For the first time in history, there is a realistic possibility that major medical breakthroughs within the next decade may correct, cure or find new treatments for genetic disorders. This expectation provides hope to many millions of American whose lives are touched by one of more than 3,000 hereditary conditions. Until recently, prenatal diagnosis by means of MSAFP testing, CVS, amniocentesis, etc., afforded no options for corrective treatment. Today, phrases like "gene therapy," "enzyme replacement therapy," "bone marrow transplants," and "genetic engineering" offer hope where no hope existed before.

It is hard to imagine a scenario in which a cure for a dying baby would be withheld because the parents do not have medical insurance to pay for health care. While the cure may still be a dream, the scenario is a reality for 36 million Americans today who do not have health insurance. Many such Americans are being turned away from hospital emergency rooms, denied medication, or refused surgery because they are uninsured.

Americans who do not have health insurance usually fall into one of several categories: those who cannot afford to purchase it; those whose employers do not offer insurance benefits; and most especially, those who (cont'd on p. 4, col.1)

In the year and a half which has transpired since the June 1985 symposium out of which this organization has grown, we have evolved from a steering committee with the charge to explore the concept of a cross-disabilities coalition to a full-fledged functioning organization, one that is dealing not just with plans but with programs, one that involves leaders from a dozen national organizations, as well as representatives of divergent professional communities including health care, educational and legal professions.

We recognized at the outset the difficulty of melding the divergent purposes of our many constituencies. In my column in our first newsletter I indicated that we had made an enthusiastic start. Indeed, the enthusiasm continued, and the work and cooperation which we required from those involved in our initial efforts was forthcoming. It is gratifying for me to see that my vision of a unified effort of addressing the common problems and circumstances that face us all is a shared vision among the many volunteers with whom we have worked and interacted over the past year and a half.

We go from here not only justified in our original thinking, but inspired by the depth of support and cooperation which we have found from many different voluntary support groups, the professional (cont’d on p. 3, col. 2)
Editorial Comment

Those of us who deal with the life-long involvement of having a person in our family affected by a genetic disease are well enough familiar with the immediate medical concerns -- be they life threatening, chronic, developmental, or merely temporary in nature. If there is one anguish that is greater than dealing with the physical and mental suffering of that affected individual, it is the concern that by caring for that individual the welfare of an entire family unit might be threatened.

Availability of appropriate health care services of individuals so affected is as of this writing not an area that has been the recipient of an appropriate level of either state or federal policy. The result of this is that within the current scope of the health care delivery system there are substantial deficiencies which result in devastating and non-reversible effects upon many of the families of our constituency. How cruel to be told that to save the life of one newborn child you must "spend down" the efforts and life work of conscientious parents, and remove from the economic system otherwise responsible, productive, taxpaying citizens. What logic is there by absence of policy in maintaining a system which by its complacency permits inappropriate expenditures of funds to support medical institutions which do not serve the patients but only serve the providers.

The base line of our concern is not purely the availability of appropriate insurance, but the propriety of the health care delivery system. We hear it said often in the conferences which we attend on this subject that there is an in-place system which serves the vast majority of Americans well for their health care needs, and therefore as we address changes within that system we need to be mindful that we should not affect the ability of that system to continue its good work.

We would argue that a system that leaves 30-37 million Americans without the ability to interact with that system because they are not covered by any appropriate form of health insurance negates that argument. We would suggest rather that there are a number of areas that need to be reviewed in a critical but constructive sense:

Should the availability of health care be inextricably linked to current active job status?

Should qualification for some level of health insurance be tied either to participation in a "group" or to preemptive guarantee of no discernible risk?

Should society in general bear the costs of providing care for uninsured individuals by means of unplanned cost shifting through out-patient emergency care at public hospitals?

Should families face the option of placing uninsurable children for adoption rather than destroying the economic circumstance of the balance of that family?

Should the already accepted societal burden of paying for non-covered individuals be more equitably distributed?

Our questions are many, and no answer that we find will be simple nor universally accepted. It is our conviction, however, that it is the responsibility of the advocacy community, health care providers, policy makers, and institutions alike to find together the means by which we will alleviate the deplorable circumstance with which many of our families are confronted.

We do not believe that that answer lies in addressing the concept of catastrophic care alone. We believe that the health care delivery system warrants major and continuing re-examination in all its aspects. We in the Alliance continue to interact with all members of the aforementioned communities. It is our continuing conviction that the best result which we can reach will be found in that kind of cooperative effort, and it is to that goal which we are dedicated.

It is our hope that in the coming decade we will see the kind of change needed to achieve our goals.
Life Insurance Breakthrough—Health Insurance Study

The Alliance is pleased to announce that it has located a provider of life insurance for individuals who have genetic conditions. The concept behind this particular program is one which affords individual underwriting based on actual medical status without prejudice to any particular "genetic" condition. This program is currently available and information can be obtained by writing to the Alliance central office.

Please note that there is an information request line included on page 7 of this newsletter. We will be pleased to respond to individual or organizational inquiries.

Health insurance is one of the continuing areas designated by the Board of Directors of the Alliance as a priority for the coming year. There is little to offer our constituencies other than work-related group policies or high-risk pools (available in only twenty percent of the states).

In order to impact upon policy development in this area, we have undertaken to identify the actual number of individuals in our constituency who are uninsured or underinsured as regards health insurance. We are at the present time developing the protocols which will result in a cross-disabilities study to determine that population in usable data-set form. If you or any of your constituent organizations would be interested in participating in this particular effort, we would appreciate your immediate response so that we may include you in this study. Additionally, we would appreciate any input you may have with regard to existing studies which might comprehensively address this problem.

Please note that you may simply indicate your interest in this study by checking the appropriate line on the information return form on page 7 of this newsletter.

(cont’d from p. 1, col. 2)

I offer sincere thanks to all those volunteers—consumers and professionals alike—who have helped bring about this organization and have helped guide and direct its ongoing operations. While my writing of a year ago was enthusiastic but cautious as to our ability to interface our divergent interests in a continuing and constructive sense, I am now confident about our prospects. We have shown by our ability to meet together, to recognize our mutual needs, to identify our mutual goals, and to formulate plans of action that will address these in an immediate and constructive sense, that the need for and viability of this organization is both immediate and justified.

I closed my last column to you with the words I would like to reiterate as being as important now as they were then. We need planning, patience, hard work and cooperation. And we need your help. We look forward to receiving your input.

Greg Weigle

Memberships/general correspondence to:
ALLIANCE OF GENETICS SUPPORT GROUPS
38th & R Streets, NW
Washington, DC 20057
(202) 625-7853

ALLIANCE published quarterly
Editor: George McCoy

Information in this newsletter may be reprinted with credit given to source.
are deemed "uninsurable" by the health insurance industry.

An uninsurable person is often one who has a pre-existing condition documented before he/she applies to a company for a health insurance policy. Most commonly, uninsured people are women who rely upon their employed husband's medical insurance, or individuals within a family (such as a child) who are not covered under the family’s group health plan. Perhaps the wage earner learns after he has changed jobs that his new insurance plan will not provide benefits to a member of his family.

People with genetic disorders in their family are more vulnerable than others to this problem. Insurers make their profit by insuring healthy people and they employ insurance actuaries who calculate the amount of risk attached to a disorder. Risk is not simply defined in medical terms; it also involves other factors. For example, a blind child may have a better chance of getting health insurance than an adult who has just become blind. This is because insurance actuaries assume that adults who have recently lost their sight have a higher risk of being hurt in an accident than a person who has been blind from birth.

In some cases, if a child is diagnosed with a serious genetic disorder, siblings in that family may be denied health insurance because it is assumed that they may carry the disorder. For example, the brother of a child with neurofibromatosis may be uninsurable until after age 21, when the risk of getting NF becomes zero. Unfortunately the great majority of genetic disorders are "orphan diseases," each affecting fewer than 200,000 Americans (as defined by the Federal Orphan Drug Act, PL 97-414). Because they tend to be a low priority for scientific research, statistics often do not exist to document risks or actual costs. Therefore, people with orphan diseases may routinely be denied health insurance in the absence of actuarial statistics. The family may have no way to prove that the insurance company is wrong in its assumption, and even if it does, there may be a very limited ability to appeal the insurer’s negative decision.

Voluntary health agencies working on behalf of genetic disorders have one goal: cure the disease and go out of business. Unless the devastating problem of health insurance is solved, the patients who most need new treatments, procedures and cures will not be able to obtain them.

Recently the Federal government began to discuss the problem. The dialogue of many of the task forces and study groups discussing "catastrophic health insurance" seems to be focusing more on long term care for the elderly rather than the acute care needs of the young. There must be a balance in any legislation that evolves from these discussion groups. Can our nation continue to treat health care as a privilege, rather than a right? Genetics support groups, as a part of the advocacy community, can and will make their voice heard in the resolution of these many concerns.

If you would like to know what Congress plans to do about this problem in 1987, contact your Senator or Representative. Then let the Alliance know what you found out!

-Abbey S. Meyers, Executive Director, National Organization for Rare Disorders (NORD)

(Editor’s note: The National Organization for Rare Disorders was one of the few groups asked to testify on behalf of consumers before the Task Force on Catastrophic Health Insurance created by Dr. Otis Bowen, Secretary of the Department of Health and Human Services. Additionally, Ms. Meyers has been appointed to the newly formed commission on orphan diseases.)

Publication of this newsletter has been aided by Education Grant #14-72 from the March of Dimes Birth Defects Foundation.
The Federal Role: Communication Networks

Consumers of services offered by Federal programs are enjoying a growing influence in reviewing the policies and priorities of Federal agencies. As people affected by genetic disorders, we may be consumers of various services, including payment of medical expenses, quality control of medical providers, and scientific research into new treatments or cures for our respective conditions.

The Genetic Diseases Services Branch is trying to involve consumers in its activities. The Federal agency is a part of the Division of Maternal and Child Health, which is responsible for much of the Federal funding directed toward genetic diseases. As Acting Chief of the Branch, Ed Duffy has, over the past few months, continued the work of the Chief at the time of the inception of these initiatives, Dr. Al Noonan.

E. Robert Arrindell, DSW, former Social Work Consultant for the Branch, was instrumental in the formation of the Alliance during its Steering Committee days. Before a promotion called him away from an active role with the Alliance, Dr. Arrindell cited the funding given by the Branch to the Mid-Atlantic Regional Human Genetics Network (MARHBN) as one example of the Branch’s effort to strengthen the role of consumers. Part of this money has been used to support the Steering Committee as it worked to develop the Alliance.

Arrindell pointed out that the beginning of the current policy can be traced to 1972, with passage of the National Sickle Cell Disease Control Act which established ten comprehensive sickle cell centers. In 1974, the National Institutes of Health (NIH) transferred a portion of its funds to the Health Services Administration, Maternal and Child Health Program, to set up sickle cell-related education, screening and counseling projects. In 1976, Congress recognized that other genetic disease service programs were needed and passed the National Sickle Cell and Other Genetic Diseases Act. In 1978, the Federal government provided support for the establishment of statewide genetic (cont’d on p. 7, col. 1)

The Federal Role: National Council on the Handicapped

The National Council on the Handicapped is an independent Federal agency which reports directly to the President and Congress on matters relating to disability. Part of its role is to establish liaison with groups representing disabled people (including groups representing the interests of people with genetic conditions). The National Council was required by the 1984 amendments to the Rehabilitation Act to make a comprehensive assessment of all Federal laws, programs, and policies affecting citizens with disabilities; recommend priorities for funding; and suggest needed changes. In response to this charge the National Council has released a report entitled Toward Independence, which makes a number of recommendations for changes in Federal laws and program priorities. All of the recommendations have potential application for families and individuals affected by genetic disorders; some relate to prevention of disability make specific reference to genetic conditions.

For a copy of this report, contact the National Council on the Handicapped, 800 Independence Avenue, SW, Washington, DC 20591, (202) 453-3846 voice or TTY. You may also write to the Superintendent of Documents, US Government Printing Office, Washington, DC 20402. The report’s stock number is 052-003-01022-4; the price is $3.75.

The National Council on the Handicapped was originally created by Congress as a part of the Rehabilitation Services Administration in the Office of Special Education and Rehabilitative Services, in the Department of Education. In 1984, when Congress amended the Rehabilitation Act, it moved the National Council out to the Department of Education and gave it independent status. In view of its unique position with Congress and the President, genetics groups may wish to establish contact with the National Council and stay current on its activities and agendas. For more information about the Council’s plans, contact Mr. Lex Frieden, Executive Director of the Council, at the above address.
Following is a list of the Officers, Directors and Advisors of the Alliance. For your reference an organizational or professional affiliation is noted.

**OFFICERS**
President -
*Greg Weigle, Down Syndrome, Vienna, VA*

Vice-President for Consumers -
*June Vavasseur, Sickle Cell Disease, Los Angeles, CA*

Vice-President for Professionals -
*Joan Weiss, LCSW, The Johns Hopkins Hospital, Chevy Chase, MD*

Treasurer -
*Lee Kitchens, Short Statured People, Ransom Canyon, TX*

Secretary -
*George McCoy, Hemophilia, Raleigh, NC*

**DIRECTORS**
Betsy Anderson, Spina Bifida, Boston, MA
Paula Brazeal, Leukodystrophy, Sycamore, IL
Colleen Brown, Immune Deficiency, Buena Park, CA
John Carey, MD, University of Utah Medical Center, Salt Lake City, UT
*Jessica Davis, MD, North Shore University Hospital, Manhasset, NY*
Luba Djurdjivonic, MS, Genetic Counseling Program, Binghamton, NY
Desiree Dodson, Prophyria, Montgomery, AL
Delores Goldfinger, Neurofibromatosis, Cincinnati, OH
Neil Kurlander, LLB, Marfan, Baltimore MD
Jayne Mackta, Tay-Sachs, Morristown, NJ
*Abbey S. Meyers, National Organization for Rare Disorders, New Fairfield, CT*
Robert F. Murray, MD, Howard University College of Medicine, Washington, DC
Jay Peddy, Huntington’s Disease, Chicago, IL
Arlene Pessar, RN, Dystrophic Epidermolysis Bullosa, Brooklyn, NY
Darnelle’ D. Pinkard, MSW, Sickle Cell Disease, Houston, TX
*Jean-Paul Richard, Osteogenesis Imperfecta, Rockville, MD*
Joseph Smith, III, Tuberous Sclerosis, Annandale, VA

**ADVISORY COMMITTEE**
*Robert C. Baumiller, SJ, PhD, Georgetown University, Washington, DC*
Edward Duffy, Division of Maternal and Child Health, Rockville, MD
Kathleen Kirk Bishop, MSW, Division of Maternal and Child Health, Rockville, MD
*Beverly Raff, PhD, March of Dimes, White Plains, NY*

*The above people designated with a star served on the original Alliance steering committee. In addition, the four people listed below also served on that original committee.*

Marcia Boyle, Immune Deficiency
Ruby Horansky, Huntington’s Disease
E. Robert Arrindell, DSW, DMCH
Arthur Salisbury, MD, March of Dimes

---

**March of Dimes Shows Interest and Support**

Charles L. Massey, President of the March of Dimes Birth Defects Foundation, has announced that his organization has awarded a grant to the Alliance of Genetics Support Groups to cover the costs of its newsletter for one year.

The March of Dimes has a long record of support for programs working in the area of genetic disorders and other congenital conditions. The Foundation also helped the Alliance during its steering committee phase.

Greg Weigle, President of the Alliance, said, "We are pleased to have the continuing support of the March of Dimes. We are certain that our efforts will continue to complement the stated goals of the March of Dimes and will enhance the efforts which they have long supported."
(cont'd from p. 5, col. 1) service programs. Today, the Genetic Diseases Services Branch serves as one of the Federal government's focal points for genetic programs.

The Branch has identified several priorities, including establishment of statewide genetics projects; development of an inter-regional council "CORN;" creation of psychosocial programs for individuals and families affected by genetic disorders; special outreach to at-risk and underserved populations; studying reimbursement issues; and, most recently, new-born screening for hemoglobinopathies.

The Genetic Diseases Services Branch has committed itself to listening to the needs of consumers. We in the future will continue to interact with these efforts.

---

Information Return Form

_____ I would like to receive more information about membership.
_____ I would like to receive the newsletter, Alliance.
_____ I would like to contribute to future newsletter issues.
_____ I would like information about the Alliance Speakers' Bureau.
_____ I would like information about life insurance (see p. 5).
_____ I am interested in the health insurance study (see p. 5).

My area of expertise is _____________________________________________________

Name ___________________________________ Title ______________________________

Organization or Profession __________________________________________________

Address _____________________________________________________________________

Phone (____) _____________________________________________________________________
The Alliance is dedicated to fostering a partnership among consumers and professionals in order to enhance education and service for and represent the needs of families and individuals affected by genetic disorders.

The Alliance's first goal is to enhance educational efforts concerning genetic disorders. The Alliance is particularly interested in increasing public and professional awareness of the effects of genetic disorders. For genetics support groups, the Alliance hopes to enhance awareness of cross-disability similarities, help avoid conflict, and identify resources that groups can use to grow stronger.

The second goal is to enhance the availability and appropriateness of services. As part of its program, the Alliance intends to help identify gaps in services, or needed service delivery improvements.

The third goal is to represent the common needs and concerns of its constituents. The Alliance will provide a forum for identifying common issues, and establish communications channels with government agencies, professional groups, service providers, and other consumer organizations.

Membership is open to support groups, professional organizations and interested individuals. For information on membership please see the information return form on page 7.