



Pursuing Our Mission

International WAGR Syndrome Association
Annual Report 2010

International WAGR Syndrome Association
PO Box 392
Allen Park, Michigan, USA
48101

WWW.WAGR.ORG

Year in Review

The Mission of the International WAGR Syndrome Association is to promote international knowledge and awareness of WAGR/11p Deletion Syndrome and its complications and treatments, to stimulate research and to reach out to those affected by WAGR/11p Deletion Syndrome in an effort to improve their lives.

Promoting Knowledge and Awareness

- Participated as Member Organization in International Rare Disease Day, February 28, 2010
- Attended Genetic Alliance Conference on Information Development, March 2010
- Created Facebook and Twitter profiles, IWSA Facebook Cause raised \$1,897
- Our website, WAGR.ORG obtained Seal of Approval from Health on the Net Foundation, and received more than 17,000 “hits”
- Our semi-annual print newsletter, *WINGS*, reached more than 650 individuals, families, physicians, teachers, therapists and donors in 23 countries
- Our monthly online communication, Constant Contact, reached 350 inboxes per month with news, information, and links

Stimulating Research

- Continued partnership with National Institutes of Health WAGR/11p Deletions, and Aniridia Study, Phases I and II
- Attended Conference on Clinical Research for Rare Diseases, September 2010
- Provided assistance for a presentation entitled, “Quality Improvement in Rare Genetic Disease: The Role of Disease Registries in Knowledge Acquisition and Guideline Development,” given by Carol Clericuzio, MD at the Conference of the American College of Medical Genetics, March 2010
- Conducted survey of adults with WAGR/11p Deletion Syndrome in association with Carol Clericuzio, MD

Reaching Out to Those Affected

- Sponsored WAGR Weekend 2010 in Gaithersburg, Maryland, USA
- Produced DVDs of WAGR Weekend presentations
- Maintained Email Discussion Group with nearly 200 members
- Created Lending Library for parents
- IWSA Medical Consultant provided medical information, resources and information to parents and medical professionals
- IWSA Educational Consultant provided support and information for educational issues to parents, teachers and administrators

Fiscal Responsibility

- Became a member of the Guidestar Exchange
- Completed all requirements for “Good Governance and Ethical Practice” issued by the US Panel on the Nonprofit Sector

“A small body of determined spirits, fired by an unquenchable faith in their mission, can alter the course of history.”

Mahatmas Ghandi

OFFICERS AND BOARD
October 2010 – October 2011

Officers

President *Catherine Luis * New Jersey
Vice President *Tammie Hefty * Wisconsin
(President 2009-2010)
Secretary * Julie Dell * Pennsylvania
Treasurer * Jeff Hefty * Wisconsin

Board of Directors

Chairperson *Annie Prusakiewicz * Michigan
Member * Shari Krantz * Maryland
Member/Educational Consultant * Rhonda Sena * New Mexico
Member/Health Consultant * Kelly Trout * Texas
(Chairperson, 2009-2010)

IWSA Gifts Coordinator * Elizabeth Duffy * California
IWSA Leaders Consultant * Nikki Hoffman * Pennsylvania

*****All IWSA Leaders are volunteers*****



Back Row, L-R: Elizabeth Duffy, Rhonda Sena, Annie Prusakiewicz, Catherine Luis, Kelly Trout
Front Row, L-R: Shari Krantz, Jeff Hefty, Tammie Hefty, Julie Dell (not pictured: Nikki Hoffman)

***“Volunteers are not paid, not because they are worthless
- but because they are priceless.”***

Anonymous

1997: Annie Prusakiewicz takes over from June, newsletter becomes "Reaching Out, The WAGR/Aniridia Network"



Annie and Nicholas

1996

1999

Kelly and Caroline



1997

1996: June Kuntze sends out one-page "Aniridia, Chromosome 11p Deletion Support" newsletter

1999: Kelly Trout meets Annie, starts email group with four WAGR families



June, Ryan, and Bob

The History of the

2000

2004



2000: Seven families meet for a "WAGR Weekend," decide to become a support group. Catherine Luis launches www.wagr.org

2002



2004: Membership in the Reaching Out Network reaches 100 families. The RON becomes a nonprofit, the International WAGR Syndrome Association

2002: 29 families in the Reaching Out Network complete MedQuest, a survey of conditions associated with WAGR Syndrome



Catherine and Irma

"What you do today can improve all your tomorrows."
Ralph Marston

2006: Joan Han, MD, begins comprehensive WAGR Syndrome/11p Deletions, and Aniridia Study at the US National Institutes of Health



2005

2008



2005: Data from the MedQuest is included in "WAGR Syndrome: A Clinical Review of 54 Cases" and is published in the journal, Pediatrics

2006

2008: Phase II (clinical evaluations) of the WAGR Syndrome/11p Deletions, and Aniridia Study begins at the NIH

International WAGR Syndrome Association



IWSA families celebrate the 10th Annual WAGR Weekend

*From a one-page newsletter
to a nonprofit organization with 198 families in 23 countries,
our goals have remained the same -*

*Information, Support, And
Hope for the Future!*

*"We must always have old memories, and young hopes."
Arsene Houssaye*

2010 Year End Statement

Income	
Contributions	\$13,777.50
Corporate Contributions	500.00
Grants	<u>1,000.00</u>
Total Income	<u>15,277.50</u>
Expenses	
Promotional - Constant Contact	210.00
Board Meeting	946.69
Conference Fees	100.00
Technology - Acct. Software	253.80
Technology - Website	119.50
Gifts	135.00
Legal & Professional Fees	125.00
Miscellaneous	98.62
Office Expenses	80.59
Mailing/Postage Business	731.45
Rent or Lease	40.00
Stationery & Printing	473.00
Newsletter	1,511.00
Supplies	209.76
Travel - Conference	689.64
WAGR Weekend Expenses	2,320.53
Family Assistance Scholarship	881.95
WAGR Weekend Meals	<u>1,789.81</u>
Total Expenses	<u>10,716.34</u>
Net Income	<u>\$4,561.16</u>



**IWSA has earned the Guidestar Exchange Seal,
and meets all Guidestar standards for nonprofit transparency and accountability**



Update on the WAGR Syndrome, 11p Deletions and Aniridia Study at the National Institutes of Health

IWSA continues to support and be encouraged by this comprehensive study being conducted at the NIH in Bethesda, Maryland. Phase I began in 2006, and to date 64 patients have enrolled. Phase II, which involves clinical evaluations, began in 2008, and to date 33 individuals have visited NIH to participate in this important research project.

While Phase II of the study continues to include a wide variety of tests, a major research focus in 2010 involved examining autism features. According to Joan Han, MD, lead investigator for the study, many patients with WAGR/11p Deletion Syndrome previously diagnosed with autism spectrum disorder did not actually meet observational criteria when evaluated at the NIH by experienced child psychologists using standardized measures.

Dr. Han notes that visual and cognitive impairment, accompanied by concurrent medical illness in early childhood, may have been confounding factors to the proper diagnosis of autism. Despite the overall lower prevalence of actual autism spectrum disorder, researchers did, however, observe that many WAGR/11p Deletion Syndrome patients do exhibit some autism-like symptoms and these symptoms may be more common in those individuals whose genetic deletions include the *BDNF* gene. More studies are underway to confirm these findings, and to better understand the role of *BDNF* in neurocognitive function.

Dr. Han and the NIH research team presented three abstracts of their findings at nationally and internationally-attended conferences in 2010, and while the abstracts show similar results they were presented in different venues to further share the information and findings. Enrollment in the study remains open. Additional information can be found on the IWSA website: www.wagr.org



2010 Fundraisers and Partners

*"Thank You!" to all our generous donors and fundraising families.
You make it all possible!*



Clockwise from top left: Julie Dell presents a check at WAGR Weekend for \$1,775, proceeds from donations and her family's Sub Sandwich Sale. Shari Krantz organized an online flower sale, and raised over \$400. Jeff, Tammie, and Evie Hefty teamed up with the Milwaukee Admirals to raise over \$700. Annie Prusakiewicz and the Riverview Community School District raised \$1100 with "Casual Clothes for a Cause." A generous grant from the March of Dimes Michigan Chapter supported the publication of our newsletter. Donating to IWSA is easy - and free - when you shop online through GoodShop.com and designate IWSA as your charity.

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