



MYASTHENIA GRAVIS FOUNDATION
JIM L. WALKER ARIZONA CHAPTER

The Roadrunner

"Learning to Cope with Knowledge and Hope"



Summer 2001

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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 author or speaker 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.

- **FROM THE DESK OF.....**Sonya Watkins, Executive Director
Summer temperatures are around the corner but I could not go without saying God has blessed us with a beautiful Spring! I hope this newsletter finds everyone feeling well.

As we have entered this New Year, I have thought often about what is in store for Myasthenia Gravis. What should we be hoping for in the future? What should we expect from our medical caretakers and our Arizona Chapter of the Myasthenia Gravis Foundation? I am a firm believer that the 21st Century with all its technology and advances in medicine will produce the cure for MG! I believe we should all have hope, and look forward to healthier lives! I also know that the Arizona Chapter is dedicated to first serving the patient by helping to educate patients about the disease they live with along with their families and friends. I also know that the Arizona Chapter is dedicated to supporting and helping educate the medical community in its quest for a cure as well as better more friendly therapies.

I know these things because I am blessed to work with the most dedicated group of Board Members and Support Group leaders. They encourage and help implement goals and plans to serve you better. At our Annual Meeting in January, we committed to implementing a much needed physician referral system. In addition, we will be implementing a Continuing Education Program that is well thought out and run by our Nurses Advisory Board. This educational program is designed to educate emergency care physicians, EMT's and Nurses that may be in contact with myasthenics at some point in their career. In the fall, (November) we are working with other disease foundations to sponsor an annual Social Security Disability Workshop in order to help with some of the frustrations associated with SSD.



WHO'S WHO...

NOTE NEW ADDRESS OF NATIONAL

National Foundation Office
5841 Cedar Lake Road, Suite 204
Minneapolis, MN 55416
Telephone (952) 545-9438 or (800) 541-5454
Fax (952) 545-6073
E-Mail, myastheniagravis@msn.com

AZMG Executive Committee:

Trevor D. Lloyd, Chairman (480) 802-0730
Edward C. Kaps, Past Chairman (480) 837-8728
Alex Haas, Vice Chairman (480)840-5502
Vicki Case, Treasurer (602)285-1509

Board of Directors

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Dino Gotsis	Luann Green
Scott Green	Alex Haas
Edward C. Kaps	Trevor D. Lloyd
Jim LoVecchio	Tammy Paz-Combs
Marilyn Ricci, RN	Dale Short
Lawrence Teitel, M.D.	

Medical Advisory Board

Dr. Lawrence Teitel	Barrow's Neurological Institute
Dr. Joseph Drazkowski	Barrow's Neurological Institute
Dr. Kumarswamy Sivakumar	Barrow's Neurological Institute
Dr. Todd Levine	Good Samaritan Hospital

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Peggy Marquard

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Jackie Adams

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Chris Budwill



• **MGFA MEETING IN LAS VEGAS, 2002.....**

The national meeting of the Myasthenia Gravis Foundation of America will be held in Las Vegas in the spring of 2002. We hope that many of our members will be able to attend this informative, fun event. We will be notifying you of the exact dates and hotel location as soon as it is finalized.

• **WE HAVE MOVED OUR WEBSITE.....**

**Our new web address is
www.geocities.com/azmgfa.**

We would like to thank the AZMG office manager, Chris Budwill, for all her hard work on our new site. We will be updating this on a regular basis, as our goal is to keep you informed on the latest happenings with the AZMG chapter and MGFA.

• **HELP!!! WE NEED YOUR SUPPORT.....**

In January, we mailed out our 2001 AZMG membership information. To date, we are down considerable from 2000. Our goal, is to double our membership by the end of June, 2001. If you have not sent in your membership information, call the AZMG office or visit our website at www.geocities.com/azmgfa.

Remember, this drive is critical to the AZMG foundation, as these funds go towards patient services, support group operations, educational literature, and general operating expense. For example, these funds will assist in:

1. Mailings: newsletters; information to new myasthenics
2. Brochure development: currently working on a mailing which will go to all AZ Primary Care Physicians, Neurologists, Ophthalmologists, Dentists, etc. on diagnosing and care of MG patients.
3. Educational seminars: in process of developing a continuing education program for Nurses and EMT's, involving training for emergency care personnel who may come in contact with MG patients.

As you can see, the need is great, and we need you!



From the MGFA Site

- **NEWEST INFORMATION FROM MGFA...**

April 10, 2001 **Ephedrine Sulfate** should be back in the distribution pipeline by mid-May 2001 according to Westward Pharmaceuticals, the manufacturer. Westward has made a commitment to continue the manufacture of this drug according to information given the MGFA.

In addition, the following update from ICN in a letter to the MG National office as follows:

March 22, 2001

Debora K. Boelz
Myasthenia Gravis Foundation of America
5841 Cedar Lake Road, Suite 204
Minneapolis, MN 55416

Dear Deb:

ICN recently completed our annual product pricing review. Recent price history of Mestinon revealed that in 2000 there was no Mestinon price increase and in 1999, three small increases totaling 10%.

A decision has been made to adjust pricing of Mestinon 60 mg tablets. Effective March 22, 2001, the price of Mestinon 60 mg tablets will increase by 7%. Your members will probably see the difference in price when their next prescription is filled. Our notification to drug wholesalers will result in the immediate re-pricing of inventories at the wholesale and retail levels.

Your assistance in notifying patients of this information will be very much appreciated.

It is the intention of ICN to keep the Myasthenia Gravis Foundation informed of changes that may affect your membership. Please feel free to call me at (800) 548-5100, ext 3034 with any comments or questions.

Sincerely,
Karen L. Chapman
Product Manager

cc: Myasthenia Gravis Association of Western PA
Myasthenia Gravis Foundation of California
The Myasthenia Alliance for Health and Wellness

- 
- **ALTERNATE DAY THERAPY...**
<http://www.msnews.org/jpred.htm>

PREDNISONE

If you are on Prednisone, this website will help you understand the Alternate Day Therapy rationale and how it may help some of us with the Prednisone side effects.

ADT (Alternate Day Therapy)

ADT is a corticosteroid dosing regimen in which twice the usual daily dose of corticoid is administered every other morning. The purpose of this mode of therapy is to provide the patient requiring long-term pharmacologic dose treatment with the beneficial effects of corticoids while minimizing certain undesirable effects, including pituitary-adrenal suppression, the Cushingoid state, corticoid withdrawal symptoms, and growth suppression in children.

The rationale for this treatment schedule is based on two major premises: (a) the anti-inflammatory or therapeutic effect of corticoids persists longer than their physical presence and metabolic effects and (b) administration of the corticosteroid every other morning allows for re-establishment of more nearly normal hypothalamic-pituitary-adrenal (HPA) activity on the off-steroid day.

A brief review of the HPA physiology may be helpful in understanding this rationale. Acting primarily through the hypothalamus a fall in free cortisol stimulates the pituitary gland to produce increasing amounts of corticotropin (ACTH) while a rise in free cortisol

inhibits ACTH secretion.

Normally the HPA system is characterized by diurnal (circadian) rhythm. Serum levels of ACTH rise from a low point about 10 pm to a peak level about 6 am. Increasing levels of ACTH stimulate adrenocortical activity resulting in a rise in plasma cortisol with maximal levels occurring between 2 am and 8 am. This rise in cortisol dampens ACTH production and in turn adrenocortical activity. There is a gradual fall in plasma corticoids during the day with lowest levels occurring about midnight.

The diurnal rhythm of the HPA axis is lost in Cushing's disease, a syndrome of adrenocortical hyperfunction characterized by obesity with centripetal fat distribution, thinning of the skin with easy bruisability, muscle wasting with weakness, hypertension, latent diabetes, osteoporosis, electrolyte imbalance, etc. The same clinical findings of hyperadrenocorticism may be noted during long-term pharmacologic dose corticoid therapy administered in conventional daily divided doses. It would appear, then, that a disturbance in the diurnal cycle with maintenance of elevated corticoid values during the night may play a significant role in the development of undesirable corticoid effects. Escape from these constantly elevated plasma levels for even short periods of time may be instrumental in protecting against undesirable pharmacologic effects.

During conventional pharmacologic dose corticosteroid therapy, ACTH production is inhibited with subsequent suppression of cortisol production by the

adrenal cortex. Recovery time for normal HPA activity is variable depending upon the dose and duration of treatment. During this time, the patient is vulnerable to any stressful situation. Although it has been shown that there is considerably less adrenal suppression following a single morning dose of prednisolone (10 mg) as opposed to a quarter of that dose administered every 6 hours, there is evidence that some suppressive effect on adrenal activity may be carried over into the following day when pharmacologic doses are used. Further, it has been shown that a single dose of certain corticosteroids will produce adrenocortical suppression for two or more days. Other corticoids, including methylprednisolone, hydrocortisone, prednisone, and prednisolone, are considered to be short acting (producing adrenocortical suppression for 1 1/4 to 1 1/2 days following a single dose) and thus are recommended for alternate day therapy.

The following should be kept in mind when considering alternate day therapy:

Basic principles and indications for corticosteroid therapy should apply. The benefits of ADT should not encourage the indiscriminate use of steroids.

ADT is a therapeutic technique primarily designed for patients in whom long-term pharmacologic corticoid therapy is anticipated.

In less severe disease processes in which corticoid therapy is indicated, it may be possible to initiate treatment with ADT. More severe disease states usually will require daily divided high dose therapy for initial control of the disease process. The initial suppressive dose level should be continued until satisfactory clinical response is obtained, usually four to ten

days in the case of many allergic and collagen diseases. It is important to keep the period of initial suppressive dose as brief as possible particularly when subsequent use of alternate day therapy is intended. Once control has been established, two courses are available: (a) change to ADT and then gradually reduce the amount of corticoid given every other day or (b) following control of the disease process reduce the daily dose of corticoid to the lowest effective level as rapidly as possible and then change over to an alternate day schedule. Theoretically, course (a) may be preferable.

Because of the advantages of ADT, it may be desirable to try patients on this form of therapy who have been on daily corticoids for long periods of time (e.g., patients with rheumatoid arthritis). Since these patients may already have a suppressed HPA axis, establishing them on ADT may be difficult and not always successful. However, it is recommended that regular attempts be made to change them over. It may be helpful to triple or even quadruple the daily maintenance dose and administer this every other day rather than just doubling the daily dose if difficulty is encountered. Once the patient is again controlled, an attempt should be made to reduce this dose to a minimum.

As indicated above, certain corticosteroids, because of their prolonged suppressive effect on adrenal activity, are not recommended for alternate day therapy (e.g., dexamethasone and betamethasone).

The maximal activity of the adrenal cortex is between 2 am and 8 am, and it is minimal between 4 pm and midnight. Exogenous corticosteroids suppress adrenocortical activity the least, when

given at the time of maximal activity (am).

In using ADT, it is important, as in all therapeutic situations to individualize and tailor the therapy to each patient. Complete control of symptoms will not be possible in all patients. An explanation of the benefits of ADT will help the patient to understand and tolerate the possible flare-up in symptoms, which may occur in the latter part of the off-steroid day. Other symptomatic therapy may be added or increased at this time if needed.

In the event of an acute flare-up of the disease process, it may be necessary to return to a full suppressive daily divided corticoid dose for control. Once control is again established alternate day therapy may be re-instituted.

Although many of the undesirable features of corticosteroid therapy can be minimized by ADT, as in any therapeutic situation, the physician must carefully weigh the benefit-risk ratio for each patient in whom corticoid therapy is being considered.

Store at controlled room temperature 15° to 30° C (59° to 86° F).

References:

1. Fekety R. Infections associated with corticosteroids and immunosuppressive therapy. In: Gorbach SL, Bartlett JG, Blacklow NR, eds. *Infectious Diseases*. Philadelphia: WB Saunders Company 1992:1050-1.2. Stuck AE, Minder CE, Frey FJ. Risk of infectious complications in patients taking glucocorticoids. *Rev Infect Dis* 1989;11(6):954-63.

(The Upjohn Company, 12/94, 810 342 016, 691015)

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ASK DR. LEVINE...

Send in your questions today!

For the past 4 years, the Arizona MG Chapter has wanted to offer the Roadrunner subscribers and Arizona MG patients a Q&A forum, utilizing a local MG specialist. We would take questions from you, the patients, and forward them to this specialist. We would then select a few to publish in each newsletter as well as on our website. After several attempts, we have finally found a specialist willing to take on this task.

Dr. Levine is a local neurologist who works out of Good Samaritan Hospital in Phoenix and specializes in MG and other neuromuscular diseases. He has graciously agreed to help us with this project.

Here how it will work...

1. Submit a question to the Arizona chapter office via mail, fax, or e-mail.
2. We will forward these questions to Dr. Levine
3. We will select 2-3 to publish at each newsletter and also publish them on our website
4. Not all letters will be addressed on an individual basis. We will do our best to cover a variety of informative subjects, but please understand that we may not be able to publish all that we receive.



Surf For MG Internet News, Updates, Sites of Interest

SURF THE NET FOR MG INFORMATION:

These sites are current as of the printing of this newsletter:

- ARIZONA CHAPTER:
www.geocities.com/azmgfa
- NATIONAL MG FOUNDATION:
www.myasthenia.org

The web sites listed below carry this disclaimer: The following links contain information on myasthenia gravis that *has not* been reviewed by the Arizona Chapter of the Myasthenia Gravis Foundation. The AZMG assumes no responsibility for the content of these pages. Decisions on individual treatment should always be made by a physician.

- WEB MD articles of interest:
 - a. Pregnancy & MG:
http://webmd.lycos.com/content/dmk/dmk_article_3961208
 - b. Eyelid Repair:
http://my.webmd.com/content/asset/dam_surgery_eyelid_lift
- MYASTHENIA GRAVIS MAILING LIST:
This is a discussion and support list for those suffering from Myasthenia Gravis.
http://goodstuff.prodigy.com/Mailing_Lists/mg_mail.html
- MYASTHENIA GRAVIS LINKS:
<http://pages.prodigy.net/stanley.way/myasthenia/>
- OCULAR MG INFO:
<http://trfn.clpgh.org/mga/ocular.html>
- NOAH: (New York Online Access to Health) good general information.. <http://www.noah-health.org/english/illness/neuro/myasgra.html>
- JACKSON GASTROENTEROLOGY DYSPHASIA DIET: for those who experience swallowing difficulties, this is an informative site. <http://www.gicare.com/pated/edtgs07.htm>

- NFCA (National Family Caregivers Association): <http://www.nfcacares.org/>
- CAREGIVER RESOURCES:
<http://www.makoa.org/caregiver.htm>
- MEDLINE PLUS HEALTH INFORMATION (MG page):
<http://www.nlm.nih.gov/medlineplus/myastheniagravis.html>
- GENTIVA HEALTH SERVICES:
http://www.gentiva.com/myasthenia_gravis/gravis_about.html

NOTE: for information on disability and related issues, check this out!
http://www.gentiva.com/access/access_services.html

- Suzanne Rogers of "Days of Our Lives" is our National Spokesperson. Log on to her website and thank her for her support.
http://www.daysofourlives.com/castcharacters/act_rogers.html



BEAT THE HEAT

BEAT THE HEAT WITH COOL CLOTHING

....by Jackie Adams

Here it is again...just in case you missed it in past newsletters.

While searching the internet for some articles to publish, I came across several sites about people who suffer a variety of health problems that makes them sensitive to the heat. This sparked my interest, since we are in the “Heat Mecca” of the U.S. and myasthenics are heat sensitive.

One of the articles I came across was from the University of Alabama in Huntsville, which wrote of how “cool suites” and “cool vests” helped kids who were sheltered from the outdoors lead lives that are more normal. In the article it states how Sarah Ann Moody, of Hampton VA, founded the HED Foundation. This is for people who suffer from Hypodrolic Ectodermal Dysplasia, people born without sweat glands and how the “cooling vests” help protect their vital organs.

I further searched internet sites that offered the “cool vests” and other items as well. Some of these companies claim that these vests can maintain a 65-degree F. temperature for up to 2.5 hours, even in the most extreme heated environments. Firefighters and long distance runners also use many of these products. While I am not personally endorsing any of these companies, I believe they offer a useful product.

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Therefore, I am listing the names and phone numbers if you wish to call and research.

Again, the AZMG chapter has not done any extensive research on these companies. As always, please contact your physician who will know what is best for you.

COOLTEK
Manufactured & Distributed by
Heat Relief Products Int'l, Inc.
1991 Crocker Road, Suite 600 Cleveland,
Ohio 44145-1962
Toll-Free 888-849-3657 Fax: 440-899-
7208
(Outside the U.S.: 1-440-892-3336)
E-MAIL: Info@HealRelief.com

CoolSport
1880 W. Carson St. #F328
Torrance, CA 90501
Phone: 310.618.1590
www.remote-ability.com/staycool.htm
Send E-Mail to: ron@remote-ability.com

Barbosa Cool Products
1-800 445-0902
(214) 358-6857 | Fax (214) 351-7035
<http://www.barbosacoolproducts.com>

Glacier Tek
1-800-482-0533
P.O. Box 120642
West Melbourne, FL 32912-0642
Fax (321) 676-5950
Customer Service: info@glaciertek.com



MEMBERSHIPS & MEMORIALS

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.

MEMBERSHIPS

Christian & Mary Ellen Brent
Earnest & Doris Morrison
F.O. Kline
Richard & Vicki Case
Leonard & Marlene Rochwerger
Edward Kaps
Harry Henley
Ronald & Marilyn Kincaid
Mary LaMarra
Saleta Dilwood
Paul & Elizabeth Leatham
Ethel Brock
Lucille Middleton
James & Ruth Whitten
(Debbie Compton B-Day)

MEMORIALS

In Memory of Edward Flynn:

Maryann & Larry Perron
A.L. Amend
Kathryn Weil
Melanie Backman
John O'Hara
Kevin Kelly
Samuel & Margaret Swisher
Sally Boyle
Joseph & Albene Constance
Kenneth Perron
Carl & Julie Tierney
Lois Anderson
Ed Caliendo
Mary McCormack
Keith & Carol Pederson
Tsuneo Miyazuki
Sarah Dugan
Robert & Nancy Penner

In Memory of Jim Walker:

Jayne Korth

In Memory of Ruth Schwartz

Louis Bellotti

In Memory of William Douglass

Evelyn Wagner

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HONORARIUMS

David Potter (honor of Anna Potter)
Joseph Baldwin (honor of Lois Carter)

CIRCLE OF CHAMPIONS

ASL Hydraulic - Platinum
Trevor Lloyd - Silver
(*In memory of Marilyn Lloyd*)
Affiliated Neurologists – Bronze
Gordon & Marilyn Peters – Bronze
Robert Lee – Bronze
Robert & Phyllis Andersen - Bronze

LIFETIME MEMBERSHIPS

Ruth Goldberg
Gordon & Marilyn Peters
J. Clarke Stevens, MD
Cookie Shifris
Pat Hullinger
Joan Nolph

DONATIONS

Alex Haas
Roscoe Combs
Marcella Crane
Border Transport
Jim & Tammy Combz

CHAPTER SUPPORT

Valley of the Sun United Way
Gentiva Health Services

WALK A THON

Banner Health Arizona



SUPPORT GROUPS STATEWIDE

We would like to thank the Support Group Leaders that held their meetings this year and assisted the office in visits to ill patients, calls to new members as well as their monthly meetings! These are the meat and potatoes of our foundation. We LOVE YOU GUYS!

There will be no meetings at your local group during the summer due to the heat and vacations. However, that DOES NOT mean that you cannot contact your leaders or the chapter office. The office WILL be open and our compassionate care committee will help with your needs.

Starting in the fall there will be changes in our support groups. After many years and dedication, Dan Stringer has retired from leading the Scottsdale Support Group and has asked that someone take over his responsibilities. We are going to miss him tremendously as I know the people in his group will even more. IF there are any of you interested in helping in this area, please contact Vicki Case or Sonya Watkins.

We are also pleased to announce that we will be starting a Northern Arizona, Flagstaff Support Group chaired by Rachel Adams a local Flagstaff myasthenic and “Mrs. Flagstaff”. Look for an article and information in our next newsletter on Rachel and her dedication to MG.

Please remember to thank the following people for their dedication and hard work!

NORTHWEST VALLEY

Northwest Valley Support serves the following cities: El Mirage, Glendale, Peoria, Sun City, Sun City West, Surprise, West Phoenix and Youngtown. Meeting notifications will be sent to members of the Support Group. If you would like to attend these meetings, please contact **Vicki Case, (602) 285-1509**

CENTRAL VALLEY:

This group services the greater Metro Phoenix area. If you would like to attend these meetings, please contact **Vicki Case, (602) 285-1509**

EAST VALLEY

The East Valley Support group serves Apache Junction, Casa Grande, Chandler, Gilbert, Mesa, Tempe, and other East Valley communities. For further information, please contact **Dave and Ina Sue Shapiro (480) 895-9091 OR Peggy Marquard (480)461-8786.**

NORTH VALLEY

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. For further information, please contact **Dan Stringer, (480)941-1801**

TUCSON/SOUTHERN ARIZONA

The Tucson Area MG Support Group serves all of Tucson and surrounding areas. Call **Jan & Jim LoVecchio (520) 889-6910**

HELP LINE...PHONE FRIENDS TELEPHONE HELP LINE

If you are having some difficulties with MG or are newly diagnosed, maybe you are a loved one of a myasthenic and need some answers. For whatever reason, the following people have volunteered to be a phone friend and help with your question or need. Do not hesitate to call any of them....they are the greatest!



If you are interested in becoming a Phone Friend, please call the office as soon as possible and we will be happy to add your name!

Sonya & Greg Watkins	602-439-0663	Myasthenic/Husband	35-45
Vicki Case	602-285-1509	Myasthenic	35-45
Peggy Marquard	(480) 461-8786	Myasthenic	46-59
Jan & Jim LoVecchio (Tucson)	(520) 889-6910	Myasthenic & Husband	46-59
Trevor Lloyd	480-802-0730	Husband	60-70
Margo Weaver	(623) 933-7073	Myasthenic	60-70
Alex & Jo Haas	480-840-5502	Myasthenic/Wife	70-80
Ed Kaps	480-837-8728	Myasthenic	70-80

• **FUNDRAISER...**

SAPPHIRE NECKLACE RAFFLE...Tickets on Sale Now!A beautiful 79-carat faceted, rough multicolor sapphire beaded necklace has been donated to the AZMG chapter. It contains red, white, yellow, and blue sapphires with emeralds and the clasp is 14 kt. Gold. This same necklace has been sold in fine department stores for over \$1,000.00. The drawing will be held during the 2001 MG Walkathon in October (exact date TBA). You need not be present to win.

If you are capable of displaying a flyer at your place of business, church, anywhere and everywhere, or if you can sell raffle tickets, PLEASE contact the AZMG office. The tickets are being sold for just \$5.00 each, and unlimited quantities may be purchased.

In many workplaces across the state, fundraising campaigns are beginning for the United Way and the National Voluntary Health Agency. Donations made through an employer as payroll deductions can be designated to go the Arizona Chapter of the Myasthenia Gravis Foundation.

United Way and Combined Federal Campaigns

If you are a federal employee or have family members that are, please remember us in your Combined Federal Campaign through the National Voluntary Health Agency. The CFC code for Federal Government Employees is 0537 (this includes military).

If you are not a federal employee and would like to be a donor through the regular United Way Campaigns run through the state, our donor code is 2021.

If you have any additional questions, please do not hesitate to call or speak with the Human Resource department of the company your work for.

A special thank you in advance for remembering us!