



MGFA National Conference
March 26 to 28, 2017

Astor Crowne Plaza Hotel
739 Canal Street, Corner of Bourbon Street
New Orleans, LA



Living Your Best Life with MG
Overview – Conference Program

Come a Day Early and Walk -- 2017 Annual New Orleans Walk

Saturday, March 25th
Lafreniere Park (Metairie, LA)
Check in 9:00 am - Walk Ceremony 10 a.m.
To learn more go to <http://www.mgwalk.org/>

Saturday, March 25th 2:00 pm -- Registration Begins

Conference Day 1 -- Sunday, March 26th

9:00 – 5:00 pm Registration Open
Exhibits Open

2:00 – 2:10 pm Welcome & Opening Remarks -- Astor Ballroom 1 - 3
 Tommy Santora, New Orleans Support Group Leader

2:10 – 2:35 pm Unwrap the Gift -- Astor Ballroom 1 - 3
Vickie Petz Henderson, MD, Keynote Speaker, MG Patient, Blogger: My Right Side Up Life, Arkansas Support Group Leader

2:40 – 3:30 pm Plenary: Becoming a Take Charge Patient -- Astor Ballroom 1 - 3
 Part 1: **Take Charge of Your Care**
 Panel with Nancy Law, MGFA CEO; Mike Ursic, MGFA Communications & Conference Development Committees Denise Trombly, Volunteer Leader, MGA of New England and Kim Eldridge, Patient & Community Services Committee

Concurrent -- Special Session for Support Group Leaders
2:40 to 5:45 pm -- Toulouse B
 Three hour workshop for SG Leaders. To RSVP, contact Nakeshia Betsill at nbetsill@myasthenia.org

NOTE: TBD = To Be Determined; TBC = To Be Confirmed



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Conference Day 1 -- Sunday, March 26th -- Continued

- 3:35 – 4:25 pm Part 2 of Being a Take Charge Patient -- **Being Prepared for Emergencies --**
Astor Ballroom 1 - 3
- Panel with Sally O’Meara, RN and Bruce Yelverton, former EMS
Director, and Shannon Wilson
- 4:30 – 5:15 pm Breakouts:
1. **Intro to MG -- Bienville**
MG for beginners – Michael Pulley, MD, University of Florida
College of Medicine
 2. **Test Yourself -- Iberville**
Are you an MG expert? – Katherine Ruzhansky, MD, Medical
University of South Carolina
 3. **Sero-Negative -- Bourbon**
Charlene Hafer-Macko, MD, Associate Professor of Neurology,
Geriatrics and Physical Therapy Rehabilitation Science University of
Maryland, School of Medicine (UMSOM), and Celia Meyer, RN
- 5:15 – 6:30 pm **Rest Period**
- 6:30 – 8:30 pm **Reception -- Astor Ballroom 1-3**
Enjoy a selection of hors d’oeuvres & socialize with fellow
conference goers
- 7:00 – 9:00 pm **Nurses Dinner -- St Louis Room**
International Management Guidelines for Myasthenia Gravis: A
Nursing Perspective -- Marilyn Ricci, RN

NOTE: Speakers to be determined (TBD)



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Conference Day 2 – Monday, March 27th

7:00 – 7:45 am Yes You Can Exercise with MG – An Exercise Class -- Iberville

Julia Naumes, OTD, OTR/L

Charlene Hafer-Macko, MD

7:00 – 6:00 pm Registration Open -- Astor Gallery Foyer

7:15 – 8:00 am Breakfast -- Astor Ballroom 1-3

7:30 – 11:30 am Exhibits -- Astor Gallery Foyer

8:00 – 8:45 am Get Moving to Improve Your Health -- Astor Ballroom 1 - 3

Charlene Hafer-Macko, MD

Associate Professor of Neurology, Geriatrics and Physical Therapy
Rehabilitation Science, University of Maryland, School of Medicine
(UMSOM)

8:50 – 9:30 am Thymectomy – 9:00 to 9:45 am -- Astor Ballroom 1 - 3

Gil Wolfe, MD

Irvin and Rosemary Smith Professor and Chair of the Department of
Neurology in the University at Buffalo's School of Medicine and
Biomedical Sciences

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Conference Day 2 -- Monday, March 27th -- Continued

9:35 – 10:20 am MG Research Panel – What’s happening now in MG Research

-- Astor Ballroom 1-3

- Robert Ruff, MD, PhD-- Retired Chief of Neurology at the Cleveland VA Medical Center and National Director of Neurology for the Department of Veterans Affairs
- Gil Wolfe, MD -- University at Buffalo's School of Medicine and Biomedical Sciences
- Gary Cutter, PhD – Professor of Biostatistics, University of Alabama, Scientific Director of the MG Patient Registry
- Richard Nowak, MD – Assistant Professor of Neurology, Director, Yale Myasthenia Gravis Clinic
- Jon Lindstrom, MD – Trustee Professor in Neuroscience, Perelman School of Medicine, University of Pennsylvania

10:20 – 10:45 am BREAK with Refreshments & Exhibits or Nap Time

10:45 – 11:45 am Breakouts:

1. MG in Children and Young People -- Bienville

Ann Tilton, MD, Professor of Clinical Neurology, Chief, Section of Child Neurology

2. Clinical Trials – What are they? Why participate? -- Toulouse B

Jurgen Venitz, MD, PhD, Professor of Pharmaceutics, School of Pharmacy, Medical College of Virginia of Virginia Commonwealth University

Róisín Armstrong, Vice President, Global Development Team Leader, Alexion

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Conference Day 2 – Monday, March 27th – Continued

3. Maximize Your Energy & Effectiveness -- Iberville

Julia Naumes, OTD, OTR/L

11:50 – 1:45 pm Luncheon – Collect your Bag Lunch and bring it to a Share & Care Session if you wish -- See list below:

12:15 – 1:45 pm Share & Care Sessions

- Millennials Managing MG [Born 1977 or later] -- Bienville
Mike Ursic, Member of Communications and Conference Planning Committees; Niki Grossheim, Support Group Leader, Julia Naumes, OTD, OTR/L
- Boomers Building a Life with MG [Born 1976 or earlier] -- Toulouse B
Denise Trombly, Volunteer Leader, MGA of New England
- Parents of Children or Adults with MG -- Iberville
Terri Adams, Parent, Support Group Leader
- Family & Supporters of People with MG – Hospitality Lounge 4th Floor
Kathryn Rodriguez, Support Group Leader

1:00 – 6:00 pm Exhibits

1:50 – 2:45 pm Breakouts:

1. Nutrition & Supplements – Astor Ballroom 1- 3

Rachel Adams, DCN – Can nutrition help you cope with MG? Learn optimal practices for your relationship with food.

2. Refractory MG – Bienville –

A Focus Group with Katherine Ruzhansky, MD, Medical University of South Carolina

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Conference Day 2 – Monday, March 27th – Continued

3. Awareness & Fundraising in Your Community – Iberville

Tara DiMilia, TellMed; Rich Mauch/Danielle Saccente, MGFA Walk Department; Paula McGinnis, Walk Volunteer; Betty Ross, Fundraising Consultant

4. Explaining MG to Family, Friends, and to Strangers – Toulouse B

Tommy Santora, New Orleans Support Group Leader; Mike Ursic, Communications Committee; Alexis Rodriguez, Atlanta Support Group Leader; Brittany Foley, Walk Team Captain; Trudy Stafford, RN, Nurses Advisory Board Member

2:50 – 3:10 pm Break – coffee, exhibits, rest time.

3:15 – 4:00 pm

Chat Tables – Astor Ballroom 1 – 3

Drop by an interesting topic and chat with like-minded conference goers. Led by volunteers with an interest or experience in the area.

Topics & Facilitators:

- Advocacy – Kim Eldridge, Patient & Community Services Committee
- Awareness & June Is MG Awareness Month – Tara DiMilia, TellMed Communications
- Fatigue – Tracey Young, Beaumont, TX Support Group Leader
- Fundraising in Your Community – Betty Ross, Fundraising Consultant
- IVIG – Sue Klinger, Board Member, New York Support Group Leader
- Nutrition – Rachel Adams, DCN
- Parents of Children with MG – Dr. Ann Tilton; Toni Brown, Connecticut Support Group Leader
- Patient & Community Services – Suzanne Ruff, PhD, Chair Patient & Community Service Committee; Nakeshia Betsill, Volunteer Program Manager
- Plasmapheresis – Lindsay Mochco & Rachel Kilian, MMBT, Medical Science Liaison-Therapeutic Apheresis, Terumo BCT
- MG Walk Campaign – Rich Mauch & Danielle Saccente, Walk Department; Paula McGinnis, Walk Volunteer

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Conference Day 2 -- Monday, March 27th -- Continued

4:05 – 5:05 pm

Breakouts:

1. **Dental Considerations -- Bienville, Note: Goes to 4:35**
Gene Casagrande, DDS, Director of International & Professional Relations, Milestone Scientific
2. **MG in the Workplace -- Astor Ballroom 1-3**
Tommy Santora, New Orleans Support Group, Moderator; Brooke Duncan III, Adams & Reese, LLP, Labor & Employment Team; Charlene Watkins, Human Resources, WWL-TV, New Orleans, Louisiana, A TEGNA Company; Scott Taylor, Audi USA Manufacturing; Ronnie Adams, Booz Allen Hamilton, Lead Associate
3. **Health Professionals Roundtable -- Iberville**
Charlene Hafer-Macko, MD – Associate Professor of Neurology, Geriatrics and Physical Therapy Rehabilitation Science, University of Maryland, School of Medicine (UMSOM) -- **All Health Professionals in Attendance Welcome**
4. **MG and Aging -- Bourbon Room**
Yuebing Li, MD, PhD, Cleveland Clinic

4:35 pm

Understanding MG Medications --Toulouse B

Robert Ruff, MD, Chairman, M/SAB, Retired chief of neurology at the Cleveland VA Medical Center and National Director of Neurology for the Department of Veterans Affairs

5:00 pm

Exhibits

Share & Care Sessions

- Managing Family Challenges – -- Toulouse
Toni Brown, Support Group Leader
- Workplace Challenges – Iberville
Pamela Hyman, Support Group Leader
- Coping Strategies – -- Bienville
Jessica Simmerman, Support Group Leader
- Advocating For Yourself – Hospitality Lounge-4th Floor
Rebecca Molitoris, Support Group Leader

6:00 pm

Break

6:30 pm

Awards Dinner -- Astor Ballroom 1-3

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Day 3 -- Tuesday, March 28, 2017

- 7:00 – 7:45 am **Yes, You Can Exercise with MG** – An Exercise Class – Toulouse B
Charlene Hafer-Macko, MD
Julia Naumes, OTD, OTR/L
- 7:00 – 11:50 am **Registration -- Astor Gallery Foyer**
Exhibits -- Astor Gallery Foyer
- 7:15 – 8:00 am **Breakfast -- Astor Ballroom 1 - 3**
- 8:00 – 8:55 am **Being a Woman OR, Being a Man with MG** -- Astor Ballroom 1- 3
Amanda Guidon, MD, Massachusetts General Hospital; Niki Grossheim, Support Group Leader, WI; Robert Ruff, MD, Chairman, M/SAB; Tommy Santora, New Orleans Support Group Leader
- 9:00 – 9:45 am **Concurrent Discussion Breakouts**
- For **Men** – Bienville
Tommy Santora, Support Group Leader
 - For **Women** –Astor Ballroom
Niki Grossheim, Support Group Leader
 - For **Family & Supporters** – Iberville
Kathryn Rodriguez, Support Group Leader
- 9:45 – 10:15 am **Break**

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Day 3 -- Tuesday, March 28, 2017 -- Continued

10:15 – 10:40 am **MG Strong – Nancy Law** -- Astor Ballroom 1-3

10:45 – 11:45 am Exhibits

Breakouts:

1. **The MG Journey** -- Astor Ballroom 1-3

Jon Shinefeld, RN, Temple University Hospital, Moderator; Suzanne Ruff, PhD, Psychotherapist; Trudi Stafford, RN; Marsha Bode

2. **Tackling Insurance Issues** – Toulouse

Dan Larriviere, MD, Ochsner Medical Center, New Orleans, Moderator; Jon Wilcox, Patients Rising Co-Founder; Michelle Dulashaw, MG Association of Western Pennsylvania; AxelaCare representative TBD

11:50 – 12:45 pm Luncheon -- Astor Ballroom 1 - 3

12:45 – 2:00 pm **Ask the Professionals -- Panel of Experts Q&A**

-- Astor Ballroom 1 - 3

- Charlene Hafer-Macko, MD
- Robert Ruff, MD, PhD
- Jurgen Venitz, MD
- Marilyn Ricci, RN
- Katherine Ruzhansky, MD
- TBD

2:00 pm

Closing Remarks -- Sue Klinger, Board Vice Chairman

NOTE: Speakers to be determined (TBD)