WINGS

WAGR Information, News, Gorilla Stories

International WAGR Syndrome Association
P.O. Box 392 Allen Park, MI 48101

www.wagr.org
Spring/Summer 2010

From the President's pen

by Tammie Hefty

Are you ready for this??? As I sat down to read through this issue of our WINGS Newsletter, I guess I wasn't prepared. I should have had my tissues to dab at the tears that were quickly cascading down my cheeks. Somehow, this newsletter seems to be the clearest representation of what our non-profit group is about. As Kelly Trout and I were talking on the phone today, I said to her, "This <newsletter> is a mosaic of all we are."

The stories contained in the pages that follow are stories of struggle, triumph, mystery, magic, disappointment, and victory. They are stories from across the globe, literally. They are stories about our lives as Gorilla parents, and the lives of our individual and uniquely-incredible kids.

Through the eyes of Jenny, we can learn what the NIH research is like for our kids. Finally, we learn about different ways that people can contribute to the financial stability of the IWSA as a non-profit organization.

Before we plunge into the pages of this exciting issue, I just want to remind you that in July we'll be holding WAGR Weekend 2010, a celebration of 10 years! Please visit the website www.wagr.org to RSVP and learn more details about the weekend. Also, I continue to take names for those who are interested in having the Caring Quilt delivered to their home for a brief stay. Contact me at tammiehefty@yahoo.com if you would like to get on the list!

Finally, be sure to check out our annual report which is available on our website http://wagr.org/annualreport09.html. The annual report helps everyone see and communicate where our funds go as a non-profit group, and how the IWSA continues to live out its mission: ***to promote international knowledge and awareness of WAGR syndrome and its complications and treatments, to stimulate research and to reach out to those affected by WAGR syndrome in an effort to improve their lives.***

You can get a printed copy of the IWSA's 2009 annual report by emailing your request to Tom Cox at gocox84@juno.com.

Hayden Dell & Evie Hefty with the IWSA Caring Quilt

On the Inside

Silver Linings

WISH AND HOPE

(or the story about my little alien)

by Shaqir Arapi

Once I dreamt a little boy hugging me... In my dream I knew the dark-haired boy was my son and felt kind of happiness beyond words, incomparable to anything experienced before.

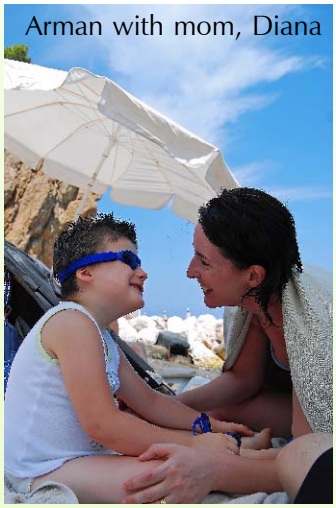
It was a cold December day when the Blue Fairy came to grant our 14 years long wish. Through the nursery display glass I watched this little blond thing stretching tiny arms and crying out loudly and I thought my heart is going to burst from the overwhelming joy. My son Arman has finally arrived!

Before he was born, one morning while taking a shower the name popped in my head. As I am not a psychic I had googled it and one of the top the results said it's a boy name, meaning wish and hope. Mind you, throughout the whole pregnancy we didn't know the baby's gender.

When the doctor at IVF centre in Istanbul gave us the pregnancy results I tried hard to remain calm. After two failed attempts I had learnt to take good news with a grain of salt so to easier digest the disappointments.

Of course in each phase something can go wrong - so did happen twice to us. The pregnancy also carried certain risks considering our age and first pregnancy factor. So the following long nine months spent mostly fearing all possible syndromes and baby defect.

Little I knew my worst fears would come in "a package". When on the second day of Arman's life our doctor told us:



Arman with mom, Diana

"You've got to take urgently your baby abroad to some specialized eye hospital - or he will go blind" my heart almost failed from the unbearable sorrow… Oh I did beg the Blue Fairy to return and correct the terrible mistake… but, alas…

I was holding this little bundle with strange looking eyes and a funny drip valve on his head and thought: "Man, where I'm going to take my little alien? It was about the holiday season time when all flights are usually booked. Not to mention visas and financial constraints.

But then miraculously our good friends in Istanbul got us flights and arranged appointments in a well known eye hospital. Arman had had his first glaucoma treatment there. After that many others followed…as well as, in different Istanbul hospitals, hernias, undescended testicles and short urethra correction surgeries.

By then our savings had reached the bottom. Forgot to mention we live in a war-torn country where ordinary things like jobs, insurance, specialized medical care, etc. are still a dream.

Then in 2007 the most feared comes. A routine ultrasound scan revealed "suspicious cysts" growing on both kidneys! Our urologist in Istanbul suggests immediately removing a kidney - of course for an "astronomical" fee. That's when the real panic kicked in.

Desperately I write, call, appeal, plead and knock on all doors. I write also to the group and ask for advice. The incredible IWSA crew and shipmates mobilize and an immense support follows. We try to get to the USA but St. Jude turned us down. Time is ticking away and our desperation grows.

Then miraculously, through Catherine Luis, we were introduced to the extraordinary Monica of Wilms@Home, a Scotland- based charity. She wrote to all her contacts, hospitals, charities. Then amazingly she gets a positive response from German Children University Hospital in Tuebingen.

She even finds the "Stiftung Kinderhilfe", a German charity that will help us with the surgery expenses! Doctors clean up both kidneys and the pathologist confirm that tumors were in fact "nephroblastomatosis" - an awkward word that basically means: no Chemo is required! Which, considering our financial situation then, was a truly miraculous news!

Since then we've managed somehow to do the all kidneys, urologic, ophthalmologic and neurological controls at the Tuebingen University complex - an amazing place with a great history and incredible doctors and personnel. Best of all it's a German state-owned hospital so we go there with a peace of mind that we are not going to be ripped off and persuaded to undergo another worthless surgical treatment. Just like it happened in a private hospital when after the supposedly a simple hernias lifting/testicles descending procedure Arman actually

lost a testicle. Or the "short urethra" also supposedly simple procedure that went horribly wrong and we ended up spending a month (and a fortune) in another private hospital.

Despite all, my little alien did pretty well. He made his first steps when he was two. Since then he's been roaming restlessly. His favorite place is the kitchen with the all cupboards and drawers full of shiny cutlery. I'm convinced when he grows up he's going to be a cook.

He seems to have lost sight in one eye, but thankfully so far he's been doing all right with the other eye. Lately he refuses to wear sunglasses outdoors. Instead he prefers to spin them. He's become and expert in simultaneously clapping hands and spinning things.

He loves going out and has an amazing sense for orientation. OK, sometimes he suddenly stops, raises his head up and stares at the clouds. Our hometown river also fascinates him. Every time we pass by he will stop and clap delightfully to the river. Actually my little alien has always loved water. Still sometimes furiously protests when the bathing is over. Last summer, for a first time we went together on vacation. Like a little hippo he would dip in the water and remain on the shore all day long joyfully clapping and singing to the ocean.

Arman Arapi

When I return home after a stint abroad I walk into the room and sit on the couch. Armanturns his head a little sideways so to focus better and when recognizes me he runs, hugs and kisses me in his alien way by sticking his nose in my mouth. No, he doesn't talk yet, but we perfectly understand each other. He's taught me communicating by higher means than spoken words.

And in the meantime his hair has turned completely dark. Now it looks just like the boy's hair in my dream…

An Unexpected Gift

by Keri Haertel

Growing up I always felt ordinary, I didn't stand out in a crowd and was average at everything. I wished there was something I was good at, something that made me special, but that wish never came.

My pregnancy with my second daughter, Katie, was considered normal. I was 35 and was considered "advanced maternal age" and had lots of ultrasounds and checkups. Katie started measuring small around 36 weeks and was put through non-stress tests until the 39th week when her heart rate decelerated, I was sent to the hospital for an induction. They eventually performed a c-section and Katie was found to have a true knot in her umbilical cord. Katie arrived at 1:45 am, August 28th 2007. My husband kept commenting on how big her pupils were but no one seemed to be concerned. Katie had jaundice so we saw a doctor daily, each time, Steven would mention her big pupils. On day five, Katie saw her regular pediatrician who referred us to a pediatric ophthalmologist. It was on this day we were told Katie had Aniridia. We were devastated. All I could think about was how mean kids can be. I was bullied as a kid, remember how ordinary I am, I just couldn't imagine what she might go through. This was before we knew anything about Aniridia (besides the obvious no irises). We were then referred to a geneticist who informed us Katie had the deletion for WAGR Syndrome-I gained a little perspective after this!

Katie Haertel

Katie was diagnosed with Glaucoma at six weeks old. We are lucky enough to live in the Northeast, so we were referred to Dr. Theresa Chen. She was once fellow to the one and only Dr. David Walton! Dr. Walton assisted in Katie's tube shunt surgery. To this day, I refer to him as Santa Claus, he showed up five minutes after I left the operating room and left five minutes before I came down to

Forward newsletter submissions, stories, pictures or ideas to:

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see her after the surgery. Does he really exist?? I guess I'll never know!

Katie entered our state's early intervention program when she was a month old. Through them, Katie is overcoming a speech delay and is being treated for under responsive sensory processing disorder as well as poor motor planning. She is also seen by a visual therapist. Her functional vision is actually quite good

The Haertel Family

so I hope no one ever tells her how bad her vision really is!

Our WAGR journey has certainly had its ups and downs. We were unfortunately asked to leave our first daycare because they felt they couldn't handle Katie's needs (she wears glasses, is patched two hours a day, and I asked them to document any new developments). Being asked to leave was a blessing in disguise (although heartbreaking at that time); our new daycare documents development for every child in their center, it is their policy. They have been open to Katie's therapies and are willing to brush her, patch her, and pretty much do anything we need them to do. They will even allow us to spray paint their playground with a transition line for Katie so she doesn't trip coming off the playscape! They have been wonderful to both Katie and her big sister Alexa.

WAGR Syndrome has forced me to slow down. I've always been one of those people who is three steps ahead and doesn't take the time to appreciate the little things. WAGR Syndrome doesn't allow for that! I've been forced to slow down and smell the roses-my first red flag came when Katie had the stomach flu and I was convinced it was Wilms' Tumor! Luckily, Katie's doctors are patient…with ME! I've been given the opportunity to slow down and appreciate everything my children do and to appreciate their differences. Alexa was always a quick learner and advanced developmentally. Katie is more like me, she prefers the scenic route, she takes her time until she gets it just right and then WHAM-she hits you with it!

Katie is one of the sweetest kids you'll ever meet. She loves to cuddle, laugh, adores her big sister (and vice versa), and her personality makes everyone in her presence happy. Through my children, I've learned not to take things for granted, some things are worth fighting for, and to truly enjoy their childhood, it doesn't last forever. Through the journey of WAGR Syndrome I have had the opportunity to meet the most amazing people and to be in contact with amazing therapists and doctors. Sometimes in situations like this, you can feel sort of isolated on your own island. I am happy to report; my island is quite crowded with supportive friends and family, and great resources!

I'm still that ordinary person I was growing up, I still don't stand out in a crowd and I still don't have that one thing that makes me *special*. What has changed is I have one very special child (two really!)! I refer to Katie as my "unexpected gift" and she truly is. Katie will be three at the end of August. She still has a speech delay, we are working on her sensory issues, her Glaucoma is stable, and she remains Wilms' free. I've never been prouder of her accomplishments. Martina McBride says it best, "Everyone calls you amazing, I just call you mine". I love you Katie!

A Joyous and Complicated Life, John Randall Hudson

by Gue' P. Hudson

It is a typical Saturday morning at the Hudson household. John is playing his music ("I Can't Help Myself, Sugar Pie Honey Bunch" by the Four tops, music from Wrestle Mania X, and "Silent Night") and dancing in his room. His dancing is so important to him. Smiling, he turns in circles and as the circles get larger, he moves more quickly. He loves his dancing and treasures his morning ritual. At 28 years of age, he has much for which to be grateful.

I wanted to start his story giving you a sense of the joy in John's life. In spite of all of his medical problems, John has a full and enriched life. "Hands for Hire" is his day program, which he attends three days a week, and the other two days are community days with his job coach. During his community days, he has a volunteer job at the local Board of Education shredding their documents, and when he finishes, he does community errands. He lives most of the time in a host family home and comes back to our home several weekends a month. He has two older brothers and a wonderful sister-in-law who all nurture and help support him.

John has aniridia with all of the classic symptoms. He has a moderate developmental disability, legal blindness, and had


John Hudson

a Wilms' tumor. He is not able to read or write, but thanks to early speech intervention, he is very verbal. His emotional IQ is very high and he can hear subtle changes in voice and knows what that might communicate. His motor skills are awkward and clumsy. Because of his limited intellectual skills, he is not able to use a cane or have a Seeing Eye dog. Often folks who see him in the community do not realize how little John can see until he bumps into them. People can get very angry before they realize that he is virtually blind.

John was born February 9, 1982 and he was our third son. His brothers, who were healthy children, were four and five when John was born. During his first month of life, I did not notice anything unusual except that he would bury his head in my shoulder when we would go outside. We left the hospital thinking we had a healthy son. It was during his one-month well exam with our pediatrician that we learned we had a son who had aniridia.

John developed Wilms' tumor at 15 months. After the removal of his kidney with the tumor, he had 18 months of chemotherapy to prevent the cancer from coming back. When they removed the kidney with the cancer, our doctor told us the remaining kidney did not look quite right and to monitor it. John had numerous surgeries on his ears to have tubes inserted to relieve the pressure on his eardrums caused by ear infections. These surgeries prevented damage to his hearing. He developed a horrible case of chickenpox and he came close to dying when he was six years old. He had poxes in his eyes, ears and all over his body. He was hospitalized for two weeks and recovered. However, the disease created permanent scars on his cornea, which affected his vision. At the end of the first decade of his life, the remaining kidney became a concern.

The second decade focused primarily on a kidney transplant. When John was 11, his blood work showed that his remaining kidney had begun to fail. All of our family members were tested and his Dad was the only match. His Dad began a new diet and exercise program and got in great physical shape so he could give John his kidney. On December 11, 1995 John received his Dad's kidney. I am so very happy to tell you that John's kidney is doing well and his Dad is also doing well. We routinely have blood drawn and visit our nephrologist regularly. John takes several critical medicines twice a day for his kidney. Some of the medicines have encouraged weight gain, which is tough for John. However, we are thrilled that John's kidney is healthy. At the end of the second decade of his life, John's eyes began to develop more serious problems.

Cataracts and glaucoma are part of the syndrome of anridia. He was born with cataracts and as he began puberty, the cataracts began to grow and block his vision. The cataracts were removed and John had a cornea transplant because of the scarring from the chickenpox. After the surgery, the eye pressure began getting more pronounced. John had two surgeries to control the glaucoma. Both failed. Our doctor recommended another surgery to put shunts in the eyes. We did that and, with drops, have been able to control the pressure for now.

The troubling news is that all of the surgeries have affected John's vision. He has poor vision in his right eye and no vision in his left eye. The left eye's cornea transplant failed. The left eye has also had four serious eye infections that have been very tough to control. The kidney medicines reduce John's immune system, so he is much more susceptible to infections. At this time, we are considering a very complicated surgery on his left eye for this summer, hoping to regain some vision in his left eye. If this surgery is not successful, John will have to live with very limited vision in his right eye, no vision in his left eye.

The difficulty in maintaining any functioning vision for John has been a surprise to me. We have terrific eye specialists, experienced with aniridia patients, but I remember what a doctor at MD Anderson told us. We went there when John was born, because the leading researchers in aniridia were there. She said aniridic eyes are different from other eyes. They do not respond or heal like normal eyes. She was so right.


Gue & John Hudson


Burt & John

My advice is to find very good doctors who have experience with patients who have aniridia. Begin early trying to get state support for your child. It takes patience and tenacity, and with state budgets so tight, it takes even more of both. The financial support of the Medicaid Waiver, which covers most of John's expenses in his day program and host family, is critical for his life.

Finding a good day program and host family can also be a challenge. Look at all of your options and try to find the right one for your son or daughter. I would also strongly urge you to join organizations that are fighting for the resources and rights for persons with disabilities. We need many voices in this fight. Others in our support community have lots of information about day programs, host families and state support.

John's life has been a journey, a joy and an education. He has given us so much wisdom about life and doing the most with what you have. Obviously, we wish John did not have anirdia and the deletion in chromosome 11, but we love John for who he is and the gifts he has brought to the world and us. We look forward to our next chapter.

Off to Kindergarten

by Shizue Cohen

Five-year-old Darius goes to kindergarten in town. He attends a special education program with two other boys. Darius receives numerous services at school, including twice a week physical therapy and speech, and three times a week occupational therapy. He has a low vision therapist who sees him once a month and also helps his teachers to work with him.

It was a big transition for Darius to go to kindergarten without his twin brother. After many years of being together constantly--same school and classroom, same friends and play activities--the boys went off to different classrooms. Initially it was very stressful for both of the boys but things are fine now. Darius takes the bus all by himself every morning without complaint. He loves his school, friends, and teachers. Next year Darius may repeat kindergarten as he is now one of the youngest in his grade.

Hopefully, his social life will be more comfortable and manageable. And of course, the academic part will be more understandable for him too.

Right now he is learning his alphabet, can recognize all the letters and make their sounds, and is learning to write. And, if you can imagine, he doesn't want me to help him with his homework!

Darius' vision is 20/100 and he is without irises. He doesn't like to wear his glasses but does wear them at school. He also wants to wear sunglasses when it is sunny. So far his kidneys are fine and are being monitored every three months. His pediatrician keeps asking ME when his ultrasounds can be extended to every six months or more! Last year Darius had an extra fistra repaired after I discovered he had two openings for urine flow. The surgery well and the recovery, while difficult at times, went pretty well too.

Cooking, music, Bob the Builder, and pretend play are among Darius' favorite things. And he loves to eat! I really have to watch what I feed him as I know the issues with food in WAGR Syndrome are serious. He loves to play outside but with his vision, OT, and PT difficulties, I work hard to make play fun for him. He doesn't really like sports or following the rules and waiting his turn.

Darius gives me such a hard time with many things, but he is healthy and can do most of the things a five year old can do. I see many more challenges in the future but right now he is doing very well. I am so proud of my funny, happy, and sometimes cranky little boy!

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My NIH Experience

by Jenny Langley

On the 1st of November 2009 I set off for an adventure of a lifetime. I was travelling thousands of miles around the world to go to the National Institutes of Health to participate in the WAGR Syndrome Study. I was excited about this trip for many, many reasons. One of them being that I'd never even left Europe before. Another was that no medical expert had ever looked at me as a whole person before; I'd always been to an Ophthalmologist who looked at my eyes and nothing else or the nephrologist who looked at my kidneys but nothing else. So I was looking forward to having lots of different tests to find out exactly how WAGR Syndrome affected me. Also over the years many parents on the listserv have asked me "Are you SURE you have WAGR Syndrome? You don't appear to have any learning difficulties or mental retardation at all" So I wanted, if possible, to see if there was any explanation as to why I have WAGR but not the 'R' part. I wanted to take part in the WAGR study so that I could give parents and other individuals with WAGR hope for the future.

I think mostly I just had the usual anxieties that travelling to a new country brings - "how will I cope with such a long flight (8 hours)? What will the food be like, or more importantly what will the tea be like? Should we take our own teabags? What will the place we are going to stay be like? Will there be a hair dryer? How will we get around the hospital? Will we have enough time in our schedule for tourist outings? Will we manage to fit in a visit with Shari and Amy? What will the public transport be like? How different will America be in general to the UK? Specific questions about the study were 'What will they find? Will they tell me I don't have WAGR syndrome after all? Will I be any help to the study - will my results be 'interesting enough' to Dr Han? What will Dr. Han and Shannon be like? What tests will be done on me and will any be painful or uncomfortable? What happens next after all these tests are done? Will my doctors at home listen to me when I repeat the findings to them?

The trip didn't start off too well, we nearly missed the plane, due to our coach driver not turning up and getting to the airport with less than 15 minutes before check in closed! The trip didn't end too well either, we had to extend our visit and change our flights home due to some test results that warranted further investigation. But the bits in between were AMAZING, FANTASTIC and INCREDIBLE!

Dr. Han and Shannon were so lovely, they couldn't wait to meet me and introduce themselves. When they walked in the room, a nurse was busy taking my vitals, and my mum said Dr. Han practically had to hold herself back from talking to me as she was so excited! Over the two weeks that I was there, Shannon came to many of the tests with me and her encouragement and support was very much appreciated. I also loved meeting all the doctors and specialists, who were all lovely too.

Some highlights:
Doing the whole tourist thing and visiting the White House. My mum and I were especially interested in seeing the space module that Neil Armstrong went to the moon in, at the Air and Space museum. It was incredible to think that thing in front of us had actually gone up to space and back! Meeting Amy and her mum Shari - we had such a wonderful time with them.

The Cheesecake Factory restaurant, that Shari and Amy took us to was incredible; I don't think we have anything like that in the UK. Plus the chocolate milkshake I had was huge!!

Having Amy tell me what tests I should expect to have and offering me encouragement - "Don't worry about the MRI, it's not scary and you can leave your own clothes on if you want!" - Thanks Amy. The fact that Dr. Brooks - the NIH ophthalmologist said the exact same things as my consultant back home had said for many years - very reassuring.

The Family Lodge was a lovely place - very homey and welcoming. We enjoyed the ability to email my dad and sisters back at home and update them on everything.

It was interesting to compare the differences between what facilities there are for visually impaired people in the US and UK. I particularly found it interesting that crossing the road on my own was a lot more difficult in the US than back at home. I was amazed though at the lifts (elevators) in the Family Lodge - they bleeped a number of times depending on what floor you were on. So for example on the third floor it would beep three times. We do have talking lifts at home, but not ones that beep like that, which I prefer. I would have liked to be able to use the computers at the Family Lodge and the NIH but they had no software installed for visually impaired patients.

Funny moments:
Learning all the different words used in the US compared to those we use in the UK. A few times these differences made me laugh:
The woman booking us in loved our British accents and said "Can I have your cell phone number" We explained that in the UK we call it a 'mobile'. She thought this was great and said she was going to ask everyone for their mobile number from then on all day, just to see their reactions. We saw her again a few days later and she said she'd tried it on her daughter, who actually knew what a mobile was.
A nurse asked me if I needed help with my snaps. I said "Snaps??

What are they?" So she put my hand on one to show me - I said "Ooh we call those poppers!" Amy was talking to my mum and mentioned something about her 'bangs', my mum was totally stumped, but I knew what she meant - her fringe!

Another nurse asked me to spell out the name of one of my eye drops; I said "A z o p t". Then he just stood laughing at me! When I asked what was so funny he said - "You just said 'zed', it was so cute, we say 'zee' here!"

The MRI guy told me to take all my clothes off, I said "Even my knickers?" He stood there in silence for a bit then said "undies, yes keep those on". Later he said, "Where are you from?" and when I said "England, he said, "Oh I should have guessed that when you said knickers, I've only ever heard that word used on TV!"

Other funny moments included me and Shannon wrestling with many stupid gowns and trying to figure out how to put them on!

Doing the smell test was pretty funny - being from the UK we didn't know what some of the options were and had no clue what they were meant to smell like - for example root beer and pumpkin pie.

Some of the questions that the neuropsych team asked me were pretty funny too - "Who was president at the time of the Civil War?" my reply - "I don't have a clue but I can tell you who the Prime Minister was during the 2nd World War". Another funny question I still don't know the answer to was "What is the similarity between a crown and a badge?" Answers on a postcard please!

Getting on a bus was quite funny and embarrassing. In the UK, you get on the bus and pay the driver and they in turn give you a ticket. So we got on the bus to go to the mall to do some shopping and expected it to be a similar thing. The driver must have thought we were stupid, ignorant British tourists - there was a queue behind us so they just waved us straight onto the bus. We didn't realise you had to put a special token into a machine!

Tests:
Here is some of the tests I found fun or enjoyed taking part in:
The neuropsych testing session was fun, I think they took full advantage of 'how super brainy' I am, because we easily went over the four hours scheduled and had an extra session that lasted another two and a half hours! I enjoyed doing the various tests.


Dr. Han, Jenny & NIH team

I enjoyed audiology, but they worked me very hard, I had to listen to several things and repeat them back. Sometimes I had one number in one ear and at the same time I had another number in the other ear, I had to say the number I heard in my right ear first and then the number I'd heard in my left ear after that. It was hard, especially when it got to double figures! I also didn't do very well with the length and pitch recognition tests, at one point the examiner said to me "Try harder". So I was a bit peeved at that! The hot and cold test was good fun, I had to put my hand in a bucket of cold water. Shannon said I lasted twice as long as she had.

Not a test as such, but I really learnt a lot from Dr. Kopp, the kidney specialist. He showed me some pictures and explained all about FSGS in great detail and at what point they thought I was at. I felt he treated me like a proper adult. The only bad thing about his talk, was that my mum wasn't there at the time, so she missed it.

The tests I didn't like:
The nerve conduction test was painful! I felt self conscious with the 'food party'/lunch buffet test. I think Shannon expected me to delve in and help myself but with buffets I like to be not just told what is available but to be helped too. I asked Shannon to help me put stuff on my plate and she was happy to help.

The MRI lasted an awfully long time. I wish I'd asked for music. I dozed on the first one but then on the second the guy said I had to try and stay awake because I needed to breathe in and out.

Results:
What I learnt about myself:
The geneticist confirmed I do indeed have WAGR Syndrome. I have decreased temperature sensitivity in my fingers and toes - possibly attributed to chemo side affects. That explains why I can stick my hands in a boiling hot bowl of washing up water and come out of the shower bright red, not realising how hot I'd had it! I have more birthmarks than the average person. I have abnormal and smaller than normal teeth and some missing teeth. I have the early stages of FSGS, Dr. Han has suspected this for years but my neph at home had not started me on medication. So Dr. Han started me on an ACE inhibitor. I am severely low in Vitamin D and now have to take Vitamin D and calcium tablets. I also have mild scoliosis and a bone abnormally at the top of my spine. I have a poor verbal memory and am not able to clearly define words. I have a small pineal gland and may need to use melatonin to help me sleep better. I have mild audio processing difficulties and hip girdle weakness. My ovaries are fine, one was hiding but they eventually found it and I have a benign tumour in my breast.

So was it worth it?
Well there were many times when I thought: Why am I doing this? Like when both my mum and I felt very rough on the airplane going there. But overall it was an amazing experience and I learnt so much from it. I am so glad I went. It has helped to answer many questions, but unavoidably it's left me with many more I know this isn't study related, but if I'd never gone to the NIH I'd never have know about the breast lump I have - and it's certainly a good thing that they found it because now we know it needs close monitoring. Same with the FSGS, I am extremely thankful to Dr. Han for actually taking action and starting me on medication because I've had protein in my urine and slightly high blood pressures for several years now. Dr. Han felt so passionately that I needed treatment that she started it herself and told me not to worry about telling my consultant at home, they would deal with that too. What I also liked was the fact that if there was any concern over any of the test results, another appointment was set up to investigate further. One time this happened was with physiotherapy, they assessed me and then decided they would like to order some further x-rays to find out more.

The help and support from Dr. Han and her team of amazing doctors didn't stop at the end of my visit. After I got home, I found I could email Dr. Han about any concerns I had after an appointment for example. I emailed her when I was experiencing difficulty with my vision and my consultant at home was recommending I have cataract surgery. She got straight in touch with Dr. Brooks and asked for his advice and he emailed me back with some very useful information and questions to ask my doctors.

Thank you Dr. Han, Shannon and the team for helping me discover more about me and what I can do to improve my life.

My advice:
I'd recommend the study to anyone - it can give you frightening results yes and you definitely should be prepared to receive some results that you are not expecting, but it will give you an amazing insight into your child's condition and how best you can help them. If you've not signed up for the study, I would say to you, "Why? Do you have specific concerns that are stopping you from considering it? Then go ahead and ask Dr. Han or Shannon, they are more than willing to help and answer any questions you may have. Also you don't just get their advice during your time you are at the NIH. I've exchanged many an email with Dr. Han since I returned to the UK about some of the results. I'm able to update her after any appointment I have and hear her opinion on what my doctor has said - almost like getting a second opinion. Recently when I told Dr. Han I was possibly having a cataract operation, she went straight to Dr. Brooks for advice - without me even asking.

Your won't regret going to the NIH, it's an amazing place, with amazing doctors and specialists. It's like a totally different world or planet, where everything is about 'your child' or in my case 'me'. Nothing was too difficult to arrange, nothing was too much trouble. At one point, they lost my eye drops… their attitude was, we were the ones who lost them so we'll do everything we can to find them or replace them. They were still looking for them around 8pm and were even considering going to the Navy hospital to see if they could replace the missing drops.

I have a pair of blue fluffy PJ's that I brought from Macy's on my very last night in America. I wear them now and remember what an incredible adventure it was.

For more information on how you can participate in the WAGR Syndrome study at the NIH please contact:

Dr. Joan Han (301) 435-7820
hanjo@mail.nih.gov or
Shannon Fuhr, BA (301) 402-6762
fuhrshan@mail.nih.gov

WAGR Syndrome is a very rare disorder. Physicians are generally not familiar with this condition, or with the features and complications of it. People with WAGR syndrome benefit greatly when family caregivers, medical professionals, teachers and therapists learn as much as possible about the disorder, and become active partners in their care. "WAGR" is an acronym. The letters stand for the most common features of this disorder.

W-Wilms' tumor
A-Aniridia
G-Genital and/or urinary tract abnormalities
R-Cognitive delays/developmental disabilities

People with WAGR Syndrome have many things in common, but they are also individuals. It is important to remember that a given individual with WAGR syndrome may or may not have or develop the same conditions.

THANK YOU

Earlier this year, Catherine Luis' sister's father in-law, Santo Algarotti, passed away. Catherine is an IWSA cofounding member as well as past president. The IWSA greatly appreciates the donors who made generous donations in Mr. Algarotti's memory.

Giovanna Algarotti
Eugene & Carol Biczak
Angela Kavalesky
Evelyn Rudolf
Christopher Shanahan
Donald & Louisa Smith

Hockey and Hope

by Tammie Hefty

Aaron, Jeff, Tammie & Evie

"Sticks down, drop the puck. Sticks down, drop the puck." Those were the words Jeff used to give Evie a quick tutorial in how to drop the puck to start the Admiral's hockey game on March 7, 2010. It's not every day that a parent gets to be on the jumbotron with his or her kid; but on that day, it was a dream come true for Jeff and Evie; okay, mainly Jeff.

Sometimes, you just never can tell what might be waiting around the corner for you. When you deal with WAGR Syndrome, you start to, unfortunately, wait for something bad. As I sat on the opposite side of the ice from Evie and Jeff, I marveled at the complete joy I was experiencing at that moment in time. We were in the midst of a miracle. We were able to spread the word to an ice rink full of people about WAGR Syndrome, the lack of knowledge about WAGR Syndrome in the general public, and the need for awareness so that people like Evie can get the early intervention, both medical and educational, that they need. I remember the feeling of "How did I get here?" when I stood in the hospital room with Evie after she was diagnosed with cancer; and I had those same thoughts as I sat at the Bradley Center the afternoon of our special game, but it came with a different emotion attached to it.

This all started when a friend of mine on Facebook sent me an e-mail asking if I'd like to do a fundraiser for the IWSA by having a night out with the IWSA during a Milwaukee Admirals hockey game. Really? Was that even possible? Of course I would love to do something like that, but I never thought it would come to be. We have all seen the football players dressed in pink and throwing out a pink football for breast cancer awareness, but, as Tom Cox responded to me when I asked the IWSA leaders if they thought we could endorse this hockey game endeavor: How else will we ever see the American League Baseball players wearing zebra stripped caps if we don't start with this hockey game?

Evie greets some of the Admiral players

Aaron, my friend, is the play-by-play announcer for the Admirals, a team that plays hockey in Milwaukee, Wisconsin and are affiliated with the National Hockey League team, The Nashville Predators. The way we were going to raise money was by Jeff and I selling tickets to the game through invitation of our family and friends. We were to have the people we referred contact Aaron directly for the tickets, and we would get $4 of every ticket sold by Jeff or me. As we all well know, it's tough to get a lot of people to commit to an event…so the tickets were hard to sell. My sister and brother-in-law made the long six hour journey from their home in Minnesota. Jeff's parents, uncle, and cousin, and boyfriend, came along to Milwaukee as well. Some wonderful friends of ours the Antonsons and the Bieris brought their families too. It meant so much to have people rally around us to raise funds for the IWSA and too see Evie on her special day.

But, those ticket sales alone weren't going to equate to very much. Aaron wanted to do more. So, he came up with the idea to have a silent auction during the game to raise additional funds for our cause as well. He solicited items from different hockey players around the country. We had autographed hockey pucks from people like Chris Chelios and Patrick Kane; cinch-sacs autographed by players like Jack Skille and Jake Dowell; a goalie stick signed by the entire Admirals team; and two jerseys that were autographed as well. Our silent auction yielded nearly $700 when it was all said and done.

Outside of the financial gain for the IWSA, I was interviewed on the jumbotron during an intermission regarding WAGR Syndrome, Evie, and the IWSA; and I was interviewed live on radio as well. Wow! To be able to reach such a large number of people was monumental in my mind.

In short, we all had a blast, and we raised money for a great cause. Many people have said to me, "Tammie, you do such wonderful things for "x, y or z". But, I look at it differently: it doesn't take incredible people to do incredible things…it takes incredible opportunities and the courage within oneself to take those opportunities and make the most of them.

WAGR Weekend 2010
Celebrating 10 Years

Please don't forget to mark your calendar today and join us this July 23-25th in Gaithersburg, Maryland for our **10 Year Celebration - WAGR Weekend 2010**

SpringHill Suites by Marriott
9715 Washingtonian Blvd
Gaithersburg, MD 20878

(301) 987-0900 or (888) 287-9400
Rooms are limited - first come, first served

Tentative Itinerary

Friday, July 23rd

6-8 PM Meet & Greet, SpringHill Suites
8:30 PM - Mom's/Ladies' Night Out (location to be determined)

Saturday, July 24th

9 AM - 7 PM Bohrer Park at Summit Hall Farm
9:30 AM - Group photo
10 AM - Noon IWSA Introduction, NIH Updates with Dr. Joan Han, Q&A with Dr. Han and NIH Ophthalmology/Nephrology team
12:00 PM Catered Lunch Provided
1 PM - 6 PM Bohrer Park activities (water park, putt-putt golf, skate park)
6 PM Pizza Party (assorted pizza and salad)
8:30 PM - Dad's Night Out (location to be determined)

Sunday, July 25th
Morning visit and tour of the NIH (if there is enough interest)

Families must RSVP for WAGR Weekend 2010 by visiting:

http://www.wagr.org/wagrweekendevents.html

For more information on the Gaithersburg, MD area, contact Shari Krantz by email: classicshari@yahoo.com

IWSA Officers & Members

President - Tammie Hefty
Vice President - Catherine Luis
Secretary - Julie Dell
Treasurer - Jeffrey Hefty

Board Chairperson - Kelly Trout
Member - Annie Prusakiewicz
Member - Tom Cox
Member - Shari Krantz
Member - Rhonda Sena

We would like to thank the March of Dimes Southeastern Michigan Chapter, for providing the IWSA a Community Award Grant for 2010. This money will offset some of the printing/mailing expense of WINGS so that we can continue to provide this to our readers free of charge.

Education Questions?
Families & Professionals please Contact:

Rhonda Sena, M.Ed
Educational Consultant

CasaSena5@yahoo.com

Health Questions?
Families & Physicians please Contact:
Kelly Trout RN, BSN
IWSA Health Consultant & Liaison to our Medical Advisory Board.
KellyTrout@sbcglobal.net

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

The Counseling Staff - Rod Flint, Joy Hoffer, Annie Prusakiewicz & Olga Tsipras

On behalf of all our families, the IWSA board and officers would like to thank everyone that has made monetary donations to our great cause. We could not carry out our mission without your support. THANK YOU! THANK YOU! THANK YOU!

Moving?

Don't miss out on future issues of WINGS. Please send us your new address.

Email our IWSA Secretary, Julie Dell hcdtank@yahoo.com

Casual Clothes for a Cause (C-3) Day is a long standing tradition in the Riverview Community School District.

Friday, January 15, 2010 was designated as C-3 day for the International WAGR Syndrome Association. I am pleased and humbled with the support the IWSA has received from the great staff in Riverview. This year $1,030 was raised for the IWSA, which brings the amount raised over the past four years close to $3,500

THANK YOU PIRATES!!

by Annie Prusakiewicz

International WAGR Syndrome Association

YES Enclosed is my gift

( ) $25 ( ) $50 ( ) $100 ( ) $_____

*Your Name:*_____

Street Address/P.O. Box: _____

*City:*_____ *State/Province:* _____

Zip Code: _____ *Country:* _____

*In Memory of:*_____

*On behalf of:*_____

Mail to: *IWSA*
P.O. Box 392
Allen Park, MI 48101

THANK YOU FOR YOUR TAX DEDUCTIBLE DONATION

International WAGR Syndrome Association
PO Box 392
Allen Park, MI 48101

Donate

We are now able to accept online donations through PayPal. Please visit www.wagr.org and click on the donate button.

Deliver to: