



WINGS

WAGR Information, News, Gorilla Stories

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

www.wagr.org
Fall/Winter 2011

To all our IWSA families, friends and donors,

Southgate, Michigan was the destination for sixteen WAGR families this past summer. We had families drive and fly in from the east coast, midwest, west coast and even had one family travel from Northern Ontario to be with us for WAGR Weekend 2011.

"Awesome" is the one word that best describes the feelings of most people that were in attendance.

The weekend got off to a great start at the Meet and Greet when "Hooper" the Detroit Pistons Mascot stopped by to visit all the children, large and small. He dazzled the kids with his basketball dunking skills, entertained them with a magic show, signed autographs and took pictures with all our WAGR families.

Moms and dads enjoyed their individual nights out of bonding,

sharing personal stories, challenges and experiences with other moms and dads.

Saturday morning WAGR parents were able to share information in an open roundtable forum while the kids spent time with volunteers.

After lunch many families enjoyed an afternoon of cosmic bowling at Roosevelt Lanes. The kids loved the fluorescent blinking lights and bowling in the dark.

Dr. Joan Han from the National Institutes of Health was able to speak with us via Skype in the afternoon. She provided our families with a WAGR Study update and answered questions from the audience.

Our families enjoyed the pizza party Saturday evening. The kids especially loved burning off calories dancing to "The Limbo", "YMCA" and "Twist" afterwards.

On Sunday a number of our families watched the Detroit Tigers beat the Chicago White Sox at Comerica Park, courtesy of the Negro Foundation. It was a 90+ degree day, but a wonderful way to close out an amazing weekend.

I would like to thank everyone that supported our wonderful weekend event: my loving family for all their love and support; the businesses in the area who made donations; all our volunteers; friends and family members that made financial contributions; Carol Gambotto who captured our weekend memories; Westcott Chiropractic Center who sponsored "Hooper"; the Southgate YMCA who donated gym time; the staff at the Southgate Holiday Inn and everyone else that had a part in making this weekend a tremendous success.

Most of all I would like to thank the IWSA Board, Officers and leaders who donate their time carrying out the mission of the IWSA in an effort to improve the lives of children with WAGR/11p Deletion Syndrome.

by Annie Prusakiewicz
Board Chair/WINGS Editor
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The Princess Palace

Kelsie moved into a brand new, 5-bedroom home on March 1. I was really freaked out. She was thrilled. She waived for about two minutes when I left her there the first night, but she hasn't looked back since. She emails me every day so I feel very connected and aware of what's going on. We have "date night" together every Monday. We go to dinner and grocery shopping, two of her favorite activities. She doesn't need much help at the grocery store. I built her a shopping list in order of the store with check boxes. She uses her debit card to pay, and now her EBT/Food Stamp card too. She thinks she is hot.

The biggest problem was weight gain. Looking back, however, it looks like she was on a gaining trajectory the last two years, so I can't say it was just the house. Took her to the nephrologist to get her numbers checked and she has no damage from the extra weight yet. She's riding an exercise bike and trying to make healthy choices, but it's tough to know if she really has much ability to control it. She's about 130 pounds, maybe 4'9" tall?

They have turnover issues, but it's a small town, so there's a pool that's relatively safe to pull from. They have agreed to keep only girls in the house and only female staff. They have other houses that are mixed and some all boys too. Meal planning for dinners hasn't been the best. I've pushed them to use a nutritionist to develop the menus for all five houses they have in town, but have not made much progress. They've

also struggled with the bills some, but the head staff person that really stunk at it is gone and it seems to be getting better. Kelsie gets \$700 a month from SSI and pays \$250/mo rent and utilities out of that. I didn't have access to her food stamp money until recently, so her SSI was paying groceries too, but that should get better now.

I went a little crazy and decided to remodel my little townhouse. No need to upsize now that the kids are moving on. It's been very demanding and expensive, but very worthwhile. Rockie (16 and driving) moved into Kelsie's former room in the basement and Bryce moved into Rockie's old room, so we all have a lot more space. It's really a new life for all of us.

I wasn't able to bring Kelsie back to my house until pretty recently because of the remodeling/moving/painting, etc. I was very excited to have her come spend the night finally, for Rockie's birthday weekend, including plans to spend the day on the boat. Everything was great, until the boat plans got scrapped due to the rain. She went into an OCD meltdown and started yelling and even hit me. I took her home to her house, grateful to have that option. I'm sad that I probably need to keep our visits to the routines that she loves-dinner & grocery shopping, at least for now.

The truth-which I've always shared with this group-is that I feel guilty, but I feel relief too. The first night I was driving with Rockie and said, "Wow, if we die in a car crash tonight, I don't have to worry about what will happen with Kelsie". We love her dearly, and we will never abandon her, but we've also started to have glimpses of what "our" lives can be too.

Rockie and Bryce are AWESOME siblings, but I'm glad they are getting time without Kelsie and the demands of having her in their lives every day.

So life is good. We are all healthy and happy. And I've apparently achieved the American dream--granite countertops. Looks like cruise control for awhile. Oh, I switched jobs last December, from the Department of Human Services to the Department of Education at the State of Iowa. It's been a good move, leaving a terribly abusive workplace is always a good move. And my sweetheart, Rich, is retiring from DHS next week, so he'll be out of there too.

I went to a workshop for special ed parents last weekend. I'm going to try and communicate with other parents and special educators that Kelsie was able to learn to type with a 40 IQ. I think it's pretty significant that she is able to email me every day. I went to IEP meetings for years and was asked what I wanted Kelsie's life to look like when she was an adult. I had not idea. But if they had asked me, do you want her to be able to email you, go grocery shopping with a debit card, make some spending money in a sheltered workshop a few hours a week, go to a fun "Discovery" day program the rest of the week, and live in a bubble-gum pink room in the Princess Palace, I would have said YES, sign us up for all of that.

Sorry I've been checked out of this group for a YEAR. It's been a transition for me. A very good one. Hope you are all doing well too.

by **Connie Brooks, IA**
(Kelsie WAGR-19; Rockie-16 & Bryce-13)



Tammie, Jeff & Evie Jo Hefty

WAGR Weekend and the Spotting of the Me-too Bird

Birds of a feather flock together~English Proverb

If you take a general science class, or even a more detailed ornithology class, I can guarantee you will never learn about one the most incredible species called the Me-too Bird. One reason you don't learn about the Me-too is that it does not breed the way that other living things breed. The Me-too spontaneously develops only when the situation arises; only when all the specific conditions are met. For this reason, the Me-too is a very rare species; something to be honored and held in high esteem. Another reason one rarely learns about the Me-too is that many people in society have never seen one themselves, and, therefore consider the Me-too to be among the likes of Bigfoot, or the Lock Ness Monster. They believe the Me-too is a legend, a myth, or merely an over-exaggerated figment of one's imagination.

There is, however, one place where you can count on seeing a Me-too population explosion. It occurs typically in the summer months, and has only occurred (in documented

history) on the North American continent. The Me-toos have migrated around the continent, often on the East coast, but this year, the Me-toos rested in Detroit, MI for their annual nesting event.

Named after its recognizable cry, the Me-too sounds sometimes mournful, but more often delighted, and always carries its distinct sound "Me-too, Me-too, Me-too..." Because the Me-toos can only gather for a short period of time, the song of the Me-too often carries on late into the evening, or even the early morning hours...It's as if the Me-toos don't want to miss one minute of their time together for that very special weekend.

As our Evie grows older, it seems like the spotting of the Me-toos becomes more and more important to our family. We have "grown-up" together as parents, adults, and caregivers, and we remember our children from one year to the next ; so much so, that the Me-toos can sometimes get drowned out by the "He's-sobigs" and the "You-mustbe-prouds". For some reason, when we are among the Me-toos, we just feel a little more relaxed, a little more "normal" and a little less overwhelmed by life as we know it.

At the end of the nesting event, the Me-toos are carried off by their families back to all different corners of the globe. There are certainly tears; tears of joy for having had so much fun, tears of exhaustion for trying to fit years of separation from one another into three days, and tears of sadness for not being able to have the Me-toos around us for another year or more. Those same Me-toos are then sustained by different forms of technology like the telephone or the computer. You

see, in order for the Me-toos to escape extinction, they must be fed continuously by the power of the Me-too call...even if the call is written in an e-mail, it is still powerful enough to keep the Me-toos alive.

I don't know where I would be today without the magical Me-too. As a matter of fact, my Me-too is looking a little pale and somewhat starved today. So, let me see what I can do about that. Has anyone else had to put nineteen drops a day into their child's eye??? Me-too! Has anyone else been frustrated when people have said, "Oh your baby looks so sleepy?" Me-too! Has anyone else felt the frustration of trying to schedule coffee with a friend while working around OT, PT, speech and vision appointments? Me-too! Has anyone else ever yelled at their child's nephrologist? Me-too...

by Tammie Hefty, Wisconsin

A Grandma's View

Getting to know those I had just seen and heard about on the internet was worth the trip from Washington! Although Wes has



the start of kidney disease he has not had Wilms' tumor so all of you are my heros. Your trials and triumphs you

have been through have been both heart wrenching and heart enlightening to me.

It was especially wonderful for Wes to get together with some other teenagers like Nicholas, Amy and Alex. Teenage years are not easy for anyone, espe-

cially a child with special needs! Wesley is so loved at his high school and we don't go anywhere that someone doesn't come up and say hi Wes. However it isn't the same as having that special someone to go hang out with.

Thank you Amy, Alex and Nicholas for making his trip so fun. To Shari, Rhonda and Annie who share the everyday challenges that I share I think of you often. I start to tear up just thinking of the hugs, smiles and wonderful conversations with Irma and Caroline. Catherine and Kelly have been my inspiration since I met them eleven years ago when they welcomed me to my first WAGR weekend and forever will stay in my heart. There are many I didn't feel I got to really know but at least now I can put a face to the names I see on the internet. Thanks to all who opened up their hearts and let us in! A big hug and thank you to the Prusakiewicz family for making all this possible by hosting WAGR WEEKEND 2011!

by Grandma Bev Schmer, Washington

Traveling to my First WAGR Weekend

My experience at WAGR Weekend was fun. It was different this year for me because I got to travel instead of our family being the hosts. My mom and I flew from Washington, DC to Detroit, Michigan. Annie P and her family live there and were the hosts and they did an awesome job of planning all the activities that were so much fun.

When I first got to the hotel, the boys were all really happy to see me. Alex, Wes, and Nick were all waiting for me at the pool. Kelly Trout said if she had a penny for everytime they asked, "when is Amy going to get here?" she would be a rich woman! I really liked staying in the hotel and enjoyed having my friend Alex Sena staying down the hall from me because I only get to see him once

a year. The food in the restaurant was very good and it was fun on the day of the board meeting because Alex and I got to eat in the restaurant by ourselves. I thought it was really cool that we got to meet Hooper, the mascot for the Detroit Pistons, on Friday at the Meet and Greet. All of the kids enjoyed that! I also thought it was really fun to all go bowling. It was so cool how the bowling alley was designed and a fun afternoon spending time with everybody. I liked the pool at the hotel too and gave me a chance to spend time with Alex from New Mexico and Wesley from Washington State. I also enjoyed spending time with my two older girlfriends, Irma from New Jersey and Caroline from Texas. Kelly Trout, Caroline's mom, calls us the "triplets"! It is neat to hang out together and talk about what's going on in the world. We all get along really well because we all have the same personalities.

I wish I could travel to WAGR Weekend every year because it is more fun when you travel to see everyone! I hope everyone will come to Maryland again next year for WAGR Weekend!

by Amy Marshall, Maryland
(16 yrs old with WAGR)

"The Triplets"

Irma, Amy and Caroline



Caroline & Kelly

A Few Things I Learned at WW2011

1) "Cosmic Bowling" means that the bowling alley is dark, with fun lights everywhere, and the bowling balls actually glow. Kids with WAGR *LOVE* Cosmic Bowling. Possibly because they're much better at it than their parents.

2) Contrary to what you might think, magic shows are not lost on our kids. Even when they can't see the details of a trick, they're delighted anyway. Must be magic!

3) Grandparents, Aunts, Cousins, Siblings, and Friends who come to WAGR Weekend just don't get it. They don't understand how extraordinary they are. How impossible it is to express how much it means to us that they are there. We hope they'll figure it out eventually, because they're a permanent part of the IWSA family now.

4) Start training for WAGR Weekend early in the year. Put plenty of sleep in the sleep bank so you can make several big withdrawals, exercise your vocal cords so you can talk nonstop, drain your tear ducts so they won't constantly overflow, and build up your abs so they can withstand prolonged laughter. All the work is worth it, though. There's no high like a WAGR Weekend high!

Thanks Annie!

by Kelly Trout, Texas



Mary, Rebecca & Chuck Grayson

OUR FIRST WAGR WEEKEND

Chuck: For me, the most enjoyable and positive experience I had during the WAGR weekend was to meet with the dads and grandfathers. It was really great to be able to share in depth about experiences with our children and the challenges that our children have and what they and we have gone through. It was very helpful to hear the other guys thoughts and feelings also. It helped me to feel like my experience made sense to them and that their experience resonated with mine. I also really liked being able to talk with some of the kids and to have them become interesting and fun real people and not just faces in a photograph.

Mary: What I found most remarkable and moving was that many kids were accompanied not only by parents but by extended family also. Their caring, loving concern was very obvious. Putting the names with the faces of kids and relatives I have only known from the newsletter was great fun although challenging to keep straight. Everyone shares a diagnosis and certain similar circumstances. I learned some useful information and hopefully shared some as well. I was impressed by the commitment of those who work to make the organization successful. Annie and Clem put forth enormous effort to make sure we all had an enjoyable time and along with Nicholas and Ashley were kind and gracious hosts.

Rebecca: To be honest, I would say

the best part of WAGR Weekend was just getting to meet everyone-- all of the kids and young adults who have WAGR and are going through the syndrome. They have many of the same challenges I have. When I met all of them I didn't feel like I'm the only one. I didn't feel alone. What were the other highlights of the weekend? I enjoyed bowling and trying for a strike. Swimming was great. Sitting in the hot tub with a new friend and talking was fun. I especially liked the pizza/ dance party. I'd like to keep in touch through Facebook!*

by **Chuck, Mary and Rebecca Grayson, Michigan**

Our Treasured Weekend Experience

Everyone told me that the first couple of years is the toughest. And they weren't kidding. In the last 19 months I have learned a lot about what's important in life. I have learned many lessons from my son, who has WAGR Syndrome. I have learned to expect things to change. I have learned to practice patience on a new level with my children, and I have learned not to be so patient with those that care for my son. The WAGR email group has been a "sender" of many of those lessons. To read other stories, and to have someone else, whom you

have not ever met, send you a comforting word, or just let you know that they have "been there done that", makes that island of uncertainty seem a little less scary. I never thought that I could experience emotions more powerful than those. I was wrong.

My family and I attended WAGR Weekend 2011. The timing of this weekend came at the end of Noah's chemo protocol and just prior to a couple of surgeries. Leading up to this point, our family had figured out a "system" of juggling work, appointments, therapy and feeding (Noah's biggest obstacle). We, like most families, figure it out as we go along. We start out with a plan, but we've learned that the plan is subject to change at any moment and we need to be prepared for anything.

On this weekend, I was prepared for my son to have a meltdown, or prepared for my daughter to have a tantrum or prepared that we might have to run to the ER. What I was not prepared for was the treasure of emotion and love that I was embraced with from the moment we arrived. On the Mom's night out, I don't know that I said much, but I was so moved by the other stories and other lessons that were shared. Not only listening to the actual words that my fellow Super Moms spoke, but also learning from their actions, their emotions, their tears and their laughter. For the first time in a while I felt like I innately belonged to this group of people. We were magically joined together by our amazing children. I was not an outsider looking in, nor was I in a fishbowl for others to examine. Even though I have never met any of the fellow WAGR families prior, those three days felt like home at heart.

by **Jennifer Gromek, Ohio**



The Gromek family - Jason, Jennifer, Emily, Noah & Grandma Barb



Dolly, John, Colin, Cade & Corinne Carlson

An Awesome Weekend Experience

We are the Carlson family and we attended WAGR Weekend 2011 for the very first time. We have an 11 yr old daughter, Corinne, with two rare disorders: WAGR Syndrome and Dandy-Walker Variant. Corinne has two brothers Colin, 8 years old and Cade, 4 years old who keep us all busy.

We have known Corrine had

WAGR Weekend 2012 Save the Date

The Krantz/Marshall Family will be hosting WAGR Weekend 2012 in Gaithersburg, Maryland, July 20-22, 2012.

Join our families next summer in Maryland for a weekend of fun, camaraderie, and information!

This location is perfect for families wanting to participate in the NIH WAGR Study AND attend WAGR Weekend. The NIH campus is just 15 miles from Gaithersburg, Maryland. Plan your study participation to coincide with WAGR Weekend and meet with our families for some R&R while you obtain information and insight about WAGR Syndrome. For further information, contact Shari Krantz at classicshari@yahoo.com

WAGR Syndrome since she was born but only have been educated through doctor appointments and life experiences. It wasn't until two years ago when I was searching the web for more information about the disease and ran across the International WAGR Syndrome Association website. I

read the entire site and was so excited about all the new information I gathered. I loved the sections about "Guide for Physicians" and "Check List for Parents", I found these two tabs to be very informative.

I often find I'm educating doctors on WAGR and it feels so good to be ahead of things and know what to look for and how to be proactive when other medical challenges happen unexpectedly.

We were only able to attend part of the weekend event but we learned so much and were so impressed. My husband and I left there feeling awesome to have met other families with children like our daughter. We were able to meet families in our area that we can reach out to and make a connection. We look forward to the next weekend and spending more time getting to know other families and sharing information.

Thank you very much for organizing and facilitating the weekend. All your efforts are very appreciated.

John, Dolly, Corinne,
Colin and Cade Carlson,
Michigan



Catherine, Tim & Margaret Hanson

A Welcoming Experience

This was my first visit to WAGR Weekend and I enjoyed it very much. Ever since discovering the group, I have always wanted to go to a WAGR Weekend. Since this past year it was in Michigan it was a great opportunity to visit family in addition to the weekend. At the weekend, I really enjoyed putting faces to names since discovering the website.

The bowling event was especially fun for the children. My husband and I learned a lot, even after 23 years with Sarah. We wish this organization had been around when she was born. Of course, my favorite part was the Mom's night out for the camaraderie and welcoming atmosphere. The Dad's night out was also a favorite of my husband. All in all, a beneficial weekend for anyone who attends, we hope to go again.

by Catherine Hanson, mother of Sarah (WAGR, 23 years old), Texas



Sarah helping Emily and Jaxon



The NIH WAGR/11p Deletion Research Study Team
(left to right): Joan, Tanvee, Emily, Melanie, and Amanda

An Update from the NIH

Greetings from the National Institutes of Health (NIH) in Bethesda, Maryland! We have lots to report since our last update. Sadly, we have said good-bye to Shannon Fuhr, the previous WAGR/11p deletion study coordinator. Shannon has gone back to school to become a physician assistant. Our previous high school volunteers, Jamila Crossman and Matt Tsang, have also moved on to Brown University and Emory University respectively. We wish all of them the best of luck with their studies.

If you attended this year's WAGR Weekend, you may have been introduced to our current NIH team on our video - we hope we can meet you in person at the next WAGR Weekend.

Here's our team: Joan Han, MD is a pediatric endocrinologist who trained at Harvard Medical School, Boston Children's Hospital, Nemours Children's Clinic (Jacksonville, FL), and the NIH. Joan is deeply appreciative that she has had the privilege of studying WAGR/11p Deletion Syndrome for the past five years - every child is so wonderfully

unique and special. Amanda Huey, a recent Williams College graduate, took over coordinating the WAGR/11p Deletion study in May and has enjoyed meeting many new families. Melanie Hicks recently joined our group after graduating from Emory University with a degree in biology and a focus on pre-medical studies. She serves as the research study coordinator for children with other types of rare genetic disorders associated with obesity and neurocognitive deficits.

Finally, Emily Yin and Tanvee Singh are two new high school volunteers, both from Walt Whitman High School in Bethesda, Maryland.

We are happy to report that we are continuing to make good progress on our phenotype-genotype study. Our goal is to learn how each person's particular deletion (genotype) affects the clinical symptoms (phenotype). We now have a total of 37 families who have come to the NIH. In addition, since our last update, two abstracts have been presented at scientific meetings. The first, **"Agenesis of the Olfactory (CN I) and Abducens (CN VI) Nerves in WAGR Syndrome,"**

was presented the American Society of Neuroradiology 49th Annual Meeting in Seattle, Washington in June 2011. This abstract reports that absence or incomplete development of nerves in the brain, specifically nerves associated with smell (CN I) and outward eye gaze (CN VI), is not uncommon in patients with WAGR syndrome. This suggests that the genes on chromosome 11 around the WAGR region are essential for the development of these nerves in the brain. The second, **"Morphologic Alterations in Brain Structure in Patients with WAGR/11p Deletion Syndrome,"** was presented at the Organization for Human Brain Mapping's 17th Annual Meeting in Quebec City, Canada, also in June 2011. This abstract summarizes structural brain differences between patients with WAGR/11p Deletion Syndrome and patients with aniridia. The findings suggest that other genes on chromosome 11 besides PAX6, the gene that causes aniridia, may contribute to brain structure.

We are grateful to everyone who has participated, and we are continuing to enroll patients for the phenotype-genotype study, so please let us know if you are interested in learning more. In addition, we are busy planning a new clinical trial to study the effects of a medication that may replace some of the functions of brain-derived neurotrophic factor (BDNF) in patients who have deletions involving the gene that produces BDNF. We hope to launch in 2012, so please stay tuned!

With many thanks,
The NIH WAGR/11p Deletion Research Study Team



Vanessa & Aydin

Giving Back to the IWSA

by Vanessa Richter
Fundraising Chair

*Life is an echo -- what you
send out comes back.*
- Unknown

In August of 2005, my niece Aydin Duffy came into this world and changed our lives forever. During a very difficult time in our lives, she brought joy, hope and lots of laughter. We all adored Aydin and could not get enough of her infectious laugh. Shortly after her birth, my sister Elizabeth noticed that there was something not quite right about Aydin's eyes. This realization started a long journey filled with appointments, surgeries and chemotherapy treatment leading to a diagnosis of WAGR syndrome for Aydin.

Through this experience, my sister found the IWSA and finally found a place that she felt at home with others who could relate to their experience with WAGR. She called me ecstatic after her first WAGR Weekend and told me that she felt that she finally found friends who understood and could relate to her WAGR journey. She was so happy that Aydin had met so many friends and that they

shared so many amazing experiences with other WAGR families. Hearing her speak, I knew that I wanted to get involved in the organization and help other families that needed to find their "home".

I volunteered last year to be the Fundraising Chair for the IWSA, and have had the pleasure of working with an amazing group of women dedicated to helping others and raise awareness of WAGR Syndrome. We have been working hard on our fundraising efforts and come up with creative ways that we can all get involved with fundraising for an organization that has helped us connect with lifelong friends, raise national and community awareness, and provide resources for those going through this journey.

Call to Action

For the IWSA, fundraising is the only way that we as a non-profit raise money to pay for all of our programs and events. Without fundraising dollars, WAGR Weekend, the WINGS Newsletter and other programs supporting WAGR families would not be possible. During this month, the Fundraising Committee would like to ask you to help us with our Fall Fundraising Drive! **Our goal is to raise \$3,000 dollars by the end of November! With your help we can meet and exceed this goal.**

How You Can Help

If each of us takes part in our fundraising drive then we will be able to meet our goal. The Fundraising Committee has put together a list of ideas that can help you get started. We realize that everyone is busy and we have put together ideas that take just a few moments!

Fundraising Ideas

We have detailed below ideas that you can easily organize that will help educate others about WAGR and fund critical programs that help our families.

Tell Your Story

Why are you a member of the IWSA? Just as I shared my story above, you have a unique story of why you are part of this organization. Write down your story and share it with your family, friends, facebook contacts, coworkers and neighbors. If you ask 20 people for \$5.00 you would have \$100.00 dollars. Did you know that \$100.00 provides lodging for a family to attend WAGR weekend?

Casual Clothes for a Cause

Who doesn't love to wear jeans on Friday? Talk with your company management and coordinate a "Casual Clothes Day for a Cause". Each person who would like to wear casual clothes can donate to the IWSA for a suggested donation for the opportunity to have a dress down day. You can provide information about WAGR and the IWSA and help educate your coworkers about how this organization has affected your life. Your workplace is already dressing casually? Why not coordinate a theme day such as Hawaiian Shirt Day or an 80s Day? For each \$5.00 donation a copy of the WINGS newsletter is distributed to a WAGR family in the US.

Birthday Donation Instead of Gifts

Having a birthday party this year? Ask your family and friends to donate to IWSA rather than a gift. Let your family and friends know that you would prefer to have donations made in your honor. You could expand this idea to anniversaries, weddings or holiday

parties. For each \$25.00 donation a gift can be purchased for a hospitalized child.

Zumba-thon

What could be better than combining exercising and giving back? Work with a local gym to host a Zumba-thon (or any other exercise Yoga, Samba, Salsa, etc.) During the Zumba-thon have instructors take turns leading sessions. Participants can Zumba as little or as much as they want during the event. Each participant donating \$15.00 helps keep our online communication newsletters to our members throughout the world.

Corporate Matching Gifts

Many organizations will match donations that their employees make to not-for-profit organizations. It does not hurt to ask your employer if they have a matching gift program or if they are interested in starting one! If you made a donation of \$25.00 and your company matched that gift you would be making a \$50.00 donation that can provide assistance for families during WAGR weekend.

We hope that one of these ideas inspires you to help us during our fundraising drive and makes it easy for you to take action. We know that with your help we can surpass our fundraising goal and help sustain our programs and services to WAGR families throughout the world. We have an opportunity to give back and educate others about our organization. You are IWSA and together we provide connections, friendships, support and research support for those affected by WAGR.

*"I support the IWSA with annual financial donations because I have always been close to my granddaughter, who has WAGR/11p Deletion Syndrome. Fortunately, Amy and her family have always lived near to my husband and me and we have been involved with her care from the time she was born. Supporting the WAGR group has given us the opportunity to continue to be involved and to help make a difference in Amy and my daughter's lives, as well as other families with WAGR children. I see firsthand how important the group is for providing support, friendship, and information to my daughter and granddaughter. I also have had the pleasure of meeting and getting to know many of the families and am glad my daughter and granddaughter have this wonderful support."
---Cheryl McCullen, Grandmother*

Zoinks! It's a Zumbathon for Zebras!!!

As I was doing my Zumba workout one night on our Wii game system, I started thinking about how fun Zumba is and how fun it would be to do it with friends. Then my brain took a leap onto another train of thought: Could I raise money for a charity while having this kind of fun?

I knew of a gal who is a trainer at a privately owned fitness club in Madison, WI called Pinnacle. Because Pinnacle is not a nation-wide chain, I thought maybe they would be interested in some publicity!

I contacted my acquaintance at Pinnacle and she put me in touch with the Fundraising Fitness Community chair who specifically coordinates fundraising events like the one I dreamed up while doing my workout.

Susan set the wheels in motion and our Zumbathon fundraising event this fall. I can't wait to update you all on the results in our next WINGS Newsletter or Constant Contact E-Communication. Until then, I encourage you all to think up ways you can raise money and have fun at the same time. I guess I can call this event Zumba for Zebras!!!

Tammie Hefty, Wisconsin

A memorial donation was made in memory of: Clara Swayze

IWSA Officers & Members

President - Catherine Luis

Vice President -

Tammie Hefty

Secretary - Julie Dell

Treasurer - Nikki Hoffman

Gift Coordinator - Elizabeth Duffy

Board Chairperson -

Annie Prusakiewicz

Member - Jeff Hefty

Member - Shari Krantz

Member - Rhonda Sena

Member - Kelly Trout



We would like to thank the March of Dimes Southeastern Michigan Chapter, for providing the IWSA a Community Award Grant for 2011. 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.

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.

Casual Clothes for a Cause Day

Once again the Riverview Community School District has chosen to support the IWSA through a C3 Day. It will take place on Friday, December 16, 2011.

The generous staff of the RCSD has donated over \$5,000 over the years to our organization.

You can help make this a national event and raise awareness for WAGR Syndrome.

Ask your work place to support Casual Clothes for the IWSA on December 16th. Employees make a small donation to dress down, wear something black & white (zebras) or think of your own other creative option for this day. It's just in time for the holidays. What a better way to support a much needed cause.

Thank you
Pirates for your continued support. ARGHH!!

by Annie Prusakiewicz

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!**

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



International WAGR Syndrome Association

YES Enclosed is my gift

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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.

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