"Shoot for the moon; the worst that can happen
is that you end up somewhere in the stars."

Bill Demby

This Alert functions as a vehicle of communication between the Alliance and its constituency. It is our goal to
provide timely and useful material in a readable, easy access format. Feel free to send in your announcements,
share your ideas, or ask for help.

Jayne Mackta, Editor

PLANNING UNDERWAY: To build on our commitment to serve both families with genetic concerns and
healthcare professionals, the Alliance is planning an exciting new program to expand the role of families in
the genetics education of primary care providers and those working in managed care settings. By bringing
together families and genetics professionals, the project aims to give families access to current genetic
information and available support resources from caregivers in their communities as well as on the national,
state and regional level. Trained consumers will be prepared to help healthcare providers understand the
impact of genetic disease on individuals and families as well as the kinds of information, support and re-
sources affected individuals and their families require. Members interested in participating in the planning
of the Alliance Consumer Regional Genetics Training Program should contact Donna Foster at the office.

More on the BREAST CANCER GENE: Following an announcement by the National Institutes of Health
that a mutation known as 185delAG on the BRCA 1 gene may be more prevalent among Jewish women of
Ashkenazi descent than the general population, Senators Feinstein and Mack held hearings on cancer and
genetic testing. One purpose of the hearing was to highlight advances made in identifying genes for various
disorders. More important was the caution to consumers that this most recent discovery does not mean that
a cure has been found for breast cancer. Nor does it mean that every woman who has the mutation will be
certain to develop breast cancer. Additionally, it is important to understand that most cases of breast cancer
are not genetic. Nor does the fact that the breast cancer gene is not present in a family insure that a woman
will never get breast cancer. Indeed, the risk remains 1 in 8 in the general population, underscoring the
importance for all women to have timely mammograms, whether or not breast cancer has occurred within
their family. Questions were raised about testing for a disease for which no cure has been found, in which
case testing may increase anxiety rather than decrease it. Likewise with other genetic tests, information about
an entire family, not just the person tested, may be generated. Dr. Francis S. Collins, director of the National
Center for Human Genome Research, pointed out that the HUGEM survey conducted by the Alliance and
Georgetown University Child Development Center indicates that nearly 1/3 of families with genetic
disorders have already been turned down for coverage of genetic services. He cautioned that efforts to create
legislation protecting against genetic discrimination must be accelerated as the availability of presympto-
matic genetic testing becomes more widespread.

NEW GROUP: The International Organization of Glutaric Acidemia has been formed and will be meeting
on December 6 in conjunction with the first GA-1 Symposium in Strasburg, PA. Contact Cay Welch,

The Alliance ALERT is a publication of the Alliance of Genetic Support Groups

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Alliance is funded in part by project #MCJ-241009-03 from the Maternal and Child Health Bureau (Title V Social
Security Act), Health Resources and Services Administration, Department of Health and Human Services