



International WAGR Syndrome Association *Annual Report 2008*

Communications

Our newsletter *WINGS* is mailed two times per year, free of charge and can be downloaded from our website.

This is our most powerful tool for reaching anyone interested in learning about WAGR syndrome, our organization and families.

Each issue provides personal stories, pictures, the latest IWSA news and medical information.

<http://www.wagr.org/newsletters.html>

The IWSA website is continually being updated. We recommend individuals visit periodically to keep up with the latest news.

WAGR.org continues to be a great resource for families, physicians, educators and therapists seeking information.

Education

As recommended by our Education Consultant Rhonda Sena, M.Ed. we purchased Wrightslaw Webinar CD's. They are available for our families to check out when needed.

Wrightslaw is the leading website about special education law and advocacy.

Anyone interested in learning more or borrowing the CD's please contact Rhonda at - Casasena5@yahoo.com

Technology

IWSA purchased the QuickBooks online accounting software program to help Treasurer, Jeff Hefty manage our financial business.

MedQuest Survey

Our online survey "*WAGR Syndrome: The Kidney and Urinary Tract*" is currently underway.

This is the first of a series of surveys we plan to execute in the upcoming year. Results will be published on the website.

Our hope is to share the information we gather to stimulate research and interest in WAGR syndrome.

If you are interested in participating in the survey please contact:

Kelly Trout, RN, BSN – Health Consultant – KellyTrout@sbcglobal.net

Catherine Luis – President – CatherineLuis@msn.com

Tammie Hefty- Vice President – Tammiejo@mhtc.net

Recent Research and Publications

International WAGR Syndrome & 11p Deletion Research Study

Phase I is ongoing and Phase II enrollment opened in November 2008.

We are very excited and hope that all our families will consider participating in this research project.

If you have any questions regarding this research project or enrollment please feel free to contact Joan or Kristen.

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Department of Health and Human Services
National Institutes of Health
Eunice Kennedy Shriver National Institute of Child Health and Human
Development

We are grateful to our families for participating in the NIH/NICHD and University of Miami studies.

This year two major articles were published!

New England Journal of Medicine 2008 Aug 28;359(9):918-27.

Brain-Derived Neurotrophic Factor and Obesity in the WAGR Syndrome

Han JC, Liu QR, Jones M, Levinn RL, Menzie CM, Jefferson-George KS, Adler-Wailes DC, Sanford EL, Lacbawan FL, Uhl GR, Rennert OM, Yanovski JA.

Cytogenetic Genome Research 122:181–187 (2008)

Characterization of 11p14-p12 deletion in WAGR syndrome by array CGH for identifying genes contributing to mental retardation and autism

S. Xu , J.C. Han, A. Morales, C.M. Menzie, K. Williams, Y.-S. Fan

Fundraising and Donations

We continue seeking creative ways to fundraise and attract potential donors to support our mission.



The IWSA received a 2008 Community Award of \$1,000 from the March of Dimes Michigan Chapter. This award offset some of the expense for the printing and mailing of our 2008 "WINGS" newsletters.

End of the Year Ask Letter

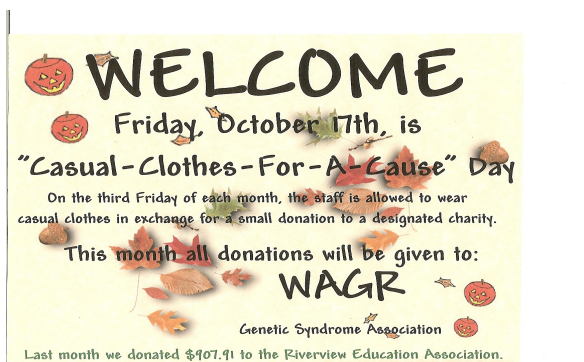
Thanks to our board member Tom Cox for executing our first end of the year letter solicitation for donations. This was a huge success and we plan to do repeat it every year.

Gorilla Giving



Julie Dell, IWSA Secretary & Historian along with family, friends and co-workers collected their spare change and donated more than \$1,800 to IWSA. She presented this generous donation to Annie Prusakiewicz at WAGR Weekend 2008.

C-3 Day – Casual Clothes for the IWSA



Riverview Community School District, MI

Annie Prusakiewicz, - IWSA Chair Person and Wings Editor, united her co-workers in support of our cause.

This is the third year Riverview Community School District in Michigan held a C-3 day for the IWSA.

They have raised almost \$2,400 to date for our organization.

Staff members paid a minimum \$5 to "dress down" or wear jeans on this day.

Spread the word!

United Way



Donations through United Way continue to be a steady source of income. We appreciate all who participate through their employer and hope others will consider this method of donation. Our designation number for EWay participation is **822798**.

iGive.com



Online shopping through iGive.com continues to generate income for IWSA. iGive.com donates a percentage from every sale to our organization. We recommend that before you make on-line purchases, you find the retailer on iGive.com to take advantage of this incredible fundraising opportunity.

GoodSearch



Each internet search raises funds for IWSA. We hope you'll not only use GoodSearch as your main search engine from now on, but will also tell your friends, family and co-workers so they, too, can start using GoodSearch.com to support our organization!

Welcome to:



Taylor, Michigan

Our deepest gratitude to the many donors and sponsors who helped fund a wonderful WAGR Weekend event.

Our yearly event full of fun, food and fellowship was a great success.

Ten families gathered from across the United States and Canada in Taylor, Michigan.

Many thanks to the entire **Ramada Inn** staff for making everyone feel welcomed.

Riverview National Honor Society Students

Rachel M. & Vana K., 9th grade student Brandon D. and mom Audrey volunteered to entertain our children on Saturday morning during the parent round table discussions.

Julie Ames, Riverview High School Math Teacher donated DJ services for our Saturday night family pizza party. Needless to say the music and dancing was a big hit!



Taylor Lanes – Taylor, MI

They provided discounted bowling for all our families to enjoy a wonderful fun filled time at the alleys! It was a fabulous way to spend the afternoon.



The Henry Ford Museum, Dearborn, MI

Provided admission tickets that used by our families.



Sam's Club, Southgate, MI

Thoughtfully donated a gift card to IWSA which was used to purchase WAGR Weekend sweets.



Outback Steak House, Southgate, MI

Also donated a gift card and free appetizer coupons which were placed inside our family welcome bags.



Build-A-Bear Workshop – Saint Louis, MO

Generously donated eight huggable bears for our children. They were a big hit with the children.



False Alarm
Information Tracking Software
www.falsealarmssoftware.com

Frank Farren - WAGR dad - Owner of **False Alarm, Livonia, MI**
Kindly sponsored our Friday Night Meet & Greet.



Shari Krantz - WAGR mom - IWSA Board Member and President of **Classic Auto Body, Inc., Gaithersburg, MD**
Shari kindly provided sponsorship for WAGR Weekend 2008 event.