

2016 MGFA CONFERENCE ADDRESS: TOGETHER WE ARE STRONGER

About Nancy Law: Nancy Law is the newly appointed CEO for the Myasthenia Gravis Foundation of America (MGFA). She is a person with MG and served on the National Board of Directors for nearly nine years. Nancy had retired in 2015 from a 28-year career with the National Multiple Sclerosis Society, and was working as a consultant to the pharmaceutical industry on issues related to patient program design and enhancing doctor/patient relationships, when she was asked to take the MGFA CEO position.

SPEECH TRANSCRIPT

Just about 20 years ago, I was at a conference very much like this one. I had worked for the National Multiple Sclerosis Society for 10 years. I knew almost from day one that I had found my career, serving people with chronic illness and disabilities. I was about to be promoted into a national leadership position — the VP of programs and service. I was on track.

But at that conference, a funny thing happened. I suddenly could not speak more than a sentence or two. My voice simply disappeared. I thought I was tired. I thought I had a sinus infection — and my GP put me on antibiotics. I thought — this will pass. But it didn't. And then my face got numb, and I couldn't chew very well, and couldn't dry my hair, and I knew. I had been the imbedded social worker in the Ohio State University MS Clinic for four years. I knew just enough, to say to my GP — this is no sinus infection — these are neurological symptoms.

Of course, I was no neurologist. Just like people today, exploring the Internet, I had just enough information to be terrified. And wrong. I was one of the lucky ones who was obviously sero-positive — so diagnosis was quick and easy. I think I am one of the only people I know, who when told by my doctor, solemnly and with great care, "I have bad news---you have myasthenia gravis" said, "Really? That's okay. That's great!" Because I had already decided I had ALS. Having gone to that dark corner, MG sounded pretty good.

I was in a unique position. When diagnosed with MG, most of us don't know any neurologists. I knew more than a hundred by name. But even so, even with proximity to the major city of Denver, there were still very few options in finding a physician with expertise in MG management. This is still true today. And this is one of the challenges that MGFA is taking on: expanding our reach with the goal that every person with MG has access to the care that they need.

Each of us with MG has our own story. No two are quite alike. That is why people in the MG Community began to say we are the "snowflake disease." True for me, too. The next step in my journey was finding out I had a grapefruit-sized thymic tumor. It had been spotted on a chest X-ray some 8 years



previously — misdiagnosed as an enlarged heart. Good news, Nancy — your heart is fine. Bad news, Nancy, you have a great big mass in your chest. Did you not notice your left lung was out of play?

Misdiagnosis or delayed diagnosis is a part of the experience of so many with MG.

So the big old tumor had to come out. This was January. Still in denial, I proposed that August sounded like a good time for me to take off work and have the surgery. “Get real” said my new neurologist. I had the surgery in February. It turned out to be a giant, thankfully benign, cyst. The mature chest surgeon said, “I have never seen one of these in 40 years of practice, and I will never see another.” It was so big, and crushing my heart and phrenic nerve, that he couldn’t get to it through the sternum, but had to go in from the left side. I am the only person I have ever met who still has half a thymus. Snowflakes!

And I thought I was cured. I didn’t really have MG! I had a tumor — and it was gone. I went back to work, got off all meds except a little mestinon, now and again, and life was good. Until I just couldn’t seem to get a deep breath. And had trouble walking without having to stop and catch my breath. And couldn’t seem to be able to breathe very well lying down. So of course — being an intelligent woman, I went to the ER, right? No, I got on a plane from Denver to New York for a business trip. I didn’t go to the ER until I got home — and then went straight from ER to ICU. Then, and only then, did I begin to truly understand what MG can do.

So began my acquaintance with prednisone, Imuran, IVIG and other MG treatments. It was also my wake up call to join the MG Community. I began to volunteer for MGFA in 2006. I believe that this is where I am meant to be. I want to help to lead this organization to change the world for people living with MG.

The theme for this conference is, “Together, we are stronger.” If we embrace this — there is nothing we can’t accomplish. We may have weak muscles, but we do not have weak will, and we are not weak or ineffectual people. Every one of us has a talent or skill to contribute to our cause. Each of us has a voice, and a story to tell. We may be, by definition, living with a rare disease, but that does mean that it has to be one that no one knows or understands. If we, who know what MG can do, don’t step up and work together — who will?

Like snowflakes, as individuals we may at times feel fragile; but together, we can create a blizzard. We can change the world. Cultural anthropologist, Margaret Mead observed,

“Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has.”

But it will take all of us. One of our challenges is that there are a lot of MG organizations. This is not necessarily a bad thing — it means lots of people are working on making a difference for people with MG! We are all working towards many of the same things — but too often our efforts are fragmented — even redundant. We can be stronger if we figure out how to work together. We did this in the Multiple Sclerosis Community. Eight organizations that had previously barely acknowledged the others’ existence, agreed to form an MS coalition. Instead of seeing each other as competitors, we became collaborators: around advocacy, special projects, raising awareness, and program delivery and coordination.

I believe we are at time in our organization where we can take the lead in uniting the MG Community, too. So it is my plan to reach out to all organizations — large and small — who support people living with MG, those that are national but include MG as part of their mission (like MDA and NORD) as well as those that provide services within a geographic area — and those that are virtual, such as social media groups, to begin to dialogue about how we can support each other's work and coordinate our efforts. I confess to being an optimist, but I think we can put history where it belongs — in the past! And focus forward by putting people living with MG in the center of every decision we make and everything we do.

It is important as we expand our reach that we are also very clear and very focused on what we want to accomplish: MGFA is your organization.

Here are our operational goals for 2016 — and just a few highlights

RESEARCH:

We drive cutting edge research that will lead to greater understanding, better management and eventually a cure for myasthenia gravis, MG.

We are at a very exciting time in MG. There are clinical trials happening that may lead to targeted therapies. We need better treatments in MG, -those that are more effective, and with fewer side effects. Our goals are to use our funds to leverage funding from others, and you will hear about some of these results — the thymectomy trial results and new guidelines for treatment protocols — in later sessions.

PATIENT SERVICES:

We provide information and connect people with MG and their families to resources and to each other for support, education, and access to optimal medical care and wellness.

As a unified organization, we embrace our responsibility to serve people affected by MG — no matter where they live. Thanks to a generous grant from AxelaCare, we have been able to bring almost all of our 50 support group leaders to their first in person training and networking session. We have plans to grow this network and heard just this month from five different people ready to volunteer and start new groups. And we are positioned to help them do just that. We are just a couple of months away from launching a new one-to-one telephone support program —MG Friends, to be sure that every person living with MG can connect with others.

AWARENESS:

We raise awareness about myasthenia gravis, targeting health care providers, legislators, and the general public

In 2016, we are going to have the best Awareness Campaign the MG Community has ever seen. And the strategies have come from the MG Community, channeled into a campaign by skilled PR professionals. Every one of you here today can have access to our June Awareness toolkit. We embrace Teal and Snowflakes! Already this year, as a result of interest generated by our walks and our new Snowflake Campaign, we have had TV coverage in NINE different communities. Who cares about 50 shades of gray? I am into 50 shades of Teal. The MG community has spoken.

AND IN ADVOCACY:

We advocate for issues important to people living with MG in both the public and private sector, collaborating with other health organizations to expand our reach and strengthen our voice

Already this year: We are building or connections and coalitions. We have joined Research America, worked together with the National Organization on Rare Disease, and lent our support to campaigns from the **American Autoimmune Related Diseases Association**. We have supported legislation for family caregivers, and worked with individuals whose insurance has denied critical treatments. Working with our MSAB, we are creating template appeal letters for MG treatments that are commonly denied, like IVIG and Cellcept. WE are raising our voices, and we are going to be loud.

And of course — all of what we want to accomplish takes money:

Our GOAL: We identify and pursue the most promising fund raising strategies to maximize revenue to support our mission.

Of course what is a key awareness strategy is also our signature fundraising strategy: the MG Walk. This year we will have Walks in more than 35 communities from coast to coast and a virtual walk as well. Each one of us can leverage our resources by asking friends and family to support us. And we have been deliberate in our decisions about Walk, knowing full well that we may not make any profit in certain communities, but that we are still committed to leveraging this event in raising awareness and bringing with MG together. But we are working on other resources too — planned giving, donor development, developing interest from those doing endurance events like marathons and triathalons. And we will create a toolkit for those creative souls who want to go for a “DIY” fundraiser. Want to do a golf event? Have at it! A silent auction or cocktail party — thank you. A sky diving event, or a beer drinking contest — well, let’s talk. But within reasonable risk we embrace the creative ideas people can do through their own circle of friends and interest.

MANAGEMENT AND STEWARDSHIP

We adhere to gold standard non-profit management practices, minimizing overhead while ensuring quality in staffing and efficiency in infrastructure and operations.

This has meant some changes in how we do business, including changing financial management, acquiring and learning a new database and adjustment in staff roles — and perhaps most important of all, leveraging the awesome power of volunteers! Even just since I started my role, I have been overwhelmed by what our volunteers are willing to help us accomplish: in addition to our amazing community and support group leaders, and our walkers and team captains, we have help from former bankers monitoring our finances, meeting organizers doing community programs, database and website experts, top MG physicians, scientists and nurses who contribute hours of their time as speakers, advisors, and advocates. We have PR and awareness experts, and smart business people. We may have a small staff, but when we leverage the power of volunteers, we are no longer a small organization. We become powerful. Relentless. Unstoppable.

So here is the question for each of us to ask ourselves: “What can I do?”

There is a place for each one of us. We are that group of committed citizens who can change the world. You don't have to have a special talent. Any of us can fund raise. Every one of us can increase awareness. Wear teal — or paint your nails with snowflakes. Dare people to ask.

The late Christopher Reeve said, *"So many of our dreams at first seem impossible, then they seem improbable, and then, when we summon the will, they soon become inevitable."*

So here is my dream. I believe we can defeat MG. Not so many years ago, it was thought that surgery on the heart was impossible. Now it happens thousands of times each day. Once, space flight only existed in science fiction. Now it is almost routine. Once, lives were devastated by polio. In most of the world, at least, polio is a distant memory.

Once, 30 percent of people with MG died. That's right. 30 percent of us would not be here. Today, thanks to advances in science, that is no longer the case. But MG still devastates lives — and dashes the hopes and dreams of many. And, quite honestly, most of us are dependent on treatments that were developed for other conditions, years ago. We have no targeted disease modifying therapies for MG. This is unacceptable. In multiple sclerosis, a much more complex disease — there are 14.

One of our pathways to new treatments is already at our fingertips — it is our patient registry. We have some work to do to make some changes so it is more user friendly, but when that is completed, expect to hear from MGFA in a campaign to grow this resource that can entice industry to invest in MG.

If we work together, I think that the dream of better treatments, and eventually a world free of MG, will, as Chris Reeve said, indeed, soon become inevitable.

Together, we are stronger. Together, we can change the world. Together, we can achieve a World Without Myasthenia Gravis.