

Western Pennsylvania's *Keystone of Hope!*

Spring 2011



Our Story of Triumph

By Doris Grafton

My late husband, Ronald Grafton, was diagnosed with myasthenia gravis in September 1992. This is our story.

Ron and I met in 1953 when he and his family moved to our community. We were in third grade. Our school house was a little one-room country school with a pot belly stove in the center of the floor. I always admired him. We went to school, to church, to youth group, to 4-H, and to high school together and lived only one mile apart. It was a year after high school graduation that we discovered we were more than just friends and on October 3, 1964, we were married. We were blessed with a son in 1966 and a daughter in 1971, and Ron, with the help of many family members and friends, built our home in 1972.

Ron was employed with Eljer Pottery in Ford City, beginning his work career in 1963. He went to night school and received an Associate's Degree in Business. He did well, worked hard, but always strived to do better. All went well until 1992 when he came home from golfing one evening and complained of seeing two golf balls on the course. There was no improvement the next day so we went to the emergency room. There were many tests, much speculation and a couple weeks passed. Then his doctor asked him if he could chew a sandwich. He said, "No." That was all the doctor needed to hear as he suspected myasthenia gravis. Our neurologist, Dr. Berk, confirmed the diagnosis with a tensilon test. Ron was scheduled for a thymectomy in October 1992. We were told this was an unusually short lapse of time. The diagnosis of the disease is sometimes a quite lengthy process. What we thought would be a reasonably short hospital stay turned out to be a 35-day stay with two weeks in ICU. There were complications, many hours at his bedside, many prayers — but what rejoicing when he finally came home.

He made a remarkable recovery and returned to work only a couple months after surgery. The demands of Ron's position as plant superintendent didn't seem to cause problems for a while, but in time it was just too much. He had hospital stays from



Ronald Grafton

time to time and was given prednisone which would bring him out of a crisis. He took mestinon daily. In 1999, on the advice of his doctor, he finally had to quit working. Through his tears outside the doctor's office he told me that was the hardest thing he ever had to do.

When one door closes, another opens. We were blessed with our first grandchild, then another in 2000 and another in 2002. They were the joy of his life. He said if he had to quit working he wanted to be able to spend time with his grandchildren, volunteer more at the local fire hall and our church and be active in sportsmen's clubs. He was able to do all of that. He continued to take mestinon daily and had to rest throughout the day. Some days were better than others. He made each day count.

Tragically on March 11, 2003, we had a gas explosion in our home. We could not smell gas. I had just gone upstairs and Ron was in the basement. He opened a door and the house exploded, pinning him in cement rubble under the porch. He was just 58 years old.

What wonderful memories we have! He accomplished what he set out to do! God blessed us with 37 years of marriage, two children and three grandchildren. We were blessed to have wonderful doctors those 11 years we lived with myasthenia gravis and we DID triumph over the disease. Ron never gave in. Our faith, our family and our friends saw us through. There is nothing you can't handle in this world if you put your trust in Almighty God! No matter the circumstances, you can triumph! It will soon be eight years since Ron left us, but his legacy remains. The lives he touched, the people he encouraged, his work ethic, his faith and determination will never be forgotten. I was blessed to be a part of his life and I am so thankful.

Editor's Note: Mrs. Grafton and her family have purchased a substantial life insurance policy naming MGA as the benefactor. The board of directors and staff members are inspired by this family's story and their generosity. To learn more about planned giving, please contact MGA at 412-566-1545.

In Memory of Antonia "Toni" Merlo

Toni Merlo, 66, passed away unexpectedly on December 10, 2010. A graduate of the Carlow College Nursing Program, she started her career at Mercy Hospital where she later served as Department Head for Mercy's MG Unit.



Memories from Donna: In the early '70s Toni was the head nurse on the old 3 East which, at the time, served as the neurology unit at Mercy Hospital. I was only nine years old when we met; she was a big woman with a gruff exterior and a big heart that quickly dried my tears and put my fears at bay. Her compassion, her patience and her quick wit even had the doctors under her spell. Before her retirement to take over her father's trucking business Toni helped many MG patients and their families deal with the difficult medical situations that myasthenia gravis can cause. I could relate many stories from my friendship with Toni during my young years, but there isn't enough room in this newsletter. Suffice to say that she was a wonderful nurse, a good friend, and a force to be reckoned with. I will always remember her fondly and with a smile. My heartfelt condolences go out to her son, Christopher, her family and friends.

Some thoughts from Sharon Gaines: Toni was the best nurse I ever knew. I met her when I was 12 years old and she became a big part of my teenage years. My dad brought me to the MG clinic in Pittsburgh from Washington, DC, because he heard it was the best place to be treated for MG. Dr. Robert Blume was the physician who decided that I needed to be in the hospital to get my meds regulated. My dad left to go back to DC and naturally I felt alone and terrified. So this nurse came to talk to me, and her name was Toni Merlo. She sat down with me and explained what would happen and how things were run there on the unit. She also expected me to stop crying and be strong. Her kindness and compassion helped me feel safe and secure. That was the beginning of my long relationship with her and the MG Clinic. She helped me to face my illness with strength, courage and integrity. She expected all of her patients to face the challenges before us, but none of us could have done it without her support and encouragement. She was one of a kind. Thank you, Toni!



Join us for the 17th Annual All-Star Sports Memorabilia Auction

Sponsored by
The Koter Group at Morgan Stanley

Proceeds benefit the
Myasthenia Gravis Association of Western Pennsylvania

When: Saturday, April 16, 2011
(Doors open at 6 p.m.)

Where: The Lexus Club at PNC Park

Cost: \$30 per person, includes buffet, cash bar, raffles, auctions, grab bags, and more!

Only 250 tickets will be available!
Call 412-566-1545 for more details.

Approximately 125 autographed sports related items will be available. Many items signed by a variety of local and national sports stars will be on display within the LIVE and SILENT auction areas.

Free autographs from special celebrity guests!

To order tickets or for more information, call 412-566-1545 or email dkalisek@mgawpa.org.

MGA
490 East North Ave #410
Pittsburgh, PA 15212

Anyone wearing their favorite team apparel to the event will be eligible for a special prize drawing!

Tickets will be sold on a first-come first-serve basis!

United Way Donor Designation

If you donate to a United Way agency in Western Pennsylvania, did you know you can designate your donation to directly benefit **MGA**? When making your donation, simply designate your payment to MGA by using the following codes:

UW of Allegheny County #82
UW of Beaver County #4861
UW of Butler County #5981
UW of Erie County #45146
UW of Mon Valley #1178
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If you are a state or federal employee and want to use payroll deduction to make a donation to MGA, please check with your employer to verify the following codes:

SECA (For State Employees): Use **S460124** (please note, the first character is the letter "S")

CFC (For Federal Employees): There were some changes and we have been informed that **#38076** is our current five digit code. Again, please double check, especially if you live in Allegheny, Armstrong, Clarion, Crawford, Erie, Fayette, Forest, Greene, Lawrence, Mercer, Venango, Washington, or Westmoreland counties.

If you have any questions regarding United Way donor designation, SECA or CFC, please feel free to call the MGA office at 412-566-1545.

Thank you for your continued and generous support of MGA.

MGA Staff Attending MGFA National Conference

MGA's staff members will be attending the MGFA national conference this year. Although we cannot coordinate a group activity, we would love to see you there if you can make it!

The National Conference combines the Foundation's annual business meeting with the opportunity for patients and their families to learn more about the disease and its treatment, current research and tips to learn "how to live" with MG from experienced medical professionals and fellow patients.

The 2011 National Conference will be held May 4-6, 2011, in Baltimore. You can register online at www.myasthenia.org

To make online hotel reservations, go to www.tremonts.com. From the Tremont home page click on the reservations tab. The reservations page will pop up. Guests are to enter arrival and departure dates as well as the group code, which is MGFA2011. **Important: you must enter this code in the group code box not the corp/promo code.**

Donate your car to Goodwill and help MGA

MGA has created a partnership with Goodwill Industries to begin an auto donation program.

You may now donate your used vehicle (car, truck, motorcycle, van, boat, or motor home) to MGA of WPA.

We can use any vehicle – running or non-running!

Your car will be towed to the auction site, all at no cost to you. **You also receive a tax-deduction in the full amount of the sale.**

But perhaps best of all, proceeds raised from the auction of your vehicle go towards MGA to help support our program services. All of the paperwork and details are also done for you. Avoid the hassle of trying to sell it for yourself! Simply call the MGA office for more details.

Contact MGA to donate.
412-566-1545



Easy Ways to Help the MGA with Your Online Shopping and Searching!

www.goodshop.com

Choose the Myasthenia Gravis Association of Western Pennsylvania and shop at most of the online stores you already use, with no extra cost to you – just make sure to use the store's link from the Good Shop site and we'll receive a percentage of your purchase! Using their search engine also helps raise money for the MGA. You can download their toolbar so you don't have to remember to go through their website. *Encourage those who purchase office supplies for your company to use it as well!*

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When you get there answer the question to "Who do you search for?" Enter Myasthenia Gravis and click 'verify'. Then choose **Myasthenia Gravis Association - Western PA (Pittsburgh, PA)**. **MAKE THIS YOUR HOME PAGE!**

Dentistry and Myasthenia Gravis

Dentistry can be a part of normal healthcare for the myasthenic and should not be feared or avoided. The objective of this article is to give both the dentist and the myasthenic a basis for understanding and communication that will result in good dental health and the prevention of future major problems.

Basic Problem: Myasthenia gravis (MG) presents as a neuromuscular disorder characterized by progressive weakness and fatigue of the voluntary muscles and made worse with exercise and relieved by rest. MG is believed to be an autoimmune phenomenon with a reduction of acetylcholine (Ach) receptors at the neuromuscular junction. Muscles contract when Ach from the motor nerve axon vesicles interact with the Ach receptor of the postsynaptic area on the muscle, causing depolarization and contraction of muscle. Ach is hydrolyzed by acetylcholinesterase (Ach E) after the depolarization. A process, activity, or drug that interferes with any of these steps will result in a decrease in response of muscle to stimulations resulting in weakness. Most myasthenics have elevated amounts of antibodies that bind to Ach receptors. Therefore, a reduction of Ach receptors is believed to be the basic problem in MG. The dentist and staff should first understand that the myasthenic does not have a contagious disease and is not a threat to staff or other patients.

Clinical Findings: MG most often affects other muscles innervated by the cranial nerves, in women more frequently than men (3:2). Any age group can be affected but is notable for women in the 20s and 30s and men in the 50s and 60s. Many, but not all, myasthenics experience eye problems (ocular muscles) such as droopy eyelids (ptosis), double vision (diplopia), blurry vision, and weakness of eyelid closure. Some may experience difficulty swallowing and chewing and slurred speech (laryngeal and pharyngeal muscles) and weak neck (head holding) muscles. Additionally, there may be weakness or abnormal fatigue of the proximal muscles of the arms (especially) and legs. Although about 16 percent of myasthenics have symptoms restricted to the eyes, the majority have involvement of oropharyngeal and limb muscles. Partial remissions sometime occur. Some (5 percent) myasthenics have thyroid dysfunction. Weakness will often increase with hot weather, fever, systemic illness, infections, exercise, a hot bath, stress, menstrual cycle, and drugs that display a neuromuscular blocking effect. Myasthenics often experience frustrations in getting diagnosed with fluctuating symptoms that are dismissed as a psychiatric problem. Diagnosis is eventually made with the demonstration of: fatigue on muscle testing; improvement after giving an anticholinesterase drug; repetitive nerve stimulation tests; and antibodies to the acetylcholine receptor.

Medical Treatment: The standard anticholinesterase drug for MG is Mestinon (pyridostigmine) although there are several others. Few patients experience complete relief and may find that medication requirements vary during the day or from day to day. The most common side effects of inhibitors are

gastrointestinal. Some patients may also have an increase in bronchial secretions, bronchospasm, oropharyngeal weakness, or respiratory insufficiency. Some MG patients take corticosteroids (prednisone) and commonly have had the thymus gland removed (thymectomy), sometimes including a thymoma. For severe situations, plasma exchange (plasmapheresis) may give temporary improvement to avoid respiratory assistance.

Dental Treatment: The controlled myasthenic is able to tolerate productive dental sessions with some modest accommodations from the dentist (and staff) and with planning and cooperation from the patient.

Appointments: Usually morning appointments will work best, depending upon when the patient is at his/her best. It will help for the patient to take medication so there will be optimal oral and neck strength for the dental appointment. Patient and the dental staff should cooperate on appointment scheduling and patient should plan on being rested to the greatest extent possible so there is less chance of needing to cancel the session. The patient should allow time to arrive and rest a bit. In hot weather it will help to arrive and refresh in the air conditioned office. The myasthenic is more susceptible to infection, especially if taking immuno-suppressant drugs or prednisone. Bring the patient back to a dental chair to relax a few minutes rather than sitting in the waiting room closely with others. The patient can take comfort in knowing that modern dentistry embraces "universal precautions". Dentists and assistants routinely wear gloves and masks before starting intraoral procedures. All equipment and supplies should be previously set up and organized so the procedure can be efficient and productive. Appointments should usually avoid long sessions. For example, if several crowns were being prepared, temporary coverage should be made and impressions deferred to another appointment, if the patient becomes fatigued.

History: The amount of treatment, chair position, and head support can be planned based on the patient's problems, if any, with swallowing, holding head up, breathing, or choking. Some may have no problem at all, others a severe problem. Severe or uncontrolled cases and those on life support will usually be best treated through hospital dentistry programs or special patient care programs in larger health centers and dental schools.

Chair Position: Usually it is more difficult for the myasthenic to lie way back. It may help to be more upright to avoid closing the throat or regurgitating fluids. The dentist and patient need to find a compromise that can be tolerated by the patient yet give adequate access to the mouth to permit proper and safe dental treatment. The patient may wish to try a small neck pillow to support the head. However, most modern dental chairs are contoured and have adjustable cup-shaped head rests that support the head.

Procedures: A chair-side assistant is highly recommended using a good oral evacuation suction and a hand-held, self-directed, evacuation ejector to remove saliva and water. Rubber dam tooth isolation is very helpful whenever possible. The tooth is on the dentist's side and the patient can move the tongue and saliva ejector around on the other side without worry about choking or aspirating. Root canals can be done as well as restorations and crowns. Use a rubber mouth prop if it is difficult to keep the jaw open but periodically remove it for a rest break and don't over-stretch the mouth. (The dentist and assistant should try a mouth prop themselves for a more realistic concept of limits). A pediatric-sized handpiece may be used for posterior areas with limited access.

Attitudes: Everyone will do better trying to accommodate the situation. Positive reinforcement gets most patients to go "the extra mile" and try to tolerate the procedure rather than intolerance, rushing or impatience. Dentist and patient should cooperate on moderating costs. Most dentists experience high overhead costs. But the myasthenic does also, often having major medical costs and needing special transportation or facing extra visits to accomplish a procedure.

Anesthetics and Medications: Local anesthesia is much preferable to general anesthesia for the myasthenic. Fortunately, most routine dentistry is done with local anesthesia. There is no contra-indication to nitrous-oxide with oxygen for light sedation. Lidocaine ("xylocaine" and other brands) may exacerbate MG intravenously but should not be ruled out locally if needed. Mepivocaine ("carbocaine") has few side effects, has shorter duration and is a good first choice. Use anesthetic vasoconstrictors if needed to get adequately lasting and profound anesthesia. Vasoconstrictors may need to be avoided if the patient reacts unfavorably, as with some non-MG patients. An aspirating syringe for local anesthetics should be the standard of care with dental local anesthetics. No one thrives on pain or stress. Avoid bilateral mandibular blocks due to swallowing problems. Match the anesthesia to the procedure and have the patient remain in the chair until swallowing control no longer needs suction or saliva ejector assistance and the patient feels in control. Some patients find intraligamental injection adequate for very localized anesthesia. However, this only lasts a short time and is contraindicated for a tooth with periodontal disease.

The dentist should contact the patient's physician for concurrence on use of antibiotics or sedatives. Prednisone or immuno-suppressants may result in easier infection or healing

taking longer. Drugs that may exacerbate MG include (but are not limited to) intravenous lidocaine, aminoglycoside antibiotics (gentamicin, streptomycin, etc.), polypeptides, tetracyclines (Aureomycin, Achromycin, etc.), clindamycin (Cleocin), ampicillin, erythromycin (E-Mycin, Erythrocin) and diazepam (Valium). Every MG patient does not react to all these medications and no drugs are absolutely contra-indicated, but certainly any potential to impair neuromuscular transmission must be weighed against the need to treat the disease or problem. Establish close monitoring and effective communications with the MG patient taking medications.

Surgery: Most oral surgery and periodontal surgery is done under modest amounts of local anesthesia. If intravenous sedation or a general anesthetic is necessary, then the myasthenic needs both an oral surgeon and an attending anesthesiologist. Both should be given the Myasthenia Gravis Association's phone number and a list of medications that may aggravate MG. The oral surgeon cannot do the surgery and adequately tend to the myasthenic's general anesthesia and respiratory status. Any use of neuromuscular blocking agents will obviously require reparatory support and extended post-operative attention for the myasthenic.

Prevention: The best dentistry is prevention! Regular brushing with fluoride-containing toothpaste and cleaning between teeth with floss are extremely important even if difficult to do. Electric toothbrushes and floss holders are available. A very small "proxibrush" (looks like a miniature bottle brush) is made to clean under bridge pontics and where large spaces exist between teeth. When the brush wears out a new one can be mounted on the handles. These items are available without prescription in drug stores and supermarkets. Chlorhexidene ("peridex") or fluoride mouth rinse or gel are sometimes prescribed for periodontal (gum) and caries (decay) prevention and are acceptable for the myasthenic. Proprietary mouth washes do not take the place of brushing. Use a denture brush (or an electric toothbrush if necessary) to clean dentures or partial dentures inside and out. Lay them on a wet wash cloth in the sink to avoid dropping them and to make brushing easier. A dental "waterpick" will help get food particles from around braces and bridgework but brushing and flossing are unmatched for getting rid of the sticky film of bacteria and deposits known as plaque that causes caries and periodontal disease.

The myasthenic is urged to see the dentist routinely and stay on regular recall. Sometimes the occlusion may need adjustment if jaw muscles are especially weak. Small cavities and routine hygiene scaling of the teeth beats major restorations, abscesses, and extractions. Avoid emergencies. Modern dentistry has made big advances in techniques, materials, and treatment and is not the trauma that older persons remember from their childhood. Teamwork between patient, dentist, anesthesiologist (if needed) and the MG-treating physician means good, routine dental maintenance with minimal risk!

Reviewed for publication by the Medical Advisory Board of the Myasthenia Gravis Association of Western Pennsylvania. 2009



Cytokinetics Study and the Myasthenia Gravis Association

The Myasthenia Gravis Association of Western Pennsylvania and Allegheny General Hospital have been selected as one of the study sites for a medication trial for a potential new medication for MG. According to a January 4, 2011 press release on Cytokinetics' website:

"This Phase IIa EoE clinical trial is a double-blind, randomized, three-period crossover, placebo-controlled, pharmacokinetic and pharmacodynamic study of CK-2017357 in patients with generalized MG. At least 36 and up to 78 patients may be enrolled at approximately 15 study centers in the United States. Patients enrolled in the trial will receive single oral doses of placebo, 250 mg, and 500 mg of CK-2017357 in random order. A wash-out period of at least 7 days (to a maximum of 10 days) will be employed between the individual doses for each patient.

"The primary objective of this hypothesis-generating clinical trial is to assess the effects of CK-2017357 on measures of muscle strength, muscle fatigue and pulmonary function utilizing the standardized Quantitative MG score, Manual Muscle Test, and MG Composite score ... based on non-clinical and clinical results generated to date, we believe that we may be able to demonstrate potentially clinically relevant pharmacodynamic effects of CK-2017357, even after a single dose." (from www.cytokinetics.com/press_releases/release/pr_1293829122).

Cruise Planners of Coraopolis

Cruise Planners of Coraopolis is pleased to have a great relationship with Myasthenia Gravis Association of Western PA and



has committed to donating 25 percent of their commission on any cruise or hotel bookings made through Cruise Planners of Coraopolis. Myasthenia Gravis Association of Western PA continues to address the medical, social and emotional needs of those affected by MG. It is our hope that through Cruise Planners' affiliation with MGA of WPA, we can be instrumental in the continuing education of MG and to support the best quality programs for families affected by MG. We also hope to provide Myasthenia Gravis patrons and partners the opportunity to enjoy the benefits of a relaxing vacation while contributing to one of their favorite organizations. For booking information go to www.bonbinicruiseplanners.com, email tgyr@cruiseplanners.com, or call Tracy Gyr at 412-269-0575.



Supporting Each Other

By Amanda Anderson

One of the most effective ways to combat stress is through sharing with someone who has experienced the same difficulties. This is why support groups connected to many organizations are so important. The MG support group is a great way for patients to connect with each other, share strength and hope, and offer solutions to others going through similar trials. Each month the group covers any number of topics which are suggested by members or chosen by our staff. This past month we focused on MG and exercise. Fortunately there are MG-appropriate exercise programs in our area. The Parkinson Wellness Foundation has an exercise program which is approved by our treatment center and is appropriate for people with MG. If you would like to know more about this program, give us a call.



Amanda Anderson

If you would like to attend one of the support group meetings, we meet on the third Saturday of each month from 1-2:30 p.m. in the Singer Library on the first floor of AGH unless otherwise stated. Call us at 412-566-1545 to receive additional information. We would love to see you!

Another wonderful social services opportunity which we have been involved in is participation in several clinics which serve homeless and underinsured people around the North Side. We have found that there is a population of individuals who may not be receiving care for their MG due to poverty or homelessness. We are getting the word out to clinicians and others who serve the community who assist this population to receive free and prompt medical care. If you would like to know more about this opportunity, give us a call.

As always, thank you for your involvement in healing and strengthening each other.

Thank you for helping MGA raise more than \$15,500 during the annual appeal in 2010!!

These donations were received between November 1, 2010, and February 15, 2011.

**Perpetual Donation:
In Honor of**

Ron Grafton

By Doris Grafton and Family

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