



myasthenia gravis association

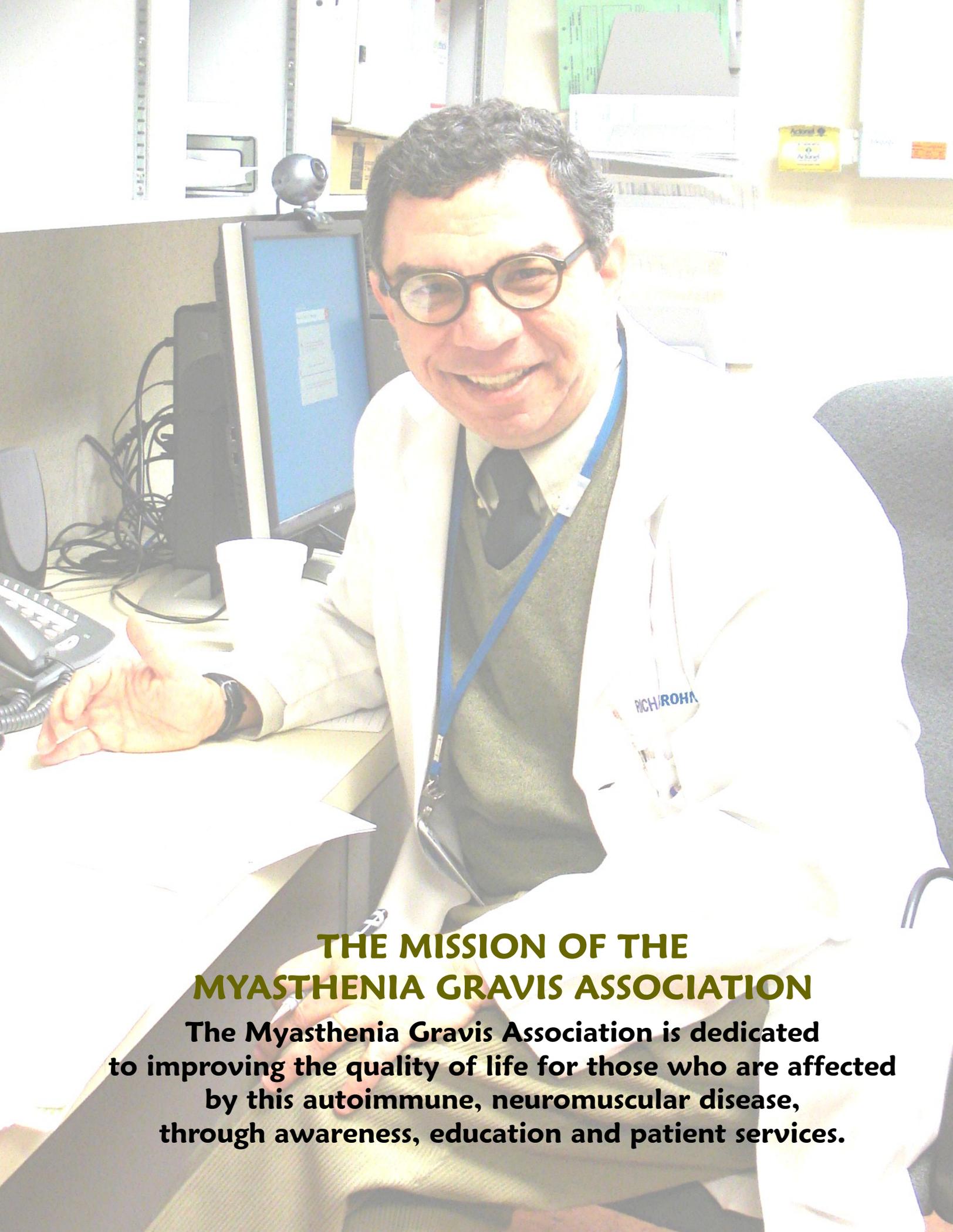
MGA

serving missouri and kansas

Celebrating 50 years



STRENGTH & HOPE THROUGH CONNECTIONS



THE MISSION OF THE MYASTHENIA GRAVIS ASSOCIATION

The Myasthenia Gravis Association is dedicated to improving the quality of life for those who are affected by this autoimmune, neuromuscular disease, through awareness, education and patient services.

WHAT IS MYASTHENIA GRAVIS?

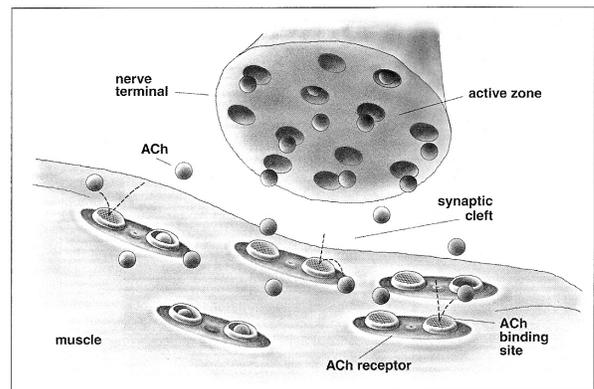
The first descriptions of Myasthenia Gravis, (MG) cases occurred more than 300 years ago, yet it was not until a series of discoveries in the mid 1970s that an understanding of and general consensus that MG symptoms are due to an autoimmune response impacting neuromuscular functions developed. The distinctive feature of MG is fluctuating muscle weakness, made worse by use of those muscles and improved at least partially by resting them. The muscles affected are called voluntary muscles ... muscles that we use all the time, such as those used to move the eyes or hold the eyelids open. The muscles used for facial expressions, chewing, talking or swallowing can be selectively affected. MG can affect neck muscles holding up the head which can go into spasm because they are weak. Muscles affecting the limbs can prevent a person from accomplishing activities of daily living such as holding up an arm to comb hair, shave, shampoo or put on make-up. Getting out of the bathtub or up from a sofa, climbing stairs or walking distances may be impaired. We take these muscles for granted until they don't work as expected.

With MG, the body's immune system mistakenly attacks and destroys its own special proteins (acetylcholine receptors) located on the muscle surface where a nerve meets the muscle. If some acetylcholine receptors are destroyed the muscle response is reduced and weakness occurs.

The seriousness of MG is particularly noticeable when some muscles that we use in breathing are affected. If the ability to breathe becomes insufficient, the patient is said to be in a "Myasthenic crisis" and mechanical breathing assistance in a hospital may be necessary. Different muscle groups are affected from patient to patient and some only have Ocular Myasthenia involving the eye muscles. Although MG can be fatal if a respiratory crisis is not treated immediately, with proper treatment, normal life expectancy is the rule.

Myasthenia Gravis means "grave weakness". It can affect people of all racial and ethnic groups and in both sexes, from infancy to old age. It is not uncommon for family members to have the same or different autoimmune diseases and some individuals can have more than one autoimmune condition. The prevalence rate of patients with MG is estimated to be 1 in 5,000, but because MG is often misdiagnosed, the rate may be higher. At present, the cause of MG is unknown and there is no cure.

Similar to other chronic diseases, treatment can be complex, debilitating and expensive. Potent medications and intravenous immune globulin (IVIG) and plasmapheresis, which are dispensed in a drip method through a vein, can provide side effects in themselves. Because the thymus gland is an organ involved in the development of the immune system, removal is often recommended for patients diagnosed with MG. The operation is called a thymectomy and although there may be a lessening of symptoms and reduction of MG-related drugs, there are risks with surgery and relapse is possible. As always, patients must become their own health care advocate in order to deal with insurance companies, pharmacies, physicians and other allied health professionals.



DISCOVERING OUR ROOTS

In 1954, while Joan & Rev. William Stackhouse were in West Africa, Joan was diagnosed with Myasthenia Gravis. Joan and Bill were missionaries with the United Presbyterian Church but after Joan's diagnosis, they returned to New York so that she could receive treatment. Just as Joan became aware of the MG Foundation of America in NYC, Bill was transferred to Kansas City where there wasn't a MG group and the nearest MG clinic was at the Mayo Clinic in Minnesota. In 1960 Joan set her sights on forming a local association and received support from their pastor, his wife and other parishioners of the Southridge Presbyterian Church in Mission, Kansas. Joan met Cecile Wu, who was also living with MG and motivated by their shared diagnosis, and with the cooperation of other MG patients and doctors in the community, the MGA was established. The charter meeting of the Kansas City MGA was held at Menorah Medical Center on April 9th, 1961. Later that year, the United Campaign



(United Way) provided the association's first grant of \$2,500 enabling them to hire the MGA's first Executive Director. In 1962, Dr. William Wu, MGA's first Medical Advisory Board Chair and Joan, were instrumental in establishing the first MG outpatient clinic at Menorah Medical Center to be under the direction of Dr. Dewey Ziegler. In 1964, Dr. Ronald Youmans assumed directorship and established a MGA office space at the hospital. Soon after, a MG Drug Bank through the Menorah Pharmacy was developed and made it possible for those living with MG to afford costly medications. In the 1960's being diagnosed with Myasthenia Gravis meant that there were limited treatment



options, lack of understanding and fear. An organizational emphasis was placed on increasing public awareness and providing professional education as well as educating patients, providing support and linking patients with MG-knowledgeable neurologists and community resources.

The first few years were filled with growth and excitement and little did these early MGA pioneers realize that they were laying the foundation for an association that would become an innovative health services non-profit in the greater Kansas City area that would help thousands of people living in Kansas and Missouri for over 50 years.

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Drug Helps Harness Rare Disease

A DERIVATIVE of the same drug used to combat the effects of curare, which tropical Indians used in poison arrows, is being used effectively to combat a rare muscular malady.

The disease is myasthenia gravis, which weakens the muscles.

A greater Kansas City chapter of myasthenia gravis has been organized by the Rev. William Stackhouse, 5223 Maple street, Mission, and his wife, Mrs. Joan Stackhouse, 52, who has been a victim of the disease since 1954.

There are about 300 known cases of the disease in Greater Kansas City. More than 120 victims are members of the new chapter.

John Marrow, now chairman of the chapter, explains that the disease develops a biochemical block between nerve endings and muscles. The block keeps muscles from responding, thus affecting speech, swallowing, and movement of the eyes and limbs.

A woman physician at a London hospital in 1934 was confronted with a diagnosis she had classified as myasthenia.

The doctor studied the patient and discovered that the disease showed the same effects of crippling the nervous system as does curare, the Indian poison. A drug called neostigmine was developed from the poison antidote and about 75 per cent of all myasthenia sufferers today take it regularly.

In critical cases of myasthenia, some patients have been known to take as many as 450 pills a day. In most cases,



A MYASTHENIA GRAVIS VICTIM, Mrs. William Stackhouse, makes plans with her husband, the Rev. William Stackhouse, for a move to New York City, where he will take over new duties as an officer of overseas missions for the United Presbyterian church.

the dosage is from 20 to 30 pills where he will assume new duties at a cost of about 9 cents a pill, as an officer of the overseas mission work.

At the time Mrs. Stackhouse first became ill, she and her husband were missionaries in Africa. They returned to the United States and Mr. Stackhouse was named secretary of overseas mission work for the United Presbyterian church.

Seeking the aid of some of their church patrons and myasthenia patients, the couple formed the area chapter in 1961. Through neostigmine, Mrs. Stackhouse now is able to lead a normal life. She is the mother of three children, Virginia, 12, Charles, 10, and Paul, 5.

Mr. Stackhouse and his family leave June 1 for New York, where he will assume new duties as an officer of overseas missions for the United Presbyterian church. The chapter received about \$4,000 from the United Campaign fund last year. The budget was \$5,000. A referral clinic and drug bank are maintained by the chapter at the Menorah Medical Center. "It is difficult to understand that a person may be physically unable to smile," Mrs. Stackhouse said. "Yet myasthenia is no more contagious than a broken bone."



ADVANCING THE CAUSE

The MGA began as a chapter of the national Myasthenia Gravis Foundation of America located in New York. Non-profit status was simplified by chapter affiliation and a united relationship enhanced both associations.



In 1994, the MGA voted to unaffiliate with the national association and form their own 501(c)3 non-profit association. Over the years programs and services have developed because of patient, family and caregiver need and because of the need to promote public awareness and educate health professionals. Support for the MGA has come from many directions. Menorah Medical Center provided an office and MG Outpatient Clinic for over 30 years and Research Medical Center then supported our MG Clinic and office for the next ten years, and they continue to help the MGA today. The MGA has been very fortunate indeed to have the assistance of these fine medical institutions and to have safe and affordable office space.

100,000 Americans have nerves that can't communicate with their muscles.



"There is no permanent cure for Myasthenia Gravis. No prevention. Let's find one." TONY RANDALL
National Campaign Chairman



mission. The United Way's leadership and guidance has enabled the MGA to grow as a professional association and meet every principle and guideline mandated for charitable non-profits. Funding from the United Way has meant that qualified staff can be hired to advance the cause. The balance of funding from volunteer efforts,



membership drives and contributions from members, family and friends, has made the difference in the MGA's ability to serve. It is heartwarming to recognize the generosity of so many who choose to improve the lives of those living with Myasthenia Gravis.



MGA LEADERSHIP

For 50 years, physicians, patients, relatives and friends have enthusiastically worked to expand MGA programs, support research and provide professional services. Until a cure is found, the Myasthenia Gravis Association serving Kansas and Missouri will continue to provide information and referral, support groups, newsletters, MG Clinics, public awareness and professional education.

Each year at our annual meeting, a **Board of Directors and Officers** are elected to fulfill our mission through financial and organizational responsibilities. The Board creates a yearly strategic plan and is expected to meet its goals and objectives. Board members are chosen because they can bring experience and expertise to move the association forward. Some Board members are people living with MG, some are professionals in a health-related field that impacts MG and others simply believe in the mission and want to make a difference. Part of the fiduciary responsibility of the Board of Directors requires making sure that the association has the financial resources it needs.

The Board hires and oversees the actions and performance of an **Executive Director** that is responsible for the day-to-day administration, leadership and on-going

success of the MGA. Working in tandem with the Executive Director, the **Program Coordinator** provides administrative support and coordinates MG Clinic activities, Support Groups and the annual benefit/auction.

Neurologists, Ophthalmologists, Nurses and other allied health professionals join the **MGA Medical Advisory Committee**. The Committee compliments the Board's effectiveness by bringing unique knowledge, skills, credibility and recommendations. They also act as ambassadors for the association and assist with fundraising aspects of the association.

Over the years hundreds of **volunteers** have given their time and talent to enhance the MGA mission. From helping with annual benefit/auctions, annual meetings and support groups, organizing MGA Walk For Awareness events,

selling holiday cards, candles, cookies and plants, to helping in the office and updating our membership lists.....the MGA couldn't do without these generous acts of kindness. Because our annual benefit/auction requires year-long organization, a **Benefit/Auction Committee** directs the work needed for a successful fund-raising event. Thanks to all these marvelous people who have enabled the MGA to exist for over 50 years!



PROGRAMS & ACTIVITIES INFORMATION & REFERRAL

The MGA staff provides information about MG to callers and sends out **NEW PATIENT PACKETS** to those newly diagnosed or to those who are new to the MGA. The packets contain over 20 pieces of literature of interest to those living with MG or their families or friends. Many patients share this information with their physicians. The MGA **website** is the place to go



NEW PATIENT PACKETS



to discover information about MGA events and activities, photos of our members and of those associated with the MGA. The website provides links to videos of past support group presentations, and to MG-related resources. The MGA makes **referrals to MG-knowledgeable neurologists** through recommendations from our members. The MGA **informational brochure** is available for members to give to their physicians, for distribution at health fairs and to the general public.

CONNECTIONS

The heart of the Myasthenia Gravis Association is associated with our quarterly newsletter that reaches over 1,000 people living in Kansas and Missouri. The newsletter contains articles about MG research, treatment, other health-related issues, links to resources of interest and MGA sponsored events. Those living with MG are invited to submit their personal stories about being diagnosed and their journey in coping with the disease. Whether patients, caregivers, family or friends are able to attend MGA sponsored activities, the newsletter provides a connection to better understanding and managing MG. It also promotes a sense of camaraderie and confirms that there are others who are dealing with similar issues. Advertising (for a modest rate), is always welcome.



Celebrating 50 years MAKING OUR HISTORY COME ALIVE

In 1954, while Joan & Rev. William Stackhouse were in West Africa, Joan was diagnosed with Myasthenia Gravis. Joan and Bill were missionaries with the United Presbyterian Church and soon after Joan's diagnosis, Bill's work brought them to Kansas City. Joan was aware of the MG Foundation of America in New York, but there wasn't a MG group in KC and the nearest MG clinic was at the Mayo Clinic in Minnesota. Joan set her sights on forming a local association and received support from their pastor, his wife and other parishioners of the Southridge Presbyterian Church in Mission, Kansas. Joan met Cecile Wu, who was also living with MG, and motivated by their shared diagnosis, and with the cooperation of other MG patients and doctors in the community, the MGA was established. The charter meeting of the Kansas City MGA was held at Menorah Medical Center on April 9th, 1961. The following year, the United Campaign (United Way) provided the association's first funding.



In 1962, Dr. William Wu, MGA's first Medical Advisory Board Chair, was instrumental in establishing the first MG Clinic at Menorah Medical Center to be under the direction of Dr. Dewey Ziegler. In 1964, Dr. Ronald Youmans assumed directorship and established a MGA office space at the hospital, and a United Way grant helped to professionalize the association's activities. Soon after, a MG Drug Bank through the Menorah Pharmacy was developed. The first few years were filled with growth and excitement. Thanks to all those who gave of their time and dedication!



SUPPORT GROUPS



It can be difficult for family and friends to understand the consequences of living with Myasthenia Gravis. While one day you may be able to achieve the tasks of daily living, the next day you may not. Being able to communicate with others who are also



dealing with symptoms, going through similar

treatment

and coping with the side effects of medication can be valuable. Support Groups provide an environment for shared learning from personal experience and from formal presentations. Guest speakers of interest to those living with MG provide information and raise consciousness. Opportunities for socialization and links to community resources are appreciated.

MGA Support Groups are held in Kansas City, Springfield, St. Joseph and North Kansas City, Missouri and in Wichita, Lawrence and Hays, Kansas.



MYASTHENIA GRAVIS CLINIC

AT THE UNIVERSITY OF KANSAS MEDICAL CENTER

It's frightening to be diagnosed with a chronic disease, let alone diagnosed with one so few have heard of and one that you find difficult to pronounce. Yet for those who are patients at the University of Kansas Medical Center Neuromuscular Clinic, a program partnership between the clinic's four Myasthenia Gravis specialists and the Myasthenia Gravis Association of Greater Kansas City provides expert diagnosis, patient education, treatment and support.

The KUMC MG Clinic was organized in 2002 under the leadership of Dr. Richard Barohn, Chair of the Neurology Department, who at the time was also serving on the Myasthenia Gravis Association Board of Directors. Dr. Barohn is a world renowned MG specialist and MG researcher. His team of Dr. Mazen Dimachkie, Dr. Mamatha Pasnoor and Dr. April McVey create a unique opportunity for patients and their families to receive care based on the most current research and treatment methods. An effort is made to schedule MG patients on Tuesday mornings and before each patient appointment, the MG clinic physicians and current Fellows gather in a conference room to discuss patients' symptoms, progress and treatment plan. While the physicians confer, the MGA's Program Coordinator meets with the patient and family that may attend in the patient's room. The coordinator offers a personal and less scientific approach to care and support for the patient in their everyday quest to live a more healthy life. The coordinator also helps patients gather their thoughts and concerns so that the most will be made of their physician appointment. This collaborative approach is of great value to patients and offers the kind of support that encourages patients to take control of their health and helps in the management of living with a chronic disease.



AMY EHLERS, MGA PROGRAM COORDINATOR
AND A PATIENT



DR. RICHARD BAROHN



DR. APRIL McVEY



DR. MAZEN DIMACHKIE



DR. MAMATHA PASNOOR



MYASTHENIA GRAVIS CLINIC

WITH DR. MICHAEL SCHWARTZMAN

NEUROLOGICAL CONSULTANTS

A specialist in neuromuscular disease, Dr. Michael Schwartzman has been associated with the Myasthenia Gravis Association since 1993 when he and Dr. John Sand became the primary neurologists managing the MGA's MG Clinic at Research Medical Center. The MG Clinic was a collaborative effort between the MGA, Research Medical Center, Health Midwest and Kansas City Clinical Neurological Associates. In 2002, Dr. Schwartzman moved his office to Neurological Consultants of Kansas City on the Plaza with offices at Saint Luke's Medical Center's South and Lee's Summit locations. At the same time, Dr. Sand acquired MD ElectroDiagnosis, an electronic testing center for neurological and muscular diseases. The MG Clinic moved with Dr. Schwartzman and continued its activities with Diana Wilmoth, RN as Volunteer Coordinator. Diana served on the MGA Board of Directors for many years and is a person living with Myasthenia Gravis. Committed to educating and supporting MG patients and their families, as well as fulfilling the mission of the MGA, Diana has coordinated Dr. Schwartzman's MG Clinic for over 10 years. Because of Diana's nursing background and MG status, she has a unique perspective on MG health education. Consequently, many of Dr. Schwartzman's MG patients agree to have her accompany them during their physician appointments. Dr. Schwartzman and Diana provide a multi-disciplinary approach to the treatment of MG. Patient appointments are less stressful and provide for more understandable and useful information. There is encouragement for patients to become their own health advocates and participate in prevention.



MG CLINIC COORDINATOR, DIANA WILMOTH, RN, A PATIENT & DR. MICHAEL SCHWARTZMAN

ANNUAL MEETINGS



Annual Meetings usually take place in November and provide an opportunity for members and friends to gather and to review the work of the association from the previous year and to welcome new Board members or new Officers. Inspiring guest speakers present topics of interest to MGA members, their family and friends and provide an educational experience that is unique to our area. A panel of local health professionals offer additional MG-related information and are available

for a much anticipated question and answer period. The annual meeting also provides an opportunity to thank special people for their volunteer efforts. The MGA especially appreciates those that enhance the quality of life of those living with MG and those who provide support for the Myasthenia Gravis Association.



A luncheon, sponsored by ARJ Infusion Services follows the program and cake and raffle prizes create a festive mood. As with every MGA event, it is hoped that those attending will not only leave with useful information, but will meet new friends who are living with MG, and meet those caring for someone with MG. Since MG affects only 1 in 5,000, it is important to learn and share with others in similar circumstances.



PUBLIC AWARENESS

"I never heard of Myasthenia Gravis; what is it?" Since only 1 in 5,000 is likely to have MG, many people are not be aware of this neuromuscular, autoimmune disease. Therefore the MGA is committed to raise awareness throughout the year. MGA staff, Board of Directors, Medical Advisory Committee and volunteers are available to speak to community groups, educational institutions, businesses and other non-profit organizations.

MGA Walks For Awareness provide opportunities for family and friends and local sponsors to support those living with MG, along with a fun way to raise money for programs and services.

Every June to observe MG Awareness Month, the MGA communicates with newspapers, TV and radio media to education the public about MG and the MGA.

Approximately 400 appeal letters are sent to business and services every year for support of the MGA annual benefit. Included in this appeal for auction items or gift certificates and for sponsorship, are flyers describing MG and programs and services of the MGA.



PROFESSIONAL EDUCATION



Besides the MGA Annual Meeting, presentations and training sessions are offered to physician offices, hospital staff and to other health-related professionals by members of our Board of Directors, Medical Advisory Committee and MGA volunteers. New Patient Packets and other MG literature are available for physician offices free of charge.

Every June, in recognition of MG Awareness Month the MGA selects a profession that impacts the lives of those living with MG and mails specific information that may be of help in treating MG patients. Recent mailings have be sent to neurologists, first-responders and ophthalmologists in MO & KS.



RESEARCH: THE SEARCH FOR A CURE

Research is essential to ensuring better treatment and, hopefully, a cure for myasthenia gravis. Studies are usually conducted for one of the following purposes: to study the cells that may be involved in autoimmune disease and specifically in MG for the purpose of developing targeted treatments; to study the genetics involved in those with MG; to test whether medications or treatments used for other diseases are effective in treating MG; and to test current MG medications and treatments to determine how effective they really are. The hope is always to discover or develop treatments that will better control the symptoms of myasthenia gravis or slow/stop the disease process, with the fewest side effects, so that patients can have the greatest quality of life possible. Research is done locally, usually in teaching hospitals and often as part of national or international multi-center trials, and it is also done in research laboratories and hospitals around the world. Clinical trials involving patients can be viewed at www.clinicaltrials.gov. Because myasthenia gravis is a rare disease, it does not receive the publicity and therefore the research funds that some other diseases have. If you are interested in contributing towards research for MG, please contact the Myasthenia Gravis Association at (816) 256-4100 or mgakc@sbcglobal.net, or the Myasthenia Gravis Foundation of America at (800) 541-5454 or mgfa@myasthenia.org.



FUNDING AND STABILITY

For over 50 years the Myasthenia Gravis Association has been able to provide programs and services, professional education and increase awareness because of the generosity of our members, donors, sponsors, the United Way, grants, those contributing to the annual benefit and Walk For Awareness. ARJ Infusion Services, providing caring, comprehensive, cost conscious home infusion therapy to people affected by chronic disorders, has been a major sponsor of the MGA for many years. Contributing to MGA support groups, annual meetings, newsletters, Walk for Awareness and benefits, we are grateful to ARJ for their support.



DR. JOHN & MELINDA SAND AT A MGA
BENEFIT/AUCTION



ARJ INFUSION SERVICES



(816) 256-4100 • www.mgakc.org

THE REASON WE'RE HERE

WHAT MGA MEMBERS SAY ABOUT PROGRAMS, SERVICES & EVENTS



"I really feel taken care of at the KU Medical Center MG Clinic. The doctors are great and Amy, who meets with me before my appointment, is so supportive and kind. It's a unique blend of compassionate people."
Wei Ji, Overland Park, KS



Amy Ehlers, Program Coordinator with a MG patient at KU Medical Center MG Clinic



"My mother has Myasthenia Gravis and as a caregiver, the MGA has given me lots of practical and scientific information to help me in the planning of her care. The support group and other activities are a real boost to our routine."
Carol Dziadik-Turner, Kansas City, MO



Carol Dziadik-Turner & Mother Anna



"I was diagnosed with MG 5 years ago and it's been a rough ride, but it's been easier because of my wonderful wife, Charlotte, my loving family and because of the Myasthenia Gravis Association. I can't attend many of the activities anymore, but it's good to know that you're still here for me and others."
Don Aaron, Former Leavenworth County Commissioner,



Don Aaron, Charlotte & Family



"As a 17-year-old high school student, it's been difficult to talk to other kids about my having Myasthenia Gravis. But since I've been going to MGA activities, I've gained confidence and feel better about disclosing my MG. I've met a few more kids my age with MG through the Myasthenia Gravis Association and now we're emailing each other. That's great."
Brandon Elliott, Eudora, KS



Brandon & mother, Heidi

MGA ANNUAL MEETING



"The MGA Annual Meeting is educational but it also helps me understand where the funding and donations go and it's good to see that the money is spent for all the right reasons. The MGA touches my life."
MGA Volunteer, Deborah Anderson, Kansas City, MO



Deborah Anderson



HOW YOU CAN HELP

BECOME A SPONSOR

- Annual Meeting
- Annual Benefit/Auction
- Annual Walk For Awareness
- Sponsor *MG Awareness Month* outreach activities

VOLUNTEER AND GIVE OF YOURSELF

- In the MGA office
- At a MGA event
- Talk or email with others living with MG or with their caregivers
- Raise awareness about MG & the MGA by speaking with others
- Coordinate a MG Support Group in your area
- Contribute to the newsletter - your story, professional article, creative work, etc.

STRENGTHEN THE ASSOCIATION

- Become an annual member
- Attend or donate toward the Annual Benefit/Auction
- Ask your family & friends to make a contribution & attend the MGA Benefit
- Honor or memorialize family or friends with a contribution
- Take out an ad in the MGA quarterly newsletter
- Solicit auction items or certificates from your local stores for the MGA Benefit
- Underwrite the cost of the annual membership drive
- Underwrite the cost of MGA office supplies or other office expenses
- Leave a legacy and make a bequest



**Myasthenia Gravis Association
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