The Roadrunner

Myasthenia Gravis Foundation Jim L. Walker Arizona Chapter

Fall 2000

This edition of *The Roadrunner* is dedicated to the memory of Jim L. Walker.

From The Desk Of...Sonya Watkins, Executive Director

- It was a busy summer with many changes and challenges for the Arizona Chapter. From losing our lease and moving our office to the eastside to planning a fall Walk-a-thon – *"our plate is full."*
- We are very excited about the patient program in the planning stages and the ideas being generated by the people who volunteer to help our chapter.
- We are also so pleased and honored to have Beth Behr join us in the office. Give her a welcome call, she'll appreciate it.
- It is with great pride and honor we dedicate this edition of *The Roadrunner* to Mr. Jim L. Walker. Our chapter experienced a great loss on March 21 when we heard that Jim had passed away. I do not believe we will ever fully understand the impact he made on so many myasthenic's and their families through the years. I, as many, knew the true joy it was to talk to the first myasthenic after diagnosis and I, as many, can remember that person being Jim. Jim made me have hope and he encouraged me to take control of MG by educating myself and getting involved with the chapter. I will forever love and remember Jim for his soft, and tremendous strength along with his love and dedication he had for our cause.

In 1972, he and a few others started this chapter with a dream. His dream was to provide education and patient services through support groups and many other programs. His dream came true because of his hard work and continued dedication. Jim served in many capacities in this chapter from running the office as the Manager to serving on the Board of Directors. All those years, he always served others even when his health was not the greatest. He retired from managing the office in 1996, but continued to serve as a board member to his passing. At his retirement, the chapter voted unanimously and with great pride to name our chapter: The Jim L. Walker, Arizona Chapter of the Myasthenia Gravis Foundation.

Thank You Jim!

Look Inside

How To Reach Us

Jim L. Walker
Arizona Chapter
Myasthenia Gravis Foundation

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New Office Administrator

Some of you may have noticed a different voice on the other end of the telephone when you call the office. That is because it is with great pleasure we announce the employment of Beth Behr to our chapter office. Beth is a certified LPN nurse with a great deal of understanding and compassion for people with chronic illnesses. She decided to work part time and go in search of employment that was not necessarily monetarily enticing but gratifying also. In fact, she stated that "having a job that I enjoyed everyday to get up for that also makes me feel good about doing is most important". It was ironic when we found her because that was the attitude we were looking for. So when we reviewed her skills and they matched too, we felt it was a "match made in heaven"!

Please join us in welcoming Beth Behr to the Arizona Chapter. The next time you call the chapter office, she'll be there to help you!

Walk-A-Thon Volunteers Needed

As indicated in the enclosed flyer, our 1st Annual Suzanne Rogers (MG) Walk For Strength is Dec. 2 at Papago Park. Come work off your Thanksgiving feast and enjoy a day of exercise and fun! We even think Santa Claus will appear!

We are in great need of volunteers that will help the day of the event and help get pledges and walkers involved. If you are a myasthenic who is healthy and feeling like walking – DO IT and help those that don't. We have plenty of flyers that can be passed out at businesses, church youth groups, schools, boy and girl scout groups etc., etc. This event will be highly publicized and every little bit of assistance and volunteerism is needed. Please call the office and talk with Beth if you would like to help.

Upcoming Dates To Remember

Look for invitations and information in your mail

- 17th Annual Family Picnic, Sunday, Nov. 19
- 1st Annual Suzanne Rogers Walk for Strength, Dec. 2
- 2001 Annual Meeting, Jan. 27

National Foundation Office

Myasthenia Gravis Foundation of America
123 W Madison Street, Suite 800
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Telephone (312) 853-0522 or (800) 541-5454
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Loving Thoughts From The Family Of Jim Walker

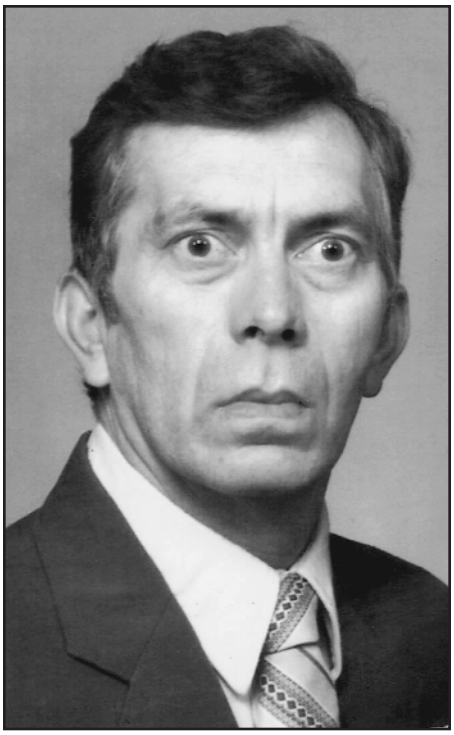
March 21 was a very sad day in the lives of those who knew and loved Jim Walker. He was a great man.

My dad's death wasn't unexpected. The doctors hadn't given him much more time. It wasn't the MG that finally beat him but congestive heart failure. He was denied his request to be put on the heart transplant list – his age, weight (lack of) and MG were factors. He was such a fighter, constantly battling for his health, it's hard to believe even a bad heart could have taken him. Even though death is sad for those of us remaining, and we miss him terribly, we celebrate the life he lived.

His MG may have weakened his muscles but he was a very strong man. It takes strong man to accept a disabling disease. He didn't complain or wasn't bitter about life's turns, but celebrated what he was able to do. He became the "stay at home" parent when our mother had to get a job to support the family. He found a craft in woodworking and became extremely good at it, making treasured things for his friends and family. He got involved with the MG Chapter. He was devoted to his family. He was patient, gentle and kind.

My dad loved his work with the MG Chapter. Me made so many wonderful friends. He thoroughly enjoyed talking with a new myasthenic and offering help and hope. And he received so much in return. He was so honored with the luncheon the chapter gave him when he "retired" from being the office administrator after 23 years and with the chapter being named after him. I don't think he was able to truly express how much that meant to him. For all of you who offered your friendship to him and who were so willing to help when he asked, you were truly a blessing.

My dad loved his family. He was proud of all of his children and grandchildren. he admired my mother for her love and strength in accepting the role as the family breadwinner, his caregiver, his chauffeur, and at times his muscles. Their love and



dedication to each other was an example to us all.

My dad had time to make some plans before he died. And it was his wish that any memorials be sent to the MG chapter he loved so much. On behalf of the family, thank you so much for those who generously gave to the chapter in his memory. It was a loving way to honor and remember him. Thank you and God bless you.

New Office Location

In May we lost our office lease. This was a set-back which resulted in some changes in telephone numbers and a little confusion in where we were located. We have since obtained a new lease and we are extremely pleased to announce our new location.

Please feel free to stop in any time to visit the office and volunteer some time for office administrative work.

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azmgfa@aol.com (Sonya Watkins)
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Nursing Spectrum.Com Offers CE on MG

Nursing Spectrum Career Fitness Online is a media company that promotes the recognition and support of the nursing community. Their locally targeted magazines (currently Illinois/Indiana, New York New Jersey, Washington DC/Baltimore, Florida, and Philadelphia/Tri State Region) and premier web site serve as the backbone of their company. Through the RN-led staff, they provide relevant, compelling, and timely information while offering cost-effective, innovative services, events, and products.

"Our magazines are widely read by RNs. As part of our continuing commitment to the nursing community, we have dedicated this site to Career Fitness, which we define as – keeping a career in shape through frequent assessments, a positive attitude, healthy work habits, and regular activities that build skills, knowledge, and professional networks."

They offer continuing education classes ONLINE and one of their most current one is on MG! For those of you who are not online, we are printing the article in its entirety.

Myasthenia Gravis: A Baffling Neuromuscular Disorder

by Jean Marie Ruhl, RN, MSN

The goal of this program is to update and enhance nurses' knowledge about the presentation, diagnosis, and treatment of myasthenia gravis (MG) from crisis to chronicity

After you study the information presented here, you will be able to

- Describe the pathophysiology, incidence, and manifestations of MG.
- Identify complications associated with MG.
- List medical and nursing measures intended to maximize wellness and promote lifestyle adaptation to the disease.

"I feel like I have to think about breathing."

"I'm trying to get more exercise, but I can hardly walk around the block without feeling like I have to sit down."

A 42-year-old mother of two teenagers articulates what it is like to live with MG. Her symptoms of two years – diplopia, extreme fatigue, and an inability to hold her head erect – finally erupted in a myasthenic crisis that required mechanical ventilation for a week and multiple plasmapheresis exchanges. Three months after her crisis, she had a suprasternal thymectomy. Since her operation, periods of improvement led to tapering her steroid dose, only to be followed by exacerbations and more plasmapheresis. This new sick role has shredded her former lifestyle. She can't work. She just fights for disability benefits.

Nurses from many sectors of healthcare ó emergency departments, critical care and medical/surgical units, apheresis centers, practitioners' offices, and home healthcare settings – encounter patients coping with MG in exacerbation, stability, or remission. A thorough knowledge about the disease process, treatment, and available community support is essential for nurses to promote maximal wellness and prevent complications in people with MG.

A Well-Known Disease

MG is one of the best understood of the autoimmune disorders, which include rheumatoid arthritis, glomerulonephritis, and scleroderma. With advances in respiratory care and immunotherapy, this "grave" disease no longer lives up to its name ("myasthenia" is derived from the Greek words for muscle and weakness and "gravis" means weighty in Latin). However, due to its rarity (15 per 100,000 people) and wide range of clinical presentations, diagnosis can be delayed by months or years.[1] Although it can strike at any age, MG usually first afflicts women in their 30s and 40s and men after age 50. Although MG is not considered a genetic disorder, a higher frequency of autoimmune disorders occurs in the family

continued on page 5

members of its victims.[2] Many patients with generalized MG may have an associated autoimmune disease.[3] A transient form of MG occurs in 12% to 15% of infants born to myasthenic women, which probably results from the transplacental transfer of antiacetylcholine (antiACh) antibodies.

MG is a neuromuscular disorder characterized by a gradual onset of fatigue and skeletal muscle weakness that typically improves with rest. It is marked by long periods of remission with intermittent exacerbations, although the course of the illness is extremely variable.[4] At its insidious onset, patients may present with diplopia, ptosis, and nystagmus because the disease often affects ocular muscles first. Ocular myasthenia includes and is limited to this cluster of symptoms. In time, facial

muscle involvement becomes prominent. Attempts to smile result in a snarling expression, and chewing becomes tiresome. Should the disease progress, patients may develop difficulty swallowing and articulating, indicating bulbar muscle involvement. At this point, a delay in diagnosis in these patients can put them at risk for aspiration. Neck muscles weaken, and patients become unable to hold their heads erect. Left to progress, proximal limb muscles (triceps and quadriceps) are affected next. Symptoms worsen with repetitive use of affected muscles and improve with rest. Symptoms are also worse toward the end of the day, when patients become tired. Nevertheless, with proper treatment and lifestyle alterations, many patients with MG stabilize with little disability.

A Problem at Neuromuscular Junctions

MG is a chronic disorder of neuromuscular junctions at which antibodies attack acetylcholine-receptor sites (AChRs), disabling normal impulse transmission. Normally, acetylcholine (ACh) is stored at the terminal end of axons and released at the neuromuscular synapse, where it binds with AChRs on the folds of postsynaptic motor-end plates. When sufficient interactions between ACh and AChRs occur, effective neuromuscular transmission takes place, and a muscle contraction is stimulated. Current research about the pathology of MG shows that a dysfunctional immune system produces antiACh antibodies that accumulate at neuromuscular synapses and "clog" AChRs, hence the autoimmune response.[5] Normally, postsynaptic motor-end plates have many folds on which AChRs are situated. In patients with MG, the motor-end plates of affected muscles flatten, reducing the surface area available for binding ACh with AChRs.[6] In addition, pathological studies of the neuromuscular junctions have found that patients with this disease have only about one-third as many AChRs than normally expected.[7] Therefore, when ACh is released, there are fewer sites for it to bind. The severity of fatigue and weakness correlates with the reduced number of AChRs. The combination of these abnormalities reduces neuromuscular transmission, resulting in ineffective muscle contraction and fatigued muscles.

The thymus gland is implicated in the autoimmune process of the antiACh antibody production associated with the onset of MG. The thymus is active during infancy and early childhood in the development of systemic immunity, but it normally shrinks in size by adulthood.[5] However, at least 60% of myasthenic individuals are found to have either thymic hyperplasia or a thymoma; most improve clinically after thymectomy.8 The exact cause of this thymic anomaly is unknown.

Diagnosis of Myasthenia Gravis

A patient's history of gradual weakness with ocular and bulbar involvement often prompts practitioners to seek consultation with a neurologist. However, with myriad symptoms, MG can be a diagnosis of exclusion. Traditional studies (serum blood counts, electrolytes, and renal and thyroid profiles) and computerized tomography (CT) can rule out the possibility of

continued on page 6

other diseases. Tests that pinpoint the diagnosis of MG include edrophonium (Tensilon) testing, repetitive nerve stimulation (RNS), single-fiber electromyography (EMG), and serum AChR antibody titers.

Testing with edrophonium is a first-line method to confirm suspected MG. It is often used with patients who have some degree of respiratory muscle involvement. Edrophonium is a short-acting drug that transiently improves muscular strength in the presence of MG by inhibiting the breakdown of ACh by the enzyme cholinesterase. The onset of a response to IV edrophonium is 30 seconds and the effects last for five minutes. An improvement in muscular strength and a reduction of ptosis is considered a positive test. A placebo injection of saline may be given in addition to the edrophonium in order to increase the validity of the results.[9]

RNS and EMG assess the adequacy of neuromuscular transmission. In RNS, electric shocks are delivered at a rate of three per second to a proximal muscle nerve within the facial, deltoids, biceps, or trapezius groups, while action potentials are recorded. A rapid reduction in the amplitude of evoked muscle action potential of at least 10% by the fourth or fifth trial is a positive response. A single-fiber EMG is a highly sensitive, but technically difficult, test during which the action potentials of adjacent muscle fibers innervated by a single nerve are recorded simultaneously. An abnormal amount of variation or "jitter" in the response of the adjacent muscle fibers is considered pathologic. Although positive results of both these tests correlate highly with the diagnosis of MG, they can also be positive in other neuromuscular diseases.

The detection of serum AChR antibodies is the most specific test for the diagnosis of MG. The test is positive in 70% to 90% of patients with generalized disease and nearly 100% specific. Individuals in remission or with only ocular symptoms, however, may have a positive titer of only 29% to 50% of the time.[1] With all diagnostic testing, correlation of results with clinical symptoms is critical in confirming the diagnosis.

Treatment Goals

Treatment to control MG has improved dramatically over the past 40 years. After stabilization, patients can expect to have a normal lifespan. Although rare, some patients initially present in myasthenic crisis with respiratory failure that requires intubation if their forced vital capacity (FVC) is less than a liter.[4] Myasthenic crisis can also occur in a previously stabilized MG patient. Stress or infection usually precipitates this life-threatening event, and mechanical ventilation may be necessary until the patient is stable again.

The usual treatment goals are to promote neuromuscular transmission and to combat the autoimmune response.[10] Anticholinesterase (AChE) drugs can medically boost neuromuscular transmission. Because of the variability of symptom severity in patients with MG, drug therapy is administered on an individual basis. Pyridostigmine (Mestinon) and neostigmine (Prostigmine) are oral AChE drugs that prevent the breakdown of ACh, allowing more ACh to be available at the receptor sites. Patients who cannot tolerate pyridostigmine use Prostigmine, a chemical analog of neostigmine. These medications have an onset of 30 to 60 minutes and their therapeutic effects last only three to four hours. Because of this, patients require doses at least four times a day. A sustained-release form of pyridostigmine is available for nighttime use to prevent muscle weakness upon awakening. After diagnosis, patients initiate a dosing schedule that they tailor to their own needs. Patients should be taught to schedule doses to coincide with times when they need maximal drug effectiveness, such as during meal time for those with bulbar involvement.

Adverse effects of pyridostigmine and neostigmine are directly related to the degree of parasympathetic stimulation. Because ACh is the primary

continued on page 7

neurotransmitter of the parasympathetic nervous system as well as skeletal muscles, the effects of both are enhanced with the use of these drugs. As a result, patients who take these medications may complain of abdominal cramping, diarrhea, and excessive salivation with nausea. They may experience cardiovascular effects, such as hypotension and bradycardia. Patients on AChE therapy are at risk for the onset of cholinergic crisis due to overdosing. The manifestations of cholinergic crisis are a result of "locking up" the available receptors with ACh.[5] Atropine sulfate, temporary pacing, and a reduction in dosing of pyridostigmine or neostigmine may be necessary.

Patients who do not respond well to AChE therapy require immunosuppressive therapy. Prednisone is the initial drug of choice to improve symptoms and promote remission. These patients need to be taught about the adverse effects of prednisone as well as the dangers associated with sudden cessation of the drug.

To avoid the long-term adverse effects of prednisone, after two to six months of therapy, patients begin immunosuppressive therapy with azathioprine (Imuran). Azathioprine, when used instead of or in conjunction with a lower dose of prednisone, has less frequent adverse effects. Because of teratogenic effects, women intending to conceive should not take this drug. Signs of intolerance, which generally occur early on, include leukopenia (white blood cell count <3,000 mm3), hepatotoxicity, and an acute, flulike idiosyncratic reaction that either precludes its use or requires a smaller dose. The beneficial effects of azathioprine may not be evident for up to a year after treatment has begun.

Cyclosporine and cyclophosphamide (Cytoxan) are less commonly used immunosuppressive drugs. Although cyclosporine is highly effective, its serious adverse effects and high cost limits its use to patients who are unable to tolerate corticosteroids or azathioprine. Cytoxan is prescribed only when other drugs have failed because of the high incidence of bladder cancer and hemorrhage related to its use.

Thymectomy improves the long-term outcome in at least 50% of younger patients with MG, with 35% attaining long-term remission.2 A 1998 epidemiological study found that the highest remission rates occurred in patients who had a thymectomy in the absence of a thymoma.1 The removal of thymic tissue reduces B- and T-cell activity responsible for the production of antiACh antibodies. The most thorough surgical approach to thymectomy is an open-sternal technique where the gland can be directly visualized and completely removed. Patients need several days in an acute care setting for monitoring for complications of thoracic surgery, such as pneumothorax, hemorrhage, and infection. An alternate, less-invasive technique is a suprasternal approach with mediastinoscopy. Although the hospital stay is shorter, the long-term results may not be as effective if the entire thymus is not removed. Because of the long life of T-cells, patients may not experience improvement in symptoms for up to 10 years postoperatively. In the meantime, the same vigilance of symptoms and compliance to medication must be faithfully exercised. No controlled clinical trials support thymectomy as a standard treatment for MG, although empirical results are favorable.

Short-term therapies during exacerbation to prevent myasthenic crisis include plasmapheresis and high-dose IV immunoglobulin (IVIG). During plasmapheresis, the patient's blood serum is removed and filtered to eliminate circulating antiACh antibodies, thus temporarily improving symptoms. A typical treatment course consists of five exchanges of three to four liters each during a two-week period. Symptoms improve within 24 to 48 hours after the first treatment, and its beneficial effects last for several weeks. Risks of plasmapheresis include hypotension as well as those associated with the use of a large-bore vascular access and sometimes a tempo-

continued on page 8

rary, indwelling, central-venous catheter. IVIG also provides short-term improvement of symptoms through a nonspecific suppressive effect on the immune system. As with plasmapheresis, improvement in symptoms occurs quickly.

Self-Care – Promoting Independence

Above all, patients need to become managers in their own medical regimens in conjunction with healthcare providers. However, patients and families require time to accept this lifelong illness. Individualized teaching sessions, comprehensible written information, and follow-up in the community can provide them with the knowledge to avoid exacerbations and a plan that helps their return to activities of daily living. Local support groups organized by the Myasthenia Gravis Foundation of America (800/541-5454; www.myasthenia.org) can dispel feelings of isolation and frustration by teaching coping skills.

Survival in the community after discharge is dependent on:

1) support from knowledgeable family and friends,
2) adherence with medications,
3) an awareness of the events that may trigger exacerbation,
4) conservation of energy to avoid fatigue.

Patients need to educate themselves as well as those in their support systems about the pathology and treatment of MG. Establishing a care system with the family to monitor the patient and provide support when necessary will encourage independence as well as keep the patient safe. Medical information should also be readily accessible to healthcare providers who may have to treat these patients in the event of crisis. Patients should wear a MEDIC-ALERT identification bracelet to elicit appropriate emergent treatment when needed.

Any physical or emotional stress that affects the immune system can provoke an exacerbation. These stresses include illness, exhaustion, fever, trauma, hormonal changes, and excessive temperatures. Medications that interact at neuromuscular end-plates or interfere with ACh may also aggravate symptoms and should be avoided. Patients should keep a list of these antagonizing medications, as well as a schedule of their current medications and dosages, with them at all times.

Patients may have to confront the well-intentioned advice of family and friends. Statements such as "If you'd exercise more, you might feel better" indicate a lack of understanding of the disease process of MG. Low-impact aerobic exercise may improve functional status and lessen fatigue in less-ill people.[11] However, because muscle fatigue is a potential trigger for exacerbation, patients need to incorporate energy conservation modifications into their daily lives.

Living with myasthenia gravis requires patience, knowledge, and support. The responsibilities of daily routines can quickly become overwhelming for patients fighting to retain their normal lifestyles. Compliance with anticholinesterase and immunosuppressive medications is essential for patients to maximize muscle function and to minimize the potential for complications. Patients may benefit from contact with support groups or counselors who can validate their emotions and provide guidance and hope for the future.

Medications That Aggravate Symptoms Related to Myasthenia Gravis

- Beta-adrenergic blockers
- Morphine sulfate
- Diuretics
- Procainamide and quinidine
- Barbiturates
- Tricyclic antidepressants
- Neuromuscular blockers
- "Mycin" antibiotics (vancomycin, amikacin, neomycin, erythromycin)

Cholinergic Versus Myasthenia Crisis Symptoms of Cholinergic Crisis

- Profound generalized weakness
- Impaired respiratory function
- Excessive pulmonary secretions
- Abdominal cramping
- Diarrhea

continued on page 9

Symptoms of Myasthenia Crisis

- Sudden exacerbation of muscular weakness
- Rapidly developing respiratory distress with dysphagia
- Vital capacity less than 1.0 liter

Suggestions for Energy Conservation[12]

1. Sit whenever you can.
2. Organize your day to allow for rest periods.
3. Use energy-saving assistant devices whenever possible (power tools and appliances rather than hand tools, carts and baskets to hold items, walking aids, motorized wheelchairs).
4. Schedule strenuous activities at peak medication times.
5. Obtain a handicapped parking sticker.
6. Shop by telephone, mail, or Internet whenever possible.
7. Wear an eye patch if diploplia is present; alternate it from eye to eye to avoid eye strain.
8. Begin meals with cold foods rather than warm to minimize muscle weakness.
9. Avoid foods that crumble and could be aspirated (chips, toast).

Jean Marie Ruhl, RN, MSN, is a staff nurse on the critical care unit at Pottstown Memorial Medical Center and an adjunct faculty member at Reading Area Community College in Pennsylvania.

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What Is AOAD?

Arizona Office For Americans
With Disabilities
1700 W. Washington, Suite 164
Phoenix, Arizona 85007
Voice: (602) 542-6276
TTY: (602) 542-6686
ADA/disability
related resources: (800) 358-3617
WWW.know-the-ada.com

"The Arizona Office for Americans with Disabilities (AOAD) will be recognized as a leader in providing strong and consistent guidance to eliminate discrimination against individuals with disabilities."

What can the AOAD do?

- Answer Americans with Disabilities Act (ADA) related questions.
- Help develop a plan to achieve maximum accessibility.
- Train employers and employees on federal and state disability laws.
- Evaluate agency or company compliance programs.
- Provide resources materials.
- Assist people with disabilities in understanding their rights

Americans With Disabilities Act – An Overview

Title I of the Americans with Disabilities Act prohibits employers from discriminating against qualified individuals with disabilities in job application procedures, hiring, firing, advancement, compensation, job training and other terms and conditions of employment.

Companies with 15 or more employees should be aware of these key aspects of the law:

- An employer is required to make a "reasonable accommodation" to the known disability of a qualified applicant or employee if it does not impose an "undue hardship" on the operation of the employer's business. What actually constitutes an undue hardship will be largely determined on a case-by-case basis. The concept of undue hardship includes any action that is:
  – unduly costly;
  – extensive;
  – substantial;
  – disruptive; or
  – that would fundamentally alter the nature or operation of the business.
  – Employers may not ask job applicants about the existence, nature or severity of a disability.

- The employer cannot require a job applicant to take a medical examination before making a job offer. A job offer may be conditioned on the results of a medical examination, but only if such an exam is required for all new employees. Moreover, the employer must establish that physical qualification standards are job-related and consistent with business necessity.

- An employer is not required to lower existing production standards applicable to the quality or quantity of work for a given job in considering qualifications of an individual with a disability, if these standards are uniformly applied to all applicants and employees in that job.

- The Act does not apply to employees with temporary disabilities that have no long-term effect such as an employee with a broken arm that will heal.

- When an employee is no longer able to perform in a job due to disability, the employer must consider reassigning the employee to another position that is available.

- The Act protects persons with AIDS and HIV disease from discrimination.

- The Act requires that covered employers post a notice describing the provisions of the Act. If you require such a notice, please contact this office, and we will obtain for you such a notice at no charge.

- The Act permits employers to ensure that the workplace is free from the illegal use of drugs and the use of alcohol. However, it does provide limited protection for recovering drug addicts and for alcoholics.

If you have any questions concerning the applicability of the Act to your company, please do not hesitate to call upon us.

Something To Ponder

submitted by Terry Riley

- Do not undermine your worth by comparing yourself with others. It is because we are different that each of us is special.
- Do not set your goals by what other people deem important. Only you know what is best for you.
- Do not take for granted the things closest to your heart. Cling to them as you would your life, for without them, life is meaningless.
- Do not let your years slip through your fingers by living in the past, nor in the future. By living your life one day at a time, you live all the days of your life.
- Do not give up when you still have something to give. Nothing is really over until the moment you stop trying.
- Do not be afraid to encounter risks. It is by taking chances that we learn how to be brave.
- Do not shut love out of your life by saying it is impossible to find. The quickest way to receive love is to give love; the fastest way to lose love is to hold it too tightly.
- Do not dismiss your dreams. To be without dreams is to be without hope; to be without hope is to be without purpose.
- Do not run through life so fast that you forget not only where you have been, but also where you are going. Life is not a race, but a journey to be savored each step of the way.

Unknown

Web Address To Note

www.mdausa.org/publications/101hints/index.html
101 ways to "Help-with-Ease" for patients with Neuromuscular Disease. A do-It-Yourself Owner's Guide by Irwin Siegel, M.D. and Patricia Casey, M.S., OTR/L 1996.

Preface

This little booklet was written to assist patients with neuromuscular disease in handling their tasks of daily living. All the hints it contains have been field-tested and proven useful. Most were suggested by patients or their families. Only a few have been gleaned from the literature. In this sense, the pamphlet, like the Heloise books, is truly a do-it-yourself owner's manual. Usually, "Help-With-Ease" hints don't require any special tools or equipment. Most of the gadgets described can be easily made with materials at hand in the ordinary household or purchased at a grocery, hardware or fabric store or ordered from readily available self-help catalogs.

We hope these hints will help you and your caregivers tend to your daily tasks of eating, grooming, dressing, sitting, transferring, communicating, getting around, using the toilet, working, recreating, traveling, shopping and sleeping. If you or yours have a suggestion you would like us to include in a future edition of our "Help-With-Ease" hints, send it on and we'll make it 102, 103, or even 110 or more hints next time.

Dr. Irwin M. Siegel co-directs several Chicago-area MDA clinics. He is the author of The Clinical Management of Muscle Disease, Muscle and Its Diseases, and The Clinical I, a collection of vignettes and essays.

Patricia Casey is an occupational therapist serving four Chicago clinics. She is also active in local ALS clinical programs and drug studies. Ms. Casey has published numerous scientific articles on the role of occupational therapy in the management of neuromuscular diseases.

Special People

You probably have noticed the major change in appearance of our newsletter. We would like to acknowledge and thank Jackie Adams for her continued dedication in getting out the newsletter and two new individuals and their companies who have joined our team by providing graphic artwork and printing free of charge. These two special people are Kim Sertich from **Page One Productions** in Phoenix and Thom Meaker from **Meaker the Printer** also in Phoenix. Without their caring contribution, this educationally informative newsletter would not be possible. Thank YOU!

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We would like to thank the following for the generous support through monetary aid in these areas. Without your charitable generosity our program services for the MG Patients of Arizona would be impossible.

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Support Groups Statewide

PHOENIX

Northwest Valley
Northwest Valley Support serves the following cities: El Mirage, Glendale, Peoria, Sun City, Sun City West, Surprise, West Phoenix and Youngtown. Meetings are held at the Arrowhead Wellness Center on the third Saturday of each month. A meeting notification will be sent to members of the Support Group. If you would like to attend these meetings, please contact Vicki Case at 602-285-1509.

North Central Valley
This group services the greater Metro Phoenix area. A meeting notification will be sent to members of the Support Group. All meetings will be held at the Wellness Connection at Chris-town Mall. If you would like to attend these meetings, please contact Vicki Case at 602-285-1509.

East Valley
The East Valley Support group serves Apache Junction, Casa Grande, Chandler, Gilbert, Mesa, Tempe, and other East Valley communities. The group meets every two-three months, Saturday mornings at the Chandler Regional Hospital, located at Dobson and Frye Roads. For future meeting schedules, please contact Dave or InaSue Shapiro at (602) 895-9091.

North Valley (Scottsdale Area)
The Scottsdale Support Group serves East Phoenix, Fountain Hills, Moon Valley, Paradise Valley and Scottsdale. Notification of meetings will be sent to all those on the mailing list who reside in these areas. Meeting are held at the Scottsdale Senior Center. For further information, please contact Dan Stringer at (480) 941-1801.

TUCSON

The Tucson Area MG Support Group meet every 2nd Saturday of the month, 10:30 a.m. at Woods Public Library at 3455 N. First Ave. Call Jan or Jim LoVecchio for date confirmation at (520) 889-6910.

Surf For MG Internet News, Updates, Sites Of Interest

For those of you who have access to the internet, there are several great MG web sites. Here are just a few…

- Arizona Chapter Web site: www.geocities.com/HotSprings/Resort/453O
- Myasthenia Gravis Foundation: 'This has wonderful resources such as locations of chapters nationwide, research & educational services, etc. www.myasthelia.org
- links to numerous Myasthenia issues:Http://pages. prodigy. net/stauley way/myasthenia
- Useful travel information for those with disabilities: www. access-able .com:
- A fun site with lots of the info!! www.noah.cuny.edu/neuro/MGmyasgra.html
- Just as the name applies…lots of links to different pages dedicated to MG: Http://home. pacbell.net.ego-1935/myalinks.htm
- Purpose of this web site is to connect MG patients with information as well as each other. Lots of testimonials: Http://pages.prodigy. com/lifewithmg
- Http://mediswww.cwru.edu.dept/neurology/ myasthenia.html
- National Family Caregivers Association: www.nfcacares.org
- Resources for Caregivers: http://www.eskimo. com˜jlubin/disabled/ caregiver.htm

11 Year Old Comes to Phoenix for Thymectomy

Teddi Bears From First American Title Employees Lend Comfort

In March our office received a call from a woman from Virginia who stated that her 11-year-old daughter has MG and that she needed a thymectomy. For various reasons she was coming to Phoenix to have her surgery at the Phoenix Children's Hospital. Her mom and her were very scared and needed some comfort and voices from those who understood. Her father lives in Gilbert and we quickly learned that Logan was truly loved by all involved. This young patient's name is Logan Paris.

Our office lent assistance with education, literature and a friendly voice. We were then made aware of assistance this small family needed to fly to Phoenix and receive this very needed surgery. We quickly called our friends at First American Title who were already busy selling some very adorable Teddi Bears and going to donate some of the proceeds to our Chapter.

When we were able to share with them this families need, the employees of First American were so excited and generous to work on selling the bears quickly and sending us all the proceeds in order to assist Ms Paris and her mom.

On Behalf of both our chapter and the Paris family we would like to thank the employees of First American Title for their continued ongoing support of our chapter and it's patients we serve.

A special note, we have just learned from Logan's father, that she is doing much better and seems to be in beginning stages of remission.

GOOD LUCK LOGAN!

Special Persons Report!

This summer some special people were instrumental in helping us to receive a sizable unrestricted grant from the St. Luke's Charitable Trust Foundation.

Mr. Clement Vaughn, who has been a long-time board member, recently retired from the trust and was able to appoint our chapter the recipient of a grant traditionally given by outgoing board members to their choice of charity.

We are so grateful to Mr. Vaughn in thinking of us and our patient's needs. In addition, we would like to express our heartfelt gratitude to the St. Luke's Foundation for their continued support to our community charities in awarding millions of dollars a year to charities across the state like ours.

Together organizations like theirs helping organizations like ours will continue to make a huge difference to humanity.

Searching For A Sister

Hi!

I am in search of my half sister who is 19 years older than me. I am 43 years old. She use to live in the Omaha, Neb., area in 1995. She said she was moving to Arizona. She has myasthenia gravis and has had it since she was 19 years old (time frame would be I think 1958).

We are not close because of our dad died in 1960 when I was only 3½ years and we did not have the same mother. But, I am in search of her. Her name is Patty Rae Slight (maiden name was Paterson) like mine. If you know of her in your records – is there a way to get a message to her? You have my email address give to her this is for medical questions; very important to me.

Thank you very much if you find her in your records of Arizona.

Golf Tourney Raises $2,500

This year's golf tournament was held at the award winning Stonecreek Golf Club. It was a warm clear day. Ms. Suzanne Rogers, our national spokesperson, and star who plays Maggie Horton on the daytime drama, *Days of Our Lives*, made a special appearance. She signed autographs and thanked the golfers and family members who attended. The golfers had a wonderful time and enjoyed the banquet and auction immediately following.

Our chapter's fund-raising effort cleared a little over $2,500 for this event. We are so appreciative of all the golfers and businesses who continue to help us reach our success.

Without the support and efforts of many people on the golf committee and family and friends of the Arizona Chapter, such events would not be possible and funds would not be raised to keep providing the services that myasthenics need.

Watch for upcoming newsletters and mailings with information about the 2001 Golf Tournament. Our goal next year is $10,000. Please consider participating and we hope to SEE YA THERE!

We are extremely grateful to the following sponsors who donated at least $100 to sponsor a TEE.

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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.