

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.

ALWAYS
MOVING



FORWARD

2017

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

"Always Moving... Forward!" was the theme of ANN's 2017 Biennial Conference in Minneapolis, Minnesota. This theme, suggested by a member of ANN's growing online community (topping three-thousand members in 2017) is a fitting way to highlight areas where ANN continued to move forward in 2017, and where we have set our sights for 2018 and beyond.

Looking back at 2017, we celebrate hosting our largest conference to-date with over 200 people; adults, families and kids attended three tracks of excellent, informative and fun programming. Even a few "non-human" visitors joined us. I'm speaking of course of the animals from the Minneapolis Zoo who helped kids at Camp Nystagmus discover the variety of visual capability and functions across the animal kingdom.



A personal highlight was an inspirational address from American Ninja Warrior Nico Gentry, who has become a national ambassador for ANN and continues to raise awareness and inspire us all.

2017 also saw tremendous movement forward in our social and online communities. ANN's YouTube channel, where we feature videos from previous

year's conferences, saw 10x growth from 600 video views in 2016 to over 6,000 views in 2017. Similarly ANN's Facebook Page and Community also saw strong growth. ANN's Official FB "Page" has over 2,500 followers and the "American Nystagmus Network" FB Community has grown over 50% year over year with more than 3,000 current members.

On ANN's Website www.nystagmus.org, we have seen the growth of our FB community take away from the growth of our web visit (up only 7% year over year). This has been offset by people remaining 30% longer on the website, likely reviewing additional resources that we continue to refresh.

Looking forward, 2018 is a "non conference" year for ANN. We will focus on creating a solid foundation for sustained growth. This includes hiring ANN's first Executive Director who will lead the organization in establishing critical development, organization, and programming structures.

This important work will require volunteer support as well as focused development efforts in the form of grants, major gifts, and continued member support. We thank you for your continued support as we build and grow the American Nystagmus Network.

Always Moving Forward,

Thank you,
Jim Conley

Thank You to Our Donors

The American Nystagmus Network would like to thank the sponsors of the 2017 Biennial Conference, as well as the individual donors who have generously supported both the conference and our mission.

Gold Sponsors



Joshua Schulman

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Silver Sponsors



Evelyn and Juan González
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Laura Smith
Jay Wilson

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.

2017 ANN Conference



ANN's 2017 Conference was our largest and most successful yet. Over July 28-30, in Minneapolis, MN, over two-hundred people traveled from across the US to attend ANN's biennial conference. The top reasons people attend the conference are to learn more about nystagmus itself, and to learn about how to live with nystagmus. And, as always, they came to make new friends and to reconnect with old ones.

The conference included a variety of content. The agenda was divided into three tracks: for people with nystagmus, parents of children with nystagmus and a Camp Nystagmus tailored to children with nystagmus. People could learn about treatment options, research, workplace and school accommodations, as well as tips, tricks and everyday hacks for living with nystagmus. There were also many options for interaction, with break-out sessions and panel Q&A discussions. The keynote speaker, Dr. James Phillips, taught us all about eye movements and nystagmus, and even offered to perform eye-movement recordings for anyone at the conference!



2017 ANN Conference (Continued)



We were especially excited to have American Ninja Warrior Nico Gentry attend the conference. Nico has brought national attention to Nystagmus through his appearance on American Ninja Warrior and is a new friend and hero for our community. Nico spoke to the conference about living with nystagmus, and he spoke about his experience tackling the American Ninja Warrior course. He also generously spent time chatting with all who attended.

Feedback was overwhelmingly positive. Nearly everyone who completed our survey reported an overall excellent experience. The most highly rated sessions were “Nystagmus in a School Setting,” and “Tips and Tricks for Living with Nystagmus.” Almost everyone liked the conference venue and enjoyed visiting Minneapolis. Excellent organization, passionate volunteers, and generous donors all contributed to raising the bar for our next conference in 2019.



International Exposure for ANN



The American Nystagmus Network was invited to speak at the Vision 2017 international conference on low vision in The Hague, Netherlands! ANN's vice president Joe Ambrico, presented a talk titled, "Living with Nystagmus: Support in the Internet Age." It included a description of ANN and what we strive to do to support all those affected by nystagmus. The international exposure among the research community is vital to our support and advocacy for those with nystagmus.

One of the sessions at the Vision 2017 conference was entirely devoted to research implementation - how to get science to transition to treatment. The session presented perspectives from several countries (Netherlands, UK, Spain, European Union) on how to effectively implement research and share results to avoid duplication of efforts. It is extremely encouraging to see a strong focus on "clients" of low-vision research - the patients with the conditions - to provide them with better and more timely care. There also was a discussion about the importance of patient advocacy groups (such as ANN!) in finding research subjects for clinical trials and for communicating the results of research studies. Overall, it was a very encouraging conference!



American Nystagmus Network, Inc. 2017 Financial Report

American Nystagmus Network, Inc Statement of Activities January - December 2017

Total Income

Conference Income	
Conference Fees	51,418.04
Total Conference Income	\$51,418.04
Fundraisers-wristbands	150.00
Membership	2,935.00
Donations	18,406.70
Total Income	\$72,909.74

Expenses

Administrative Costs	
Accounting Software Services	447.15
Insurance	
Event Insurance	468.00
Total Insurance	\$468.00
Internet/Website	756.00
Mailbox Rental & Expenses	282.08
Total Administrative Costs	\$1,953.23
Conferences	
Member Conferences	59,414.34
Total Conferences	\$59,414.34
Scholarships	
Scholarship Management Fees	1,363.00
Scholarships Awarded	5,000.00
Total Scholarships	\$6,363.00
State Registration Filing Fees	555.00
State Registration Filing Services	2,455.00
Total Expenses	\$70,740.57
Net Operating Income	\$2,169.17
Net Income	\$2,169.17

Online Community Report

As social media continues to drive awareness and engagement with ANN, this year we are adding a section to document the important role that online communities have begun playing in supporting our mission “To improve the quality of life for all persons and families affected by nystagmus, through organized community support, education, and public awareness.”

Success in our primary communities was driven by volunteer support from Brianna Walit and Zohaib Farrukh. Moving forward we will continue to invest in our primary communities on Facebook and YouTube and invest in secondary communities pending additional volunteer support.

ANN maintains two primary and three secondary online communities including the following:

Primary Communities:

- American Nystagmus Network Facebook Page
- American Nystagmus Network Facebook Community

Secondary Communities

- YouTube - American Nystagmus Network (138 subscribers)
- Instagram: @american_nystagmus_network (67 followers)
- Twitter: @nystagmusorg (135 followers)

Facebook Page

- Total Page Followers - 2,566
- Page Likes - 2,557

Top Page Fan Cities:

New York, NY - 29	Morgan City, LA - 15
London, England, United Kingdom - 27	Indianapolis, IN - 15
Los Angeles, CA - 24	Houston, TX - 15
Chicago, IL - 20	Philadelphia, PA - 13
Berwick, LA - 17	Dallas, TX - 12

Facebook Community:

- 3,093 Total Members - 2,327 Active Members (~75% female 25% male)
- 327 Posts - 4,793 comments - 7,757 reactions

Top Member Cities

New York, NY - 40	Philadelphia, PA -18
Los Angeles, CA - 28	Tucson, AZ - 16
Houston, TX - 25	Lagos, Lagos State, Nigeria * - 14
Chicago, IL - 19	Orlando, FL - 13
London, England, United Kingdom -18	Lafayette, LA - 13

ANN Scholarship Spotlight



Caitlyn Faulhaber

My goal is still to graduate from Centenary with my Accounting degree and CPA certification. My career goals are basically the same, to work with a company/organization that is very active with community involvement. I believe the company needs to be about their employees and not always about the money. My long-term goal is always about being or doing my best at all times.



Benjamin Fritz

I intend to earn a bachelor's degree at the University of Nevada, Reno in Electrical Engineering within 4 years. After this I plan on entering the workforce immediately as an engineer, with the possibility of returning to college for a master's degree. My long term goals include having a career that I enjoy and making enough money to support myself and financially help my close family. My participation in rigorous classes throughout high school and into college will help me attain these goals in a timely manner. I plan to continue working throughout college to pay for tuition.

Kristin Kitko

I am currently a school counselor at Durant High School. I have decided to go back to school to pursue my Master's in Social Work in order to help more people. As a social worker, I will be able to meet clients where they are instead of sitting in an office waiting for them to come to me. I am interested in helping families that are dealing with substance abuse issues, as well as military families dealing with all the stresses that come with being in the military and constantly in a state of transition.



Marcela Palomo

I am attracted to the multidisciplinary nature of a business degree as a pathway to develop my organizational and leadership skills while gaining an understanding of key elements needed to promote progress and sustainability in every society. I enjoy hearing about different cultures and traveling to new places. Therefore I am very interested in the possibilities a business degree may offer to join a company or agency with an international presence to create positive change at a global scale. Also I am very interested in pursuing graduate studies in international affairs and global development.

Michael Wageman

I want to help and give back to people who have lost the ability to perform necessary tasks or participate in activities that they enjoy. I plan to finish my undergraduate studies at University of Mary Hardin-Baylor. Then I plan on going to PT school where I will obtain a Doctorate of Physical Therapy.

2017 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

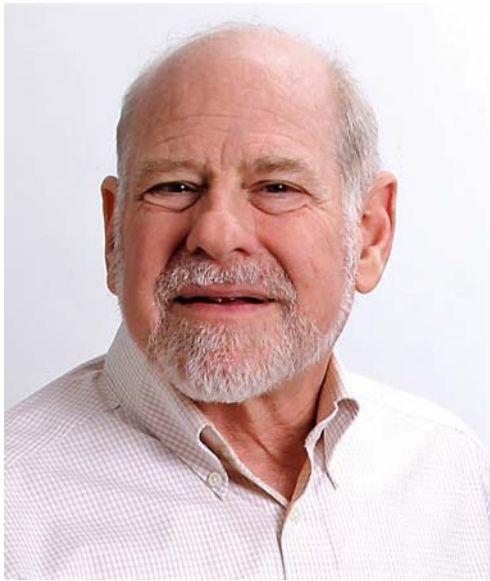


How to Apply

- Diagnosis of Nystagmus is required to be eligible.
- Applications ***must*** be post marked by **May 31, 2018.**
- The scholarship management service will notify the ANN Board of Directors of the awardees on July 1, 2018.
- Letters notifying applicants of their status will be sent out in July 2018.
- Checks mailed to the awardees on August 15, 2018 payable to the institution.

Updated scholarship application information is posted on the ANN website.

In Memoriam: Former Board Member Mike Arm



With a heavy heart, the American Nystagmus Network announces the loss of our cherished member Mike Arm. Mike was a hero to thousands of people with Nystagmus. He leaves a legacy of compassion, grace and tremendous progress towards our mission to improve the quality of life for all persons and families affected by nystagmus.

Mike's warm and friendly smile, his strength and his guidance, his perseverance through adversity and his sheer courage brought comfort to everyone who was fortunate enough to have met Mike at ANN's many conferences over the years. And even those who never met him were assisted along in their journey through Mike's diligent and thoughtful behind the scenes work with ANN. He was tireless and comforting, responding to hundreds of concerned parents who wrote desperate and anxious

email messages to ANN. He later established a web presence that extended ANN's reach and impact further than anyone could have imagined.

In light of Mike's innumerable contributions to the organization and in loving memory of his dedication, hard work, and unique and inspiring charm and grace, I wanted to let the nystagmus community know that the American Nystagmus Network will honor Mike through the naming, in perpetuity, of a scholarship each year to a student who, like Mike, inspires us and exhibits unique courage and perseverance in both their academic studies and approach to life itself.

We will miss Mike, but we will never forget him. And this scholarship will carry his name and his compassion, dedication and spirit to future students and will serve as a beacon and inspiration to the entire ANN community.



ANN Board Members at the 2015 Conference