



WINGS

WAGR Information, News, Gorilla Stories

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

www.wagr.org
Fall/Winter 2009

From the President's pen

My mom and dad often started our phone calls when I was in college with, "What group did you join now?" So, it came as no surprise to my friends and family when I took on the role of secretary for the IWSA a few years back. My mom, dad, grandma and grandpa have all held officer positions with the Association for Retarded Citizens in the county where I grew up, so I come from a long line of leaders and advocates for those with special needs.

But, my involvement with the IWSA is representative of so much more. Our family has raised over \$30,000 with our Relay for Life team in the four years since Evie was diagnosed with Wilms' Tumor. This year,

though, it was bittersweet. I realized that cancer is a "socially acceptable" disease with lots of support and lots of voices calling out to quell its continuous sprawl. Not so with WAGR syndrome. How many of us heard about WAGR before we became a parent or grandparent of a child with it? If our family threw its support behind the IWSA, the American Cancer Society would likely not notice our absence.

As I filled our paperwork for Evie to be granted services from one group or another, I realized that some syndromes have the fortunate circumstance of being "well-known", recognizable, understood. I couldn't check the box for Down Syndrome, or Cerebral Palsy. I had to try to describe in detail everything my daughter goes through on a day, week, month, to gain any hope that she would be granted services from the county.

But let's think about this...40 years ago, my grandma was told that my uncle who was born with Down Syndrome should have been put in an

institution. Where will WAGR Syndrome be in 40 years? I believe that with a voice, with advocacy, with parents like those in the IWSA, with social networking on Facebook and Twitter, WAGR Syndrome will be just as known as Down Syndrome is today. We won't have to explain why they don't have irises, why they appear to be so tired, why they always wear sunglasses, why their speech is difficult to understand...people will KNOW WAGR Syndrome.

It's with that hope in mind, it's with that passion in my heart that I decided to step out of my comfort zone and accept the role of President of the IWSA. I have fears of failure, as would anyone, but, with an incredible board of leaders and officers, and the support of wonderful families like yours, I know that we will continue to blaze a trail for our kids to lead incredibly successful and miraculous lives.

Tammie Hefty

On the Inside

Silver Linings	pg 2-4
Gorilla Giving	pg 5
WAGR Weekend 2009 Memories	pg 6-7
NIH update	pg 8
The Caring Quilt	pg 9
Become an Asker..and a Giver	pg 10
WAGR Weekend 2010 - A	
Celebration of 10 Years	pg 12



Silver Linings

As soon as I read the email from Kelly Trout regarding Dr. Joan Han's research at the National Institute of Health, I wanted Holly to be involved.

We completed Stage 1 of the WAGR Study at the NIH, which involved bloods being taken from Holly, her dad and myself. It also involved completing Holly's medical history along with medical history on the extended family. Holly's extended family is spread over a few states in Australia but thankfully with the internet sharing the information was made easier. Our involvement with Dr Han has been amazing, even at this early stage of the program she was able to give us some findings from the bloods and provide us and Holly's specialists with support.

As word spread through our friends and family about the NIH program more and more people were asking how they could help us. In South Australia our empty drink containers (cans and bottles) have a .5c deposit on them. We decided to collect bottles and cans. The response was amazing! I remember one day getting a phone call from a hotel that had a weeks worth of "empties" for us. We collected over \$850 from the hotel. In the end Mum and Dad ended up raising over \$6500 AUD during a period of three years. We were also amazed to receive a donation of \$5000 from a friend.

The support and generosity of people was just overwhelming.

Dr. Joan and her assistants have been in touch with us since the very beginning and have kept us up to date on what was happening with the program, the birth of Joan's little boy, and when Stage 2 of the WAGR Study began. We were lucky to coordinate our visit to the NIH with the upcoming WAGR Weekend in Maryland. So we were set, Holly was booked into the NIH for a two weeks stay, and then we were to go to Gaithersburg to join other WAGR families for a wonderful weekend.

Our first stay was in Hollywood. From there we caught a train to San Diego. In San Diego, we went to Sea World. The highlight was a character breakfast where we had breakfast with Elmo and friends. To say she was excited that morning was an understatement, she was over the moon. Her little face lit up when she saw Elmo walk into the open air restaurant. We also managed to

catch the Shamu Show, which had Holly standing up squealing and applauding. The weather in San Diego was perfect and Holly and Mark took advantage of it, relaxing in the hotel pool each afternoon.

After six beautiful days in San Diego we flew to Maryland and we were on our way to the NIH. Meeting Joan (Dr. Han) & Shannon (Dr. Han's assistant) was just wonderful. We couldn't believe that after nearly three years of planning we had made it. What struck me most about the team at the NIH was how valued we felt and how appreciative they were that Holly was part of the research. Each procedure was explained to Holly and her permission was sought prior to any examination commencing. At no point did we feel like an appointment was rushed because another patient was waiting. Each therapist and specialist gave Holly the time to settle in before starting their examination. I can not speak highly enough of the people that we came into contact with at the NIH--especially Dr Joan Han, Shannon, Kiera, and Mark who really did go out of their way to make us feel at home.

We are still waiting on some of the final reports to come in, but thanks to the NIH and Dr Joan, we have made some adjustments to Holly's life that will hopefully help her to avoid some complications in the coming years. For that I am truly grateful.



With our two week visit at the NIH finished, we travelled 20 minutes down the road to Gaithersburg to join the WAGR Weekend hosted by Shari Krantz and her family. The foyer of the Hotel was filled with excited WAGR Families greeting each other, an amazing site after eight years of communicating via the internet. It was so nice to finally meet Kelly, with her gentle reassuring nature settling my nerves about the weekend. I still couldn't believe that we were in the same room as the people whose names I knew from the WAGR Group site--it was amazing. We Mums went out that first night for a few drinks and nibbles. It felt natural to sit and discuss the issues that each of us were having with our children and yet it was amazing because it just doesn't happen every-day.

Day two saw the children play together in the gym whilst Dr Joan Han and Shannon spoke about the NIH Study. Wow! This information session was amazing. It felt so good to know that Holly was part of this fantastic study that has helped her and will continue to give us and future WAGR families' answers. The afternoon was free time to spend at the fantastic water park and the mini golf course, all provided free thanks to Catherine, John and Irma Luis. After a couple of hours swimming Holly was exhausted and we retired back to the room where she napped. That evening, Holly and I stayed in and prepared for our next leg of the trip

whilst Mark went out on the Dad's Night Out.

At this point it was hard to believe we were on the last leg of our trip. We were headed for Disneyland. It was simply the most beautiful place. Holly's' face lit up each of the three days we walked into the park. It is a truly magical place for big kids and small.

On our flight home, we reflected on the highlights of our journey. The American people were just beautiful. I had been told that we could expect to walk down the street and not be made to feel different. This was very true and very much appreciated. We feel more empowered with our knowledge of WAGR Syndrome. Meeting the families, children and watching Holly play with the other kids is a memory that I hold dear. Our bond as a family is stronger and we will never say we can't do something again; we have after all traveled half way around the world together.

Tricia Gerahty - Australia

It's my pleasure to write my personal recap about WAGR Weekend 2009, which I attended. It was really great time and I will never forget it.

I met all of you in person and was able to chat with everyone. It was really nice and gave me new view on living with rare disease. I study pre-med at University of Gothenberg in Göteborg in Sweden, and in January 2010 will start medical school at the Sahlgrenska



Karina, Poland & Josh, Michigan

Academy at Gothenberg University. This is one of the best medical schools in Europe and the best in Nordic countries. I decided to come back to Europe (after summer internship at the NIH) due to very high costs of medical schools, hard admission process for applicants with foreign undergraduate education, and difficult rules with health insurance in the US. In all European Union member countries education is free of charge as well as health and social insurances. We "pay" for them in taxes - I buy candies and pay for my education and treatment! Doctors here are not as American doctors (those who I

Forward newsletter submissions, stories, pictures or ideas to:

Annie Prusakiewicz
P.O. Box 392
Allen Park, MI 48101
E-mail: TheMooZoo@aol.com

know). Here they don't take care of the patient but the disease only. I especially miss Dr. Han's care at the NIH. No one doctor here is as wonderful as she is.

I remember all nice moments during those three days of WAGR Weekend in Gaithersburg, Maryland. The ladies probably remember best my blooper at the restaurant during Friday night out! Saturday was really great. Dr. Han's lecture very interesting especially due to her ability to talk about really difficult scientific problems in very easy to understand words. Afternoon at the swimming pool was enjoyable time and I felt as a child. Why not act like a child? I learned to play mini-golf. Adult education of child's game is so funny!

One of my best recollections from WW '09 is long and very interesting conversations with other teenagers, including Laura, Ashley, and Jessica.

It was a great time for me and I can't wait to meet you all again next year! Best wishes from cold Sweden!

Karina M. Sasin, Poland

Let me tell a little about my family. My husband Don and I have been married 29 years. We have 12 children: our oldest son is 26 and married with three daughters; our second son is married and just had his first anniversary; our 3rd son came with us to WAGR Weekend, he is a full time college student who lives at home; and our 4th son is a Marine stationed in Georgia.



We also have four daughters from 17 to 10, then an eight-year old son, a five-year old daughter, a four-year old son, and Joshua, who is 19 months old.

Our big adventure started last May with a phone call telling us that we were selected to receive financial assistance from the IWSA so we could attend WAGR Weekend 2009. Our planning started with maps, scheduling time off from work, setting up reservations, and figuring the miles between rest stops that the kids would be able to withstand. We decided to drive during the night, so we took off at midnight on Friday, with the hope that the small children would sleep through most of the 14-hour drive from Michigan. Miraculously it worked--the little ones did not wake up until after 8 am when we stopped for breakfast.

When we got to the hotel it was about 4pm. In the lobby there were several WAGR group families. I was able to finally meet Annie and Kelly,

two of the people I have talked with on the phone and I was finally able to put faces to the voices. Soon it was time for the meet and greet, where we introduced ourselves and were able to put more faces to names. After meeting some of the other WAGR children, my children were amazed at how much Joshua looked like some of them. My husband and I agreed that there are common characteristics between Joshua and the other children, kind of like a common bond, a family of sorts.

The meeting with Dr. Han was exciting but at the same time scary because she related some new things they have found that our children can be experiencing, some of it I did not know, like the auditory stuff. We wondered if Joshua was having problems with this because at 19 months he only says about four words. Dr Han definitely answered a lot of our questions and quelled a lot more of our fears. She also talked about the BDNF and since we just got Joshua's blood test back from

Dr. Han and found out that Joshua is missing his gene for this, we were able to hear of the problems that this issue can bring. That is where the scary comes in, because she told us of the complication to Joshua's health if his weight is not keep in check. Dr. Han also mentioned the pancreatic attacks some children are having without us even knowing because of their higher pain threshold, which was very interesting, and good to know. Dr Han also took the time to visit with every parent privately.

I think one of the best things I took away from the weekend is that there are other moms and dads dealing with some of the same things as we are going through and they CAN really say "yeah, I really know what you are dealing with" because when some of my friends say that in the back of my mind I am thinking "no you don't". It was great seeing the children who have had cancer playing and being normal children so even if we get a "bad bean's" test we know it is survivable and there are others who have dealt with it and I can call them and find out what they did to medically deal with what ever is thrown at Joshua.

The final thing I can say is that I think that we have been truly blessed to have the WAGR group to email, or call because in the last 13 months we have had a lot of things thrown at us as a family, because Joshua's diagnosis did not only effect Joshua but every one else. It was great

for Joshua's older siblings to see that there are other kids dealing with all that comes to being a WAGR sibling and it helped them to not feel so alone.

Paula Peckham, Michigan

Gorilla Giving - You CAN Make a Difference



Last year we decided we needed to do something for this great organization to help off set some of the cost that goes into making the IWSA operate. So, I shot an email to our family and friends, challenging them to help us raise at least \$500 to take to WAGR Weekend in Michigan. I also sent a few letters out to our employers and told them how the IWSA has helped us since Hayden was born. To our surprise we went way over our goal of \$500 and raised \$1,800 for the IWSA.

As we came home from WAGR Weekend I was very proud that we

got to give back. It made me feel really good. I said to my husband, "You think we can do even better next year?" "We can try!" he said. So, once again this year I sent an email to our family and friends and wrote letters. I knew with the economy the way it is our chances of reaching our goal to go over \$1,800 was going to be hard.

We decided to do a sub sale to help us achieve our goal. It was so easy to do. I just called the local deli, picked a date, made an order form, put the forms at our places of employment, friends offered to help and we ended up selling 261 subs and profited \$482. I hardly did anything!

In the end, we went over our goal and raised \$2000 for the IWSA. I, of course, could not present the money at WAGR Weekend in Maryland without lots of tears. I get very emotional when I think about how the money is going to be used. The money will put a newsletter in the hands of a new gorilla mom who is scared of what the future holds for her child. It will also help offset the costs of the IWSA website for that new mom to look up medical information, which she can give to her child's doctors who have never seen a patient with WAGR Syndrome before. It could also help that same mom get her family to WAGR Weekend so she can feel the amazing bond in person that she has with other families she met on our e-mail WAGR discussion group.

If just asking for a donation will help a new mother feel "less alone" in WAGR World, then I'll do again. I remember that feeling.....don't you?

**Julie Dell, proud mama to
Hayden**

WAGR Weekend 2009 Memories



The Krantz & Marshall Family



The Cox Family



Hayden, Aydin & Nick



Evie



Elizabeth & Nathan



Julie & Tammie



Aly & Jack



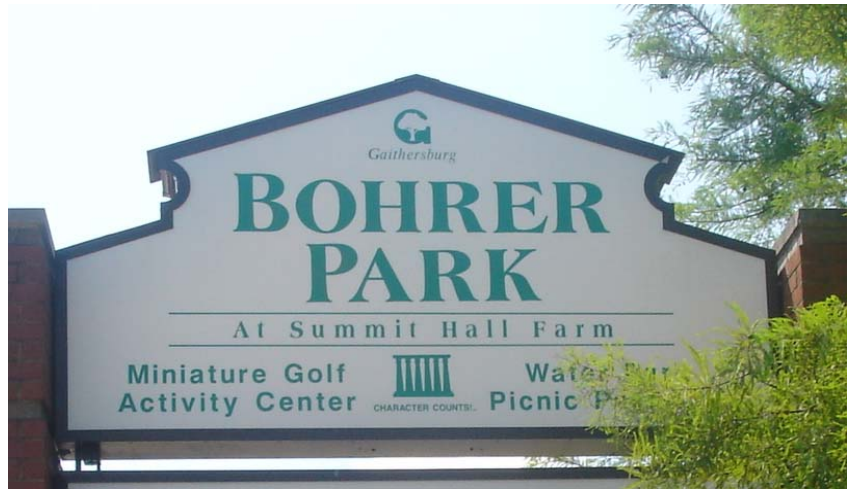
Dr. Han & Emanuelle



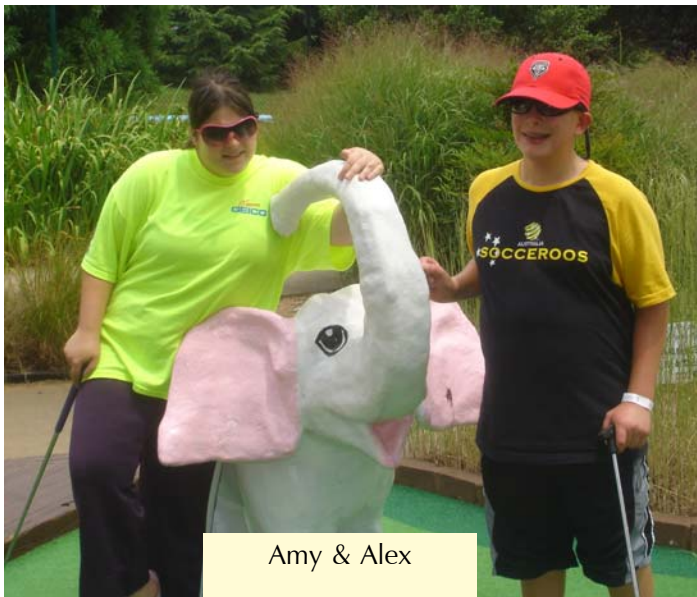
Irma, Robyn, Kelly, Laura & Norma



Ashley, Clem, Nick & Laura



Thank You!



Amy & Alex

Our Hosts: The Krantz & Marshall Family
 Sarah Heegaard
 Frank Coviello
 Double K Contractors, Inc.
 Frye Insurance Associates, Inc.
 Gaithersburg Garage Door, Inc.
 Gerald and Carol Gimmel
 George and Joan Horman
 Claudia Lawler
 Cheryl McCullen
 Morton's Towing and Recovery
 Potomac Disposal, Inc.
 Thomas Chiswell, Inc.
 David Vidmar
 George and Kim Walter
 Roy and Sue Carpenter
 Richard and Michele Krantz
 Richard and Jewel Melberg
 Robert and Rachel Reilly
 AKZO Nobel Coatings, Inc
 Lions Club, Gaithersburg, Maryland



Julie, Hayden, Brian, Monica, Jaxon, Steve & Maddie

WW Volunteers
 Wesley and Brittany Marshall
 Claudia Lawler
 Barbara Akinmade
 Josepha Babendreier
 Mike Wert
 Nikki Hoffman

Special thanks to Joe Hance and family of Gentleman Jim's Restaurant, Gaithersburg, MD and to Jessica Jovanovic, Glaceau Smartwater

We could not have done this without your support.

NIH UPDATE



We are happy to report good progress with the WAGR Syndrome Research Study at the National Institutes of Health (NIH) in Bethesda, Maryland.

First, we would like to introduce ourselves, both existing and new members of the research group. Joan Han, MD, is a board certified pediatric endocrinologist and the principle investigator for the WAGR study. After attending college and medical school at Harvard University, she trained in pediatrics at Boston Children's Hospital and in pediatric endocrinology at Nemours Children's Clinic in Jacksonville, Florida and at the NIH. Working along side Dr. Han is Shannon Fuhr, BA, the new research assistant coordinating the WAGR study. She

graduated from Vassar College in New York with a degree in Neuroscience and Behavior with a focus on pre-medical studies. In addition, we have two student volunteers, Christina Zheng and Mark Lee, both from Walt Whitman High School in Bethesda, Maryland.

Currently, we are continuing the Phase I stage of the study and are making significant advancements in Phase II, which would not be possible without the remarkable and much appreciated involvement from the wonderful families of the IWSA. We have had 57 families from all around the world participate in Phase I, which launched in June 2006. In Phase I, participants of any age are involved in an outpatient study. This includes a blood draw and collection of medical records. One or both of parents may also choose to have their blood drawn, but this is completely optional.

To date, nineteen families have participated in Phase II, which launched in November 2008. Phase II is an option for participants age 6 years and older, and consists of a week-long inpa-

tient stay, during which a comprehensive evaluation is conducted to explore the relationship between gene deletions (genotype) and clinical symptoms (phenotype). The studies include blood and urine samples, radiology imaging, and examination by multiple doctors specializing in various fields, including nephrology, ophthalmology, endocrinology, neurology, psychology, audiology, dental, and psychiatry. After your stay at the NIH, all of the results are explained and sent to you as well as to your child's doctor.

From our studies, we have learned that individuals with deletion of the brain-derived neurotrophic factor gene are at greater risk of developing obesity and also appear to have higher pain tolerance. Also, we have observed that having a larger deletion size is associated with shorter adult stature. These findings have been reported at scientific meetings and in publications. We are also making interesting observations about differences in facial structures, auditory processing, and eye movements. These latest findings are still preliminary but we hope to report to you more details in the near future. We are very appreciative of participating families and invite more families to join our research study.

If you would like to participate in Phase I and/or Phase II of the study or if you have any other questions about research at the NIH, please feel free to contact Shannon or Dr. Han.

Shannon Fuhr, BA
(301) 402-6762
fuhrshan@mail.nih.gov

Joan Han, MD
(301) 435-7820
hanjo@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-mental retardation/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.

IWSA Caring Quilt

by Tammie Hefty

One day when I was on Facebook, I got an announcement from the Madison Area Down Syndrome Society group to which I belong stating that a quilt was in the area and that the people with Down syndrome who lived in the Madison area could get his or her picture taken with the quilt to post on Google Maps. I clicked on a link and it took me to a map with little pins scattered on a globe. I clicked on a pin and it brought up a picture of an adorable child wrapped in a blanket, with the child's location as a subscript. This got me to thinking, "It certainly would not take us long to send a blanket around the world to spend some time with each of our IWSA families!"

I proposed my idea to the officers and board members of the IWSA. Catherine Luis went out and purchased a quilt before I could even blink an eye. The quilt is multi-colored and covered in zebras. How beautiful for our children, each one of a kind, and yet connected by their deletions of some little genes that most of us had never heard of before WAGR syndrome.

So, now the fun begins! We are going to send our Caring Quilt around the globe! I have acquired a notebook that will be used as a journal to travel with the Caring Quilt from WAGR home to WAGR home. The Caring Quilt will stay with a family for approximately a week before being sent to the next family. When and if possible, I'd love to have a photo taken with the family or child

wrapped in, sitting on, or holding up the Caring Quilt so we can start to put our photos on Google Maps and create a mosaic of our families around the world.

I will need each family who wants to participate to send me their names and address so I can create a flow chart of travel for the Caring Quilt. Families are asked to journal while having the Caring Quilt so we can get a glimpse of what was going on with the family at the time. The Caring Quilt may be with a family that's going through treatment for Wilms', through recovery from another illness, through diagnosis of some sort, or through nothing dramatic at all besides being the family of a person with WAGR syndrome. Questions can be explored in the journal like: When did you learn about WAGR syndrome, what has affected your family the most, (for example: glaucoma, Wilms' Tumor, learning disabilities), how does the IWSA help you, what is your outlook on life with WAGR syndrome being a part of it?

What is our goal with the Caring Quilt? Our goal is for us to feel connected physically because it's very difficult for all of us to get together with one another. Our goal is to give a piece of ourselves to one another by traveling vicariously through our Caring Quilt and wrapping one another in the hugs we so desperately long to give over cyberspace. Can you even imagine what it will be like for the new family who joins our group to



Hayden (PA) & Evie (WI)

receive the Caring Quilt in the mail and read the journal that has the thoughts, feelings and experiences of another family with WAGR penned on its pages? The Caring Quilt will be an extension of our selves that is free to mingle with our families and give comfort, hope, and assurance to those who may have otherwise felt alone.

The first step to sending out the Caring Quilt is to let me know that you would like to participate! Please send me, tammiejo@mhtc.net your names, addresses, and e-mail addresses so I can begin a roadmap for the Caring Quilt's travels. When you receive the Caring Quilt, you should receive an instruction sheet, the journal and the quilt itself. Of course, since this is her maiden voyage, we expect there will be bumps along the way, but that's all to be expected when we are talking about WAGR syndrome! We will take this a day at a time and see just what our Caring Quilt can do.

I am indebted to the founding members of this group and relish in the new families' witty accounts of life in a WAGR household:

*Ask and learn and read away
There's a WAGR friend around every day.
Whatever your worry, whatever your fear
Someone will help, far or near.
Relish the child you have been sent
For you are special and to you they were meant.
And one day soon, you will find
Someone has a question with you in mind.
Things you have learnt, you will pass on
And your experience will help another be strong.
Love life and live life for every minute
As this world is a better place with you in it.*

**Written by Vicky Jones,
Mom to Megan, United Kingdom**

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.

Become an Asker...and a Giver

by Shari Krantz

For many years I have supported numerous local charities, activities, and events. There was never a question whether I would buy Girl Scout cookies, raffle tickets, pizza kits, and magazine subscriptions. Neighborhood kids and local businesses could always count on me to help out with a purchase or donation. I never gave much thought to how the money would be spent, who would manage it, or how much was being raised. That all changed when I became involved with the International WAGR Syndrome Association (IWSA).

As a non-profit organization, the IWSA relies solely on donations and volunteers to carry out its mission. In my role as an IWSA board member and WAGR parent, I am involved with planning and budgeting as well as many other association tasks and projects.

Our most important event each year is WAGR Weekend, our annual "reunion". As the host family for the 2009 WAGR Weekend, I naively volunteered to raise money to help offset some of the event costs. In my board member role, I knew what the event would cost and how many volunteers would be needed. While we had money budgeted for the event, I also knew that we had lost previous years' fund-

ing from several sources and it would be challenge to replace it. I had quickly gone from being a giver to being an asker. At first this new role was uncomfortable and uncharted for me, but it became my mission. Feeling very passionate about our cause, I turned to family, friends, and my business community for financial support. I was completely overwhelmed by the generous and compassionate response. The IWSA not only received monetary gifts and offers for volunteer assistance at WAGR Weekend but donated items like water bottles and gifts for the kids. I was also afforded the opportunity to share my personal experiences of raising a WAGR child. I found that most people who support charities prefer to give to organizations that they have a connection to--ones where they know the people it helps, the services it provides, and that the money is used to serve a great need.

One of the largest expenses for WAGR Weekend is financial assistance we provide for families who may not otherwise be able to attend. We were thrilled to assist five families in 2009--from Pennsylvania, Michigan, Australia, and Wisconsin. The delight and camaraderie we all shared with the children and parents were priceless!

With WAGR Weekend 2009 behind us and plans underway for the 10th IWSA anniversary celebration and WAGR Weekend 2010, I am planning to be an asker once again. This time I will be experienced and have the pleasure of sharing how our generous donations are being used.

IWSA board members and officers are also tasked with developing and encouraging participation in our fundraising efforts. The variety of donation methods has increased tremendously through use of the internet and social networking sites and our volunteer team has come up with some very creative avenues. While you can continue to contribute through the United Way, there are numerous other ways too. No donation is too small. Visit our website at www.wagr.org to see which method is most convenient for you and your family, friends, and coworkers.

LOVING MEMORIAL THANK YOU

Earlier this year, Catherine Luis' mother, Marion Romano passed away. Catherine is an IWSA cofounding member as well as past president. The IWSA greatly appreciates the following donors who made generous donations in her memory

*Toys R Us, Co.
Flemington Supply Inc.
Ira Samuels & Shelly London Samuels
Diane & Tim McGuire
Anthony & Marie Donato
Austin & Jeanne Elia
Todd & Robin Rosenfeld
J. or M. Funderburk
Lucia & Santo Algarotti*

We know it takes a village to raise a child. We are learning that it takes many villages to support the missions and goals of organizations like the IWSA. Like I did, consider being an asker--share your story and ours--and help the IWSA continue to serve families facing the challenges of raising and caring for children and adults with WAGR Syndrome.

The IWSA will be forming committees in early 2010. We are looking for people who are interested in working on these committees. If you believe in the mission of the IWSA and have time available to devote to our cause, WE NEED YOU. Please contact Shari Krantz at classicshari@yahoo.com. No job experience required. Please consider sharing your time, talent and treasures with the families that need you the most.

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



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

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.

Please
Join
Us!

WAGR Weekend 2010

Celebrating 10 Years

Mark Your
Calendar
Today!

Planning is underway for WAGR Weekend 2010 -- Celebration of 10 years.

WAGR families and friends will meet in Gaithersburg, Maryland, July 23-25, 2010, for a weekend of fun, friendship, and camaraderie. Our activities will take place at Bohrer Park at Summit Hall Farm where there is air conditioned meeting space and gymnasium, a fabulous water park for kids and adults of all ages, playgrounds and walking paths, a skate park, and miniature golf course.

Arrangements for hotel space, speakers, and planned activities are currently being finalized and additional information will be posted in the near future on our website at www.wagr.org

Gaithersburg, Maryland is located in suburban Washington, DC, which is convenient for visiting our Nation's capitol and the National

Institutes of Health, where the WAGR Syndrome Study is underway.

We hope you can join us for a weekend of celebration, friendship, and fun!

WAGR Weekend Family Financial Assistance Scholarships are available. For more information please contact Tammie Hefty at tammiejo@mhtc.net or (608) 347-6356



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



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

Deliver to: