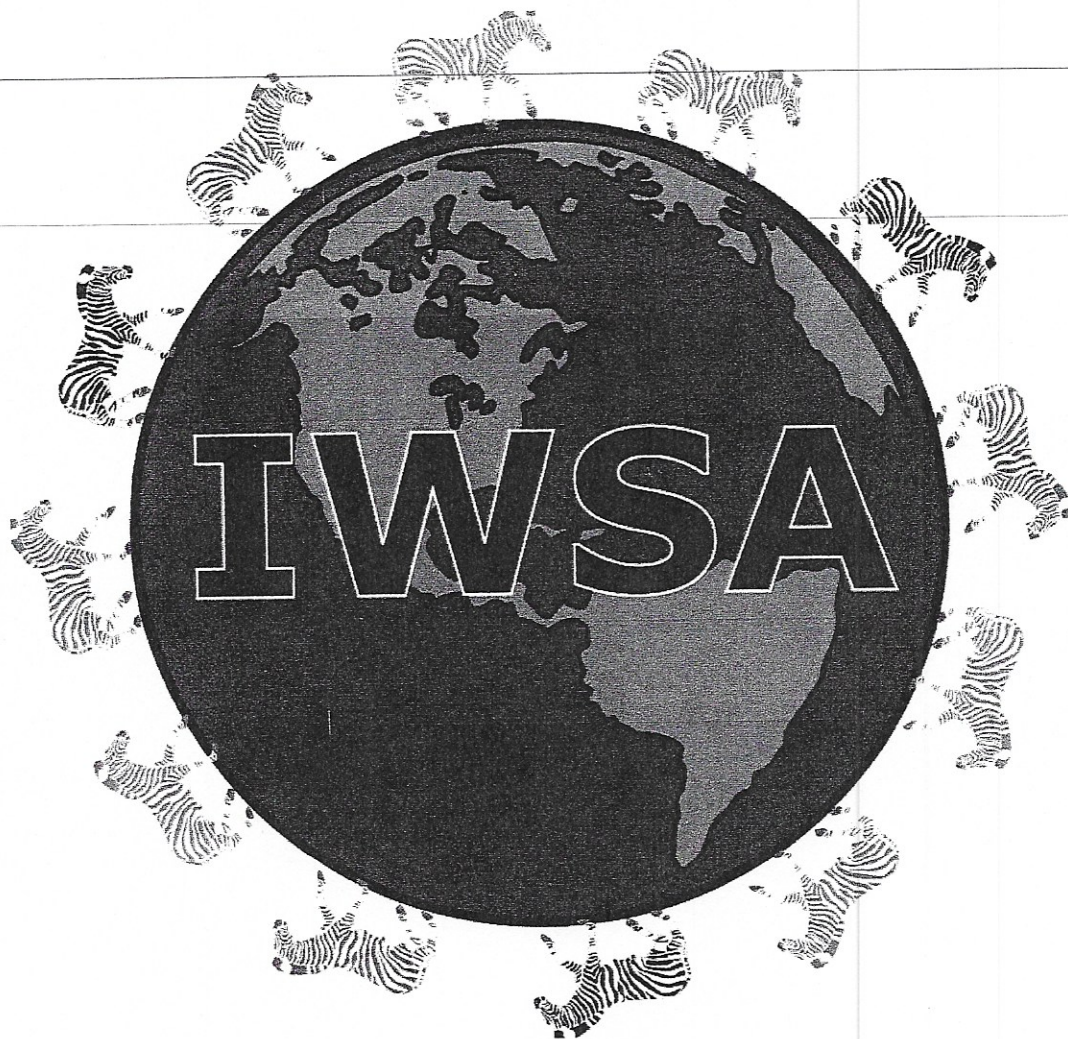


*International WAGR Syndrome
Association*



Annual Report 2007

2007 has been an amazing year for the IWSA in so many ways.

Our WAGR syndrome research projects with Dr. Yao Shan Fan at University of Miami, and Dr. Joan Han of National Institutes of Health have already proven to be valuable in information as well as leading to publications for both principal investigators.

~~Dr. Han presented her findings at the Endocrine Society conference in June and Dr. Fan presented his findings at The American Society of Human Genetics conference in October. Their presentations were well received at both of these conferences.~~

We are grateful for the successful collaboration between NIH and University of Miami.

We had the opportunity to assist in the collaboration of writing information about WAGR syndrome for the National Organization for Rare Disorders (NORD). <http://www.rarediseases.org/>

NORD is a world renowned resource for anyone seeking information about any rare disease or disorder including WAGR syndrome.

We also worked with Dale Halsey Lea, MPH, RN, CGC, FAAN, National Human Genome Research Institute/National Institutes of Health and Dr. Joan Han on a publication Questions & Answers fact sheet on WAGR syndrome. It is now published at Genetic and Rare Disease Information Center aka GARD. (<http://www.genome.gov/10001204>)

A unique situation arose when one of our overseas families needed assistance in getting medical attention for their child. Through the internet we connected with Monica Griesbaum, the founder of Wilms' @ Home. (<http://www.wilmsathome.org.uk/>)

Wilms' @ Home is a European children's cancer charity established in 2004 that works to help children, their families and survivors directly affected by Wilms' Tumor. Monica played an invaluable role in assisting our WAGR family obtain the necessary medical assistance their child needed to ensure his survival. Wilms' @ Home is an excellent resource for our families overseas and we thank them for all their support.

Each summer the International WAGR Syndrome Association, hosts an event we call WAGR Weekend. In the past it has been held in cities like Manassas, Virginia (state of incorporation), Yardley, Pennsylvania and Pigeon Forge, Tennessee.

"WAGR Weekend" is an annual event, which brings together families of children with WAGR syndrome. It's hard to imagine the joy and sense of belonging that a weekend like this gives a family who may feel isolated on a day to day basis. It's a very special event: a wonderful chance for parents to meet and learn from each other, a unique opportunity for the children to see "someone just like me," and a much-needed respite, giving families a chance to renew their strength and spirit. WAGR Weekend is a fun, emotional, joyful, and very memorable experience for everyone. During WAGR weekend our children get to be part of the majority, no longer the minority for one spectacular weekend.

Close to 30 families gathered in Manassas, Virginia in July 2007 for this annual weekend event. Families traveled from all across the United States and Canada to take part in this magical weekend. The IWSA was able to provide financial assistance to families that wanted to attend but due to financial constraints would not have been able to otherwise.

The relationships formed during these annual events are life long and the support between the families gives them the strength they need to return home, implement suggestions from other parents, and be a strong advocate for their child as they access services that they may otherwise have missed. The tears flow at the end of the weekend and everyone vows to return the following year, no matter what it takes to get there. The level of support is unsurpassed by any other source.

We have expanded the organization's web site (www.wagr.org) that continues to provide a wealth of information and resources for any one looking for information on WAGR Syndrome. It has proven to be an excellent portal for families, physicians, teachers and therapists to contact us. Last fall the Physicians Guide published on the web site was also updated.

Our bi-annual newsletter "WINGS" (WAGR Information, News & Gorilla Stories) continues to be the glue that binds our organization. We are thankful for all the financial donations that make it possible for us to continue to print and mail our newsletters for free. The newsletters are mailed to all IWSA members as well as anyone wishing to be on our mailing list.

SurveyMethods.com has donated a two year free subscription as a gift in kind to our organization. This is an online survey software program that enables us to create professional surveys to collect data and analyze data.

The IWSA e-mail discussion group has grown by leaps and bounds this year. We now have over 150 members! This continues to be an excellent support system for individuals or families affected by WAGR syndrome.

Our fundraising opportunities continue to grow. This past year we have added LittleTikes <http://www.wagr.org/iwsalittletikes.html> and Flowerpetal.com <http://www.wagr.org/iwsaflowerpetalcom.html>. A portion of the proceeds from each sale is donated to IWSA. We continue to fundraise through United Way contributions, matching gifts by employee/employer, IWSA logo shop, iGive shopping, Goodsearch search engine & shopping.

International WAGR Syndrome Association
Profit & Loss
 January - December 2007

	Totals	
Income		
Non-Profit Income - Corporate Contributions		284.70
Non-Profit Income - Other Non Profit		934.58
Non-Profit Income - Personal Contributions		6,062.41
Non-Profit Income - Retailer Contributions		136.47
Total Non Profit Income	\$	7,418.16
Total Income	\$	7,418.16
Expenses		
Conference Fees		75.00
Technology - website		438.95
Gifts for Sick Families		261.04
Legal & Professional Fees		225.00
Board Business		68.29
Miscellaneous		15.13
Mailing/Postage		872.60
Organizational Fees		25.00
Rent or Lease		60.00
Stationery & Printing		1,259.72
Newsletter		696.52
Supplies		102.37
Taxes & Licenses		95.00
Travel		137.65
WAGR Weekend Family Assistance Scholarship		1,982.80
WAGR Weekend		7,093.00
Total Expenses	\$	13,408.07
Net Operating Income	\$	5,989.91
Net Income	\$	5,989.91

“The mission of the IWSA is to promote international knowledge and awareness of WAGR syndrome and its complications and treatments, to stimulate research and to reach out to those affected by WAGR syndrome in an effort to improve their lives”

Board of Directors

Anne Marie Prusakiewicz	Chairman of the Board, Co-Founder, “WINGS” Editor
Karen Rose	Co-Founder
Rose Mallon	Co-Founder

Officers

Catherine Luis	President, Co-Founder
Karen Rose	“Acting” Vice President
Tammie Hefty	Secretary
Becky Deas	Treasurer
Julie Dell	Assistant Secretary

Corporate Address:

P.O. Box 392
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www.wagr.org

International WAGR Syndrome Association

Annual Report 2008

Communications

The IWSA website, WAGR.org, is our most powerful and comprehensive tool for reaching anyone interested in learning about WAGR Syndrome and the IWSA. The website is continuously being updated and provides a broad range of information from research, studies and surveys to recent diagnosis to parent, physician and educator information. It also provides helpful information links, instructions on how to donate to IWSA, how to join our online discussion group, and IWSA activities. WAGR.org continues to be a great resource for families, physicians, educators and therapists. We recommend individuals visit periodically to keep up with the latest news.

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

The newsletter is the cornerstone of our organization. It enables us to reach all families for information sharing and staying connected with each other. It's our collective voice and family scrapbook. Each issue provides personal stories, pictures, the latest IWSA news and medical information.

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

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.

Joan Han, MD
WAGR Syndrome Study
Principal Investigator
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Kristen M. Danley, BS
WAGR Syndrome
StudyCoordinator
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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.

**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 repeat it every year.

Gorilla Giving

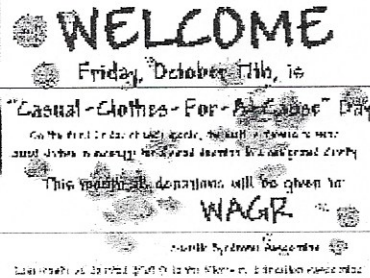


Annie & Julie

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