

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.



2022 ANNUAL REPORT

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President's Message

Greetings fellow nystagmus friends!

I am quite grateful that life is returning to some semblance of normalcy in the post-pandemic era. We at ANN are looking forward to returning to an in-person conference in the summer of 2023! We are still in the planning stages, but I expect it to be similar in format to our previous conferences. It will be great to see some new and returning faces! I hope you will be able to join us for several days of education and camaraderie!

At ANN we are in a transition period. One of our most knowledgeable, helpful, resourceful, and productive board members, Evelyn Gonzalez, is taking a step back. Evelyn has contributed so much to ANN over her tenure, most notably managing many successful conferences. I personally want to thank Evelyn for all her service to ANN. I am also very grateful that Evelyn will still contribute to ANN, but in a more advisory capacity.

This brings me to my next point, an appeal for volunteer support! We need people to help carry out the projects for ANN as Evelyn reduces her role. Our key areas in need of support are fundraising and grant-writing, website administration, and social media management. If ANN has been of help to you in the past, please consider volunteering to give back! You can start the process by filling out our volunteer form on our website at: www.nystagmus.org/volunteer-for-ann.

This may be a time of transition for ANN, but it is also an exciting time! We have many opportunities in front of us to really expand our support to all those with nystagmus. I look forward to hearing from you!

Your fellow nystagmite,
--Joe



Sponsors and Donors



Thank you to our 2022 sponsors and donors

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ANN Resource Updates

Thanks to Delta Gamma Foundation, ANN had an opportunity to showcase at the American Association for Pediatric Ophthalmology and Strabismus (AAPOS) and American Optometric Association (AOA) conferences in 2022. The ANN resources committee went to work creating and refreshing resources to spread awareness of both nystagmus and our ANN community to the medical professionals in attendance.

The ANN resources committee continued the great moment from 2021 and persists in generating and refreshing content for people with nystagmus, parents of children with nystagmus, friends of the ANN community, and health care professionals.

In 2022, ANN took action to rebrand Wobbly Wednesday based on requests from the ANN community! ANN is fortunate to have several educators supporting the Board of Directors who were able to rebrand the materials to Nystagmus Awareness in Schools. New to the collection in 2022 are grade level specific lesson plans which allow teachers and parents to cater presentations to all students. There was also a brand refresh on the short stories and activities pages that accompany those plans. ANN would like to thank the families and educators in our community who will use this material to spread awareness in classrooms around the country and abroad.

If you are skilled in or enjoy writing, marketing, research, and publication and are looking for a way to support ANN and advance our reach, please send an email to info@nystagmus.org for more information on how you can join the resources committee.

The ANN 2022 Board Retreat

The ANN Board of Directors (BOD) held a strategy planning session in Rutherford, NJ in July 2022. Members of the board took to planes, trains, and automobiles to gather from around the country with the primary objective to advance the ANN mission and core focus into 2023 and beyond.

ANN's mission is to improve the quality of life for all persons and families affected by nystagmus, through organized community support, education, public awareness, and research.

The ANN BOD reaffirmed its commitment to advancing that mission and set lofty, long-term goals to become the leading organization in spreading the global awareness of nystagmus and exponentially increasing ANN's reach for our community.

Goals for ANN, 2023 and Beyond

1. Provide organized support for the Nystagmus community by:
 - Hosting biennial conferences and support more frequent regional gatherings
 - Maintaining an active social media presence where community members feel safe, engaged, and known
 - Maintain a current library of Nystagmus resources on the ANN website
2. Inspire, empower, and equip self-advocacy for people with nystagmus by:
 - Providing resources on the ANN website for school, work, and living with Nystagmus
 - Providing networking, panel, and community engagement opportunities for people with Nystagmus
 - Maintaining an active ANN membership and social media community who can mentor, consult, or assist one another

The ANN 2022 Board Retreat (Continued)

3. Spread awareness of nystagmus outside of the ANN community and grow global research capabilities by:
 - Exhibiting at a minimum of 2 professional conference annually
 - Hosting a research workshop for global awareness and studies at a minimum of every four years in conjunction with biennial ANN community conference
 - Maintaining current brochures and informational packets for professional conferences and engagements

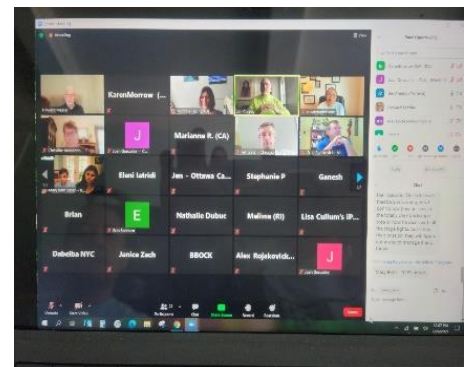
To achieve these goals in 2023, ANN has to increase the volunteer base that supports the growth and operation of the organization. The ANN BOD is supported by 9 volunteers located throughout the United States, with varying backgrounds, professions, and personal connections with nystagmus. ANN is looking to recruit 9-12 passionate volunteers to work with the BOD and support the many committees, social media platform tasks, and planning needs of the organization. The time commitment and tasks vary so widely, that we encourage community members to send an email to info@nystagmus.org if there is any interest to contribute to the organization in either large or small ways.

ANN is recruiting for volunteers of all backgrounds and skillsets, but has an immediate need for volunteers specializing in the following areas:

- Fundraising and Donor Relations
- Social Media Platform Management & Content Development
- Website Design & Administration (advanced skills not necessary)

Current ANN Structure

- Board of Directors & Governance Committee
- Finance Committee
- Resources & Outreach Committee
- Website Oversight & Administration
- Social Media Committee
- Biennial Conference Planning Committee
- Fundraising & Member Growth Committee
- Scholarship Committee



Call for Volunteers

ANN Needs Your Help!

ANN is an all-volunteer nonprofit. Everyone who works for ANN donates their time and talents to make this organization run. But we need your help with some specific areas! Do you have some expertise and are able to donate some time to ANN?

- Social Media: Do you have an active social media presence? Can you help ANN communicate with our members more effectively on various social media platforms (Facebook, Instagram, Twitter, TikTok, etc.)? Can you help create social media posts that communicate our message and engage our community?
- Website Administration: Do you have experience maintaining and updating WordPress websites? Can you help us update our website, and make regular additions? We really need some support here!

If you can help in these areas or have other talents you could offer to ANN, please contact us at info@nystagmus.org or apply on our website at www.volunteer.nystagmus.org.



Conference Announcement

2023 Biannual Conference
Save the Date: July 28-30, 2023
Nashville, Tennessee

Join the nystagmus community for a weekend of education, community, and good old-fashioned personal camaraderie! We are excited to welcome everyone back to an in-person conference.

Conference Highlights

In 2023 the conference returns to an in-person event. The conference will include presentations by experts with time for questions, moderated group discussion sessions for those with nystagmus, parents, and teens. Additionally, our program dedicated to children, Camp Nystagmus, returns with fun and educational activities for the younger attendees.

Conference Venue

The Inn at Opryland
A Gaylord Hotel
2401 Music Valley Drive
Nashville, TN, 37214



Book your hotel reservations for the group rate using the link on our website.

Check our website frequently as we finalize the details and post updates.

www.nystagmus.org/conference

ANN Board of Directors



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Joseph Ambrico
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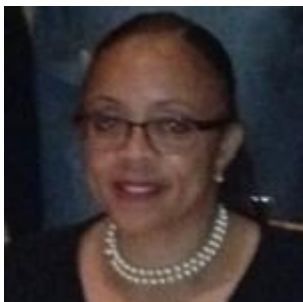


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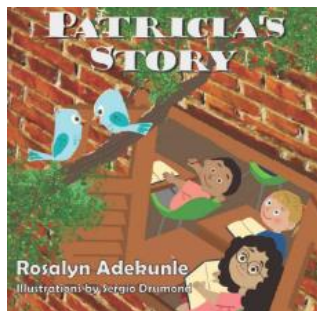
Nystagmus Children's Books on Amazon



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

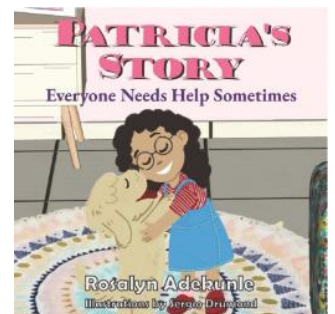
All royalties from these books are donated to ANN.

Follow the Author: <https://www.amazon.com/stores/author/B087QN1ZG3>



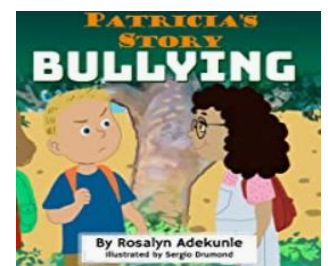
Believing in yourself goes a long way. This story is about the journey of a young girl as she starts her first day in kindergarten. Patricia was born with nystagmus, an eye condition that affects her vision. Despite this condition, she does not let it affect her confidence and her ability to socialize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

Patricia experiences bullying for the first time. Bullying is unwanted aggressive behavior that can be continuous. There are multiple ways of dealing with bullying and Patricia's Story is one of them. No one deserves to be bullied.



American Nystagmus Network, Inc.

Financial Report

January-December 2022

Income

| | |
|---------------------------------|----------|
| Donations | \$16,699 |
| Membership | \$1,363 |
| Cardinal Health Volunteer Grant | \$3,500 |
| Amazon Smile | \$1,661 |
| Delta Gamma Grant | \$6,000 |

Total Income **\$29,223**

Expenses

Administrative

| | |
|--------------------------------|---------|
| Labyrinth | \$1,998 |
| Shipping Store | \$278 |
| QuickBooks Online | \$195 |
| Hostcentric | \$631 |
| Hartford Insurance - Event | \$465 |
| Great American Insurance - BOD | \$706 |
| Wild Apricot | \$2,536 |

Total Administrative Expenses **\$6,809**

Program

| | |
|-----------------------|---------|
| Board Meeting Housing | \$2,478 |
| AAPOS Trade Show | \$6,700 |
| AOA Trade Show | \$3,178 |
| Podcast | \$2,000 |
| Scholarship | \$4,000 |
| Administrative Fees | \$207 |

Total Program Expenses **\$18,563**

Total Expenses **\$25,372**

NET INCOME **\$3,851**

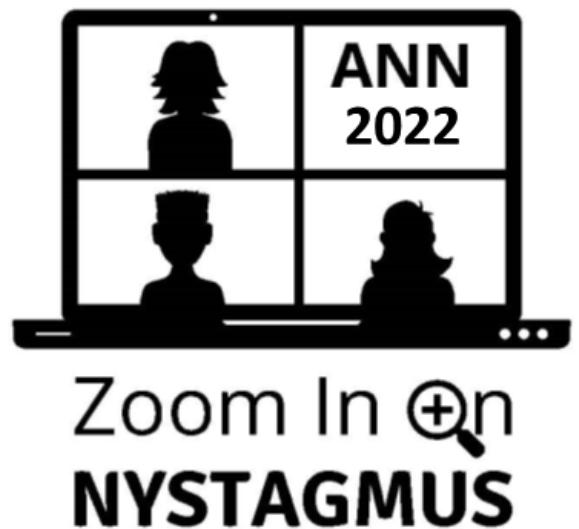
ANN Scholarships

2022 Annual Scholarship Report

ANN is always striving for improvement. We revisit our In-house scholarship process and procedures every year. We are determined to be transparent and efficient in our scholarship process.

Out of a group of qualified scholarship applicants, ANN was successful once again in choosing five (5) deserving scholarship recipients. Our 2021-2022 recipients each received \$1,000 scholarship awards. Our total awards amounted to \$5,000. We thank our donors and supporters who helped make this possible. The five recipients featured in the annual report appreciated ANN's financial award. Our youth are the future of ANN and can keep ANN flourishing throughout the future.

Thank you to all our financial supporters of ANN's Scholarship Program. It is because of you we can encourage and aid in the continuation of the academics of our nystagmus community.



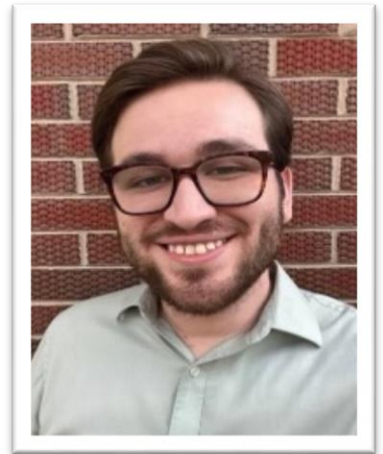
ANN Scholarship Spotlight

Ella Broadhurst



I am a freshman at Southern Methodist University and I plan to go into the business field. I was born with nystagmus. Despite challenges with nystagmus, I played competitive sports all my life. Growing up doctors told me that playing sports and getting my unrestricted driver's license would not be possible, so looking back and being able to achieve both have felt amazing. In high school I was involved in the global sustainability program and the girl's varsity soccer team all 4 years. I also raised money for the Leukemia Lymphoma Society. I look forward to what's next at SMU!

Jonas Byson



Jonas is a graduate student from Wilmington, NC who believes in a better future. He was born with infantile nystagmus and macular Hypoplasia. While his visual impairments have often acted as roadblocks for him, they have also been critical factors in his passion for building a more equitable world. He is currently pursuing a Master's Degree in Community Development from North Carolina State University in Raleigh.



Rachel Cutler

I graduated from Zeeland East High School (Zeeland, MI). My nystagmus is part of ocular albinism which I've had since birth. I've been a cheerleader my entire high school years. For the past three years my summer job was at John Ball Zoo in Grand Rapids. I also volunteered for several years at a no-kill rescue shelter for cats and dogs. I want to turn my passion for animals into a career. I'll attend Cornerstone University in Grand Rapids, MI in the fall, cheering on their cheer team, and focusing on a pre-veterinary or biology major.

ANN Scholarship Spotlight

While a student at Brookfield Central High School (Brookfield, WI) I was active in various sports and clubs, including captain of my school's varsity football team, co-president of the Red Kettle Club, and captain of the drumline. I participated in DECA and competed at the international level 2 years in a row. In my free time, I played in an intramural basketball league where my team won the championship in both my junior and senior years. I recently graduated with a 4.0 GPA (4.575 weighted) and will attend the University of Wisconsin-Madison to pursue double majors in finance and real estate.



Finley Wistrom



John Stricklen

I serve as instructor of secondary language arts at the Ohio State School for the Blind. I have been legally blind since birth, with diagnoses of albinism and nystagmus. I experience firsthand the challenges that nystagmus presents, yet these challenges allow me to better understand and meet the unique needs of my visually impaired students. I am so thankful to have been awarded the 2022 ANN Scholarship. These funds will help me to pursue the Certified Assistive Technology Instructional Specialist (CATIS) credential at Western Michigan University, which in turn will both enhance my practice as a Teacher of the Visually Impaired (TVI) and help me to better support access to educational technology in my language arts classes.

Apply for the ANNual Scholarship

- Diagnosis of nystagmus is required to be eligible.
- Applications must be submitted by May 31.
- Notifications are sent to the awardees on July 1.
- Official award letters notifying applicants of their status will be sent in July.
- Checks made payable to the institution will be mailed to the awardees on August 15.

Visit the ANN website for more scholarship information.

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.

Again, thanks to family, friends, volunteers and donors for your support of ANN!

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Visit us on [Instagram](#). Visit our [YouTube](#) channel.



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