



SUMMER 2013, VOLUME 1 ISSUE 1

### Mission Statement:

We are dedicated to improving the lives of persons affected with Myasthenia Gravis through awareness, education and patient support services.

### Connect With MGS:

**Phone:**  
1-800-799-4923

**Mail:**  
The Myasthenia Gravis Society  
PO Box 590105  
Birmingham, AL 35259-0105

**Email:**  
[support@myastheniagravisociety.com](mailto:support@myastheniagravisociety.com)

**Web:**  
[www.myastheniagravisociety.com](http://www.myastheniagravisociety.com)

**Twitter:**  
[@MGS\\_Support](https://twitter.com/MGS_Support)

**Facebook:**  
Myasthenia Gravis Society

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## Message From The President

1st Issue!

Members, Members' Families and Friends,

Hello to all! I hope by now you have received your letter announcing the formation of the Myasthenia Gravis Society (or the MGS). We are proud to bring you this new resource in your journey with myasthenia! There are many new possibilities with our organization – new partnerships, research opportunities, awareness campaigns and most importantly, enhanced patient support and services! We are the same people who led the Alabama chapter of the Myasthenia Gravis Foundation and our mission to find a cure and end MG has not changed. We are even more determined and will be here to answer your questions or give advice or encouragement whenever you need us. Please call us! We'd love to hear from you.

As a first order of business, we'd like to encourage you to become a member of the MGS. As a new organization, we rely on member dues and donations to provide patients with the level of support

that we ourselves wish to receive. Many of our board members, including myself, have myasthenia. We've lived with the symptoms and the obstacles just like you. We, more than anyone, understand what is lacking in the community and we aim to fill those gaps through the work of the Myasthenia Gravis Society, but we need your help! Please take a few minutes to fill out the membership form and drop back in the mail to us.

Note that on August 15th at the Homewood Library, one of our dear friends and fellow myasthenic, Avery Yearby, will be signing copies of his new book, "The Road to the Pickens Baptist Singing Men Through Myasthenia Gravis". He will be there signing copies between 6:00-7:00 p.m. and 20% of the proceeds of his book will go back to the MGS. Many of our board members will be there as well. This would be an excellent opportunity for us to meet you and for you to tell us what needs you'd like the organization to fill.

## Message From The President Continued...

I hope to see you there! curing Myasthenia Gravis. Their your family in any way. contributions to the board were the least of their accomplishments in life. Sincerely yours,  
 Finally, I can't write to our members without mentioning the We honor them every day by staying passing of two of my favorite people and former board difference and remembering their members, Dr. George Oetting and talents and gifts to us. Both are already Dr. Robert Sherrill. Both were greatly missed. outstanding men of character and were dedicated to the cause of Please let me know if I can help you or

*Christi Bova*

## "My Story": Melissa Ray

When I was born I appeared to be normal except that my eyes were stationary. The theory at that time was that my eye muscles had not developed fully before I was born or that my birthmother was very young. Since I was adopted this remained a mystery. When I was four my pediatrician tried to talk my parents into experimental eye surgery to see if he could make my eyes move. Luckily my father was a firm believer in "if it isn't broken don't fix it," since I could see with no real problems, I did not have surgery.

I was always a little slow physically and had a hard time keeping up with other kids. I had pneumonia about 12 times in as many years. If someone had a cold or the flu I got it and it usually took me twice as long as others to get over it. I was diagnosed with asthma. I spent a lot of time in doctor's offices because I was "sickly". Some of them were very good and very understanding but some of them were not. I think the first time my mother ran into a not so understanding doctor was in New York when I was a few months old. He took one look at my mother and one look at me and his first thought was that I was a late in life child that was being neglected. He did a complete turnaround when he found out I was adopted. Another not so understanding doctor told my mother that it was all in my head and I was making myself sick. But by far the worst doctor we ever saw was a very young doctor at children's hospital that accused my mother of having Munchausen by Proxy. He was so arrogant and sure of himself he treated her horribly. When my regular pediatrician found out what the "young doctor" had done he went ballistic. If the doctor at the hospital had only known or asked about all the amazing things my mother did to try to help me, he never would have treated her so badly.

When I was seven we lived in an apartment complex with a pool. The pool was at the bottom of a long flight of stairs. I had no problem getting to the pool but could not climb the stairs to get home. My mother would



*Melissa's favorite things to do are plant flowers and work in the yard.*

have to carry/drag me up the stairs home. Walking any distances was very difficult when I got tired. In our apartment the bedrooms were upstairs, there were many nights when I was very tired that my mother would have to get me up those stairs any way she could. Once she even had to sit on the stairs with me in her lap and basically slide up the stairs. I would drop my fork or spoon unexpectedly while eating. It would just fall from my hand. When I was very tired chewing would be a little difficult and my eyes would be droopy. My pediatrician wanted to admit me to the hospital for some tests. I was given Tensilon with no effect. I had so many tests I could not name them all. They took enough blood to test for just about everything under the sun. My antibody test came back normal. The EMG was not conclusive. After a week in the hospital the doctors were able to rule out Muscular Dystrophy, and a long list of other illnesses. This trip to the hospital was truly traumatic for me. Being poked, prodded and tested would be upsetting to any seven year old but not getting an answer made it worse. I felt very alone.

I learned to cope with my limitations. I learned how to turn my head certain ways to compensate for no eye movement. I learned that I did better earlier in the day than in the afternoon, so if I had an activity I tried to do it in the mornings. I also discovered that when I got really tired if I drank orange juice or ate a banana and rested a little, I began to regain a little strength. When I became so weak that I could not get around I ate salt. I even carried salt packets from fast food restaurants in my purse for emergencies.

As the years went by I just resigned myself to this being my life. I always felt alone and like no one knew what I was going through. Some days were better than others, I could go for weeks and not get tired and then one day I would just crash and be so tired I could barely walk. From time to time my doctor would read an article about some illness or another and they would bring me in for a test but nothing would come from it. I was tested again with Tensilon and still nothing happened. When I was twenty-one I underwent surgery for an unrelated issue and had a bad reaction to the anesthesia. A very observant recovery nurse realized I was in trouble. I was on a ventilator for twelve hours and it took another six hours after that before I could swallow on my own. I knew what was going on but could not communicate with anyone and could not even move my arms to reach out for help. It was so frightening. I think it must be what a stroke victim feels like. Even then the diagnosis the doctors came up with was an allergy to Succinylcholine Chloride. No one ever put all the pieces of the puzzle together.

I tried very hard to be like my friends; it took a lot of effort and very often was disappointing because I just could not do it. I even began taking horseback riding lessons. This helped my legs a bit but really helped my self confidence.

When I was in my early thirties I began falling a lot. The final straw was when I was walking in the parking lot at work and fell behind a car. When I used to fall it would take me a little while to get up and sometimes I needed help standing up. Lucky for me the driver of the car realized I was no longer in sight and he got out to check on me. The near tragedy of almost being run over made me decide to try again to find out what was wrong with me.

After several visits to a general neurologist, he made an appointment for me to see Dr. Oh. Dr. Oh had performed my EMG 25 years before so I was not overly excited about seeing him and did not think much would come from it. Dr. Oh decided to try an injection of Neostigmine since I had no reaction to Tensilon. My husband left the room for a minute and when he returned the shocked look on his face was priceless. He stood there a minute then turned and yelled out the door "come quick". Apparently my eyes were wide open. My husband said I was "popeyed", he was worried they had messed something up. Dr. Oh just grinned when he came in. That was the day my life changed. It seems strange that being diagnosed with Myasthenia Gravis

was a relief for me. Finally I was not alone. There were other people that knew how I felt and there was a medication that could improve my quality of life. It had taken 32 years to finally put a name on what was wrong with me. After further investigation Dr. Oh determined that I have Congenital Myasthenia Gravis. Shortly after my diagnosis I became involved with the Alabama Chapter, MGFA.

My life has changed so much since then, I am able to walk up stairs without pulling myself up with my arms and I don't fall much anymore. I have gone back to school and received an Associate's degree. I know many who have been diagnosed with MG don't feel the same way I do about hearing that news, but for me it meant that I had a name for it and I was not alone. After 32 years of being isolated I am one of a group and I can reach out to others and offer support and maybe even a little awareness to others.

*Melissa Ray*

## We Morn The Loss, But Celebrate The Lives Of: Dr. George Oetting and Dr. Robert Sherrill

**Dr. George Oetting**, Ed.D. died on February 19, 2013 at his home in Montgomery, AL. He was retired from the U.S. Air Force, and was an educator with the Alabama Medical Association for many years. He became a member of the Alabama Chapter, Board of Directors in 2000 and continued to serve until his death.

When the Myasthenia was diagnosed, many things in his life changed. He loved traveling and visiting his friends all over the world. With MG, traveling was more difficult and risky. The desire to travel was still there so he did the research and wrote "The Meandering

Myasthenic". This article was published in the Alabama Chapter Newsletter and he was a co-author of an article with the same information that was published in the MGFA newsletter. He was instrumental in bring the MG nursing workshops in Montgomery.

He loved the Zoo. So instead of a public memorial service, he requested that his family and friends gather at a bench at the Zoo, that is named in his honor. He will be missed.

**Dr. Robert Sherrill**, M.D. passed away on May 6, 2013. After graduating from High School in Lakeland FL., he graduated from the University

of Tennessee, School of Medicine. He practiced medicine in Tampa, Florida for 17 years. He then transferred to Birmingham to become the Medical Director of Cooper Green Hospital, a position he held for 12 years. He was the founder of Alabama Medical Review, which later became The Alabama Quality Assurance Foundation. In 2000 he became a member of the Board of Directors of the Alabama Chapter, and served faithfully until 2011, when he resigned from the Board. We shall miss his dry humor and gentle guidance.

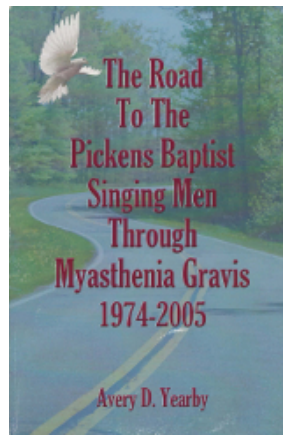
## We Need You!

We need volunteers to get the MGS up and running. This is a NEW organization and we need NEW ideas. We will be having a yearly meeting where we will elect board members. Will YOU consider putting your name on the ballot? The board meets monthly to discuss and handle the business of the MGS. We are currently meeting at the Homewood Library. Please consider making a difference by volunteering to serve on the Board of Directors.

## The Road To The Pickens Baptist Singing Men...

We are happy to announce the signing of "*The Road To The Pickens Baptist Singing Men Through Myasthenia Gravis*", written by *Avery Yearby*, an MG patient and a member of the Board of Directors of the MGS. This is a personal story about Avery's love of singing and how MG affected his singing, and his life. The books are \$10.00 each and Avery will be at the Library to sign your copy. (This would be a great gift for people on your

Christmas gift list that you want to remember).



The MGS is honored to receive 20% of the proceeds from book sales to use for patient support, education and research.

We hope to see the Homewood/Birmingham folks at the Library on Thursday August 15th 6:00 to 7:00 p.m. There will be another signing at the Annual meeting, time and place to be announced.

August 15, 2013  
6:00 to 7:00 P.M.  
Homewood Library  
1721 Oxmoor Road  
Homewood, AL

## Belk Sale---About more than money!

Of course, the Belk Sale is a fund raiser. However, that is only part of the intent and probably NOT the most important. The important thing about selling someone a \$5 ticket is that when you say this helps the Myasthenia Gravis Society, they look at you with that funny look on their face and ask, what it that? This gives you a "foot in the door". You can tell them what MG is!!! That it is an autoimmune disease; that it causes weakness that improves, somewhat, with rest but then returns; it can affect anyone; it is not contagious; give them a copy

of our informational "Green Card". **The best part is that you have now made someone aware of MG who did not even know it existed!**

The best way to reach more people in your area is to work with your local Belk store. Go to the Belk Customer Service Department and tell them that you are interested in being a part of the Charity Day Sale. They will give you tickets to sell and tell you every thing else you need to know. They are always thrilled to have another charity joining them, along with schools, churches and other organizations. We have our 501c3

so we are a qualified charity. Our next Belk Charity Sale will be Saturday, November 9th, 2013.

If you are interested in sponsoring your own Belk Charity Sale, first talk to someone in Customer service. They have all the answers. You will probably need our tax exempt number and we can easily furnish that. Let us know if we can help in any way. Call us at (205) 253-1568 or 800-799-4923.

## MG Support Group in the Birmingham Area!

### INNER STRENGTH

Inner Strength is a Myasthenia Gravis support group for patients, family members and caregivers. The group was founded in 2011 by Registered Nurse and Myasthenia Gravis patient Staci Hayes Machado to provide education, fellowship and support to the MG community in Alabama. The support group meets the second Tuesday of every month at the North Shelby Library on Cahaba Valley Road in Birmingham, AL. For more information about Inner Strength, contact Staci Hayes Machado at (205) 807-2106 or email [mginnerstrength@gmail.com](mailto:mginnerstrength@gmail.com) and follow us on Facebook.

## Telephone Support Links>>>>Patient to Patient



The following individuals have consented to have their names and phone numbers listed so that MG patients and families may call them. This is another way patients may link to other patients and families who have shared experiences with MG. We thank all of these individuals for their willingness to share their time and experience.

### **Anniston/Oxford/Gadsden:**

Al Perez, (256) 435-3445  
Judy Cunningham, (256) 547-7996

### **Auburn:**

John Higgs, Jr., (334) 887-6944

### **Bessemer:**

Barbara Marlar, (205) 424-8593

### **Birmingham Area:**

Melissa Romeo, (205) 879-7484  
Melissa Ray, (205) 620-1233  
Arlene Stuckey, (205) 253-1568  
Christi G.Bova (205) 834-0784  
Cindy Graham, (205) 680-5805

### **Crossville:**

Johnnie Sue Pluckett, (256) 659-2762

### **Dothan:**

Daphine Baten, (334) 794-6351

### **East Brewton:**

Elton Langston, (251) 867-5202

### **Gordo:**

Avery Yearby, (205) 364-7201

### **Hueytown:**

Pat Taylor, (205) 491-6448

### **Huntsville:**

Brenda Pierce, (256) 828-3853  
Dal Kirkland, (256) 651-5020

### **Mobile Area:**

Angie Waters, (251) 937-4433  
Dr. H.C. Mullins, (251) 928-0905

### **Montgomery:**

Voncille G. Wilson, (334) 244-0509  
Kathy King, (334) 244-0196

### **Ozark, AL:**

Susie Thomas, (334) 774-3957

### **Trussville:**

Allan Howard, (205) 655-8276

### **Columbus, GA:**

Gordon Estes, 706-593-6128

**We need volunteers from surrounding states where we have members, especially Tennessee and Mississippi. If there is no volunteer from your area, please consider volunteering for this supportive cause!**

## New Members... Thanks For Your Generous Donations.

Julian Fagan  
Bob E. Banks  
Jack L. Campbell  
Patricia V. Barber  
John Higgs  
Charles W. Breaux  
Vivian E. Crane  
Nancy Gore  
Daphine Baten  
Jimmy D. O'Dell

Wilferd J. Schmidt  
Johnnie D. Plunkett  
Danueline M. Brown  
Allan G. Howard  
Patricia Taylor  
Adolf Perez  
Luther L. Hill  
Chassel L. Pugh  
Brenda Booth Thornton  
Virginia G. Parker

Mary J. Greene  
Betty Markham  
Kenneth O. Brewton  
Elizabeth L. Massengale  
Kathryn A. King  
Thomas E. Doster  
Melvin C. Smith  
Anne G. Renfroe  
Susie Thomas

## MG Patient Registry

There is a new patient registry for those that have Myasthenia Gravis. "The Myasthenia Gravis Patient Registry is an active database of persons with Myasthenia Gravis (MG), developed for the purposes of research, treatment, and patient information." You can find more information at:

Web: [www.mgregistry.org](http://www.mgregistry.org) || Email: [MGR@MGRegistry.org](mailto:MGR@MGRegistry.org) || Phone: (855) 337-8633



## MEMBERSHIP CATEGORIES

- Individual - \$15.00 *(You would like to become a member.)*
- Family - \$30.00 *(You, your spouse and any children would like to be a member)*
- Executive - \$50.00 *(Your business would like to be recognized as a member)*
- Lifetime - \$1000.00

## MEMBERSHIP INFORMATION

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Phone (Home): \_\_\_\_\_ Phone (Other): \_\_\_\_\_

Email: \_\_\_\_\_

*(Email addresses are collected for MGS use only)*

May we include your name in the MGS Newsletter?

 Yes No

Would you prefer an electronic version of the Newsletter?

 Yes No

## MEMBERSHIP INVOLVEMENT

I would like to help the MGS by becoming a member:

 Individual Family Executive

Please check all that apply:

 New member Renewal Change in email/phone/address This is a gift

My gift is in  honor or  memory of: \_\_\_\_\_

Please send an acknowledgement to: \_\_\_\_\_

**Total Amount Enclosed:** \$ \_\_\_\_\_

Thank you for supporting the Myasthenia Gravis Society. MGS is a 501(c)(3) not-for-profit organization and your contributions may be tax deductible. Please make checks payable to Myasthenia Gravis Society (P.O. Box 590105, Birmingham, AL 35259-0105).

Belk Charity Sale  
Saturday, November 9th

Save The Date:



Myasthenia Gravis Society  
P.O. Box 590105  
Birmingham, AL 35259-0105