

# AMERICAN NYSTAGMUS NETWORK



**American Nystagmus  
Network**

To improve the quality of life for all persons and families affected by nystagmus, through organized community support, education, public awareness, and research.



# 2019 ANNUAL REPORT

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**Nystagmus is an involuntary eye movement which usually results in some degree of visual loss. The degree and direction of eye movement, amount of visual loss, and resulting impairment varies greatly from person to person.**

# President's Message

Bringing focus to 2020.

Friends,

As we enter this year, saying or hearing twenty-twenty on a daily basis, I'd propose we embrace the opportunity to define what twenty-twenty means to each of us; that we "own" what we want to achieve and who we want to become in "2020" as individuals and as an organization.

This starts with a look back at 2019. First and foremost we celebrated our **Twelfth Bi-Annual ANN Conference** as well as our **2nd Global Nystagmus Research Conference** in Washington, D.C. Researchers from around the world let us know that the best thing we can do as a community is to advocate for funding for Nystagmus research within our own cities and states. Grassroots funding efforts are key to unlocking research opportunities and the global research community needs our help.



This year, we also welcomed two **new board members, Caroline Randazzo and Domenica Pasinella** who will help set our course for the new decade including better programming and governance, as well re-shaping our volunteer program.

We also saw growth in our **ANN Facebook Community** which continues to expand and thrive welcoming new members every day. With over 4,500 members, the community as well as **ANN's Facebook Page** are wonderful resources for our community as is our ongoing **ANN Scholarship Program**.

For myself, I'll be stepping down as President this year. Twenty-twenty seems like an appropriate year to bring focus to my life outside of ANN, including launching a new app linking fitness to charitable giving and focusing on other professional and personal responsibilities, giving ANN an opportunity to bring new focus and energy to our work in the decade ahead.

I'm incredibly proud of what we accomplished in 2019 and look forward to the decade to come as we work together to improve the quality of life for all persons and families affected by nystagmus, through organized community support, education, and public awareness.

Thank you,  
Jim

# Thank You to Our 2019 Donors

The American Nystagmus Network would like to thank the sponsors of its 2019 Biennial Conference, as well as the individual donors who have generously supported both the conference and our mission.

## Gold Sponsors



DELTA GAMMA  
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Evelyn and Juan González  
Joshua Schulman

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The American Nystagmus Network (ANN) is run by an entirely volunteer Board of Directors. Annual dues from members supports the day to day operations of ANN. However, donations are the backbone for additional services provided by the organization.

# 2019 ANN Conference



ANN's biennial conference was held July 26-28 in Washington, D.C. and attended by nearly 200 individuals linked to the nystagmus community from across the United States and Canada. The ANN Conference was preceded by the Nystagmus Research Workshop hosted by ANN and attended by researchers from around the world. Additional information on the hugely successful, collaborative medical panel can be found on pages 7 & 8.

The ANN Conference provides people with an opportunity to connect with others impacted in some way by nystagmus, making new friends, or reconnecting with old ones. The top reasons provided for attending include learning about nystagmus, connecting with the community, and sharing tips on how to live with and navigate challenges associated with nystagmus. The sense of community at the ANN conference provides a feeling of belonging and connection, as participants are eager to share their story and learn from others who are on a similar journey.

The conference makeup included a robust and varied agenda which was primarily divided into three tracks: people with nystagmus, parents of children with nystagmus, and "Camp Nystagmus" which is tailored to children with nystagmus. Participants learned about treatment options, research, workplace and school accommodations, as well as tips, tricks, and everyday hacks for living with nystagmus. There were also many options for interaction, with break-out sessions and

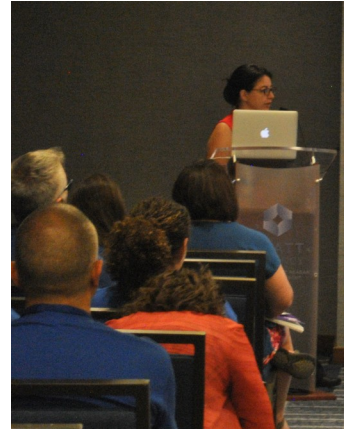


Q&A discussions. Participants had the opportunity to select from a variety of panel discussions, tailoring the event to their own desired content. This year the Keynote address was given by several motivational speakers living with nystagmus who shared their personal experiences with challenges, opportunities, and gaining a healthy perspective regardless of vision.



## 2019 ANN Conference Continued

ANN was especially excited to have researchers who attended the Nystagmus Research Workshop stay to participate in the Conference. Many served as panel leads in interactive sessions, sharing their research, and providing participants an opportunity to engage in Q&A. Topics included living with nystagmus – driving, school accommodations, and functional vision, as well as clinical areas including genetics, mental well-being, and treatment research. All sessions were well attended and powerfully energetic!



Camp Nystagmus was designed for children school aged K-8th who either have nystagmus or have family or friends who do. The camp provided a day's worth of activities for Conference participants ranging from interactive activities, to panel discussions, and a lovely movie reception. The children were able to meet others with nystagmus, learn and talk about nystagmus, and have fun with new and old friends!

Feedback on the Conference was overwhelmingly positive. Survey results showed an overall excellent experience for participants, with high ratings on the research-based sessions, keynote speakers, and tips for living with nystagmus. Washington, D.C. was a great location in that the conference was well attended and easily accessed by the ANN community. Excellent organization, passionate volunteers, and generous donors all contributed to an enormously successful event!



DELTA GAMMA  
FOUNDATION

Thank you Delta Gamma  
Foundation for making  
Camp Nystagmus possible!

# ANN Hosts the 5th International Nystagmus Research Workshop

The American nystagmus network proudly hosted an international nystagmus research workshop this past summer. This was the second research workshop that ANN hosted, and the 5th nystagmus workshop overall when including those hosted by the UK's Nystagmus Network. ANN hosted the workshop in Washington, D.C. on July 25-26, 2019, just prior to its biennial member conference.

The research workshop brings together those on the forefront of nystagmus research. Workshop attendees included: eye doctors, surgeons, scientists, and engineers – all of whom are investigating nystagmus. The purpose of the workshop is for these experts to share their recent work with their colleagues, to exchange ideas, and to create new ones. Overall, the goal is to advance the understanding and treatment of nystagmus.

Delegates to the workshop came from around the world to share their work. The US, the UK, the Netherlands, Australia, and China all sent delegates to the workshop. The topics presented covered a wide range of nystagmus-related effects on the visual system. Several delegates presented work on the details of the nystagmus eye movements themselves, including eye tracking techniques and the often-overlooked torsional component to the eye movement. Others discussed how nystagmus affects people in real life, beyond the typical doctor's office eye chart. Finally, several presented recent work on treatments for nystagmus, ranging from contact lenses to pharmacological and surgical methods.



## ANN Hosts the 5th International Nystagmus Research Workshop (continued)

The workshop format is similar to other academic conferences attended by the researchers. The researchers are each allotted time to present their recent work to their fellow attendees, who are then given a chance to ask questions and discuss the results.

One key difference in this workshop over other academic conferences is its exclusive focus on nystagmus. Other conferences might have a single nystagmus presentation, or perhaps a single session (of maybe 4 nystagmus presentations) out of the whole event. Nystagmus is often but one topic in a sea of vision research. At this workshop, however, nystagmus is the sole focus, so it can be discussed in much greater depth. A second key difference in ANN's workshop is that there are dedicated open-discussion sessions to brainstorm new ideas. At typical academic conferences, discussion is typically confined to the short question and answer period following a presentation, which is usually only a few minutes. At this workshop, the dedicated discussion sessions give the researchers valuable collaboration time that they ordinarily never get.

In the open-ended workshop discussions, the researchers tackled several issues. These issues included identifying the most important un-answered research questions, as well as advice to fellow researchers about successfully conducting nystagmus research. Additionally, they brainstormed ways that researchers - as well as support organizations like ANN and NN-UK - can increase awareness about effective treatments and how they can foster collaboration on nystagmus research.

Overall, the workshop was very successful. All of the delegates reported having a constructive experience, and the survey feedback was positive. Further, some new collaborations were formed, pairing surgeons with experts on eye movement recording and analysis to accurately measure surgery effectiveness. ANN is dedicated to supporting nystagmus research, and looks forward to continued support and interaction with the





# ANN Board of Directors

**ANN is excited to announce that we have two new board members!**



## **Caroline Randazzo**

Caroline is an HR Director for a trading firm in Chicago. She has 3 children and her son has infantile nystagmus. Caroline also serves on a local board in Chicago called The Network, which advocates against domestic violence.



## **Domenica Pasinella**

Domenica is the newest member of the ANN Board and joined in July. Her oldest child was born with infantile nystagmus. After finding ANN on social media, it was evident to her that this was a strong rooted community in which her family wanted to belong. Domenica brings a background of nonprofit board service and project management proficiency. She is currently a Director in Operations for a nonprofit health plan in New York state with 7 years of health insurance experience. She also has two Master's degrees in Education. She and her husband live in upstate NY with their two children and two energetic pups.

## **2020 ANN Board of Directors and Officers**

Jim Conley, President

Joseph Ambrico, Vice-President

Rosalyn Adekunle, Secretary

Katherine Ealey, Treasurer

Kerri Nagle, Director

Evelyn González, Director

# American Nystagmus Network, Inc. 2019 Financial Report

## American Nystagmus Network, Inc. 2019 Finance Report January - December 2019

### Revenue

Conference Income	
Conference Donations	\$14,383
Conference Fees	\$20,110
Conference Grants	\$ 8,500
<b>Total Conference Income</b>	<b>\$42,993</b>
Donations	\$11,680
Memberships	\$ 2,824
<b>Total Revenue</b>	<b>\$57,497</b>

### Expenses

Administrative Costs	
Accounting Software	\$ 670
Face-to-Face Board Meeting	\$ 807
Insurance	\$ 1,123
Internet Services	\$ 2,194
Mailbox Rental & Expenses	\$ 281
<b>Total Administrative Costs</b>	<b>\$ 5,075</b>
Conference	\$76,802
Scholarship Management Fees	\$ 1,350
Scholarship Awarded	\$ 5,000
State Registration	\$ 2,178
<b>Total Expenses</b>	<b>\$90,406</b>
<b>Revenue Less Expenses</b>	<b>(\$32,908)</b>

Prior year donation revenue was carried over into 2019 enabling us to cover conference expenses.

# ANN Scholarship Spotlight

## Timothy Cordes

I am currently enrolled in a registered nurse certification program and will complete my degree in May of 2020. After graduation I want to become a psychiatric nurse. This field will allow me to combine my passions for social science, nursing, and helping a population who is commonly forgotten. After starting to work as a nurse, I want to earn a Master's degree, and then teach both criminal justice and nursing courses.

I am a pilot and would enjoy aviation as a side job or even as a retirement job. My eyes will not allow me to be able to fly the big airliners, however there are other pilot jobs I can pursue. I enjoy teaching and one day hope to become a flight instructor. After I achieve my current pursuits, I will find a new interest to study. Education only ends when curiosity about the world ends.

## Faith Evans

I plan on attending the University of Nevada, Reno to pursue a degree in broadcast journalism and minor in statistics. I would love to work for a radio station or podcast company as a reporter and ghost writer.

## Jamie Ford

I hope to complete my Bachelor of Music Education degree in the Fall of 2020. After that, I plan on becoming an elementary music teacher. I hope to inspire and encourage young children to become involved in music as they grow up.

## Zoe Johnson

I plan to go into the physician assistant career. In particular, I want to be a physician assistant for pediatric emergency care. I will be going to the University of Oklahoma for my undergraduate degree in biology. I plan to go to the University of Oklahoma Health Science Center in Oklahoma City for physicians assistant school.

## Grace Lueschen

In the fall, I will be attending the University of North Texas to major in Instrumental Performance. I dream of becoming a member of a major orchestra while teaching private lessons. In the future, I want to become a horn professor at a college or university to help others pursue music professionally. Most importantly, I want to be able to transform others' lives through music and share the acceptance it brought me.

**2019 was a good year for the ANN Scholarship program. Once again we were able to give five(5) one thousand dollar scholarship to our nystagmus community. There was an increase in applicants which supported our hopes of increasing our scholarships in the future. To date, we have been able to provide over forty-thousand dollars in scholarships. We are inspired to do more. With your help and support, we will.**

## ANN Scholarship Spotlight (Continued)

The American Nystagmus Network is pleased to announce that those pursuing a post-secondary education have the opportunity to apply for an academic scholarship.

ANN typically awards up to five (5) scholarships of \$1,000 each for a total of \$5,000.



### How to Apply

- Diagnosis of Nystagmus is required to be eligible.
- Applications ***must*** be submitted by **May 31, 2020**.
- The scholarship management committee will notify the ANN Board of Directors of the awardees on July 1, 2020.
- Letters notifying applicants of their status will be sent out in July 2020.
- Checks mailed to the awardees on August 15, 2020 payable to the institution.

Updated scholarship application information will be posted  
on the ANN website.