

Network News

Greetings and welcome to Network News (issue 11). If there are other members of your support group that would be interested in this communiqué, please let us know and we will add to our distribution list.

TWISTED. The dystonia documentary, *TWISTED*, will be nationally broadcast on PBS's Independent Lens Series on Tuesday, January 30, 2007. As each PBS market is independent, there is some flexibility in the air times. For the most current schedule on days and times that *TWISTED* will air in your community, please visit the PBS website at:

www.pbs.org/independentlens/broadcast.html?editst=y You can enter your zip code and will be given specifics for your area. A kit containing *TWISTED* Action Items including a press kit, a media tool kit, and letters to send to family and friends encouraging them to watch the program will be mailed to all leaders the week of January 22nd. If you do not receive and would like a kit, please contact Jennifer.

The PR firm that DMRF is working with is pitching *TWISTED* to all national health and medical reporters. The Independent Lens PR firm is presently pitching the story to 800+ journalists nationwide and the top 100 TV/film critics.

PBS has an excellent website featuring *TWISTED*. If you have not yet viewed it, we encourage you to do so. The website is www.pbs.org

The DMRF is now selling individual copies of the film for personal use. The film is 54 minutes in length and can be purchased from the DMRF by phoning 312-755-0198 or e-mailing twisted@dystonia-foundation.org The cost is \$37 US or \$43 Canadian (which includes shipping and handling).

Internet search engine. Please consider using Good Search at www.Goodsearch for all of your internet searches. It's very easy to use. Right under where you type in your search you can choose the Dystonia Medical Research Foundation and we will receive a penny for every search. If enough people sign on, we can easily raise funds for research. Please pass along.

Brain Bank. Please remember the importance of registering as a Brain Donor to help advance dystonia research. Donations are needed from both affected individuals and non-affected family members. There is much that researchers can learn about dystonia through the study of brain tissue. Anyone who is interested in learning more is invited to contact Martha Murphy, Brain Bank Liaison by e-mailing brainbank@dystonia-foundation.org or by phoning 619-822-3001.

Dystonia Awareness Week. Mark your calendars for June 3-9, 2007.

Artists with Dystonia. We recently received an inquiry from an artist who has dystonia. She is no longer able to practice her art and is looking to connect with others who may be in a similar circumstance. Her name is Evelyn Grazaiani and she can be reached at dryahalom@aol.com

Clinical research studies. Merz Pharmaceuticals has launched a website for clinical research studies in need of volunteers with blepharospasm and cervical dystonia to examine potential new treatments. Visit the website at www.dystoniastudies.com to see an overview of the study eligibility requirements as well as brochures with more detailed information about the studies. Individuals also may learn more about dystonia and the drugs being studied. For more information and/or to determine your eligibility, call toll free 1-800-984-0433 or visit the website at www.dystoniastudies.com

Dystonia in the news. An article entitled *Beyond Wrinkles* appeared in the January 22nd issue of *U.S. News and World Report* and featured Board Director **Art Kessler**. *USA Today* featured a story on January 15th about best-selling mystery author **Martha Grimes** who was recently diagnosed with spasmodic dysphonia. *The Delaware News Journal* included an article on dystonia (1/16) which featured **Art and Bernie Hindle** of the Southeast Pennsylvania Dystonia Support Group. If you would like a copy of any of these articles, please let us know.

Outreach. The next time you visit your neurologist's office, please make sure that there is an ample supply of dystonia literature in the waiting room. If not, please contact the national office and we will gladly send a Physician Lit Kit to them. This is a great opportunity for us to reach persons who are newly diagnosed.

Membership Dues. The 2007-2008 membership cycle is quickly approaching. Running from April 1, 2007 through March 31, 2008, the membership dues of \$40 should be sent directly to the national office (vs. through support groups). This ensures that members are recognized and given all of the privileges that membership entails. A renewal form will be sent out with the Spring 2007 issue of the *Dystonia Dialogue*.

IRONMAN. A dear friend of Pat Brogan is competing in the Lake Placid Ironman on July 22, 2007. Rebecca Matteo is using this event to raise funds for the Dystonia Foundation through the Janus Charity Challenge Program. Her goal is to raise \$25,000 and the top fundraiser will be awarded \$10,000 to their charity. To donate to Rebecca, please visit her webpage at <https://www.kintera.org/faf/donorreg/donorpledge.asp?ievent=186368&supID=143238159> <<https://www.kintera.org/faf/donorreg/donorpledge.asp?ievent=186368&supID=143238159>> Rebecca is now selling DMRF baseball caps to help in raising funds. The are \$20 each which includes shipping and handling. To order, contact

Rebecca at 919-622-3464 or at rmatteo@email.unc.edu Proudly wear a dystonia hat and support Rebecca and her heroic efforts.

Headquarters News... The next issue of the *Dystonia Dialogue* is scheduled to be mailed in March of 2007. A Regional Symposium will be held in the Spring in Chicago. The DMRF has tentatively scheduled the 4th Annual Children and Family Symposium for August 10-12 also in Chicago. Anyone with questions can contact Jennifer at the national office.

Of Note.... Happy travels to **Rosalie and Rich Lewis** who are vacationing in the South Pacific. Happy 40th Birthday wishes to Junior Board member **Beth Farber** on January 31st. Congratulations to **Pat Brogan** who raised \$27,000 at his 3rd Annual Help Find a Cure fundraiser on December 22nd. Look for a complete write up on Pat's event in the next issue of the *Dystonia Dialogue*. Many thanks to **Shidfar Shahriary** and **Sally Presti** of the Washington D.C. support group who participated in the local NBC Health Fair and distributed dystonia literature. We are very proud of **Paula Gates**, co-leader of the Massachusetts Dystonia Support Group, who was honored at the Seventh Annual Martin Luther King, Jr. awards celebration in Danvers, MA on January 15th. Paula was recognized as 'an individual who has shown a deep commitment to social justice and leadership in advancing the ideals espoused by Martin Luther King, Jr.' Paula is working with a committee to host a Freedom to Move Dinner Dance on May 4th in Danvers. **Faye Goldstein** recently gave a presentation on dystonia to a local women's club in Las Vegas. Faye mentioned that 'most people had no idea of what dystonia was and the feedback was terrific.' Thanks, Faye, for your efforts. Faye also attended the Juice Newton concert in her area. In the middle of the show, Juice stopped and talked about dystonia. She also had literature at the table where she was signing autographs. **Martha Murhpy** and her support group member **Paul Fowler** were instrumental in engaging Juice in our cause. Our thoughts are with **Michael Ross**, son of Board VP **Karen Ross** who underwent DBS on Thursday, January 16th. Goodluck to DMRF Board Member **Sandy Weil** who is hosting the 8th Annual Brunch & Games in Boca Raton, Florida on January 23rd. We are most appreciative to Sandy for her tireless efforts all year round. Welcome to our newest support group, the Central Florida Dystonia Support Group. Leaders are **Jonna Barker** at barkmom@myexcel.com and **Cheryl Nichols** at canorlando@earthlink.net All leaders are encouraged to drop them a note of welcome.

Quote of Note... To the world you may be one person, but to one person you might be the world. -*Anonymous*

Network News will be sent via e-mail each month. We hope this will facilitate communications between national and our key volunteers. This has been sent

bcc to protect your e-mail privacy. Please send tips, comments or suggestions for Network News to jmolski@dystonia-foundation.org



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