2018 Award Winners

Innovations in NM and EDX Science

Inside Look Into the AANEM Annual Meeting

Next Stop... Washington, DC!

Hani A. Kushlati, MD
AANEM Member
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ANNUAL MEETING
The AANEM Annual Meeting is the premier educational event for those involved in neuromuscular (NM) and electrodiagnostic (EDX) medicine. Members enjoy a substantial registration discount. The meeting is a mix of cutting-edge sessions and hands-on workshops from leading experts in neurology, PMR, and other disciplines. Attend to build professional relationships and keep current in your practice.

EDUCATION
Keep up-to-date in your practice and meet your education and maintenance of certification requirements with exclusive AANEM products developed by our experts.

NEWS SCIENCE EDITORIAL BOARD (NSEB)
The NSEB reviews more than 30 medical journals to identify important, newsworthy items in the field and summarizes pertinent manuscripts to share with AANEM colleagues. The NSEB consists of physicians from varied backgrounds, practice settings, etc.

MUSCLE & NERVE JOURNAL HIGHLIGHTS
*Muscle & Nerve* is a monthly, peer-reviewed, interdisciplinary publication of original scholarly contributions centered on studies of the muscle, the neuromuscular junction, and peripheral motor, sensory, and autonomic neurons.

MEMBERSHIP
As a member of AANEM, you are an important part of a prestigious community of healthcare professionals dedicated to strengthening the field of NM medicine and providing the highest quality patient care. AANEM provides you with the tools you need to stay current in your field such as access to relevant research and educational information and opportunities for networking and community-building across primary specialties.

FOUNDATION
The AANEM Foundation provides funds to help develop the next generation of researchers to advance the science and practice of NM and EDX medicine with the ultimate goal of improving the lives of patients with NM diseases.

ADVOCACY
AANEM’s advocacy efforts aim to improve the quality of patient care. We monitor state and federal issues, work to ensure appropriate reimbursement, create position statements to educate lawmakers and insurance companies, and fight against fraud and abuse.

PRACTICE
AANEM offers several resources to help you run your practice such as coding and billing information as well as details surrounding government healthcare programs and rules (MACRA, EHR, MIPS, PQRS, etc). AANEM also provides position statements on key topics and evidenced-based guidelines to help you deliver quality patient care.

PROFESSIONAL STANDARDS
AANEM’s Professional Standards department helps medical professionals attain and maintain certifications demonstrating knowledge in their field and commitment to patient care. This is achieved through preparation and successful completion of the American Board of Electrodiagnostic Medicine (ABEM) exam, maintaining certifications through continuing medical education, and the Maintenance of Certification Program (MOCP). Technologists may earn certification through successful completion of the Certified Nerve Conduction Technologist (CNCT) exam; there is also a process for CNCT certification maintenance. AANEM acknowledges laboratories for achieving and maintaining established levels of quality, performance, and professionalism through the EDX Laboratory Accreditation program.
This 84-page supplement to *Neurology Reviews* includes articles of clinical interest on a host of rare disease topics, including Batten disease, CTX, muscular dystrophy, Lennox-Gastaut syndrome, Huntington's disease, CADASIL, Hurler syndrome, and much more.
Summer will soon be coming to an end and autumn is just around the corner. And, you know what that means … it’s almost time for the AANEM Annual Meeting!

I hope you will join me this year in the Washington, DC area for the AANEM Annual Meeting taking place October 10-13, 2018, at the Gaylord National Resort & Convention Center. This facility is a magnificent waterfront resort located right on the Potomac River with plenty of entertainment nearby … not to mention its proximity to our nation’s capital and all the history that resides there. This fantastic location gives us the opportunity to bring in many of our colleagues from the FDA, NIH, and other DC centers to join us and share their expertise at our meeting.

I am excited about the educational content of this year’s meeting. We have brought back many of our popular sessions from previous meetings, but to keep things fresh, we have plenty of new topics to be covered, including 13 brand new workshop sessions (see the Annual Meeting pages of this issue for more information).

I have chosen Precision Medicine in Neuromuscular and Musculoskeletal Medicine as the plenary topic for the meeting. Precision Medicine takes into account the differences between individual patients and moves away from a ‘one-size-fits-all’ approach to medicine. It means looking at patients as individuals and finding treatments and prevention strategies that are more tailored to the patient. Our goal for the plenaries in 2018 is to help everyone apply this new method of looking at patients. See our exciting lineup of plenary speakers on the following page.

I know that socializing, networking, and having fun at the AANEM Annual Meeting is just as important as the educational content, so we have set aside plenty of time to ensure that happens. We also have interactive activities and events planned (like speed networking) to enable you to meet some new people.

The AANEM Annual Meeting is one I look forward to every year. It is a great time for collegiality and networking and the educational content is unmatched in quality. In my time at AANEM and at the AANEM Annual Meetings over the years, I’ve built many strong friendships and I’m eager to get to know even more of you. So, won’t you please join me in DC? It’s not too late to register. For more information, visit www.aanem.org/meeting.

Warm Regards,

[Signature]

ERIC J. SORENSON, MD, AANEM PRESIDENT
As chosen by Eric J. Sorenson, MD, AANEM President, the theme of the 2018 annual meeting is Precision Medicine in Neuromuscular and Musculoskeletal Medicine.

“For years, we have heard about coming therapies in neuromuscular medicine for untreatable diseases. The hope was always down the road. But now we are in an unprecedented era in medicine with the arrival and approval of a number of new therapeutics. This brings a whole new set of challenges that we are just starting to deal with as clinicians.

This is a fantastic opportunity to join our colleagues from across the country and beyond to discuss how we best meet our patients’ needs as we struggle with the implementation of precision medicine,” said Dr. Sorenson.

The plenary sessions at the meeting will also focus on this theme.

“The invited plenary speakers are worldwide leaders in the development of novel neuromuscular therapeutics and will share their expertise on how to translate this into clinical practice.

The speakers will address ethical questions on how to pay for medications and how to support our patients,” Dr. Sorenson continued.

ALS and Related NM Diseases in the Precision Medicine Era

Matthew B. Harms, MD
Associate Professor of Neurology
Department of Neurology
Columbia University

Orphan Drug Pricing – A View from the Trenches

A. Gordon Smith, MD
Chair of Neurology
Virginia Commonwealth University

FDA Regulation of Cell Therapy

Wilson W. Bryan, MD
Director, Office of Tissues & Advanced Therapies
Food and Drug Administration

RNA-targeted Mechanisms and Therapeutics for ALS

Timothy M. Miller, MD, PhD
David Clayson Professor of Neurology
Washington University

From Assessing Evidence to Determining a “Fair” Price: How Should the Value of New Treatments for NM Disorders be Evaluated?

Steven D. Pearson MD, MSc, FRCP
Founder & President of the Institute for Clinical and Economic Review
Department of Bioethics
National Institutes of Health

Precision Medicine Therapeutics in Duchenne Muscular Dystrophy: Dystrophin Restoration and Exercise Mimetics

Craig M. McDonald, MD
Professor & Chair
Department of Physical Medicine & Rehabilitation
University of California, Davis
Neurology, PMR, & Technologist Tracks at the Annual Meeting

There’s something for everyone at the 2018 AANEM Annual Meeting, but with so many options, it may be tough to decide which sessions to attend. Your annual meeting schedule can be customized however you’d like; but, if you need assistance, here are some of the top sessions by specialty:

**Neurologists**
- Diagnosis and Treatment Breakthroughs in Genetic Testing
- Effective Strategy Multidiscipline Clinic
- Emerging Therapies and Controversies
- Interactive Case Based Approach to Genetics and Neuropathology
- SMA Practical Issues

**PMR Physicians**
- Brain Computer Interface/Functional Recovery
- Exercise for NM Disease
- Neuroprosthetics
- US Assessment of MSK Mimics
- Use of Electrodiagnosis and US for Evaluation of Focal Neuropathies of the Upper Limb

**Technologists**
- Basic Nerve
- Basics With the Experts
- Demyelinating Neuropathies
- Entrapment Neuropathies
- Ethics

Special sessions are also being offered by the Hereditary Neuropathy Foundation, the Myasthenia Gravis Foundation of America, and the Peripheral Nerve Society. These sessions are open to all meeting attendees.

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**Speed Networking**

Looking for a fun, easy way to network at the AANEM Annual Meeting? Want to build connections with peers, leaders, and other professionals in NM and EDX medicine?

Register to attend our speed networking event on October 10 (space is limited).

Speed networkers will make approximately 10 - 11 connections during the session. Don’t forget your business cards!
13 New Workshops at the 2018 AANEM Annual Meeting!

AANEM is excited about the lineup of sessions planned for this year’s annual meeting, including 13 new workshops! Read about our new workshop offerings, make note of the ones that interest you, and register now before they fill up!

Due to the nature of workshop sessions (smaller, hands-on demonstrations), there is limited seating available. To keep general registration costs lower, workshop sessions are not included with the general registration fee. More information is available at www.aanem.org/meeting.

Back by Popular Demand!
After some time away from the AANEM Annual Meeting, these workshops are being offered again in 2018:

- Anatomy & Kinesiology of the Shoulder/Upper Limb
- Hands-on Practical Instrumentation
- Intraoperative Monitoring
- MUAP Quantitation
- NCS Basics
- Physical Exam of the Athlete: Cervical Spine and Upper Extremity
- Physical Exam of the Athlete: Lumbar Spine and Lower Extremity

1. **Blink Reflex**
   Faculty: Jun Kimura, MD

2. **Chemodenervation for Head and Neck Conditions: Dystonia, Sialorrhea, Migraine**
   Faculty: Atul T. Patel, MD, MHSA

   Faculty: Michael C. Munin, MD

4. **NM US Basic Lower Extremity**
   Faculty: Lester S. Duplechan, MD, and Sarada Sakamuri, MD

5. **Quantifying the NM Exam: QST Quantitative Sensory Testing Dynameters**
   Faculty: P. James B. Dyck, MD

6. **NM US Basic Upper Extremity**
   Faculty: Shawn Jorgenson, MD, and Elena Shanina, MD

7. **Sonographic Needle Guidance for Carpal Tunnel Injections**
   Faculty: Elena Shanina, MD

8. **US-Guided Treatment of Peripheral Mononeuropathies**
   Faculty: John W. Norbury, MD

9. **Tarsal Tunnel**
   Faculty: William L. Doss III, MD, MBA

10. **You Make the Call – NM Edition**
    Faculty: Mohamed Kazamel, MD

11. **Performing Arts Medicine**
    Faculty: Bonnie J. Weigert, MD

12. **Optimizing the Evaluation/Management of Peripheral Nerve Trauma: Multidisciplinary Approach**
    Faculty: Matthew E. Miller, MD, David E. Reece, DO, and Jonathan K. Smith, MD

    Faculty: Jeffrey A. Strakowski, MD
## Annual Meeting Registration Details

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<tr>
<td><strong>August 4 - September 25, 2018</strong></td>
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<td>Full Attendance</td>
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<tr>
<td>Technologists, Collaborators, Researchers</td>
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<td><strong>NONMEMBER</strong></td>
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<tr>
<td>Physicians</td>
<td>$500</td>
<td>$575</td>
</tr>
<tr>
<td>Residents &amp; Fellows</td>
<td>$375</td>
<td>$450</td>
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<tr>
<td>Technologists, Collaborators, Researchers</td>
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Guests registration is available for $25.

Register Online

www.aanem.org/register
$ave on Session Materials
Pre-order when you register for the meeting!

2018 Annual Meeting Collection
With so many great sessions being offered at the 2018 AANEM Annual Meeting, it would be impossible to attend every session in person. However, AANEM has a solution - the 2018 Annual Meeting Collection, a digital download of session presentations. The download will include many presentations and presenters’ commentary (as audio of most presentations will be recorded live at the meeting).

Purchasers of the 2018 Annual Meeting Collection will receive CME/CEUs for sessions in which CME/CEU was offered. The link to the digital download will be available approximately 2 weeks after the annual meeting.

Only $200
pre-order price with meeting registration before 9/25

$300 when purchased at the meeting
$450 AANEM member price after 10/13
$780 nonmember price after 10/13

$ave on Workshop Materials
Pre-order when you register for the meeting!

2018 Workshop E-Bundle
The 2018 AANEM Annual Meeting is offering a variety of workshops, including 13 that have never been offered before! Due to the nature of the workshop setting (e.g. hands-on demonstration session), AANEM encourages in-person attendance. However, if in-person attendance is not possible for all of the workshops you’re interested in, AANEM is offering the 2018 Annual Meeting Workshop E-Bundle.

Purchasers of this bundle will receive handouts from the workshops that utilize handouts (40 or more) via a single, downloadable PDF. These handouts contain the teaching points of the workshops.

Only $50
pre-order price with meeting registration before 9/25

$75 when purchased at the meeting
$100 AANEM member price after 10/13
$250 nonmember price after 10/13
Training Programs Enjoy Many Benefits of TPP!

When a training program joins the AANEM Training Program Partnership (TPP), the residents and fellows of that training program and the training program director receive a number of benefits. One of the best perks of joining the program is a significant discount on the AANEM Annual Meeting.

Beyond the annual meeting discount, residents and fellows in the TPP gain access to hundreds of AANEM learning materials. In addition to exclusive educational content, they receive free AANEM membership as well as other valuable member advantages such as discounts on educational products.

Have you heard the new TPP price for 2018-2019 is just $253? The low $253 joining fee enables an institution to enroll all residents and fellows in the neurology or PMR department. For further TPP details and to enroll, visit www.aanem.org/TPP.

TPP Questions? Contact AANEM at 507.288.0100.

“The University of Arizona Department of Neurology Clinical Neurophysiology Fellowship has been part of the TPP for 2 years now. The AANEM provides high quality, density rich knowledge for learners of all levels, serving as an excellent resource for our trainees. The TPP has benefitted our residents and fellows in the following ways: discounts to attend the annual meeting, free educational materials, and access to the services of the AANEM. I have also found the TPP useful for Program Directors as it connects us with one another and allows us to share resources and ideas.”

- Holli A. Horak, MD

TPP Annual Meeting Benefits

- 
  Residents/Fellows: The standard registration fee for each resident/fellow is only $160 (AANEM applies a $265 credit)
- 
  Program Directors: The standard registration fee for one program director is only $245 (AANEM applies a $455 credit)

Exclusive TPP Educational Content

Residents and fellows in the TPP have access to:
- 400+ materials in the Online Resource Library
- 400 knowledge assessment questions
- Challenging cases
- 10 case studies
- 9 oral cases
- Muscle & Nerve content
  - 22 Editor’s Choice articles
  - Dozens of Noteworthy Cases
- Self-study curriculum (addresses the ACGME milestones)
- Presentation: Value-based Genetic Testing in Muscle and Nerve Disease
- AANEM’s suggested reference list

Submitted by Shan (Sarah) Chen, MD, PhD  
Additional comments by David B. Rosenfield, MD

Contactin-associated protein-like 2 (CASPR2) is a neuronal adhesion molecule of the neurexin superfamily known to form a protein complex with shaker-type voltage-gated potassium channels such as Kv1.1 and Kv1.2. In fact, antibodies to VGKCC are not directed against Kv 1 channels, but to the complex.

Human autoantibodies to CASPR2 have been associated with neuromyotonia and Morvan’s syndrome. A common feature in these patients is neuropathic pain. However, the mechanism by which CASPR2 modulates nociceptive function is unknown.

Dawes and colleagues isolated CASPR2 autoantibodies from 2 patients with very high titers of CASPR2 IgG and injected them into healthy mice for 2 or 3 weeks. These mice had high CASPR2 titers at the end of the experiment and these antibodies were found mostly on the surface of sensory neurons, i.e., dorsal root ganglion (DRG), only some in the sciatic nerve, and none in spinal cord and they resulted in mechanical pain-related hypersensitivity in the absence of neural injury or overt inflammation.

Genetic knockout mice lacking CASPR2 (Cntnap2/-) demonstrated enhanced pain-related hypersensitivity to noxious mechanical stimuli and heat. They showed that both primary afferent excitability and subsequent nociceptive transmission within the dorsal horn were increased in Cntnap2/- mice.

They further demonstrated that CASPR2 regulates DRG excitability and membrane Kv1 channel expression at the soma membrane.

Dr. Chen’s Comments: Pain is one of the cardinal signs of inflammation. Increasing studies have been linking immune system to the pathogenesis of pain. Previously it was thought that autoantibodies cause tissue damage and inflammatory reactions.

This work showed that patient CASPR2-antibodies cause a loss of Kv1 channel membrane expression and hyperexcitability in DRG without nerve injuries or inflammatory responses. This is the first example of passive transfer of an autoimmune peripheral neuropathic pain disorder. This group further showed that either immune or genetic-mediated ablation of CASPR2 enhanced the excitability of DRG neurons in a cell-autonomous fashion through regulation of Kv1 channel expression at the soma membrane. Therefore, CASPR2 has a key role in regulating DRG excitability. Interestingly, CASPR2 mutations have been linked to autism spectrum disorders, in which sensory dysfunction is increasingly recognized. This work provides a rationale for testing CASPR2 antibodies in chronic pain patients and possible immunotherapy.

Also commented in “Autoantibodies Hurt: Transfer of Patient-Derived CASPR2 Antibodies Induces Neuropathic Pain in Mice” in the February 21, 2018 edition of *Neuron.*

Dr. Rosenfield’s Summary and Comments: All of us see patients with pain that is difficult to explain and treat. In this article in *Neuron,* the authors discuss that contactin-associated protein-like 2 (CASPR2) antibodies cause loss of Kv1 channel membrane expression and hyperexcitability in DRG without preexisting nerve injury or inflammation. These authors demonstrate in mice that one can passively transfer an autoimmune peripheral neuropathic disorder in which CASPR2 has an important role in regulating DRG excitability and posit that these antibodies might even have a role in autism spectrum disorders.

Submitted by David R. Mayans, MD  
Additional comments by David B. Rosenfield, MD

Over the last year, we have highlighted a couple of articles involving Nusinersen as a novel treatment for spinal muscular atrophy (SMA). Another trial has been completed and the data was shared in this article. The initial trial data involved children with SMA type 1 diagnosed within the first 2-6 months. This trial involved patients diagnosed with SMA with symptom onset after 6 months of age and their age at the onset of the trial between 2 and 12. There were a few exclusion criteria including the need for invasive or noninvasive ventilation, contractures, severe scoliosis, or gastric tube.

Patients were divided into two treatment groups, less than 6 years of age and older than 6 years of age. They were randomly assigned in a 2:1 fashion to treatment with Nusinersen versus sham procedure. Nusinersen was administered on days 1, 29, 85, and 274. Eighty-four were assigned to the Nusinersen group and 42 were in the control group. The patients were followed for 15 months. The primary endpoint of the study was a change in the Hammersmith Functional Motor Scale-Expanded (HFMSE). An interim analysis showed a significant improvement in the treatment group compared to placebo so the trial was terminated early. More than half of the treatment group had a clinically significant improvement in the HFMSE score while only 26% of the placebo group had improvements.

Dr. Mayans’ Comments: This is another study adding to the growing body of evidence that Nusinersen is effective at not only slowing the progression of SMA, but leading to improvements in strength and gain of function in SMA patients. While this may seem like “old news” due to the studies on younger kids over the last year, this study and treatment are truly groundbreaking in the treatment of this disease.

Dr. Rosenfield’s Summary and Comments: The authors of this article remind us of the complex nosology of small fiber neuropathy (SFN). They reviewed a large cohort of SFN patients and note that 43% had at least one of the following: autoimmune diseases; sodium channel mutations, diabetes mellitus including glucose intolerance, and vitamin B12 deficiencies were more prevalent than reported literature findings, followed by alcohol abuse, chemotherapy, monoclonal gammapathy of undetermined significance, and haemochromatosis. In patients who were already known with a possible underlying condition at screening, additional underlying conditions were still found in another 26.7% of patients.

Based on these results, it is recommended that patients with pure SFN are screened at least for autoimmune diseases, sodium channel gene mutations, diabetes mellitus including glucose intolerance, and vitamin B12 deficiency, even when they already have a potential underlying condition at referral.

Dr. Keole’s Comments: This study was interesting because it highlights the causes of SFN.

Dr. Rosenfield’s Summary and Comments: The authors of this article remind us of the complex nosology of small fiber neuropathy (SFN). They reviewed a large cohort of SFN patients and note that 43% had at least one of the following: autoimmune diseases; sodium channel mutations, diabetes, B-12 deficiencies, alcohol abuse, chemotherapy, monoclonal gammapathy of undetermined significance and haemochromatosis, reminding us once again that the underlying nosology of SFN is extensive.

Thank You to Our News Science Editorial Board Members!
Dr. Rosenfield's Summary and Comments: In 2016, Nusinersen (marketed as Spinraza) became the first medication FDA approved for treating SMA. The medicine is intrathecally administered to treat SMA with a mutation in SMN1. SMA is caused by loss of function mutation in the SMN1 gene which codes for survival motor neuron (SMN) protein. Patients survive due to low amounts of the SMN protein produced from the SMN2 gene. Nusinersen modulates alternate splicing of the SMN2 gene, functionally converting it into an SMN1 gene, thus increasing the level of SMN protein in the CNS.


Submitted by Leigh Maria K. Ramos-Platt, MD
Additional comments by David B. Rosenfield, MD

In 2004, a committee of experts in the treatment of SMA (the majority associated with 5q11.2-q13.3) created a task force. The result of their collaboration was the 2007 published SMA Standards of Care (SOC) document. The SMA SOC likely resulted in improvement of natural history in all SMA types. With the current research climate and the approval of Nusinersen in December 2016, the SMA community recognized the need for the SMA SOC document to be updated. Nine areas of SMA care were addressed:

1. Diagnosis and genetics
2. Physical therapy and rehabilitation
3. Orthopedic care, growth, and bone health
4. Nutrition
5. Pulmonary care
6. Acute care in the hospital setting
7. Other organ involvement
8. Medication
9. Ethics and palliative care

Part 1 of the updated set of guidelines was recently published. This first part addressed the first four areas of SMA care.

This document is quite detailed with references to other key manuscripts in SMA care. Highlights of the updated guidelines include:

1. Both SMN1 and SMN2 copy number should be assessed if there is clinical suspicion for SMA.
2. A multidisciplinary approach was identified as a key element in the management of SMA patients.
3. Physical assessments including a focused evaluation of the musculoskeletal system should be performed every 6 months.
4. Regular sessions of physical therapy are needed with specific goals based on the type of SMA and current clinical presentation of the patient.
5. Prolonged cast immobilization (>4 weeks) for long bone fractures should be avoided.
6. Nutrition discussions and interventions should include those targeting swallowing dysfunction/dysphagia, weight control, and gastrointestinal dysfunction. These topics as well as growth issues are best evaluated/discussed by a dietician and tailored based on the patient’s SMA type and current clinical presentation.

Dr. Ramos-Platt's Comments: The updated SMA SOC document is timely given the emerging publications of the results of landmark studies in the field. The full document can be found in the February 2018 issue of Neuromuscular Disorders.

Dr. Rosenfield's Summary and Comments: Mercuri et al (New Eng. J. Med., 378:625-35; 2018) extended clinical trials of Nusinersen beyond the previously established 2 to 6 months of age in patients: they treated young children with an average age of 3 years. Mercuri et al (Neuromuscular Disorders; 28: 103-115; 2018) review the “Diagnosis and Management of SMA, part 1” with data on how to treat these patients and possible side effects.
Don’t Miss These Popular Muscle & Nerve Articles!

Editorials Accompanying Manuscripts
Articles of particular importance are now often accompanied by editorials written by experts in the field.

June 2018:

Editorial - Quality measures: Do they measure up? By Sasa A. Zivkovic, MD, PhD, and Pushpa Narayanaswami, MD

June 2018:

Editorial - Magnetic resonance imaging in facioscapulohumeral muscular dystrophy by Doris G. Leung, MD, PhD

July 2018:

Editorial - Electrophysiologic lessons from the European multicenter study of Guillain-Barré syndrome subtype diagnosis by Richard A Lewis, MD

July 2018:
Manuscript – Calcium channel autoimmunity: Cerebellar ataxia and Lambert-Eaton syndrome coexisting by Zalewski N, Lennon VA, Pitttock SJ, McKeon A

Editorial - Lambert-Eaton myasthenic syndrome and cerebellar ataxia: Is response to immunotherapy a clue to pathogenesis? by Philip A. Ambrose, MBBS, MRCP, and Paul Maddison, MD, FRCP

July 2018:
Manuscript - Toenail mercury levels are associated with amyotrophic lateral sclerosis (ALS) risk by Andrew AS, Chen CY, Caller TA, Tandan R, Henegan PL, Jackson BP, et al.

Editorial - Mercury and motor neuron disease: Hooked on a hypothesis by Doreen T. Ho, MD, and James A. Russell, DO
Invited Reviews in June and July 2018 Issues

Almost every issue of *Muscle & Nerve* features at least one Invited Review. Members of AANEM can receive FREE CME CREDIT from selected Invited Reviews designated for credit by the AANEM.

**June 2018:** Chronic inflammatory demyelinating polyneuropathy and malignancy: A systematic review by Yusuf A. Rajabally, MD, FRCP, and Shahram Attarian, MD, PhD

**June 2018:** Local blood flow in peripheral nerves and their ganglia: Resurrecting key ideas around its measurement and significance by Douglas W. Zochodne, MD, FRCPC

**July 2018:** Neuromuscular complications of immune checkpoint inhibitor therapy by Noah A. Kolb, MD; Christopher R. Trevino MD; Waqar Waheed, MD; Fatemah Sobhani, MD; Kara K. Landry, MD; Alissa A. Thomas, MD; and Mike Hehir, MD (CME available)

New Fellow on the Editorial Board

Congratulations to Shannon LaBoy, MD, MS, who was selected to serve as the resident/fellow member on the *Muscle & Nerve* Editorial Board for 2018-2019. As part of this opportunity, Dr. LaBoy will learn to critically evaluate and review submitted manuscripts and become familiar with the workings of an academic journal. During the year, Dr. LaBoy will work with each of the journal’s associate editors and post information about journal articles on social media. Dr. LaBoy is a NM fellow at Vanderbilt University, having completed her neurology residency at the University of Florida.

“This will be an unparalleled opportunity for me as a young neurologist to receive guidance on how to critically evaluate manuscripts from different physicians across the country and from different programs. I’m looking forward to getting the behind the scenes glimpse into the work that goes into running a well-respected scientific journal. In the next year, I’d like to increase interest in *Muscle & Nerve* and neuromuscular medicine in general among residents.”
- Dr. LaBoy

The *Muscle & Nerve* Editorial Board would also like to thank Crystal J. J. Yeo, MB, BChir, PhD, MRCP(UK), who was the inaugural resident/fellow member to serve in this role for 2017-2018. Dr. Yeo recently completed her neurology residency at Houston Methodist Hospital, Texas Medical Center, and is now a NM fellow at the Partners/Harvard Program.

“It was a remarkable and rewarding experience working with and learning from the editors on the intricacies of the submission and peer review process. Another aspect of the job I enjoyed was working to enhance the discoverability and interest in journal articles by monitoring journal performance and using social media. It was a great educational experience and an excellent opportunity.”
- Dr. Yeo
Download the App!

Make room for one more app on your iPhone, iPad, and iPod Touch – the Muscle & Nerve app. Now, while on the go, it’s possible to stay current on studies of the muscle, the neuromuscular junction, peripheral nerves, neuromuscular disease, and novel treatments. All you have to do is download the Muscle & Nerve app onto your iOS device.

Current Muscle & Nerve subscribers may “pair” their iOS device with their personal or institutional subscription to enjoy full access of the app.

With the app, you:
- Are notified when a new issue is available
- Stay current with the latest articles through Early View
- May download articles and issues to review offline
- Can save favorite articles for quick and easy access
- May share articles with colleagues or students

To download the app, visit the iOS App Store.

AANEM’s Latest Podcasts

Looking for a new podcast?

The latest AANEM podcasts focus on articles covered in recent editions of Muscle & Nerve.

- Subcutaneous Versus Intravenous Immunoglobulin for Chronic Autoimmune Neuropathies: A Meta-analysis
- Complex and Simple Clinical Reaction Times are Associated With Gait, Balance, and Major Fall Injury in Older Subjects With Diabetic Peripheral Neuropathy
- The Value Transformation of Health Care: Impact on Neuromuscular and Electrodiagnostic Medicine

Find these and all AANEM podcasts at www.aanem.org/podcasts.

AANEM’s Ultra EMG Program

February 11-16, 2019 | San Diego, California

Enhance your knowledge of ultrasound and EMG!
Live demonstrations and practical skills sessions!
25+ CME credits!

Learn from leading experts:
Chair: Jeffrey A. Strakowski, MD
Katharine E. Aller, MD
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Registration opens in October 2018
www.aanem.org/ultraemg
The Lifetime Achievement Award is AANEM's highest honor, and for 2018, AANEM is proud to announce James A. Leonard, Jr., MD, as its recipient. This award recognizes an AANEM member who has been a major contributor in the fields of NM and EDX medicine through teaching, research, and scholarly publications.

Dr. Leonard says he went to medical school with the mindset that he was to become a pediatrician. However, physical medicine and rehabilitation (PMR) started to seep into his mind between his first and second year of medical school when he had an opportunity to participate in a 3-month research and clinical summer trainee program in the PMR department at the University of Michigan (UM).

"Following this summer experience, my intent was still to be a pediatrician. However, as I went through clinical rotations in my third and fourth years, I began working with patients who had considerable rehabilitation needs. I found that many of my medical colleagues did not see these needs or were not concerned about their patients' needs in this area," Dr. Leonard recalled.

That is when he began to see PMR as an attractive field of medicine.

"What I liked most was the fact that I would be able to follow my patients from cradle through adulthood to their passing from life … I have been privileged to provide care to many of my patients for the entirety or much of their lives, and in the process, have gotten to know their families, children, grandchildren, and great grandchildren." 

Dr. Leonard served in the military reserves for 17 years after active duty. His work rehabilitating military and civilian patients with amputations has earned him the reputation as one of the foremost authorities on the subject. He has coedited texts, written multiple works, given hundreds of lectures, presented

Continued on next page
at board review conferences, and participated in research. He has received multiple teaching awards from UM and has been the recipient of the Distinguished Clinician Award from the American Academy of Physical Medicine and Rehabilitation (AAPMR).

In addition to this work rehabilitating patients with limb loss, caring for patients with NM disease and peripheral nerve problems has always been a large part of his practice.

“The performance and teaching of electrodiagnostic medicine has always been a major part of my duties. I was an active faculty attending in our main EMG lab up until the time of my retirement sabbatical. Over the last decade of my active faculty career, I was associated with our multidisciplinary Pediatric/Adult Brachial Plexus and Peripheral Nerve Clinic being responsible for the electrodiagnostic studies as well as participating in the clinical evaluations and rehabilitation plans for many of these patients,” he said. “Now that I am officially retired and an Active Emeritus faculty member, I will continue to do some clinical care with Amputee Program and the Brachial Plexus and Peripheral Nerve Clinics as well as collaborating on various research projects. The fun is that I can now do this on my schedule.”

Working with patients has been and continues to be what Dr. Leonard enjoys most about his job.

“I have always thought of PMR as primary care for a special population of patients – individuals that often other colleagues feel uncomfortable working with because of their impairments. I have been privileged to be able to provide care to many of my patients for the entirety or much of their lives, and in the process, have gotten to know their families, children, grandchildren, and great grandchildren,” noted Dr. Leonard.

Dr. Leonard is excited about the significant recent technological advances in prosthetics to help improve the lives of amputee patients.

“The goal is to develop a prosthesis which will come as close as possible to replacing the function of the human limb. We are getting closer but still have a long way to go. I am very proud to be associated with a group of surgical, engineering, and other rehab colleagues that have developed some groundbreaking research toward developing a prosthesis which will ultimately be controlled through direct peripheral nerve interface. Spin off from this research work has led to successful new surgical techniques for controlling phantom pain and eliminating neuroma formation which has been a longstanding issue for many living with amputation.”

Dr. Leonard started his higher education at Maryknoll College in Illinois, then received a Bachelor of Science degree from the University of Detroit, followed by his medical degree from UM. He continued at UM for his residency in PMR serving as Chief Resident his final year. After his active duty in the military, Dr. Leonard returned to UM and worked his way up the ranks. He became a clinical professor and served as the PMR residency program director and then the PMR department chair, each for more than 10 years.

As for his participation in AANEM, Dr. Leonard went to his first AANEM Annual Meeting in 1975 as a senior resident and has been a member since 1976. He has held dozens of formal positions on committees and served as both AANEM President and the Chair of the American Board of Electrodiagnostic Medicine. Dr. Leonard was the Secretary Treasurer from 1990-1993 and served on the AANEM's Finance Committee from 1987 through 2018 and as the AANEM Historian from 2006-2015. He helped AANEM through name changes as well as fundamental changes in the organization's mission to grow from primarily an EDX medicine association to incorporate and embrace NM medicine. He was awarded with AANEM's Distinguished Physician Award in 2010.

AANEM thanks Dr. Leonard for his lifetime of dedication to medicine, teaching, research and service.

AANEM is honored to announce Yuen T. So, MD, PhD, as the recipient of the 2018 AANEM Distinguished Physician Award due to his contributions as a clinician and educator as well as his overall support of AANEM activities. Dr. So is a Professor of Neurology and Neurological Sciences at Stanford University. He has been on the AANEM Board of Directors since 2015. Prior to his participation on the AANEM Board, Dr. So was a member, chair, and co-chair of the AANEM Practice Issues Review Panel. He's been an AANEM member since 1988.

Dr. So became interested in NM and EDX medicine as an undergraduate student in electrical engineering. He had started working in a visual neurophysiological laboratory and said he was “fascinated by the electrophysiological underpinning of the nervous system.”

Continued on next page
“That’s what led me to neurology. During my neurology residency, I learned about the power of electrodiagnostic tools in making a clinical diagnosis, and I realized very quickly that was something I wanted to do,” Dr. So recalled.

“Compared to the central nervous system, the peripheral nervous system is more approachable and can be investigated with far greater precision. The history, physical examination, and the electrodiagnosis can be deployed to diagnose peripheral nervous system diseases very accurately. To me, it is absolutely satisfying,” he continued. “As I ventured further, I came to appreciate another merit of neuromuscular medicine: the field is remarkably diverse with a wide range of diseases. It never gets boring. I am constantly learning.”

Dr. So says that aside from patient care, teaching has been the most gratifying aspect of his career.

“Teaching and patient care go hand in hand. They make a routine clinic more fun and together they make me a better clinician,” he said.

Working with residents was of special importance to him. “Residents are smart, diligent, and eager to learn. They always asked tough questions and kept me on my toes. They probably taught me just as much as I taught them,” he said.

Dr. So says finding out he won the 2018 AANEM Distinguished Physician Award came as a “complete surprise.”

“Receiving this award is, without question, the most memorable career moment for me. I am deeply grateful to the AANEM Awards Committee and all of the years of support from the AANEM,” he said.

Dr. So has received many acknowledgements throughout his career. He has been included in multiple listings of top physicians, such as Best Doctors in America from Best Doctors, Inc., Top Physicians from Consumers’ Research Council of America, and San Francisco Magazine’s list of Top Bay Area Physicians. In 2015, he received the Association of American Medical Colleges (AAMC) Humanism in Medicine Award for his work at the Stanford University School of Medicine.

Dr. So has co-authored 78 peer-reviewed journal articles in publications such as Muscle & Nerve, Neurology, Annals of Neurology, as well as many others. Dr. So has also contributed to dozens of books and non-peer-reviewed publications on topics related to neuropathies, nutritional deficiencies, HIV infection, and the effects of toxins on the nervous system, among others.

Dr. So received his Bachelor of Science degree from Northwestern University. He later earned his doctor of philosophy from Rockefeller University and his medical degree from Yale University. Dr. So completed his residency in neurology and a fellowship in EMG and NM diseases at the University of California, San Francisco (UCSF).

Dr. So has been at Stanford University since 1999, where he is currently the Vice Chair of Clinical Services and Chief of the Neurology Clinics. During his first year at Stanford, he won the Lysia Forno Award for Teaching Excellence from the residents of the Department of Neurology and Neurosciences.

Prior to his work at Stanford, Dr. So worked at Oregon Health Science University (OHSU) as an Associate Professor of Neurology, Director of the Medical Student Clerkship, Director of the EMG Laboratory, and Co-Director of the Neuromuscular Program. In 1998, the residents of OHSU’s Department of Neurology voted him Most Outstanding Teacher.

Early in his career, Dr. So worked as the Director of the Clinical Neurophysiology Laboratory at San Francisco General Hospital and as Assistant Professor in Residence in Neurology at UCSF. In 1993, the residents of the Department of Neurology granted him the Golden Upgoing Toe Award for Most Outstanding Teacher.
AANEM is pleased to honor Ted M. Burns, MD, as the recipient of the 2018 Distinguished Researcher Award. Each year, this award is given to an AANEM member who has made significant research contributions in clinical neurophysiology and NM disease.

Clinical research — particularly research in the assessment and treatment of myasthenia gravis (MG) — has been a central part of Dr. Burns’ career. This focus led Dr. Burns to develop the MG Composite and MG Quality of Life scales which are recognized worldwide as the standard end-points for ongoing clinical trials.

“It bugged me a little that we had outcome measures that told us the myasthenia drug worked in a large clinical trial setting; however, many of these trial outcome measures were challenging to use in clinic settings, especially on an individual patient level,” said Dr. Burns. “One thing led to another, including a wonderful collaboration with Dr. Don Sanders, Mark Conaway, and many others, and we created outcome measures that I think are pretty useful in clinic. I especially like having an efficient, easy-to-use tool for estimating and understanding the quality of life of the MG patient… one that can parse out the different aspects of the patient’s struggle. It’s personally rewarding to know that others also find the outcome measures we created useful.”

Dr. Burns explains that the development of the MG scales led to a similar effort for chronic acquired polyneuropathy, resulting in the creation of a disease-specific quality of life measure (CAPPRI) for these patients.

“I’ve also been a patient, battling cancer on and off for 5+ years now,” explained Dr. Burns. “In fact, I developed chemo neuropathy back in 2013, so it’s been rewarding that I have also found the CAPPRI as an efficient way for me to convey my personal experience with chemo neuropathy. I really think these scales can be useful in conveying the patient struggle in an efficient, standardized way, and this can help clinicians better understand the true clinical status of the patient.”

Dr. Burns has been a member of AANEM for his entire career. One of the things he is most known for as a leader within AANEM is his innovative work in developing podcasts for the association. He created the AANEM podcast series in August 2006.

“At the time, I don’t think anyone was doing podcasting for medical education, so it was a way-out-there idea in early 2006. Remember iPhones didn’t yet exist. But it was too good of an idea to ignore and I could not get it out of my head, so I reached out to the AANEM,” Dr. Burns recalled. “I simply loved the idea of on-demand audio interviews with authors of recent peer-reviewed publications. It seemed perfect. When AANEM gave me the ‘green light,’ my first thought was, ‘Oh heck! What have I gotten myself into? I’ve never interviewed anyone in my life! This is going to be a disaster!’ But, we figured out what made the most sense, sorted out the technical questions, and started. It took a while for people to listen, but once they did and realized the value of it, it really caught on.”

Over the years, podcasts have become a vastly popular part of AANEM’s educational efforts. By 2015, Dr. Burns had produced more than 100 podcasts on various NM topics. He conducted more than 80% of the podcast interviews and served as chair of the AANEM Podcast Editorial Board. In 2007, he created the Neurology podcast series. Each podcast in this series has been downloaded thousands of times.

Dr. Burns grew up in a Kansas City suburb. He graduated from the University of Kansas with a bachelor’s degree and a medical degree; then, he completed a neurology residency as well as a clinical neurophysiology fellowship at the University of Virginia (UVA). Following that, Dr. Burns completed a fellowship in peripheral nerve disease at the Mayo Clinic in Rochester, Minnesota. He was a Senior Staff Neurologist at the Lahey Clinic in Boston and a member of the consulting staff at Boston Children’s Hospital for 2 years before joining the faculty at UVA. Dr. Burns is currently the Harrison Distinguished Teaching Professor in the Department of Neurology at UVA. He has served as the director of UVA’s residency and clinical neurophysiology training programs and his educational skills have been recognized at UVA through membership in the Academy of Distinguished Educators, the Dean’s Teaching Award of Excellence, and the Master Educator Award.
Due to his longstanding work advocating on behalf of EDX medicine, AANEM has selected Raghav Govindarajan, MD, as the recipient of the 2018 AANEM Advocacy Award.

Upon receiving this news, Dr. Govindarajan said, “This is the highlight of my career. I would like to thank the AANEM, its board, staff, and members for bestowing me this honor.”

Dr. Govindarajan explained that he began advocating for EDX medicine as a resident.

“It is up to us to maintain standards in our analysis and reporting and actively identify and report bad apples who are hurting EDX medicine and, more importantly, harming patients.”

Dr. Govindarajan sees advocacy as a continuum.

“It involves teaching and exposing learners to the fascinating world of EDX medicine, providing quality EDX care to patients, serving as a resource to referral providers, advocating at a grassroots level, and finally, advocating nationally.”

One of Dr. Govindarajan’s advocacy projects has involved working with private insurers to help curb the spread of mobile EDX labs in Missouri.

“One of Dr. Govindarajan’s advocacy projects has involved working with private insurers to help curb the spread of mobile EDX labs in Missouri.

“Working with private insurers has been a steep learning curve. It is very slow and frustrating with dead ends in many cases. However, persistence is the key. If you show up enough times, are pleasant, and have resources that can help them save money, they will eventually come around and listen. Missouri is the SHOW-ME state and I was eventually able to show the private payers the waste and, more importantly, the harm mobile labs were causing through various examples of studies I had collected.”

As a member of AANEM’s State Liaison Committee, Dr. Govindarajan has actively participated in AANEM’s “Day on Capitol Hill” for the last 4 years.

“AANEM Hill Day is one of the highlights of my AANEM membership. It was intimidating at first to go to Congress to advocate about EDX medicine, but with experience, it has become easy, satisfying and even fun,” he said. “Just a few years ago, the staff in Congress was not even aware of the existence of EDX medicine; now, they are becoming very aware of it and the issues plugging us. The AANEM staff has done tremendous work and thanks to the work of AANEM’s past presidents like Peter Grant, Vincent Tranchitella, and members like Mohammad Saeed and Ben Warfel, we have made significant headway.”

In addition to his participation in Hill Day, Dr. Govindarajan’s advocacy involvement has included serving as a speaker in the advocacy sessions at recent AANEM Annual Meetings.

“The AANEM Annual Meeting is the premier neuromuscular event in North America that attracts members from all over the country. I strongly feel that the meeting is the right venue to spread awareness about quality in EDX and highlight the advocacy work being done so members are aware of it and more members participate,” he noted.

Dr. Govindarajan completed his residency at the Cleveland Clinic and a NM fellowship at Washington University in St. Louis, Missouri. He is an Assistant Professor at the University of Missouri in the Clinical Neurophysiology department. He has been a member of AANEM for the last 5 years and has served on numerous AANEM committees. His past AANEM awards include the Best Abstract Award, the President’s Research Initiative Award, and the Residency and Fellowship Member Recognition Award.
The AANEM Awards Committee is pleased to announce Shirlyn A. Adkins, JD, as the recipient of the 2018 AANEM Distinguished Service Award based on her past, current, and future contributions to the missions of AANEM and the AANEM Foundation.

Adkins was hired at AANEM in 1993 as the administrative services manager and began serving as executive director in 1995, a position she still holds today.

Adkins says she’s seen quite a bit of change at AANEM over the past 25 years.

“When I first started, we only had one pharmaceutical company that exhibited at our annual meeting and everything else was EMG machines and supplies. The exhibit hall is very different today. The Foundation has become much more relevant in the last 5 years with all the changes we have made and I’m excited to watch it grow to the next level,” she said.

“Technology changes of course, have been huge. When I first started, we didn’t have a website, there was no social media, and I had to communicate with the Board and membership via the fax machine!”

Of all the projects and initiatives Adkins has spearheaded over the years, she is most proud of adding advocacy to the AANEM.

“I think we can make more of a difference to patients by funding more research. It is exciting to see new treatments being developed for patients with neuromuscular diseases,” she noted.

Adkins says there’s a lot to like about her job … perhaps that is why her career at AANEM has been so longstanding.

“There is always a new challenge ahead of me and I am constantly looking for the next great thing to move the organization forward. I enjoy the people I work with – the staff and the members. I have made lots of friends over the years through my work at AANEM. I also enjoy the freedom I have had to be able to try new things. The Board has always been supportive which has made my job easy,” she said.

Adkins earned a Bachelor’s of Business Administration from UW-Madison in 1987 and a Juris Doctor degree in 1990 from the University of Minnesota. She practiced law for 3 years before beginning her career at AANEM.

“Adkins has helped AANEM grow and evolve through a number of achievements over the past 2 decades. Some of these include:

- Maintaining the AANEM as a member responsive, efficient, financially sound organization
- Assisting the Board with strategic planning to expand the scope of the organization beyond EDX medicine
- Growing the AANEM and AANEM Foundation’s combined assets from about $1M to $13M
- Establishing the ABEM Maintenance of Certification Program and the CNCT examination
- Overseeing the creation of the EDX Laboratory Accreditation program

— Shirlyn A. Adkins, JD

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Member Spotlight

Featured on our front cover is Hani A. Kushlaf, MD. Dr. Kushlaf is an Associate Professor of Neurology and Pathology and Director of the Neuromuscular Medicine Fellowship at the University of Cincinnati in Ohio. Dr. Kushlaf received his certification from the American Board of Electrodiagnostic Medicine (ABEM) in 2013.

Since joining AANEM in 2008, Dr. Kushlaf has submitted 11 abstracts for the annual meeting. He received a Residency and Fellowship Member Recognition Award for his abstract in 2015 and was selected as a President's Research Initiative abstract award winner in 2017. For 2018, Dr. Kushlaf was involved as an author on the abstract that was the runner up for the Golseth Young Investigator Award.

Why did you join AANEM?
I believe it’s important to join the main organization that deals with one’s work. I have enjoyed and performed EMG for many years and rely on AANEM to provide advice, guidelines, etc. in the field of EMG and neuromuscular disorders. I have not been disappointed.

Can you tell me about your medical background?
I graduated from the University of Tripoli in Tripoli, Libya. I then finished neurology residency at the University of Kentucky followed by three fellowships in muscle disease and peripheral nerve disorders at the Mayo Clinic in Rochester, Minnesota, and an advanced neuromuscular medicine fellowship at Duke University.

Why did you join AANEM?
I was introduced to AANEM while training in residency at the University of Kentucky. I remember Dr. Kevin Nelson, who was the electromyography lab director at the University of Kentucky and AANEM treasurer at the time, telling me about AANEM and that I should join the AANEM if I wanted to pursue a career in neuromuscular medicine. I listened and have no regrets. I appreciate all the facets of professional development that AANEM offers.

Would you encourage others to join AANEM?
If your primary interest is electrodiagnosis and neuromuscular medicine, then I’d definitely encourage you to become a member. AANEM is a smaller organization than other large subspeciality organizations. You will find the AANEM Annual Meeting completely dedicated to your primary interest. AANEM membership also allows you to network and collaborate with neuromuscular experts.

You attended the 2017 AANEM Annual Meeting. What did you learn there that you applied in practice following the meeting?
I learned additional tips on performing neuromuscular ultrasound including easier ways of doing diaphragmatic ultrasound.

You are ABEM-certified. How can attending the AANEM Annual Meeting help those wishing to become ABEM-certified?
Attending the annual meeting reinforces the electrodiagnostic concepts tested on the ABEM exam. There are many sessions and workshops that help tremendously.

You’ve been to six annual meetings so far. What are you looking forward to at the 2018 AANEM Annual Meeting?
I’m looking forward to creating a schedule that helps me grasp the all-important updates in this field. I’m excited about the abstract sessions. I will participate in the meetings for the AANEM committees I belong to – the Neuromuscular Self-Assessment Exam Committee and the MOCP Exam Committee. I’m going to attend the Myasthenia Gravis Foundation of America session as I was recently elected to be a member of the Myasthenia Gravis Scientific/Advisory Board. Lastly, I’m looking forward to networking and staying in touch with my wonderful neuromuscular friends.
Golseth Young Investigator Award Winners

The Golseth Young Investigator Award, honoring AANEM Founding Member, Dr. James Golseth, is presented annually to a medical student or physician in the early stages of his/her career for original research in NM and EDX medicine. For 2018, a Golseth award winner and a runner-up were selected.

Winner: Katherine Clifford, BA
Title: Thymectomy is Not Associated With Clinical Improvement in a Multi-Center Cohort of Patients with Anti-MuSK Myasthenia Gravis

“My project investigates the impact of thymectomy as a treatment in anti-muscle-specific kinase (MuSK) myasthenia gravis (MG). I analyzed data from a pre-existing dataset from a multi-center cohort of patients with anti-MuSK MG in order to evaluate clinical outcomes in patients treated with thymectomy compared to those not treated with thymectomy. We did not find thymectomy to be associated with a greater likelihood of a favorable clinical outcome in anti-MuSK MG,” explained Clifford.

“I could not be more thrilled to receive this prestigious award. I would like to thank my research mentor, Dr. Michael Hehir, as his mentorship was instrumental to my success. Winning this award is also a testament to our multi-center collaboration, and I would like to acknowledge all of our co-authors for making this project possible.”

Clifford says she hopes her research will have an impact on guiding clinical decision-making and therapeutic management for patients with this rare subtype of MG. She is looking forward to presenting her research at the 2018 AANEM Annual Meeting as well as “learning about ongoing research from experts in the field of neuromuscular medicine.”

Clifford says it is an honor to have her research recognized by the AANEM.

Clifford is a fourth year medical student at the University of Vermont Larner College of Medicine and will graduate in May 2019. She is applying to a neurology residency program and will be pursuing a clinical and research career in neurology.

Runner-up: Long Davalos, MD
Title: Erythromelalgia and Sensory Neuropathy in Autoimmune Hepatitis: A Case Study

“I was very excited and confused at the same time when I found out I was selected for the Golseth Young Investigator runner-up award,” said Dr. Davalos. “I never thought I would win the award, so I had to double-check my email.”

Regarding his abstract: “This case was about a patient who was diagnosed with autoimmune hepatitis and concomitantly presented sensory neuropathic symptoms and erythromelalgia. Based on the progression of the disease, and further testing, it seemed that the neurological findings had an autoimmune component,” he explained. “We submitted this case because, to my knowledge, it was not previously reported. Additionally, we wanted to make physicians aware of this potential association, so treatment can be directed into controlling this autoimmune response.”

Dr. Davalos is Peruvian and graduated from medical school at Universidad Peruana Cayetano Heredia. He is currently a neurology resident at the University of Cincinnati and is planning to start his NM fellowship in July 2019.
Best Abstract Award Winners

One abstract is chosen each year to receive the AANEM Best Abstract Award honor; however, for 2018, a runner-up was also selected.

Winner: Goran Rakocevic, MD
Title: Quantitative Clinical and Autoimmune Assessments in Stiff Person Syndrome: Evidence for a Progressive Disorder

Dr. Rakocevic said he submitted his research to the AANEM Annual Meeting because “AANEM is the most appropriate venue for neuromuscular medicine practitioners.” He is looking forward to the 2018 annual meeting to “learn about updated practice parameters in neuromuscular medicine including recent research efforts.”

He also appreciates the time to interact with his colleagues and friends from different institutions and countries.

When he found out he was receiving the AANEM Best Abstract Award, Dr. Rakocevic said, “I was and still am pleasantly surprised. Every opportunity to present research and exchange ideas at the AANEM Annual Meeting is a rewarding experience and privilege in itself.”

Dr. Rakocevic works at Thomas Jefferson University in Philadelphia, Pennsylvania as an Associate Professor of Neurology, Director of the Neuromuscular EDX Laboratory, Clinical Director of the Jefferson Weinberg ALS Center, and Director of the NM Fellowship Program.

“Stiff Person Syndrome is a rare yet fascinating neurological disorder rich in symptomatology and manifestations, a challenge to study in a systematic and longitudinal fashion in one center because of its disabling nature over time. The highlight of our abstract is the evidence for faster progression of disablement than originally reported and believed.”

Runner-up: Shruti Raja, MD
Title: Validation of the Triple Timed Up-and-Go Test for Clinical Assessment in Lambert-Eaton Myasthenia Patients

Dr. Raja’s research focused on assessment of Lambert-Eaton Myasthenic Syndrome (LEMS) and was sponsored by the AANEM Foundation through a Clinical Research Fellowship Award in Autoimmune Neuromuscular Disorders.

“The abstract and project overall sought to validate a variant of the functional mobility ‘get up and go’ test that has been used in geriatrics, orthopedics, and in some neurologic conditions but not in neuromuscular conditions. For the project, I wanted establish that the 3TUG, a variant of this test, can be used to assess LEMS patients. To accomplish this task, I looked at several different aspects of the 3TUG—reproducibility in LEMS patients, construct validity and correlation with patient and physician assessments of disease severity using data from the recently published DAPPER trial of 3,4-diaminopyridine free base in LEMS patients. We found that the 3TUG test is reproducible, has construct validity based on correlation with Lower Extremity Functional Scores, and is responsive to changes in a patient-reported weakness scale and a physician assessment. We also evaluated the relationship with other outcomes from the DAPPER trial, but these correlations were not significant. Overall, when combined with the prior demonstration of the 3TUG’s reliability, the findings indicate the 3TUG is a valid tool for assessing disease severity in LEMS patients. The 3TUG also requires little additional equipment, making it a very practical tool for assessing LEMS patients.”

“I was quite surprised because I did not expect there would be so much interest in this rare condition. After the initial surprise, I felt like the recognition would really help advance the field because we really don’t have a practical way to assess LEMS patients and how they are doing other than self-reporting and physician assessment which may not capture all of the functional limitations of the condition.”

Dr. Raja graduated from Emory University with a Bachelor of Science in biology and from medical school at Jefferson Medical College of Thomas Jefferson University in Philadelphia, Pennsylvania. She completed a residency in adult neurology at the University of Maryland Medical Center and then relocated to Duke University for a fellowship in NM medicine. In 2016, Dr. Raja began a drug development fellowship and a Masters in Health Sciences (MHS) in Clinical Research through the Duke-NIH Clinical Research Training Program. She earned her MHS degree in May 2018. Dr. Raja will continue at Duke as an Assistant Professor in the NM Division of the Department of Neurology.
Technologist Member Recognition Award Winners

The AANEM Technologist Member Recognition Award encourages technologists to take a leading role in conducting research in NM and EDX medicine. Technologists can receive this award for being the first and presenting author of an accepted abstract at the AANEM Annual Meeting. For 2018, two individuals were selected to receive this award (one as a runner-up); both will receive a $200 cash award and will have their abstract published in *Muscle & Nerve*.

**Winner: Favio C. Bumanlag, BA**

Title: Clinical, Laboratory and Electrodiagnostic Features of Zinc Deficiency-induced Peripheral Neuropathy

Bumanlag says he felt “humbled and honored to be recognized” to receive the 2018 Technologist Member Recognition Award. Bumanlag's research focused on zinc deficiency induced peripheral neuropathy.

Bumanlag is looking forward to attending the annual meeting to discuss his research and “gathering more input and opinions on this topic from members attending the poster board presentations.” He is also excited about meeting AANEM members and attending sessions on EDX testing.

Bumanlag works in the Department of Neurology as the chief technologist at the Lewis Katz School of Medicine at Temple University in Philadelphia, Pennsylvania. Prior to his work as a technologist, Bumanlag worked as a high school physics teacher after having completed his bachelor's degree and graduate school in Manila, Philippines. Bumanlag has been an active member of AANEM since 2010. He was also the recipient of AANEM's Technologist Member Recognition Award in 2016.

“Zinc, an essential trace element, plays a critical role in maintaining normal structural and functional conditions in the body. Peripheral nerves are susceptible to damage when zinc deficiency occurs. There isn’t much literature written about zinc deficiency induced peripheral neuropathy and recognition of it will help physicians and technologists effectively manage patients.”

**Runner-up: Ali Arvantaj, CAP**

Title: Agarose Based Acetylcholine Reduces Quantitative Sudomotor Axon Reflex Test’s (QSART) False Positives

Arvantaj’s research focused on false positives on the QSART test.

“There are two ways to perform QSART. The first way involves using liquid acetylcholine (ACh); the second involves using agarose gel based ACh. Most labs use the first approach, liquid ACh, as it is easier to make. The second approach, making agarose gel based ACh, is more difficult as it requires special lab equipment and training. However, when an autonomic laboratory is equipped with the technology to make agarose gel based ACh, it not only makes the technical aspect of performing the QSART easier for the technologists (no leaks, possibility of placing the capsules very distal on the limbs) but also reduces the false positives of the test. In our study, we showed that using agarose gel reduced the technical difficulties of performing the test and therefore significantly reduced the number of false positives,” Arvantaj explained.

“This presentation would not exist without the help of my co-authors and continuous support of Dr. Bashar Katirji,” said Arvantaj. “Additionally, as someone who is involved with both EMG and autonomic testing, I cannot think of a finer journal than *Muscle & Nerve* for publication of this abstract.”

Arvantaj continued by saying that the AANEM Annual Meeting is “the ideal venue to present our team’s work while learning from pioneers in our field.” He considers the meeting to be “one of the most prestigious neuromuscular assemblies” and is looking forward seeing all of the research presented at the abstract poster sessions.

Arvantaj works as a lead autonomic technologist at University Hospitals Cleveland Medical Center in Cleveland, Ohio.
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AANEM Foundation International Fellowship and IFCN Award Recipients

The AANEM Foundation International Fellowship Award provides an opportunity for physicians who practice in economically developing countries to apply for funds to support their education through attendance at the AANEM Annual Meeting. Approximately 5 International Fellowship Awards are granted annually (there are 6 winners in 2018). All applicants are also automatically considered for awards funded by the North American Chapter of the International Federation of Clinical Neurophysiology (IFCN).

AANEM Foundation International Fellowship Award Winners
Fabio Barroso, MD, Argentina
Otto J. Hernandez Fustes, MD, MSc, Brazil
Naglaa A. Gadallah, MD, Egypt
Nina Khizanishvili, MD, Georgia
Mrinal Kumar Acharya, MBBS, MD, India
Pradnya Dhargave, MD, India

IFCN Award Winners
Rajeev Ojha, MD, DM, Nepal
José M. Crespo, MD, Argentina
Oksana Haiko, MD, PhD, Ukraine
Juan Ignacio Lopez, MD, Argentina
Sergio Morales, MD, Argentina
Fatima Pantiu, MD, Argentina
Wagner Cavalcante, MD, Brazil
Dong Zhang, MD, China
Thomas Torres Cuenca, MD, Columbia
Haiden Pérez, MD, Columbia
Joel V. Gutiérrez, MD, PhD, Cuba
Hala Elhabashy, MD, Egypt
Abeer A. El-Zohiery, MD, Egypt
Maha Ibrahim, PhD, Pakistan
Sarah Siddiqui, MBBS, FCPS, MRCP, Pakistan
Ahmad Wali, MD, FCPS, DABCN, Pakistan
Ma Luisa Gwenn F. Pabellano-Tiongson, MD, Philippines
Dong Hwee Kim, MD, PhD, Republic of Korea
Je-Sang Lee, MD, Republic of Korea
MinKyun Sohn, MD, Republic of Korea
Albina Tretiakova, PhD, Dsc, Ukraine
Myat Thura, MBBS, MD, United Kingdom

President’s Research Initiative Award Recipients

For 2018, Eric J. Sorenson, MD, AANEM President, chose Precision Medicine in neuromuscular and musculoskeletal Medicine as his topic for research for the AANEM Annual Meeting. Abstracts submitted on this topic are automatically considered for the President’s Research Initiative Award; however, only 10 abstracts or fewer are chosen to receive this honor. In addition to receiving recognition at the annual meeting, winners of this award each receive $500 cash and have their abstract published in Muscle & Nerve.

2018 President’s Research Initiative Award Winners
Ryan Castoro, DO, MS
Naglaa A. Gadallah, MD
Anza B. Memon, MD
James Nussbaum, PT, PhD, SCS, EMT
Bhaskar Roy, MD, MMST
Hui Yang, PhD

Residency and Fellowship Member Award Recipients

The AANEM Residency and Fellowship Member Award encourages young physician members to conduct research in NM and EDX medicine. The awards are given to AANEM members currently enrolled in residency or fellowship programs. Those who are the first and presenting author of an accepted abstract for the annual meeting receive a $200 cash reward.

2018 Residency and Fellowship Member Award Winners
Samah Aburahma, MD
Yasir Al-Khalili, MD
Tristin Allen-Jouaibi, MD
Bethany A. Calabrese, DO
Bei Cao, MD
Ryan Castoro, DO, MS
Cesar A. Colasante, MD
Mathieu Cuchanski, DO
Long Davalos, MD
Marine Didelez, MD, PhD
Behzad Elahi, MD, PhD
Obel-Aiyoua Irumudomon, MD
William Jens, DO
Stacy Jordan, DO
Ehtesham Khalid, MD, MRCP, FCPS
Nikolai Khromouchkine, MD
Tiffany Lee, MD
Mary McClanahan, MD
Gabrielle Nguyen, MD
Shruti Raja, MD
Gregory Robbins, MD
Conor Ryan, MD
Nirav Sanghani, MD, DM
Shuja Sheikh, MD
Adnan Solaiman, MD
Thomas Torres Cuenca, MD
Rocio Vazquez Do Campo, MD
Stefanie Wolf, MD
Chelsea Zale, DO
Silent Auction Donations Needed

Want to help raise money for the AANEM Foundation for Research & Education? Then, consider donating an item to the silent auction at the AANEM Annual Meeting. Popular items donated in the past have included vacation getaways, jewelry, artwork, autographed textbooks, and electronics. To donate a silent auction item, visit www.aanemfoundation.org/donate/silent-auction-donations or email foundation@aanem.org. The fair market value of all auction donations is tax deductible to the extent of the law.

Don’t have an item to donate? Then, be sure to check out the silent auction at this year’s meeting in Washington, DC, and bid on items that interest you. Your money will go toward a good cause – research grants and awards given by the foundation to help find treatments and cures for NM diseases.

One of our exciting donations for 2018 comes from Cadwell Industries, Inc. It’s the Cadwell Sierra Summit Two-Channel EMG/NCS system (List Price: $27,354) which includes:

- A fully loaded software package with all NCS and EMG protocols including Blink, RNS, SFEMG, MUNE, Auto MUP Analysis, Interference Pattern analysis, Autonomic testing and more.
- An Integrated Ultrasound software license (Ultrasound hardware not included).
- Portable configuration with laptop and roller bag.

Come prepared to bid on this Cadwell EMG/NCS system and other amazing items!

Not interested in the silent auction? Your direct donation to the AANEM Foundation for Research & Education can be made online at any time at www.aanemfoundation.org/donate.

Looking for Research Funding?

Learn more about research funding opportunities from the AANEM Foundation: www.aanemfoundation.org/Research.
Taylor’s Many Blessings in Life: Faith, Family, Friends, Hockey, and Myasthenia Gravis

For Taylor Williamson, life is centered on her strong circle of family and friends as well as her Christian faith. Just 21-years-old with one year left of college, Taylor already has many achievements for which to be proud.

The girl who first skated at 11-months-old is now a Division I athlete, having played 3 seasons on the women's hockey team at the University of Minnesota. In 2016, Taylor's life was at an all-time high, as she helped her Golden Gopher team win the national women's hockey championship.

But in February 2017, things began to feel out of sorts for Taylor.

"From time to time, I started noticing inconsistency when I was speaking. I wasn't sure why it was happening, but it was embarrassing, frustrating, and really concerning. I thought the speaking issue would subside, but then I started experiencing some facial problems … mainly my inability to smile," said Taylor.

Taylor next noticed a difficulty in chewing and swallowing food. Then came the muscle weakness.

"When I started having a droopy left eye, I became very concerned. However, out of all those symptoms, my slurred speech happened the most. The most frustrating part of it all was having a difficult time getting normal words out of my mouth," Taylor recalled.

It took a few months, but eventually Taylor found the strength to tell her parents.

"After telling them, within 12 hours, we had scheduled a visit to see a doctor. At that appointment, my speech really came crashing down and they immediately scheduled an MRI where they found a mass in my brain."

One day later, Taylor was admitted to the hospital for emergency brain surgery.

"We all thought this was the reason behind my symptoms and the outlook was positive. Brain surgery obviously takes a toll on a person’s body, but it seemed to have solved my speech issue -- for the time being," she said.

Taylor was cleared to begin physical activity again in June 2017. That summer, Taylor was training her hardest to get her mind and body back to the level needed to compete with her teammates -- some of the best women's hockey players in the world.

"As the summer of 2017 wore on, my family and I noticed my slurred speech creeping back. Concerned, I went back to my neurosurgeon, who called for another MRI. But, there was nothing alarming on the scans. In his words, my brain was 'pristine.'"

Relieved, Taylor continued along with her training regimen. It was in late August 2017 when Taylor noticed a significant decline in her athletic performance.

"My muscles would fatigue extremely quickly when skating. My stick handling skills had regressed to the point where I could barely hold onto my stick. On top of that, my shot was alarmingly weak and I could hardly keep up with my teammates."

Beyond the athletic decline, Taylor's inability to communicate was becoming more of a challenge and she could barely chew or swallow her food.

"To cap things off, there would be times where I could hardly put my hair up in a ponytail because my arms were so weak."

The doctors kept telling Taylor it could take 6 months to a year to fully recover from brain surgery and that the symptoms should subside. So, Taylor decided to forge ahead. She made it through summer training camp and told herself she would play in the season opener on September 29, 2017, to see how her body would perform in an actual hockey game.

"That game was the beginning of the end and all five symptoms locked me down midway through the second period. I pulled myself from the game and everyone could tell something was very wrong."

Taylor spent that night in the ER. A number of doctors examined her to determine what was going on.

"It was a resident on call that had a hunch it was myasthenia gravis. He wanted to run a test to see if this rare disease was causing my problems," Taylor recalled.

The resident had to consult his attending physician before they could complete any NM autoimmune tests. A couple of hours later, the resident returned saying his attending physician didn't think the myasthenia gravis test was necessary.

But Taylor trusted this resident's hunch. She told him to run the blood test anyway.

"He ordered the labs which ended up changing my life forever," she said.

At the end of that week, the attending physician who initially said there was no chance Taylor had MG, called Taylor to inform her that she had, in fact, tested positive for it.

"At that point, my dad and I reached out to a Myasthenia Gravis group in Minnesota for advice and direction. They
had given us three recommendations for neurologists."

They ended up selecting Guarav K. Guliani, MD, a neurologist in St. Paul, Minnesota, and member of the American Association of Neuromuscular & Electromyotaxic Medicine (AANEM).

“It was Dr. Guliani who ultimately diagnosed me with generalized MG,” noted Taylor.

MG is a disorder causing weakness and easy fatigue of voluntary muscles. It is caused by a breakdown in the communication between nerves and muscles, usually because of an immunological problem. Early symptoms include eyelid drooping, double vision, weakness of the face, swallowing, chewing, and weakness of the limbs. Anyone can get MG, but women are more likely to have it.

After receiving the diagnosis, Taylor says she was in complete shock.

“I immediately called my mom not knowing what to do or think. She was in just as much shock as I was, but then said to me: ‘You know what T? At least we have an answer!’ My mom was exactly right. There was no mystery anymore, and for that, I was so thankful.”

Taylor explains that in that moment, God had presented her an answer to so many prayers.

“I was introduced to a new obstacle that is arguably the toughest challenge I have gone through in my entire life. All I focused on from that point forward was having faith, staying positive, and taking this scary and difficult battle day by day.”

One of the hardest parts for Taylor was being unable to play the sport she loves so dearly.

“I was out of competitive hockey starting on September 29, 2017. There is no question that sitting in that press box during games was miserable, but I relied on my faith that God has a path and was determined to stay positive and strong for my family and friends. Sure, I was battling a disease, but I kept thinking that there are a lot of other people dealing with worse things than me.”

After being out of hockey for nearly 3 months, Taylor laced up her skates again on Christmas Eve 2017.

“Just like my dad said to me when I first found out I had MG, these diseases cannot and will not control us. We will control them.”

To treat her MG, Taylor takes 3 different types of medication: Pyridostigmine, Prednisone, and Azathioprine. She visits Dr. Guliani every 6 weeks to complete muscle and blood tests and discuss how she’s feeling on her medication.

Taylor has not been alone on her MG journey and says she is thankful for her strong support system.

“I can honestly say I don’t think there are many families these days that would have handled this experience as well as my family has. My friends have also been incredible. Whether we were at the rink or at home, they always managed to get the biggest smile on my face and make me laugh so hard that I no longer remembered the challenges I was facing in life. I am so blessed for each person that has been there and supported me. It’s hard to find words to say how thankful I am.”

Taylor is very passionate about ensuring there is continued funding for scientific research in NM and MSK diseases.

“The first reason continued research is needed is because there is no clearly listed cure for MG. People with MG and other...”

Continued on next page
NM diseases have amazing goals and aspirations for their lives and the thought of letting those goals go unachieved because of the lack of research crushes me.”

Taylor says any donation can go a long way.

“Your donation could be the difference maker for some kid’s life that still has their whole future ahead of them.”

Taylor has 1 year left at the University of Minnesota and is unsure of what’s to come after graduation. She says one of her future goals will involve getting the word out about NM disease research and funding.

Many people would not consider a disease a blessing, but for Taylor, MG has been one of the biggest blessings in her life.

“It has made me a better person, given me a new perspective on life, and opened so many doors for me to help and meet new people.”

Meet James Higginson: Award-Winning Artist and Guillain-Barré Syndrome Survivor

Photographer/director/artist, James Higginson, has accomplished much in his 60 years. Among his numerous accolades, he has received an Emmy Award for his set decoration work on the 1980’s show “Pee-Wee’s Playhouse,” international film festival awards for his 2012 feature length experimental art film, “Willful Blindness,” and completed a new documentary, “Devout.” James was hoping to release his documentary in 2017, but in September 2017, while working on house renovations, his hands and feet went numb.

“I thought this was weird, but I chalked it up to being 60-years-old and working like a dog doing reconstruction as though I was 20-years-old,” said James.

James noted that over the course of the next 4 days, his legs and arms became increasingly heavier. After 2 days, he had trouble walking up stairs and explained that he could almost observe his muscles progressively failing to function. James says he tried to deny there was something wrong until he was literally crawling around his house unable to walk or support his body weight to stand.

James has been living between the US and Germany for about 13 years, but he also purchased a home in the small Sicilian village of Gangi; Gangi is where James was when the numbness in his body set in. After crawling around his new home, numb with pain, James was carried out of his home and loaded onto a plane to Berlin, Germany, where he immediately went to the hospital.

“My regular German doctor had suggested I go to the Aguste-Viktoria Hospital since they have, in his opinion, the best neurological ward in Berlin. Perhaps I was lucky that on this night, the receiving doctor in the ER was one of the neurological team doctors. I believe she saved my life. Within 3 hours, I had full body x-rays, an MRI, and a spinal tap. By 6:00 am, she had the diagnosis and was confirming with the head of neurology. When the doctor uttered the words, Guillain-Barré syndrome, I had never heard of this insidious, aggressive disorder nor known anyone who had been afflicted by it,” he said.

Guillain-Barré Syndrome (GBS):

• Is also known as Acute Inflammatory Demyelinating Polyradiculopathy (AIDP).
• Can occur anytime in life and in anybody (male, female, young, or old).
• Affects 1 out of every 100,000 people.
• Is a nerve disease with significant weakness as the primary symptom.
• Has an unknown cause.
• Has a history of developing rapidly.

Continued on next page
“When the doctors were 90% positive I had GBS, they wanted to immediately begin the immune globulin intravenous (IVIG) treatment since the numbness had progressed up to my waist. They would perform the electrodiagnostic tests the next day which are necessary for a 100% GBS confirmation. They feared that if they waited on the IVIG, the disease could progress into my chest cavity,” James explained.

As you can imagine, a lot was going through James’ mind when he received the GBS diagnosis.

“When the doctor told me what it was, I could barely focus. I only wanted the pain to end, or to die. Either was fine at that point. I think I said, ‘Do whatever you need to do if it is possible to save me and/or stop this pain.’ I was not even focusing on the fact that I was paralyzed from the waist down,” he said.

James has received a positive reaction since beginning his GBS blog.

“I have received so many calls, emails, and messages from my family, friends, colleagues, prior students, and new acquaintances, and I thank them for the words of support, encouragement, and love. It means so much! I could not get through this without them all. I have also appreciated hearing the stories from other GBS survivors. Sharing their stories with me has given me hope and inspiration to push harder,” James explained.

It is that human connection that is helping James now and got him through those early days of recovery in Berlin.

“Though it seemed I was alone in Berlin during my recovery that was absolutely not the truth. I was speaking often with family and friends and received daily calls from my mother, my mentor and friend Enno, and dear friend Judi. Whether I was feeling well or horrible, it didn’t matter; they called. ‘They never missed a day. I came to depend on this constant.’”

James would like to see more research conducted on GBS, so that better advice and guidance can be given to patients.

“GBS is a disease that I would not wish on my worst enemy. I will do whatever I can to spread the message of GBS so to spare others pain and possible financial ruin. The power of social media is real and we are all connected. It is an obvious choice to me to be open and share my journey, the good and bad, with others,” he said.

James says that it’s important to support scientific research and education to gain a deeper understanding of this disease.

“If you have never heard of GBS, then that in itself is a reason to support an outreach and education program to spread awareness and understanding so the public knows the onset symptoms.”

When asked for a quote that gives James inspiration, he shared this: “We are never given anything we cannot handle. What we do with each challenge and how we move forward is the true test of individual character.” In September 2017, James was given the biggest challenge of his life: GBS. His desire to overcome this terrible disease, to battle it with dignity, and blog about his remarkable journey has proven to be an inspiration to so many.
Meet Kristin: Mother, Social Worker, and Charcot-Marie-Tooth Survivor

Kristin Gelzinis had a normal, active childhood. She always enjoyed being outdoors – skiing, running, rollerblading, and biking. By 18, she was working and going to school full-time, and by 21, she was nearly done with nursing school. It was at that time, however, that she started running into some medical problems.

“My legs had gotten very weak and my balance was really off. The things I used to do were no longer an option. I could barely lift myself up,” Kristin said. “I was falling a lot and experiencing significant pain.”

By 23, Kristin says that her medical problems stopped her in her tracks and totally disabled her.

“My bones had deteriorated so much that I could barely walk. I developed osteonecrosis (a bone disease that causes chronic pain and joint degeneration) in every joint and I was on high doses of prednisone to help my breathing. My muscles had atrophied so fast. The doctors were stumped and I was so very depressed. My life as I had known it was over,” Kristin recalled. Kristin explains that it took her a “few years and a few tears” to get an actual diagnosis.

“Once I finally stopped feeling sorry for myself, I took control and started demanding answers,” she said.

“I saw a few different neurologists who ran testing, but it wasn’t until I had my son at age 31, that my neurologist finally figured out the diagnosis. I had Charcot-Marie-Tooth (CMT) Type 4C.”

After learning of her disease, Kristin says a lot of thoughts ran through her mind.

“Part of me was relieved that I finally knew what was causing my problems and part of me was really scared for my future.”

CMT is the most common inherited neuropathy. It affects the patient’s balance, lower legs, arms, and hands. Over time, patients develop bilateral foot drop and may become completely immobile.

“CMT 4C is one of the rarer types of CMT, so it affects everyone differently. For me, it’s impacted my balance and coordination, and my muscles have atrophied. It’s hard to walk without the use of crutches and leg braces. I have difficulty swallowing and most importantly, it affects my breathing. Part of my diaphragm no longer works which means I need to be extra cautious around those who are sick.

“I’ve been hospitalized three times in the past year due to respiratory failure,” Kristin explained.

Kristin said that prior to her diaphragm paralysis, she just had to see her neurologist once a year to keep up on symptoms and pain management.

“Now with the diaphragm paralysis, I’ve been seeing my pulmonary doctor every few months, a new neurologist, and a new thoracic surgeon. But, it’s hard to live like this. I mean, you wake up with a snuffle and wonder if that’s going to be the next thing that causes respiratory failure.”

Living with this disease causes a tremendous amount of frustration and fear for Kristin.

“No matter how hard I try to get stronger and keep my body in good physical shape, I will always have CMT as an underlying issue that rips out everything that I have worked for. After this last hospitalization, I am coming back even weaker and more uncertain of my future. For the first time in a very long time, I am scared.”

Kristin was advised to stop pursuing a career in nursing after receiving her CMT diagnosis. She took some time off to determine her next move and decided to go back to school to earn a master’s degree in Social Work along with her Social Work license. After that, she began working with children, families, and adults. However, once her son reached school age, and she began interviewing at various agencies, she was told her crutches were a liability.

“I have decided to put work on the back burner, for now anyway. I want to continue focusing on raising my son and working on my health,” Kristin said.

Kristin does spend time doing volunteer work – advocating for CMT patients and leading various support groups for individuals with the disease. Kristin's
greatest passion is CMT-Connect – holistic workshops with an educational and empowerment approach developed in collaboration with the Hereditary Neuropathy Foundation. She also runs a robust Facebook group called CMT Stand by Me for CMT patients and caregivers. Additionally, she goes to schools to promote empathy for kids with disabilities.

Kristin says it’s extremely important that more research and studies are conducted on CMT.

“While I’m here in my hospital bed, I cannot help but worry about my future. Will it be cut short somehow? Am I receiving the right treatments? I’m terrified. I don’t want to leave my family and I never want to leave my son. Right now, I feel my doctors are giving me their best guesses as to what they should do next and best guesses on my health are no longer good enough for me. I need more confidence and that will not happen until CMT research is properly funded.”

Kristin strongly suggests that people give from the heart and donate to help those living with NM diseases because, as she says, “You never know whose life you can change by donating.”

Despite feeling scared and frustrated by her disease, Kristin will continue to press on with as much strength as she can.

“I will keep looking for answers. I will keep fighting for others. I will keep going forward until maybe one day we find something to help all of us.”

Help support the researchers who are finding the treatments and cures for tomorrow. Donate to the AANEM Foundation today.

[www.aanemfoundation.org/Donate]
If you’ve ever wanted to play an active role in helping your elected state officials better understand NM and EDX medicine, now is your chance!

“Having our 2018 AANEM Annual Meeting in DC is a great opportunity for AANEM members to join our advocacy efforts. We welcome assistance from our members to help us do this important work,” said Millie Suk, JD, MPP, AANEM Health Policy Director.

Prior to meeting with elected officials, AANEM encourages members to read the Guide to Legislative Advocacy: aanem.org/AdvocacyGuide. This guide provides a brief overview of the powers of Congress, how a bill becomes law, and tips on contacting your legislator. It includes sample letters, emails and scripts for meetings and phone calls with legislators.

When communicating with legislators:
- Focus on the impact to the patient with a neuromuscular (NM) disorder.
- Stress the importance of the patient receiving the correct diagnosis to reduce costs for both the patient and the healthcare system.
- Focus on the cost savings to the overall public in terms of health insurance costs, time off of work, and disability costs.
- Emphasize overarching issues facing patients with NM disorders, which include the importance of funding NIH research, faster FDA approval for drugs, and ensuring access to clinical trials.

Thank you for your support of AANEM's advocacy efforts. Please consider a donation to the AANEM advocacy fund today. Visit www.aanem.org/Advocacy/Advocacy-Fund.

Donations are not tax deductible.
New Guide on MACRA & The Quality Payment Program

AANEM members: A new how-to guide is available to you that plainly and succinctly describes all of the steps involved in participating in the Quality Payment Program. It also provides details specific to physicians working in NM and EDX medicine.

MACRA & The Quality Payment Program (QPP): A Guide for AANEM Members is:
- Divided into chapters with direct links to resources to enable clinicians to easily find answers to specific questions.
- Laid out sequentially so it can be read cover to cover if you’re looking for a complete overview and explanation of the program.
- Designed to cover all your needs from “Easiest Ways to Avoid a Payment Penalty: What are the Minimum Requirements?” to “How to Get a Positive Payment Adjustment.”

“This practical guide goes through the basics and explains the actual steps involved in participating in the QPP … from how to select quality measures to how to actually report your data, even if you don’t have an electronic health record. It also explains how to access and interpret your scores,” explained Millie Suk, JD, MPP, AANEM Health Policy Director.

View the guide at aanem.org/QPPGuide

Learn more about QPP at the Annual Meeting
Do you have specific questions about the QPP? Bring them to the 2018 AANEM Annual Meeting in Washington, DC where an entire “Ask the Expert” session is being devoted to MACRA and the QPP. Updates for 2019 will also be shared.

The MACRA annual meeting session is being held Thursday, October 11, at 8:00 am. Look for more information in the planning guide at www.aanem.org/meeting.
Global vs. Technical Billing

Our members often ask questions about performing nerve conduction studies and needle EMGs on their patients at a hospital. If the physician brings their own technician or performs the nerve conduction portion of these tests themselves, would the physician be able to bill the global code and/or the technical component for these studies? According to the American Medical Association’s Resource-Based Relative Value Scale (RBRVS) 2018 Manual (page 110):

“Profession and technical component modifiers were established for some services to distinguish the portion of a service furnished by a physician. The professional component includes the physician work and associated overhead and professional liability insurance (PLI) costs involved in three types of services:

- Diagnostic tests that involve a physician’s interpretation, such as cardiac stress tests and electroencephalograms;
- Physician diagnostic and therapeutic radiology services; and
- Physician pathology services.

The technical component of a service includes the cost of equipment, supplies, technician salaries, PLI, etc. The global charge refers to both components when billed together. For services furnished to hospital outpatients or inpatients, the physician may bill only for the professional component because the statute requires that payment for nonphysician services provided to hospital patients be paid only to the hospital. This requirement applies even if the service for a hospital patient is performed in a physician’s office.”

Under Medicare policy, physicians cannot bill directly for the technical component of a procedure if performing these services in a hospital setting. The Medicare Diagnostic Related Group (DRG), by law, covers the technical component of Medicare services for inpatients. So, when submitting bills to Medicare, the physician may only submit for and be reimbursed for the professional component of these studies. This rule does not necessarily apply to non-Medicare payers, unless they use the DRG policy.

This does NOT mean that physicians cannot reasonably be reimbursed for the part of the technical component to which they are entitled. A physician would have a claim on at least part of the technical component of services performed in the hospital if he/she:

A) Owns the equipment;
B) Employs the technician who performs the test; or,
C) Personally performs the test.

Even if the hospital owns the equipment, if either B or C is true, then the physician can bill the institution for part of the technical component. While the physician cannot bill the carrier for the technical component under the DRG system, he/she may either bill the institution or establish a separate contract with them in order to receive the appropriate reimbursement.

Want more information on this topic?

The most comprehensive source for EDX and NM coding is the AANEM 2018 Online Coding Guide. Purchase it at www.aanem.org/purchasecodingguide.

Attending the annual meeting in DC? Stop by the AANEM membership booth and we’ll connect you with our coding expert, Carrie Winter, RHIA, Health Policy Manager.
What is ABEM and how is it related to the AANEM? We recently visited with Anna Vredenburg, Professional Standards Senior Coordinator at AANEM, to help break it down.

“The American Board of Electrodiagnostic Medicine or ABEM is an independent credentialing body for the field of electrodiagnostic medicine. ABEM is a committee of the AANEM, a membership organization dedicated to the advancement of neuromuscular, musculoskeletal and electrodiagnostic medicine,” explained Ms. Vredenburg. “Both ABEM and AANEM work nicely together to ensure advancement in these areas and exist to help improve the quality of patient care for those living with neuromuscular and musculoskeletal diseases.”

Receiving board certification is a common pursuit of many physicians and technologists committed to demonstrating expertise in their chosen profession. The ABEM offers 2 such certifications:

- **ABEM Initial Certification** for physicians
- **Certified Nerve Conduction Technologist (CNCT) certification** for technologists

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**ABEM Initial Certification**
Physicians can become a Diplomate of ABEM in the subspecialty of EDX medicine by successfully completing the ABEM Initial Certification Exam.

**Maintenance of Certification Program**
A physician’s ABEM certification is good for 10 years. To maintain this certification, Diplomates certified after 1994 must successfully pass the MOCP exam once during their 10-year cycle. Additionally, ABEM Diplomates are required to demonstrate their commitment to lifelong learning through completion of Category 1 CME activities.

**CNCT Certification**
Technologists can become a Certified Nerve Conduction Technologist by successfully completing the CNCT Exam. This exam demonstrates competency in the performance of nerve conduction studies.

**Technologist Maintenance of Certification Program (TMOCPP)**
A technologist’s CNCT certification is good for 5 years. To maintain this certification, candidates are required to demonstrate their commitment to lifelong learning through completion of recertification activities.

Visit [www.abemexam.org](http://www.abemexam.org) for more information.
Congratulations to ABEM’s Newest Diplomates!

The following physicians successfully passed the 2018 American Board of Electrodiagnostic Medicine (ABEM) Certification Examination. The passing rate for first-time exam takers was over 90% this year.

Raymond Alcuri, MD  
Ziad Alhumayyed, MBBS  
Brian Altman, MD  
Muhammad Arshad, MBBS, MD  
Nassima Baba-Ahmed, MD  
Taylor Bear, MD  
Suur Biliciler, MD  
Ibrahim Binalsheikh, MD  
Keith Burchill, MD  
Harina Chahal, MD  
Seung Chang, MD  
Sophia Cheng, MD  
Vivian Chin, MD  
Carroll Cooper, MD  
Annie Daniel, MD  
Leslie Delfiner, MD  
Kunal Desai, MD  
Priya Sai Dhawan, MD  
Alexander Dietz, MD  
Xiaoli Dong, MD  
Matthew Elliott, MD  
Elizabeth Fojtik, MD  
Laura Foster, MD  
Thomas Foster, MD  
Rachana Gandhi, MD  
Christopher Geiger, DO  
Sweta Goel, MD  
Erich Gottwald, DO  
Khatuna Gurgenshashvili, MD  
Bilal Hameed, MBBS  
Wenzhuan He, MD  
Naglaa Hussein, MD  
Cindy Jadoo, MD  
Nan Jiang, MD  
Joslyn John, MD  
Manisha Kak, MD  
Michelle Kaku, MD  
Joseph Kamerath, MD  
Tara Kersten, MD  
Mounir Khalil, MBBeH  
Sreekanth Koneru, MD  
Steven Kreis, DO  
Christopher Kurahashi, MD  
Patrick Kwon, MD  
Theresa LaBarte, DO  
Alicia Lazeski, BS, MD  
Bob Lee, MD  
Kent A. Logan, MD  
Rabia Malik, MD  
Robert McAnelly, MD  
Matthew McAuliffe, MD  
Rosina Medel, MD  
Justin Mendoza, DO  
Kurt Mildenstein, MD  
Eric Mittelmann, MD  
John Morren, MD  
Jonathan Morrill, MD, MA  
Sally L. Niles, MD  
Shawn Peterson, DO  
Gabriel Pilar, MD, MFA  
Joseph Platon, DO  
Madhavi Prasad, MD  
Nassim Rad, MD  
Saria Refai, MD  
Alissa Romano, DO  
Bhaskar Roy, MBBS  
Bishnu Sapkota, MD  
Kelly Scott, MD  
Abdel Shaikh, MD  
Lihong Shen, MD, PhD  
Mark Shoreman, MD  
Keziah Sully, MD  
Trissy Su, DO  
Melanie Taylor, MD  
Joel Torres, MD  
Jayesh Vallabh, MD  
Julio Vazquez-Galliano, MD  
Nuttawan Vongveeranonchai, MD  
William Westerkamp, MD  
Ashley Whyte-Rayson, MD  
Amanda Witt, MD  
Andrew Wong, MD  
Ning Sarah Yang, MD  
Tatjana Zdravkovic, MD  
Lawrence Zeidman, MD  
Dr. Ling Zhang, MD  
Shangming Zhang, MD

Certificate of Recognition (International):
Abdulrahman Ali, MD  
Joy Vijayan, MD

The following physicians scored in the top 10%:
Leslie Delfiner, MD  
Bilal Hameed, MBBS  
Tara Kersten, MD  
Christopher Kurahashi, MD  
Eric Mittelmann, MD  
Shawn Peterson, DO  
Kelly Scott, DO  
Mark Shoreman, MD  
Joel Torres, MD  
Nuttawan Vongveeranonchai, MD

“I think becoming ABEM-certified is a great way to advertise and represent your expertise in electrodiagnostics. The exam questions were straightforward and relevant. To study, I found that using AANEM’s old EDX self-assessment exams was most helpful. The online SAEs helped me become familiar with the format of the exam.”
- Sarah Yang, MD

“I took the ABEM Exam because EMG/NCS is a large part of my practice and I think it is important to show competency by becoming board certified by the ABEM. I am working toward achieving EDX Laboratory Accreditation for our lab through AANEM and this was a step in that process. Since EMGs are such a large part of my practice – I do hundreds of them per year – my preparation for the exam was quite minimal. I studied for a few hours a day for about a month.”
- Tara A. Kersten, MD
Congratulations to ABEM’s Newest CNCT-certified Technologists!

The following technologists successfully passed the 2018 Certified Nerve Conduction Technologist (CNCT) Certification Examination.

Ali Arvantaj, CNCT  
Franklin Baird, CNCT  
Whitney Ball, CNCT  
James Fikes, CNCT  
Ashley Hanlon, CNCT  
Alisha Johnson, CNCT  
Wayne Johnson, CNCT  
J Jones, CNCT  
Aimee Kennedy, CNCT  
Nasir Khan, CNCT  
Krista Lampman, CNCT  
Nicholas Lawless, CNCT  
Sihui Li, CNCT  
Luis Mendez, CNCT  
Olesya Oligrad ska, CNCT  
Licette Olvera, CNCT  
James Quigley, CNCT  
Nurul Sainuddin, CNCT  
Ardiana Sejdiu, CNCT  
Lindsey Weikel, CNCT  
Evan Westwood, CNCT  
Kyla Wickham, CNCT

ABEM Certification Opportunities for 2018-2019

Maintenance of Certification Program (MOCP) Exam  
Registration Opens August 1, 2018  
Exam: November 28 or December 1, 2018

ABEM Initial Certification Exam  
Registration Opens October 1, 2018  
Exam: March 13-16, 2019

Certified Nerve Conduction Technologist (CNCT) Exam  
Registration Opens March 1, 2019  
Exam: May 29 or June 1, 2019  
Dates are subject to change.

Current ABEM Diplomates & CNCT Technologists

4,086  
Total Active ABEM Diplomates

308  
Total CNCT Certified
COMPLEMENT-MEDIATED DESTRUCTION OF THE NMJ OCCURS IN MANY PATIENTS WITH ANTI-AchR+ gMG¹

Autoantibodies to the acetylcholine receptor (AchR) are detected in up to 88% of gMG cases.

C1q
Anti-AchR autoantibodies bind to AchRs, triggering C1q binding
COMPLEMENT CASCADE INITIATED

C5a and C5b
C5a to C9 (TCC)
TCC damages the postsynaptic membrane, causing muscle damage and weakness

Indications and Usage
Generalized Myasthenia Gravis (gMG)
Soliris is indicated for the treatment of adult patients with generalized Myasthenia Gravis (gMG) who are anti-acetylcholine receptor (AchR) antibody positive.

Important Safety Information

WARNING: SERIOUS MENINGOCOCCAL INFECTIONS
Meningococcal infection may become rapidly life-threatening or fatal if not recognized and treated early.

- Comply with the most current Advisory Committee on Immunization Practices (ACIP) recommendations for meningococcal vaccination in patients with complement deficiencies.
- Immunize patients with meningococcal vaccines at least 2 weeks prior to administering the first dose of Soliris, unless the risks of delaying Soliris therapy outweigh the risk of developing a meningococcal infection.
- Monitor patients for early signs of meningococcal infections and evaluate immediately if infection is suspected.

Soliris is available only through a restricted program under a Risk Evaluation and Mitigation Strategy (REMS). Under the Soliris REMS, prescribers must enroll in the program. Enrollment in the Soliris REMS program and additional information are available by telephone: 1-888-SOLIRIS (1-888-765-4747) or at www.solirisrems.com.

Please see additional Important Safety Information on the following page and accompanying Brief Summary of full Prescribing Information.
Contraindications
Soliris is contraindicated in:
- Patients with unresolved serious Neisseria meningitidis infection
- Patients who are not currently vaccinated against Neisseria meningitidis, unless the risks of delaying Soliris treatment outweigh the risks of developing a meningococcal infection

Warnings and Precautions
Other Infections
Soliris blocks terminal complement activation; therefore patients may have increased susceptibility to infections, especially with encapsulated bacteria. Additionally, Aspergillus infections have occurred in immunocompromised and neutropenic patients. Children treated with Soliris may be at increased risk of developing serious infections due to Streptococcus pneumoniae and Haemophilus influenza type b (Hib). Administer vaccinations for the prevention of Streptococcus pneumoniae and Haemophilus influenza type b (Hib) infections according to ACIP guidelines. Use caution when administering Soliris to patients with any systemic infection.

Infusion Reactions
Administration of Soliris may result in infusion reactions, including anaphylaxis or other hypersensitivity reactions. In clinical trials, no patients experienced an infusion reaction which required discontinuation of Soliris. Interrupt Soliris infusion and institute appropriate supportive measures if signs of cardiovascular instability or respiratory compromise occur.

Adverse Reactions
The most frequently reported adverse reaction in the gMG placebo-controlled clinical trial (≥10%) is: musculoskeletal pain.

Please see full Prescribing Information including boxed WARNING regarding serious meningococcal infection at www.Soliris.net.

WARNING: SERIOUS MENINGOCOCCAL INFECTIONS

Life-threatening and fatal meningococcal infections have occurred in patients treated with Soliris. Meningococcal infection may become rapidly life-threatening or fatal if not recognized and treated early [see Warnings and Precautions (5.1)].

- Comply with the most current Advisory Committee on Immunization Practices (ACIP) recommendations for meningococcal vaccination in patients with complement deficiencies.
- Immunize patients with meningococcal vaccines at least 2 weeks prior to administering the first dose of Soliris, unless the risks of delaying Soliris therapy outweigh the risk of developing a meningococcal infection. [See Warnings and Precautions (5.1) for additional guidance on the management of the risk of meningococcal infection].
- Monitor patients for early signs of meningococcal infections and evaluate immediately if infection is suspected.

Soliris is available only through a restricted program under a Risk Evaluation and Mitigation Strategy (REMS). Under the Soliris REMS, prescribers must enroll in the program [see Warnings and Precautions (5.2)]. Enrollment in the Soliris REMS program and additional information are available by telephone: 1-888-SOLIRIS (1-888-765-4747) or at www.solirisrems.com.

Table 2: Preparation of Soliris

<table>
<thead>
<tr>
<th>Soliris Dose</th>
<th>Diluent Volume</th>
<th>Final Volume</th>
</tr>
</thead>
<tbody>
<tr>
<td>300 mg</td>
<td>30 mL</td>
<td>60 mL</td>
</tr>
<tr>
<td>600 mg</td>
<td>60 mL</td>
<td>120 mL</td>
</tr>
<tr>
<td>900 mg</td>
<td>90 mL</td>
<td>180 mL</td>
</tr>
<tr>
<td>1200 mg</td>
<td>120 mL</td>
<td>240 mL</td>
</tr>
</tbody>
</table>

Gently invert the infusion bag containing the diluted Soliris solution to ensure thorough mixing of the product and diluent. Discard any unused portion left in a vial, as the product contains no preservatives.

Prior to administration, the admixture should be allowed to adjust to room temperature. If the admixture is not at room temperature (18°-25°C, 64-77°F), the admixture must not be heated in a microwave or with any heat source other than ambient air temperature.

Table 2: Supplemental Dose of Soliris after PE/PI

<table>
<thead>
<tr>
<th>Type of Plasma Intervention</th>
<th>Most Recent Soliris Dose</th>
<th>Supplemental Soliris Dose With Each Plasma Intervention</th>
<th>Timing of Supplemental Soliris Dose</th>
</tr>
</thead>
<tbody>
<tr>
<td>Plasmapheresis or plasma exchange</td>
<td>300 mg</td>
<td>300 mg per each plasmapheresis or plasma exchange session</td>
<td>Within 60 minutes after each plasmapheresis or plasma exchange session</td>
</tr>
<tr>
<td>≥600 mg</td>
<td>600 mg per each plasmapheresis or plasma exchange session</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fresh frozen plasma infusion</td>
<td>≥300 mg</td>
<td>300 mg per infusion of fresh frozen plasma</td>
<td>60 minutes prior to each infusion of fresh frozen plasma</td>
</tr>
</tbody>
</table>

2.6 Preparation

Dilute Soliris to a final admixture concentration of 5 mg/mL, using the following steps:

- Withdraw the required amount of Soliris from the vial into a sterile syringe.
- Transfer the recommended dose to an infusion bag.
- Dilute Soliris to a final concentration of 5 mg/mL by adding the appropriate amount (equal volume of diluent to drug volume) of 0.9% Sodium Chloride Injection, USP; 0.45% Sodium Chloride Injection, USP; 5% Dextrose in Water for Injection, USP; or Ringer’s Injection, USP to the infusion bag.

The final admixed Soliris 5 mg/mL infusion volume is 60 mL for 300 mg doses, 120 mL for 600 mg doses, 180 mL for 900 mg doses or 240 mL for 1200 mg doses (Table 3).

Table 3: Preparation and Reconstitution of Soliris

<table>
<thead>
<tr>
<th>Soliris Dose</th>
<th>Diluent Volume</th>
<th>Final Volume</th>
</tr>
</thead>
<tbody>
<tr>
<td>300 mg</td>
<td>30 mL</td>
<td>60 mL</td>
</tr>
<tr>
<td>600 mg</td>
<td>60 mL</td>
<td>120 mL</td>
</tr>
<tr>
<td>900 mg</td>
<td>90 mL</td>
<td>180 mL</td>
</tr>
<tr>
<td>1200 mg</td>
<td>120 mL</td>
<td>240 mL</td>
</tr>
</tbody>
</table>

Vaccination reduces, but does not eliminate, the risk of meningococcal infections.

In clinical studies, 2 out of 196 paroxysmal nocturnal hemoglobinuria (PNH) patients developed serious meningococcal infections while receiving treatment with Soliris; both...
had been vaccinated [see Adverse Reactions (6.1)]. In clinical studies among non-PNH patients, meningococcal meningitis occurred in one unvaccinated patient. In addition, 3 out of 130 previously vaccinated patients with aHUS developed meningococcal infections while receiving treatment with Soliris [see Adverse Reactions (6.1)].

Closely monitor patients for early signs and symptoms of meningococcal infection and evaluate patients immediately if an infection is suspected. Meningococcal infection may become rapidly life-threatening or fatal if not recognized and treated early. Discontinue Soliris in patients who are undergoing treatment for serious meningococcal infections.

5.2 Soliris REMS

Because of the risk of meningococcal infections, Soliris is available only through a restricted program under a Risk Evaluation and Mitigation Strategy (REMS). Under the Soliris REMS, prescribers must enroll in the program.

Prescribers must counsel patients about the risk of meningococcal infection, provide the patients with the REMS educational materials, and ensure patients are vaccinated with meningococcal vaccine(s).

Enrollment in the Soliris REMS program and additional information are available by telephone: 1-888-SOLIRIS (1-888-765-4747) or at www.solirisrems.com.

5.3 Other Infections

Soliris blocks terminal complement activation; therefore patients may have increased susceptibility to infections, especially with encapsulated bacteria. Additionally, Aspergillus infections have occurred in immunocompromised and neutropenic patients. Children treated with Soliris may be at increased risk of developing serious infections due to Streptococcus pneumoniae and Haemophilus influenzae type b (Hib). Administer vaccinations for the prevention of Streptococcus pneumoniae and Haemophilus influenzae type b (Hib) infections according to ACIP guidelines. Use caution when administering Soliris to patients with any systemic infection [see Warnings and Precautions (5.1)].

5.6 Infusion Reactions

Administration of Soliris may result in infusion reactions, including anaphylaxis or other hypersensitivity reactions. In clinical trials, no patients experienced an infusion reaction which required discontinuation of Soliris. Interrupt Soliris infusion and institute appropriate supportive measures if signs of cardiovascular instability or respiratory compromise occur.

6 ADVERSE REACTIONS

The following serious adverse reactions are discussed in greater detail in other sections of the labeling:

- Serious Meningococcal Infections [see Warnings and Precautions (5.1)]
- Other Infections [see Warnings and Precautions (5.3)]
- Infusion Reactions [see Warnings and Precautions (5.6)]

6.1 Clinical Trial Experience

Because clinical trials are conducted under widely varying conditions, adverse reaction rates observed in the clinical trials of a drug cannot be directly compared to rates in the clinical trials of another drug and may not reflect the rates observed in practice. Meningococcal infections are the most important adverse reactions experienced by patients receiving Soliris. In PNHI clinical studies, two patients experienced meningococcal sepsis. Both patients had previously received a meningococcal vaccine. In clinical studies among patients without PNH, meningococcal meningitis occurred in one unvaccinated patient. Meningococcal sepsis occurred in one previously vaccinated patient enrolled in the retrospective aHUS study during the post-study follow-up period [see Warnings and Precautions (5.1)].

Generalized Myasthenia Gravis (gMG)

In a 26-week placebo-controlled trial evaluating the effect of Soliris for the treatment of gMG (gMG Study 1), 62 patients received Soliris at the recommended dosage regimen and 63 patients received placebo. Patients were 19 to 79 years of age, and 66% were female. Table 8 displays the most common adverse reactions from gMG Study 1 that occurred in ≥5% of Soliris-treated patients and at a greater frequency than placebo.

Table 8: Adverse Reactions Reported in 5% or More of Soliris-Treated Patients in gMG Study 1 and at a Greater Frequency Than in Placebo-Treated Patients

<table>
<thead>
<tr>
<th>Reaction</th>
<th>Soliris (N=62)</th>
<th>Placebo (N=63)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abdominal pain</td>
<td>5 (8)</td>
<td>3 (5)</td>
</tr>
<tr>
<td>General Disorders and Administration Site Conditions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Peripheral edema</td>
<td>5 (8)</td>
<td>3 (5)</td>
</tr>
<tr>
<td>Pyrexia</td>
<td>4 (7)</td>
<td>2 (3)</td>
</tr>
<tr>
<td>Infections and Infestations</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Herpes simplex virus infections</td>
<td>5 (8)</td>
<td>1 (2)</td>
</tr>
<tr>
<td>Injury, Poisoning, and Procedural Complications</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contusion</td>
<td>5 (8)</td>
<td>2 (3)</td>
</tr>
<tr>
<td>Musculoskeletal and Connective Tissue Disorders</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Musculoskeletal pain</td>
<td>9 (15)</td>
<td>5 (8)</td>
</tr>
</tbody>
</table>

The most common adverse reactions (≥10%) that occurred in Soliris-treated patients in the long-term extension to gMG Study 1, Study ECU-MG-302, that are not included in Table 8 were headache (26%), nasopharyngitis (24%), diarrhea (15%), arthralgia (12%), upper respiratory tract infection (11%), and nausea (10%).

6.2 Immunogenicity

As with all proteins, there is a potential for immunogenicity. The detection of antibody formation is highly dependent on the sensitivity and specificity of the assay. Additionally, the observed incidence of antibody (including neutralizing antibody) positivity in an assay may be influenced by several factors including assay methodology, sample handling, timing of sample collection, concomitant medications, and underlying disease. For these reasons, comparison of the incidence of antibodies to eculizumab in the studies described below with the incidence of antibodies in other studies or to other products may be misleading.

The immunogenicity of Soliris has been evaluated using two different immunoassays for the detection of anti-eculizumab antibodies: a direct enzyme-linked immunosorbent assay (ELISA) using the Fab fragment of eculizumab as target was used for the PNH indication; and an electro-chemiluminescence (ECL) bridging assay using the eculizumab whole molecule as target was used for the aHUS indication, as well as for additional patients with PNH. In the PNH population, antibodies to Soliris were detected in 3/196 (2%) patients using the ELISA assay and in 5/161 (3%) patients using the ECL assay. In the aHUS population, antibodies to Soliris were detected in 3/100 (3%) patients using the ECL assay. An ECL-based neutralizing assay with a low sensitivity of 2 mcg/mL was performed to detect neutralizing antibodies for the 3 patients with aHUS and the 5 patients with PNH with positive samples using the ECL assay. Two of 161 patients with PNH (1.2%) and 1 of 100 patients with aHUS (1%) had low positive values for neutralizing antibodies. None of 62 patients with gMG had antibodies to Soliris detected immediately following the 26-week active treatment. No apparent correlation of antibody development to clinical response was observed.

6.3 Postmarketing Experience

The following adverse reactions have been identified during post-approval use of Soliris. Because these reactions are reported voluntarily from a population of uncertain size, it is not always possible to reliably estimate their frequency or to establish a causal relationship to Soliris exposure.

Cases of serious or fatal meningococcal infections have been reported.

8 USE IN SPECIFIC POPULATIONS

8.1 Pregnancy

Risk Summary

Limited data on outcomes of pregnancies that have occurred following Soliris use in pregnant women have not identified a concern for specific adverse developmental outcomes (see Data). There are risks to the mother and fetus associated with untreated paroxysmal nocturnal hemoglobinuria (PNH) and atypical hemolytic uricemic syndrome (aHUS) in pregnancy (see Clinical Considerations). Animal studies using a mouse analogue of the Soliris molecule (murine anti-C5 antibody) showed increased rates of developmental abnormalities and an increased rate of dead and moribund offspring at doses 2-8 times the human dose (see Data).

Alexion’s PNH and aHUS disease registries collect pregnancy outcomes in women exposed to Soliris during pregnancy. To enroll or to obtain information, contact www.pnhregistry.com or www.ahusregistry.com, or call (215)-616-3558. In cases where gMG patients become pregnant, call (215)-616-3558.
A pooled analysis of prospectively (50.3%) and retrospectively (49.7%) collected data in more than 300 pregnant women with live births following exposure to Soliris have not suggested safety concerns. However, these data cannot definitively exclude any drug-associated risk during pregnancy, because of the limited sample size. Animal Data Animal reproduction studies were conducted in mice using doses of a murine anti-C5 antibody that approximated 2-4 times (low dose) and 4-8 times (high dose) the recommended human Soliris dose, based on a body weight comparison. When animal exposure to the antibody occurred in the time period from before mating until early gestation, no decrease in fertility or reproductive performance was observed. When maternal exposure to the antibody occurred during organogenesis, two cases of retinal dysplasia and one case of umbilical hernia were observed among 230 offspring born to mothers exposed to the higher antibody dose; however, the exposure did not increase fetal loss or neonatal death. When maternal exposure to the antibody occurred in the time period from implantation through weaning, a higher number of male offspring became moribund or died (1/25 controls, 2/25 low dose group, 5/25 high dose group). Surviving offspring had normal development and reproductive function.

8.2 Lactation

Risk Summary

Although limited published data does not report detectable levels of eculizumab in human milk, maternal IgG is known to be present in human milk. Available information is insufficient to inform the effect of eculizumab on the breastfed infant. There are no data on the effects of eculizumab on milk production. The developmental and health benefits of breastfeeding should be considered along with the mother’s clinical need for Soliris and any potential adverse effects on the breastfed child from eculizumab or from the underlying maternal condition.

8.4 Pediatric Use

Safety and effectiveness of Soliris for the treatment of PNH in pediatric patients have not been established.

The safety and effectiveness of Soliris for the treatment of aHUS have been established in pediatric patients. Use of Soliris in pediatric patients for this indication is supported by evidence from four adequate and well-controlled clinical studies assessing the safety and effectiveness of Soliris for the treatment of aHUS. The studies included a total of 47 pediatric patients (ages 2 months to 17 years). The safety and effectiveness of Soliris for the treatment of aHUS appear similar in pediatric and adult patients [see Adverse Reactions (6.1) and Clinical Studies (14.2)].

The safety and effectiveness of Soliris for the treatment of generalized Myasthenia Gravis in pediatric patients have not been established.

Administer vaccinations for the prevention of infection due to Neisseria meningitidis, Streptococcus pneumoniae and Haemophilus influenzae type b (Hib) according to ACIP guidelines [see Warnings and Precautions (5.1)].

8.5 Geriatric Use

Forty-five patients 65 years of age or older (15 with PNH, 4 with aHUS, and 26 with gMG) were treated with Soliris in clinical trials in the approved indications. Although there were no apparent age-related differences observed in these studies, the number of patients aged 65 and over is not sufficient to determine whether they respond differently from younger patients.

17 PATIENT COUNSELING INFORMATION

Advises the patient to read FDA-approved patient labeling (Medication Guide).

Meningococcal Infection

Prior to treatment, patients should fully understand the risks and benefits of Soliris, in particular the risk of meningococcal infection. Ensure that patients receive the Medication Guide.

Informs patients that they are required to receive meningococcal vaccination at least 2 weeks prior to receiving the first dose of Soliris, if they have not previously been vaccinated. They are required to be revaccinated according to current medical guidelines for meningococcal vaccines use while on Soliris therapy. Inform patients that vaccination may not prevent meningococcal infection [see Warnings and Precautions (5.1)].

Signs and Symptoms of Meningococcal Infection

Inform patients about the signs and symptoms of meningococcal infection, and strongly advise patients to seek immediate medical attention if these signs or symptoms occur. These signs and symptoms are as follows:

- headache with nausea or vomiting
- headache and a fever
- headache with a stiff neck or stiff back
- fever
- fever and a rash
- confusion
- muscle aches with flu-like symptoms
- eyes sensitive to light

Inform patients that they will be given a Soliris Patient Safety Information Card that they should carry with them at all times. This card describes symptoms which, if experienced, should prompt the patient to immediately seek medical evaluation.

Other Infections

Inform patients that there may be an increased risk of other types of infections, particularly those due to encapsulated bacteria. Additionally, Aspergillus infections have occurred in immunocompromised and neutropenic patients. Inform parents or caregivers of children receiving Soliris for the treatment of aHUS that their child should be vaccinated against Streptococcus pneumoniae and Haemophilus influenzae type b (Hib) according to current medical guidelines.

Discontinuation

Inform patients with PNH that they may develop hemolysis due to PNH when Soliris is discontinued and that they will be monitored by their healthcare professional for at least 8 weeks following Soliris discontinuation.

Inform patients with aHUS that there is a potential for TMA complications due to aHUS when Soliris is discontinued and that they will be monitored by their healthcare professional for at least 12 weeks following Soliris discontinuation. Inform patients who discontinue Soliris to keep the Soliris Patient Safety Information Card with them for three months after the last Soliris dose, because the increased risk of meningococcal infection persists for several weeks following discontinuation of Soliris.

Manufactured by:

Alexion Pharmaceuticals, Inc.

100 College Street

New Haven, CT 06510 USA

US License Number 1743

This product, or its use, may be covered by one or more US patents, including US Patent No. 6,355,245 in addition to others including patents pending.

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## AANEM CALENDAR OF EVENTS

### 2018

#### August
- **1** ABEM MOCP Exam registration open
- **3** Early-bird registration for the 2018 AANEM Annual Meeting ends
- **4** Regular registration for the 2018 AANEM Annual Meeting begins

#### September
- **17** Hotel reservations due for the 2018 AANEM Annual Meeting
- **25** Online registration ends for the 2018 AANEM Annual Meeting
- **30** ABEM MOCP Examination application and refund request deadline

#### October
- **1** ABEM Examination application registration open
- **9** AANEM Board of Directors fall meeting
- **9** Onsite registration opens for the 2018 AANEM Annual Meeting
- **10-13** AANEM 2018 Annual Meeting

#### November
- **10** AANEM attends AMA House of Delegates meeting
- **26** Proctored EDX and NM SAE registration opens
- **28** ABEM MOCP Examination administration (day 1)

#### December
- **1** ABEM MOCP Examination administration (day 2)
- **15** Deadline for CME recording for the 2018 AANEM Annual Meeting
- **31** CME recording deadline

#### January
- **25** AANEM Board of Directors/Finance Committee Meeting

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## Resident & Fellow Inclusive JumpStart

**Wednesday, October 10, 2018**

1:30 pm – 5:30 pm

Learn advanced techniques from EMG experts during this small, interactive, hands-on workshop designed for residents and fellows.

Space in this workshop is limited and it generally sells out. Advance registration is now available at a discounted rate of $40 through September 25.
Don’t miss the 2018 AANEM Annual Meeting!
Washington, DC | Oct. 10-13, 2018