As the world shrinks and knowledge expands, the need for an international alliance of networks of genetic support groups grows. This report of the first International Gathering of Networks of Support Groups is a baby step toward finding ways to open channels of communication in order to overcome the isolation of individuals and families affected by genetic disorders wherever in the world they live.

Support Group Networks Gather during Int’l. Congress of Human Genetics

Saturday, October 5 was an exciting first. Representatives from different countries gathered at Georgetown University in Washington, DC to share experiences and resources as the first step toward organizing an international alliance of networks of support groups.

Sponsored by the Alliance of Genetic Support Groups and Georgetown University, the meeting was supported by a grant from the Ethical, Legal and Social Implications Program (ELSI) of the National Center for Human Genome Research, National Institutes of Health. Robert C. Baumiller, S.J., formerly Director of the National Center for Education in Maternal and Child Health as well as the Division of Genetics, OB/GYN Department at Georgetown University, and Jayne Mackta, president of the Alliance, served as moderators.

The keynote presentation was an eloquent statement by Dr. Nancy Wexler on “The Human Genome Project and the Future of Genetic Support Groups: International Cooperation.” She chairs ELSI and is president of the Hereditary Disease Foundation.

This newsletter documents an historic day and responds to the delegates’ request for a concrete outcome from the day-long exchange. All agreed that the strategies for forming an international alliance of support group networks be developed and possible sources of funding be explored.

The following countries made presentations: Australia; Hungary; India; Netherlands; Norway; Republic of South Africa; and USA. Several countries brought materials for display. See attached listing for participants and contacts.

Possible Objectives Offered

Ineke Roelofsz-Beltman, deputy director of VSOP, the alliance of national support groups concerned with hereditary and congenital disorders, The Netherlands, proposed objectives for an international alliance:

* To increase medical and public awareness about genetic disorders.
* To establish a forum for the exchange of ideas, information and experiences and the deliberation of policy.
* To collect and disseminate materials.
* To study ethical/psychosocial/legal aspects of genetics.
* To further genetic counseling and the provision of information.
* To support new groups.
* To focus interest of international bodies like WHO on genetics and congenital disorders.
* To hold meetings where various topics of common concern can be discussed.

Paul Mendelsohn, president of Neurofibromatosis, Inc., urged that an international network should immediately work together in the development of policy to protect individuals from the misuse of genetic testing and screening information.
SAIDA, The Southern African Inherited Disorders Association was formed in Johannesburg in 1974 at the request of a couple who had a child with Tay-Sachs disease. Since Tay-Sachs is a rare condition in South Africa, the staff of the Department of Human Genetics at the University of the Witwatersrand who were first approached, decided that it would be better to start an association to encompass all inherited disorders. There are now 20 groups under the umbrella of SAIDA. Educational activities include:

- Lectures and symposia; leaflets on common disorders
- Annual calendar containing listing of SAIDA support groups is distributed to medical practitioners
- Awareness weekends, during which groups put up displays at popular shopping centers
- Biannual newsletters sent to final year medical students; includes a directory of support groups
- Travel grants to scientists and group leaders
- SAIDA prize, awarded to the medical student who achieves the highest marks in the 3rd year human genetics examinations
- Annual support parent training program
- Provision of Thalassemia pumps for couples who cannot afford this necessary treatment
- START (Strive Towards Achieving Results Together) program for trained assistants who are taught to stimulate retarded children who don't have access to such programs.

VSOP, an alliance of 35 national support groups concerned with hereditary and congenital disorders in the Netherlands, represents 200,000 families in Holland. Together with the Ministry of Health and the seven regional genetic counseling centers, a program has been set up directed to high school students, ages 15 and older, people considering parenthood, pregnant women, and couples at risk. The program has begun to place advertisements in newspapers. VSOP is preparing a comprehensive collection of educational materials for the various target groups.
The Association of Genetic Support of Australasia (AGSA) encompasses Australia and New Zealand. The Association grew out of needs identified through The New South Wales Genetic Education Program which was established by the NSW Department of Health in 1988. One project is the publication of a catalogue of genetic support groups to give professionals a referral source. Now in its third edition, the catalogue lists 56 support groups. It was during the development of the first catalogue that a need for a network of support groups was recognized. A public meeting was called to launch AGSA in October 1988. 250 people attended. AGSA aims to:

- Educate the medical and allied health professionals and community about genetic disorders.
- Lobby government bodies, both Federal and State, for appropriate funding for genetic services.
- Provide a contact point for families who are affected by genetic disorders so rare they do not have their own support group.
- Facilitate accessibility to individual support groups.
- Provide a forum for the exchange of information between support groups regarding common concerns and availability of community services.

OF SPECIAL INTEREST: The NSW Department of School Education has contracted with Dr. Kristine Barlow, Program Director of the New South Wales Genetic Education Program, to develop 20 lessons to be taught in the compulsory health curriculum for students aged 12 to 16 years. This will insure that all students, not just those who study biology, will be aware of the importance of genetics in health and human development. Kristine has promised to make this curriculum available to interested groups through the International Alliance.

E-Mail May Be the Answer for Int'l. Communication by Deborah de Leon, MS, Movement Disorder Group

Genetic support groups, genetic service providers, voluntary organizations, and alliances or coalitions of such groups all appear to share the same consumer advocacy goals: outreach, education, enhanced awareness, and improved communication. On an international level, there are organizations such as the World Health Organization (WHO) or UNESCO that should be approached as possible resources for developing an international alliance of networks of genetic support groups. Other possibilities are the Human Genome Project (HUGO) and the European Communities Genome Program (Eurogem) because they already function in a coordinating capacity for programs operating in different countries.

Electronic Mail (e-mail) telecommunications allow for prompt, efficient and inexpensive international networking. There are a number of e-mail systems to which people interested in sharing information about genetic support groups or services might have easy access. For example, Bitnet and Internet are both free for many university affiliates. The procedure is quite simple. One needs only a personal computer and a modem in order to call a computer that is on the Internet system. There are also a growing number of fee-for-service e-mail systems including Sprintnet*, AT&T mail*, Compuserve*, Infonet, GE mail, and MCI mail*. Those starred are currently the only ones that connect to the Internet system. Sprintnet has the greatest international access at the moment. Compuserve, while the most expensive of the systems, has multiple public forums for leaving questions or comments and for receiving replies. Several forums of particular interest to our potential members would be TELECOM, IBMEUR, and GENEALOGY forums. The Internet also has a forum system, although responses to questions are much slower.

We will explore the exciting possibilities of e-mail to facilitate communication and share the recommendations with you in the near future.
Sharing Thoughts on the International Gathering

This international meeting of genetic support advocates has many and varied roots throughout the world. Every parent of a special needs child and every affected individual regardless of culture, tradition, economic status or social position feels a kind of isolation, a separation from the rest of humankind. This feeling too often is only understood by someone else with similar experience. With the knowledge that I am not alone comes the ending of isolation and the recognition that we are all the family of man.

With isolation comes depression and in some sense, death; with association comes positive sharing, hope and life. The formalization of this alliance of supporting networks has progressed as families and individuals have raised their voices and as sensitive professionals have recognized us more as people rather than parents or cases. Further, we have made progress as the general public have come to realize that we are all the same inside, regardless of the minor external and really peripheral differences which we allow to separate or differentiate us from one another.

This world-encompassing meeting is the newest dimension in our evolution. While we in our own communities, our families, our local support groups and our countries are at various stages of progress, the common experience is that we all have similar needs and hopes and demands. Let us build on each other’s successes and learn by each other’s mistakes. Perhaps someday no one, anywhere, will feel isolated for very long, and we will be sure that our perspective is heard as medical genetic advances occur.

Robert C. Baumiller, S.J., School of Health Sciences
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As Canadians, we welcome the chance to join an international linking of networks. Although we are fortunate to have many well established groups in our country, we are certain to benefit from the experience of other countries whose approaches to genetic services differ from our own. As well, we would like to have the opportunity to assist other countries/organizations, in their efforts to develop new support groups. The ability to exchange addresses and names of support groups with other countries would allow families that we know who travel or are moving to another country to be in contact with people who understand their special needs.

In Canada, we have just completed a directory of Canadian Genetic Support groups which will be updated on an annual basis and is maintained and supported by our national organization of genetic counselors. This places us in an excellent position to link with international support groups since this permanent organization is responsible for the directory and will therefore be a permanent contact for other countries to obtain the Canadian information they require.

Clair Goldsmith, Children’s Hospital of Eastern Ontario
Nancy Scanlan, Children’s Hospital of Western Ontario

For many parents of a child with a genetic disorder, their first contact with a support group signals the end of isolation and the start of a fellowship and mutual support system which may carry them through a lifetime of tragedy, distress or difficult adjustments.

How wonderful then, to see the beginning of an international fellowship of fellowships! This new contact may bring us extra knowledge, help, advice, empathy, and a feeling of community with others throughout the world who face similar challenges.

It is ironic that much of our knowledge about genetics has been derived from studies of genetic abnormalities. By studying the mechanisms of aberrations, we learn a whole lot about how things normally work. Let’s extend the analogy from science to human relationships. Perhaps this super-super support group for a variety of disorders can set the example in the field of international relationships in general.

Faced by special and unusual challenges, we have joined together to form a world-wide community of support. The emphasis is on what we have to offer rather than on what we can get out of it. It would be gratifying if we could serve as an example to others working for common and not-so-usual causes like the battle against hunger and the quest for international peace. Let’s go for it!

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