Alliance of Genetics Support Groups

On August 13 this year, a steering committee which was appointed at the recent symposium "Genetics Support Groups: Volunteers and Professionals as Partners" convened. The committee's purposes, as directed by the symposium's participants, were: to organize a task force; to enumerate goals and objectives of the task force; to secure funding for the committee and task force; to develop a means of communicating progress of the task force among individuals and organizations; and to consider the feasibility of affiliating with the National Organization for Rare Disorders.

The participants at the steering committee meeting were: Marcia Boyle, Jessica Davis, Ruby Horansky, Lee Kitchens, George McCoy, Jean-Paul Richard, June Vavasseur, Greg Weigle, and Joan Weiss. Consultants were E. Robert Arrindell, M.S.W., Genetics Diseases Services Branch, DMCH; Robert C. Baumiller, S.J., Ph.D., Division of Genetics, Georgetown University Hospital; and Beverly Raff, Ph.D., March of Dimes Birth Defects Foundation. The participants agreed to have Greg Weigle serve as chairman of the committee.

After a lengthy discussion on the purpose of the Alliance, the steering committee came up with a number of proposals. These may be stated as follows:

1. To raise the consciousness of the general public and professional community concerning the effect of genetic anomalies on those affected and their families.
2. To share organizational information.
3. To monitor and comment on pertinent legislation.
4. To educate existing public organizations on how to better serve the group's constituency.
5. To address national issues where a consensus exists among constituent groups.
6. To encourage intra-communication among constituent organizations.
7. To help avoid policy conflicts among constituent organizations.
8. To enhance each group's awareness of existing cross-disability similarities.

The committee agreed that "information" was the single, common, dominant purpose of the Alliance. The

Welcome

Greetings from your Nation's Capital. We would like to introduce you to this organization: Alliance of Genetics Support Groups, and its newsletter, the Alliance. We are a group in its formative stages, bringing together many different voluntary genetics support groups around the country. Our steering committee consists of nine members: seven from the field of voluntary support groups, and two from professional fields closely allied with these groups.

As an outgrowth of a recent symposium, "Genetics Support Groups: Volunteers and Professionals as Partners," our purpose is to explore the feasibility of, and need for, a formal ongoing organization. To this end we have developed the enclosed questionnaire for your response. Based on the responses to the questionnaire and the input we have already received, we will recommend a form and scope for this Alliance.

You will continue to be advised on the progress of the Alliance through this newsletter. Our current plan is to publish a quarterly newsletter with interim updates, if necessary. We are asking for your ongoing participation in this endeavor. We are aware of the diverse natures of our constituent organizations and realize that only with mutual communication will we succeed.

We have made an enthusiastic start. As you read the following articles, you will get a sense of how far this idea has traveled in a short time. But enthusiasm, however great a motivator, will not be sufficient to produce a solid, functioning organization. For this we need planning, patience, hard work, and cooperation. And we need your help. We look forward to receiving your input.

Greg P. Weigle,
National Down's Syndrome Congress
Joan O. Weiss, A.C.S.W.
Senior Social Worker, Genetics
Johns Hopkins Hospital

gathering, sharing, and dissemination of good, accurate information concerning genetic anomalies and their effects on all aspects of the lives of individuals and families is of paramount importance.

The steering committee recognized the need for continued autonomy of each organization. This was evident from the lengthy discussion concerning the name of this

A Coalition of Voluntary Organizations and Professionals
The Time for Networking is Now

The symposium was a great success, according to your evaluation and the positive feedback that we are still receiving. You, as participants, were the ones who made it work so well. A book is being published by the Division of Maternal and Child Health and the March of Dimes Birth Defects Foundation based on the proceedings of this conference.

From your collective evaluation the highlights of the sessions were as follows:

1. The workshops on self-help and life cycle needs.
2. The workshops on self-help for families in crisis.
3. The workshops on how to start a self-help group.
4. The workshops on networking: a) educating health care professionals and b) a strategy on lobbying.
5. The workshops on self-help for family members and on peer counseling.

One of the strong recommendations that came out of the symposium was for the formation of a task force to create a coalition of all the genetics support groups. I trust that you will be pleased to learn that the process has begun.

The planning committee elected a steering committee composed of the following symposium participants: Robert J. Beall, Cystic Fibrosis Foundation; Marcia Boyle, Immune Deficiency Foundation; Jessica Davis, North Shore University Hospital; Ruby Horansky, Huntington’s Disease Association and the National Organization for Rare Disorders, Inc. (NORD); Lee Kitchens, Little People of America and the Human Growth Foundation; George D. McCoy, National Hemophilia Foundation; Jean-Paul Richard, OINCA; June Vavasseur, National Association of Sickle Disease, Inc.; Greg Weigle, National Down’s Syndrome Congress; and Joan O. Weiss, Johns Hopkins Hospital. Professional advisors include E.

(cont. from page 1)

Robert Arrindell, M.S.W., Division of Maternal and Child Health; Robert C. Baumiller, S.J., Ph.D., Georgetown University; and Beverly Raff, Ph.D., March of Dimes Birth Defects Foundation.

The steering committee, convened by Greg Weigle, met in Arlington, Virginia on August 13th, with the generous support of the March of Dimes Birth Defects Foundation. It was emphasized that whatever alliance is founded through the efforts of the steering committee, this should not affect the individual organizational structure and goals. Hopefully, the networking which began at the symposium will continue to be strengthened through the formation of this projected coalition of voluntary genetics organizations.

The enclosed questionnaire is important in that only with your comments and suggestions will we be able to create a truly representative coalition. We count on you to help build a strong alliance of all the genetics voluntary organizations.

I look forward to our continuing cooperative efforts to open up communications, learn from one another, and educate the public, as well as individuals and families represented by our genetics support groups.

Historical Background

In the spring of 1983 a national symposium took place in Baltimore, Maryland on “Genetic Disorders and Birth Defects in Families and Society: Toward Interdisciplinary Understanding.” Like our recent symposium on genetics support groups last June, the first symposium was supported by the March of Dimes Birth Defects Foundation and the Division of Maternal and Child Health, along with Mead-Johnson, and sponsored by the Johns Hopkins Medical Institutions. The symposium evolved because of a recognition of the need to consider the social and psychological impact of genetic disorders on families and society, in a time of ever-increasing scientific advancements. A second impetus for the initial symposium was the need for an interdisciplinary focus on genetics. Participants included affected individuals and family members, physicians, educators, social workers, nurses, genetic counselors, pastoral counselors, lawyers, nutritionists, and bioethicists. This was the first national interdisciplinary conference dealing with educational needs of professionals in genetics, patient and family needs, and advocacy issues.

Out of one workshop on “Family Support Groups: Setting Goals” came the suggestion that a coalition of the individual support groups be formed to legitimize them, help them become a unified force with a unified purpose, provide them with a link to the scientific and research communities and to the political power structure, and help with public education. One clear message from that first symposium was the need for voluntary genetic organizations to share information with one another and with professionals in a future conference. That future has already become the past.

We have had that conference, again with the support of the March of Dimes Birth Defects Foundation and the Division of Maternal and Child Health, and the sponsorship of Georgetown University and Johns Hopkins. Over eighty genetics voluntary organizations sent representatives to Washington, DC in June, 1985. The networking that began there at the Ramada Renaissance was extraordinary, not just at the sixty-odd workshops and the Marjorie Guthrie Memorial Banquet or at the opening sessions at which Beverly Sills spoke, but, most of all, between sessions and before and after workshops.

And now, the future belongs to you — in the shape of a national alliance of voluntary genetics groups.

Many thanks.
Greg Weigle
Steering Committee Chairman

Joan O. Weiss, A.C.S.W.
This questionnaire has been developed by the Steering Committee of the Alliance to explore the opinions of all affected organizations about the future direction of a genetics network. Please feel free to circulate copies of the questionnaire to your members, as well as to other organizations which might be interested. However, we need your answers to our questions if we are to know how best to shape the Genetics Alliance to meet the needs of your organization.

**NEEDS**

1. **How useful** would your organization/group find the following types of services if they could be provided to you by a national organization of genetic disease groups:

<table>
<thead>
<tr>
<th>Technical Assistance in:</th>
<th>Very Useful</th>
<th>Somewhat Useful</th>
<th>Slightly Useful</th>
<th>Not Really Useful</th>
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<tbody>
<tr>
<td>a. Fund-raising</td>
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<td>b. Membership organizing</td>
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<td>c. Legal matters</td>
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<td>d. Legislative activities at state level</td>
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<td>e. Legislative activities at national level</td>
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<td>f. Public relations</td>
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<td>g. Self-help groups</td>
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<th>Information about:</th>
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<tr>
<td>a. Federal programs and agencies</td>
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<tr>
<td>b. State programs and agencies</td>
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<td>c. Proposed legislative and regulatory changes</td>
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<td>d. Genetic research studies</td>
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<td>e. Available genetic services</td>
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<th>Networking with:</th>
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<tr>
<td>a. Genetics voluntary organizations at the national level</td>
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<td>b. Professional organizations at the national level</td>
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<tr>
<td>c. Genetics voluntary organizations at the regional, state, or local level</td>
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<tr>
<td>d. Professional organizations at the regional, state, or local level</td>
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<th>Coordinating:</th>
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<tr>
<td>a. National public education efforts</td>
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<td>b. National legislative efforts</td>
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<tr>
<td>c. National fund-raising campaigns</td>
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2. **What other services might a national organization of voluntary genetics groups offer which would be useful for your group/organization?**

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

3. **How important do you think it is for voluntary genetics groups to develop a national organization to provide services like these?**

______ Very Important ______ Fairly Important ______ Not Too Important ______ Not At All Important
GOALS

4. We have listed below a series of potential goals for a national organization of genetic disease groups. Please indicate the degree to which you agree or disagree with the statement as a central goal for the proposed national organization:

<table>
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<tr>
<th>Strongly Agree</th>
<th>Neutral</th>
<th>Disagree</th>
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<td>1</td>
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a. To raise public consciousness about genetic disorders and affected families  
b. To share information about state laws, insurance regulations, funding, legislation, etc.  
c. To alert the public to legislation and public policy affecting genetic diseases  
d. To assist existing public organizations to serve more effectively  
e. To address national and ethical issues where a consensus exists  
f. To share organizational information among member groups

5. What other goals do you think should be included in the formal statement as the core objectives of a national organization of genetic disease groups?

______________________________________________________________________________

______________________________________________________________________________

6. Considering the goals listed in Question 4, and other goals you may have added in Question 5, please indicate below what you think should be the three most important goals of the national organization, in order of priority, if possible:

First: ________________________________________________________________________

Second: _____________________________________________________________________

Third: _______________________________________________________________________

7. Is there anything you think that such an organization should not include in its goals or objectives?

______________________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________

ORGANIZATION

8. Should the national organization be incorporated as a charitable corporation (501(c)(3)) so that it can raise and administer donations or should it be restricted to an informal coalition?

______ Charitable Corporation  
______ Informal Coalition

9. Do you think membership in the national organization should or should not be open to the following types of organizations or persons?

<table>
<thead>
<tr>
<th>Type of Organization/Person</th>
<th>Should Be</th>
<th>Should Not Be</th>
<th>Don't Care</th>
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</thead>
<tbody>
<tr>
<td>a. Incorporated disease groups</td>
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<tr>
<td>b. Unincorporated disease groups</td>
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<tr>
<td>c. Foundation sponsors</td>
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<tr>
<td>d. Corporate sponsors</td>
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<tr>
<td>e. Federal agencies</td>
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</tbody>
</table>
f. State agencies

g. Professional groups

h. Research groups

i. Unaffiliated professionals

j. Unaffiliated individuals

10a. Do you think voting membership—i.e., the right to elect officers and directors, as well as pass by-laws—should be extended to all members or only certain types of members?

___ All members (Skip to Question 11)

___ Certain members (Answer Question 10b)

10b. To whom should voting membership be restricted?

________________________________________________________

11. Should the organization establish its own medical and professional advisory boards?

___ Yes

___ No

12. Should the organization try to develop its own staff or rely on volunteers from member organizations?

___ Own staff

___ Member organization staff

FINANCING

13. Should the national organization establish annual membership dues?

___ Yes

___ No

14. Should membership dues be uniform or based upon a sliding scale?

___ Uniform

___ Sliding scale

15. Should the national organization seek funding from the following sources:

   Yes          No

   a. Government grants
   b. Government contracts (e.g., clearinghouse)
   c. Foundation grants
   d. Corporate donations
   e. Individual donations
   f. National fund-raising activities
   g. Local fund-raising activities
   h. Other (Specify) ____________________________
16. If a national alliance for voluntary genetics groups was established, how likely do you think your organization/group would be to join it?

____ Definitely join
____ Probably join
____ Probably not join
____ Definitely not join

17. How likely do you think it is that your organization would be able to provide the national organization with:

<table>
<thead>
<tr>
<th></th>
<th>Very Likely</th>
<th>Somewhat Likely</th>
<th>Somewhat Unlikely</th>
<th>Very Unlikely</th>
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<tbody>
<tr>
<td>a. Modest membership dues</td>
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<tr>
<td>b. Participation on committees</td>
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<tr>
<td>c. Local coordination</td>
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<tr>
<td>d. Technical expertise in certain areas</td>
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<td>e. Participation in legislative matters</td>
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18. The name of the organization proposed by the steering committee is Alliance of Genetics Support Groups: A Coalition of Voluntary Organizations and Professionals.
   Do you think this proposed name is appropriate for the type of organization that you have just addressed in this questionnaire?

____ Yes
____ No

Additional comments ____________________________________________
________________________________________________________________
________________________________________________________________
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THANK YOU FOR YOUR TIME AND SUGGESTIONS.
We have purposely allowed an extended deadline for returning this form in order to get as many responses as possible. Please return it as soon as possible rather than waiting until the deadline is preeminent.

PLEASE PLACE THIS QUESTIONNAIRE IN THE MAIL BEFORE DECEMBER 31, 1985 TO:

Alliance of Genetics Support Groups
38th and R Streets, N.W.
Washington, DC 20057
Input by Support Groups Can Make a Difference in Education

Human genetics instruction has become a vital component of health and science education for medical professionals and the lay public. Interest in human genetics expertise is mounting, as demonstrated by an increasing number of seminars and conferences addressing genetics topics. Presently there is a burgeoning movement to introduce genetic topics into primary and secondary schools. Genetics support groups, such as those comprising the Alliance, can make a significant contribution to the development and implementation of various genetics educational programs. Who better understands diagnostic procedures, modes of treatment, and the impact of inherited disorders than the families and professionals actively participating in support groups? For years support groups have worked to raise funds for research, educate lay and professional groups, and provide psychosocial support to families. In addition, many publish newsletters, distribute excellent educational materials, and provide speakers—all of which contribute to various aspects in genetics. Communication with genetic support groups will strengthen the efforts of genetic centers, state genetics programs, and regional networks involved in genetics education.

Various genetics education materials have been developed for use in grades kindergarten through twelve. The Biological Sciences Curriculum Study (BSCS) Center for Education in Human Genetics has cooperated with several groups to produce the following textbooks and educational packages.

- **You, Me and Others**, a K-6 program, was developed by BSCS with support from a March of Dimes Birth Defects Foundation grant. This program addresses three major units, "Variety," "Change," and "The Chain of Life." Each unit consists of a 20-page teacher's guide containing lesson plans, reproducible masters, and suggestions for student activities. The three units are available at $5 per unit or $12 for the complete set from: March of Dimes Birth Defects Foundation, Supply Division, 1275 Mamaroneck Avenue, White Plains, NY 10605. The complete BSCS curriculum upon which the units are based can be obtained by writing to BSCS, The Colorado College, Colorado Springs, Colorado 80903.

- **Genes and Surroundings**, a junior high/middle school program, was developed under grants from the Health Services Administration, Bureau of Community Health Services, Genetic Disease Services Branch. Twenty-five activities demonstrate major concepts in genetics including variability, continuity, patterns of development, and interaction of genotype and environment. These books can be ordered from: Kendall/Hunt Publishing Company, 2460 Kerper Boulevard, P.O. Box 539, Dubuque, IA 52001.

- **Basic Genetics: A Human Approach**, developed under a grant from the National Science Foundation, is a 6- to 8-week course for high school students. The student book contains almost 50 separate activities that demonstrate the basic principles of human genetics and address the individual and societal issues arising from the application of this new knowledge. A comprehensive teacher's guide provides detailed instructions for each activity and strategies for organizing effective classroom discussions about science/society issues. The Basic Genetics student book sells for $4.75 and Genes and Surroundings student book sells for $3.95 each; the teacher's guide for Basic Genetics costs $6 and Genes and Surroundings sells for $5.

- **Living With Cystic Fibrosis** has been developed by BSCS for use at the high school level. Development of this program was supported by a grant from the Cystic Fibrosis Foundation. The topic is presented to students in a newspaper format, The Helena Daily Telegraph. Living with Cystic Fibrosis conveys a great deal of information about basic human genetics while discussing the psychosocial issues related to a chronic heritable disorder. Copies of the teacher's guide and the student newspaper are available from local chapters of the Cystic Fibrosis Foundation.

High school teachers, particularly, have shown increasing interest in the introduction of human genetics into life science, child development, and family life classes. Several genetics centers have implemented successful teacher training programs, which vary in length from one to several days and are usually part of a continuing education program for the teachers. These training programs are organized with specific teacher-oriented features in mind:

1. The focus is on educating the teachers, not the students. Each teacher reaches 100 students each year.
2. The lecturers are chosen for their ability to relate to the teachers. Ideally, the audience will be comfortable enough to ask questions throughout the sessions.
3. The audience is kept as homogeneous as possible, making the course easier to teach. For example, a group of senior high school biology teachers will have similar needs, experiences, background knowledge, problems, and questions.
4. The workshops primarily attempt to provide teachers with current information and to broaden their perspectives of what constitutes genetics.
5. The workshops emphasize the impact of human genetic disorders on the individual and society, as well as the importance of understanding genetics concepts and their applications. Actual case histories are used where appropriate.

Members of the Alliance can have an impact on the development of genetics educational materials as well as teacher training programs. Educational materials can be reviewed and shown to school personnel who might use them in the classroom or to initiate training programs in their school. Teacher training workshops provide an excellent opportunity for members of genetics support groups to share their expertise and experience with educators. Genetic services centers and state genetics coordinators can provide information about ongoing educational programs. Members of the Alliance of Genetics Support Groups should not miss the opportunity to make an impact on the genetics education movement.

Anna Hamilton, B.S.
Genetics Associate
National Center for Education in Maternal and Child Health
Conference Survey Findings

Individuals from voluntary genetics organizations attending the June conference were given a questionnaire to find out more about the ways in which they assist their members. Survey questions addressed six general areas, and were designed to identify current attitudes and trends in the service delivery field. The following is a summary of the responses.

Services and Activities

Organizations provide technical services and coordinate activities. Specifically, they most frequently offer peer counseling; information about genetic disorders and self-help activities to their members; and distribute information to the public. Also, the majority of the survey responses support both individual and group advocacy, and fund-raising activities.

Referrals

Voluntary organizations receive most of their members through references from outside sources. Social workers and nurses are the most common referral origins, but the survey indicates that a number of people respond directly to the organization's own advertising as well.

Outside sources most often refer members for assistance, particularly medical care and genetic services. Positive relationships with the organization's professionals usually result. Of these professionals, only one-third serve as leaders of their groups; most are involved mainly as lecturers, consultants, and advisory board members.

Services Related to Specific Genetic Concerns

A majority of the organizations provide basic services, such as education about the disorder and help with emotional adjustment. Also, nearly one-half inform the extended family of the genetic nature of the disorder, make children aware of their own reproductive risks, and assist in the decision-making process concerning their risks.

Personal Impact of Genetic Disorders on Families

Many respondents claim the genetic disorder has brought their families closer together. However, a number of stresses are noted, most commonly financial burden, strain among members of the immediate and extended families, and disruption of plans for having children.

Genetic Counseling

Most members have had helpful genetic counseling, but existing barriers continue to prevent people from receiving help. They see as the greatest barriers a lack of need, a perceived lack of available genetic services, and local physicians' failure to make referrals. In addition, members recommend more education about genetic counseling for both general physicians and patients. Write-in comments stress the importance of the manner and timing of genetic counseling, the need for multiple sessions, and increased financial and emotional (supportive) counseling. Over one-fourth of the respondents express concern about the lack of basic medical care for affected individuals.

Voluntary Genetics Organizations and Professionals

In the open-ended section of the survey, the responses indicate a desire for health care professionals to be more knowledgeable about specific disorders, more involved with the voluntary genetic groups, and more sensitive to individual needs as well as organizational needs.

Many members believe they can better assist professionals by disseminating more information about their disorders, and sensitizing professionals to the personal nature of their disorders.

Joan O. Weiss, M.S.W., A.C.S.W.
Rita Beck Black, D.S.W.

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