

January, 2007

Dear Network Leader:

I hope this letter finds each of you well, and your 2007 is off to a great start. As we move into the New Year and establish our plans, I feel it is so important to reflect upon 2006, the 30th anniversary, and our collective accomplishments, many of which were firsts. Below you will find the report that I recently created for our Board of Directors. I felt it was imperative that I share this with our Leaders, too, as you are the strength of the DMRF:

- We co-sponsored, with the NINDS, a workshop on the state of dystonia research that brought together most of the leading researchers in the field today, including those from Europe. It is our plan to have the summary of this workshop published next year.
- This year was a year of building partnerships – with the Bachmann Strauss Dystonia and Parkinson Foundation to host the Advances in Dystonia Conference in January and then later to co-sponsor a New York City screening of *TWISTED*.
- Our partnership-building continued with the development of the Dystonia Advocacy Coalition (DAC) – bringing together the dystonia patient advocacy organizations to strengthen our voice on legislative matters and hopefully also in awareness. Groups that have joined the DMRF in creating the DAC are NSDA, NSTA, DySTonia, Inc, and the BEBRF. April 17 and 18 will mark our first joint Advocacy Day in 2007, something we can all take pride in. These partnerships are important not only because they allow us to reduce the duplication in our work but it sends a message to our various audiences – we can work together to achieve our mutual goal – a cure for dystonia. It also creates a louder voice that will be heard!
- We strengthened a partnership with the Dystonia Study Group this year through our work to co-host a meeting to review and revise the ratings scales used to evaluate dystonia patients. This work is ongoing but is again an example of the importance of relationships and partnerships as we move forward to tackle all the work that must be done.
- In February we had the opportunity to hear from most of the researchers we have funded in the last two years regarding the work we supported and the progress we have made. These types of meetings are important, and we look forward to continuing to host them every other year as they bring young researchers together with experienced scientists and help keep people working on dystonia.
- At the annual meeting we also awarded the first Fahn Award to Dr. Bill Dauer. Our Board of Directors continues to be impressed with the investigators selected to receive our grants. They are bright, enthusiastic researchers who truly are partners with us in achieving our mission. We are grateful to our Scientific Director Dr. Mahlon DeLong for

his dedication to the Foundation and to his ability to recruit appropriate individuals to our Medical and Scientific Advisory Council to help us with our work.

- In May we held our first ever Cure Dystonia Initiative Advisory Council (CDIAC) meeting. This is a robust group of individuals who possess talents and contacts and are willing to help us achieve our CDI goal of identifying new therapies for all of the dystonias while working toward the cure. Congratulations to Jan Craig for her tireless work on our research program.

- The May workshop on torsinA and the nuclear envelope brought together the leading minds in these fields to examine where we are in this area of research and what we need to do next.

- We worked with Dr. Caroline Tanner, funded by NINDS to do dystonia epidemiology work, to host a meeting in February on how this study should be designed to give us the information we need. We are still years away from having the answers to our questions, but we have started and the dialogue is important.

- The brain bank donation program was re-launched this year with staff support provided by the brain bank liaison. A promotional plan was developed and implemented. Inquiries are logged and tracked, and interest in the program is rising. This will help our research efforts greatly.

- 2006 may be remembered as the year of *TWISTED* as we worked with film maker, Laurel Chiten to bring this remarkable film to many communities across the country – building awareness and reaching new audiences along the way. We sponsored screenings in 10 cities this year and just held one on the SONY Campus in Los Angeles on January 11<sup>th</sup>. Additionally, the DMRF is a national partner with ITVS to plan and implement another 30 screenings. We have received funding to work with Laurel in the development of a special features DVD that we will distribute to our network of support groups and also use it in the development of new groups.

- A DVD highlighting the Foundation was produced this year and should be available in early 2007. This is something we have wanted to do for a long time and will be a big help to our fundraising efforts.

- Our network has grown this year. We have five new support groups working to support those in their communities with accurate information and advice but also with the identification of key individuals who are willing to join with us in this battle. This year we saw more individuals hosting fundraising events and doing letter writing campaigns or joining us in advocating for legislative changes.

- This spring we held our first ever combined Leadership Training and Advocacy Day in Washington, DC. It was the biggest Advocacy Day to date (about 100 people), and we were treated to having our keynote address delivered by NINDS Director, Story Landis, PhD.

- We opened our first Regional Office in Chicago and are looking to this program to help us deepen our outreach and development efforts in Chicago and other key communities in the future. This is an extremely important program if we are to continue to grow financially and have our development efforts keep up with the demand for support of our research plans.
- Our PR efforts were bolstered by the use of a Chicago-based PR firm and our work with producer John Golden. We had numerous press placements and a cable program featuring dystonia. Additionally, the DMRF worked with CCA and Rem Murray on the PSA campaign that included an article in *Reader's Digest*.
- Our website was redesigned to feature many of the new programs we have available – including but not limited to CDI and advocacy. It will launch early in 2007.
- Our development efforts are expanding, and we are exploring new income streams – such as the car donation program and individual events. **I am so proud of the collective efforts of our Network—fundraising events raised \$151,000 in 2006 which is a 60% increase over 2005.**
- I personally attended group meetings and fundraisers across the country in Detroit, Philadelphia, Baltimore, New York City, North Carolina, Chicago, Nebraska, and others. At every site I was welcomed with open arms and thanked for all the Foundation does. It was so clear to me that these people are finally feeling that what they do makes a difference. I am truly devoted to the network of volunteers for they are our future.

In addition, I have participated in countless interviews and events and continue to serve on the NORD Board of Directors. This work has provided me with the opportunity to travel across the country this year and meet with many of the people who turn to us for help in managing dystonia. I am impressed by the confidence they have placed in the DMRF. My commitment to you and to the Foundation remains strong. I know we can do this – together. Thank you again for all of your efforts. I feel privileged to work with each of you and am grateful for all of you - for your hard work, dedication, and commitment.

If there is anything I can do for you at any time, please let me know. My email address is [melspells@aol.com](mailto:melspells@aol.com) I hope we have the opportunity to visit at one of our events this year.

With my gratitude,  
Claire Centrella  
President