



**American Nystagmus Network**

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MOVING



FORWARD

**2017 Conference | Minneapolis, MN | July 28-30**

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# 2017 ANN Conference Schedule

## Friday, July 28, 2017

### 5:00 p.m. Break out:

- |                                       |                        |
|---------------------------------------|------------------------|
| 1) Adults with Nystagmus              | <i>Lake Minnetonka</i> |
| 2) Parents of Children with Nystagmus | <i>Calhoun B</i>       |
| 3) Children                           | <i>Calhoun A</i>       |

**6:00 p.m. President's Welcome and Reception** *Skygarden*

**7:00 p.m. Research Updates from Around the World** *Great Lakes Ballroom*

Nystagmus is an active area of medical research. There are many researchers at universities and institutions around the world performing cutting edge studies on nystagmus. Several of these researchers will come to us by video to introduce themselves and describe their latest work.

**Evening Social** *Suite 720*

Following the presentation feel free to join us for an evening social in suite 720.

## Saturday, July 29, 2017

**8:15 a.m. Breakfast** *Great Lakes Ballroom*

Breakfast is served from 8:15 a.m. to 8:45 a.m.

**8:45 a.m. All-Day Children Activities**

**Camp Nystagmus** *Calhoun A*

While the adults, teens and parents attend the conference, a day camp "Camp Nystagmus" for children (K-8) will be held concurrently. The camp will bring together students for a fun day that allows them to discuss what it is like to have nystagmus or to have a family member with nystagmus.

**Babysitting** *Calhoun A/Suite 721*

Children under 4 will be participating in the beginning of Camp Nystagmus then they will move to suite 721. Please pick up your children before lunch and dinner. Children should attend meals with their parents.

**9:00 a.m. Keynote - Eye Movement Recordings** Dr. James Phillips, Ph.D. *Great Lakes Ballroom*

Eye movements are valuable and necessary components of most human activities. Misdirected eye movements result in significant challenges in performing the activities of daily life. Elimination of eye movements also poses significant challenges. Both of these occur with disease, injury, and abnormal development, and also with the treatment of these conditions. One such condition is congenital nystagmus.

Eye movement recording can yield valuable insights into the cause of congenital nystagmus. It can also be used clinically in support of treatment for patients with nystagmus. In classic congenital nystagmus, there are orbital eye positions that are associated with minimal eye movements (the so-called “null point”). There is often a progression in the characteristic (or waveform) of the eye movements with age, such that large amplitude pendular eye movements ultimately becomes small amplitude jerk movements. The jerks are thought to be associated with repositioning the fovea (the high resolution part of the retina) on objects of interest in the visual world. Specific waveforms are known to be associated with compromise of specific regions in the central nervous system. Treatments can be evaluated with longitudinal oculomotor recording, providing before and after treatment comparisons of the nystagmus eye movement. However, despite all of the promises of eye movement recording, it cannot actually directly define the functional benefits of the various treatment strategies that are currently available.

**10:30 a.m. Break**

**10:45 a.m. Session 1**

**Common parental and provider concerns related to congenital nystagmus**

Dr. Avery Weiss, M.D.

*Calhoun B*

This workshop will address typical questions. What is my child’s visual potential? • Which nystagmus parameter is the best predictor of visual acuity? • Perceived nystagmus intensity? Nystagmus waveform? Eye velocity? • Is his/her visual world in continuous motion? How is the visual world stabilized? • Does he/she need neuro-imaging? • What is the evidence that my child would benefit from nystagmus surgery? • If so what is the expected level of visual improvement in terms of visual acuity? • Nystagmus intensity? • Head turn? • Does my child have a disorder confined to the eye or do I need to be concerned about an underlying systemic disorder? • Will my child be able to drive a car? • Under what circumstances would my child benefit from glasses? • Is there conclusive evidence that I should pursue nystagmus surgery to reduce the motion blur in infancy because it limits visual acuity development? • Is the family history of similarly affected relatives important? • What is the significance of the FRMD mutation identified in familial cases of IN in the absence of a visual sensory defect?

**Tips for Living with Nystagmus**

James Rath &amp; Jim Conley

*Lake Harriet*

This interactive session focuses on peer-to-peer coaching. We uncover tips, strategies and tools we use at home, at work or school, and while traveling to overcome some of the challenges in our daily lives. Past participants often recall finding simple, yet life-altering techniques that help reduce stress, and raise productivity and satisfaction with many of life's everyday tasks. We'll also examine how we approach life and challenges on both "good days" and "bad days" and learn strategies from one another to keep perspective and to keep moving... forward no matter what kind of day we're having.

**11:45 a.m. Lunch***Great Lakes Ballroom***1:00 p.m. Session 2****Nystagmus in a School Setting**

Evelyn Gonzalez

*Calhoun B*

This workshop will explore the difference between IEPs and 504s and how they apply to students with nystagmus. Come learn the difference between accommodations and modifications and see examples from real classrooms. Gain knowledge on how to prepare for a meeting with various school educators. Strategies for state and national testing will also be covered.

**Driving with Nystagmus**

Aida Webber

*Lake Harriet*

In this session, Aida Weber, licensed certified driving rehab specialist and a MN licensed driver instructor for the Courage Kenny Rehab Institute in MN will review common standards for driving and the various driving assessment methods. She'll also touch upon available adaptations (which vary from state to state) and will review considerations that balance independence with safety and the changing views around driving for millennials and adults today.

**2:00 p.m. Break****2:15 p.m. Session 3****Low Vision Resources and Options - Dr. Dennis W. Siemsen, O.D. *Lake Harriet***

In this session we'll examine various vision specialties and low vision resources that are available to parents and patients with nystagmus. Our goal will be to help you communicate effectively and efficiently with medical and non-medical partners and providers as you chart your course to navigate the best treatment, accommodations or other low vision resources. We'll also leave time for Q&A to learn how Dr Siemsen deals with patients and families as they seek treatment from various eye-related specialties at the Mayo clinic.

**2:15 p.m. Session 3**

**Animal Models to Aid Our Understanding of Infantile Nystagmus**

Dr. Linda Mcloon, Ph.D.

*Calhoun B*

A number of recent studies have suggested the children with albinism and nystagmus show evidence of slower maturation of the retina, which resulted in increased visual acuity over the early school years. We have examined the extraocular muscles removed from children having normally scheduled surgery to improve head position in nystagmus from both children with nystagmus alone and from children who have both albinism and nystagmus. We have made a number of observations that suggest, similar to what was described in the retina, that there is a slower maturation of the connections from the brain that control eye movements. We are working with animal models of nystagmus to determine how these maturational differences might be accelerated to decrease nystagmus and hopefully improve vision.

**3:15 p.m. Break**

**3:30 p.m. Session 4**

**Adult Nystagmus Panel**

*Lake Harriet*

A panel of adults with nystagmus will answer questions from the audience. In this session we look for common themes, questions, challenges, and tools we all use to live our best lives. The discussion is open, honest, and a terrific way to gain perspectives and to form bonds with other participants that will last throughout the conference and beyond.

**Teen Panel**

A panel of high school and college students with nystagmus will answer questions from the audience. Students supporting students cover the gamut of topics from individual plans to handling social situations and everything in between!

**4:30 p.m. Break**

**6:00 p.m. Dinner**

*Great Lakes Ballroom*

**7:00 p.m. Evening Social**

*Suite 720*

Following dinner, feel free to join us for an evening social in suite 720.

**Sunday, July 30, 2017**

**9:00 a.m. Membership Meeting**

*Lake Minnetonka*

*(Breakfast will be served for membership meeting attendees)*

Join us for the ANN membership meeting. During this meeting we'll discuss ANN's finances, priorities for activities, support fundraising, and board membership and volunteer opportunities. Everyone is welcome and encouraged to attend. Discussion items include:

- ANN budget
- what we have planned for ANN's future,
- open forum to ask the ANN Board of Directors questions
- general business for the organization.

**10:30 a.m. Close of the Membership Meeting**

## Speaker Biographies:

### James. O. Phillips, Ph.D.

Keynote



Dr. Phillips joined the faculty at the University of Washington in 1998, and is currently a Research Associate Professor in the Department of Otolaryngology-Head and Neck Surgery. He is also the Director of the Dizziness and Balance Center at the University of Washington Medical Center (UWMC), the Vestibular Diagnostic Laboratory at UWMC, the Roger Johnson Clinical Oculomotor Laboratory in the Division of Ophthalmology at Seattle Children's Hospital. Prior to joining UW, he earned a Ph.D. in Psychology and in Physiology from the University of Washington. Dr. Phillips teaches in the Departments of Otolaryngology-HNS, Ophthalmology, and Speech and Hearing Sciences. He is a faculty research affiliate of the National Primate Research Center, the Virginia Merrill Bloedel Hearing Research Center, the Center on Human Development and Disability, and the Autism Center at the University of Washington. He is also a faculty affiliate of the Center for Navigation and Communication Sciences at the University of Rochester and the Center for Integrative Brain Research at Seattle Children's Research Institute. He is on the Medical and Scientific Advisory Board of the Vestibular Disorders Association.

Dr. Phillips explains his research interests as follows:

Our group studies the brainstem control of oculomotor and vestibular function. We work on developing treatment and diagnostic technologies for vestibular and oculomotor disorders. We study the genetics of these disorders and the development of eye, head, body movement. We are also trying to understand the underlying neural mechanisms that subserve these functions in infants and adults.

### Avery H. Weiss, M.D.

Session One



Dr. Weiss was born and raised in Gainesville, Florida. He earned his bachelor's degree from the University of Florida. He completed his medical degree at the University of Miami. Following his internship and residency in internal medicine he was a research fellow and then completed his ophthalmology residency at Washington University in St. Louis, Missouri. He then completed a fellowship in pediatric ophthalmology at Children's Hospital National Medical Center in Washington, DC.

Avery H. Weiss, MD, is chief of the Division of Ophthalmology at Seattle Children's Hospital and professor of ophthalmology at the University of Washington, School of Medicine. His clinical interests include visual disorders, eye movement abnormalities, cataract and glaucoma, retinoblastoma and orbital tumors, ocular malformations and ophthalmological manifestations of systemic diseases.

His research focuses on three areas: 1) visual cortical function in infants with optic nerve and brain malformations, visual pathway tumors, amblyopia and cortical visual impairment; 2) eye movements in normal children and children with brain tumors, malformations, nystagmus, and characterization of abnormalities of the oculomotor plant in craniofacial disorders; and 3) assessment of macular development, probing local retinal function and development of retinal imaging techniques to study congenital and genetic retinal diseases. He served on the editorial board of EyeNet, official journal of the American Academy of Ophthalmology, and he received an honor award in recognition of his contributions to the academy. He has published 90 papers and book chapters, and he has been ad hoc reviewer for 18 journals.

## Speaker Biographies (cont.):

### Jim Conley

Session One

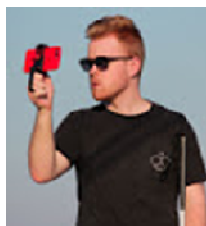


Jim joined the board of the American Nystagmus Network in 2011 and became board president in 2015. Jim has nystagmus. From 2014 through 2017 Jim worked at YouTube where he led Creator Education and Professional Certification programs for millions of YouTube creators around the world.

Jim has traveled extensively both for his job and for enjoyment and is happy to share tips and tricks for using technology to bring the world closer. Jim has an B.A. from Georgetown University and a Masters in Education from Harvard University. He has various hobbies including photography, writing and karaoke.

### James Rath

Session One



James is a legally blind [Ocular Albinism, Nystagmus], filmmaker, director, actor, and Pokémon Master. His YouTube channel has over 11,000 subscribers and half a million views. James' videos explore his passion for technology, accessibility, and living on the spectrum of blindness. James' breakout video "How Apple Saved My Life" resulted in James sitting down for coffee with Apple CEO Tim Cook on his channel. He continuously provides feedback for companies such as Apple on their efforts of accessibility.

### Evelyn González

Session Two



Evelyn, her husband, and four college age children live in San Leandro, CA. Her oldest and youngest sons both have INS. Evelyn holds a degree in biology from the University of Maine and worked in the field of cytogenetics for nearly a decade. She returned to graduate school and received a M.Div. degree from the Dominican School of Philosophy and Theology at the Graduate Theological Union in Berkeley, CA. She served for eight years as the Director of Youth and Young Adult Ministry for the Diocese of Oakland. One of her responsibilities was to write curriculum. As a parent of two children with nystagmus, she became very aware of how accommodations for various student needs could enhance the curriculum for these students. Currently, she serves as a school board trustee for the San Leandro Unified School District. She also serves on the board of the Mid Alameda County Special Education Local Plan Area.

### Aida Lacson Weber

Session Two



Aida Weber has a Master's Degree from the Medical University of South Carolina with experiences ranging from acute care, inpatient rehabilitation, outpatient rehabilitation, day program, skilled nursing therapy and home health therapy with an expertise working with spinal cord injuries. Presently, she is working as a certified driving rehab specialist and a MN licensed driver instructor for the Courage Kenny Rehab Institute in MN.

She administers comprehensive driving assessment including the clinical and the behind-the-wheel portion, provides driving lessons as needed as well as recommend adaptive equipment for clients in many of the offsite locations including Golden Valley, Coon Rapids, Buffalo, New Ulm and Cambridge.

## Speaker Biographies (cont.):

**Dennis W. Siemsen, O.D.**

Session 3



Dr. Siemsen works in Rochester, MN and specializes in Optometry. Dr. Siemsen is affiliated with Mayo Clinic Hospital-Rochester Methodist Campus and Saint Marys Hospital. A frequent speaker and educator, Dr. Siemsen often leads patients through an interdisciplinary approach to vision care helping ensure patients and families can navigate the specialties and treatments or accommodation options available to them across a variety of low vision diagnoses.

**Linda K. McLoon, Ph.D.**

Session 3



Dr. Linda McLoon is currently a tenured Professor in the Departments of Ophthalmology and Visual Neurosciences and Neuroscience at the University of Minnesota. She received her B.S. from the State University of New York at Binghamton and her PhD in Anatomy from the University of Illinois at the Medical Center in Chicago. She undertook postdoctoral studies at the University of Washington and the Medical University of South Carolina. She currently studies potential mechanisms for and treatments of diseases of the extraocular muscles (EOM) with a focus on pharmacologic approaches to the treatment of ocular motor disorders. She is the author of over 93 peer-reviewed publications and 20 book chapters. Dr. McLoon serves the EY section as their elected Trustee for the Association for Research in Vision and Ophthalmology (ARVO) and is current Vice-President. Additionally, she is on the editorial board for the journal *Investigative Ophthalmology and Visual Science (IOVS)* and the journal of the American Association of Ophthalmology and Strabismus (AAPOS), served as the Orbit Section editor for the Elsevier *Encyclopedia of the Eye*, and co-edited a book on *Craniofacial Muscles*. Her research has a long history of National Institutes of Health (NIH) funding as well as support from numerous private research foundations. She has served the research community by participation in a number of study sections for NIH and other national and international foundations. In her laboratory, she has mentored over 50 undergraduates, 60 medical students, as well as numerous graduate students and fellows.

Dr. McLoon explains her research interests as follows:

My laboratory focuses on developing pharmacologic treatments for a number of diseases of the eye and orbit. We study craniofacial muscles and their innervation with a focus on extraocular muscles (EOM). Strabismus and Infantile Nystagmus: Eye movement disorders affect the ability of the visual system to process the visual world correctly. Ongoing processes of remodeling in adults suggest that pharmacologic manipulation of the EOM for treatment of strabismus and infantile nystagmus is possible. We were the first lab to demonstrate that direct muscular injection of insulin growth factors I or II results in significant increase muscle force generation and myofiber size. Sustained delivery of these and other muscle signaling factors results in significantly altered muscle size and force generation that continues for several months after treatment ends. We have treated a strabismic non-human primate and improved its eye alignment, demonstrating proof of principle. However, it is clear that we need to change the brain if these changes are to be sustained. We are now studying how various perturbations in the EOM periphery might alter synapses and perineuronal nets on the ocular motor neurons that innervate these muscles. In a collaborative study, we are assessing how these growth factors alter neuronal firing patterns. We are also comparing whether different growth factors have different effects on the innervating motor neurons. Hopefully, we will be able to generate a new treatment for the millions of children who suffer from these ocular motor disorders.

