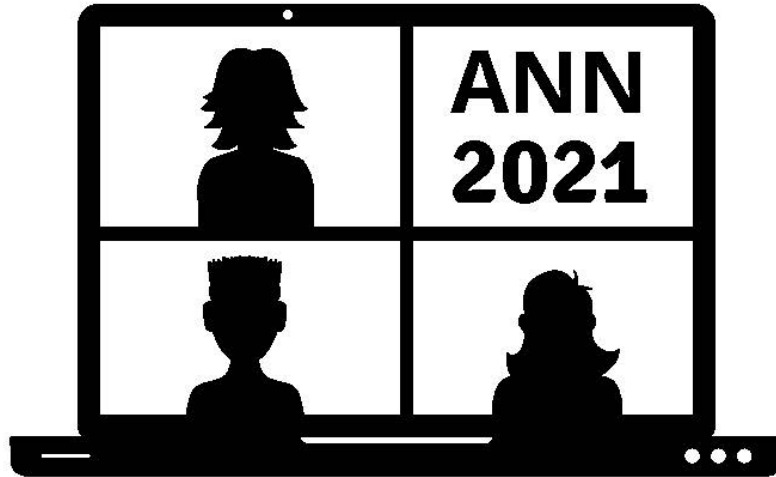




**American Nystagmus Network**



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Support Into Focus



**2021 ANN Conference  
July 23 - 24, 2021**



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# 2021 ANN Conference Schedule

## Friday, July 23, 2021

6 PM Eastern Time/5 PM Central/3 PM Pacific **Breakout Sessions:**

Join the session of your choice to connect with other people with similar experiences of nystagmus.

- **Adults with Nystagmus**
- **Parents of Children with Nystagmus**
- **Teens with Nystagmus**
- **Partners/Siblings/Friends of Adult with Nystagmus**

7 PM ET/6 PM CT/4 PM PT **Break**

7:15 PM ET/6:15 PM CT/4:15 PM PT **President's Welcome and Conference Introduction**

7:45 PM ET/6:45 PM CT/4:45 PM PT **Breakout Rooms for Informal Conversations**

9 PM ET/8 PM CT/6 PM PT **Informal conversations end**

## Saturday, July 24, 2021

10 AM ET/9 AM CT/7 AM PT **Research Updates from Around the World**

Learn what is new in the field of nystagmus research. Presenters from around the world will share their nystagmus research with conference attendees.

11 AM ET/10 AM CT/8 AM PT **Break**

11:15 AM ET/10:15 AM CT/8:15 AM PT **Session 1**

**Genowhat? (Genetics of Nystagmus)** - Dr. Jay Self, BM, FRCOphth, PhD

Where are the mis-stacked building blocks? A basic review of genetics will be presented to provide a solid foundation. We will then delve into the genetics of nystagmus, including what we know so far, why it is important, and what testing can be done.

## **Creating a healthy mindset for your nystagmus - Dr. Howard Maziar, MD**

This interactive seminar starts with looking into research in common challenges and perceptions around living with nystagmus. We will look at research findings made in “Living with nystagmus: a qualitative study” conducted by Rebecca Jane McLean, Kate C Windridge, and Irene Gottlob and present some of the common themes among research participants who explored daily challenges presented by nystagmus. This session will also provide an open discussion into strategies and tools for dealing with stressful situations that can arise as we move through our everyday lives and how to establish a healthy mindset in the face of common challenges.

## **Driving with Low Vision - Dr. Henry Greene, OD, FAAO**

A diagnosis of nystagmus does not automatically make you ineligible to drive. In most states in the US, Australia, the Netherlands, and some provinces in Canada, individuals with a visual impairment may be eligible to drive using bioptic telescopes. This presentation briefly explores the issues regarding vision and safe driving and how low vision experts can prescribe biopic telescopes to enhance driving safety.

12:15 PM ET/11:15 AM CT/9:15 AM PT      **Break**

12:30 PM ET/11:30 AM CT/9:30 AM PT      **Session 2**

## **Living with Nystagmus - Jim Conley**

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.

## **Enhancing Distance Vision for the Visually Impaired - Dr. Henry Greene, OD, FAAO**

Vision not only supports our ability to read but it is also an important social sense. It allows us to make eye contact, read body language, and feel connected to the world around us. Individuals with a visual impairment may feel isolated and studies show that some even become depressed. This presentation explores how low vision experts assess and treat distance vision issues and how distance-oriented vision aids can help individuals academically, vocationally, and socially.

1:30 PM ET/12:30 PM CT/10:30 AM PT      **Break**

1:45 PM ET/12:45 PM CT/10:45 AM PT      **Lunch Conversations**

- Sports and Nystagmus
- Awkward situations & Misconceptions
- Nystagmus in a school setting
- Parents of children with Nystagmus
- Teens with Nystagmus
- Adults with Nystagmus
- Navigating Health Insurance

2:45 PM ET/1:45 PM CT/11:45 AM PT **Break**

3:00 PM ET/2:00 PM CT/Noon PT **Session 3**

**A Story of Discovery and Change: What We Learned From Studying Nystagmus In Infancy and Childhood** - Dr. Richard Hertle, MD

This presentation will summarize decades of research and experience diagnosing and treating nystagmus in infancy and childhood.

**Pharmacological Treatments for Nystagmus** - Dr. Ed Chin, PharmD

Treatment of nystagmus has been proposed to include medical, optical, surgical, and other miscellaneous treatments. Most treatments aim to suppress abnormal eye movement without affecting regular eye movements. Others seek to negate the visual consequences of abnormal eye movements. Choice of treatment depends on the type of nystagmus and its characteristics. Even though some patients will benefit from one treatment approach, others will require a combination of treatments. This presentation will explore the different types of nystagmus and what pharmacological therapy has been beneficial to patients.

4:00 PM ET/3:00 PM CT/1:00 PM PT **Break**

4:15 PM ET/3:15 PM CT/1:15 PM PT **Session 4**

**Teen Panel**

A panel of high school and college students with nystagmus will answer questions from the audience. The possible topics cover the gamut of topics from nystagmus in school to handling social situations, and everything in between.

**Adult Panel**

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

5:15 PM ET/4:15 PM CT/2:15 PM PT **Break**

5:30 PM ET/4:30 PM CT/2:30 PM PT **General Session**

7:00 PM ET/6:00 PM CT/4:00 PM PT **End of Conference**

Informal Conversations Rooms available until 9 PM ET/8 PM CT/6 PM PT

# Speaker Biographies

## Session 1



### **Mr. Jay Self, BM, FRCOphth, PhD**

Jay Self BM FRCOphth PhD is Associate Professor of Paediatric Ophthalmology at the University of Southampton (UK). He is a Consultant Ophthalmologist at University Hospital Southampton (UK). He has a special interest in general paediatric ophthalmology, paediatric cataract, nystagmus and ophthalmic genetics. His research program is closely aligned with his clinical practice

Jay completed his higher specialist training in Paediatric Ophthalmology in Southampton and Manchester and his research training through an MRC Clinical Research Training Fellowship/PhD in Ophthalmic Molecular Genetics. Jay's research interests cover a range of disorders affecting vision in children including nystagmus, albinism, genetic disorders of the eye, amblyopia and paediatric cataract. His team combines expertise in genetics, bioinformatics, eye-tracking and clinical trials.

Jay works closely with the Royal College of Ophthalmologists (RCOphth) in a number of roles, including member of the genomics working group, chair of various national masterclass training courses, and has represented the college for media communications. He is an advocate of public engagement in science and has delivered many public address lectures and open floor sessions for over 10 years. Jay and his team are passionate about translating research findings into clinical practice and improving the care for children with visual disorders by improving diagnostics, developing new treatments, and disseminating best practice.



### **Howard. Maziar, MD**

Dr. Maziar is a practicing psychiatrist in Atlanta, GA. Dr. Maziar graduated from Medical College of Georgia in 1972 and has been in private practice for 40 years. He completed his residency in psychiatry at the University of Maryland Medical System in 1975 and is Board Certified in Psychiatry. In addition to his private practice, Dr. Maziar has been active in organized medicine serving as President of the Georgia Psychiatric Physicians Association in 2011-12.

In 2008 he was named Georgia Psychiatrist of the Year. The Award recognizes Georgia psychiatrists for exceptional contributions to their patients, profession, and community. Dr. Maziar has infantile nystagmus and lives in Atlanta with his wife. This is his third conference.



### **Henry Greene, OD, FAAO**

Dr. Greene, a graduate of the Pennsylvania College of Optometry, is a leader in clinical low vision care and in the development of telescopic low vision aids for the visually impaired. From 1974 through 1977, he studied low vision rehabilitation at the Industrial Home for the Blind in Brooklyn, NY, with Dr. George Hellinger, an early pioneer in the field of low vision. While in New York, Dr. Greene published papers regarding the vision issues associated with hearing loss while a consultant at the St. Francis de Sales School for the Deaf. From 1977 through 1980 he directed the Low Vision Clinic at the Blind Association of Western New York, in Buffalo, NY. After moving to North Carolina in 1980, he joined the faculty of the Department of Ophthalmology at the University of North Carolina in Chapel Hill to establish their low vision program, where he ultimately rose to the rank of Professor.

## Speaker Biographies

### Session 2



#### **Jim Conley**

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. Today, Jim works for Twitter where he continues to work in education and will soon launch Twitter Flight School, a professional education program for global media planners.

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 earned a B.A. from Georgetown University and a Masters in Education from Harvard University. He has various hobbies including photography, writing, and karaoke. He lives in New York with his husband Josh.

## Speaker Biographies

### Session 3



#### **Richard Hertle , MD**

Dr. Richard Hertle is an investigator in the areas of nystagmus and eye movement disorder. His current titles include, Professor of Ophthalmology, Northeast Ohio Medical College, SUMMA Medical Center Department of Ophthalmology, Director, The Children's Vision Center and Chief of Ophthalmology, Akron Children's Hospital Medical Center, Akron, Ohio, USA.

Dr. Hertle received his Bachelor's Degree from The Ohio State University and his Medical Degree from Northeast Ohio Universities College of Medicine. Following medical school, Dr. Hertle completed fellowships and residencies in Ocular Motility, Emergency Medicine, Ophthalmology, and Pediatric Ophthalmology and Strabismus at a variety of medical centers around the country. Dr. Hertle came to Akron in 2010 to grow the Pediatric Ophthalmology service after six years as Chief of Pediatric Ophthalmology and Strabismus at Children's Hospital of Pittsburgh and Professor of Ophthalmology and Bioengineering at The University of Pittsburgh Medical Center.

He has been principal investigator on a number of NIH-funded research projects, including ongoing studies on the treatment of strabismus, nystagmus and amblyopia. An avid researcher and publisher, Dr. Hertle has over 200 referred publications and almost as many abstracts, editorials, reviews and invited lectures. He currently serves as a reviewer for multiple journals and has been a recipient of over a million dollars of research funding.



## Speaker Biographies (continue)

### Session 3



#### **Ed Chin, PharmD**

Ed has a Doctor of Pharmacy from Ohio Northern University, completed the Nuclear Pharmacy Certification Program from Ohio State University, and has a Master of Business Administration from Western Governor's University. He is now working as a nuclear pharmacist with Cardinal Health.

Growing up with infantile nystagmus, he realized the importance of learning to master mobility and technology, and to obtain the latest healthcare clinical information. He spent time learning about multi-modal transit throughout his childhood with his passion for logistics. He adapted to technology early, such as by helping his friends configure their email boxes and writing websites in the '90s, to ensure he would be impacted positively if there ever was a digital divide. Finally, to complete his dream to improve his vision, he went to pharmacy school to learn how to read his medical chart to better communicate with various healthcare providers. This journey allowed Ed to establish a healthcare team that met his needs.

Ed Chin is on a mission to help others with nystagmus. Ed joined ANN's Board of Directors in 2020, after attending his first ANN Conference in Washington, DC in 2019. Attending the ANN conference allowed him to create new friendships, meet other individuals with nystagmus, and learn "life hacks" or workarounds that helped him to be successful in his daily routine. With support from the Resource Committee, he has authored workplace resource articles and curated a list of apps for the visually impaired. Ed lives in Columbus, Ohio, and spends his time serving on various local and national boards, singing with Harmony Project, practicing yoga, riding mass transit, and traveling abroad to immerse himself in different cultures.