"I am an idealist. I don’t know where I’m going but I’m on my way.”
Carl Sandburg

ALLIANCE ALERT

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.

HAVE YOU HEARD? The Alliance wants to celebrate success. Too often, we get horror stories from families who can not get the help they need. The list of obstacles continues to grow, but usually some communication failure between a patient and/or family with a professional is part of the problem. We believe there are just as many success stories out there, but no one ever takes the time to relate what works...only what doesn’t. We want to recognize those exchanges between professionals and consumers that should be the norm, but sad to say, are typically the exception. Consequently, The Alliance is seeking nominations for a new award called “The Artful Listener”. This award will be presented annually to the service provider (physician, nurse, social worker, genetic counselor, or other individual rendering service to an individual or family affected by a genetic disorder) who has demonstrated that while “hearing is a gift; listening is an art.” The purpose of this award is to increase awareness of the fact that listening is an invaluable key to understanding and helping others. Send your success stories to Joan Weiss at the Alliance. The first award will be presented at the Peer Support Training Conference scheduled for March 30 - April 1 in Washington, D.C. The Alliance will present certificates suitable for framing to all nominees.

CO-SPONSORS NEEDED FOR HEALTH INSURANCE EQUITY ACT: Taking our lead from NORD On-Line, we urge you to ask your constituents to write to their own Congresspeople and request they co-sponsor the Health Insurance Equity Act (H.R. 2649) introduced by Rep. Doug Walgren (D-PA). If passed by Congress, this Act will prohibit health insurance companies from denying policies to people with pre-existing health conditions. We quote from the August 18 issue of NORD On-Line: “People who have been denied health insurance, those whose policies have been cancelled, those who have experienced extraordinary escalation of premiums due to a serious diagnosis, and those who are concerned that their policy might be cancelled will have significant stories that can have a major impact. Remember, Congress is hardly aware of this problem because most elected officials believe that the 37 million uninsured Americans are poor people who can’t afford insurance. It is up to us to illustrate that middle class families often cannot buy health insurance at any price if they have a pre-existing illness.” Have your constituents send copies of their letters to Rep. Doug Walgren, House of Representatives, 2241 Rayburn Building, Washington, D.C. 20515, Attention: Glenda Booth.

ALTERNATIVE MODELS FOR SELF-HELP SOUGHT: Alliance member Ed Madara is working on a how-to-guide for providing mutual aid and support by and for patients and families through the development of correspondence, phone, newsletter, computer, and video-exchange networks. He would like to hear from anyone or any group that feels they have done any of these well in order to learn what successful strategies they found helpful. Write or call Ed at the Self-Help Clearinghouse, St. Clares-Riverside Medical Center, Denville, New Jersey 07834; telephone: 201/625-9565.


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