IWSA

# WINGS

## WAGR Information, News, Gorilla Stories

**International WAGR Syndrome Association**
**P.O. Box 1346 Manassas, VA 20108**
**www.wagr.org**
**Spring/Summer 2007**

## The President's Corner

Dear Families and Friends,

This past year has been very busy for our organization.

Currently we have two research projects underway with open enrollment, please read about them and consider participation. WAGR syndrome is so rare that every person counts in these studies.

A private, very generous donation made it possible for the IWSA to contribute $10,000 to The John T. MacDonald Foundation Center for medical genetics to help fund the first phase of Dr. Fan's research at the University of Miami Leonard Miller School of Medicine.

For those families that have not yet signed into our discussion group we encourage you to do so. It's a great forum to connect with other families and you may just find someone in your area! We are very proud that we began with seven families in 1999 and now have connected with more than 100 families all around the world.

Our website has been renovated and continually being updated. Please take the time to visit and feel free to contact us with ideas suggestions and most importantly photos.

You may be aware of the MedQuest Survey we did back in the 2003 in which 54 families participated. This survey helped establish a database of information and statistics on WAGR syndrome. It was also used as reference in two publications.

Kelly Trout and I will be working on a new survey and everyone will be contacted when we begin this project. Each family will receive a final copy of the MedQuest Survey 2007 when the project is complete.

by: Catherine Luis

## IWSA New Logo

Did you notice something different in the upper left hand corner of the newsletter? Many of you might remember the old Reaching Out Network logo, the one with the people holding hands around the globe.

Well, together with help from board members and officers, a twelfth grade Graphics Arts student from Michigan designed the IWSA's new logo which, incorporates various colors of zebras around the globe.

We are very grateful to this student and appreciate all her efforts.

### On the Inside

## Gorilla Stories

I remember way back in 1988 when my son Ryan was born and there was no information out there on WAGR syndrome. Being a nurse, I scoured the medical journals and read everything I could get my hands on. I remember putting an ad in the "Exceptional Parent" magazine, and after six months, received two letters from parents. I am so grateful for how far we've come. I have learned a lot from sharing of information.

As some of you know, my son Ryan has WAGR syndrome, Chromosome 11p 13.2-14 deletion, bilateral Wilms' tumors at age 14 months, aniridia, etc. He has had many of the same issues as other children with this syndrome. At age 4, he was officially given the diagnosis of mental retardation, autism, ADHD, OCD, and oppositional defiance. It has been a roller coaster of emotions and heartache, yet also of joy in his accomplishments. I remember thinking that he would never learn to talk; yet now he doesn't keep quiet!!

Ryan is now 18 years old, and we are busy doing the steps we have been told are important at this age. First, we consulted a lawyer familiar with special needs planning and guardianship. We finalized our wills, and set up a special needs trust. Ryan is eligible for SSI, but cannot have any assets in his name beyond $2,000. This process took about four months to complete, including setting up a custodial checking account for Ryan in my name. SSI payments can only be direct deposited in this type of account. We also just finalized guardianship for Ryan. Guardianship is recommended since our children cannot advocate for themselves, nor make appropriate decisions, yet are seen as adults in society once they turn 18. Next, we will apply for Medical Assistance. We have been told that MA helps pay for a group home. I don't know if these steps are necessary in all states, yet have been told this is the process in Minnesota. We never had applied for TEFRA, which is an arm of MA before a child turns 18, since the copay is based on parent's income, making our copay quite high. Once 18, there is no copay for the child as it is based on the child's income, not the parent's income. We aren't sure when we will proceed with any group home decisions - not for a while I'm sure. In Minnesota, Ryan can go to school until the age of 21. He will go to a transition program after this final year of high school. He is currently doing a combination school and work program.

I don't know if this helps anyone, but I learned most of this by asking lots of questions, and hope it helps some of you. Ryan has been pretty healthy, however was diagnosed with "Focal Segmental Glomerular Sclerosis" a year and a half ago based on a kidney biopsy. I have been told they don't know exactly what causes it, yet it is likely due to the syndrome and Wilms' occurrence. He had no symptoms of this other than excess protein in the urine. It can show up in the teenage years, yet it is important to recognize it early, so that the proper medication can be given to keep the kidneys less stressed. He is on Enalapril 15mg a day, and his protein amounts have lessened quite a bit. He sees a nephrologist every 6 months. His eye pressures have been elevated, and he has been on eye drops for many years already. He is also on Seroquel and Abilify to help moderate his behavior. The puberty years exacerbated his anxiety and obsessive-compulsive behaviors, and the medication has helped quite a lot. He participates in Special Olympics. If you have not pursued this, I highly recommend it. I never thought that Ryan would enjoy it as much as he does. He loves the bowling, swimming, and track, and recently earned a Silver medal in bowling.

I hope that I can meet you all someday. Maybe WAGR weekend could be in Minnesota some year.

June Kuntze

Ryan,
June,
&
Bob
Kuntze

## Gorilla Stories
### Continued

Gemma is doing really well medically, she attends The Eye Hospital on a regular basis still but is now under the Glaucoma Team who have managed to get her pressures under control (to the point that she's on no eye drops for the first time ever!!) Unfortunately, though Gemma lost all her vision last year in her left eye although it was so gradual she and we didn't even notice. Gemma still attends Oncology for ultrasound scans twice a year and she also attends Endocrinology as she started to go through puberty early. They are giving her Zoladex injections every 3 months to keep this in check.

We have been giving it serious consideration for Gemma to take part in the NIH study. I have asked Gemma if she wants to participate and she is definitely up for it. It would be great to be included in an in depth study all about WAGR and all that it entails. It would also give Gemma the opportunity to have access to other medical avenues that are not available to her in the UK unless there is a specific need for it. Gemma has never had access to Neurology, Cardiology and Imaging studies apart from the abdomen and has never had a lipid check/cholesterol check ever in her life and Gemma is a very large child.

Academically Gemma's very fortunate as she attends a private school for blind and partially sighted children that our Local Education Authority pay for, class sizes are very small and she has an IEP which she follows as well as following the National Curriculum. We are told Gemma is naturally gifted with her mental maths but is a little behind than the average child with other subjects, which we think is fantastic considering her difficulties. Gemma is also hoping I can arrange for her to have horse riding lessons on a Wednesday evening, which means she would have to stay overnight at school. This she is very, very, very excited about (Little Miss Independent).

Fiona Whitby

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## "A Silver Lining"

## Wandering the Desert Together

by: Tammie Hefty

I've often thought about my past and how simple and carefree my life was before the letters W-A-G-R took form and became a word. Yet, as simple as life may have been and as much as I yearn for a simple life, I know that I cannot go back.

Singer/songwriter Sara Groves sums up my dilemma in her song "Painting Pictures of Egypt."

***I've been painting pictures of Egypt,***
***Leaving out what it lacks,***
***The future feels so hard and I want to go back,***
***But the places that used to fit me,***
***Cannot hold the things I've learned,***
***And those roads were closed off to me while my back was turned.***

These lyrics take the story of Moses leading his people through the desert after they fled Egypt and slavery. While they wandered in the desert, they must have been thinking about the life they left behind. Even though they were slaves, they had a life and routine and perhaps even more of the creature comforts than they had while out in the desert. But they were in search of more and had to persevere because after tasting freedom, they had changed too much to go back to the life they once lived.

I feel the same about my life now that I have Evie and know about WAGR syndrome. The life I lived before was full of free time to draw, read, exercise and watch re-runs of Golden Girls. I was in the church choir, had flexibility to pick up extra hours at work, and visited our clinic once a year for my annual appointment. I lived a happy, carefree life.

I look back know and realize that I lived a good life, but it was not a rich life, it was not a tested life. Since learning about WAGR syndrome and the challenges my daughter would face, my heart has been broken more times than I can count. Each time it broke, I experienced the transcending effects of letting others surround me and encourage me. It's almost like I am Alice in Wonderland, and I can't go back through the door I came in through because I've grown so much larger that the doorframe no longer fits me. Although this wonderland can be scary and surreal, I have also met some incredible characters who have helped me along my way.

If it weren't for WAGR I wouldn't know the supporting family from IWSA. If it weren't for WAGR, the Mt. Horeb Relay for Life Community goal would not have been reached in 2006 because Evie would not have had cancer. If it weren't for WAGR, I would not be starting school in the fall to become a Special Education teacher.

While there are times that I feel I am wandering in the desert, I look back at "my Egypt" and see how barren it was, how much passion in lacked. Sara Groves concludes her song with this thought:

***If it comes too quick, we may***
***not appreciate it,***
***Is that the reason behind all***
***this time and sand?***
***If it comes too quick, we may***
***not recognize it,***
***Is that the reason behind all***
***this time and sand?***

I cannot go back to "my Egypt." I will continue to walk up and down the dunes of the desert because I know that I am better for it. I will take the hands of those who walk with me and we will mend our broken hearts together. We know that without pain we would not understand joy, and without sickness we would not understand health. As a group of Gorilla Moms and Gorilla Dads, we have agreed that no one should wander in the desert alone.

***Let's wander together.***

***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.**

# NIH Research Update

Dear Families of the International WAGR Syndrome Association,

On behalf of my assistant, Carolyn Menzie, and myself, I want to extend our deepest appreciation to the IWSA for all the help and support you have given to us for the WAGR Syndrome Research Study at the National Institutes of Health (NIH). We also want to thank the many wonderful families who have volunteered to participate. We are very grateful for all the time and effort you have put into supplying us with precious blood samples and comprehensive medical records. So far, we have enrolled 38 families, and we invite and encourage other families to consider participating as well.

In the first phase of our study, we have been examining the association between deletion of the gene for brain-derived neurotrophic factor and the risk of becoming overweight during childhood. We have interesting preliminary results to be presented at the Pediatric Academic Societies' Annual Meeting in Toronto, Canada on May 7, 2007. After this meeting, we will be permitted to distribute our findings, and we eagerly look forward to sharing them with you.

For the next phase of our study, we are making all the necessary arrangements to conduct comprehensive clinical evaluations at the NIH in Bethesda, Maryland. We apologize that we are experiencing a delay in our projected start date for this phase of the study. We had originally hoped to begin this summer, but unfortunately, it will take several more months before we will be ready. Physicians from many subspecialties are involved with this study, including nephrology, oncology, ophthalmology, neurology, psychiatry, dentistry, cardiology, immunology, physical medicine and rehabilitation, and, of course, endocrinology (that's my area ). Coordinating all of these doctors and making sure that we optimize each patient's visit to the NIH will require extensive and careful planning.

We thank you all again for your tremendous generosity and patience. We hope that together we can all work towards learning new information, which will improve the health care of children and adults with WAGR Syndrome.

Sincerely,

Joan Han, M.D.
(301) 435-7820
hanjo@mail.nih.govi

**Forward newsletter submissions, stories, pictures or ideas to:**
**Annie Prusakiewicz**
**2063 Regina Ave.**
**Lincoln Park, MI**
**48146**
**E-mail:**
**TheMooZoo@aol.com**

# WAGR Weekend 2007

## Comfort Suites - Manassas, VA

http://www.comfortsuitesmanassas.com/
7350 Williamson Blvd.
Manassas, Virginia 20109

703-686-1100 (Reference Group Name: WAGR Group)

***Each family is responsible for making their own room reservations with hotel using telephone number above***

## All Events Will Be Held in Manassas Ballroom

### Friday, July 20, 6-8p.m. - Meet and Greet

Please join us for a light dinner reception. We will be serving sandwiches, other finger foods and beverages.

### Friday, July 20, 9-midnight - Gorilla Moms W(h)ine and Cheese Night

### Saturday, July 21, 10a.m.-3p.m. - Information and Sharing

Please come and participate in an informational and social meeting with plenty of opportunity for questions and answers. There will be presentations in the morning, supervised activities for children and lunch will be provided. *Special Guest: Dr. Joan Han - NIH*

### Saturday, July 21, 6-8p.m. - Pizza Night

Please join us for a casual family event. We will be serving pizza, snacks, beverages and desserts.

### Saturday, July 21, 9p.m.-Midnight - Gorilla Dads Night

**Special Group Rate at Hotel: Only $89 each night**
**This includes deluxe continental breakfast each morning!**

**All meals and events listed above are free!** To confirm number of adults and children in your group and/or to request consideration for travel assistance grant, please contact Kim Pillow Williams at **Towandakim@yahoo.com** or call **703-361-5437.** Priority will be given to families who have never attended a WAGR Weekend.
**Please make reservations with hotel directly.**

# WAGR Syndrome Research Project Dr. Yao-Shan Fan University of Miami School of Medicine

by: Kim Pillow Williams

**A**re you suffering from confusion about our current research projects?

You're not alone. Amazingly, we have TWO major facilities and TWO wonderful research doctors, BOTH fascinated with our kids! Their names? Dr. Han and Dr. Fan. Who's on first?

The answer: They both are!

While Dr. Joan Han is gathering information and samples of our children's blood to be used for a large clinical study at National Institutes of Health (NIH) in Bethesda, Maryland, USA, Dr. Yao-Shan Fan is now beginning to gather samples for his long-term genetic study of WAGR syndrome at University of Miami School of Medicine in Miami, Florida, USA.

In order to be involved in both studies, blood has to be sent to both locations. This can all be done with one blood draw, as long as you have both boxed kits ready to send as soon as your samples are drawn.

Dr. Yao-Shan Fan has recently asked that we speed up our collection for his studies as he is already finding wonderful information from the samples he has received. The first phase of his research is to try to determine why so many children with WAGR syndrome are affected by Autism Spectrum Disorders. Dr. Fan has previously discovered the genetic cause for developmental delay in a group of children who had syndromic features, but no known syndrome. His work is very exciting!

The discovery of a single gene would not provide a complete answer. There will almost certainly be an interaction between several genes, but these early discoveries could be a key step in development for effective treatments in the future. Dr. Fan is hard at work to discover all he can from our children, and for our children.

There have been delays in both Dr. Han's and Dr. Fan's work, as it's never easy to get funding issues, other projects and red tape cleared away to begin a new project that will be such a focus. However, both projects are in full swing now, and here's how to participate in Dr. Fan's research project at University of Miami. Simply call or send an e-mail to Dr. Fan's co-worker saying that you would like to participate:

**Ana Morales, MS**
Genetic Counselor
The Dr. John T. MacDonald Foundation Center for Medical Genetics
Leonard Miller School of Medicine
University of Miami
1601 NW 12th Ave, Rm 5037
Miami, Florida , 33136
Phone: 305-243-3823
Fax: 1-866-390-2482
Email:
amorales4@med.miami.edu
Web Site:
http://medgen.med.miami.edu

Ms. Morales will send you everything you need to participate in Dr. Fan's research. There will be a consent form to sign (one for each blood sample) and a one-page checklist to fill out of your child's conditions associated with WAGR syndrome.

This is just a checklist, but of course you are always welcome to add any other information you feel might be helpful. The kit will also contain laboratory instructions and a prepaid Federal Express form, and you will take this to your child's physician or your local laboratory (wherever you normally have blood drawn) and they will draw a small sample from the child and parent(s) if parents are participating. Ideally, Dr. Fan would like a sample from the child and both parents, but any level of participation is welcomed.

I strongly encourage everyone to participate in both studies. Please do as much as you can individually, because collectively, we are about to move mountains in the world of medical research, for our children and for all those to come, both with WAGR syndrome and with only the individual conditions associated with it. The sun just got a little bit brighter here on Planet WAGR, and we have both of these fine physicians, their teams and our families to thank for it!

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## Parenting Children With Special Needs - Without Losing Your Mind

By Kim Pillow Williams

That got your attention, right? It doesn't matter whether you are parenting your special needs child as a couple, a single parent, a relative newlywed or a blended family, it's stressful, time-consuming and takes its toll. I've done my parenting each of these ways, so with that experience behind me, I'd like to share some things I've learned along the way.

**Parenting as a couple** - Having a child with special needs will either tear you apart or pull you together, creating an unbreakable bond. In some cases, it may do both. Everyone handles stress differently, and that applies to even the most solid couple. It's not unusual for Dad to go to work every day out in "the real world" while Mom stays behind on "Planet Special Needs" coordinating doctor's appointments, therapy sessions, therapeutic recreation, IEP meetings, lab work, support group discussions, plus regular activities for the other children in the family like soccer, PTA, the orthodontist and Tae Kwon Do. She has to get the laundry done, grocery shop, have the oil changed, purchase a birthday gift for her mother-in-law, wrap it, and get it to UPS before they close. Dad comes home and collapses on the sofa, expecting a break, a kiss and a hot meal. Mom sees Dad and collapses into tears, desperate for some assistance with the child who's mid-tantrum and/or dinner that's about to burn into something unrecognizable on the stovetop. He snaps. She snaps. Suddenly they're not looking or feeling much like "the perfect couple."

**Parenting as a single parent** - This is the hardest job you'll ever do. It's difficult enough in "normal" circumstances, but when your child has special needs, there's a whole new level of difficulty. When your child has a fever in the middle of the night and you're out of Tylenol, you have to bundle him up and drag him with you to the all night pharmacy. When he's up all night you have to go to work the next day on twelve minutes of broken sleep. If behavioral issues are a problem, then maybe by the end of the day YOU are the one ready to lie down on the floor kicking and screaming. You depend on your older children far too much and feel guilty for it. You long for the days where you could "run to the market" for something and it didn't require two hours of intensive planning and accommodations for your child's behavior, mobility device, bus schedule, therapy session and in-home counselor. A night out away from it all? Not unless you've waded through the years long Waiver waiting list, have respite services written into your Consumer Service Plan, located a qualified provider and coordinated carefully with a friend who will understand if you get a phone call in the middle of dinner and have to leap up and run out. "Running away from home" ceases to be an activity you only associate with teenagers.

**Parenting as a relative newlywed** - The bloom has fallen off the rose. The dreams of wine, roses and soft music by candlelight have quickly turned into hovering by the crib of your little patient in ICU and being plunged into a world where you don't even understand the language. The medical terms alone are enough to frighten you, and when the early intervention people show up, they've got a whole new set of words you don't understand. They spit them out quickly like you're supposed to be able to keep up. No one offers a glossary, much less an interpreter. As you watch their lips moving, you feel your eyes glaze over as you're nodding because you know your child needs these "services", whatever that involves. You don't have time to shower, much less remember you have a spouse, and while Mom sits at home shell-shocked and trying to function, Dad has gone to work to stare at his computer and try to remember what he's being paid to do while his mind is back home wondering if his child will ever walk, talk, read, or throw a ball.

**Parenting as a blended family** - One of you was placed unwittingly in this situation and the other of you chose to participate. For those who believe no one can love a child as much as their parent, let's review quickly what love is. If it involves being patient and kind, there may be times the stepparent finds this easier than the biological parent. As biological parents, we are preprogrammed to love our children intensely, but with that comes preprogramming to be passionate, intensely disappointed, devastated when something doesn't go "right" and more than devastated when a new diagnosis occurs. The emotion we have for our children can be productive, yes, but it can also be disruptive and even destructive if channeled incorrectly. Sometimes we need to let the stepparent "step" in and help because they are able to be neutral. There are times when that's a huge plus. Events that drive us to tears and emotional turmoil might be handled by the stepparent in a logical, reasonable fashion. They can talk the parent off a ledge and see the whole picture instead of focusing on one event. They are a handy set of ears when the specialist is telling us something new and our head has gone numb with the latest diagnosis.

Okay, that's us. Now explain what you meant about not losing our minds...?

If you're a part of "the perfect couple" the first thing to do is forgive each other for the differences in the way you each cope with stress.. Dad may throw himself into work and Mom might be on the Internet searching for answers every minute she's not reading about the latest techniques, methods, devices and therapies. She's deep in information and Dad is just hoping it will all go away. Mom says "Be careful at the playground. He doesn't like vestibular movement activities. We don't want to create any post-traumatic stress response and trigger the adrenal system into... you know what?... I'll just come along with you...." Dad says "I just wanted to put him on the swings like the other Dads... why is that a problem?"

Dad should respect Mom's concerns and trust that she's not overreacting. She's with the child all day, sees more, might knows a bit more and has invested more in what affects the child's overall condition, in great detail. Mom needs to step back and allow Dad to parent on his own. Sometimes Dads can show Moms just how "normal" our kids can be. While it's true they often learn just how "normal" our kids are not, it's just as likely that the cracker they offer won't choke the child to death, they'll survive the germs at Chuck E. Cheese and they might even enjoy mini-golf even though we were certain they'd use the club as a weapon to strike another child.

Respect each others' need for a break. Support each other even if you don't understand what the other is feeling. Talk about your feelings and never be judgmental. You're a couple and a team. You will have differences in coping and parenting styles. With few exceptions, neither is better or worse or more right or wrong. Spend as much time together as you can without the children. If you can't get a sitter, make time for wine, cheese and a board game after they go to bed. Watch a movie and order Chinese food. Commit to taking a day off once a month to spend the day together while Junior is in school. Go to lunch, go for a walk, visit a flea market or craft show, tour a winery, take a lunch cruise, or just crawl back into bed together with the newspaper, a pot of coffee and a basket of muffins. Remember the things that brought you together as a couple.

Single parents have it the toughest. Their support system must often come from outside of the home. If you have older children, use them, but not too much. Accept help from neighbors, family, the teenager down the street, friends from church, and local social service agencies. Make chunks of time for yourself when you can. Take a day off and soak in a tub, go shopping, make a lunch date with a friend, clean your house if it will make you feel more organized, splurge on a new pair of shoes, work in the garden, sit in the bookstore or library and read in total peace and quiet, get up 30 minutes early or back your child's bedtime up 30 minutes for a little extra time each day to read, organize, meditate or pray. Some parents "barter" with a neighborhood teen. "You have a day in my house away from your parents. Do all the laundry and in between you can watch TV and eat Doritoes. If you clean the kitchen while you're there, I'll give you money to order pizza. Dust and vacuum, it's $10 cash." You'd be amazed how many 15 year old girls will snap up a deal like that and love being able to try what they learned in Home Ec while watching soap operas

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

and MTV for an afternoon. Pamper yourself when you can. Don't feel guilty about indulging occasionally. It'll help you to fill up your own vessel so you won't run dry from constantly pouring yourself out for other people.

The Newlyweds can follow some of the same advice as the "perfect couple." Make a commitment early on that you will remove divorce as an option. For many couples, the stress becomes so great that divorce begins to look like an easy solution because you haven't been married that long and you haven't become but so entwined, right? Wrong. No matter how short a time you've been together, you are bound together by the blood of your child. Divorce won't stop you from having to co-parent your children. It will only make you do it from different locations. Established couples may already understand that, having been through many trials, tribulations and stresses during years of marriage, but when the first real stress you have is the birth of a special needs child, walking away can look pretty tempting. After all, isn't it enough that you have to deal with the child's issues? Now we have to deal with the spouse's issues too?

Respect your spouse if they are plunged into a depression. Encourage them to get professional help if necessary. Don't forget how to be playful. Make time for yourselves. Try to squeeze in as much romance as you can. Remember that if you pull together and get through this stress, it will only strengthen your marriage. Seek counseling services. Join a support group, different ones if possible, so you can each feel free to discuss ALL the aspects of your stress, as a parent and as a partner. Give each other space, but hold hands, stick together, show appreciation for one another and say it all out loud.

For blended and step families just allow for plenty of time together. You're mature newlyweds and you knew what you were getting into better than anyone. Don't give up on romance, but remember that you have to plan it out instead of relying on spontaneity. Biological parents should be open-minded about allowing stepparents a space in the child's life. They've become a part of the team. Have them join you at IEP, medical appointments, school meetings, and include them in everything. You're not doing this alone any longer, so don't try to shoulder it all yourself. It's time to relax and say "Now I've got a partner to support me." Let them handle bedtime routine if they have more patience by the day's end. Teach them medicine/medical procedures so you are replaceable. Appreciate the stepparent for volunteering for this position, even if they do things differently. Children can thrive on having a caretaker with a different approach. This is how they learn to be flexible.

Finally, and most importantly, we are only capable of good quality parenting if we've first taken care of ourselves. This is why, on an airplane, you are instructed to first place the mask over your own face, then assist your child or other passengers. If you have no oxygen, you are of no use to anyone. You will suffocate. First, breathe deeply, take care of yourself, then you will be able to provide the best assistance to your child and others you love. Your family will thank you because you'll be there for them for many years to come.

### Fundraising Ideas:

Bottle & Can drive
Bowling or Golf Outing
School Penny Wars
Bake Sale or Garage Sale
Euchre Tournament/Card Party

Barb DeGregorio, Joy Hoffer &
Olga Tsipras

## "C3" Day a HUGE Success

One Friday every month is designated Casual Clothes for a Cause Day (C3 Day) in the Riverview Community School District. Staff members pay at least $5 to "dress down" or wear jeans on this day. Money raised is donated to preselected charities.

Friday, March 16th was designated International WAGR Syndrome Association day.

The generous staff in the Riverview Community School District raised close to $850 dollars for the IWSA.

**Way to go "Pirates".
Thank you for your
generosity & support!**

Do you have a fundraising idea or opportunity? Maybe your work place would like to host their own C3 day for the IWSA? We would love to hear from you. Please e-mail your ideas to TheMooZoo@aol.com

**Yes**, you <u>CAN</u> make a difference!