A MESSAGE FROM THE PRESIDENT

By David Kohn

As I write this message today, I am thinking about our unsettled world—the terrorist attack in Paris, the terrible tragedy in San Bernardino. There are many things to learn from such horrific events, but for me it is to appreciate my life and the lives of the loved ones around me. I’m reminded that life can be taken away, with a blink of an eye, whether it is a terrorist bomb, a careless driver or a disease. While myasthenia gravis can be debilitating, due to an unforeseen bomb, a careless driver or a disease. While the terrorist attack in Paris, the terrible tragedy in San Bernardino.

I have hands-on experience treating myasthenia gravis and I have volunteered countless hours almost fifty years at the Foundation. For those who have attended our board meetings, the name of the world’s largest and foremost myasthenia gravis organization is familiar. I’m proud to say that it was not at the Commerce Casino. While after the terrorist attack in Paris, the terrible tragedy in San Bernardino.

In October of 2015, the Foundation had its semi-annual fall patient meeting at the Westin in Pasadena. Yes—it was in Pasadena and not at the Commerce Casino. While after the terrorist attack in Paris, the terrible tragedy in San Bernardino.

As such, if you have any ideas, feel free to contact me or our office anytime. Finally, please remember the Myasthenia Gravis Foundation of California when making your non-profit charitable contributions. Our organization appreciates your support, no matter how large your donation.

Yesterday, today and beyond

By Luis A. Chui, MD

Foundation of California. As a consequence of this achievement, the development of tests to detect antibody to AchR was introduced. Now and in the future, it is one of the most valuable diagnostic tests for MG.

Where do we stand today? Currently, we have made significant progress in broadening the diagnostic tools such as the development of newer antibodies like MuSK (Muscle specific kinase). This antibody is positive in about 40% of patients that have no negative antibody to acetylcholine receptors. An interesting observation is that patients that have MuSK positive antibody MG, have a complement clinical presentation. They have predominantly early bulbar symptoms (difficulty with speech and swallowing) been more common in female and they do not respond to thymectomy and cholinesterase inhibitors.

The main approach in the treatment of autoimmune MG is immunosuppression in combination with plasma exchange or immunomodulation with intravenous immunoglobulin is the accepted treatment.

Recently, the use of monoclonal antibody (Rituximab) targeting to B cells, is reported with very good results, especially in anti MuSK Ab. MG.

What is the future? The amount of research done in the past decades has increased significantly our knowledge and understanding of MG. Newer and novel mechanisms of treatment such as biologicals, induction of tolerance to AchR (T cell vaccination, vaccination with AchR epitopic domains of antigen specific), skeletal muscles activator and stem cell transplantation, especially in late onset severe MG.

In closing, we believe that the Myasthenia Gravis Foundation of California is committed to support further research, education and patient support in the future.

A NEW LOOK

The Myasthenia Gravis Foundation of California has launched its new website. It is still a work in progress and you may expect changes and additions to be made on an ongoing basis. Also, please feel free to visit our website or contact us if you have any suggestions or comments that may enhance this site, especially as an information resource for newly diagnosed MG patients.

You may visit our website at www.myasthenia.ca.org.
First symptoms occurred May of 2006 when I was camping in beautiful Yosemite. My body was feeling heavy and I was tired even though it wasn’t even 1:00 o’clock in the afternoon yet. I didn’t know what was going on (looking back I did have stress). Weeks later, on vacation in Las Vegas, I didn’t get enough rest and I was extremely tired. At a fair, the smell from the grill burned my eyes. I took a hot bath, got into bed and an unbelievable amount of perspiration just started pouring off of me. The next morning my eyes were stuck together, my brothers complained about my driving. Looking back, I now realize that my eyelids were drooping.

I used Echinacea because I was under stress (which stimulates the immune system, probably not a good thing for me at the time). My doctor thought I had a sinus infection and gave me an antibiotic which exacerbated my MG weakness. I got better. But a few days later, driving eastbound towards the sun, I was able to get to work but, once there, I started walking into walls. Another doctor thought I might have a viral and eye infection. She referred me to an ophthalmologist who wanted me to have an MRI. He thought something could be pressing against my brain stem or perhaps I might have had a stroke. The MRI was okay so he sent me to a neurologist. Initially, this doctor thought I might have Lyme disease because I had been around deer. Blood work revealed that my Acetylcholine Rec Binding was 1.5 H. I lost muscles tone in my arms and thighs, found it hard to eat, comb my hair and push up from sitting.

I got diagnosed on Halloween in 2006: myasthenia gravis. My aunt had myasthenia gravis. I started crying and asked the doctor to write the words down. I was prescribed pyridostigmine and a high dose of prednisone. Although I got better, I couldn’t sleep and needed sleeping pills. In December, I had double vision but my neurologist said I could drive to work but I took the train. I changed neurologists. My second opinion was in 2007 because I didn’t want to have this disease. That December, I experienced involuntary muscle movements and was diagnosed with dystonia in the summer of 2010. My double vision came back in May of 2012. I was taking pills with a form of magnesium in them (not good) but when I stopped taking them, my vision got better.

Between 2006 and 2012, I saw ten neurologists. In May of 2015, I started having blurred vision and double vision so my neurologist upped my pyridostigmine and prednisone. We discussed IVG and I attended a support meeting, sponsored by the MG Foundation, to learn more about this treatment. At the meeting, I picked up an MG Survival Guide, read and reread it. I learned to avoid chemical cleaning agents and so I stopped using them at home; my vision got better.

My suggestions to other patients - if you have problems, read and reread the MG Survival Guide, attend MG support group meetings to give and get support. Today, I’m doing awesome, thanks to a higher power and my medication. Thank you to the Myasthenia Gravis Foundation of California for what you are doing for us patients. It’s an honor to write this article for the MG News now in my ninth year of being diagnosed with MG, once again, at Halloween-time.
Back in the Fifties, when I was a little girl, my mother was frequently sick. When she started to use a wheelchair, she explained that she had a rare neuromuscular disorder called myasthenia gravis. She was twenty years old, I started to experience random weakness. I married at twenty-one back East who also had MG. How odd that such a rare disorder occurred twice in one family. Then odd became odder. When I was twenty years old, I started to experience weakness and worked out my medication. I was put in a hospital in a MG crisis. I was put in the hospital. The test results came back positive! My primary physician joked that he would have to find another patient for my MD. He spent a week in the hospital, given tube feeding. He has a positive attitude and a sense of humor. He is home now, trying to stabilize his Mestinon along with tube feeding. He has a positive attitude and a caretaker-wife with some MG background. Who would have thought? What are the odds?

At the end of those 17 years, I met and fell in love with my current husband. I was able to wean myself off Mestinon and became more physically active than I had ever been. Love made all things possible.

Today, my husband and I have been together for 30 years. He was always athletic, running, biking, skiing, hiking, lifting weights. He was a good catcher. Several months ago, he started slowing down a bit. Instead of riding his bike 30 miles, he rode 20. He had a cough for about a year, but it suddenly got worse and he started getting weaker and weaker.

In the last four months, he has been in the hospital three times. The doctors couldn’t figure out what was wrong. At the end of his second hospitalization, the hospitalist told my husband she wanted to test him for MG. My mouth fell open.

The test results came back positive! His primary physician joked that maybe MG was an STD. He put in referrals to see a neurologist. We had to wait too long for an appointment in spite of urgent calls. By the time we saw the neurologist, my husband was in crisis.

He spent a week in the hospital, given tube feeding. He has a positive attitude and a caretaker-wife with some MG background. Who would have thought? What are the odds?

Dr. Monica Roach

FALL MEETING

Forty-five MG patients and family members gathered at the Westin Hotel in Pasadena for the fall meeting held on Sunday, October 25, 2015. Dr. Tynonoo Cash, Neurologist and Assistant Professor at UC Irvine was the speaker and her topic was “Myasthenia Gravis: What’s New?” She began her presentation with an overview of MG, its history, who is most at risk for developing the disorder and symptoms. She went on to discuss the cause of the disease using a detailed diagram comparing the neuromuscular junction of a normal patient to one of an MG patient. Patients were deeply interested seeing what was occurring in their bodies on a cellular level. Dr. Cash then segued into a discussion of how MG could cause other autoimmune or non-immune disorders. She concluded her talk with updates on the disorder and ongoing research projects, highlighting the trials at UC Irvine. Ending her presentation, she opened the floor to questions. The meeting ended in tradition with a raffle drawing and refreshments.

MG TRAVEL TIPS

Here are a few traveling tips for those with MG to help make the trip safe and pleasurable.

1. Talk with your doctors: Discuss your medical condition and any possible risks or challenges.

2. Research your destination: Choose a destination you’ll be physically comfortable with; consider the level of planned activity and necessary access to venues; check on any local conditions that might present a risk; ascertain availability of MG knowledgeable medical assistance. Call the MG office before you leave for names of local knowledgeable doctors and hospitals. Browse the Internet for travel assistance to/in the planned locale.

3. Consider the stress of traveling: Plan accordingly. Be prepared. Buy your tickets in advance, arrange your ride to the airport or station, figure out what you’re going to pack, and arrange help with the luggage. There could be delays, missed connections, baggage to schlep, or long distances to walk. Schedule two hours between connecting flights. Request a bulkhead seat. Avoid waiting in lines – get ticket and boarding pass ahead of time. Pace yourself, plan activities at peak energy times, schedule downtime. Buy attractions tickets ahead of time that allow you to bypass long lines. Plan resting time on the day of arrival and the day of returning home. Travel with a companion who knows about and is understanding of your MG. Know your limitations and don’t be shy about communicating what you can and cannot do. Consider getting a handicapped placard for your car.

4. Getting around: Use handicap transport in airports; reserve wheelchairs and electric scooters at destinations; use luggage with wheels; arrange for pre-checking of luggage; use curbside check-in; pack as much as possible in checked luggage and carry on a lightweight carry-on; take extra cash to use for taxis and travel expenses to avoid more challenging transportation.

5. Medications: Always carry them in your carry-on; keep them in the original prescription bottles; carry extra meds in case you can’t get unexpected, necessary refills; carry some on daily excursions, keep them in a dark, cool, non-humid place. The Transportation Security Administration (TSA) requires travelers to inform TSA staff at the beginning of the security process if they are carrying liquid or injectable meds.

6. Documents to carry: Doctors’ notes/medical history; list of medications; allergy information; emergency wallet card; medical alert jewelry; a description of MG and what to do in a MG emergency to give to first responders and emergency room doctors; mustard phones; ‘in case of emergency’ phone numbers.

7. IVIG: Have a treatment a few days before leaving; have your neurologist help arrange treatments at your destination if needed.

8. Jet Lag: Drink plenty of water to stay hydrated, cut down on alcohol; eat light; nap. Ask your neurologist about taking any sleep aids. Be well rested before your MG travel.

9. Heat and Health Tips: Carry a battery-operated fan, take cool showers, use ice and a cool cloth on face, neck and pulse points. Avoid infections by washing hands frequently; using anti-microbial hand sanitizer; avoiding crowds and people coughing; and avoiding unclean places, tap water, and dirty toilet facilities. Consider drinking bottled water. Avoid to nausea and diarrhea flu-like symptoms quickly. Carry a first aid kit and insect repellant and use unscented make-up, soaps and deodorants.

10. Buy Travel Insurance: Make sure it covers pre-existing conditions, especially any costs for MG. Does it include trip cancellation and evacuation insurance?

11. Important websites:

- MG News & other publications.
- www.mg.org
- Myasthenia Gravis Foundation of California: All members receive a few complimentary issues of MG News and other publications.
- MG News & other publications.

- Watch for the 2016 Membership Drive starting August to December 31, 2016.
- Your membership provides patient services such as support groups, physician referral, MG clinic, drug bank, MG News & other publications.
- You have a chance to win the following Donated prizes:
  - $500 Cash
  - $250 Gasoline Gift Certificate
  - Ipod
  - $100 Target Gift Card

- Readers are encouraged to correspond directly with members of the Medical Advisory Board of the Myasthenia Gravis Foundation of California with respect to questions or comments related to MG.

- Please send your correspondence to the Myasthenia Gravis Foundation of California.

- All members receive a few complimentary issues of MG News and other publications.
GIFTS IN HONOR OF...

Sandra Archer  “Happy Holiday Season”  Nikki & Howard Applebaum
Mr. & Mrs. Gregory Kotanjian  “Happy Holiday Season”  Nikki & Howard Applebaum
Larry Lane on Father’s Day  Russell & Mindy Lane
Mr. & Mrs. Gary Friar & Family  Nikki & Howard Applebaum
“Happy Holiday Season”  Nikki & Howard Applebaum
Future Research & our Son The Hanchett Family
Brendan Johnson  Jeanne Legg
Dr. Bryne Kane  “Happy Holiday Season”  Nikki & Howard Applebaum
Mr. & Mrs. David Kohn  “Happy Holiday Season”  Nikki & Howard Applebaum

GIFTS IN MEMORY OF...

Norman R. Anderson  Beatrice Anderson
Toby Brown  Elizabeth Brown
Stella Christenson  Kathryn Lee
Margie DeVry  Bob & Sharon McClelland
Grace Ehrlich  Irwin Ehrlich
Michael Hannah  Paul Hannah
Gene King  Maxine King
Richard E. Lewis  Melissa Pungilin
Sandy Love  George Love & Children
Saundra Love  Valerie Morgan
Louis Powers Merrifield  William Merrifield
Mitch  Howard & Nikki Applebaum
Dr. Monica Roach  Myasthenia Gravis Foundation of California
David Kohn, President
Board of Directors & Staff

H O N O R  F U N D  A N D  M E M O R I A L S

TO HELP – OR TO BE HELPED

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YOUR SUPPORT AUXILIARIES

CENTRAL COAST
Chair: Vicky Dunven
EAST BAY/HAYWARD
Chair: Bob Boike
2016 Meetings – Aug. 7 & Nov. 6 at St. Rose Hospital, Hayward, CA. You will be notified by flyer.
FRESNO
Chair: Joy Kiser
2016 Meetings – MDA Office, Fresno Sept. 6
INLAND EMPIRE
Chair: Gail Myatt
Fall Meeting in October or November 2016 at Kaiser Hospital, Riverside, CA
You will be notified by flyer.
LANCASTER
No Chair
LOS ANGELES
No Chair
We are combining meetings at this time with San Fernando Valley Auxiliary.
You will be notified by flyer.
LAS VEGAS
Chair: Joan Silverstein, Co-Chair: Cindy Yurek
You will be notified by flyer every other month
ORANGE COUNTY
Chair: Lynne Krygier
PALM SPRINGS
No Chair

SACRAMENTO/STOCKTON
Chair: Joy Baird
2016 Meetings – July 16 & Oct. 15
You will be notified by flyer.
SAN DIEGO
Chair: Katie Boyer
You will be notified by flyer.
SAN FERNANDO VALLEY
Chair: Ed Cholakian
2016 Meetings – You will be notified by flyer.
SAN GABRIEL VALLEY
Chair: Marie Magrdchian
SANTA ROSA
Chair: Ron Crawford
SOUTH BAY/SAN JOSE
Chair: Terri Sessions
VENTURA
No Chair
We are combining meetings at this time with San Fernando Valley Auxiliary.
You will be notified by flyer
Plan to attend one of the Share groups located in your area. When you need to talk to someone who has MG, call the chair of your nearest group. Learn more about MG and share your experiences with other MG patients. Feel free to invite your spouse, family or friends to any of these meetings.

HAZEOU MOVED? – ARE YOU MOVING?

Please send your new address to:
Myasthenia Gravis Foundation of California
6055 E. Washington Blvd., Suite 350, Los Angeles, CA 90040

CONTRIBUTE VIA HONOR FUND AND MEMORIALS

Whenever a birth, birthday, anniversary, graduation, or any special event occurs, mark the event with a donation to the Myasthenia Gravis Foundation of California in the name of the honoree who will receive a beautiful card honoring the occasion.

And Speaking of Giving,

there’s another way: Via your Last Will and Testament and Trusts. Consult your lawyer and your accountant as to the various options you have to “do good” upon your death – lasting good to help pay for research, patient support, our Drug Bank, MG clinics, etc.

Be sure to specify the Myasthenia Gravis Foundation of California as the recipient of personal or real property or a share of your estate’s residue.