

**MGFA Board Meeting, Walk &  
National MG Conference – April 15 – 17, 2018  
Kansas City, MO**

Saturday, April 14

MG National Walk – Gather at the Intercontinental on the Plaza Hotel Pool

- 10:00 am Walk Registration opens
- 11:00 am Walk begins

Sunday, April 15

- 7:15 – Support Group Leaders Breakfast<sup>1</sup> -- Pavilion 1 -- Mezzanine
- 8:00 – 12:00 – Board Meeting – Roof Top Bar – Top Floor
- 8:00 am to 12:30 Support Group Leaders Program -- Pavilion 1 -- Mezzanine
- 9:00 am to Noon Exhibitor Set-up – Alameda Ballroom, Pre-Function -- Ground Floor
- 10:00 – 12:00 – MG Friends Breakout Room – Pavilion II -- Mezzanine
- 10:00 am to 5:00 – Registration Open – Alameda Ballroom Foyer – Ground Floor
- 12:30 – 6:00 pm – Exhibit Hall -- Open – Alameda Ballroom Foyer – Ground Floor
- 1:45 pm – Conference Begins – Alameda Ballroom Salons 1 A & B – Ground Floor

Exhibitors:

- |                           |                        |
|---------------------------|------------------------|
| 1. The Assistance Fund    | 9. MGFA Registry Table |
| 2. Leapcure               | 10. Alexion            |
| 3. PRA Health             | 11. Catalyst           |
| 4. MGA of CA              | 12. Argenx             |
| 5. MGA of KC              | 13. Ra                 |
| 6. Andrew Kaufman, Author | 14. Briova             |
| 7. NORD                   | 15. Terumo             |
| 8. EveryLife Foundation   | 16. Kroger             |
|                           | 17. Global Genes       |

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**CONFERENCE**

DAY ONE—Sunday, April 15

10 am to 5:00 pm – CONFERENCE REGISTRATION\_– Alameda Ballroom Foyer – Ground Floor

12:30 to 6:00 pm -- EXHIBIT HALL– Alameda Ballroom Foyer – Ground Floor

**Plenary Sessions – Alameda Ballroom Salons 1 A & 1 B – Ground Floor**

1:45 -- 1:55 PM

**Welcome**

Ed Walsh, Chair, MGFA

Allison Foss, Executive Director, MGA-KC

2:00 – 2:25 PM

**Keynote Presentation**

Andrew Kaufman, Bestselling Author of Thrillers & MG Patient

2:30 – 3:15 PM

**New Treatment Pathways in MG**

James Howard, MD, Distinguished Professor of Neuromuscular Disease  
Professor of Neurology & Medicine; Chief, Neuromuscular Disorders Section;  
UNC School of Medicine

Linda Kusner, PhD, MSAB Chair/ Assistant Research Professor, George  
Washington University

3:20 – 3:50 PM

**Patient-Centered Outcomes Research Institute (PCORI)**

Pushpa Narayanaswami, MD; Associate Professor of Neurology; Harvard  
University

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DAY ONE—Sunday, April 15-- Continued

Concurrent Break-out Sessions:

1. 4:00 – 4:45 pm

- a. **Understanding Clinical Trials and How They Help Patients** – Presenters: Lisa Marie Dilworth, Moderator, Director of Therapeutic Expertise, PRA Health Sciences; Petra Duda, Senior Director of Clinical Research, RA Pharma; Roisin Armstrong, PhD., Vice President, Global Development Team Leader, Alexion; UK; and Laura Herbelin, RN, EMG Tech and Research Instructor & Tina Liu, RN, Clinical Coordinator of Kansas University Medical Center – Salon 1 A & B – Ballroom
- a. **MG 101** – Yuebing Li, MD, PhD, Neurologist, Cleveland Clinic – Pavilion III - Mezzanine
- b. **Understanding IVIg**--Alison Walsh, MD, Clinical Associate Professor, Jefferson University Hospitals – Pavilion II -- Mezzanine
- c. **Maintaining Your Brain Health with MG** – Richard Macko, MD, Professor, University of Maryland, Medical Center – Pavilion I -- Mezzanine

2. 4:55 – 5:40 pm

- a. **Health Professionals with MG Session** – Sally O’Meara, RN, Oakland University School of Nursing; Cheri Heitman, RN; Kim Eldridge, MG Patient – Pavilion II
- b. **Test Yourself--Are You an MG Expert?** – Constantine Farmakidis, MD, Kansas University Medical Center – Pavilion III – Mezzanine
- c. **Action in the Rare Disease Arena** -- Lisa Douthit, MGFA Advocate; Kristen Angell, Associate Director of Advocacy for the National Organization for Rare Disorders (NORD); Kendall Davis, Senior Manager, Strategic Alliances, Global Genes; Lindsey Cundiff, Associate Director of Patient Engagement; EveryLife Foundation – Pavilion I -- Mezzanine
- d. **How You Can Benefit from The Role of Neuromuscular Clinic Nurses – UKMC:** Judy Ray LPN; Jessie Melton LPN; Kendra Nowak RN; Aubrey Grover LPN ~~– Pavilion II – Mezzanine~~ Alameda Ballroom 1 A & B

**5:40 – 6:30 Break, Exhibits – Ballroom Foyer – Ground Floor**

**With Book Signing by Andrew Kaufmann – TBC???**

**6:30 – 8:00 Reception – Rooftop Ballroom**

7:30 Young Adults Social

7:00 – 8:30 Nurses Dinner and CME Presentation – TBC – Pavilion I - Mezzanine

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DAY TWO – Monday, April 16<sup>th</sup>, 2018

- 7:00 – 7:45 am      Exercise Class – Pavilion I -- Mezzanine
- 7:30 – 8:15 am      Breakfast – Alameda Ballroom – Salons I & II
- 8:00 am to 5:00 pm   Conference Registration – Ballroom Foyer – Ground Floor
- 8:00 am – 5:30 pm    Exhibits – Alameda Ballroom -- Foyer

Plenary Sessions – Alameda Ballroom – Salons 1A & 1B

- 8:15 – 9:15 AM      **Supporting One Another** – Rebecca Molitoris, Cleveland Area Support Group Leader & Author – Discussion groups at tables with signage for Patients and Family/Friends/Caregivers
- 9:20 – 10:10 AM    **Crisis/Emergency Management** – Being prepared; knowing what to do; avoiding it! Panel with Amanda Guidon, MD, Massachusetts General Hospital; Dennis Allin, MD, Director of Emergency Medicine, Kansas University Medical Center; Judy Ray, RN, Kansas University Medical Center
- 10:10 – 10:30      Refreshment Break – Ballroom Foyer – Ground Level
- EXHIBIT HALL – Ballroom Foyer – Ground Level
- 10:35 – 11:35      **The State of MG Today** – Alameda Ballroom 1A & B – Ground Level –  
Dr. Mazen Dimachkie, Professor & Executive Vice-Chair, Neuromuscular Division Chief, Clinical Neurophysiology and Neuromuscular Medicine Fellowship Director;  
Dr. Mamatha Pasnoor, Associate Professor Neurology, Kansas University Medical Center
- 11:40 – 12:00      **Know Your Numbers** -- Sally O’Meara, RN, Oakland University School of Nursing
- 12:05 – 1:30        **Lunch – MGFA Awards Presentation**  
Alameda Ballroom 1A & B – Ground Level
- 1:30 – 1:50         **Be the Change** – Nancy Law, CEO, MGFA -- Alameda Ballroom 1A & B – Ground Level

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DAY TWO – Monday, April 16<sup>th</sup> – Continued

**Breakouts:**

1. 2:00 – 2:45

- a. **Do What You Love, While Fundraising for MG!** (DIY Fundraising) – Betty Ross, MGFA Director of Development – Pavilion I -- Mezzanine
- b. **Be the Change:** Table Rounds in plenary room on topics such as: raising awareness, work, family/friends, life style & health, fun & hobbies Leader – Nancy Law, CEO, MGFA – Pavilion III – Mezzanine
- c. **Make Your Clinic Visit Count! Understanding Your Clinic Visit** – Daniel Larriviere, MD, JD, Acting Chair, Department of Neurology, Residency Program Director, Ochsner Health System – Rooftop Bar – Top Floor
- d. **Thinking About Starting a Family?** – Niki Grossheim, Support Group Leader; Mike Ursic, MGFA Board Member; Rachel Higgins, Support Group Leader; Katherine Ruzhansky, MD, MGFA Board Member – Plaza Room – Top Floor
- e. NURSES ADVISORY BOARD PLANNING MEETING – Pavilion III – Mezzanine TBC

2. 2:55 – 3:40

- a. **Types of MG** – Yuebing Li, MD, PhD, Neurologist, Cleveland Clinic – Pavilion I -- Mezzanine
- b. **Thymectomy – What, Why, How** – Richard Barohn, MD, Professor, Chair of the Department of Neurology; Emmanuel Daon, MD, FACS, Program Director, Cardiothoracic Surgery Residency Program, Kansas University Medical Center; Eric May, MD, anesthesiologist & MG patient, Saint Luke's Hospital of Kansas City – TBC – Pavilion III – Mezzanine
- c. **Building Exercise into Your Life** – Charlene Hafer-Macko, MD, Associate Professor of Neurology, University of Maryland; Adam Silverstein, Patient & Brandi Reimers, Patient – Rooftop Ballroom
- d. **Your Child & MG** – Araya Puwanant, MD, University of Pittsburgh Medical Center – Pavilion II - Mezzanine
- e. MG Organizations Meeting – Plaza Room – Top Floor

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DAY 2 – Monday, April 16<sup>th</sup> – Continued

3. 3:50 – 4:40

- a. **Building a Career with MG in Mind** – Victor Mendevil; Tommy Santora, Communications; Julia Naumes, OTD, additional panelists TBC – Plaza Room -- Rooftop
- b. **Nutrition – Eating to Promote Wellness** -- Ken Sharlin, MD, MPH, IFMCP, Neurologist, consultant, functional medicine practitioner, author, and speaker – Pavilion III - Mezzanine
- c. **Helping Your Child with MG Succeed** – Emma Cifaloni, MD, Professor of Neurology, University of Rochester Medical Center; with Anaya Mitchell & Marilyn Mitchell, M.A. Ed. S Deputy Executive Director, Office of Special Education, Newark Public Schools – Pavilion II - Mezzanine
- d. **Seronegative MG** – Mamatha Pasnoor, MD, Kansas University Medical Center; Charlene Hafer-Macko, MD, Associate Professor of Neurology, University of Maryland; Celia Meyer, RN, Celia Meyer is a RN and a Navy veteran.; Cheri Heitman, RN; Marcia Lorimer, RN, Marcia is Assistant Professor Emeritus at Duke University School of Nursing -- Pavilion 1

4:40 – 5:10 Refreshment Break – Alameda Ballroom Foyer

EXHIBIT HALL

4. 5:15 – 6:00

- a. **Young Adults Share & Care – Pavilion I – Mezzanine**
- b. **Men’s Share & Care – Pavilion III - Mezzanine**
- c. **Women’s Share & Care – Rooftop Bar – Top Floor**
- d. **Family Members Share & Care – Plaza Room – Top Floor**

6:00 -- 6:30 Break – Dress for Dinner-- *Put on your bling!* Or have a nap!

**6:30 – 9:00 Gala Dinner – Walk Awards – Alameda Ballroom**

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DAY 3 – Tuesday, April 17<sup>th</sup>

7:00 – 7:45                    Exercise Class – Pavilion I - Mezzanine

7:30 – 8:15                    Breakfast – Alameda Ballroom Salons II & III – Ground Floor

8:00 to 9:40 am              Conference Registration

8:00 – 1:00                    Exhibits

Plenary Session:            8:40 – 9:30    **Is Your Glass Half Full?** Positive Psychology, Coping – Melissa Wohlust – Alameda Ballroom Salons 1 A & B

Breakout Sessions:

9:40 – 10:30

1. **Walk Your Way to MG Fundraising Success** – Rich Mauch, National MG Walk Director – Pavilion I - Mezzanine
2. **Remission – What, Why, How** – Michael Hehir, MD, Neurologist & Associate Professor, University of Vermont Medical Center & Larner College of Medicine – Pavilion III - Mezzanine
3. **Better Breathing** – Peer to Peer discussion of breathing aides – Sally O’Meara, RN; Cheri Heitman, RN – Rooftop Bar
4. **Tackling Health Insurance Issues & Coming Out on Top** -- Michelle Dulashaw – TBC – Plaza Room – Top Floor

10:30 – 10:50 – Rest & Refreshment Break – Mezzanine Level & Top Floor

11:00 – 11:45

1. **Building MG Awareness**—June Awareness plus general – Tommy Santora & Alexis Rodriguez – Pavilion I -- Mezzanine
2. **Getting Your ZZZZ’s – Sleep and Wellbeing** – Suzanne Ruff, PhD, Psychologist, Veterans Administration, Retired – Pavilion III--Mezzanine
3. **Speech & Swallowing**— Cheri Heitman, RN; Sally O’Meara, RN, Oakland University School of Nursing; Kim Shirley Eldridge – Rooftop Ballroom– Top Floor
4. **Biomarkers in MG Research**—Milvia Pleitez, MD, Neurologist, Methodist Houston – Plaza Room – Top Floor

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|---------------|---|
| 11:55 – 12:50 | LUNCH (Awards) – Alameda Ballroom Salons 2 & 3 – Ground Floor                                 |
| 12:55 – 1:50  | <b>Ask the Professionals</b> -- a panel; audience questions – Alameda Ballroom – Salons A & B |
| 1:55 – 2:00   | Closing Remarks – Alameda Ballroom – Salons A & B   |

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