

**Amyloidosis Support Groups Presents the  
5th ATTR/Hereditary Amyloidosis Support Meeting - 10/27/2017-10/29/2017**

*Hilton - Chicago O'Hare Airport Hotel, Chicago, Illinois 60666  
Amyloidosis Support Groups toll free line 1-866-404-7539*



Amyloidosis Support Groups welcomes you to the 5th Familial/Hereditary and ATTR Amyloidosis Support Group Meeting.

The conference has been organized to educate, inform and share all available information about the disease, current and future treatments, and clinical trials. We hope the expert presentations, as well as peer group support, will help to not only educate, but empower as well.

Registration starts Friday evening at 7:00pm, at the Meet and Greet in the International Ballroom (7) on the Arcade Level. You will receive a name tag and lanyard. There is an additional registration on Saturday morning just outside the Grand Ballroom on the Lobby floor. You will then receive bags, clipboards, notepaper, pens and other goodies. If you were not able to attend the Friday Meet and Greet, you will have another opportunity to get name tags and lanyards as well. Please be at Saturday morning registration early since the meeting will be starting promptly at 8:00am.

Seats towards the front are reserved for our patients and their caregivers. We do ask others to take a seat towards the back. Bathrooms next to the Grand Ballroom are reserved for our patients who are less mobile. We have made arrangements with the hotel to use the bathrooms in the Athletic Club (11). Just take the West Elevators down to the Arcade Level.

If you booked your room in our “AMY” block, you will be served breakfast from 6:30 to 7:45am on Saturday and 6:45 to 8:15am on Sunday on the Arcade level in the International Ballroom (7).

All meals will offer low and no sodium items, as well as vegetarian and gluten free alternatives for those of you who requested them.

The agenda will have more detailed information. If you have any immediate needs that you feel are not addressed, or have any questions, please text me at 708-987-7711.

We would like to take this opportunity to thank our participants from the Amyloidosis Community (doctors, medical professionals, presenters and volunteers). We would also like to thank our Pharma Sponsors, Alnylam, Ionis, Pfizer and Prothena for their financial support for much of this weekend.

Muriel Finkel

Amyloidosis Support Groups Inc.

[www.AmyloidosisSupport.org](http://www.AmyloidosisSupport.org)

## **ATTR - HEREDITARY AGENDA**

**Friday Night Meet and Greet. Registration: 7:00-9:30pm** (bar closes at 9pm) International Ballroom)

**Saturday Morning Breakfast: 6:30-7:45pm** (International Ballroom - 7)

**Registration 7:00-8:00am** (Grand Ballroom - Lobby Level)

### **MEETING – SATURDAY OCTOBER 28, 2017 (Grand Ballroom)**

6:30-7:45am	<b>Breakfast:</b> Seating in the <b>International (7); Orchard (14); and Lake Shore(15)</b> rooms on the <b>Arcade level</b> with <b>Food Buffet setup in State (8)</b> room.
8:00-8:10am	<b>Welcome – Muriel Finkel</b>
8:10-8:20am	<b>Why are we here? – Dr. Gertz</b>
8:20-8:30am	<b><u>Nomenclature.</u></b> (ATTRmt or hATTR) – <b>Dr. Benson</b>
8:30-8:55am	<b><u>TTR Amyloidosis Overview.</u></b> Wild Type (wt) and Mutant (mt). – <b>Dr. Maurer</b> <i>Q and A (5 minutes)</i>
8:55-9:20am	<b><u>NON ATTR.</u></b> Fibrin. Apo. Alect2 and others. (Where do they come from? Is the liver involved?) – <b>Dr. Berk.</b> <i>Q and A (5 minutes)</i>
9:20-9:45am	<b><u>Genetics.</u></b> Who should be tested? When, why, how, who, and what? How does insurance work? – <b>Agre, M.S., CGC.</b> <i>Q and A (5 minutes)</i>
9:45-10:10am	<b><u>Diagnosis.</u></b> Biopsy Fat Pad, Cardiac, Nerve, Scan PYP, others) – <b>Dr. Picken</b> <i>Q and A (5 minutes)</i>
10:10-10:35am	<b>BREAK (25 minutes).</b> Utilize Arcade Level, Room 11 (Health Club) bathrooms first.
10:35-11:00am	<b><u>Cardiac – (Heart before and after TTR)</u></b> Why and how is heart affected? Which variants are seen the most? – <b>Dr. Grogan.</b> <i>Q and A (5 minutes)</i>
11:00-11:25am	<b><u>Neuropathy- (Nerves before and after TTR)</u></b> Why are nerves affected? Which variants are seen the most? What can be done about Carpal Tunnel, PN, AN? – <b>Dr. Waddington-Cruz.</b> <i>Q and A (5 minutes)</i>
11:25-11:50am	<b><u>GI (Gastro-Intestinal)</u></b> When is it the disease or neuropathy? How do we treat? Which variants seen the most?)- <b>Dr. Clarke.</b> <i>Q and A (5 minutes)</i>
11:50-12:15pm	<b><u>Solid Organ Transplant</u></b> – (When? Which variants do best? Trials - When?) – <b>Dr. Dispenzieri.</b> <i>Q and A (5 minutes)</i>
12:15-1:15pm	<b>LUNCH:</b> Seating in the <b>International (7); Orchard (14); and Lake Shore(15)</b> rooms on the <b>Arcade level</b> with <b>Food Buffet setup in State (8)</b> room.
1:15-1:35pm	<b>Anylam Presentation – Pritesh Gandhi</b>
1:35-1:55pm	<b>Ionis Presentation – John Berk</b>
1:55-2:15pm	<b>Pfizer Presentation – Leslie Amass</b>
2:15-2:35pm	<b>Prothena Presentation – Wagner Zago</b>
2:35-2:55pm	<b>Non Clinical Trial Treatments</b> (Diflunisal, doxycycline, Green Tea/ EGCG, Anti-Oxidants, Ursidal, Tudca others) – <b>Dr. John Berk</b>
2:55-3:25pm	<b><u>Pharma and Non Clinical Trials Treatments.</u></b> <i>Q and A (all on dais with Dr. Morie Gertz as moderator)</i>
3:25-3:55pm	<b>BREAK (30 minutes)</b> Utilize Arcade Level, Room 11 bathrooms first.

### **BREAKOUT SESSIONS: 3:55pm - 5:30pm - (Listed on next page ⇨)**



**More bathrooms are on Arcade Level, Room 11.** We ask bathrooms adjacent to the Grand Ballroom be saved for patients who are less mobile as there are only a couple of each. See Map on page 4.

## ATTR-HEREDITARYAGENDA (continued):

**Breakout Sessions: 3:55pm - 5:30pm (10/28/2017 Continued)**

**BREAKOUT SESSIONS ARE RUNNING CONCURRENTLY.**

**YOU MAY MOVE FREELY IN AND OUT OF ALL SESSIONS (SEE MAP TO LOCATE ROOMS).**

1. **Wild Type ATTR** – Hanna, Judge, Gertz. *(In REAR of GRAND BALLROOM.)*
2. **Cardiac** – (Symptoms, coping, and treatments) – Grogan, Ruberg, Maurer, Nativi.  
*(In FRONT of GRAND BALLROOM.)*
3. **Neuropathy, GI, Caregiving and Coping** – (Peripheral and Autonomic) - OH, GI, CT, etc.,  
– Clarke, Juster-Switlyk, Waddington-Cruz. Mayo: PT, Sarah Boyd, OT, Sarah Dahlhauser.  
*(In CHICAGO (18))*
4. **Genetic Issues and Non ATTR variants.** When to tell the kids? When and how should I be tested? – Agre, Brown, Berk, Picken. *(In TOKYO ZURICH (11,12))*
5. **Clinical Trials: Clinical Trial Representatives:** Benson, Dispenzieri, Kelly. *(In ATHENS BERLIN (1,2))*

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6:30-8:00pm	<b>DINNER:</b> Seating in the <b>International (7); Orchard (14); and Lake Shore(15)</b> rooms on the <b>Arcade level</b> with <b>Food Buffet setup</b> in <b>State (8)</b> room.
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## **SUNDAY OCTOBER 29, 2017 (Grand Ballroom)**

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6:45am – 8:15am	<b>Breakfast:</b> Seating in the <b>International (7); Orchard (14); and Lake Shore(15)</b> rooms on the <b>Arcade level</b> with <b>Food Buffet setup</b> in <b>State (8)</b> room.
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8:30am – Noon	<b><u>Q AND A WITH DOCTORS FACILITATED BY DR. GERTZ (Grand Ballroom)</u></b>  <i>Please turn in your questions to Muriel, Steve, Elinda, Pat, Paula, Liz, Mike or Tracey.</i>
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Noon – 1:30pm	<b>Farewell Lunch:</b> In the <b>International (7); Orchard (14); and Lake Shore (15)</b> rooms on the <b>Arcade level</b> with <b>Food Buffet setup</b> in <b>State (8)</b> room.
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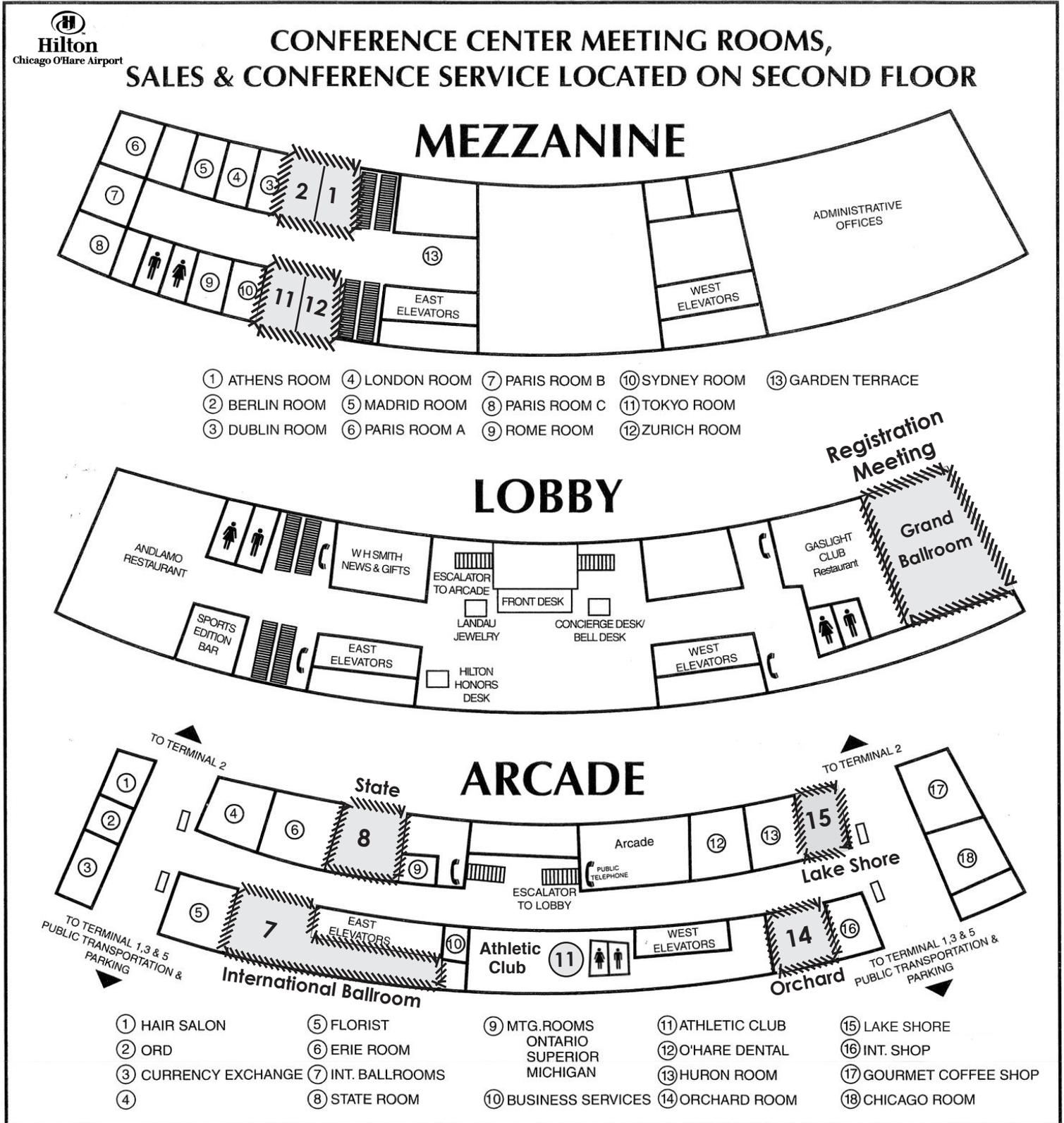
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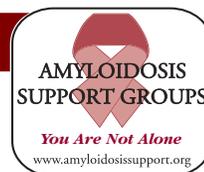
Please utilize the map below for locating meeting rooms and bathrooms.

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## AMYLOIDOSIS SUPPORT MEETING SPEAKERS AND CONTRIBUTORS



**Muriel Finkel. Founder and President of Amyloidosis Support Groups**

**Morie A Gertz, M.D., M.A.C.P., Chair.** Roland Seidler Jr. Professor and Chair Department of Medicine. College of Medicine. Mayo Distinguished Clinician. Mayo Clinic, Rochester, MN. Departments: Hematology, Cancer and Transplant Centers. Special interest: Amyloidosis.

**Merrill D. Benson, M.D. ,Professor of Medicine, Professor of Medical Genetics.** Indiana University. 2003 Pasteur-Weizmann/Servier International Prize in Biomedical Research. Interests: Amyloidosis, regulation of gene expressions; synthesis and metabolism of plasma proteins.

**Mathew S. Maurer. M.D., Medical Director,** HCM Center at New York-Presbyterian/Columbia. Advanced training in heart failure and cardiac transplantation. Specializes in heart failure and preserved ejection fraction.

**John L. Berk, M.D., Associate Professor of Medicine. Clinical Director, The Amyloidosis Center.** Director, Localized Amyloid Clinic. Boston University School of Medicine. Interests: PI, Diflunisal Trial – FDA & NIH funded Radiotherapy for tracheobronchial Amyloidosis.

**Katherine Agre, M.S., CGC, Genetic Counselor.** Mayo Clinic, Rochester, Minnesota.

**Maria M. Picken, M.D., FASN. Professor. Director, Transplant Pathology.** Interests: Amyloid, Genitourinary Pathology, Kidney Transplant and disease. Loyola University Health System, Maywood, IL.

**Martha Grogan, M.D. Assistant Professor of Medicine.** Mayo Clinic, Rochester, MN. Cardiovascular Diseases. Interests: Amyloid heart disease; Echocardiography; Reversible cardiomyopathies.

**Márcia Waddington-Cruz, M.D., PhD is Chief of the Neuromuscular Diseases** Unit at the University Hospital, Federal University of Rio, Brazil.

**John O'Brien Clarke, M.D. Director, Esophageal Program.** Clinical Associate Professor, Gastroenterology and Hepatology. Stanford University School of Medicine.

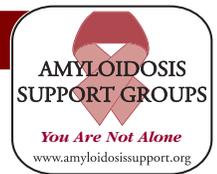
**Angela Dispenzieri, M.D.** Mayo Clinic, Rochester, MN. President International Society of Amyloidosis. Research Interests: Plasma cell disorders like primary systemic amyloidosis, POEMS syndrome, multiple myeloma, and cryoglobulinemia.

**Pritesh Gandhi, PharmD, R.Ph. Vice President Medical Affairs, Alnylam Pharmaceuticals**

**Leslie Amass, PhD. US Medical Director, Tafamidis**

**Wagner Zago, Ph.D. in Pharmacology. Chief Scientific Officer, Prothena**

## AMYLOIDOSIS SUPPORT MEETING SPEAKERS AND CONTRIBUTORS



**Mazen Hanna, M.D. Director of the Heart Failure Intensive Care Unit and Co-Director of the Amyloid Program.** Cleveland Clinic. Interests: cardiomyopathy, heart failure, heart transplantation and mechanical circulatory assist devices, pulmonary hypertension, and cardiac amyloid.

**Daniel Philip Judge, M.D. Professor of medicine in cardiology at MUSC** (Medical University of South Carolina).

**Frederick L Ruberg, M.D. Director, Advanced Cardiovascular Imaging Program.** Associate Director, Cardiovascular Fellowship Program Associate Professor of Medicine and Radiology, Boston University School of Medicine.

**Jose Nativi-Nicolau, M.D. Assistant Professor of Medicine at the University of Utah. Cardiovascular Director of the Amyloidosis Program** at the University of Utah and Huntsman Cancer Institute.

**Kelsey Juster-Switlyk, M.D. Assistant Professor in the Division of Neuromuscular Medicine** within the Department of Neurology at the University of Utah.

**Sarah Boyd, DPT/Physical Therapist.** Mayo Clinic, Rochester, Minnesota.

**Sarah Dahlhauser, DOT, OTR/L Occupational Therapist.** Mayo Clinic Physical Medicine and Rehabilitation. Rochester Minnesota.

**Dr. Jeffrey W. Kelly, Ph.D. Co-founder of FoldRx Pharmaceuticals,** Boston, MA. 2003 - Enabled Vyndaqel (Tafamidis) European Drug Agency Approval in 2011 and Japanese approval (2013). This compound was discovered by the Kelly Laboratory to treat Familial Amyloid.

**Emily Brown, MGC, CGC. Certified Genetic Counselor.** Johns Hopkins Hospital, Center for Inherited Heart Disease. Baltimore, Maryland.