



## Network News

A Monthly E-newsletter for Volunteers of the Dystonia Medical Research Foundation

June 2007

Welcome to *Network News* (issue 14). If there are other members of your local support network that would be interested in this communiqué, please let us know. Suggestions for content and helpful resources are *always* welcomed.

**Dystonia Car Magnets.** This attractive magnet is oval in shape and measures 4 3/4" by 7" and features a person with their hands tied with the saying, *Dystonia . . . Robbing the Freedom to Move*. The magnets are \$5.00 (includes shipping and handling) and are available for purchase on the website. If you would like a sample magnet to share at your next support group meeting, let us know and we will get one right out to you.

**Wristbands.** They're back! Due to popular demand, we are pleased to inform you that we have blue awareness bracelets in stock. They are \$2 each and are available in adult and youth sizes. The inscription reads TEAM DYSTONIA. We encourage everyone to become a dystonia champion and join us as we fight together for a cure.

**Support Group Challenge.** The Portland, Oregon Support Group led by Dee Linde has won our contest to collect e-mails and the group will receive a \$50 gift certificate to use for a pizza party. Thanks Dee! In our efforts to keep our members updated on the latest dystonia news, we have a new system in place that allows us to send e-mail blasts. Please continue to send names and e-mails to us so we can reach as wide of an audience as possible.

**News from Allergan.** The expanded BOTOX Patient Assistance™ Program is now available and provides BOTOX® at no charge to financially eligible patients who are either uninsured or underinsured. New eligibility criteria have been established to provide access to BOTOX® therapy for more patients experiencing financial hardship, and to make the program easier for patients and their families to understand and to use. A new and streamlined application process has been created, supported by a new Web site, [www.BOTOXPatientAssistance.com](http://www.BOTOXPatientAssistance.com), and expanded customer service hotline, 1-800-44-BOTOX (option 6), where patients can obtain personal assistance or an application.

**Macy's Shop for a Cause.** Macy's has announced that Saturday, October 13, 2007 will be the 2007 Shop for a Cause Shopping Day throughout the country. For the Shop for a Cause program, nonprofit organizations apply to participate and receive special discount cards that are sold to your friends and family for \$5. (We keep the \$5 for each discount card sold.) On Shop for a Cause Day (October 13), each shopper presents their discount card to receive discounts on any purchases. While the program is offered throughout the country, organizations must participate at the local level. Many of you organized a Shop for a Cause Event in your community last year, and we raised over \$2,000. Please determine if your group wishes to participate and go to [www.macys.com/charity](http://www.macys.com/charity) for an application for your community. Please let us know which groups are participating, so we can publicize your efforts.

**Dystonia Brain Bank.** The re-launched Brain Donor Program continues to grow and there have been 125 contacts made in the past year, with 13 persons completing their registration. Three donors have passed away this past year and their tissue was successfully retrieved and is available to dystonia researchers at the NICHD Brain & Tissue Bank at the University of Maryland. A newly revised and

designed Brain Donor brochure is currently at the printer, as is a one-page informational sheet on the program. Both should be available soon and will be mailed to all groups. We greatly appreciate each one of you, in your role as support group leaders and regional coordinators, helping to promote this important program within your support groups. Martha Murphy, Brain Bank Liaison, is happy to communicate with anyone who is interested in learning more about the donor program and answer any questions you may have. The donor registration process is really quite easy, and donors provide very valuable information to researchers working to identify more effective treatments, the cause(s) of dystonia, and ultimately a cure for this disorder. If you are interested in learning more about the Brain Donor Program, please contact Martha Murphy, Brain Bank Liaison, by e-mail at [brainbank@dystonia-foundation.org](mailto:brainbank@dystonia-foundation.org) or phone her direct cell phone at 619-822-3001. She will be glad to explain the program to you and answer any questions that you may have. Martha is located in San Diego, CA so please allow for the difference in time zones.

**Fourth Children & Family Symposium.** The date of the 4th Children and Family Symposium is scheduled for August 17-19th in Chicago. A full agenda and registration detail is available on the DMRF website at <http://www.dystonia-foundation.org/filebin/pdf/07%20kids%20symposium.pdf> We ask for everyone's help in spreading the word of this event to children and families in your area. All are welcome for a weekend of networking, learning, and fun!

**TWISTED.** We have heard from filmmaker Laurel Chiten that the special features DVD is scheduled for completion in August and all support groups will be mailed a copy at that time. Thank you for your patience.

**Headquarters News.** We are pleased to announce that Ray Chaudhuri has joined the DMRF as the Director of Strategic Alliances and Business Development (DSA). Ray has worked with the Foundation when he served as a Program Analyst for NINDS. While in this position, Ray attended a number of DMRF sponsored scientific meetings and served as a valuable resource. As the Foundation's DSA, Ray will create and implement strategies designed to advance the goals of the Cure Dystonia Initiative (CDI) with specific attention to the development of partnerships and alliances with industry, biotech companies, academic institutions and government agencies. Welcome to Beverly Saiz, the new Director of the Chicago Regional Office. Prior to joining the DMRF, Bev worked at the Emergency Nurses Association Foundation.

**Of Note...**The Alabama Dystonia Support group distributed thousands of dystonia bookmarks in celebration of Awareness Week. One of the bookmarks found its way into a nun at a monastery in town who suffers from dystonia. The nun made contact with the group and will attend the June meeting of the Alabama Support Group which now numbers 75+ members. The Danbury Walk-A-Thon organized by **Joan Mandzuk** and her son **Eric** raised \$1,600. Congratulations to the San Diego Support Group led by **Martha Murphy** for their hard work with the Shake Your Can event they held outside of the local Ralph's grocery store for Awareness Week. The group proudly raised \$200 for research. **Janice and Len Nachbar** of the Central New Jersey Support Group have recently secured free ad space in an industry magazine. Len used his talents to create 3 different sized ads and is eager to share the ads with other leaders for possible placement in company newsletters, church bulletins, local newspapers, and weekly circulars. Contact Jennifer at the DMRF if you would like copies of the ads. Congratulations to **Paula and Don Gates** of Massachusetts who raised \$26,000 for research at their recent Jimmy Buffet themed Margaritaville Dinner Dance. Paula commented, *We were delighted that we did so well, especially since we started with a goal of \$10,000. We will have another dance next year.* The same weekend the Methuen Community Chorus held a spring concert in honor of **Bob Lebrun** to benefit the DMRF. The choral group was created 37 years ago and Bob is one of its founding members. Many thanks to **Bob and Ann** for their efforts. **Jennifer Heil** of the Lexington

Support Group reported that her son N.J. works at a local health food store and collected \$100 from the dystonia donation can at his register. Thanks N.J.! Good luck to new volunteer **Nancy Present** of St. Louis who is organizing *Moving Forward- the 1st Annual St. Louis Dystonia Walk-a-thon* on July 1, 2007. Welcome to this world Ryan Samuel Kessler, son of **Art and Wendy Kessler** and Shaina Lewis whose proud grandparents are **Dr. Richard and Rosalie Lewis**. Condolences to **Rita and Guido Battaglini** on the passing of Rita's father, Walter Lachewitz, Sr. Congratulations to **Josh Rozenfeld** who was recently awarded the Teri Aronov Courageous Spirit Award at Beth Israel Hospital in New York. Since the age of 10, Josh Rozenfeld has helped raise funds and awareness of dystonia. Now 16, Josh is a frequent speaker at dystonia fundraising events in New Jersey and he also serves as a big brother-type mentor for many local children who are newly-diagnosed with dystonia. Josh's grandparents are active volunteers **Lois and Norm Gebeloff**.

**Quote of Note**...*A pessimist asks you if there is milk in the pitcher; an optimist asks you to pass the crea.* - Folk saying