

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 and public awareness.



2018

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

Friends,

It's exciting to be heading into a "conference year." We look forward to seeing old friends and new at ANN's 11th bi-annual conference July 26 - 28, 2019 at the Hyatt Regency in Crystal City, Virginia.

In 2018, support from ANN's community, donors and friends allowed us to expand our reach and engagement in a non-conference year. We introduced new programs that increased our reach and engagement in both physical and virtual communities and paved the way for ANN's future by partnering with our next generation of leaders.

In the summer of 2018, we kicked off **regional gatherings and regional camp nystagmus** held in Inglewood, New Jersey, Saint Louis, Missouri and San Leandro, California. These one-day events allowed families to gather in an informal setting, to share our experiences and challenges as well as our goals and accomplishments. Community and fellowship, connection and more than a few laughs, made these regional gatherings a highlight of the year and something we'd like to continue into the future.

In addition to regional gatherings, our virtual, online community continues to grow and thrive. With over 3,000 members in our Facebook community we introduced **new community guidelines** and have seen a continued rise in support and engagement across the community.

With an eye to the future we kicked off **ANN's Young Leaders Council**. These young volunteers bring a fresh perspective and new ideas to the organization that will continue to sharpen our focus and keep ANN relevant and responsive to our members' evolving lives and needs.

I'm incredibly proud of what we accomplished in 2018. Each of these initiatives, and so many others rely upon the generous contributions of our donors, supporters, volunteers and friends. Thank you. Please consider contributing to ANN or to setting up a monthly gift or bequest so we might continue our mission: To improve the quality of life for all persons and families affected by nystagmus, through organized community support, education and public awareness.

Thank you, and see you at the conference!
Jim



Thank You to Our 2018 Donors

The American Nystagmus Network would like to thank our donors who have generously supported the regional gatherings, camp nystagmus, and our mission.

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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 become the backbone for additional services provided by the organization.

2019 ANN Conference and Research Workshop

We are excited to announce that the **2019 ANN Conference will be July 26 - 28, 2019 at the Hyatt Regency Crystal City**. Plan to arrive for the opening session at 4:00 PM on Friday.

Prior to the conference, ANN is hosting a Nystagmus Research Workshop which will bring together nystagmus researchers from around the world. ANN hosted our last Research Workshop in 2017, prior to the New Orleans conference.

Like in 2015, we look forward to having many of the researchers stay and join us at the ANN conference. We will also have a keynote that features some of these researchers and their research.

Hotel information



Room Cost:

Single/Double Occupancy: \$95

Triple Occupancy: \$120

Quad Occupancy: \$145

Book from the ANN website to receive this price.
(Hotel registration link coming soon.)

Free hotel shuttle is provided from Reagan National Airport.

More information coming soon! Checkout our website and Facebook page for the most current conference information.

We look forward to seeing many of you in Crystal City!



2018 Regional Gatherings

2018 was an off-year for the larger ANN biennial conference, so ANN decided to expand our programs to include three regional gatherings. The events happen: June 23 in Englewood, NJ, July 28 in St. Louis, MO and August 11 in San Leandro, CA. Each event was a single day, and was structured somewhat similar to the programs at the biennial conference. The goal was to bring a portion of the conference experience to our members who are unable to travel to the conference. Additionally, the regional gatherings were able to introduce nearby nystagmus community members to each other.

Each event had two basic programs that ran concurrently:



Regional Gathering This program type was for adults and high school students who either have nystagmus or who have a family member/friend with nystagmus. Parents and adults with nystagmus had a chance for an in-depth discussion. Topics included the challenges of nystagmus, tips and tricks for living and succeeding with nystagmus, as well as nystagmus at school and work.

Camp Nystagmus This program was for students entering grades K-8th for the 2018-2019 school year. The camp is designed for both students with

nystagmus and for students with family members or friends with nystagmus. Camp Nystagmus provided a day's worth of activities. The kids got a chance to meet other kids with nystagmus, learned about nystagmus and how to talk about it with others, and simply had fun! Camp Nystagmus was funded by a grant from Delta Gamma foundation.

At the end of the day, everyone got a chance to give us feedback on the event, and on what ANN could do to support them in the future. Thank you to everyone who attend one of our gatherings.



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Thank you Delta Gamma
Foundation for making
Camp Nystagmus possible!

Volunteer Recruitment and Management Project

As an all volunteer organization, ANN relies on volunteers to do the work of the organization. Unfortunately, in the past many people have reached out to offer help but our organization did not have the capacity to accept the help at that time. Since March, we have been working on a volunteer recruitment and management project to create structures that will help us recruit and manage volunteers.

Caroline Randazzo was recruited to lead this effort. Caroline is the Director of HR and Recruitment for a company in Chicago and has a child with nystagmus. Our conferences are where we get the most offers to help, and this year we will be ready to recruit people for tasks that will really use their expertise. Watch our website and Facebook for more information on this exciting project.

Thank you Delta Gamma Foundation for providing the seed money for this project!



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Volunteer Spotlight: Brianna Walit

"No Day, But Today" The four words that inspire me. Hello! I am Brianna Walit the Social Media Manager for the American Nystagmus Network. Born and raised in Los Angeles with Nystagmus I strive to create awareness about Nystagmus.

In 2014, I graduated from California State University, Northridge (CSUN) with a degree in Cinema and Television Arts with an emphasis in Media Management. One degree under my belt, I knew I wanted to continue my education so right after I graduated I moved to New York to pursue a Masters Degree in Media Management. During my time in New York, I connected with Jim Conely (president of ANN) and the rest was history.

In 2016, I graduated from The New School with a Masters in Media Management. Since then I have moved back to Los Angeles while continuing my work with ANN. In hopes to find more ways to bring awareness and to continue educating others about Nystagmus.



American Nystagmus Network, Inc. 2018 Financial Report

American Nystagmus Network, Inc 2018 Finance Report January - December 2018

Revenue

| | |
|---------------|----------|
| Donations | \$18,831 |
| Grants | \$ 7,000 |
| Memberships | \$ 5,290 |
| Gatherings | \$ 838 |
| Amazon Smiles | \$ 634 |
| Benevity | \$ 125 |

Total Revenue **\$32,718**

Expenses

| | |
|--------------|----------|
| Scholarships | \$ 6,348 |
| ED salary | \$ 2,970 |
| Gatherings | \$ 2,791 |
| State Reg | \$ 2,022 |
| Wild Apricot | \$ 1,762 |
| Insurance | \$ 1,062 |
| Quickbooks | \$ 562 |
| Shipping | \$ 256 |

Total Expenses **\$17,773**

Revenue less expenses **\$14,944**

ANN Scholarship Spotlight

Timothy Cordes

I will began nursing school in the fall of 2018 to pursue a Registered Professional Nurse license and then will move on to earn a BS in Nursing. As an airplane pilot, my eyes will never allow me to fly big airlines, but I have the goal of becoming a flight instructor. In the past four years I have been involved in many community organizations. I am an Eagle Scout and have served as an assistant Scout Master. I have volunteered with Children's Miracle, Prairie Fest and the Criminal Justice Club. I live with Nystagmus by living the life that I would live without the condition. I believe that education only ends when curiosity about the world ends.

Drew Hovde

I was diagnosed with Congenital Nystagmus when I was 1.5 years old. I defied the doubters by getting my license and competing in varsity sports in high school and maintaining a 3.83 GPA. I have varsity letters in Cross Country and Track and I played the saxophone in concert band. My educational goal is to attend Whitworth University in Spokane Washington where I will study pre-medicine and run cross country and track. After I receive my BS degree, I plan to apply for medical school. My career goal is to become the most knowledgeable and understanding doctor I can be by helping many achieve better health. I hope to be able to give back to my community as well as my family who has made my path possible.

Victoria Syracuse

I am a rising senior at Keuka College and plan to finish my undergraduate degree in Occupational Science in 2019. I will enter my graduate year and complete two field work placements and graduate in 2020. After graduating with my masters, I will sit for the NBCOT exam so that I can practice as a registered Occupational Therapist in NY State. I am active in Sigma Alpha Pi and Circle K International. I enjoy working with kids and was a senior camp counselor at Camp Smile, a summer day camp for children who are blind or visually impaired.

Melissa Miller

A master's degree from Georgetown University's Security Studies Program will support my cross-disciplinary research interests and qualify me for a successful career in the US government with the goal of improving security at home and abroad. I attended Georgetown University from 2011-2015 and completed my Bachelors of Science in International Affairs. I was an outstanding delegate for Model UN several years in a row and was

selected to attend Harvard's World Model UN Conference in Brussels, Belgium. In undergrad, I was a member of Epsilon Sigma Alpha community service sorority and worked on the GW Hatchet School Newspaper. I also was in the University Honors Program and College Democrats. I was born with Nystagmus and as an infant wore contacts. Due to my poor vision as a child, I had difficulty seeing objects from a distance. I have always tried to participate in activities even if my coordination and vision was not as good as others. I was able to be a varsity swimmer and a black belt in Karate. As much as I can, I don't allow my vision difficulties to get in the way of achieving my goals.

Estee Cramer

My career goal is to be an infectious disease epidemiologist who studies neglected tropical diseases around the world. I love working in a research laboratory with genomic data and projects such as malaria treatment in Madagascar. I aspire to run my own lab so I have a chance to do quantitative work including data analysis and qualitative work such as interviews with community members in marginalized populations. Currently I am taking classes towards a Masters of Public Health with a goal to graduate in spring 2019. I am active in my school and community serving as a Hope Lodge volunteer and being a board member of the ACS Relay for Life. I also am active in Sigma Sigma Sigma sorority. Living with Nystagmus has helped shape who I am as a student. Although it is difficult for me to see, I have overcome many obstacles. I was even able to pass the DMV vision test and was cleared to drive last year.

2018 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 thirty -five 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 intends to award up to five (5) scholarships of \$1,000 each for a total of \$5,000 in awards in 2018



How to Apply

- Diagnosis of Nystagmus is required to be eligible.
- Applications **must** be post marked by **May 31, 2019.**
- The scholarship management service will notify the ANN Board of Directors of the awardees on July 1, 2019.
- Letters notifying applicants of their status will be sent out in July 2019.
- Checks mailed to the awardees on August 15, 2019 payable to the institution.

Updated scholarship application information is posted on the ANN website.