

# 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.



# 2015

# 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

The American Nystagmus Network's year-end report presents a unique opportunity to connect with members, donors, and our global partners as we look back at some of people, events and activities that have shaped a truly extraordinary year.

Additionally, it provides an opportunity to look forward; and, together, to create a shared vision of the organization, services and community that will shape ANN, our members, partners and supporters.

2015 was a "Conference Year" which always presents both a tremendous amount of hard work in preparation as well as a profound sense of accomplishment looking back after the event. This year was no exception. We were treated to tremendous hospitality by our hosts, the Fuhrer family and the City of New Orleans. Read on for additional details about our programs and events during the conference, and please consider volunteering now for our 2017 Conference Committee.

In addition to the member conference, this year ANN also hosted our first international Research workshop welcoming the world's top researchers on Nystagmus. Over two-days scholars, researchers and clinicians presented their recent work, collaborated on ideas for studies, and even presented breakout sessions for our members. Videos of these general sessions are available on ANN's YouTube page. This event was made possible by a generous donation. With your help we can host our second Research conference in 2019. Please consider donating to ANN on our website, [www.nystagmus.org](http://www.nystagmus.org), or by contacting us directly at [info@nystagmus.org](mailto:info@nystagmus.org).

These are just a few highlights from a very productive year. Please read on for additional detail from programs like the ANN scholarship. You'll also find details about the perennially popular Wobbly Wednesday program which continues to grow awareness and acceptance for kids with Nystagmus.

I'd also like to extend a warm and hearty thanks to our outgoing board members, especially Rick Beaudet and Michael Arm who provided vision, stewardship, and true gusto for ANN that has been a compass for ANN as we navigate into today and beyond.

We desire to grow into a world-class organization, to become a catalyst for change, awareness and support. Like our members, and those who support, nurture and care for their journey, we believe that ANN's reach lies beyond our grasp. Please read on as we **Celebrate Today's Achievements and Tomorrow's Possibilities.**

And please join us through our volunteer programs or through financial support at [www.nystagmus.org](http://www.nystagmus.org).

Jim Conley  
President



# Thank You to our Donors

The American Nystagmus Network would like to thank the sponsors of the 2015 Biennial Conference, as well as the individual donors who have generously supported both the conference 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.

# Celebrating Today's Achievements and Tomorrow's Possibilities

What do an international pop star and a dozen or so of the world's top researchers in nystagmus have in common? They were all guest "stars" at this year's biennial ANN conference in New Orleans, Louisiana. This year, ANN held its first ever international research conference inviting researchers from around the world to share their latest research, findings, and experiments in progress with a group of peers and ANN board members and sponsors. Read further for a more detailed conference rundown, including research topics from ANN Vice President Joe Ambrico.



And we had a special celebrity appearance with the incomparable Apl.de.ap from the Black Eyed Peas who has nystagmus himself. Apl arrived Saturday evening and took the stage addressing kids and parents; he spoke about some of his own struggles, and about the coping skills he developed along the way--and how these skills would turn into talents as he grew. "You see, I used to always fall down, so when someone told me about breakdancing, I thought, Great! I can do this, the floor and I are already good friends!" Following his address as a presenter, he joined the conference as a member. For Apl just being in the room with so many people who had nystagmus was an overwhelming experience. He spent over an hour sitting around a table, talking with teenagers and younger kids, relating stories, laughing, making friends and being part of our community.



# Celebrating Today's Achievements and Tomorrow's Possibilities Continued



Before we had to leave the ballroom, Apl was treated to the first ever ANN Kids dance-a-thon where kids from Camp Nystagmus showed off their skills dancing. And Apl even joined in.

As you might expect from an event in New Orleans, the food was fantastic, the good cheer was contagious, and the hospitality was simply first rate. Huge thanks to our conference committee and especially to Tony Fuhrer who went above and beyond in creating a truly extraordinary experience for everyone involved.

*Celebrating* TODAY'S *Achievements*  
AND TOMMOROW'S *Possibilities*



ANN Workshop and Conference  
July 29 - August 2, 2015



# Camp Nystagmus

ANN offered a special program for the children attending this year's conference.

Camp Nystagmus provided many activities throughout the day, including a visit by some animals from the New Orleans Audubon Zoo.

Later in the day, Camp Nystagmus participants had an opportunity to ask questions to a panel of older teens about living with nystagmus.

The day ended with older students with nystagmus modeling how they answer peer questions about nystagmus and then the camp participants practiced how they would answer the same questions.

The camp provided the opportunity for students to realize they are not alone. It was one day where everyone was connected by nystagmus.



**“My son loved the activities and animals. I appreciate the teens answering his questions and helping him feel more comfortable with his nystagmus.”**



*“It was fun!”*      *“I touched an alligator”*

*“Awesome, we saw the owl fly”*



# Nystagmus Research

2015 was an exciting year for ANN and nystagmus research! It saw ANN host an international research workshop, which is the first time ANN has directly supported medical research into nystagmus. ANN's primary mission has been supporting those affected by nystagmus, so this workshop represents a bold new step for the organization. This workshop is actually the 4<sup>th</sup> in a series, with the first 3 being hosted by the UK Nystagmus Network.

*Ok, so what is a research workshop anyway?* The nystagmus research workshop is similar in format to other academic conferences and symposia that researchers would attend. 15 notable international nystagmus experts attended this workshop. Each delegate made a short presentation (about 25 minutes) on his or her latest research into nystagmus. This is research that will be or has been recently published in scholarly, peer-reviewed journals (for example, the Journal of Investigative Ophthalmology and Visual Science, the British Journal of Ophthalmology, etc.) After the presentation, the researcher answered any questions from the rest of the delegates. Two more in-depth group discussion sessions were held as well.



While this format is common in academic research, the unusual and critical point of this particular workshop is having so many nystagmus experts together in one place. Even in today's connected world, there is no substitute for personal interaction. Feedback from the delegates was that they enjoyed the formal group discussions and the informal social interaction that the workshop created. This is partly because these delegates have rather diverse specialties in nystagmus.

## *What was talked about?*

Delegates presented their work in a variety of areas related to nystagmus. Topics were quite varied, including nystagmus's effect on vision, genetics, eye muscle physiology, drug trials, and implantable prostheses - among others. The feedback received was that the range of topics was excellent. The table on the next page provides more detailed information.





# Nystagmus Research Cont.



Delegate Name	Institution	Topic
Larry Abel	University of Melbourne, Australia	Nystagmus in the lab and nystagmus in the wild: What do we assess and how does it relate to what patients see?
Vallabh Das	University of Houston, College of Optometry	Insight into strabismus and nystagmus from oculomotor studies in animal models
Matt Dunn	Cardiff University, UK	Visual timing in infantile nystagmus
Jon Erichsen	Cardiff University, UK	The impact of nystagmus eye movements on vision
Rich Hertle	Akron Children's Hospital Medical Center, OH	Understanding Infantile Nystagmus Syndrome: The Consequence of Translational Research
Helena Lee	University of Southampton, UK	Retinal Development in Achromatopsia and Albinism: A Prospective Study of Infants and Young Children using Optical Coherence Tomography
Lee McIlreavy	Cardiff University, UK	Two dimensional analysis of horizontal and vertical pursuit in infantile nystagmus



# Nystagmus Research Cont.



Delegate Name	Institution	Topic
Rebecca McLean	University of Leicester, UK	A Randomised Controlled Crossover Trial of Gabapentin and Memantine in Infantile Nystagmus
Linda McLoon	University of Minnesota	Nystagmus at the Level of the Eye Muscles
Parachkev Nachev	Institute of Neurology, University College London, UK	A magnetic oculomotor prosthesis for acquired nystagmus
James Phillips	Seattle Children's Hospital / University of Washington	Can an implantable prosthesis reduce or eliminate acquired nystagmus in children following posterior fossa tumor resection?
Frank Proudlock	University of Leicester, UK	Visual System Abnormalities in Albinism: What do they tell us about nystagmus?
Jay Self	University of Southampton, UK	Genetic testing in Nystagmus: What's happening?
Branka Stirn-Kranjc	University Medical Center, Slovenia	Electrophysiological investigation in the child with nystagmus
Hans van der Steen	Erasmus University Rotterdam, Netherlands	Onset of nystagmus in infants with nightblindness associated, transient, tonic downgaze (NATTD)

# Nystagmus Research Cont.

*So how does this help research?*

Researchers get a chance to see new research on the nystagmus science outside of their respective area of expertise. They get to meet new people and learn about new avenues for research. In short, to quote one delegate, this is where new ideas are formed!

Another benefit to research: Jay Self (U. of Southampton) has been in contact with both Linda McLoon (U. of Minnesota) and Hans van der Steen (Erasmus U.) and is establishing a collaboration for the first time, including tentatively planning a working visit from Dr. McLoon as part of a longer term grant and collaboration. This would not have happened without the workshop!

Finally, group discussions were held to come up with ways that ANN can support nystagmus research in the future.



The most obvious and direct support would be to provide grants to fund small research projects or graduate studentships. This could be done in collaboration with other vision charities or even through crowdsourcing. Additionally, ANN can support research by being vocal supporters to research sponsors (such as the National Institutes of Health) and to raise general awareness at other conferences.

Finally, and this was universally agreed upon, is that ANN should continue to sponsor research workshops in the future. All agreed with the plan to hold workshops every two years, alternately hosted in the US by ANN and in the UK by the Nystagmus Network.



# American Nystagmus Network, Inc.

## Profit and Loss 2015

	<b>Total</b>
<b>Income</b>	
<b>Conference Income</b>	
Conference Fees	10,966.42
Conference Grants	2,860.00
Conference Sponsorships	9,100.00
<b>Total Conference Income</b>	<b>\$ 22,926.42</b>
Donations	15,585.88
Fundraisers	3,760.00
Grants	2,000.00
Membership Dues	1,170.00
<b>Total Income</b>	<b>\$ 45,442.30</b>
<b>Expenses</b>	
<b>Administrative Costs</b>	
Accounting Software Services	447.15
Face-To-Face Board Meeting	51.39
Insurance	
D&O Liability	879.00
Event Insurance	699.00
<b>Total Insurance</b>	<b>\$ 1,578.00</b>
Mailbox Rental & Expenses	222.37
Membership Management	540.00
Online Conferencing	258.40
<b>Total Administrative Costs</b>	<b>\$ 3,097.31</b>
<b>Conferences</b>	
Member Conferences	31,841.45
<b>Total Conferences</b>	<b>\$ 31,841.45</b>
Newsletter Production	613.99
Promotional/Awareness Supplies	6,661.50
<b>Scholarships</b>	
Scholarship Management Fees	1,352.00
Scholarships Awarded	5,000.00
<b>Total Scholarships</b>	<b>\$ 6,352.00</b>
Service Charges	28.00
Shipping	166.90
Sponsored Events	7,906.63
State Registration Filing Fees	939.78
State Registration Filing Services	6,327.00
Web Design	600.00
<b>Total Expenses</b>	<b>\$ 64,534.56</b>

# Wobbly Wednesday November 4, 2015

2015 was another successful year for Wobbly Wednesday. ANN sent out a total of 81 packets including 2 packets sent out to college students. Each packet contained a CD with education activities, the ANN facts sheet on Nystagmus, along with Nystagmus paraphernalia such as pencils, pens, and wristbands.

Altogether we reached over 2500 people! Wobbly Wednesday is such a great way to spread awareness and education about Nystagmus and ANN was proud to participate again this year. Continue reading below for a personal story ANN member, Mallory.



appointments. This year we included a picture of her eye surgeon. We handed them out to as many people we can. At the bottom of the card it says, "Mallory thanks you for your support" and it defines what Nystagmus is. In addition to the handouts, we order Nystagmus bracelets for her entire 2nd grade class, we bring in cupcakes with little eye balls on them, we read the story by Edie Glaser, "All children have different eyes" and Mallory's teacher allows her to have a Q and A session with all of the students who might have questions about her special eyes. Her classmates are really supportive and they look forward to our visit every year----as do we!

Mallory is a twin and at 3 months old she was diagnosed with CN. Ever since she was about 3 years old we have talked to her about her vision, her surgeries and how even though her eyes are different than most, we think she is absolutely perfect just the way she is! Each year on Nystagmus Awareness Day we make it a point to celebrate this very important day in our lives. Since it falls on a Wednesday, we are lucky to be able to raise awareness at her school every year and every year it seems to get better and better-----this year was the best one yet!

Wobbly Wednesday has become a true holiday in our family. It is a day that Mallory looks forward to every year! Now that she is 8 years old, she is very involved in the planning. Every year we make a special picture handout of Mallory with special moments throughout the year from her eye Dr's

This year, Mallory's school principal surprised us and dedicated a "dress down day for a \$1" to the American Nystagmus Network. Mallory was so surprised! They also invited her to go on the morning school video announcements and talk to her fellow students about Nystagmus. She was so excited to announce that all students can wear blue on Wednesday if they bring in \$1 and that all proceeds will go to ANN. Mallory was so touched to hear that her school raised around \$400 to benefit a cause that is so important to her.

For Mallory, Wobbly Wednesday is so much fun and seeing the joy on her face when she is speaking to her friends at school about her eyes is just priceless!!!!

Erica & Tyler Mckeon (Mallory's proud mommy and daddy)

# ANN Scholarship Recipients



**GERALYN ADAMS**

Gerallyn is an ECI Book Discussion Group Facilitator. Also a Research and Composition teacher. She is attending Salisbury University, Salisbury, MD. She anticipates graduating May 2016. Major field of study is Composition



**TAYLOR DEYOUNG**

Taylor is valedictorian and citizenship awardee. Taylor participates in volleyball, basketball and track. She is also involved in Girls' State International Missions. She is attending Southwest Baptist University, Bolivar, MO and anticipates graduation May 2019. Her field of study is Accounting.



**ABIGAIL MOTLEY**

Abigal is a member of the Virginia Tech Cross Country and Track Team. She is a Summer Youth Track League volunteer. She is also a member of the Virginia Tech Honors College. She has made the honor roll in Fall of 2013-Spring of 2015. She is currently attending Virginia Polytechnic Institute and State University, Blacksburg, VA. Her Anticipated graduation date is May 2017. Her major field of study is International Studies

## How to Apply

- Diagnosis of Nystagmus is required to be eligible.
- Applications **must** be post marked by **April 30, 2016.**
- The scholarship management service will notify the ANN Board of Directors of the awardees on May 30, 2016.
- Letters notifying applicants of their status will be sent out in June 2016.
- Checks mailed to the awardees on August 15, 2016 payable to the institution.



**CALLIE ROUSE**

Callie is news editor and photographer at the Knox College. She was a 2015 student in Charles University study abroad program in Prague, Czech Republic, majoring in International Relations and double minoring in History and Creative Writing. She's on the Dean's List. She is currently attending Knox College, Galesburg, IL and anticipates graduating in June 2017. Her Major field of study is International Relations



**KEVIN RUOFF**

Kevin is involved in cross country, swimming, track and field. He is in the science league, church youth group and enjoys reading and spending time with his little brothers. He received the 2013-14 Middlesex County Student Recognition award and 2014-15 GMC scholar athlete award. He is currently attending University of North Carolina at Chapel Hill, Chapel Hill, NC. His anticipated graduation date is May 2019. His major field of study is Chemistry

**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.**



## Board of Directors - Old and New

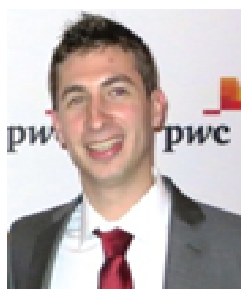
While some of our long-standing board members have decided to move on to the next chapter of their lives, we are fortunate to have added other new board members who have many talents to enhance this Board. Below is a summary of who we have added to the Board and who we say good-bye to:

### New Board Members



Kerri Nagle -- Kerri has re-joined the ANN Board this year and has been a member of ANN since 2008. It was apparent to Kerri and her husband after they attended their first ANN conference that this was a special organization

that would help them navigate nystagmus while giving support to their oldest daughter who has OA. Kerri loves seeing her daughter and other children meet for the first time at conferences as they develop their own friendships and support groups. Kerri has a Masters degree in Organizational Leadership and works with high-risk teens in her local area. She and her husband live with their children and lovable lab Oatz in CT.



David Neuburger -- David received his BSBA in Accounting and Spanish from the University of Pittsburgh. He now works as an auditor for PricewaterhouseCoopers in New York City and is working towards obtaining his CPA. David was born with

nystagmus but has been able to live a relatively normal life. He enjoys playing soccer, running and traveling. He recently ran the 2015 NYC Marathon and plans on running it again in the future.

### Departing Board Members



Richard Beudet --Rick was a Board member for over 12 years and served as ANN President in 2014-2015. He is married to Mona, herself a former newsletter publisher and former Board member. One of his children,

Alec (19) was diagnosed with nystagmus and often participated in ANN events. Rick and his family have been instrumental in the growth of ANN and will be missed on the Board. However, Rick has promised to continue working on Wobly Wednesday and other ANN activities as needed.



Michael Arm -- Mike was a long-time Board member who had previously served as ANN's treasurer and webmaster. He joined the Board in 2001 and he will be

missed very much. Mike was one of Dr. Hertle's first adult patients and through his participation and trials was able to get a driver's license at age 50. We are sorry to see Mike leave our Board, but like Rick Beudet, he has agreed to remain involved with ANN and to work on projects as needed.

## Board of Directors - Old and New Continued



Christine Smith-- Christine served on the ANN Board from 2003 to 2009, rejoined the Board again on 2011 and left us again 2013. Christine was a born leader and helped ANN evolve during her leadership.

Christine's son, Connor, has nystagmus and we are hopeful Christine will remain involved with ANN.



John Cranmer-- John was the President of ANN in 2012-2013 and ANN continued its tradition of growth during his leadership. John was an avid contributor to all ANN events and with his wife, Tricia, her-

self a past Board member, were true examples of commitment to ANN.



Gwen Brandon-- Gwen joined the Board in 2013 and her inspiration was her then 10-month young son, Will, who was diagnosed with nystagmus. Though Gwen only served one term on the Board, she will be missed.



Angie Sonnier-- Angie joined the Board in 2013 and completed one term on the ANN Board. Due to other commitments, Angie left the Board, but continues to be a champion for nystagmus. Angie

routinely volunteers with the Louisiana Special Olympics.



Cheryl Turn-- Cheryl also was on the ANN Board for one term in 2013-2015. Her son, Peyton, was diagnosed with nystagmus and she was very interested in

issues impacting nystagmus. Cheryl will be missed.



Board Members at ANN 2015 Conference



# We Need Your Help!

The American Nystagmus Network relies 100% on volunteers and donors for our services and programming.

Whether you're a parent or relative of a child with Nystagmus, an educator or clinician who wants to get involved, or someone with Nystagmus who wants to connect and contribute, ANN is seeking volunteers.

We're especially looking for support with our various committees including:

- The 2017 Conference Committee
- Social Media & Marketing Committee
- Major Donors & Fundraising Committee
- Resources & Research Committee
- Volunteer Coordination Committee

Please consider lending your talents, enthusiasm and passion to the American Nystagmus Network. You can contact us with your interest at [info@nystagmus.org](mailto:info@nystagmus.org)

The American Nystagmus Network thanks you for your support and invites you get involved as we celebrate today's achievements and tomorrow's possibilities.

Thank you



Tony Fuhrer, 2015 ANN Conference Coordinator joined by his family and Apl



Camp Nystagmus Volunteer Staff