



## Myasthenia Gravis Foundation of Illinois, Inc.

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### Annual Report 2014

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 2014

This was a great year to serve and advocate for MG patients in new and exciting ways.

##### Financial Support Program Added

In 2014, MGF of Illinois introduced its Patient Assistance Program to help MG patients who struggle with the high cost of medical care. The program covers up to \$1,000 per person in health care bills for MG patients who live in Illinois or Indiana and who have financial need.

##### Awareness Raising, Outreach, and Partnerships

- Our second **Strides Against MG Walk** took place on June 2, 2014 in Elmhurst, Illinois. The event served 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 160 participants and 30 volunteers, and support from 13 national and local sponsors. MG patients enjoyed the challenge of a physical goal, and reveled in the emotional support provided by family and friends. *(Pictured: Janet Bauer’s team)*



- MGF of Illinois was a sponsor of the November **MDA Muscle Summit** in Springfield.
- We joined the **National Coalition of Autoimmune Patient Groups**, an arm of the American Autoimmune Disease Related Association. NCAPG is working to “consolidate the voice of autoimmune disease patients so that all autoimmune disease get more attention and funding.”

## 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, nurses, and respiratory therapists. We offer a caring ear and useful information.
- **Support groups.** With the help of 10 knowledgeable leaders, we hosted a **total of 30 support group meetings** in Illinois and northwest Indiana, each one attended by four to 25 people. These gatherings provide a way for individuals to help each other – and to learn how to better cope with their own illness.
- **Publications.** Our goal is to provide MG patients with a wealth of useful information about this disease. In 2014 we mailed three issues of our primary publication, *Conquer*, to approximately 1,200 individuals. We also emailed four issues of the e-newsletter *MG Minute*.
- **Two educational seminars hosted by MGF of IL.** In May, Dr. Alex Barboi spoke to 55 people about “Side Effects of Common MG Treatments.” In October, 53 attendees learned about “Practical Strategies for Living with MG;” registered dietitians Angela Seitz and Jennifer Koman spoke about MG nutrition issues, physical therapist Brittany White addressed exercise approaches for MG patients, and Kathy Adam SLP covered speech therapy issues.
- **Electronic media.** Our website [www.myastheniagravis.org](http://www.myastheniagravis.org) was updated during 2014. We worked to enhance the user experience by making the site mobile-friendly, and improved other features. MGF of Illinois’ **Facebook group** – *Myasthenia Gravis - Snowflake Disease* - gives patients an opportunity to share concerns and find support online. In 2014 we added a **Facebook page** for the organization. And by year end, our **YouTube channel MGF Illinois** offered 22 video clips – covering topics such as MG treatments, research, swallowing and vision issues, and much more. Many presenters are nationally known MG researchers.



*Pictured: 2014 Speakers Alex Barboi, Brittany White, and Jen Koman*

## Research Funding

MGF of Illinois awarded research grants in 2014 for two pilot projects that represent unique, novel ideas that may open significant new avenues of research on MG. Awards of \$88,000 each went to:

- Betty Soliven, MD, University of Chicago, “Regulatory B Cells in Myasthenia Gravis,” and
- David P. Richman, MD, University of California, Davis, “Monoclonal Antibody Treatment of Anti-MuSK Myasthenia.”

A call for new abstracts was issued in August 2014, and several promising studies are in the review process.

## WHAT’S AHEAD IN 2015

In 2015, 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’ll host the 3<sup>rd</sup> Annual Strides Against MG Walk to raise awareness. We’ll increase our presence in underserved areas, and continue to connect with other organizations to make sure we deliver our service effectively and efficiently.