



Myasthenia Gravis Foundation of Illinois, Inc.

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Annual Report 2013

Myasthenia gravis (“MG”) is an autoimmune disease in which communication between nerve and muscle is impaired, causing muscle weakness. It can strike anyone of any race or ethnicity, at any age. The Myasthenia Gravis Foundation of Illinois is dedicated to helping people who struggle with this rare chronic illness.

MISSION – VISION – VALUES OF MGF OF ILLINOIS

Mission: To facilitate the timely diagnosis and optimal care of individuals affected by myasthenia gravis and to improve their lives through programs of patient services, public awareness, medical research, professional education, advocacy and patient care.

Vision: Eliminate Myasthenia Gravis

Values: We work to achieve our mission and vision through our organization values of care, hope, inspiration, awareness and advocacy.

KEY ACCOMPLISHMENTS IN 2013

“I just want to thank you [MGF of Illinois] for all you do. You’ve got to find light amid the darkness [with MG]. You are a ray of sunshine.” – Jen Powers

This was a great year to serve and advocate for MG patients in new and exciting ways. For instance, we hosted our first Strides Against MG walk to raise public awareness of myasthenia gravis. We introduced an e-newsletter, began a website update project, and increased contact with our support group leaders to improve the experience they offer to MG patients face to face. With strong board leadership, we’ve continued to work on completing our strategic plan for 2013-2015. Here are 2013 highlights:

Awareness Raising

- Our first **Strides Against MG walk** took place on June 2, 2013 in Elmhurst, Illinois. The event had two purposes – to raise awareness of myasthenia gravis among the public, and to raise funds so that MGF of Illinois can continue to provide support and education to MG patients and their families. The walk drew 150 participants and 25 volunteers, and support from over 10 national and local sponsors. Many participants and sponsors had not heard of myasthenia gravis before the event. MG patients enjoyed the challenge of a physical goal, and reveled in the emotional support provided by family and friends. (Pictured: Heather Lebron (right) and family)



- **Outreach.** Volunteer Ben Maravilla continued to help us raise MG awareness in Chicago’s Spanish-speaking community. He organized a group to carry the MGF of Illinois banner in Aurora’s Puerto Rican Festival Parade, led the MG entry for the Fox Valley United Way Cardboard Boat Race, connected with Chicago’s Dominican Republic consulate, and hosted an MG table at the Latin Health Fair in Chicago’s Pilsen neighborhood. *(Pictured: Ben shows his volunteer awards to Executive Director Joan Wincentsen)*



Direct Patient Services

- **Contact via calls and email.** As in past years, MGF of Illinois received **hundreds of calls and emails** from people in Illinois, northwest Indiana, and beyond. Contact came from patients, family members, social workers, pediatric nurses, respiratory therapists, and even pastors. We offer a caring ear and useful information.

Since my diagnosis, I have been seen by assorted medical practitioners and I have been asking questions and grasping for any information I could get my hands on. You spent more time with me and extended yourself more than many of the specialists I have seen and I am so grateful to you. – Pat Morgese

- **Support groups.** With the help of 13 knowledgeable leaders, we hosted a **total of 33 support group meetings** in Illinois and northwest Indiana, each one attended by four to 25 people. Attendees love these gatherings because they provide a way for individuals to help each other – and to cope better with their own illness. MGF of Illinois also supported an independent support group in Iowa by posting their meetings in our newsletter and website.
- **Publications.** Our goal is to provide MG patients with a wealth of useful information about this disease – to share inspirational stories, tips for living with the illness, as well as news on treatments and research developments. To accomplish this, we mailed two issues of our primary publication, the 12-page *Conquer*, to approximately 2,700 individuals located mostly in Illinois and Indiana, but as far as California and Maine. In addition to our print newsletter, we introduced four issues of the e-newsletter *MG Minute*. With this more cost-effective approach, we were able to expand our reach from 450 individuals in January 2013 to 540 one year later.

*“Your newsletters really helped me understand what’s going on with my eyes. I showed them to my eye doctor. My MG causes dry eyes, and I’ve found a few ways to relieve it. You’ve helped me so much – maybe by sharing [these strategies] I can help others.
– Vickv B.*

We also issued a 4-page *MG Update* as we experimented with ways to get valuable information in the hands of MG patients.

- **Two educational seminars hosted by MGF of IL.** In April, Dr. Robert Pascuzzi, a nationally known MG researcher and clinician from Indiana University, spoke to 55 people in Northbrook, Illinois. He covered many MG topics including disease symptoms, treatments, and current research studies. In October, 35 patients and family members listened to Deb Smith, M.Ed., LCPC, and Tim Fior, MD, discuss “Stress Management and MG.” Ms. Smith offered practical strategies for coping with life’s ups and downs, while Dr. Fior explained the benefits of meditation and led the group in a practice session.



Pictured: 2013 Speakers Robert Pascuzzi, Deb Smith and Tim Fior

- **Electronic media.** An update of our website www.myastheniagravis.org was begun in the summer. We worked to enhance the user experience by adding current MG news and events to the home page, improving navigation, and much more.

MGF of Illinois’ **Facebook group** – *Myasthenia Gravis - Snowflake Disease* - gives patients an opportunity to share concerns and find support online. In 2013, this group grew to 363 members! We set up a **Twitter** account, and are on the learning curve to understand how to use it effectively.

By the end of 2013, the MGF of Illinois **YouTube channel** *MGFillinois* offered 19 video clips – covering topics such as MG treatments, research, swallowing and vision issues, and much more. Many presenters are nationally known MG researchers.

Research Funding

- **MGF of Illinois’ annual grant.** MGF of Illinois issued a call for abstracts in August 2013 and has several promising studies in the review process.
- **Exercise study.** MGF of Illinois is sponsoring a pilot study that addresses exercise and MG. It is being conducted cooperatively by the GH School for Healthy Living and the University of Illinois at Chicago Neuromuscular Center. Most of 2013 was spent redefining the study and getting it through UIC IRB approval. The study is underway as of January 2014.

Organization Updates

- **The MGF of IL Board.** The board was sad to say good-bye this year to Vice Chair Deb Volpe, although she continues to be involved in the Strides walk. The board was pleased to welcome four new trustees: Anne Flanz, John Kessler, Erin O’Loughlin, and Ashok Patel.

"Your organization should be the model. You're incredible. I wish I lived in Chicago. You're always there for me and I thank you." – Howard Brickman

- **Executive Director.** As of January 1, 2013, Joan Wincentsen took over the reins of executive director from Kimberly LaBounty, and the role became a full-time position. Joan brings much experience to the role with six years of MGF of IL board service, one year as a part-time staffer, and as an MG patient herself. Leveraging the position's expanded hours, Joan has been excited to launch new projects like the Strides Against MG walk and website update. She also has enjoyed strengthening our support group connections and establishing community relationships. We are very grateful for Kim's six-years of thoughtful leadership and enthusiasm.
- **Financial balance.** For daily operations, the organization is working to increase revenue to match increased staffing expenses. We have expanded development training, added networking through nonprofit associations, and have looked for partnering opportunities through the local chamber of commerce. More important, the board has devoted its energy to identifying fundable projects that have the greatest impact for MG patients while fulfilling MGF of Illinois' mission.

WHAT'S AHEAD IN 2014

In 2014, MGF of Illinois is committed to being the best possible local resource for MG patients in Illinois and northwest Indiana. As you've come to expect, we will continue to respond to questions, connect MG patients and their general practitioners with MG-experienced neurologists, and provide information through our website, mailings, email, and social media.

We plan to increase services and advocacy:

- We'll host our second annual Strides Against MG Walk to expand efforts to raise awareness about this challenging disease, and empower those who struggle with it.
- The MGF of Illinois website will have a new look, and will be an even more effective resource.
- Another support group for central Illinois is under consideration. We will increase our presence in underserved areas of Chicago environs by attending local health fairs.
- We plan to share best practices with other organizations who serve other autoimmune and neuromuscular disease patients, to make sure we deliver our services effectively and efficiently.
- We hope to build connections with a variety of health care providers who serve MG patients – for instance, in the areas of dentistry, physical therapy, nutrition, exercise, and complementary medicine.

