

# 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.



**American  
Nystagmus  
Network**



## Navigating Health Insurance

MAKING THE MOST OF YOUR HEALTH PLAN

One of the new resources available on the ANN website!

# 2020

# 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

What a year 2020 has been! Surely, no one expected that life would throw a global pandemic at us, the likes of which we have not seen in 100 years! But with all of the challenges we have faced this year, ANN continues to support its mission. 2020 marks my first year as president of ANN, and I take on this role clearly aware of the responsibility I now hold. I wish to thank our outgoing president, Jim Conley, for his service to ANN. Jim's vision and creativity have been a tremendous asset, and we are grateful that Jim continues to contribute as a member of the Board of Directors.



I would also like to express my gratitude to Katherine Ealey, who has served as ANN's treasurer for many years. Katherine is moving on from ANN, and we will miss her dedication. She has kept the bills paid and the lights on, and we wish her well. Additionally, I would like to welcome two new board members, Ed Chin and Jessica Nickrand. Both bring a unique set of skills to the organization, and I am excited to work with them.

This year, through a generous grant from the Delta Gamma Foundation, we have undertaken an ambitious project to develop a suite of resources for our members. These resources are now available on ANN's website, and we hope you find them helpful.

Finally, in these difficult times, now more than ever it is together that we will survive. Here at ANN we remain dedicated to supporting all those affected by nystagmus.

Take care and be well,  
Joe Ambrico  
President, ANN

# Thank You to Our 2020 Donors

The American Nystagmus Network would like to thank our 2020 sponsors and donors who have generously supported our mission.

## Gold Sponsors



David and Martha Campbell  
bell  
Jim Conley  
Josh Shulman

## Silver Sponsors

The Blackbaud Giving Fund

## Bronze Sponsors

Fidelity Charitable / Kalele Family Fund  
Domenica Pasinella

## Friends of ANN Sponsors

Rita Ambrico  
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Elana Ochs  
Lori Roster  
Ben Schulman  
Angela Sobol  
James Spindler

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

# ANN Resource Project

The American Nystagmus Network received a grant from the Delta Gamma Foundation to create new resources and content for our website. This project allowed us to organize our website resources in an easy to use pull down menu. Over the years, we have created many videos on various topics but those were always in a separate YouTube channel. Now the video topics and corresponding links are organized in the resource section of the ANN website. We were also able to create new resources and content.

Here is a list of new items:

## Resources for Parents

- My Child Has Nystagmus - What I Should Know?
- Nystagmus in School Frequently Asked Questions
- Parent/Teacher Conference Nystagmus Handout
- Accommodations vs Modifications Handout
- ANN Navigating Health Insurance
- Nystagmus Info Card



## Resources for Adults with Nystagmus

- Nystagmus in the Workplace
- A Model of Successful Work Experience for Employees Who Are Visually Impaired: The Results of a Study By Dawn B. Golub
- Adaptive Needs in the Workplace for the Visually Impaired Employees
- Equal Employment Opportunity Commission Summary for Employees with Vision Impairments
- Living with Nystagmus
- ANN Navigating Health Insurance
- Apps for the Visually Impaired
- Nystagmus Medical ID Card

## Resources for Spouses and Friends

- Nystagmus Info card
- Tips for Friends

**Thank you Delta Gamma for providing the resources to make this possible!**



# 2021 ANN Conference

ANN will hold its biennial conference this summer on July 23 to 25, 2021. Due to the coronavirus pandemic, we will hold this conference virtually! Although vaccines are beginning to be deployed right now, it is still prudent to restrict large gatherings, per the guidance from the CDC.

**Mark your calendars**  
**Friday, July 23, 2021 to Sunday, July 25, 2021**



Our goal in developing this virtual conference is to re-create the in-person experience as much as possible. Virtual conferences have been done successfully by many other organizations in other disciplines, both professional and academic. The technology exists and there are multiple platforms available to make a virtual event possible. By summer, we'll all be pros at using virtual resources!



The virtual conference will be very similar in structure to the in-person conference. The event will be live, as much as possible. There will be presentations by experts with time for questions from the attendees, just like the in-person conferences. Additionally, there will be moderated group discussion sessions for those with nystagmus, parents, and children. There even will be opportunities for break-out sessions with smaller groups, or even one-on-one discussions, in much the same manner as chatting with people at an in-person conference.

There are actually several benefits of a virtual conference over an in-person event. First, a virtual conference allows more people to attend the conference. The cost of travel and hotel accommodations, as well as the time involved, makes attending the in-person events not feasible for many. Obviously, these costs are eliminated for a virtual event. Further, a virtual event gives us greater flexibility in recruiting speakers, since the cost and time commitment on their part is much less.

Overall, we are excited about the prospect of conducting a virtual conference! We are working very hard to make the virtual event as popular as the in-person event. We hope that many more people will be able to attend!

**More information will be coming soon.**  
**Check the ANN Facebook and Website for more information as it becomes available.**





# ANN Board of Directors

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



## **Ed Chin**

Ed joined ANN's Board of Directors in 2020 after attending his first ANN Conference (2019) in Washington, DC. Attending the ANN conference allowed him to create new friendships, meet other individuals with congenital nystagmus, and learn "life hacks" or workarounds that help him to be successful in his daily routine. Ed works as a nuclear pharmacist for Cardinal Health. He has a Doctor of Pharmacy from Ohio Northern University and completed the Nuclear Pharmacy Certification Program from The Ohio State University. Ed lives in Columbus, OH, and enjoys singing with Harmony Project, practicing yoga, riding mass transit, and traveling abroad to immerse himself in different cultures.



## **Jessica Nickrand**

Jessica joined ANN's Board of Directors in 2020 after going on a research spree after her twin nephews were diagnosed with congenital nystagmus. In addition to being an aunt (to 7 total nephews and a niece!), Jessica works in patient education and advocacy at the Child Neurology Foundation. She has a BA in Social Relations and Policy from Michigan State University and a PhD in the History of Science, Technology, and Medicine from the University of Minnesota-Twin Cities, and her research focuses on healthcare inequalities. Jessica lives in St. Paul, Minnesota with her husband, and enjoys swimming, Dolly Parton, and watching the Detroit Tigers.

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

Joseph Ambrico, President  
Evelyn González, Vice-President  
Caroline Randazzo, Secretary  
Katherine Ealey, Treasurer  
Rosalyn Adekunle, Director  
Ed Chin, Director  
Jim Conley, Director  
Kerri Nagle, Director  
Jessica Nickrand, Director  
Domenica Pasinella, Director

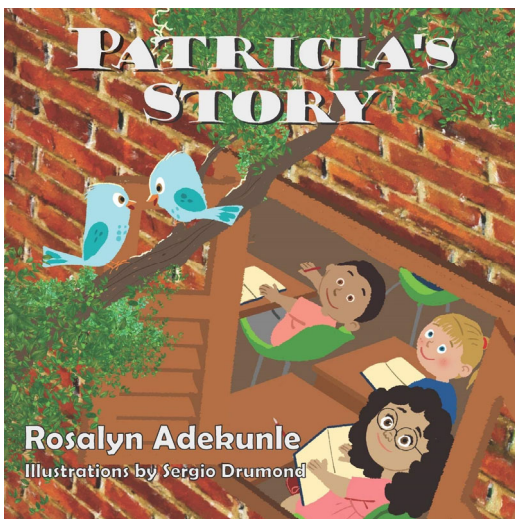
# Nystagmus Children's Books on Amazon



ANN board member, Rosalyn Adekunle (Roz) remembers growing up with nystagmus and not knowing anyone else who had the condition. Attending many ANN conferences and listening to new parents, she realized that there was a need for children with nystagmus to have stories to which they can relate. Roz modeled her character of Patricia on her own experiences of growing up with nystagmus.

Both books are available on Amazon. We look forward to the continuing adventures of Patricia.

All royalties from the book are donated to ANN



Believing in yourself goes a long way. This story is about the journey of a young girl as she starts her first day in kindergarten. Patricia was born with nystagmus, an eye condition that affects her vision. Despite this condition, she does not let it affect her confidence and her ability to socialize and enjoy school.

This is a continuation of "Patricia's Story" of building confidence and self-esteem. Patricia has low vision (nystagmus). Patricia learns that everyone needs help sometimes and should not be shy or afraid to receive help or ask for help.





# American Nystagmus Network, Inc. 2020 Financial Report

## American Nystagmus Network, Inc. 2020 Finance Report January - December 2020

<b>Income</b>	
Donations	\$23,935.81
Grants	\$ 4,500.00
Memberships	\$ 2,336.01
<b>Total Income</b>	<b>\$30,771.82</b>
<b>Expenses</b>	
Administrative Costs	
Accounting Software	\$ 785.20
Insurance	\$ 502.00
Internet Services	\$ 2,135.81
Mailbox Rental & Expenses	\$ 284.40
<b>Total Administrative Costs</b>	<b>\$ 3,707.41</b>
Paypal Fees	\$ 7.98
Scholarships Awarded	\$ 2,000.00
Service Charges	\$ 50.00
State Registration	\$ 4,044.00
<b>Total Expenses</b>	<b>\$ 9,809.39</b>
Net Operating Income	\$20,962.43

# ANN Scholarship Spotlight



## Lauryn Braxton

Lauryn Braxton is a senior in the biochemistry program at NC State University. She spends her time reading, working on research projects, playing flute, and riding horses. As a longtime advocate for animals, she is working toward a career in comparative medicine to research therapies for osteoarthritis. Lauryn plans to attend graduate school for Biomedical Engineering and related sciences this fall and plans to attend veterinary school in the future.

## Brooke Nagle

I have been a part of ANN for as long as I can remember, and I am very thankful for everything ANN has done for me. In high school, I was Student Council President, studied Italian and Spanish, and was a member of the tennis and soccer teams! This coming year, I will be studying in Hawaii for a semester. I then will attend American University in Washington, D.C., to major in political science.

ANN was able to give out two one thousand dollar scholarship to our nystagmus community. 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, 2021**.
- The scholarship management committee will notify the ANN Board of Directors of the awardees on July 1, 2021.
- Letters notifying applicants of their status will be sent out in July 2021.
- Checks mailed to the awardees on August 15, 2021 payable to the institution.

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

### Scholarship Donations Needed

Every year, ANN receives many more scholarship applications than we can fund. Please consider donating to our scholarship fund. Donations can be made by check or through our website. Please make a note that your donation is for the scholarship fund.