho-social needs of the whole person. Each year, the number of nominations grows, reaffirming our belief that professionals working with our families are highly skilled, compassionate and committed. The Alliance presents certificates to all nominees of the "Art of Listening" Award to acknowledge their willingness to take the time to communicate with individuals affected by genetic disorders and their families. We salute them all as outstanding role models.

This year, the Alliance recognizes Dr. Frederick Kaplan, who was nominated by members of the International Fibrodysplasia Ossificans Progressiva Association. He has described people with FOP as being encased in a suit of armor, an extraneous and imprisoning skeleton. It is an image that stays with him:

In one respect, FOP is a perplexing scientific riddle and one that desperately needs precise and effective solutions. In another respect, it is an inspiring story of determination, perseverance, and triumph of the human spirit — the likes of which I have never seen before nor imagined.

Fibrodysplasia Ossificans Progressiva means "soft connective tissue that progressively turns to bone." FOP is an autosomal dominant condition, and in most cases is the result of a new mutation. It is estimated that FOP affects approximately one in two million people. At the present time, researchers are aware of fewer than 200 people worldwide who have FOP.

International Fibrodysplasia Ossificans Progressiva Association was founded in 1988 by Jeannie Peeper, an adult who has FOP. IFOPA has more than 100 members in over 10 countries. In 1991, the IFOPA sponsored its first international symposium in Philadelphia, PA. Twenty-five families attended along with nearly fifty medical doctors and scientists from all over the world. For many of the families, it was the first time they had an opportunity to meet anyone else who had FOP.
Hearing is a gift; Listening is an art

The “Art of Listening” Award was created to focus attention on the importance of caring, receptive professionals in the lives of consumers. Funded by a grant from the Morris J. and Betty Kaplun Foundation, this award increases awareness of listening as an invaluable key to understanding and helping others. The award celebrates professionals who take the time to listen and understand, profoundly easing the difficult journey faced by families dealing with the uncertainties and ambiguities of a genetic diagnosis. Any professional who demonstrates an exceptional mastery of this skill is eligible to be nominated by an Alliance member for the award.

The Alliance of Genetic Support Groups is proud to present
The Kaplun “Art of Listening” Award to
Frederick S. Kaplan, M.D.
Chief of the Division of Metabolic Bone Diseases
University of Pennsylvania Medical Center

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ABOUT THE KAPLUN FOUNDATION
The Foundation was established by the late Morris J. and Betty Kaplun, refugees from Nazi persecution, to further humanitarian and Jewish concerns. The Foundation lends its support to a wide variety of educational, scientific and charitable institutions and has supported medical research in Israel and the United States at hospitals and universities, with special emphasis on eye diseases and Jewish genetic disorders.
The Alliance of Genetic Support Groups is pleased to present the "Art of Reporting" Award to **ABC News** for the production of several outstanding programs during 1996 on the ethical and social implications of genetic testing and genetic research. Our support group members have spoken of the sensitive and caring way in which they were interviewed, reflecting the producer's and interviewer's wish to understand the consumer perspective.

Some of these programs include:

*Nightline* — two programs; one pertaining to health insurance discrimination against individuals and families with breast cancer and with Fragile X; the other revealing the concerns of the dwarf community about new prenatal choices possibly leading to the eventual elimination of dwarfs.

*World News Tonight with Peter Jennings* — segment on the impact of learning one's predisposition to breast cancer on familial relationships.

*20/20 with Barbara Walters* — a special segment on the impact of Ataxia Telangiectasia on the Margus family, and the father's determination and success in getting scientists to identify the gene for A-T.

*Good Morning, America* — several excellent public education segments on genetic technology, testing, and treatment.

Accepting on behalf of **ABC News** is Kathleen Kennedy, Producer, **ABC News Nightline**.
To the Alliance of Genetic Support Groups.

Greetings and congratulations on your tenth anniversary.

As the Federal agency that has supported the Alliance since its inception, it has been both a pleasure and an inspiring experience to witness your development into an outstanding voluntary organization. For over a decade, your group of unusually dedicated consumer advocates has worked diligently for the availability and accessibility of high quality and culturally relevant genetic services.

A major reason for the success of the coalition is the remarkable vision, dedication, leadership and tenacity of your founding members and leaders. To many, the name of Joan Weiss has almost been synonymous with the Alliance. She has left her imprint on your unique organization through her dedication and untiring efforts. Through the professional-consumer partnership, Joan and Alliance lay leaders have unfailingly provided, and at times insisted on, the much needed consumers' perspective, a sine qua non for genetic services to really meet the needs of affected individuals and families.

I look forward to a bright future for the Alliance, and I value the opportunity of working with you all to ensure that our nation has the quality genetic services that its people deserve.

Sincerely yours,

Jane S. Lin-Fu, M.D.
Jane S. Lin-Fu, M.D., Chief
Genetic Services Branch
Division of Services for Children with Special Health Needs
Maternal and Child Health Bureau
“To wrest from nature the secrets which have perplexed philosophers in all ages, to track to their sources the causes of disease, to correlate the vast stores of knowledge, that they may be quickly available for the prevention and cure of disease—these are our ambitions.”

—Sir William Osler

Without Joan Weiss and the Alliance of Genetic Support Groups, we would not be able to realize these ambitions.

We thank Joan for all her advice and assistance when we began our journey. We are very grateful for her patience and leadership. She was instrumental in helping us reach the position we are in today. With her help, we have become global in just five years. We offer our congratulations on her foresight and endurance, and we wish her great success in her next endeavor. We are convinced she will embrace it with the same enthusiasm.

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The Alliance of Genetic Support Groups
Tenth Anniversary Benefit Gala

PROGRAM

Welcome
Dr. Francis Collins, Master of Ceremonies
Director, National Center for Human Genome Research

Opening Remarks
Joan K. Burns, President

Memorable Moments
Julie Kurnitz, Master of Ceremonies
Actor; Creator of the Workshop on Humor, Creativity and Chronic Illness

Presentation of Awards
Jayne Mackta, Immediate Past President

Introductions
Judy Woodruff, Honorary Co-Chairman
CNN’s Prime Anchor and Senior Correspondent

Kaplun “Art of Listening” Award
Dr. Frederick S. Kaplan

“Art of Reporting” Award
ABC News

Tribute to Joan Weiss
Dr. Victor McKusick, Honorary Co-Chairman
Johns Hopkins Professor of Medical Genetics
The Alliance of Genetic Support Groups

☐ Networking and Advocacy

☐ Voicing Genetic Consumer Concerns

☐ Support Services Helpline

The Alliance is a bridge between consumers and service providers. A flourishing coalition of voluntary genetic support groups, consumers and professionals, the Alliance serves as a national forum to address the needs of individuals and families affected by genetic disorders from a cross-disability perspective.

Most recently, the Alliance has developed two exciting collaborative programs:

The Partnership for Genetics Education is designed to enhance medical students’ and managed care organizations’ comprehension of the unique needs of and resources for individuals and families affected by genetic conditions.

The Human Genome Education Model (HuGEM) Project II, a collaboration with Georgetown University Child Development Center, aims to increase professional and consumer education of the social, ethical and legal implications of the Human Genome Project.

The Alliance of Genetic Support Groups is a 501(c)(3), not-for-profit organization. All donations to the Alliance are tax-deductible.
The Alliance of Genetic Support Groups is a flourishing national coalition that fosters a consumer-professional partnership dedicated to giving voice to common concerns of individuals and families affected by genetic disorders.

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