

Western Pennsylvania's *Keystone of Hope!*



MYASTHENIA GRAVIS
TREATMENT & ADVOCACY CENTER
at Allegheny General Hospital

*A program of the Myasthenia Gravis Association
of Western Pennsylvania*

WPAHS and MGA Teaming Up To Provide Services For Patients With Myasthenia Gravis

For more than 53 years, thousands of patients from the tri-state area have turned to the Myasthenia Gravis Association of Western Pennsylvania (MGA) for the most advanced care. Now MGA is partnering with West Penn Allegheny Health System (WPAHS) to expand these services to even more patients.

MGA has moved its Treatment and Advocacy Center to the Allegheny General Hospital Main Campus on Pittsburgh's North Side. There, patients will continue to receive the same high quality services, with additional benefits such as:

- Access to an experienced physicians group, dedicated to the treatment of myasthenia gravis
- Devoted professional staff who work diligently for those with myasthenia gravis
- Diverse educational opportunities for patients, professionals, and the community at large
- Convenient indoor parking
- And much more



Staff members from the Myasthenia Gravis Treatment & Advocacy Center at AGH include (left to right) Barbara Lefler, Donna Kalisek, Floyd Patterson and Virginia Everard, R.N.

In addition, The Western Pennsylvania Hospital provides plasmapheresis. A specialized treatment involving plasma exchange, plasmapheresis is required by MG patients who do not respond to other treatment methods, or are experiencing an exacerbation. The team at West Penn Hospital is highly skilled in caring for patients during this treatment.

For more information about the Myasthenia Gravis Treatment & Advocacy Center at Allegheny General Hospital, call 412-566-1545.

MG Treatment and Advocacy Center: Past, Present and Future

By Sylvia E. Danehy, B.S.N., R.N.

Change. What is it? How does it affect us? Change can be either a good thing or something we fear, but change is inevitable in our lives. Some changes we can control, and others we cannot. Change always contains a sense of loss — loss of the familiar. But there is no opportunity for improvement without change!



A good many of you remember me as the “nurse in the clinic” for many years. I have been affiliated with the Myasthenia Gravis Association (MGA) for over 25 years. The first 22+ years, I was the treatment center coordinator, and for the past several years I have been a member of the Board of Directors.

I remember when I first came on the scene. Patients didn't know what this new change would bring. Patients, and some staff and volunteers, didn't think that I would fit in, and I certainly wouldn't last for six months! But I found a home at MGA and developed relationships that have lasted for decades. I hope that the change of my arriving was a good thing. It was for me!

Those of you who have been around as long, or longer, than me remember many changes that have occurred in the treatment center. First there was Dr. Foldes, the man who was willing to help a group of patients who couldn't find a physician who understood MG or was willing to treat this strange disease. Then Dr. McNall was added into the mix and brought on new ideas but a continuation of quality care.

When Dr. Blume came to the treatment center, he was a young neurologist and many patients were not so sure he was going to be what was needed. Now, he is well known and loved by all. Many people feel he is the reason they are still alive and/or doing so well. Then Dr. Blume added a new doctor (Dr. Corsello) to his practice, and then another (Dr. Ulicny). These changes were hard. Everyone trusted Dr. Blume. Would these new docs be as good or care as much? I think we found out that those changes were good opportunities too.

A really big change occurred when Dr. Blume decided to retire. How could he leave? What would MG patients do? But Drs. Corsello and Ulicny continued to provide care in the same manner everyone had learned to expect. What a big change when Dr. Ulicny died. It was a shock to all of us. But life went on and other doctors became a part of our treatment center.

A big change came for me when the treatment center moved to the Health Center and Mercy Hospital brought in two doctors that no one, including myself, had ever met. Drs. Barmada and Zaretskaya seemed so different, but they were wonderful and caring doctors and we all grew to love and respect them. Another change we found we could live with!

A few years ago another change occurred: I retired. Many of you felt a loss, at least I hope so. I know I did. It was a big change in my life and a big change in the treatment center. Now Ginny is a big part of your lives and is the “go to” person who can help you with problems you encounter. She will continue to be this guiding light.

So you see, MGA and its treatment center have gone through many changes over the years. As we look at the broader picture, all of those changes, although hard at times, have made us stronger and better.

Now the MGA and its treatment center are entering a new phase. For the first time in over 50 years they are no longer affiliated with Mercy Hospital (now UPMC Mercy), but are now affiliated with the West Penn Allegheny Health System. This change was made to assure the continuation of the Myasthenia Gravis Association, and to assure that it will be able to continue to provide the services to the patients that have been a part of its mission. The administration and neurologists at Allegheny General Hospital are committed to helping you make this new change one of the best. We hope to be able to expand our patient base and extend our outreach so that no person with myasthenia gravis feels lost, forgotten or has to struggle to find a diagnosis or an informed caregiver.

Please be assured that the staff of MGA will do everything possible to help make this change another positive step in the history of the association. If you have a problem, call and get the assistance and reassurance you need.

How to Contact Us

If you have a general question or would like more information about MGA, please call us at 412-566-1545 or send an email to mgaoffice@mgawpa.org.

A Virtual Tour of the Apheresis Unit

By Raymond Beeson

Those members of the Myasthenia Gravis Association of Western Pennsylvania (MGA) whose treatment program includes plasmapheresis on either an occasional or regular basis will be interested in learning more about this unit.

First and foremost, the apheresis unit is not located at Allegheny General Hospital; it is located at West Penn Hospital in Bloomfield. West Penn Hospital is not hard to find, and parking in the hospital's garage is free to the patient. Accessing the main hospital building from the garage is quite easy as there is an enclosed walkway from the top floor of the garage into a hospital reception-desk area. From that area getting to the unit necessitates a walk following dark purple arrows woven into the carpeting; the walk ends with an elevator ride up to the unit, which is housed in an area called "the tower."

At the reception desk mentioned above (at the end of the enclosed walkway from the garage) wheelchairs are available, and whoever is accompanying the patient may then push the patient in a wheelchair to the unit. If the patient has come alone, he/she may call upstairs from the desk to the apheresis unit and ask that a transport person be sent down to take the patient by wheelchair.

One other option is available. If another person is driving, the drivers may drop off their passengers at the main entrance on Millvale Avenue. While the driver proceeds to the parking garage, the patient need only make a short walk to an elevator. The check-in area is located in the Medical Short Stay Unit on the 6th floor. The patient will then be escorted to the 8th floor for the apheresis procedure.

Apheresis patients will be quite pleased when they see West Penn Hospital's pheresis facility. Although the process will be the same, the atmosphere is quite pleasant. Each patient has the comfort, for the two hours' duration of their treatment, of a hospital bed in a private



MG patients can receive plasmapheresis treatment at West Penn Hospital.

hospital room with TV, telephone, and computer-access. (Patients must bring their own laptop computer, of course, but accommodations are available for accessing the Internet.) In addition to a windowed general waiting area, there is space/seating in the patient's room for anyone accompanying him/her, be it one, two, or more people. Since the room is a private room, other patients cannot easily overhear in-room conversations nor disturb anyone with their own conversations. Light refreshments are available and a meal will be served if you stay long enough to need one. An added amenity is that each room has its own bathroom.

An RN and a technician are always available on the floor and are within only a few steps of each room. Additionally, a hematologist is available on short notice if a problem should arise. Since the unit tries to limit the number of apheresis patients to two at any one time, patients should be very comfortable with the attention they receive.

For more information about the Apheresis Unit, contact Virginia Everard at 412-566-1545.

Floyd's Greetings

To everyone at MGA of Western Pennsylvania, greetings! Since my departure in 2000, I have shared many cherished and nostalgic memories about MGA with my friends and colleagues, and I never entertained the thought that one day I would return. I feel very fortunate because even though I left the organization, I didn't lose contact with some of the patients and staff that I bonded with while at MGA.



A year or so ago, I had the pleasure of meeting the previous executive director, Mr. Charles LaVallee, during one of the MG Patient Conferences. I was impressed with his energy and enthusiasm about the plans he had for the future of the organization. At the conference, I also had the chance to re-connect with some of the patients I had not seen since my departure and that really made attending the event worthwhile and heartwarming for me. Although, at the same time, I was saddened to learn of the passing of a few patients who over the years I laughed and cried with. I am so happy to be home again. It feels good! I'm feeling like "Dorothy" from the "Wizard of Oz," when she said, "There's no place like home." My sentiments exactly: "There's no place like MGA."

Barb Lefler, the current director, and I have discussed her vision for MGA, and especially how the role of the Advocacy and Outreach Specialist might help to make those visions tangible. One of my personal strengths is the ability to connect with people. As many of you have come to know, I like people, and I like being in a position to offer assistance when it seems like life is throwing hard-to-hit "curve balls." It's important for everyone to feel that they have a place to go or turn when times are difficult. In the past, life threw a few of our patients some "trick" balls, but we batted them. We're up at bat again, and I believe that we'll continue to deliver at least base hits every time. And, I'm also looking for a few of those home runs that we will knock out of the park, together.

Again, I am really glad to be back at MGA. I'm looking forward to catching up with old timers, and meeting all of the new comers. Thank you MGA and the West Penn Allegheny Health System for making it possible for me to come back!

Sincerely,

Floyd Patterson, MSW

Advocacy and Outreach Specialist

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Dear Friends of the Myasthenia Gravis Association of Western Pennsylvania,

Your unmatched support for this outstanding organization has led us to celebrate a new era of growth and opportunity! As MGA moves forward with our new partners, Allegheny General Hospital and the West Penn Allegheny Health System, you will see why we are celebrating. We look forward to your continued support and invite you to celebrate with us!

- Celebrate partnering with a nationally recognized neurology department
- Celebrate a team of professionals with expert experience in administering plasmapheresis
- Celebrate partnering with a health system that has a commitment to honoring MGA's model of care and the vision to assist MGA in expanding its services
- Celebrate the ability to hire staff to provide greater advocacy for patients, and outreach to the western Pennsylvania region
- Celebrate a partner that is willing to collaborate with MGA in providing outstanding community education opportunities; an educated community can ensure healthier patients by providing more responsive diagnosis times and accurate treatment for people with MG
- Celebrate MGA's ability to access AGH's corporate resources to advance the mission of the organization
- Celebrate a longer agreement that allows a more stable environment for patients with MG
- Celebrate opportunities to collaborate in joint clinical research initiatives
- Celebrate a warm and dry parking garage adjacent to the treatment center office
- Celebrate people whose lives are touched in some way by myasthenia gravis and who willingly share their means with MGA

As you can see, there really is a lot to celebrate. Additionally, MGA would like to celebrate all of the patients who have made some important decisions during this time of transition for the organization. Regardless of your choice, you can always count on MGA to serve you in the high standard you have come to expect. You are always welcome here!

This is your opportunity to assist MGA in continuing the vital work that is being done on behalf of people with myasthenia gravis. Your contribution to MGA sustains all of our essential patient support services. You do make a difference!

For your convenience, an envelope has been placed in this edition of MGA's newsletter for your contribution. MGA looks forward to celebrating your generous support!

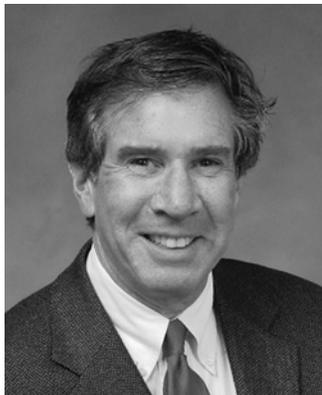
Sincerely,
Peggy Gursky
MGA Board President

Barbara Lefler
Executive Director

Meet Our Doctors at WPAHS

West Penn Allegheny Health System (WPAHS) features several prominent physicians who are on the forefront of the latest treatment options for patients with myasthenia gravis. Following are brief profiles of these doctors.

Jon Brillman, M.D.



Jon Brillman, M.D., has been chairman of the Department of Neurology at Allegheny General Hospital, West Penn Allegheny Health System since 1997.

Dr. Brillman grew up in Philadelphia, where he attended the University of Pennsylvania. At Penn, he majored in English Literature and graduated with honors in 1963.

Following his medical training at the University of Pittsburgh School of Medicine, Dr. Brillman trained for two years in Internal Medicine at the University of Pittsburgh Medical Center. He then served in the United States Navy as a diving officer on the nuclear submarine, the USS George Bancroft. In 1975, Dr. Brillman completed his neurology residency at Yale University in New Haven, Conn. Since then, he has worked at Allegheny General Hospital.

In 1988, Dr. Brillman became a full professor of neurology, director of the comprehensive stroke services, and program director for the neurology residency program. When he became chairman in 1997, the position of program director of the residency program was forwarded to his associate, Dr. Thomas Scott. However, Dr. Brillman still remains very involved in the recruitment process of the neurology residents.

Dr. Brillman is renowned for his teaching skills and received the Golden Apple Award from the students at MCP/Hahnemann University. He is the author of numerous articles on a variety of subjects in neurology and has edited a book on neurocardiology. He serves on numerous editorial boards and is a reviewer for several journals.

Honors and Awards for Dr. Brillman

- Identified as one of Pittsburgh's "Top Doctors." *Pittsburgh Magazine*, 11/81.
- Medical College of Pennsylvania, Golden Apple Award for Excellence in Teaching. Chosen by Class of 1990-91.
- Identified as one of Pittsburgh's "Top Doctors." *Pittsburgh Magazine*, 10/92.
- Inducted Fellow of the Royal College of Physicians of Ireland, October 17, 1998, Dublin, Ireland.
- *Pittsburgh Business Times*, 2003 Health Care Hero Finalist for achievement in the category of Health Care Educator, March 6, 2003.
- Listed among Nation's Best in *Consumers' Guide to Top Doctors*, July 7, 2003.

Dr. Brillman's Memberships and Offices in Professional Societies

- American Academy of Neurology - Fellow
- Pittsburgh Neuroscience Society
- National Multiple Sclerosis Society - Advisory Board
- American Society of Neuroimaging - Fellow
- American Heart Association Stroke Council - Fellow
- Association of University Professors in Neurology
- American Medical Association
- Pennsylvania Medical Society
- Allegheny County Medical Society
- Lead Author: Brillman J, Kahan S (eds) "Neurology in a Page," Blackwell Publishing, 2005

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George Small, M.D., Medical Advisory Board, Chair



Dr. George A. Small is the director of the Neuromuscular Division and the Electromyography Laboratory at Allegheny General Hospital, Drexel University School of Medicine. He is an assistant professor within the department and also heads the Clinical Neurophysiology fellowship. A resident of New York City,

Dr. Small was recruited to his present position in Pittsburgh in 1993. He is a graduate of the Jefferson Medical College, Alpha Omega Alpha, and the Neurological Institutes of New York for adult neurology residency. He completed a one-year fellowship in neuromuscular disease and electromyography at the Neurological Institute of Columbia Presbyterian Medical Center in New York before attaining his current position. A member of MGA's Board of Directors since spring 2001, Dr. Small looks forward to certifying the accuracy of informational materials available to patients and their families, as well as helping to coordinate patient, family, and professional discussions during the annual education meeting of the organization.

James M. Rossetti, D.O.



James M. Rossetti, D.O., is associate director of the Cell Transplantation Program and director of the Apheresis Program at the Western Pennsylvania Hospital.

Dr. Rossetti earned his Doctor of Osteopathic Medicine degree from the Lake Erie College of Osteopathic Medicine and completed an internship

and internal medicine residency at St. Francis Medical Center of Pittsburgh. He completed fellowship training in hematology and medical oncology at The Western Pennsylvania Hospital and is board certified in internal medicine, medical oncology and hematology. He is an assistant professor at the Temple University School of Medicine and an adjunct clinical instructor for the Lake Erie College of Osteopathic Medicine.

Dr. Rossetti is a recognized expert in hematological malignancy, with particular interest in myeloid malignancy, acute myelogenous leukemia, myelodysplasia, and cellular therapy. The Myelodysplastic Syndromes Foundation

recognizes Dr. Rossetti as a recommended specialist physician dedicated to treating disorders that inhibit healthy blood cell production. He is an accomplished clinical investigator with numerous publications in the scientific and lay literature and is a particularly sought after speaker.

Dr. Rossetti is also a leader of his institution's Virtual Hospice Program, which provides a unique complement of services for critically ill patients who cannot be moved to a traditional hospice. He serves as a member and consultant on the Western Pennsylvania Hospital's Ethics Committee.

In addition, Dr. Rossetti serves on the Advisory Board and Medical Advisory Committee of the Leukemia and Lymphoma Society, Western Pennsylvania Chapter. He is a member of the American College of Physicians, the American Osteopathic Medical Association, the Catholic Medical Association, the National Catholic Bioethics Center, the American Society of Hematology, the American Society of Blood and Marrow Transplantation, the American Society of Clinical Oncology, the Pennsylvania Society of Oncology and Hematology and the Myelodysplastic Syndromes Foundation.

Dr. Rossetti and his wife live outside of Pittsburgh, Pa. with their four daughters.

Joseph G. Sabol, M.D.



Joseph G. Sabol, M.D., is medical director of the Inpatient Medical Unit at The Western Pennsylvania Hospital.

A graduate of Washington and Jefferson College, Dr. Sabol received his medical degree from the Temple University Medical School. He then completed his internship at Mercy Hospital of Pittsburgh and his

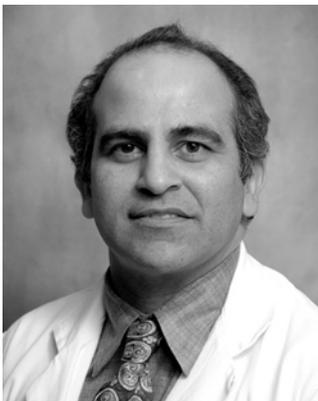
residency at Pittsburgh Mercy Health System.

Dr. Sabol started his career as an associate at David M. Reed, M.D., then held various positions at Suburban General Hospital, Mercy Hospital of Pittsburgh, McCauley Medical Associates and West Penn Comprehensive Health Care, PC.

A faculty member for the Internal Medicine Residency Program at West Penn Hospital, Dr. Sabol received the Teacher of the Year Award for 2005-2006.

Dr. Sabol has worked as a full-time hospitalist for the past 15 years. During this time, he has coordinated the care of many myasthenia gravis patients and served as their primary care doctor while they were staying in the hospital. Out-of-town physicians and family members appreciate receiving regular patient updates from Dr. Sabol.

Sandeep S. Rana, M.D.



Sandeep S. Rana is director of the ALS Center at Allegheny General Hospital.

A graduate of Maulana Azad Medical College, Delhi University, New Delhi, India, Dr. Rana completed a residency in Internal Medicine at Methodist Hospital and a residency in Neurology at the State University of New York at Buffalo. He also completed

a fellowship in EEG and Epilepsy and a fellowship in EMG and Neuromuscular Diseases — both at the University of Pittsburgh.

A prolific author, Dr. Rana has conducted a number of research studies. In addition, he serves as co-director of the Neurology Residency Program at Allegheny General and teaches medical students.

Dr. Rana has been treating neuromuscular disorders, including MG, for last 11 years. He has presented data on MG at many national and local meetings. For a number of years, he has also served as medical advisor for the Myasthenia Gravis Foundation.

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News and Notes

United Way Donor Designation

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

United Way of Allegheny County #1178

United Way of Beaver County #4861

United Way of Butler County #5981

United Way of Erie County #45146

United Way of Mon Valley #1178

United Way of Washington County #0082

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 (due to changes):

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 new 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.

MGA's 15th Annual All-Star Sports Memorabilia Auction will be phenomenal in 2009!

Ellis Cannon and his team from the Pittsburgh Sports Report will be the media sponsors for this event. Many thanks to our Signature Sponsor, The Koter Group at Morgan Stanley. Please contact MGA's office at 412-566-1545 if you are interested in lending your name to this well recognized and well attended sponsorship opportunity. Watch and listen for updated information about this outstanding event held on behalf of people with myasthenia gravis. You won't want to miss it!

Thanks to Attorneys of Reed Smith

A big thank you goes out to the diligent attorneys of Reed Smith who assisted MGA during this time of transition. Rachel, Eric, Carl and Cynthia... you are awesome!

"Dr. Z" Resigns

"Dr. Z" has resigned from MGA's Board of Directors. Many thanks to Dr. Marina Zaretskaya for her years of service on MGA's Board of Directors. Best wishes to you and your family.

Ask the Doctor

By George Small, M.D.

Does research about myasthenia gravis indicate that we are any closer to a cure?

Cures for diseases are rarely found when medical scientists directly search for them. Cures, when found, generally result from research on treatments for diseases such as myasthenia gravis, and occur by chance. As in research for other autoimmune diseases, such as rheumatoid arthritis, lupus, or Crohn's disease, our focus is on managing difficult symptoms with medications that have the fewest side effects. Since medications for autoimmune diseases weaken the body's immune system, there is a trade-off between the medication's effectiveness in keeping the disease in check, and promoting susceptibility to infection.

One method around this problem is in researching vaccines that have limited side effects, but promote significant defense against any manifestation of a disease. For myasthenia gravis, vaccine research is in its early infancy. Together with such research, and the ongoing hunt for the most effective immunosuppressant (and some luck), we are working on a cure, but more than likely will stumble upon one. Research such as that conducted for HIV infection and multiple sclerosis has followed this path. Few or no treatments even existed 15 years ago for either HIV or multiple sclerosis. New therapies have allowed us to dramatically lessen the physical and mental suffering of these conditions. And, clearly in the case of HIV infection, these therapies dramatically improve the quality and length of life.

Memorial and Honorarium Contributions (From March 2008 to October 2008)

Memorials and honorariums are meaningful ways to acknowledge important people in your life. Your donation will help support MGA's services for persons with myasthenia gravis.

If you would like to make an honorarium or memorial gift, please send the name of the person being honored or remembered. Also include an address for the person or their family (a special card will be sent notifying them of your donation), along with your contribution to the MGA office. Please contact the MGA office at 412-566-1545 for more information. You may also call the office to make a credit card donation or make your payment through our Web site, www.mgawpa.org.

Memorials:

Gail Beeson

By Sylvia Danehy

Kenneth Boehm

By Sylvia Danehy, RN

Dominic "Nick" Consello

By Sylvia Danehy, RN
Pearl McNall, MD

Norman L. Dick

By 1st Summit Bank – Directors,
Officers & Employees
Bethel United Presbyterian Church
Brush Valley Seniors
Dennis & Carol Clawson
Jane Clawson
Ernest, Geraldine, & "Bill" Conrad
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Lillian Yanz

Frances Foldes, MD

By James & Rita Marsinek

Ruth Rose Gordon

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By Maret Beal

Cecelia Wilson

By Norma List

UPMC Mercy - Department of
Laboratory Medicine Staff

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By Marcella Dobrzynski

Irene & Anita Urik

Honorariums

Carol Cordner

By Daisy Case

Carol Ferman

By Kent & Lois Stewart

*Donna Kalisek's 50th
Birthday*

By Sue & Sam Bartley

Ray Beeson

Dr. & Mrs. Robert Blume

Martha Bogan & Roy

Patricia Buck

Julie Conlon

Dr. & Mrs. Guy Corsello

Don & Patty Dancison

Mike & Marge Dancison

Bob & Sylvia Danehy

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Donna Gardner

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Bill & LaVerne Short

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Wilma Tabisz

Sheryl & Dave Uleplic

Karen Vogel

Connie Wise

Pearl G. McNall, MD

By James & Rita Marsinek

How to Contact Us

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**Myasthenia Gravis Treatment & Advocacy
Center at Allegheny General Hospital**

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Pittsburgh, PA 15212

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