



WINGS

WAGR Information, News, Gorilla Stories

International WAGR Syndrome Association
P.O. Box 1346 Manassas, VA 20108

www.wagr.org
Fall/Winter 2006

News From Your Board of Directors

On Saturday, October 14, 2006 the annual meeting of the Board of Directors for the International WAGR Syndrome Association took place by teleconference. All board members were present.

Agenda items included our budget (current treasury report was accepted, our budget remains under review), our newsletter (we will continue to print our newsletter once each year and it will be available online once or twice each year) and some discussion about how to minimize our organizational expenses. We will continue discussion on this matter.

Fundraising efforts and how best to stimulate interest in fundraising efforts within our group were discussed. We will continue working on this issue. We are also working on a new logo for our organization, so stay tuned!

The decision was made to hold WAGR Weekend 2007 in Manassas, VA on the weekend of July 20-22, 2007. So mark your calendars today!

Elections were held for Officers and the Board

Chairperson positions (board members serve for three years, but the Chairperson and Officers are elected/re-elected annually.) The results were as follows:

- President** - Catherine Luis
- Vice President** - Kim Pillow Williams
- Secretary** - Tammie Hefty
- Treasurer** - Becky Deas

- Board Chairperson** - Annie Prusakiewicz
- Member** - Rose Mallon
- Member** - Karen Rose
- Member** - Kim Pillow Williams

It was decided that Kelly Trout, our outgoing President, would continue to co-moderate our online discussion group and she will serve as a Health Consultant for our organization. She will also continue to be involved in the NIH research project.

While the configuration of our leaders has changed a bit, our only new leadership team member is Tammie Hefty. Tammie received her BA in Communication Studies from Winona State University and her MA in Communication Studies from University of Wisconsin, Milwaukee. She is an Office Administrator for a dental office in Madison, WI. Tammie and her husband Jeff are proud parents to Evie, who

has WAGR Syndrome.

Tammie has been an active member of our discussion group, has provided beautifully written material for our newsletter and received the Gorilla Award in 2006 for being such a powerful advocate for her daughter. She's excited to be joining our leadership team and we're pleased to have her on board with us.

Welcome, Tammie!

Our next meeting date is to be determined. Check our web site at <http://www.wagr.org> in early 2007 for details about the next WAGR Weekend!

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WAGR WEEKEND 2006 - PENNSYLVANIA



Hayden & Jenna

Levittown, PA -

The WAGR Weekend hosted by the Cox family was absolutely wonderful.

They, along with their community, saw to it that we were all taken care of for meals, activities and childcare. Truly amazing what these wonderful people did for our group.

The Hampton Inn was a lovely hotel. The staff and accommodations were excellent. They had a large comfortable sitting area in the lobby as well as the breakfast area where we could sit and talk throughout the weekend.

We were greeted by Miss Jenna Cox and she saw to it that we were signed in, given our information packet as well as our welcome to WAGR Weekend gift bags, which were loaded with goodies. She literally blew me away!

Meeting families for the first time always makes me nervous but that melts away quickly once we start talking about our kids. It's so impressive listening to how "gorilla" each parent is when it comes to their child.

Dr. Sarah Appel did a wonderful presentation on Aniridia and

Low Vision. She addressed many issues and concerns that many of us have as well as answering our questions.

Dr. Joan Han from the NIH and her assistant Carolyn Menzie also did a presentation on the first phase of the research on WAGR syndrome.

I'm thrilled that the families were able to meet Dr. Han and her research assistant Carolyn Menzie in person. They are wonderful people and I think our families participating in the study will be very comfortable dealing with them.



Vanessa, Irma, Caroline & Crystal

It was awesome seeing all of our children ranging in age from 18 months up to 35 years.

The fun part was getting to interact with the kids and getting to know them. I just ate up each and every one. I found myself sitting and getting flooded with memories of when Irma was a youngster. Twenty years goes by very quickly.

Many thanks to Kelli, Tom, Jenna, Jacob and their community for helping bring us all

together.

Irma is already planning for next year.

Thinking about all of you and hoping we meet next year.

Sincerely,
Catherine Luis
New Jersey

Snapshots from WAGR Weekend 2006: Andy receives all of his nourishment from a feeding tube. Being at Pinewood Pool (adjacent to our church) allowed him to really enjoy himself and the other families there. Hayden, who has had half a dozen eye surgeries, turned three during WAGR Weekend and our folks made sure he had a birthday cake for his celebration.

Another three year-old, Dylan, and his family came hundreds of miles to be with us even though he is in chemotherapy for the second time in his young life.

My eleven year-old (non-WAGR) son, Jacob, spent much of his time helping the team of church volunteers prepare and serve meals.



Kelli, Catherine, Gail, Irma & Kelly

The Farewell Concert capped things off very nicely Sunday night. Our musical guests performed Phil Collin's "You'll be in My Heart" at the end, which is a song near and dear to the hearts of many of the "Gorilla Moms". When they started that song, one mother and daughter (seated on opposite sides of the sanctuary) went to find each other and embrace.

Rev. Thomas M. Cox
Evangelical Presbyterian
Church (PCA)

WAGR Weekend 2006 Special Thanks

Our Hosts: Tom & Kelli Cox, Tom & Lynn Gessner, Lee & Pam Kennedy, Joe & Ann Little and the entire Evangelical Presbyterian Church congregation.

The speakers: Dr. Han and Carolyn Menzie of NIH

Dr. Sarah Appel on
Pennsylvania College of
Optometry

The closing concert by Steven and Robin Massie Condy along with accompanist Jamie Rankin (they also donated CD's for each family)

Sesame Place offered discount group tickets and a couple of freebies.

Free entrance to Pinewood Pool was given by Mr. Bill Reese, Director of Parks & Recreation, Falls Township, PA.

Lodging at the Hampton Inn-Newtown was discounted and administrated by Mr. Mark Auman.

Kid's Activities were supervised by EPC members and friends

and Teachers from the Pennsbury School District. The EPC church family for preparing and serving meals. EPC Youth Ministry held 2 car wash fund raisers.

Other donors:

- Little Sheet Metal of Tullytown, PA
- Faith Presbyterian Church of Anniston, AL
- Hope Church of Moosic, PA
- 1st National Bank of Newtown, PA
- and other private individuals

Kelli Cox and her fellow Creative Memories consultants and customers donated and assembled scrapbooking albums.

Tote bags and other gift items were donated by 1st Place Award and customers of Mr. Tom Gessner.

The Missing NIH Link

When Kelsie was born in 1992 it quickly became obvious to me that more research was needed on WAGR. The doctor said she was likely missing part of her brain, she was blind and would get cancer and die. Don't get too attached, he advised, put her in an institution now.

I did the tears, then the anger, and then began searching the (paper in those days) medical journals. I had finished my MPA and had begun my PhD in Health Care Policy. Surely I couldn't pull off both, but which to choose? I could see no better option but to combine the two.

My dissertation proposal was approved by my committee. I think the official title was something like "Balancing Technocracy and Pluralism at the NIH." The real title was, "How do you get on the re-

search agenda at the NIH?" The first part of my study entailed (paper) surveys of all the researchers names I could find in an NIH directory. Their response was pretty unanimous: If it's good science, it will get funded. And this is absolutely true for WAGR. We have the best gene pool out there--they would be so lucky to get to play in it!

But there was a second piece to my research--the budgets. How could new medical issues compete for funding against the entrenched, institutional structures of the mighty NIH? AIDs was trying to get a foothold among the Kidney, Eye, Cancer, and other "Institutes." It began as an "Office" along side the "Office for Rare Disorders" and the relatively new Human Genome Research "Project." But there was another new girl in town--Breast Cancer. The National Breast Cancer Coalition (NBCC) made deep inroads quickly. Their well-orchestrated lobbying got them funded.

I defended my dissertation, collected my PhD and moved on to my first teaching job. I didn't have a clue how that missing piece in WAGR would be filled. You see, I hadn't yet heard of Kelly, Catherine & Kim--our very own analog to the NBCC.

Kelly, Catherine & Kim, you are to us, what our WAGR kids' gene pool is to the NIH scientists--priceless.

Thank you from all of us,
Dr. Connie Brooks

P.S. I did file formal complaints against the original doctor (who was in charge of all medical services to disabled children for the Northern half of Arizona) to try and get him fired. I heard he was later "re-assigned."

NIH Study, Meet Dr. Han & Carolyn Menzie

Dr. Han is a pediatrician who trained at Harvard Medical School and Boston Children's Hospital. She is currently an endocrinology research fellow at the National Institutes of Health. She lives in Bethesda, Maryland with her husband, Jack, and their two turtles, two newts, two hermit crabs, and two fish.

Her hobbies include playing soccer, singing in her church choir, and flying kites.



Dr. Joan Han



Carolyn Menzie

Carolyn is in her second year at the NIH as a post-baccalaureate research study coordinator. She graduated college in 2005 from North Carolina State University with a degree in Biological Sciences and Nutrition.

She is currently applying to medical school and hopes to be a Pediatrician. She lives in Washington, DC with her dog Snoop and four other roommates. She enjoys walking her dog, reading, and traveling.

Tax Deductible Donation
The IWSA is a 501(C)(3) charitable organization. We rely on contributions from private and public sponsors.
Please consider donating today.

No, my baby isn't sleeping

by: Tammie Hefty

No, my baby isn't sleeping,
Although her eyes are closed,
She's wide awake and knows such things
A baby shouldn't know.

No, my baby isn't sleeping,
She just woke from a nap,
Her smile makes my heart burst with pride,
And I love to hear her laugh.

Evelyn means "living light",
She's that, and full of grace.
She was knit together by her Father's hands,
Not born through random fate.

I see my past
and see how I've been shaped to handle this,
And how God's brought you to my side,
For strength and encouragement.

No, my baby isn't sleeping,
She's singing her own song,
I hear her twinkling melody,
And know she's growing strong.

Her future is so bright now,
She has to shade her eyes,
What Jesus has in store for her
Will be a big surprise.

Someday soon we'll come to find
Perfection is a myth,
But our spirits will be glorified
When our hands to Heaven we lift.

WAGR Syndrome Research Study

- ❖ Children and adults with WAGR Syndrome and their parents are invited to participate in a clinical study sponsored by the National Institute of Child Health and Human Development, which is part of the National Institutes of Health (NIH)
- ❖ The purpose of the study is to learn more about how the genes involved in WAGR Syndrome affect people with this condition
- ❖ Involves sending blood samples and medical records to NIH investigators
- ❖ For more information, please contact:

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Department of Health and Human Services
National Institutes of Health
National Institute of Child Health and Human Development

Aniridia and Cataracts

Kelly Trout, RN, BSN

Cataracts occur in approximately 50-85% of people with aniridia. Cataracts may be present at birth, or can develop at any time in life. The risk for developing cataracts increases with age.

A cataract is a clouding in the lens of the eye. The lens of the eye acts like the lens of a camera, focusing light on the retina. The retina changes the light into nerve signals. These signals travel along the optic nerve to the brain, and the brain interprets them as images. If the lens is not clear, light passing through it will be scattered instead of focused and vision will be blurry.

There are different types of cataracts. A nuclear cataract is the most common type. It forms in the center of the lens. Cortical cataracts develop as "wedge-shaped spokes" in the cortex, or outer portion of the lens. A subcapsular cataract usually starts small, at the back of the lens. The term Congenital Cataract simply refers to any type of cataract that is present at birth.

No matter what type of cataract is present, if it is not affecting vision very much then there is no need to remove it. On the other hand, if cataracts are large enough or positioned centrally enough to prevent useful vision, then surgery may be required.

Surgery to remove cataracts is done by making a small incision in the side of the cornea, and removing the lens. After the natural lens is removed, an artificial lens is usually implanted. An artificial lens is called an Intraocular Implant, or IOL.

Unlike a natural lens, the curvature of a standard IOL cannot be changed by the eye. Distance vision with these lenses will be unaffected, but the patient will need glasses for near vision. IOLs which can correct near or far-sightedness are under study, but these may be associated with higher risk for glaucoma, retinal detachment, or worsening rather than improvement of vision.

One recent development in aniridia research is the Artificial Iris implant. This device can be implanted in the eye at the time of cataract surgery. It has a colored ring designed to look like an iris, and may improve vision by reducing glare. It can also give a more natural appearance to the eye. The Artificial Iris is currently under clinical trial, so there is little information yet about the long-term risks that may be associated with it.

Cataract surgery is a very common procedure, but there are important special considerations for patients with aniridia. The internal anatomy of an aniridic eye is very different from the typical eye, and the cornea is often thicker than usual as well. These differences require a surgeon with as much experi-

ence as possible. The long term risks of aniridic keratopathy (corneal pannus) and glaucoma must also be factors in the decision about whether cataract surgery is required, and when and how it should be done.

SUPER SIBS



Within the brotherhood

By Greg Duggan/ gduggan@cnc.com
Thursday, October 12, 2006

The brothers attend the University of Massachusetts in Amherst, Chris Mallon a senior and Mike Mallon a junior. Now entering his third year on Engine Company 3 - the name of the student force - the elder Mallon serves as a lieutenant. His brother is an acting lieutenant in his second year on the force.

Prior to arriving at UMass, neither brother had thoughts of becoming a firefighter, even though their grandfather's father and brothers served on the Malden Fire Department.

"A friend of mine from college said, 'Hey, I'm doing this fire department thing,'" Chris Mallon recalled. "I said, 'Cool, I'll check it out.' The next thing

I know I'm taking classes in it and signed up in it."

Mike Mallon had a similar experience, and never felt any pressure from his brother to join. Rather, he said, "It was a spur of the moment thing. I thought I'd try it out."

The force, which consists of approximately 35 students, works on a volunteer basis. Yet they have most of the same duties as the rest of the Amherst Fire Department, responding to the same calls and fighting the same fires.

During the last few weeks of August, when the brothers stayed at the station and received pay for their work, the Mallons were particularly busy. Mike Mallon said the town of Amherst suffered three major fires in that period, one that reached the status of a four or five alarm fire as it caught several neighboring buildings on fire. Not long after that call a Bank of America building burned to the ground.

"There was some structural collapse, and some of our guys almost got stuck underneath," Chris Mallon recalled. "It's scary, almost losing the people you work with."

Each Thursday night throughout the year Engine Company 3, or E3, as the firefighters call it, holds training sessions, working on new skills or practicing those that need improvement. The sessions supplement a massive training period held each August called "Wonder Week," where new recruits and returning firefighters spend 90 hours learning about any situation they may encounter while on a call. From running hose lines, practicing with ladders and rescues and

working in a house filled with smoke, the E3 firefighters work with the Amherst Fire Department to learn and refresh their skills.

Once the school year begins, the officers spend one or two nights each week in the fire station, and often work a 24-hour shift on the weekend. New recruits and one-year veterans typically work about half as much, but all firefighters carry pagers and can respond to any calls. If necessary, they can even leave class.

"I had to make a couple of sacrifices as far as extracurriculars go," Chris Mallon said. "It's a time commitment, but it's easy to manage."

Chris Mallon says he is more interested in the fire field than anthropology, his major, but remains unsure of what he will pursue when he graduates.

Michael Mallon, who is studying business and finance, has an extra year to think about career plans.

"It's more of a hobby for me, but there's always the possibility of having it become a permanent job," Michael Mallon said. "I'll see where college takes me and where I am afterwards."

Whatever the brothers decide to do after college, they still have the remainder of the school year to continue working together. And because tough brotherly love rarely intervenes, the two have a strong relationship.

"It's nice to have someone with your family to talk to," the elder Mallon said. "You can get away from the whole authority of 'I'm higher, you're lower,' and talk to someone you know already." His brother agreed.

"Once in a while the whole sibling thing comes into mind, but usually we work well together and look out for each other," Mike Mallon said. "We live together at the same station and run into each other a lot. On the fire ground it doesn't matter who you're working with. It could be your worst enemy or your best friend, you're going to work the same."

Rich, Rose, Ricky & Samantha Mallon are very proud of Mike & Chris.

Gorilla News

Gorillas in the news include Bryan and Louise Stewart, Cerys's parents, in Northern Ireland. Bryan and Louise were the co-recipients of the Gorilla Award in 2006 for not only their tireless fundraising efforts for IWSA, but for being incredible advocates for their daughter as well.

Bryan and Louise have facilitated many large donations, through their own efforts and the generous involvement of runners, breakfast eaters, coffee drinkers, police officers and lots of friends and community members! In their spare time, they are not only the proud parents of Cerys and her lovely sister Megan, but in August they welcomed twins Erin and



Derek, Cerys and Bryan Ireland

Rhys to their home!

Congratulations all around to this busy and growing family!

THANK YOU!

The International WAGR Syndrome Association would like to offer a special thanks to the Police Service of Northern Ireland and the Police College for their incredible hard work and generosity to our organization

- Mrs. Agnes Crooks, Police Service of Northern Ireland, Marathon fundraiser
- Mr. Stephen Palmer, Police Service of Northern Ireland, Marathon fundraiser
- Mr. James Peden, Marathon Fundraiser
- Mr. Connor McKimm, Police Service of Northern Ireland, Marathon fundraiser
- Mr. Richard McClelland & Mrs. Sharon McClelland, Marathon fundraisers
- Mr. Stephen Topping, Police Service of Northern Ireland, Marathon fundraiser
- Mr. John Stewart, marathon fundraiser
- Mr. Keith Morton, Police Service of Northern Ireland, Marathon RUNNER and fundraiser
- Mr. Derek Scott & Mr. Stephen Hilditch, Marathon RUNNER and fundraisers
- Mr. Adrian McQuillan, Mr. Kirk Lyndsay & Colleagues, Police Service of Northern Ireland, Marathon RUNNERS and fundraisers
- Mr. James Morrell, Marathon fundraiser
- Mr. Simon Watt & Colleagues, Police Service of Northern Ireland Tutor Unit, Marathon RUNNERS and fundraisers
- Mr. Andrew McVeigh & Red Squad 4/06, Police Service of Northern Ireland, Police training recruits surprise fundraiser
- Mr. Neil Tipping



The Silver Lining

by Annie Prusakiewicz

I am very happy once again, to have the opportunity to serve as editor and publisher for the IWSA.

I want to thank my fellow board members for their confidence in electing me as Chairperson. I plan to work hard with all our leaders to carry out our mission for the upcoming year.

Nicholas turned ten years old in September. Yes, my baby is 10. I am not sure where the time has gone.

Nicholas was really busy this summer. He attended two summer programs. He was enrolled in a 10 day Visually Impaired program in early July. This program focused on daily living skills. Students performed daily chores, which included shopping for food, cooking their meal and cleaning up afterwards. They also did a lot of fun things like riding go-carts, going to the mall, going on a picnic and attending an amusement park on their last day.

The other program was a 5 week "AI" program. This program was a sensory based program, which focused on

science curriculum.

Nicholas was also pretty active this summer. He took swimming lessons and did very well. Nicholas like many of our kids is a natural "fish" when it comes to water. He did make a lot of progress fine tuning his skills, got some exercise and was able to have fun at the same time.

Nicholas rode "Pistol" in our local county fair on August 2nd. He competed against three other kids in his class and won a second place ribbon. Not too bad for his first time riding at fair. We were very proud of him.

Right before school started Nicholas taught himself how to ride a two wheel bike. He started out slow. He got Ashley's old bike from the garage and just sat on it the first day trying to get his balance. By day two he was trying to pedal. By day three he was able to ride a few feet at a time. By day four he was riding down the block 3-4 houses at a time.

Learning to ride a 2 wheeler was a great accomplishment for Nicholas. To be honest we never thought he would be able to ride a two wheel bike. However, once again through perseverance and determination he proved us wrong.

Nicholas continues to hold his own health wise. Recent lab tests showed a decline in his cholesterol levels by almost 100 points, which is great news.

Nicholas is currently in the 4th grade. He still does most of his

academic work in a cognitively impaired classroom. He does have an opportunity to participate with his general ed peers in gym, art and music.

Nicholas' greatest memory for the year was on October 1, 2006 when he was able to throw out the first pitch at the Detroit Tigers last game of the season. This was made possible by the Make-A-Wish foundation and a generous local donor. Despite the Tigers loss, it was a magical once in a lifetime moment we were so lucky to have shared with him. GO TIGERS!!



Nicholas at Comerica Park

10/1/06

Forward newsletter submissions, stories, pictures or ideas to:

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The **IWSA** serves families all over the world in countries that include: Australia, Bavaria, Brazil, Canada, Croatia, England, France, Germany, Greece, Ireland, Israel, Italy, New Zealand, Philippines, Poland, Puerto Rico, Romania, Saudi Arabia, Scotland, South Africa, Tanzania, and The United States of America