



ANNagram

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. The American Nystagmus Network, Inc., is a nonprofit organization established in February, 1999 to serve the needs and interests of those affected by Nystagmus.

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From Your President...

2014 was a great year for ANN! Our accomplishments this year reached far and wide, and I am so proud of the work being done by ANN. We have made great strides in getting our organization introduced to the vision healthcare community. Tony Fuhrer was an exhibitor at the New Orleans Academy of Ophthalmology in New Orleans, Louisiana in March. Several board members also exhibited at the American Optometric Association national conference in Philadelphia in June. By attending these conferences we were able to make several connections with vision professionals, many of whom were completely unaware that ANN existed. We would like to continue to attend these types of conferences and plan to participate in the American Academy of Ophthalmology conference in 2015 if funding permits.

ANN sponsored 3 local events in July. We had a bowling event in North Carolina which was hosted by Katherine Ealey. Evelyn Gonzalez hosted a cookout in Oakland, California. And the Beudet family hosted a day at the National Zoo in Washington D.C. These events brought together almost 20 families that are affected by Nystagmus. We did regional events in an effort to facilitate networking across the country rather than just reaching a single regional location. If you are interested in hosting an event in your area please contact a board member for additional details. You do not need to be a board member to host an event.

The board of directors conducted our annual face to face board retreat in Philadelphia in conjunction with the AOA

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conference. We spent 2 days working on making ANN a better organization. Plans for future events were discussed as well as ideas of ways to keep ANN growing. Great ideas were discussed and the board is working on implementing many of them. Be on the lookout for a re-vamp of our website, increased presence in the Nystagmus research community, and a greater presence on social networking sites.

Your ANN Board of Directors is comprised of 14 volunteers that work very hard for ANN year round. Currently ANN has no paid employees. Last year we welcomed an additional member to our board, David Neuburger. David met with the board in June at the face to face meeting in Philadelphia, and he was invited to join the board shortly thereafter. David accepted the appointment and will bring some excellent financial knowledge and organization to ANN and we are grateful that he has agreed to serve. Fundraising demands more effort from the BOD than any other aspect of the job. We introduced the 10/10 for a Cure campaign through Crowdrise. Money raised through this campaign will be used to fund research, raise awareness and help educate people about Nystagmus. If you made already made a donation to the 10/10 for a Cure campaign we would like to say thank you. If you have not made a donation we would ask you to please consider making a donation and telling your friends and family about the campaign. <https://www.crowdrise.com/1010ForaCure>.

We reached 20% of our goal.

Wobbly Wednesday was on November 5th and what a great day it was. ANN delivered over 50 school packets that will reach over 1600 students and teachers throughout the country. We even sent a school packet to a family in The Netherlands because they do not have any organization like ANN. We would like to thank the Nystagmus Network UK for including us in the Wobbly Wednesday festivities. If you have ideas that you think could help raise awareness please let the board know.

Planning for the 2015 conference in New Orleans July 31st thru August 2nd is well under way. We are very excited about the hotel and location for our conference. Conferences are a great place to connect with others with Nystagmus and families that are dealing with many of the same issues that you may be facing. If you have never been to a conference please try to come. You will not regret it, I promise.

Happy New Year to all of our ANN families!

Rick Beaudet
ANN Inc. President



ANN Regional Events

ANN Went Bowling

On August 2nd, ANN went bowling in Charlotte, NC. This event was organized so that local Nystagmus families could get to know one another and meet other folks who are affected by Nystagmus. Our afternoon of bowling included free food/drinks, bowling, and lots of fun. Everyone had a great time bowling and we're hoping to do it again soon in the spring. So if you missed it this summer, you should plan on attending in the spring. Park Ten Lanes was a great host and the perfect place for our mixer.

– Katherine Ealey

West Coast Conference

In July, ANN had its first one-day conference in beautiful California. It was a West Coast gathering of excited people whose lives are affected by Nystagmus. The gathering was held at the Marina Inn located on the San Leandro Marina. Meals and daycare were provided so that adults could enjoy the various workshops without distraction. The workshops touched on a variety of topics including Nystagmus research, navigating the educational system, coping as an adult with Nystagmus, and special workshops for parents of children with Nystagmus. The attendees left the event energized, educated, and looking forward to future events. It was a great success!

ANN at the Zoo

Look who's at the zoo! It's ANN! During the summer we took a trip to the National Zoo in Washington D.C. We had a great turnout of the many families that deal with nystagmus. It was a great opportunity for the families to intermingle, while the kids had fun with their new found friends! A private tour was given to see the animals up close in action! The zoo staff readily jumped in to help with the visual needs of the guests. Throughout the day we learned how fast cheetahs ran, what elephant skin feels like, and where baby pandas like to hang out! We gathered at a picnic lunch that was insightful and fun for not only for the parents, but for the kids too. Many new friends were made, and there was tons of support to go around. In the long run, our trip was ZOO-pendous!

- Laura Beaudet



2014 Wobbly Wednesday Spotlight

Wobbly Wednesday 2014 was such a great success! Many of our ANN families took this day to spread awareness about Nystagmus. One particular family caught our eye and we wanted to share the story of how their 7yr old daughter celebrated International Nystagmus Awareness Day.

As November 5th drew near, we sat down and talked to her about how she would like to celebrate her special day. She had it all planned out in her head already! She knew that she wanted to bring “special eye” cupcakes, have her Daddy read a story about Nystagmus, hand out the special blue bracelets, and most importantly, she wanted to have a question and answer session to give the kids an opportunity to ask her anything they wanted to know about her eyes and her vision, so that is exactly what we did!

When the day finally arrived, we thought that we would be the ones with all the surprises that day, but much to our amazement, Mallory’s teacher, Ms. Fonteciella, had a few surprises of her own! When we walked in to the first grade classroom, we saw that Mallory’s amazing teacher had made her own special t-shirt to honor Mallory and

all of her fellow Nystagmus friends----she even decorated the t-shirt with little eye balls!!! We could not believe it! Then we learned that she had bought sunglasses for every child in the class to wear that day so that they could see what it was like for Mallory to wear glasses. She also had a craft for them to do where they decorated a smiley face with eyes and glasses to proudly hang on their classroom door! It was truly a beautiful sight.

Mallory felt so special that day, and as her parents, it warmed our hearts to see how powerful a little knowledge can be. We believe that the love and support she received that day will always be in her heart. Had we not shared Mallory’s story, her classmates may not have ever known that even though Mallory’s eyes may be a little different than most, she is still the same kind, fabulous, smart, caring, fun, intelligent and beautiful little girl that God made her!

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



Thank you Delta Gamma for your support

The Columbia University chapter of Delta Gamma partnered with ANN to raise awareness during Wobbly Wednesday. Delta Gamma's national philanthropy is Service for Sight. They work throughout the year to raise money and awareness for organizations that support sight preservation and provide aid to those with visual impairments.

Last year, the Columbia University chapter of Delta Gamma wanted to get involved with ANN's Wobbly Wednesday efforts. The chapter made a short video that gave a little background information on Nystagmus, provided information about Wobbly Wednesday and mentioned our "10/10 For a Cure" campaign. The group forwarded this video on to family and friends as well as 10 different Delta Gamma chapters around the country. To see this video, please go to www.nystagmus.com and click Delta Gamma Awareness Video.

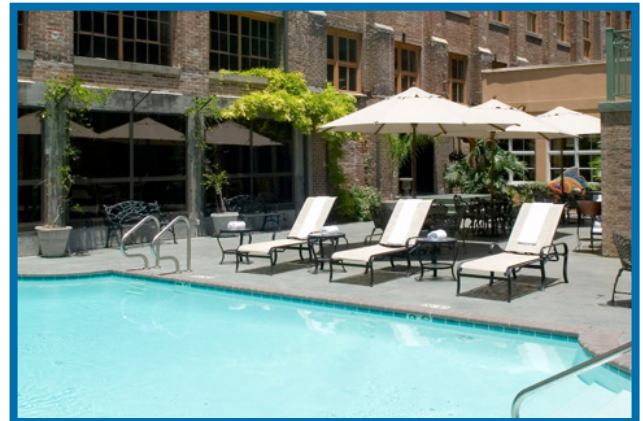
What's on the Horizon?

In the Works

ANN is excited to announce a new project to enhance the impact we can make on nystagmus. In the past ANN has been dedicated primarily to the support and education of those affected by nystagmus. Our latest project is aimed at the medical research into nystagmus. ANN will host a research workshop for those in the medical community conducting scientific research into nystagmus. This workshop would be patterned after the successful events hosted previously by the Nystagmus Network in the UK (most recently in September of 2013). It would bring together those on the cutting edge of nystagmus research to discuss their current work and collaborate on future research ideas. This project will be ANN's first foray into supporting the medical research into nystagmus, and represents a bold new step for our organization. The workshop will be held the last week in July 2015 in New Orleans, Louisiana.

9th Biennial Conference New Orleans, Louisiana July 31, August 1-2

The American Nystagmus Network, Inc. (ANN) will be holding its Ninth biennial conference on July 31st, August 1st, & 2nd in New Orleans at the Hampton Inn & Suites New Orleans-Convention Center



Set across two towers - one a historic warehouse, the other a modern build - the Hampton Inn & Suites New Orleans Convention Center hotel offers unique accommodations in the heart of New Orleans. Located in the Arts & Warehouse District, which was originally developed in the 18th century, the neighborhood is now home to many businesses, shops, restaurants and bars. The hotel is conveniently located across the street from Ernest N. Morial Convention Center and is within walking distance of major New Orleans attractions including Jackson Square, the French Quarter, Harrah's Casino, the Aquarium of the Americas and the Mercedes Benz Superdome. Hampton Inn & Suites New Orleans Convention Center is the closest hotel to the cruise terminals, making it the ideal hotel for pre/post cruise accommodations.

ANN has arranged special rates for the conference. These rates are available from 29 July 2015 - 03 August 2015, so you can extend your trip. Standard room will be \$89 per night and suites will be \$119. When making reservations please state that you are with the American Nystagmus Network (ANN) so that your room rentals will be counted for the conference.

Stay tuned to Facebook and member emails for more details and information.

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HELP US SAVE A TREE!

And some \$\$!

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Send an email to info@nystagmus.org to opt-in to the e-version of this newsletter.



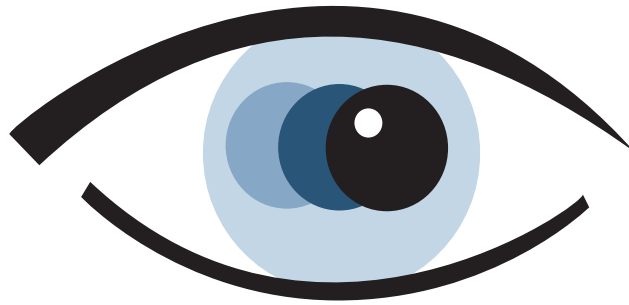
We hope to see you all there!

A banner for the 2015 American Nystagmus Network Conference. The banner features a collage of photos: an older man in a plaid shirt, a young boy in a white shirt with arms raised, a young woman in a graduation cap, a young girl in a purple shirt, and a young boy with glasses. The text on the banner reads: "Celebrating TODAY'S Achievements AND TOMORROW'S Possibilities" in yellow and purple. Below that, it says "2015 CONFERENCE | NEW ORLEANS, LOUISIANA | JULY 31 - AUGUST 2". At the bottom, there is a large blue eye icon and the text "American Nystagmus Network".

Celebrating TODAY'S Achievements AND TOMORROW'S Possibilities

2015 CONFERENCE | NEW ORLEANS, LOUISIANA | JULY 31 - AUGUST 2

American Nystagmus Network



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