MYASTHENIA GRAVIS
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ESTHER LAND: 45 YEARS CULTIVATING A COMMUNITY OF HOPE

By Holly Dykstra, MA, RD

Forty-five years ago, Esther Land set out on a mission.

It was a simple mission: create a community for those affected by Myasthenia Gravis, or MG. Esther was passionate about this. She knew firsthand how the disease could affect someone, and why support was essential.

Esther was diagnosed with MG in 1960, when treatment for the condition was minimal. She bravely struggled with the weight of the disease, seemingly alone, for years. Though she had access to information about MG from the national Myasthenia Gravis Foundation of America, or MGFA, and textbooks, she had no one to connect with for support. She lived for the next 15 years without knowing a single individual with MG.

That changed when she landed in a Grand Rapids hospital following a lengthy MG crisis. It was there she decided she wanted change. She began initiating conversations with nurses and other hospital staff to see if they knew of others in the region who struggled with MG. Reaching out to them would be the start to her mission.

"As a young person, I was very shy, but when it came to Myasthenia Gravis, I knew I had to speak out," Esther said. "I did not want any other individual to go through what I went through."

From Vision to Reality

A few months after she left the hospital, Esther's vision came to fruition. She began to reach out to individuals affected by MG from a list she was given by a Detroit MG association. She personally asked each person if they would be willing to meet in an informal setting to lend support to one another.

The responses she received were overwhelming. A group of MG patients gathered for the first time in Grand Rapids in January of 1976. They shared their stories and discussed their challenges and triumphs. It was an incredibly beneficial experience.

That's when Esther realized she was not alone in her struggle with MG.

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She also knew that others, like her, would benefit from a supportive community while navigating their MG journey. The need for a community, where there was previously none, became clear to her.

As a result, a Board of Trustees was formed and the Great Lakes Chapter of the Myasthenia Gravis Foundation of America was organized. In 2015, the name was changed to the Myasthenia Gravis Foundation of Michigan.

A Season of Growth

Esther stayed in contact with the patients she met during that first meeting – and set out to construct and expand future gatherings. With the help of the Trustees and volunteers, she worked out of her home to develop a newsletter to send to the list of contacts.

Meetings for patients and their families were planned to connect those who needed support. Esther also began developing lectures for nurses and nursing students who worked with MG patients to help them provide information and encouragement to their patients during hospitalizations.

In April following its initial gathering, the Great Lakes Chapter received its charter from the MGFA. Esther was thrilled and continued her mission to improve the lives of MG patients.

Eventually, the demands of the organization became more than she could handle on her own.

“That’s when I told the Board of Trustees we’re going to have to grow or go,” Esther said. “I couldn’t do it all by myself anymore.”

So they grew. Being resourceful, the chapter received a donated office space and was able to hire administrative staff to help with the tasks Esther had solely handled until then. That allowed her to focus more on organizing gatherings and communicating with patients.

In 1990, an executive director was hired, marking a turning point for the organization. The chapter began to soar as revenue doubled due to having the ability to host more fundraisers, such as garage sales and a golf outing.

“I saw the impact we could have when we went from being a volunteer organization to having a paid director lead our mission,” said Esther. “It was very inspiring.”

Land (right) works on the MG-MI newsletter with Chair Helen Peltin in 1976.

Inspiring Hope

The work Esther did in the early development years was no small task. While she was creating a truly beneficial resource for patients, she was also experiencing increased symptoms of MG while being employed full time. But she was resolved and asked for help from others to continue delivering her message.

If she could not speak during lectures, she brought someone with her to help deliver her message. She fought to continue her mission because she wanted to help patients live meaningful lives. Her goal was for others to view MG as she had – as an illness with hope.

“Even when I didn’t know another patient and I was in a crisis, I knew that today may not be so good, but tomorrow will be better,” Esther said. “With a positive attitude and by God’s grace, my days eventually got better.”

Esther’s passion and drive inspired those around her. Lisa Gigliotti, a member of MG-MI and creator of the Coraggio Spirit Award, describes a memory of her first meeting with Esther and the impact it had on her.

“I first met Esther in 2005 at the MGFA national conference in Grand Rapids,” Lisa said. “I was unfamiliar with the area and was looking for assistance getting around. This woman named Esther helped me to find a ride from one of the physicians that was also attending.

“Here was this woman, helping me, and I realized that she lived in Michigan. It was through her dedication and devotion that the national conference was being held in Grand Rapids. I knew that was a huge accomplishment and as I stood with her in the large ballroom of the conference center, everybody approached her to greet her and say kind words. Everyone knew Esther.

“It is phenomenal and humbling to recognize that one person’s determination and mission can touch hundreds of lives,” said Lisa.

Impact Over the Years

As time went on, Esther’s impact on others continued and the organization grew.

Regular gatherings for support and information were held in multiple regions across the state at least once or twice each year. Lisa traveled with Esther to many of these meetings.

“People across the state were not only aware of MG, but also felt encouraged that there were others thriving despite the diagnosis,” Lisa said. “Esther talked to and encouraged hundreds of people. She made it her mission to reach out to people throughout the state and country.”

Her efforts allowed the chapter to experience significant growth. MG-MI started with 20 members and now has more than 730 members who have access to a great resources with evidence-based research.

“When I was diagnosed, there was only Mestinon for treatment.” Esther said. “In addition to Mestinon, there’s now IVIG, plasma exchange, immunosuppressant drugs and many more therapies. It’s a whole new world.

“I know what different treatments for MG can do, but I want others to understand their options because everyone is different. What was my miracle drug might not be a good fit for someone else.

“I recommend each person talk with their health care provider, stay informed about MG and find the treatment plan that will make their quality of life better than it is today.”

New research and shared lived experiences provide value for and create lasting impressions on members of MG-MI. Esther hopes these benefits will continue to be available for those in need.

Land at a MG-MI event in 2018.

Future Goals

Esther currently serves as a volunteer in the MG-MI office and secretary on the Board of Directors where she continues to pursue her original mission. She enjoys meeting new patients, their families and getting an opportunity to provide support.

“My favorite thing about my position with MG-MI is talking with a patient, hearing their story and helping them learn to help themselves,” Esther said.

Going forward, Esther would like to get more medical professionals involved in MG-MI for continued support and education. She would also like to expand the topics at conferences to offer a wider variety of information and resources. Her hope is that conferences will soon return to in-person events rather than a virtual platform due to COVID-19.

“My goal is to really drive education for patients,” she notes.

She would also like to focus on training and enabling support leaders within the state and seeing someone take over some of her responsibilities within MG-MI.

“As I get older, I would like to see more people in strategic areas who will support others and the organization,” Esther said. “I enjoy the work I am doing, but others are needed. I am willing to listen to other ideas for growth and I want their support to help make the ideas happen. MG-MI can only survive with a strong volunteer base.”

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Final Thoughts

It is clear in speaking with Esther, and anyone who knows her, that she has achieved her goal of creating a community of support for others. Her immense drive and passion for helping others has changed lives and inspired hope.

“Esther amazes me,” Lisa said. “She serves at the MG-MI office almost every day of her life – as a volunteer, no less.

“When someone is newly diagnosed, so many people feel alone with this disease. But they find the phone number for MG-MI and it’s Esther who picks up. She is humble, comforting and provides so much encouragement at such a critical time. That is amazing.”

And Esther is most certainly humble.

While discussing MG-MI, she does not focus on herself and her accomplishments. Instead, she speaks fondly about the group, how it has grown and of those who have helped it become what it is today.

“I am grateful for everyone who has walked beside me to make MG-MI become what it is today,” said Esther. “We’ve come a long way, and I am very proud of this organization.”

2021 ANNUAL CONFERENCE RECAP

The 2021 MG-MI Virtual Patient Education Conference was held in October and exceeded expectations, with the conference having more than 120 registrants and averaging 52 participants per presentation.

Participants enjoyed live presentations followed by a question-and-answer period from the presenting providers. Sessions included topics on ocular MG, critical care management and anesthesia, current treatments for MG, research and emerging MG treatments. Questions not answered in the Q&A and each session’s video will be posted on mg-mi.org at a later date.

MG-MI would like to give a special thank you the event’s sponsors, Alexion and Argenx, as well as all of this year’s presenters and panelists for creating an engaging and informative conference.

THREE EASY WAYS TO CHANGE LIVES WITH MG-MI

Your donation to MG-MI can change lives. Here are three easy ways you can make an impact:

Amazon Smile. Visit smile.amazon.com and choose the Myasthenia Gravis Foundation of Michigan as your charitable organization. When you shop, Amazon will donate 0.5% of eligible purchases to MG-MI at no cost to you.

PayPal. Make a recurring donation via PayPal at mg-mi.org and select “Donate” to set up a monthly donation. Payments are tax deductible.

Facebook. Visit facebook.com/MGofMI and click “Donate” or set up your own fundraiser and link it to the MG-MI page.

SUPPORT MG-MI

MG-MI depends on your support. Be on the lookout for our annual appeal letter and consider a donation to support those living with MG.

Learn more at mg-mi.org.

SAVE THE DATE

Save the date for the second annual MG-MI Moves MG event **Saturday, June 25, 2022**, at Cascade Recreational Park, 3810 Thornapple River Drive SE in Grand Rapids.

More information will be available at mg-mi.org.

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GET INVOLVED WITH MG-MI

Do you have a connection to Myasthenia Gravis, a passion to advocate for MG patients and caregivers, or want to contribute to a great cause?

The Myasthenia Gravis Foundation of Michigan is a 501(c)(3) nonprofit organization seeking volunteers and individuals to serve on its Board of Trustees.

Board Members

MG-MI's Board of Trustees lead and strengthen its programs and events to support those with MG and their families. MG-MI is seeking applicants who are well-connected leaders, quality fundraisers, organized and enjoy event-planning.

Applicants should be passionate about finding a cure for Myasthenia Gravis and other closely related disorders, improving treatment options, and providing information and support to people with MG through research, education, community programs and advocacy.

Volunteers

MG-MI relies on its wonderful group of volunteers to assist its Board of Trustees with its programing and events. There are countless ways to get involved. Volunteers can assist in supporting key events such as the MG-MI Moves MG event, annual golf outing, support group meetings, annual conference and at the MG-MI office. Hours are flexible and range from an annual, monthly, as-needed basis and more.

To learn more about serving as a trustee or volunteer, contact the MG-MI office by emailing myasthenia.info@gmail.com or calling 616.956.0622.

OUR MG-MI FAMILY

2021 Coraggio Award

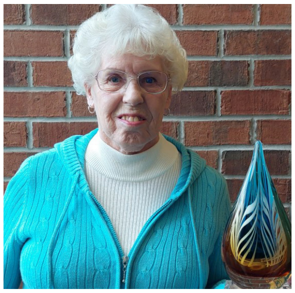
John "Jack" Sheehan was named the recipient of the 2021 Coraggio Spirit Award at MG-MI's annual conference in October.

Jack is dedicated to connecting with other MG patients and spreading MG awareness to health professionals and others.

He has devotedly attended local MG meetings for nearly 30 years and has always contributed positive encouragement to attendees. His determination to live a life of cherishing family, meeting people and raising awareness of Myasthenia Gravis is truly inspiring. In addition to celebrating his award, Jack also celebrated his 100th birthday this year. Congratulations, Jack.

The Coraggio Spirit Award was created by member Lisa Gigliotti in 2011 and is presented annually to a MG-MI member who exemplifies the award's core values of courage, perseverance and resiliency to lead a meaningful and enjoyable life with Myasthenia Gravis.

"Land"mark Award



Esther Land, MG-MI's founder, was recognized for her 45 years of service and life's work to raise awareness and support for those living with MG.

You can read her story on pages 1-4 in this issue.

2021 Volunteers of the Year Award

Board President Susan Woolner and Board Treasurer Priscilla Walden were named Volunteers of the Year for dedicating an exceptional amount of time and energy to MG-MI this past year.

Susan, a trustee since 2016, stepped in to serve as president of our Board of Trustees in January. A multi-tasker and long-distance commuter, Susan has given countless hours of time, energy and expertise. She has attended summer support gatherings, designed MG-MI's 45th anniversary shirt, coordinated interviews with our centurion patient, connected with businesses to promote our 45 years of service and spearheaded this year's patient education conference. Through her tenacity, she secured platinum sponsorships to make the conference a vibrant and profitable event.

Priscilla has served on our Board of Trustees since 2011 and as volunteer treasurer for our organization since 2012. With staffing changes in the MG-MI office, she oversaw communications by maintaining social media platforms, assisting in the production of newsletters and frequently volunteering in the office on Friday afternoons. Additionally, she assisted in planning the inaugural MG-MI Moves MG fundraiser in July that raised more than $9,000 and contributed extensively to planning and organizing this year's annual conference.

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MY MG STORY: JOHN “JACK” SHEEHAN

Our 2021 Coraggio Spirit Award recipient, John “Jack” Sheehan, recently sat down with MG-MI for a candid interview, providing details about his life and diagnosis with Myasthenia Gravis.

Born in May of 1921 in Sault Ste. Marie, Ontario, Canada, Jack and his family moved to Detroit when he was a child because his father and uncle found work with Detroit Edison.

Jack’s nickname came from his grandfather, who was born in Ireland in 1850 and emigrated to Sault Ste. Marie in the early 1900s. His grandfather was named Jack and he wanted to be called Jack like his grandfather.

In 1940, he enrolled in the University of Detroit Mercy eager to earn a college degree. However, halfway through college, the U.S. entered World War II and Jack’s life changed. He left Detroit in 1942 to enlist in the military, where he became a pilot for the U.S. Air Force.

Jack was overseas more than four years before returning to school to finish his degree in foreign trade, now known as international marketing.

He took a job with the Chrysler Corporation, which moved him and his family to many areas of the country, such as Nebraska, Kentucky, Illinois and Michigan. He then accepted a position in Lansing with Swiss pharmaceutical giant, Novartis, where he worked for 24 years.

After retiring, he was a volunteer driver for the American Red Cross for 15 years, meeting many people along the way and seeing different areas of the state.

It was on a trip driving home from Grand Rapids to Lansing that he got his first warning of MG. While driving, he began seeing two cars ahead of him instead of one.

Jack followed up the next day with an ophthalmologist, who told him his eyes were fine.

His next experience with MG came while having dinner with his wife, Lynn, and suddenly, he could no longer speak, chew or swallow. His wife thought he was having a stroke. After being treated for a stroke at Sparrow Hospital in Lansing for three days, Jack was told he may have Myasthenia Gravis and blood tests were being done to find out more. Jack’s test came back positive.

He was referred to a neurologist at Michigan State University who prescribed him Mestinon and said he should take one pill, lie down for an hour and then see how he felt. After an hour, Jack yelled to Lynn, “Hey, I can talk!”

“Those early days of living with MG were very difficult,” Jack said. “I struggled to find answers and treatments. My wife and I often felt alone, frustrated and scared, but we kept thinking there had to be someone out there who could help.”

Jack never met another person with MG until he spoke with Esther Land, founder of MG-MI. He credits her with helping him understand more about the disease and was grateful for her guidance to medical professionals who are knowledgeable about MG and all the unpredictability that comes with the diagnosis.

MG has been part of Jack’s life for fourteen years now, but when he reflects on all his amazing experiences he’s had in his 100 years, it is just a small part of his life that he has thankfully been able to manage.

If you or someone you know with MG is looking for guidance, MG-MI is here to help. You can call our office at 616.956.0622, email us at myasthenia.info@gmail.com or visit mg-mi.org.

Looking to connect with others
in the generalized myasthenia gravis (gMG) community?

Making Connections
Education and support for
generalized myasthenia gravis

Register for a free webinar or in-person event at the link below*

Register at **AlexiongMGEvents.com**

Based on the event you'd like to attend, you could receive information about one or more of the following:

- Disease education from a physician
- Stories from people living with gMG
- Tips for managing symptoms

*These events are open to gMG patients and caregivers in the United States.

ALEXION

We're plugged into the MG community

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