

# THE ROADRUNNER



MYASTHENIA GRAVIS  
FOUNDATION OF AMERICA, INC.



Myasthenia Gravis Foundation, Jim L. Walker Arizona Chapter

Winter 2009

## Letter from out going chairman

*Hi Myasthenics and Friends:*

It has been some time since I wrote to all of you so I figured I better do it now.

I sure hope that most of you are beyond MG however for those of you that are not it is my prayer that you are maintaining the disease as your doctor says for you to do.

We here at AZ MGFA are busy with helping people not only in AZ but also in other states such as New Mexico. Got a call the other day from Canada.

We have had a number of support group meetings with some attendance. As always we wish there were more people coming but according to the results of the survey there are reasons for the small attendance and the board is looking into those problems you have and we hope to see what we can do to help you come to the support groups meetings for they are very informational.

By the way those of you and there were about 50 who sent in the survey THANK YOU so much it really helps us to understand you.

I am truly sorry to advise you that due to the present Economy crisis

we have decided not to have the golf tournament in 2009. but to plan on having it in 2010.

I am sad to announce that our President Wayne Magee has resigned for personal family reasons. We will undoubtedly miss him but never forget him for all of the work he has done in helping Myasthenics. Wayne promised to help us whenever he can.

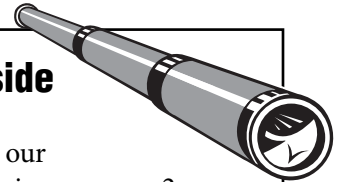
This is my last letter to you as Chairman of the Board of AZMGFA. I have been associated with you since 1995 and as Chairman for 8 years. It has been a pleasure and an honor to serve you. I plan on staying on the board for one more year to help a new Chairman who has introduced himself in another page of this newsletter. He is young and dedicated to the proposition to help all of you whatever you need

I pray that you all have a relatively healthy Holiday and I hope to see some of you at the January 2009 annual meeting in Tucson.

Love you and keep the Hope going and God Bless you ALL

Ed Kaps  
*Chairman*

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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.

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**Our Mission:** To educate the public on the scientific research achievements in treating Myasthenia Gravis while providing assistance and support for patients and their families through advocacy, fund-raising and communication.

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# Letter from our Medical Advisor:

## Treatment Update

March 2008

By: *Katalin Scherer, MD*  
*Assistant Professor of Neurology*  
*University of Arizona*



*Myasthenia Gravis Foundation*  
*Medical Advisor Katalin Scherer, MD*

Several new potential treatments have emerged for myasthenia in the past few years. The mainstay of treatment remains symptomatic treatment in milder cases with anticholinesterase medications (such as pyridostigmine). Immunosuppressive therapy (such as azathioprine, cyclosporine or mycophenolate mofetil) with or without steroids remains the main treatments for more severe disease. Acute severe exacerbations are generally treated with plasmapheresis or IVIG infusions. It is difficult to evaluate existing and new treatments in myasthenia because of the small number of patients. Here we review the recent advances in treatments for myasthenia.

### Ocular MG:

Two recent articles discuss that early treatment may prevent progression to generalized MG. Immunosuppression and thymectomy should be considered in severe

and refractory cases of ocular MG. Positive AchR abs and abnormal SFEMG in a limb muscle increase the risk of generalization.<sup>4,5</sup> A recent review by the American Academy of Neurology stresses the overall lack of evidence based treatment trials in ocular MG, however.<sup>7</sup>

### Generalized MG:

Two large randomized clinical trials were completed in the past year and neither showed a significant benefit of mycophenolate mofetil used together with prednisone, over prednisone alone. Readers should remember that failure to prove that a statistically significant difference exists is not equivalent to concluding that there is no difference. Mycophenolate has shown definite benefits in treating myasthenia gravis, and it is the opinion of many experts that further clinical investigations into its use are warranted.

Plasmapheresis remains one of the mainstay therapies for crisis, and it has been shown to be equally effective to IVIG. A recent small study found that daily plasmapheresis was as effective as every other day treatment for myasthenic crisis in the hospital. The daily therapy had the same complication rate and may reduce hospital length of stay.<sup>2</sup>

BiPAP (bilevel positive airway pressure) should be tried before intubation in patients with respiratory failure from myasthenic crisis. BiPAP (a form of non-invasive ventilation administered through a facial interface, usually a mask) may prevent the need for intubation, may shorten hospital stay and reduce the complications associated with mechanical ventilation and a lengthy ICU stay.<sup>6</sup>

Rituximab is an intravenous medication that targets and destroys certain population of immune

cells called B cells. B cells produce antibodies that attack the neuromuscular junction. There have been several case reports on the benefit of rituximab for the treatment of patients with severe generalized symptoms who do not respond or have failed other forms of aggressive immunosuppressive therapy. Rituximab has shown preliminary benefit in several antibody mediated autoimmune diseases, and the first clinical trial in myasthenia gravis is currently underway.

Etanercept is a tumor necrosis factor alpha antagonist, and has been used successfully in various rheumatological (autoimmune) disorders. Recent case reports have suggested it may be useful in selected cases of refractory MG, and larger clinical trials are underway.

Tacrolimus is an oral immunosuppressant widely used in organ transplantation. Several case series have reported it may be useful in treating myasthenia gravis. A randomized clinical trial is currently underway in Japan.

Thymectomy has been performed in MG for over 50 years and several large retrospective case series have reported benefit in selected patients. The first large, randomized clinical trial is underway. This trial hopes to answer important questions regarding the benefit of thymectomy and the type of patients who may benefit the most.

### MuSK myasthenia:

40-50% of acetylcholine receptor antibody (AchR ab) negative (previously called seronegative) patients have antibodies to muscle specific receptor tyrosine kinase (MuSK). These patients are more likely to be female and have a higher percentage of severe bulbar (meaning facial throat and neck) or respiratory muscle weakness.

*continued on page 3*

## Letter from medical advisor

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Some of these patients may not respond to the typical immunosuppressive treatments or steroids but usually respond well to plasmapheresis. In a recent report, two patients were followed undergoing plasmapheresis. The titer of MuSK antibodies declined during treatments in parallel with their clinical improvement.

There has been a case report of a child with severe generalized AchR ab positive MG, who later developed MuSK abs in conjunction with an exacerbation. We do not know whether this happens in adults, and whether MuSK should be tested in known AchR ab positive patients.

### REFERENCES:

1. Yeh JH. et al: MuSK antibody clearance during serial sessions of plasmapheresis for myasthenia gravis. *Journal of the Neurological Sciences*. 2007.

2. Trikha I. et al: Comparative efficacy of low dose, daily versus alternate day plasma exchange in severe myasthenia gravis: a randomised trial. *Journal of Neurology*. 2007.
3. Thakre M. et al: Rituximab in refractory MuSK antibody myasthenia gravis. *Journal of Neurology*. 2007.
4. Roach ES: Treating ocular Myasthenia Gravis with inadequate evidence. *Archives of Neurology*. 2007.
5. Chavis PS. et al: Immunosuppressive or surgical treatment for ocular Myasthenia Gravis. *Archives of Neurology*. 2007
6. Seneviratne et al: Noninvasive ventilation in myasthenic crisis. *Arch Neurol* 2008;65(1):54-58
7. Benatar & Kaminski: Evidence report: The medical treatment of ocular myasthenia (an evidence-based review), *Neurology*. 2007.

## Board Nominations for 2009

The following board members are nominated for the executive committee of the Jim L. Walker Chapter of the MGFA

**Chair:** Pavan Vemulapalli

New Member: Pavan Vemulapalli is the most recent addition to the AZMGFA Board. He brings strategy and planning experience from his career in the financial services industry and hopes to use his training in Operations Research to help the chapter.

Pavan was inspired to volunteer after learning about the chapter from his in-laws, Marc and Ginny Kalish. The Kalishes have been involved with the MG Foundation for

over 15 years. Pavan says he finds it inspirational to be part of a team comprised of Myasthenics, their families and medical professionals coming together to benefit the Myasthenic community. Pavan lives in Chandler with his wife Mandy and their two year-old daughter, Olivia.

**1st Vice:** Jim LoVecchio

**2nd Vice:** Stephane Borski

**Secretary:** Vicki Case

**Treasurer:** Luann Green

**Nurses Advisory Board:** Marilyn Ricci, RN

**Medical Advisor:** Dr. Katalin Scherer, MD

## Tucson Support Group Schedule

February 14

*Speaker Sandy Stein*

**Topic: Stress management for long-term illness**

March 14 Woods library 3455 N 1st ave, Tucson, AZ

April 11 Woods library 3455 N 1st ave. Tucson, AZ

Tucson Support group leader Email  
lovecchio@dakotacom.net

Jim Lovecchio call: 520-889-6910

## Phoenix Area support Group schedule

4th Saturday of Feb, March, April and May

Speaker and topic will be listed in January 2009

Location:

**The Center for Learning and Development**

3115 N. 3RD Avenue Suite 132 Phoenix, AZ 85013

Across from ST. Joseph's Hospital, inside the Park  
Central Mall

### Who We Serve

- Our mailing list consists of approximately 1,350 people
- Current Active Communication with approx. 900 myasthenic's
- Tucson & Southern AZ - 139 People
- Rural Arizona - 79 people
- Phoenix - 180 people
- Scottsdale/ Paradise Valley/ Fountain Hills - 187 people
- Gilbert / Chandler & Meas - 278 people
- 42 States & Ontario, Canada - 240 people



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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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Wayne Magee, CEO/President  
Jim LoVecchio, 1st Vice Chairman  
Stephane Borski, 2nd Vice Chairman  
Marilyn Ricci RN, Nurses Advisory Board  
Vicki Case, Administrative Asst./Secretary  
Luann Green, Treasure

**Board of Directors**  
Chris Budwill, Webmaster  
Dino Gotsis, Golf Tournament, Fund Raising  
Katalin Scherer, MD, Medical Advisory Board  
Bob Moritz, Events & Fund Raising

### **Help at Hand**

The following are volunteers who have agreed to be there day in and day out for Arizona Myasthenic's. You are welcome to call with questions concerns or advice.

- Ed Kaps (Scottsdale, Fountain Hills) 480-837-8728
- Jim & Jan LoVecchio (Southern AZ) 520-889-6910
- Vicki Case (City of Phoenix) 602-285-1509
- Pavan Vemulapalli (Phoenix area) 702-249-6689
- Marilyn Ricci 602-265-7962