

# THE ROADRUNNER



MYASTHENIA GRAVIS  
FOUNDATION OF AMERICA, INC.



Myasthenia Gravis Foundation, Jim L. Walker Arizona Chapter

Spring 2004

## From The Desk Of... Wayne Magee, First Vice Chairman

The Jim L. Walker Arizona Chapter of the Myasthenia Gravis Foundation is made up of volunteers who tirelessly devote their time to the education and awareness of this disease. More than anything over the years, we have neglected paying adequate recognition to those individuals whose interest and personal commitment have allowed us to gain their corporation's support as well. After all, only by continuing to establish long-lasting relationships with people can we grow and flourish as an organization!

To this end, I am compelled to identify some of the key people, and their businesses, who continue to make a difference in our efforts to provide you, our members, with much-needed support and information services. People like: Kim Sertich of Page One Productions Inc., who does the graphic layout for our newsletter; Chuck Shaw of Alphagraphics, at Shea Blvd. & Scottsdale Rd., who not only makes donations and reduces our printing costs, but has agreed to produce our newsletter "The Roadrunner" at no cost to the association; and, of course, Westcor Shopping Centers, in particular Tracey Gotsis, who has been there with her organization continuously throughout the years

supporting our MGFA Golf Tournament and Walk for Hope fundraising events, etc.

Most especially, we would like to devote this issue to Brian Robinson of Waddell & Reed Financial Services. Brian is a Certified Financial Planner (CFP®) which puts him among the elite in the industry.

I first met Brian a few months ago, just after he and his wife, Clarissa, had their daughter, Lilly. Brian and his company have supported the MGFA Golf Tournament in the past with Double Eagle sponsorships, but this year Brian made a huge financial commitment. I believe that he wanted to make a difference, due in part to the initiatives MG has undertaken opening the new office at the Neuromuscular Center in Scottsdale and the grants to which we have committed.

Who are Waddell & Reed? They were founded in 1937 and have become one of the most enduring names in mutual fund management and financial planning in the USA. Waddell & Reed provides services and experience in three distinct areas:

They are local financial advisors assisting clients in planning their individual financial futures.

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## How To Reach Us

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Please note that the medical views expressed in *The Roadrunner* are those of the authors or speakers and do not reflect any official position of the Arizona MG Chapter or the National Advisory Board. Please contact your physician who will know what is best for you.

# MG Central

10200 N. 92nd Ste. 101, Scottsdale, Arizona 85258  
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## What We Do Here & Why:

*By Wayne Magee*

“MG Central” is the new information and communications center for the Arizona Chapter of the Myasthenia Gravis Foundation. As we do not have a dedicated office, we’ve established a long-term agreement with the Neuromuscular Research Center, a Division of Barrow Neurological Institute, under Dr. Sivakumar and his office manager Patty Wells (480-314-1007). It is a clinical office that lets people know what we are all about.

This small 12 x 12-ft. office will have a dedicated MG phone and fax system, and will become the center for all of our communications. The phone committee can use it on Thursdays and Fridays (non-patient days), and it can be used for small meetings by MG committees and sub-committees.

During patient days, Mondays - Wednesdays, we will staff it with volunteers who can meet with new myasthenics to provide them with information on patient care, our organization and general information about how to live with MG. For those who are interested in volunteering, this is a great way to “give back” and be of value to the organization.

We can use this facility for MG training sessions and for quarterly review meetings. Marilyn Ricci and Vicki Case are starting this up to ensure our ability to reach hospitals, paramedics, and AZMGFA members.

We will also use the office for displaying brochures and literature on MG, and we will have a small TV and VHS for use in viewing videos. All of our events are promoted here, as well as general bulletin board information.

Currently, the Neuromuscular Research Center has over 100 MG patients (just like Vicki Case and myself), while the intent is not to be there solely as support to their MG patients, the hope is to enrich the lives of people afflicted with this disease in a positive way. It is reasonable that during the next 10 years we could see the number of MG patients in Arizona double to over 1,200 by the year 2014. This is one way of reaching our members and builds the Jim L. Walker Chapter in a positive and constructive manner.

Our Chapter has agreed to support the Neuromuscular Research Center with a grant of \$10,000 a year from our earnings as a way of financially offsetting costs associated with the office.

In conclusion, please help us to make good use of this new office space. We are fortunate to have a “partner” link to our association that brings quality recognition and support. Thank you for sharing the MG message for Hope!



# Medical Corner

*By Dr. Todd Levine*

## New Test Identifies 60% Of Seronegative Myasthenics

The diagnosis of Myasthenia Gravis is based on the clinical findings of muscle weakness and muscle fatigue. In addition, physicians use two laboratory tests to confirm the diagnosis. These tests include nerve conduction studies and blood tests that show the presence of specific antibodies, or proteins, in the blood that react against the acetylcholine receptor which is found on the surface of muscle fibers. However, up to 20% of patients with generalized myasthenia and 50% of ocular myasthenics do not have antibodies against the acetylcholine receptor that we can identify. In 2003, a new test became commercially available to help identify these so called seronegative (or antibody negative) myasthenics. This test identifies a new antibody called MUSK. MUSK is a protein that sits adjacent to the acetylcholine receptor on the muscle surface. In early tests, 65% of seronegative patients with Myasthenia Gravis were found to have these MUSK antibodies and not the traditional antibodies against the acetylcholine receptor. In addition, these patients looked identical to patients with MG with acetylcholine receptor antibodies. This is a major advance and the test should be considered in all patients who have MG who do not have antibodies against the acetylcholine receptor.

### **National Foundation Office**

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### **Arizona Chapter**

#### **Executive Committee**

Mary Jane McClain, Chairman, (602) 840-7877  
Wayne Magee, Vice Chairman, (480) 205-2556 (cell)  
Steve Borski, 2nd Vice Chairman, (602) 265-7962  
Vicki Case, Secretary, (602) 285-1509  
Chris Budwill, Treasurer

#### **Board of Directors**

Wayne Magee, Dr. Mary Landau-Levine, Vicki Case, Jim LoVecchio, Dino Gotsis, Clarissa Robinson, Dr. Todd Levine, Mary Jane McClain, Steve Borski, Marilyn Ricci, Terri Rundle

#### **Medical Advisory Board**

Dr. Todd Levine, Good Samaritan Hospital

#### **Nurses Advisory Board**

Marilyn Ricci, R.N., MS., CNRN, Barrow Neurological Institute

#### **Consultants and Volunteers**

Luann Green, Chris Budwill, Edward C. Kaps, Jeanne Berger

#### **Public Relations Coordinator**

Clarissa Robinson, Clarissa.Robinson@cox.net

## From The Desk Of...

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They are professional investment managers implementing financial strategies that stay on top of the latest financial information around the world.

They provide a dedicated “Client Service” function that ensures quality information and confidentiality about their account and investment strategy.

Regardless of your income, virtually anyone interested in financial planning for the future can take advantage of the wide variety of financial options available. The individual and personalized professional investment guidance offered by Brian and his associates at Waddell & Reed can be of great value to you. We endorse Brian’s organization and thank him for his generosity and continued support of Myasthenia Gravis.

Brian Robinson can be reached through his webpage at [www.BRobinson.WRadvisors.com](http://www.BRobinson.WRadvisors.com) or by phone at 602-438-7886 or fax at 602-438-2189. The Waddell & Reed office is conveniently located off Hwy 10 and Baseline Rd. @ 4415 South Wendler Drive, Suite 101, Tempe, AZ 85282.

Additionally, for any MGFA member or friend, Brian has generously agreed to significantly discount his financial planning services. Please mention MGFA to him during your initial contact!

Thanks, Brian, to you and your family, and to the employees of Waddell & Reed Financial Services. You have made a huge impact on our organization and motivated us to recognize the corporations and the people that truly make a difference.

We encourage our members and readers to make use of the services offered by our “partners.” Without their support we could not exist. Thank you again, and we will continue to recognize others in future issues.

## Calendar of Events

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|-----------|--|
| March 17: | AZMGFA monthly board meeting (every third Wed. of the month)   |
| April 3:  | The Waddell & Reed Financial Services® Golf Tournament with Sports Celebrities at Starfire Golf Club |
| April 21: | AZMGFA monthly board meeting (every third Wed. of the month)   |
| May 6-8:  | Myasthenia Gravis Foundation National Convention, Bloomington, MN                                    |
| May 12:   | Patient Services Training Meeting  |

## Patient Services

Our number one mission as an organization is to be there for our members and patients with MG. Our goal is to provide you with information, to make referrals and to provide help, hope, encouragement, and the support of a “family” in order to better help you to understand the disease and how best to live with it.

The best way to do this is through a dedicated group of people who share this same commitment. This is vital to our chapter’s success and future.

The following is a list of volunteers who serve under Marilyn Ricci, RN, MS, CNRN, and Vicki Case, Patient Services Coordinators and AZMGFA board members, who have agreed to be there day in and day out for Arizona Myasthenics:

- Ed Kaps (Scottsdale and Fountain Hills) 480-837-8728
- Jim & Jan LoVecchio (Southern Arizona) 520-889-6910
- Sonya Watkins (East Valley) 480-507-7969
- Vicki Case (City of Phoenix) 602-285-1509 or 602-290-7747
- Alex Haas (East Valley) 480-840-5502
- Peggy Marguard (East Valley) 480-461-8786
- Joy Jordon, (Northern Arizona) 928-643-7207

This group meets quarterly to discuss patient needs, and we are always in need of more volunteers. So we encourage any of our readers who want to make a difference to contact Vicki, Marilyn or any of the AZMGFA board members at any time, as your support is always welcome.

## News From Southern Arizona Support Group

*By Jim LoVecchio*

The Tucson Myasthenia Gravis support group is celebrating its 7th year. It began meeting in June 1996 and during the past seven years we have focused on providing educational support to Myasthenia Gravis patients in and around Tucson. Each year we schedule speakers on medical issues, community support, and quality of life.

Our February speakers were Dr. Bruce Sadilek, the president of the Arizona Naturopathic Association, and Dr. Timothy Miller, a neurologist at the College of Medicine, University of Arizona. Mary Jane McClain and Vicki Case attended from Phoenix.

We will have two more meetings with speakers from the University of Arizona before disbanding for the summer: Saturday, March 13 (Richard Herrier, College of Pharmacy) Topic: Vaccinations and West Nile Virus; and Saturday, April 10 (Dr. Matthew Lally, Department of Psychiatry) Topic: Overcoming Depression.

A letter about the Tucson support group and the state foundation will be mailed to all the Tucson neurologists, ophthalmologists, and optometrists in April.



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## **Do we have your current address?**

### **Help Us Save Money!**

As you know, you have been and will be receiving various pieces of correspondence and newsletters from the Arizona Chapter of the Myasthenia Gravis Foundation throughout the year. Our goal is to keep you informed. Please keep us informed as well.

***If the mailing address on this label is incorrect, please contact our office*** and give us the updated information. Each time a piece is forwarded to you by the post office, it costs our chapter 80¢ to \$1 per piece!

So, please, call us to correct any mistakes we may have made or to update us on a recent move; it will be appreciated!

You can also read Roadrunner at [www.azmgfa.org](http://www.azmgfa.org)

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