American Nystagmus Network

2024 Annual Report

American Nystagmus Network

The American Nystagmus Network (ANN) is dedicated to improving the quality of life for all persons and families affected by nystagmus through organized community support, education and research, and public awareness.

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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, the amount of visual loss, and resulting impairment varies greatly from person to person.

President's Message

Hello to my fellow Nystagmus friends!

At ANN, we tend to mark years by whether they are conference or off-conference years, because the conference is such a demand on our resources. 2024 was an off-conference year for us at ANN, but we still were very busy!

In April, once again ANN exhibited a booth at the American Academy of Pediatric Ophthalmology and Strabismus (AAPOS) conference in Austin, TX - during a total solar eclipse! Our aim at this conference is to talk to pediatric ophthalmologists, the doctors most likely to treat those with nystagmus, and make them aware of ANN. In June, we again awarded 5 scholarships to students with nystagmus. We had a near record number of applicants and wish we had the resources to award more scholarships to so many deserving students! At the end of September, we held our annual face-to-face board meeting in Atlanta, GA - during a hurricane! Well, right after hurricane Helene blew through the southeast US. But we all managed to travel to Atlanta and spent the weekend hard at work on ANN business plans.

2024 saw ANN undertake several new initiatives. We made a concerted effort to effectively utilize volunteers. We filled several committees with volunteers. Our social media committee has developed a communication plan to engage with those affected by nystagmus. We staffed a website committee with the challenge of revamping our website. We also stood up our very first junior board of directors, filled by young adults aged 13 to 22. We are excited to have them share their voices regarding the direction of ANN! Finally, our fundraising committee has been the hardest to staff, so if you have knowledge, ability, or desire to work on ANN fundraising please let us by clicking here to sign up. In the fall we launched our Nystagmus November awareness and fundraising campaign, designed and managed by our board member Domenica Pasinella, and we are so grateful for her hard work and inspiration.

Looking forward to 2025, it's a conference year! Planning is already well underway for our next conference in Philadelphia, PA next summer. We are also planning a research workshop, so we hope several of the researchers will attend and speak at the conference. We hope to see you there!

Your fellow nystagmite,
~Joe

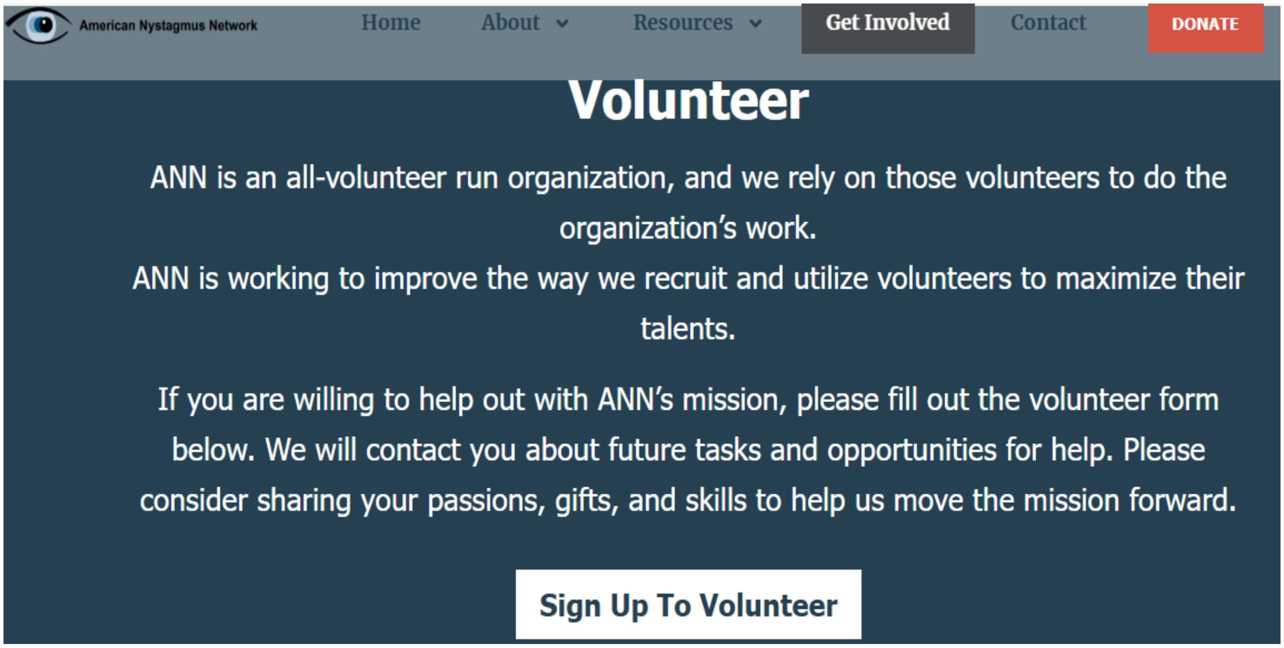
Call for Volunteers

ANN VOLUNTEER FORM

Everyone who works for ANN donates their time and talents to make this organization operate. In 2025, we have some specific areas in need:

- **Fundraising:** In anticipation of our 2025 conference and international research workshop, we need to fundraise to make those events happen. We have generated materials needed so our members can plan and host fundraisers on behalf of ANN. Events such as golf tournaments, walk-a-thon/bike-a-thon events, raffles, auctions, etc. The latest example is our Nystagmus November. We are looking forward to our members supporting ANN and its mission by hosting their own fundraiser!
- **Assistant Treasurer:** We are looking for someone to help with our bookkeeping. Do you have any bookkeeping or accounting experience and are willing to donate your time?

If you can help in these areas or have other talents you could offer to ANN, please contact us at info@nystagmus.org or sign up to volunteer on our webpage here: [Volunteer for ANN]() or by scanning the code above.



Volunteer

ANN is an all-volunteer run organization, and we rely on those volunteers to do the organization's work.
ANN is working to improve the way we recruit and utilize volunteers to maximize their talents.

If you are willing to help out with ANN's mission, please fill out the volunteer form below. We will contact you about future tasks and opportunities for help. Please consider sharing your passions, gifts, and skills to help us move the mission forward.

We Appreciate Our Donors

The American Nystagmus Network extends our sincere gratitude to sponsors and donors who have generously supported the mission of ANN, its events, and activities.

Gold

Friends & Family of Anthony Pasinella

Silver

Ade & Rosalyn Adekunle
Delta Gamma Eta Delta Chapter – University of North Florida
Levine Family Foundation
Evelyn & Juan Gonzalez
Michele & Gordon Hecht
Max McCauslin
Clarke & Liz Norvell

Bronze

Robert Crichton
Ainsley Harding

Friends of ANN

Marlene Accardo
Joe Ambrico
Rachel & Kermit Bailey
Jen Demers
Elizabeth Deraps
Steve Hecht & Barbara Boas
Lois and Paul Hummel
Krysten LeFavour
Justin Maddy
MVP Health Care
Jeff & BettyAnn Nathan
Olu Oduwole
Cathy & Al Reicheg
Stacy Schechter
Jeffrey Siperstein
Greg & Marianne Tomei
Susan Umpleby
Gary Weinstein

ANN is supported through generous donations and grants from our donors. To join ANN or donate via the ANN donor webpage, Venmo, or PayPal. Scan one of the codes here.

Donor Page
venmo

ANN Resource Updates

EXHIBITING. During April 7-10, 2024, we exhibited again at the AAPOS Conference in Austin Texas. The AAPOS meets each year to present and discuss research and network with peers. This was their 49th annual meeting. There were brand-new researchers specifically exhibiting their research related to nystagmus.

49TH ANNUAL MEETING
APRIL 7-11
AAPOS 2024
AUSTIN ★ TEXAS

The American Nystagmus Network was represented by two board members who have Nystagmus, Michele Hecht and Jeff Siperstein. The very first evening, we ran into some researchers who participated in our last ANN research conference in 2019, Dr Yang and Dr. Wang. We set up our booth with a brand-new vertical banner, lots of information and so many giveaways, including our iconic NYSTAGMUS.ORG bracelets. We also displayed the children's books about nystagmus, written by Rosalyn Adekunle.

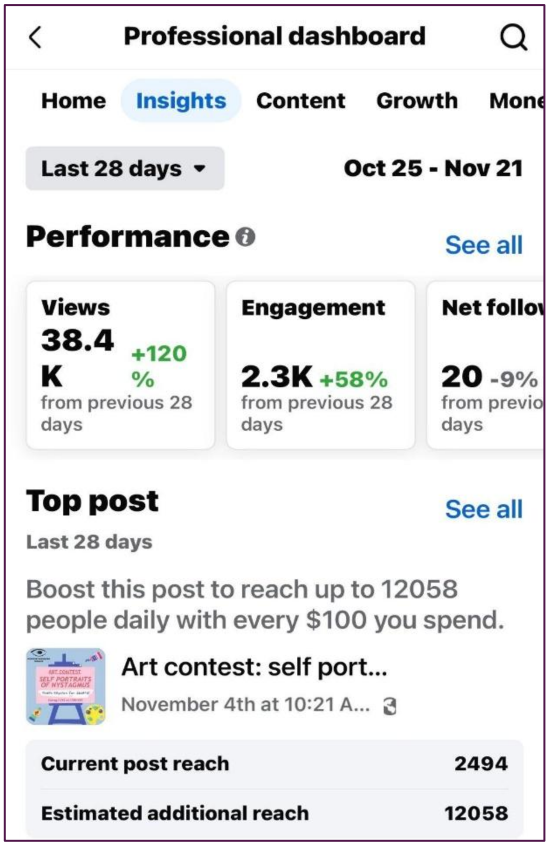
We spent time speaking with Dr. Richard Hertle who recently announced his retirement. He came to help other physicians and to say farewell. Dr. Hertle is often considered among the most knowledgeable experts on nystagmus, and he presented at many of our conferences.

This AAPOS Conference was unique in that it was specifically scheduled during the solar eclipse. The entire conference paused so everyone could head out to nearby parks to view the eclipse! Celestial events aside, below are three of the posters for the research being presented on nystagmus or other eye movement disorders. We also made connections with other exhibitors, including the CACNA1A Foundation. There were multiple vendors who were demonstrating low vision aids that could be helpful to both adults and children with nystagmus. We explained about ANN to hundreds of doctors and medical students throughout the conference.

Social Media

In 2024, we reached out to volunteers and formed a new Social Media Committee. This committee is headed by two board members, Jeff Siperstein and Greg Rojakovick, and includes 7 youth volunteers. We posted questions, videos, announcements, greetings, calendars, fundraising ideas and even Zoom links for virtual meetups.

Instagram. Since March 2024, ANN has posted more than 70 times on Instagram, has 823 followers to date and is reaching over 4,000 accounts organically. Follow us on Instagram by scanning the QR code.



Oct 25 - Nov 21

Performance

Views	Engagement	Net follo
38.4 K +120 % from previous 28 days	2.3K +58% from previous 28 days	20 -9% from previo days

Top post

Last 28 days

Boost this post to reach up to 12058 people daily with every $100 you spend.

Art contest: self port...

November 4th at 10:21 A...

Current post reach	2494
Estimated additional reach	12058

Facebook (Business Page). Since March 2024, we have posted over 77 times, with all posts shared to our Facebook group. The Facebook business page has 3,800 likes and 4,100 followers. Follow us by scanning the code on the right or via the link here.

Facebook Group. The American Nystagmus Network group on Facebook has 5,974 members, up 465 since January 1, 2024. To connect with members of ANN and the Facebook group scan the code to the left or use the link below.

X (formerly Twitter). Since March 2024, we have posted 44 times to 339 followers and reached as many as 920 accounts organically. Follow us by scanning the QR code.

Link to your favorite ANN social media here:
On Instagram
On X (formerly Twitter)
ANN Facebook business page

Website Redesign

Over the summer, ANN took on the significant task of a wholesale redesign of the ANN website at nystagmus.org. Designed in 2015, the website was pushing 10 years old! It was in dire need of updating.

AMERICAN NYSTAGMUS NETWORK

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

... the knowledge that I am truly not alone ...

The website is the front door to our online presence, and it requires clear communication of ANN's mission and activities. Our top priorities were to make resources easier to find, give information about the organization, increase community involvement, and publicize events and programs. We also wanted to add accessibility features for low vision, such as customizable font size, contrast, and screen reader compatibility.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American Nystagmus Network

The American Nystagmus Network (ANN) is dedicated to improving the quality of life for all persons and families affected by nystagmus through organized community support, education and research, and public awareness.

Nystagmus November

Nystagmus awareness and fundraising during the month of November.

2025 Conference

Preliminary planning is underway for the next ANN conference scheduled for July 18-20, 2025 in Philadelphia, PA.

Please check back soon for further details.

Donate To ANN

ANN relies on champions like you to support our mission.

We formed a website committee of volunteers Nate Martin, Jeremy Smith, and Leslie Valiant, and board members Karen Morrow and Joe Ambrico. To guide the redesign effort in a unified strategy, including all voices, we performed a needs analysis and surveyed all the members. With a strategy and theme in hand, the hard work began. As it turns out, website building can be quite time-consuming! We divided and conquered and were excited to debut the new website in October, in time for ANN's Nystagmus November programs.

There still is much work to do to improve the website. ANN wishes to thank the members of the website committee. If you are interested in helping develop and maintain our website, please reach out via our volunteer page here.

Nystagmus November

EYES ON AWARENESS

In 2024 ANN launched the first annual Nystagmus November: Eyes on Awareness Campaign! Thanks to ideas from the ANN community, this year's campaign came to life. ANN set three key intentions for the month of November which included:

1. **Community Building:** Organized community support for those impacted by nystagmus remains the #1 priority for ANN and was the primary theme for the month.
2. **Education & Awareness:** Creating and sharing information on nystagmus, community support, and ANN.
3. **Fundraising:** ANN is a volunteer driven, non-profit organization. ANN primarily raises funds to support annual student scholarships, the biennial community conference, and international research workshops.

Our calendar of events included activities like virtual community meet ups, social media campaigns, personal engagement opportunities, and national community events. See a snapshot of the activities below and key highlights on the pages to follow.

Nystagmus Education Day

Nystagmus Education Day was held on November 13th where students and educators were encouraged to spread awareness of nystagmus and share tips and tricks for supporting the visually impaired in a school setting. Community members did everything from full lesson plans and activities in their classroom, to simple gestures of gratitude for teachers and friends who make a difference in their school. It was an impactful way to spread awareness, and we are thankful for all those who participated in the day.

Thanks to a Delta Gamma grant in 2023, ANN was able to revitalize and refresh our Nystagmus Awareness in Schools materials. In 2024, this material was used to launch the first Nystagmus Education Day.

Nystagmus November

EYES ON AWARENESS

These lesson plans are packed with great content and activities to be used holistically or in pieces to create wonderful dialogues on inclusion and lots of fun in classrooms for children of all ages. The lesson plans can be found on our Nystagmus November webpage here.

Nystagmus Support Day

ANN created the first national fundraising event launching a virtual walk-a-thon open for the month of November, with live walkers heading out in their communities on November 16th. Our leading teams, Michele Hecht and Evelyn Gonzalez, raised over $1,000 each! Thank you to all who took part in this event and the fundraising efforts for the month. ANN is grateful to have the strength of the community backing the many programs the organization can offer. They are made possible by these fundraising opportunities.

In lieu of the national walk-a-thon, ANN Board member Domenica Pasinella hosted a personal fundraiser in honor of her son, Anthony. The Pasinella's picked a Football Funday featuring Anthony's favorite foods because they knew it was an activity their family and friends would enjoy. They gathered in a community center to watch an afternoon of games, enjoy great food, and fundraise for ANN. They also had a fun "rookie training camp" set up for the kids to play. They raised just shy of $3,000 which was donated to support ANN's 2025 conference and expenses.

Nystagmus November brought fun and awareness, and it was a great reminder to act with kindness. Scan the code here to learn more about Nystagmus November.

ANN Conference

We are pleased to announce the
2025 ANN Biennial Conference!
Save the Date:
July 18-20, 2025
Philadelphia, Pennsylvania

We hope you can join the Nystagmus community for a weekend of education, community, and good old-fashioned personal camaraderie!

Since hosting its first conference in Cleveland, Ohio, in 1999, ANN holds conferences in each odd numbered year in a different city across the US. These conferences are designed for fellowship among Nystagmites (as we sometimes call ourselves) and our loved ones. We discuss varying topics at each conference, and they typically include presentations on relevant interests such as insurance, low vision driving, IEP/504 plans, living with nystagmus, youth and adult discussion panels, and assistive technologies. The conferences also often include presentations from medical experts.

Every conference is typically three days starting on a Friday with dinner, a keynote speaker, and socialization. Saturday is packed with presentations, discussions, and breakout sessions. The conferences conclude on Sunday with breakfast and an open member meeting.

Conferences have been life changing for many of our attendees. Parents who don't know what is in store for their children often become more hopeful. Conferences give many Nystagmites the chance to meet others who understand their world. Frequently, this is the first time many have met someone else with nystagmus.

Frequently check our ANN website's conference page here as we finalize the 2025 conference details and post updates regarding the agenda, registration, and the hotel.

Board of Directors

Joseph Ambrico
President

Evelyn Gonzalez
Vice President

Michele Hecht
Treasurer

Vacant
Assistant Treasurer

Domenica Pasinella
Secretary

Rosalyn Adekunle

Welcome Jen Demers!

Karen Morrow

Greg Rojakovick

Jeff Siperstein

Board of Directors

ANN is excited to welcome the newest Board Member: Jen Demers

Jen Demers joined the ANN Board in 2024. Jen has two children. Her oldest has nystagmus, which is often referred to as ‘dancing eyes.’ She works as a nurse in the frosty capital city of Ottawa in Canada. Jen is a fierce mama bear and loves everything Disney.

Jen became aware of ANN while doing research after she realized the ophthalmologist following her child really didn’t understand nystagmus at all. Through ANN Jen was able to get valuable information and connection to life changing surgery for her child. Jen’s first ANN conference was the 2021 virtual event. After the first day her child excitedly said, ‘I’ve found my people.’ Jen knew at that moment they would be attending the next in person conference in 2023, at which she volunteered to assist.

JUNIOR BOARD OF DIRECTORS

Junior Board Chairperson's Update 2024:

Anna Rojakovick

In 2024 ANN launched the first Junior Board serving the American Nystagmus Network under the Board of Directors. The members of this board are young adults aged 13 to 22 who are seeking to support the ANN mission. The Junior Board’s goal is to serve the ANN community, especially children and teenagers, by creating a forum for individuals and families to come and share their stories and personal experiences with nystagmus. The Junior Board will focus on creating a tighter knit community for children, teens, young adults, and ANN community members.

ANN Financial Report

JANUARY-DECEMBER 2024

	TOTAL
Revenue	
Donations	$8,629.54
Fundraising/PayPal Giving	$11,121.34
Membership	$570.00
TOTAL REVENUE	**$20,320.88**
Expenses - Administrative	
Administrative Costs	
State Registration	$2,550.00
Mailbox / shipping expenses	$262.46
Insurance	$1,262.00
Administrative software	$3,110.40
Admin Fees	$161.64
Administrative subtotal	**$7,346.50**
Expenses - Program	
Face to Face Board Meeting	$1,752.64
AAPOS Trade Show	$4,945.76
ANN Awareness Campaign	$257.34
Scholarship	$5,000.00
Program subtotal	**$11,955.74**
TOTAL EXPENSES	**$19,302.24**
PROFIT / LOSS	$1,018.64

ANN Scholarships

2024 ANNUAL SCHOLARSHIP REPORT

ANN was successful in choosing five (5) deserving scholarship recipients from almost a record number of applicants. Our 2024 scholarship recipients each received $1,000 scholarship awards totaling $5,000. The recipients, featured in the following pages of the annual report, are appreciative of ANN's financial award. Some of our scholarship recipients become involved in ANN by being a member of our volunteer committees.

We revisit our in-house scholarship process and procedures every year. We are determined to be transparent and efficient in our scholarship process. Awards are granted without regard to race, color, creed, religion, sexual orientation, age, gender, disability or national origin.

We thank our donors and supporters who helped make ANN's Scholarship Program possible. It is because of you we can encourage and aid in the continuation of the academics of our Nystagmus community. You help us to GROW.

ANN Scholarship
Scan here to learn more about our
ANN Scholarship program and the
application process.

Scholarship Spotlight

CONGRATULATIONS TO 2024 ANN SCHOLARS

Kamry Hearns

Kamry Hearns is a travel enthusiast from small-town Pittsburg, California who loves outdoor exploration, poetry, and immersing into other cultures. She obtained a B.S. in chemical engineering from the University of California, Irvine in 2021. She is pursuing a master's degree in business and science at Rutgers University to build a career in product management within the biotechnology or medical device industries. Her professional experience includes pharmaceutical manufacturing, clinical laboratory operations, and healthcare services. These experiences combined with her journey of coping with infantile nystagmus has fueled her career goals, which involve helping impaired individuals gain access to life-changing medicines and technologies.

Nathaniel Miller

Nathaniel (Nate) Miller graduated with honors as a Georgia Scholar. In high school, Nate was incredibly involved on the math team, cross country, orchestra, and theater and has held leadership positions in several organizations. In his free time, he enjoys playing board games with friends and family as well as reading. Next year, Nate is excited to be majoring in civil engineering at Georgia Tech.

Caroline Maschke

Caroline will be attending American University in Washington, D.C. to pursue a career in health policy. She aims to help advocate for more funding opportunities for cancer, diabetes, and numerous other diseases that have touched her family. In her free time, she enjoys playing and coaching beach volleyball, swimming, and hanging out with her family.

Scholarship Spotlight

CONGRATULATIONS TO 2024 ANN SCHOLARS

Anastasia (Nastya) Morozova

She is a chemist currently completing a Master of Business Administration program. She has B.S. degrees in chemistry and mathematics. She has a M.S. in materials science and engineering. She plans to go on to pursue a PhD in chemistry and then open her own research institution. She has had nystagmus since birth, and although it slows her down, it never stops her!

Lauren Proper

Lauren Proper is from Michigan. She is fortunate enough to be attending Michigan State University in the fall where she will be pursuing a major in neuroscience and a minor in bioethics on the premedical track at the Lyman Briggs College. She has infantile nystagmus which has remained a prominent obstacle throughout her entire life. She is passionate about using her own health struggles and experiences with medical professionals to influence the way she will treat others in her future health career.

Applying for the ANNual Scholarship

Diagnosis of nystagmus is required for eligibility. Important milestones:

- Applications must be submitted by May 31.
- Official letter notifying applicants and awardees of their status are sent by July 31.
- Checks payable to the institution are mailed to the awardees by August 15.

Click the links to connect with us on social media:

Facebook Page
X (formerly Twitter)
Instagram
YouTube

Additional Featured Links:

ANN Resources

Be sure to check our Resources webpage for helpful information for your journey with nystagmus.

Books by Rosalyn Adekunle.

Visit Amazon to purchase books from one of our dedicated board members.

Dancing Eyes Podcast

Founded by fellow nystagmite, Frankie Caputo.

American Nystagmus Network

For past annual reports access our updated website at Nystagmus.org.

Contact us via email here.