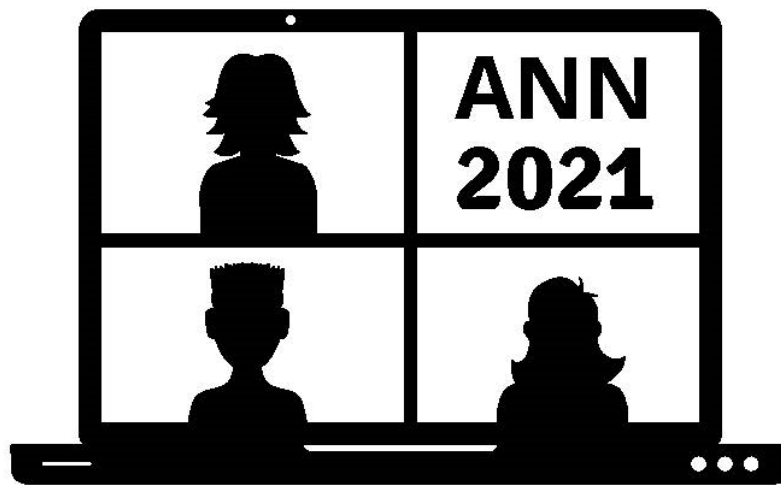


AMERICAN NYSTAGMUS NETWORK



**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.



Zoom In 
NYSTAGMUS

2021

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

President's Message

Nystagmus friends,

2021 was supposed to be the year the pandemic relented. We got the vaccines; the end is here! Not so fast, said the virus variants. If we can take anything positive from our nystagmus, it is that we are not strangers to navigating adversity. Every day we find ways to live with our varied visual impairments. Now we get to apply the same ingenuity to extended living with the coronavirus.



This year, we attempted to do just that, to find ways to reach our goals despite the obstacles. By moving our biennial conference to a virtual platform, we attempted to still provide support to all those affected by nystagmus, even though the pandemic prevented us from meeting in person. I believe that the event was a success for those who attended, and I think we should consider hosting additional virtual events in the future. A virtual event probably can't replace the in-person version, but it certainly can add to it. Something for the next conference committee to consider!

In 2021, another generous grant from the Delta Gamma foundation allowed us to continue to expand our online resources. For this year, we focused on nystagmus treatments, genetics of nystagmus, driving with nystagmus, mental health and nystagmus, nystagmus research, and understanding nystagmus as a healthcare professional. We hope these resources prove to be helpful to the nystagmus community.

I'm thrilled to welcome four new members to the board of directors! All of them contributed to making our first-ever virtual conference a success. I look forward to working with all of them on future projects.

In closing I'd like to express how grateful I am to have been able to connect again with my fellow nystagmites this past summer. You all remind me of why I do this. We are indeed stronger together!

Thank you,
Joe



Thank you to our 2021 sponsors and donors

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ANN Resource Project

ANN Resource Updates

The American Nystagmus Network received an additional grant from the Delta Gamma Foundation to create new and enhanced resources and content for the ANN website. In 2020, ANN was able to redesign the Resources landing page of the ANN website. In addition, ANN created materials that assisted the nystagmus community, focusing on large content areas and reaching a widespread ANN community base which includes People with Nystagmus, Parents of Children with Nystagmus, and Friends of the ANN community. In 2021, we had the amazing opportunity to continue our efforts for and broaden our scope to include Health Care Professionals.



Here is a list of new and enhanced items available on the Resources landing page of the ANN website:

Adults and Parents of Children with Nystagmus

- How to find a specialist and who are they?
- Inspirational Stories
- Profiles of Nystagmus
- Driving with Nystagmus by State
- Creating a healthy mindset
- Resilience in Children

Health Care Professionals and Clinical Information

- Drug Treatments for Nystagmus
- Genetics of Nystagmus
- Managing Nystagmus in Children

Nystagmus Research

- Research Updates from Around the World
- Biofeedback

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



2021 ANN Conference



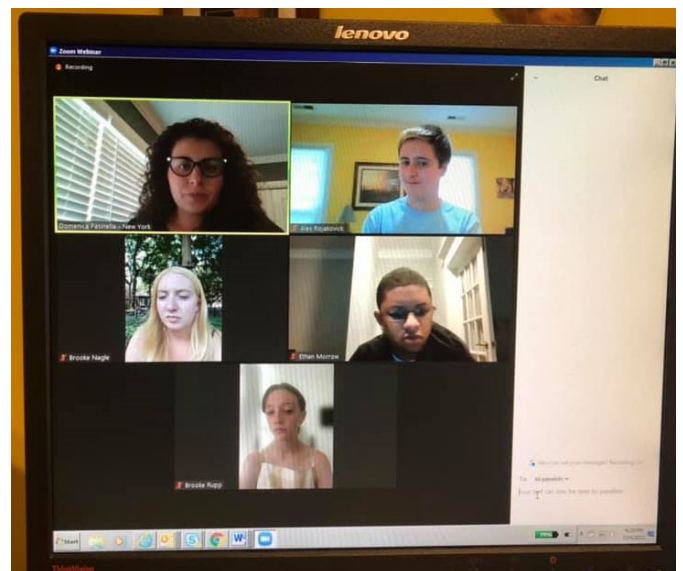
Friday was a great reminder to all attendees that this conference is truly an interactive experience! Indeed, there were lively, back-and-forth discussions among the attendees. They asked questions and shared experiences, and made new friends!

The Saturday sessions brought a mix of education and community. The day started with a compilation video of short updates from nystagmus researchers from around the world. Updates included researchers from the US,

UK, Canada, Italy, and China. Following that, there was a two-track structure with presentations and interactive question and answer sessions. Experts who joined us live included Mr. Jay Self, from the University of Southampton in the UK, Dr. Richard Hertle, from the Akron Children's Hospital, Dr. Henry Greene, founder of Occutech, Dr. Howard Maziar, a clinical psychiatrist who has nystagmus himself, and ANN's own Dr. Ed Chin, a pharmacist from Cardinal Health. We were lucky to have ANN's former president Jim Conley return to lead his ever-popular group discussion on living with nystagmus – which always creates a lively and informative conversation. Panel discussions with adults and teens rounded out the day. Nearly all of the sessions were recorded and the videos will be posted in the Resources section of ANN's website.

Overall, the event was a success. It proved that ANN's conference can be just as productive on a virtual platform. We at ANN want to specifically thank Evelyn Gonzalez, who served as the committee chair and project manager for this first-ever virtual conference. Evelyn was not planning on serving as chair this year, but when the original chair was pulled away by family circumstances, she willingly stepped back in, and we are very grateful. We are pleased that we could still provide support to the nystagmus community throughout this global pandemic. We are looking forward to seeing everyone in person in 2023!

 **zoom in!**
Bring Your Nystagmus Support Into Focus



ANN Board of Directors

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



Michele Hecht

Michele was born with nystagmus and grew up knowing very little about it. She became more interested in learning about nystagmus when her second child was born with it. She stumbled upon ANN doing a google search and attended her first conference in 2011, which was a life changing experience. She has attended 5 conferences since then and she has formed some great friendships as a member of ANN. Michele has a B.S in Business Administration from the University of Delaware and a Master's degree in Education of Middle School Math. She currently teaches sixth grade math in Bridgewater, NJ.



Karen Morrow

Karen is a new member of the ANN Board, joining in 2021. Karen, her husband, son, and daughter first attended ANN'S 2007 Conference to learn more about infantile nystagmus for her son who is affected by the condition. Karen and her family live in Augusta, Georgia. Karen brings varied experience as an engineer to include permitting/ licensing, managing various projects and programs, and conducting assessments and analysis. Her current work with the U.S. Department of Energy involves oversight of the contractors performing infrastructure and environmental projects. Karen holds a Bachelor's in Environmental Engineering and a Master's in Systems Engineering. Her other interests are mentoring and coaching youth pursuing STEM fields and volunteering as a Special Projects Lead with her church.



Greg Rojakovick

Greg joined the ANN Board of Directors in 2021. He learned of ANN after his children were born with infantile nystagmus. After attending several in-person conferences, and seeing the positive impact it had on his kids, Greg volunteered to assist with the virtual conference in 2021. Greg, his wife, and two children live in Richmond, VA. He works as a mortgage sales manager for a Fortune 500 company. In his free time, he enjoys reading, biking, and traveling.

ANN Board of Directors Continued



Dan Rose

Dan joined the board in 2021 after helping plan and market the 2021 conference. Dan is a marketing and product development leader from Madison, Wisconsin. He was born with infantile nystagmus and has worked hard to adapt to it throughout his life. Dan is an avid runner and athlete, dedicated musician, and loves working creatively in the photography and videography spaces. He is excited to support and expand ANN's mission in any way he can as a board member.

2020 ANN Board of Directors and Officers

Joseph Ambrico, President
Evelyn González, Vice-President
Caroline Randazzo, Secretary
Ed Chin, Treasurer
Rosalyn Adekunle, Director
Domenica Pasinella, Director

Volunteers Needed!



As an all volunteer organization, ANN relies on volunteers to do the work of the organization. If you are interested in helping ANN with its mission: *To improve the quality of life for all persons and families affected by nystagmus, through organized community support, education, public awareness, and research*, then go to the volunteer page on the ANN website and fill out the "I want to volunteer" form: <https://nystagmus.org/new/volunteer-for-ann>

Nystagmus Children's Books on Amazon

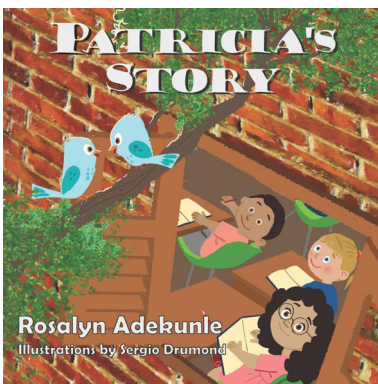


ANN board member, Rosalyn Adekunle (Roz) remembers growing up with nystagmus and not knowing anyone else who had the condition. Attending many ANN conferences and listening to new parents, she realized that there was a need for children with nystagmus to have stories to which they can relate. Roz modeled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

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

All royalties from these books are donated to ANN

<https://www.amazon.com/kindle-dbs/entity/author/B087QN1ZG3?>



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.



Patricia and Patrick become friends. Their friendship is built on acceptance, understanding and caring about each other. They do not let Patricia's eye condition (nystagmus) get in the way of their friendship. There are questions at the end of the story to inspire conversation, awareness and inclusion.

American Nystagmus Network, Inc. 2021 Financial Report

Income

| | |
|-------------------------|----------|
| Conference Registration | \$ 2,550 |
| Conference Sponsorships | \$14,430 |
| Donations | \$14,006 |
| Grants | \$ 6,500 |
| Membership | \$ 2,205 |

Total Income **\$39,691**

Expenses

Administrative Costs

| | |
|---------------------|----------|
| Website | \$ 240 |
| Insurance | \$ 686 |
| Accounting Software | \$ 823 |
| Paypal Fee | \$ 62 |
| State Registration | \$ 1,934 |
| P.O. Box | \$ 250 |
| Membership Software | \$ 2,073 |

Scholarship **\$ 5,000**

Resource Project

| | |
|------------------------|----------|
| Writer/Speakers | \$ 5,000 |
| Project Manager | \$ 1,000 |
| New York Times Article | \$ 705 |

Conference

| | |
|-----------------------|--------|
| Advertising | \$ 570 |
| Event Insurance | \$ 506 |
| T-Shirts | \$ 857 |
| Copies | \$ 292 |
| Shipping | \$ 548 |
| Supplies | \$ 58 |
| Conference Technology | \$ 398 |

Total Expenses **\$ 21,003**

Net Income **\$ 18,688**

ANN Scholarship Spotlight



Jackson Andrasky

I am currently a senior at the University of Florida. I have spent my whole life playing and being around sports. I was born with infantile nystagmus. My love for sports has always remained within me, but as I

got older I started to realize that maybe my involvement in sports didn't have to mean me playing necessarily. I found that my passion was in Sports Medicine and becoming a Physician Assistant.

I will finish my degree in Applied Physiology and Kinesiology at the University of Florida this spring. I plan to continue on with my schooling to become a Physician Assistant or work in the medical field.

I have found my passion and I am excited to help others. I graduated with a 5.2 GPA and graduated #11 in my class of over 750 students. I currently hold a 3.8 GPA and I have been accepted into the Pre-Health Fraternity at UF for academic excellence. I am always pushing myself to do better and be better. I look forward to sharing my experiences with others and finding a way to help others on their journey in life.



Chanwoo Kim

I'm a sophomore biochemistry student at Texas A&M University. I was born with bilateral cataracts and quickly developed nystagmus in both eyes. Despite some of the obstacles that came with nystagmus, I decided to study biochemistry because I

love learning about how different combinations of particles, with their own unique properties, can interact with each other in specific ways to create everything in our universe. In addition to the natural sciences, I've found that I really enjoy learning Spanish and exploring the cuisines of various Spanish-speaking countries after taking an intensive beginning Spanish course this past summer. Some of my hobbies include watching the UFC and supporting Manchester City in the Premier League; one of my wishes is to see Dustin Poirier establish himself as the undisputed lightweight champion and watch Manchester City lift their first Champions League trophy. By the time I graduate, one of my goals is to conduct ophthalmology research so that I can receive a hands-on education not only about the science behind human vision but also about how the field of ophthalmology can continue advancing to help others with vision related conditions.



Tiffany McHenry

I attended Arlington Heights High School in Fort Worth, TX. I have centralized nystagmus. Despite this, I participated in cross country, track, and soccer all four years of high school, and recently tried softball senior year. The academic clubs I participated in included the National Honor Society, Student Council, whiz-quiz, and other UIL academic events. I was the senior class vice president of the Student Council. I love reading, conducting research, and I am dedicated to trying to make the lives of those around me better. At UA, I plan on majoring in physics and minoring in interdisciplinary medical studies and Spanish. My ultimate goal is

to obtain an MD, Ph.D. so that I can conduct medical research that would allow me to treat patients with new and existing treatment options. While I am in medical school, I am planning on evaluating medical equipment and have an imaging clinic.

ANN was able to award five one-thousand dollar scholarships 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)



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.



Kyle Thurow

I am a Junior at the University of Florida pursuing a dual degree in mathematics and economics with a minor in physics. I am a pre-law student and hope to attend law

school after I graduate. Last summer, I interned for NASA at the Kennedy Space Center. I love playing and writing music. I play 5 instruments and have composed over 50 songs. I am passionate about sports and played varsity golf in high school and earned a black belt in Shotokan Karate.

2022 Scholarships

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.
- March 31, 2022 Application opens.
- Applications **must** be submitted by **May 31, 2022.**
- The scholarship management committee will notify the ANN Board of Directors of the awardees on July 1, 2022.
- Letters notifying applicants of their status will be sent out in July 2022.
- Checks mailed to the awardees on August 15, 2022 payable to the institution.

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