Integrating Consumers Into The Regional Genetics Networks

The Alliance of Genetic Support Groups
35 Wisconsin Circle, Suite 440
Chevy Chase, MD 20815

1/800/336-GENE

A report prepared by Jayne Mackta, President
April, 1992

The Alliance is funded in part by project #MCJ-11108-03 from the Maternal and Child Health Program, Title V Social Security Act, Health Resources and Services Administration, Department of Health and Human Services.
"Tell me, and I'll forget.
Show me, and I may not remember.
Involve me, and I'll understand."

Native American Saying

INTRODUCTION

This report is dedicated to the genetics community, consumers and professionals committed to insuring the availability, accessibility and utility of appropriate services for individuals and families affected by genetic disorders. It is a road map to partnership.

Part I is a history detailing where we have been and how we have gotten to where we are.

Part II describes the companions on this exciting journey who must help each other along the way.

About the Alliance

The Alliance of Genetic Support Groups is a bridge between consumers and service providers. A flourishing coalition of voluntary genetic support groups, consumers and professionals, Alliance serves as a forum for addressing the needs of individuals and families affected by genetic disorders from a national and cross disability perspective. We maintain strong linkages with voluntary, governmental and professional organizations on the local, state, regional, and national levels in order to fulfill our mission to promote the sharing and prompt dissemination of new information, strategies and technologies related to genetic services. We provide technical assistance to genetic support groups and link families whenever possible to the appropriate group or needed services.

A major focus of Alliance activity is to identify mechanisms for communication and the sharing of information. This report targets the integration of consumers into the Regional Genetics Networks as a key strategy. Taken altogether, this report will serve to heighten consumer awareness of the Networks and encourage involvement. Just as important, we hope that the Networks will find suggestions to ease consumer integration and will make use of the many different contributions that consumers can make — to the benefit of all.
Federal involvement in the health and welfare of mothers and children dates to the founding of the Children’s Bureau in 1912.

The process that led to the establishment of the Children’s Bureau still works today and underscores the important contributions that small interest groups can make in shaping public policy encouraging responsive government. This new agency was first championed at the turn of the century by women such as Lillian Wald, founder of the New York City Henry Street Settlement, Florence Kelley of the National Consumer’s League, and Jane Addams of Hull House.

The first White House Conference on Children in 1909 played a major role in bringing about the legislation establishing the Children’s Bureau. Called by President Theodore Roosevelt with impetus from those concerned with child labor issues, the conference was the first of several where people from a wide range of fields interested in or involved with children came together to develop broadly based platforms and agendas.

From the start, the Children’s Bureau crossed territorial boundaries. When no existing agency would accept responsibility for the proposed bureau, the Children’s Bureau was established as a separate agency within the Department of Commerce and Labor. Its mission was to investigate and report "... upon all matters pertaining to the welfare of children and child life among all classes of our people, and shall especially investigate the questions of infant mortality, the birth rate, orphanages, juvenile courts, desertion, dangerous occupations, accidents and diseases of children, employment, legislation affecting children ..." The Children’s Bureau initially focused on areas of research, and it was not until passage of the Social Security Act in 1935 that it was able to provide substantive programs.

By 1917, the Children’s Bureau was recommending the provision of maternal and child health services to local communities through state agencies with grants of federal funds.
matched by the states. In effect, the proposed new program expanded the function of the Children’s Bureau to include administration and supervision. Hearings were heated. Opponents feared socialized medicine, too much federal power, violations of states’ rights and meddling with mother love.

As the health aspects of the program became increasingly important, the role of the Public Health Service became an issue. One account maintains that the Public Health Service opposed the first maternity and infant care act; another that there was competition between PHS and the Children’s Bureau for control over the program and that “the Public Health Service had been derelict in not promoting this type of work with sufficient vigor to maintain its belated claim to jurisdiction.”

The Sheppard-Towner Act which was finally passed in 1922 and stayed in effect until 1929 provided grants to the states that required federal review and approval. To benefit from the act, state legislatures had to accept its general provisions and designate a state administrative agency. Under the Act, 45 states submitted programs for approval; three had programs of their own and did not apply for federal funds. As could be expected, when the act expired and federal funds stopped, few states maintained their level of programing to mothers and children; most reported decreased expenditures; nine appropriated no funds at all.

When the landmark 1935 Social Security Act was passed, it contained in Title V provisions that again provided financial support for programs to be carried out on the state level and administered by the Children’s Bureau. These included Maternal and Child Health Services [MCH], Crippled Children’s Services, and Child Welfare Services. During 1946 in an effort to strengthen child care programs, the Children’s Bureau was placed in the Federal Security Agency which became the Department of Health, Education, and Welfare [HEW]. In 1969, the MCH program was moved to the Public Health Service of HEW. As of 1992 it is known as the Maternal and Child Health Bureau within the Health Resources and Services Administration of the Department of Health and Human Services.

**MCH and Genetics**

The 1950s and ‘60s saw a broadening of MCH programs which included emphasis on services for individuals with mental retardation. In addition to the treatment of medical problems and support for research, attention was paid to psychosocial problems of patients. There was also recognition of the importance of community-based family support services. In the mid-50s, MCH supported the delivery of genetics services through the creation of multi-disciplinary clinics designed for diagnosis, counseling, and long-term management of children with developmental delays and mental retardation.

A pilot study by Dr. Robert Guthrie laid the foundation for newborn screening for Phenylketonuria that can be described as the first public health program in genetics. The 1960s brought more specific involvement when MCH began to support the development of state newborn screening programs for metabolic disorders, biochemical and cytogenetic laboratories, and training in medical genetics. There was also support for University Affiliated Facilities to provide interdisciplinary training in the diagnosis and management of handicapped and mentally retarded individuals.

MCH support of community-based sickle cell clinics in the early 1970s set the stage for the development of statewide genetics projects to serve families and individuals with a wide variety of genetic problems. A legislative mandate was provided by The Omnibus Genetics Bill of 1976, Title IV of Public Law 84-278: The National Sickle Cell Anemia, Cooley’s Anemia, Tay-Sachs and Genetic Diseases Act. It authorized a national program for basic and applied research, and testing and counseling for the diagnosis, control, and treatment of genetic diseases. Not until 1978 were funds actually appropriated, and $4 million went to MCH for genetics. Support was given to develop and disseminate information to the general public and health care providers; to improve laboratory capabilities for confirmatory diagnostic services on state and regional levels; and to assist the establishment and coordination of statewide programs. By Fiscal Year 1991, all fifty states, the District of Columbia, Puerto Rico and the Virgin Islands had received four year grants of “seed money” to develop statewide genetic services.

The Genetic Diseases Service Branch, now the Genetic Services Branch (GSB), came on the scene in 1978. Its primary objective was and continues to be to plan, implement and evaluate a program integrating genetic services into a comprehensive system of family centered, community-based care. With heightened awareness of the needs of underserved populations, the Branch encourages programs that not only increase the availability and accessibility of quality genetic services, but increase the utilization and benefit of such services. GSB administers grants and contracts that provide seed money for projects in priority areas determined by the Branch each year.
The Federal budget for MCH is voted on by Congress each year. At present, under the Maternal and Child Health Block grant legislation, 85 percent goes directly to state Title V agencies. The remaining 15 percent is used to fund discretionary programs called Special Projects of Regional and National Significance (SPRANS). These so-called “set-aside funds” provide for research; training; hemophilia diagnosis and treatment; genetic diseases screening, counseling and referral; and maternal and child health improvement project grants.

Genetics programs administered by GSB account for less than 10 percent of the total set-aside funds. Ten Regional Genetics Networks, the Council of Regional Networks for Genetics Services (CORN), and the Alliance of Genetic Support Groups, along with several other projects are SPRANS grants funded by the GSB.

Ten Regional Genetics Networks cover all 50 states, the District of Columbia, Puerto Rico, and the Virgin Islands. The New England Regional Genetics Group (NERGG) was the first Regional Network. NERGG grew out of a project contracted in mid-1977 by the MCH-funded Developmental Evaluation Clinic at the Children's Hospital in Boston. It was founded in 1978 as a consortium of genetic service providers, public health planners, consumer groups, and federal and state Maternal and Child Health personnel. The Texas Genetics Network (TEXGENE), with funding beginning in 1988, is the most recent and the last. The others are:

- Mid-Atlantic Regional Human Genetics Network (MARHGN)
- Mountain States Regional Genetic Services Network (MSRGSN)
- Pacific Northwest Regional Genetics Group (PacNoRGG)
- Pacific Southwest Regional Genetics Network (PSRGN)
- Southeast Regional Genetics Group (SERGG)
- Genetics Network of the Empire State (GENES)
- Great Lakes Regional Genetics Group (GLaRGG)
- Great Plains Genetics Services Network (GPGSN)

MCH began funding Networks in 1983 to improve access to and improve the quality of genetic services. They identify needs, share resources, and enhance communication and coordination among states within each region. Networks are encouraged to include representatives of statewide genetics programs, MCH programs, sickle cell programs, and consumers. Other purposes include:

- development and implementation of laboratory standardization and quality assurance program techniques for genetics procedures
- provision of continuing education in genetics for health care providers and the public
- continuation of efforts to provide genetics service delivery data
- examination of reimbursement issues in genetic services.

CORN, formed in 1985 after many of the Networks were established, is a national coalition of the Regional Networks, public health officials, consumers and professionals. It is run by a Steering Committee with representation from each Regional Network, the Alliance of Genetic Support Groups, and national sickle cell programs. Consumers are given a voice in CORN through the Alliance.

In 1983, MARHGN, with funding from GSB, the March of Dimes Birth Defects Foundation and others, conducted a symposium entitled “Genetic Disorders and Birth Defects in Families and Society: Toward Interdisciplinary Understanding.” One of the recommendations from this meeting was the need for a coalition to legitimize individual support groups and help them become a unified force with a common purpose. Such a coalition, it was proposed, would link groups to the scientific and research communities, further public education about genetics and genetic disorders, and provide a structure for unified political action.

In 1985, MARHGN, with the same support, conducted a second symposium entitled “Genetic Support Groups: Volunteers and Professionals as Partners.” This exciting meeting was the first actual gathering of voluntary genetic organizations. A recommendation was made to form a consortium of voluntary genetic support groups to move forward in expressing common aims. A planning committee of seven “consumers” and two professionals met in August of that year to plan the administrative structure of the proposed coalition, to develop goals and objectives, and to plan for funding the new organization.
The Alliance came into being in 1986. By-laws were adopted in February 1987, and the organization was incorporated in the District of Columbia. Non-profit status was achieved in 1988.

Support for the fledgling coalition came through MARHGN in fiscal years 1986 and 1987. In addition, the Genetic Services Branch which provided funds to the National Center for Education in Maternal and Child Health allowed the use of a portion of those funds for technical, administrative and publications support to the Alliance. In 1988, the Alliance was funded in part by a grant administered by CORN. The March of Dimes, a staunch supporter of the Alliance from its onset, provided a grant for partial support of an Alliance newsletter. Subsequently, the Alliance received a SPRANS grant of its own. Additional funds are received from organizational and individual memberships and grants. The coalition is comprised of over 170 organizational members as well as concerned individuals, both consumers and professionals.

The Alliance serves as a forum for new ideas and strategies, as an information resource and clearinghouse, and as an agent for change in the area of genetic services. By strengthening collaboration and communication between consumers and providers of genetic services, the Alliance seeks to increase national and regional awareness about genetic disorders, improve the availability and accessibility of high quality genetic services, and enhance education about the needs of affected individuals and families. We network among voluntary, governmental, and professional organizations concerned with genetic services. We identify gaps in services. We link individuals and families with support groups and refer them to appropriate professionals.

The key to fostering the consumer-professional partnership that the Alliance advocates is the full integration of consumers into the Networks. It is at the regional level that the beginning of a true working relationship, the essence of the partnership, can be realized.

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**DEFINITIONS, LABELS, EXPECTATIONS AND EMPOWERMENT**

*May I know my knowledge and its limits.*

*May I learn what you know.*

*May you learn what I know.*

*Together may we learn to do what is best.*

**Anon.**

**Who Is A Consumer?**

People with genetic disorders do not easily fit into a single category. The problems they confront may be temporary, chronic, and/or fatal; physical, psychological and/or social; medical, economic, educational, and/or political. As a consequence it is difficult to develop a definition of “consumers of genetic services” in a way that is inclusive for all people at all times. Moreover, as technology expands and information explodes, the term “consumer” will inevitably and eventually include everyone.

As there is growing sensitivity to the power of language and its ability to shape perceptions, it is neither desirable nor helpful to promote stereotypes of people on the basis of health-related problems. Equally important, depending upon the degree of the disorder that affects them, people with genetic disorders often do not perceive their disorder as a major component in their self-definition. Consequently, when approached to get involved in the Regional Genetic Networks, some people may not see such involvement as relevant to their lives; others may prefer to devote such energies and resources as they have to groups that can directly impact on their disorder; still others may have no group to work with and may discover that networking on the regional level offers new possibilities for support.

Sometimes, particular aspects of a genetic disorder such as mental retardation, short stature, or special diet requirements can be the motivation for outreach. Depending upon the overriding need at a particular time, a person might gravitate towards those who potentially can offer the most immediate and most needed support, help, and hope. People sometimes find answers and support in cross-disability groups where shared
concerns may differ in focus from those central to single disorder support groups. Medical care and treatment may have more or less significance depending upon circumstances which are constantly changing. And, in this age of specialization, a person with a genetic disorder and family members responsible for care, either need a "manager" who can determine what kind of help is required and the appropriate resources, or the "patient" must adopt a new role and accept responsibility for searching out help whenever it is needed. For many, support groups answer a significant number of these needs.

What motivation is there for people with genetic disorders or their families to get involved with yet another group — their Regional Genetics Network? Clearly for people with a high degree of involvement with their disorder whose lives are affected daily, the highest priority is to find solutions to medical problems and to find support for managing life day-to-day.

In seeking consumers to involve in the Regional Networks, therefore, it is important to make the case for such involvement. One cannot assume that people with genetic disorders or family members are likely candidates. They may need to put limited personal resources such as time, money, and energy into other groups which provide more immediate and tangible results. They may not perceive the genetic component of their disorder as the primary factor when determining where to expend personal resources. They may lack the experience and broader perspective necessary to benefit from and contribute to regional or national deliberations. They may not feel comfortable interacting with professionals in unfamiliar situations where roles are not clearly defined.

Of course, involvement is ultimately a personal issue, and the final decision to get involved rests with the individual. However, it is important to remember that "if you don’t ask, you don’t get." This axiom taken from fund raising applies to efforts to activate people as well. People tend to wait for an invitation, and those already involved in the Regional Networks, most of whom are professionals, need to reach out in a more direct manner if they are serious about wanting to broaden involvement. The benefits of attending meetings that have traditionally afforded professionals opportunities to interact, enhance skills, and keep current need to be articulated to consumers. A planned recruitment effort is a good idea, and such a plan should take into account the barriers described beginning on page 16 of this section.

For the purposes of this paper, we are limiting our definition of "consumer" to people who use genetic services. This definition includes individuals who have been told that they have a genetic disorder; parents of a child who has been diagnosed as having a genetic disorder; or anyone whose spouse or other family member has a genetic condition. Carriers and women (couples) who have prenatal testing are consumers in the broadest sense, but they are not likely to volunteer time to an organization involved with genetics unless they fit into one of the qualifying categories. This definition does not yet include people who might need or choose to avail themselves of genetic services as genetic information explodes and new technologies develop since that includes everyone.

A "professional" is defined as a person who has completed advanced studies in the specialized field of genetics and provides genetic services. The list of those who qualify includes but is not limited to physicians, genetic counselors, nurses, educators, social workers, specialized pastoral counselors, laboratory personnel, medical ethicists, and research scientists.

These definitions are based on common usage and give an incomplete picture. In fact, they might be considered labels and carry with them all the limitations we have come to expect. There is a line that traditionally is not crossed. One provides services; the other receives them. One charges for services; the other pays. One helps; the other is helped. One has power, be it in the form of knowledge, ability to treat and/or cure, to counsel or direct toward helping agencies; the other needs it.

Label Jars; Not People

Our society’s need to label people, to classify them and put them into handy categories reinforces barriers that separate consumers and professionals. Our concern is with what labels connote; that is, what these terms suggest and the flood of images conjured up when they are used. In economics, a "consumer" is one who uses goods or services. The word is based on a concept of eating up or destroying resources. To consume is to devour or to spend wastefully. In a dispute, "con" represents the negative. On the other hand, the prefix "pro" means "before, in place or position," in a debate, "pro" represents the affirmative side. A "pro" is someone who is so proficient that he or she is actually paid to do something others play at. The very word "professional" sets up a relationship of inequality.

In the world of genetics, professionals and consumers are not necessarily two separate groups of people. A genetic counselor may be the parent of a child with Down Syndrome or a physi-
cian may have an inherited heart condition. As researchers identify more and more problems that have some connection to genetic makeup, the larger the consumer group grows.

Professionals and consumers can often both be considered experts. In genetics, as in many other fields, a consumer’s life experience and knowledge are essential to making good use of the scientific information and clinical experience of the professional. Now more than ever, there is a need to foster a partnership between professionals and consumers and break down barriers to communication. New scientific information is creating ethical dilemmas for consumers, professionals, and society that have never had to be confronted in all of human history. The decisions people make in their personal and public lives will significantly impact on the future of everyone.

Given the stake we all have in the future, it is critical that we take a hard look at definitions, expectations, and relationships. In essence, we must re-adjust the balance of power and channel our strength into unlocking the tremendous potential of the consumer-professional partnership. The goal is to define roles so that they are inclusive as opposed to exclusive. We need to see ourselves as “prosumers”*, a term that does not so much suggest a blurring of the traditional roles and responsibilities but rather a heightened awareness of the multiple facets of human existence. “Prosumer” is a concept that includes everyone; it is a description of human beings who have something to contribute, something of value to share. Prosumerism takes the best of being a professional and a consumer and forges an active alliance where interdependence and mutual respect shape attitudes and motivate people to help each other to live lives of quality in a world that can ultimately be user-friendly.

The Benefits of Involvement

In many arenas, prosumers, particularly parents, are assuming increasingly new and important roles. In some cases, such input has been mandated. For example, by the mid-1980s, Title V Maternal and Child (MCH) Health Crippled Children’s Services programs required citizen input into the development of state plans for the distribution of federal public health funds. The GSB has consumer representation on its review panels for grants. In the Requests for Proposals (RFPs) circulated by MCH.

In recent years, Regional Networks were asked to describe consumer involvement in each Regional Network.

In her insightful, reasoned article entitled “Parents of Children with Disabilities as Collaborators in Health Care,” Alliance Vice President Betsy Anderson makes many relevant points about the importance of consumer participation in quality health care. What she says about parents can easily be applied to individuals with genetic disorders and their families. We reference her article which appeared in the Coalition Quarterly, The Journal of the National Network of Parent Centers [Winter/Spring 1985] because the message is so important, and has immediate application to our examination of the benefits of consumer involvement in the Regional Networks.

Anderson maintains that, “We can learn from one another. Whether parent, professional or person with a disability, each of us possesses experiences, knowledge, and perspectives that can contribute to the overall picture. While some people can be expected to have large pieces of the puzzle, others may have smaller but particularly critical pieces. To develop or to encourage development of a system where participants are discouraged from seeking solutions from others, or where it is only permissible to seek answers from particular individuals, is to narrow unnecessarily the range of resources."

Anderson suggests that the efforts to involve consumers can convey the message that contributions made by families and individuals can be important. By inviting the recipients of services into the problem-solving process, professionals make people with genetic disorders part of the solution, rather than part of the problem. Further, involvement places a value on knowledge gained through experience. The sharing of ideas and findings that arise from personal experience not only helps others in similar situations, but often proves valuable to professionals in their dealings with others. Consumers may share a philosophy, attitude, or approach to life. They may also make concrete suggestions, such as designs for a better ramp, making the PKU diet palatable, etc.

Further, existing policies and practices should be critically examined to determine what works and what does not, what is worth keeping and what is not. As the recipients of services, consumers offer a special perspective and have much to share with regard to how services are provided as well as how information is given and received. As Anderson points out, “None of us has all the answers. People are affected by and respond to situations in unique ways; for any given problem there may be many solutions, or relatively few. Even when many solutions

*"Prosumer" is a term used by Alvin Toffler in his book, The Third Wave. For this writer, it captures the essence of the new paradigm for collaborative partnership between professionals and consumers.
are possible, circumstances may render some or all of them inappropriate. In one sense there are never too many ideas or solutions, and we should encourage thought from many sources."

One of the tangible benefits of involvement for consumers is the opportunity to interact with professionals in a neutral setting. Seeing people in a relaxed environment, wearing regular clothes, talking casually, can go a long way towards breaking down barriers. At Network meetings, people generally use first names. They share information informally and are pleased to discover new ways to reach more people with research requests, funding needs, or expanded networks for care. Outside of the organized meetings, people talk to each other on a person-to-person basis, and it is amazing how much gets done. A genetic counselor is asked to participate in a video on prenatal counseling being produced by a support group. A geneticist agrees to review a consumer group’s newest public educational pamphlet. Another wants to write guidelines for helping organizations review research protocols requesting human subjects. A group with chapters all over the country agrees to publish an investigator’s search for families having a child with mosaicism for trisomy 21. A professional learns of a new support group and at last has a connection for a family she has been seeing. The opportunities and resources are virtually unlimited.

Most important perhaps is the unlimited potential of the consumer/professional partnership that can flourish in the Networks which are essentially the perfect context for change. It is at the regional level that consumers within the genetics community can identify problems and seek solutions together. They can raise a strong voice in support of common concerns. They can forge a powerful alliance and draw upon the strength, experience, and shared commitment of both consumers and professionals to make a qualitative difference in the lives of all.

**Barriers to Greater Involvement**

The biggest barrier to greater involvement is the fact that too few consumers even know that the Regional Networks exist. Those that do may not have any idea of the function of the Networks, much less of how or why they should be active. There is a limited number of professionals who are usually involved with the Networks, and they may expect meetings to be a forum where colleagues problem-solve and share information. Countless numbers of people qualify as consumers. Unlike professionals who know why they belong at Region Network meetings and the role they play there, consumers are not so sure. If they are supposed to be consumer representatives, whom do they represent? Who elects them? How are they selected? To whom do they report? Are they accountable to anyone?

The mandates and good reasons for involving consumers challenge network leaders and the salaried Coordinators to identify willing consumers and to develop plans to insure their successful integration. It is important to understand how professionals view Network meetings and attempt to continue to meet their needs. Concerns have been expressed that sessions designed to advance professional education may be diluted if it is necessary to present information in lay terms. Consequently, any plan to integrate consumers into the Networks must balance the needs and expectations of all groups involved. Planning should take in account the following:

1. **Timing.** Timing is all. As Anderson says, “People can grow, develop, and adapt. Initially, there may be questions about how much a person who is newly diagnosed or a family whose child has just been diagnosed can contribute. What is important, however, is that they receive the message that over time the majority of people do cope and that everyone has the potential for growth. This assumption is vital to people’s ongoing growth and developing self-concept. There are also times in people’s lives when they may have less to contribute than at other times; even the most competent, articulate, motivated individual may have down time.”

People are motivated to get involved for various reasons. Some people, for example, feel ready for a new level of challenge. After working on the local chapter or national level of an organization focused on a specific disorder, some may welcome the challenge of expanding their area of concern. Their ties to specific disorder groups are important links that should be encouraged, enabling the consumer leaders to serve as liaisons.

Timing of meetings is another consideration. For many professionals, Regional meetings are viewed as part of the job. They are often funded to attend these meetings which function in a variety of ways to enhance professional competence. For consumers, there is often no good time to leave home. Weekday meetings conflict with full-time jobs. Weekend meetings take time away from family, a problem for professionals as well. Meeting planners who want high attendance and low costs have recently attempted to “piggy-back” meetings where the same people are invited to attend. The object is to allow participants.
to travel on the same ticket to meetings planned back-to-back in the same location. This overlapping scheduling may have cost-savings benefits, but for consumers who work or who have caretaking responsibilities, such meetings can be a hardship to attend.

2. Funding. Networks budget travel and lodging expenses for representatives to steering committee meetings and committee meetings. Professionals who are not funded are sometimes reimbursed by employers who view Regional involvement as important to the continuing education of professionals. There seems to be consensus that consumers should be funded as well as professionals. Since funding is most definitely limited and the number of consumers who could possibly be involved on the regional level is not, it is necessary to define the role of consumers in the region and to develop criteria for selecting consumers whose expenses will be covered.

3. Burn-out. Highly motivated, almost driven people quickly become known outside of their particular disorder group and are identified as "leaders". They are asked to serve on committees, task forces, commissions, etc. where consumer input is desired or required. These people are the likely candidates to fill consumer slots on the Regional level. However, the demands upon these leaders can easily contribute to burn-out.

Burn-out is a serious problem caused by too few people doing too big a job over too long a period of time. It affects leaders who play many roles and wear several different hats. They start groups, build organizations, and do whatever needs to be done. When they are ready to move into new territory, they often look back and discover that there is no one to replace them. In many cases, they accept new positions and continue filling old ones. At some time, burn-out is inevitable. It should be noted that burn-out is not limited to consumers or volunteers. Professionals, especially in the helping professions, exhibit the same characteristics and are subject to the same syndrome.

Another factor that must be taken into consideration is the potential demands placed on the consumer by family issues related to illness. Is the consumer directly involved with the care of a child, spouse or other family member with a genetic disorder? Does the consumer have a genetic disorder? If yes, how does it impact on daily functioning? The responsibilities, the special cares and needs of people with genetic disorders and their families can intrude and disrupt plans at any time. It should not be a measure of a person's commitment if s/he is unable to attend meetings or fulfill committee responsibilities.

It may be that the reason they got involved is consuming all their time and energy. On the other hand, since most Regions hold meetings only two or three times a year, a person cannot contribute much who cannot attend meetings regularly.

4. Intimidation. The Regional Network provides a forum where consumers and professionals can interface on a new level. It pre-supposes that equity is possible, and that traditional ways of interacting can be altered. Having been trained to cure, to advise, to answer questions, many professionals have real difficulty accepting information, ideas and even advice from those they are used to helping. Some professionals may have problems setting aside their training and seeing "patients or clients" as partners in a new arena. It is necessary to allow consumers to become part of the solution in order to stop perceiving them as "part of the problem." By letting down professional facades, by learning to listen to consumers, professionals can help them overcome a sense of intimidation that in medical setting comes with the territory. With no desk, white coat or clipboard to keep consumers at a distance, professionals need to find a comfort level in dealing with "patients/clients" who are functioning in a new role.

It is just as challenging for consumers to find their comfort level in dealing in new ways with people whom they are used to perceiving as authority figures. Consumers may find themselves capable of advocating for themselves or loved ones when necessary, but often the experience is frightening or, at the very least, disquieting. Many parents share feelings of fear that their children might suffer for their assertiveness. Others, feeling helpless and/or hopeless, may rail against service providers and the system in general. Their hostility or frustration may cause them to paint all professionals with the same brush. Encounters during Network meetings offer opportunities where consumers can get to know service providers as individuals. They can see professionals interacting with different kinds of people, work with them in committees, and even solve problems together. In time, most consumers can let go of feelings engendered in medical settings and begin to open themselves to the many positive possibilities of a real consumer/professional partnership.

5. Language. Scientific language can, on occasion, be another barrier to communication. Professionals with advanced training naturally use words that lay people cannot understand. Technical language can intimidate consumers and function to reinforce the distance between helper and helpee. If professionals perceive of Regional Network meetings as an extension of
the workplace where colleagues meet, they may resent being asked to pick and choose their words. Consumers have a responsibility for making an extra effort to familiarize themselves with technical scientific terminology. They must risk feeling inferior and ask that terms they don’t understand be defined or concepts be explained. Professionals, on the other hand, should be willing to take the time to teach and be sensitive to the different educational backgrounds of consumers. Obviously when people don’t want to throw up barriers, they find the right words. When the time and place are right, both professionals and consumers will make that extra effort to speak so everyone can understand and to listen because they care about what others have to say.

6. Unresolved hostilities. It is critical that regional meetings not turn into gripe sessions. Support groups leaders are all too aware of the possibility of any meeting being sabotaged by an unhappy member with unresolved hostilities. One horror story can lead to another until the positive intent of any programming is buried by anger, disappointment, and frustration directed at the professional community. Whether the cause is an actual experience where the treatment, advice or interaction was inadequate or inappropriate or the unrelieved pressure of living with a genetic disorder or caring for a loved one for whom there is no help, professionals as a group make an easy target. Perhaps it is necessary to identify consumers who have experience working with professionals outside of a health setting and who have achieved a personal level of coping that allows for cooperative efforts and mutual respect.

A Brief Overview of the Networks

At the present time, each of the ten Regional Networks has some degree of consumer involvement. Some spell out consumer involvement in their organizational objectives. The descriptions vary from “ensuring that providers and consumers have the opportunity to discuss issues of mutual interest” to “developing a strong consumer coalition to assure a close exchange between consumers and the genetics centers.”

Since committee chairs usually constitute a Regional Steering Committee or governing council, consumers who chair committees participate in policy-making and governance. In some Regions, there are designated places for consumers, one from each state in the Region. At the present time, one Region has a consumer who serves as an officer. She happens to chair the consumer committee, but was elected by the regional’s entire membership. In another region which is a single state network, the Steering Committee has two consumer members, and the Interagency Council for Genetics Services, the major organized element to address that state’s genetic services, is currently chaired by a consumer.

Most Regions have a separate committee to address consumer issues. Usually membership is open to all, and projects benefit from the expertise consumers and professionals bring to the planning process. In one Region, the Consumer Concerns Committee acts as a voice for the interests of self-help groups and monitors activities of other committees and regional projects from the viewpoint of the consumer. The stated purpose of another is “to assure active consumer involvement to achieve the highest quality and quantity of genetic services and education.”

In addition, consumers are actively recruited to serve on other committees. While education is the one area where consumers tend to gravitate, there is a case to be made for encouraging consumers to stretch beyond the familiar and open themselves to learning about data collection, quality assurance, and reimbursement.

Consumers are usually identified through the combined efforts of regional coordinators, state genetic services coordinators, professionals involved with specific groups and other consumers. The Alliance plays an active role in identifying possible consumer participants and has convened a meeting in one region under its own auspices to bring together several consumers to stimulate involvement and provide a base for a consumer committee. Primarily the consumers are individuals from the community who are active with genetic support groups or MCH projects. Numbers vary, often restricted by budget constraints, but representation from all states within a region is desirable.

Regions fund consumer participation as they do that of professionals. Usually the cost of travel, food and lodging is covered for delegates or representatives. Consideration is beginning to be given to covering child care costs to facilitate attendance at meetings usually held a good distance from home. Consumer Committees are also receiving their own budgets for programming and projects.

Projects undertaken by Consumer Committees have included the development of regional directories of support groups and genetic services, articles expressing the consumer perspective in
Regional newsletters, and programs on a range of issues. Using the Alliance peer support training workshop as a model, some regions have replicated the program, modifying materials to fit local needs and to utilize local resources. Many regions also support consumer participation in the Alliance's national programs.

Consumers are recognized as a valuable resource, and through contacts established at Regional meetings, genetic service providers are reaching out for assistance in fund raising, legislative initiatives, and public education. Consumer groups are important sources of information for evaluating current programs and developing future ones. The impetus to establish new support groups often comes from the joint efforts of consumers active in their Regions and consumer advocates willing to offer whatever help and technical assistance may be needed.

In Conclusion

The Regional Networks provide both a formal and informal mechanism that increases opportunities for consumers and service providers to work together. A nurturing environment where asking questions is as important as providing answers, the Networks have been and hopefully will continue to be a common meeting ground that fosters collaboration, communication and creative responses to the challenges of serving individuals and families affected by genetic disorders.