

**Fulfilling Our Mission**

**International WAGR Syndrome Association  
Annual Report 2009**





# International WAGR Syndrome Association

## Annual Report 2009



*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.*

### Promoting Knowledge and Awareness

WAGR.org Website

WINGS Newsletter

Email discussion group, Facebook, Constant Contact

### Stimulating Research

National Institutes of Health WAGR syndrome Study

Rare Disease Research Hall of Fame

Rare Disease Day

### Reaching Out to Those Affected

Caring Quilt

WAGR Weekend, UK Aniridia Event

### Fiscal Responsibility

All Volunteer Staff

Fundraising

Year-end statement

## *Promoting Knowledge and Awareness...*

[www.wagr.org](http://www.wagr.org)

The website of the IWSA is a powerful tool for reaching anyone interested in learning about WAGR Syndrome and this organization. The website provides:

- Instant, **worldwide** access
- Continuously updated **information** on diagnosis and treatment
- **Resources** for parents, physicians, educators and researchers
- Instructions on how to join the online discussion group, make donations, and **contact** IWSA board members, officers, medical and educational consultants



*2009 Cost of the website*

*\$ 119.50*

# Promoting Knowledge and Awareness...

## WINGS: WAGR Information, News, and Gorilla Stories

Published semi-annually, the newsletter:

- Is **free of charge**
- Is available **online**
- Is sent to individuals, families, physicians, teachers, and donors in **20 countries**
- Contains
  - Family profiles and personal **stories**
  - **Photos**
  - In-depth **articles** on WAGR Syndrome
  - Updates on **associated conditions**
  - Information on IWSA sponsored **group events**



**2009 Cost of the Newsletter**

**\$1,265**

# Promoting Knowledge and Awareness...



**2009**  
the IWSA launched  
**Constant Contact**

Monthly online news and links delivered right to your inbox and easily forwarded to family and friends!

JOIN US ON  
**facebook**  
CLICK HERE

IWSA Facebook Cause  
"Create Awareness of WAGR Syndrome"  
1,282 Members in 2009  
\$1,210 Raised

# *Stimulating Research...*



## **National Institutes of Health WAGR Syndrome Study**

*2009*

*57 patients enrolled in Phase I*

*22 patients Participated in Phase II*



*Observations from the study so far...*

*Association of BDNF gene deletion with obesity*

*Association of BDNF gene deletion with  
diminished response to pain*

*Association of larger deletion size with shorter  
stature*

*Common differences in jaw structure*

*Pancreatitis with high triglycerides*

## Stimulating Research...



Summary of Results

- Children with WAGR syndrome have short stature that is more pronounced after puberty
- Lower final height is associated with larger deletions, but more data are needed to identify candidate gene(s) for short stature

2009  
Joan C. Han, MD inducted into  
**Rare Disease Research Hall of Fame**



*Dr. Han presents a summary of initial findings from the NIH WAGR Syndrome/11p Deletion Syndrome study at the 2009 WAGR Weekend.*

Dr. Han was nominated for the NORD Rare Disease Research Hall of Fame by the International WAGR Syndrome Association. The Hall of Fame salutes outstanding scientists and researchers around the world for their **commitment, expertise, concern for patients, and passion for excellence.** Dr. Han is the Principal Investigator for the WAGR Syndrome/11p Deletion Syndrome Study at NIH/NICHD. This study is the first ever comprehensive clinical study of individuals with WAGR Syndrome/11p Deletion Syndrome.



**Rare Disease Day**  
28 February 2010

[www.rarediseaseday.org](http://www.rarediseaseday.org)

2009

The IWSA partnered with the National Organization for Rare Disorders and Rare Diseases Europe to promote **Rare Disease Day.**

Rare Disease Day activities help increase awareness of rare disorders and encourage research.

## Reaching Out to Those Affected...



## IWSA Caring Quilt

Far Apart...

But Never Alone

In 2009, the IWSA purchased two small quilts. Beautiful multicolored zebras frolic and sleep on the stars and clouds adorning each quilt.

One quilt is stationed at the National Institutes of Health in Bethesda, MD, USA. This quilt is loaned to each participant in the Phase II NIH WAGR Syndrome Study, to use and enjoy during their stay.

The second quilt is currently traveling the world, spending a week with each WAGR family. Even though we're far apart, this quilt is a warm and sweet reminder of the friendship and caring that binds us all together.

Hospitalizations are common for people with WAGR Syndrome. When someone is hospitalized, the IWSA sends a small gift.

Whether a toy, a stuffed animal, or a basket of cheer, these gifts say

*"We're with you. Hang in there."*

2009 Cost of Gifts

\$351.11



## *Reaching Out to Those Affected...*



### *WAGR Weekend 2009*

*July 10-12*

*Gaithersburg, Maryland*

*Attended by 25 Families*

*From 9 states and 3 countries*

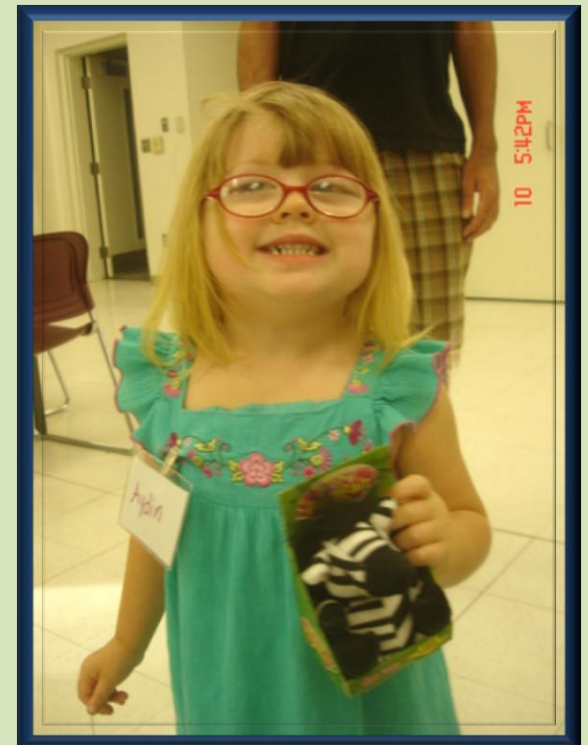
*Cost of WAGR Weekend 2009*

*\$5,145.11*

*Cost of Family Assistance Scholarships*

*\$1,265.00*

*In 2009 IWSA also provided funds for meeting space for WAGR families at the Aniridia Network International Conference, held May 16 in London, England*



# Fiscal Responsibility...



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**IWSA**

**Oct 2009-Oct 2010**

**Officers**

**President \* Tammie Hefty**

**Vice President \* Catherine Luis**

(President, 2008-2009)

**Secretary \* Julie Dell**

**Treasurer \* Jeffrey Hefty**

**Board of Directors**

**Chairperson \* Kelly Trout**

**Member \* Tom Cox**

**Member \* Shari Krantz**

**Member \* Annie Prusakiewicz**

(Chairperson, 2008-2009)

**Member \* Rhonda Sena**

*Did You Know?  
IWSA Officers and Board Members  
are all*

***\*VOLUNTEERS\****

*Cost of Salaries in 2009*

***\$0***



## *Fiscal Responsibility...*

In 2009, Chairperson Annie Prusakiewicz took the lead in initiating a formal Business Plan for the IWSA. With the help of the Detroit Executive Service Corps, a management assistance resource for nonprofit organizations, officers and board members determined short- and long-term goals for the IWSA, defined objectives, steps, costs, and time frames for each. The Business Plan will serve as an effective and ongoing template for managing the organization's programs and funds.



In 2009, the IWSA dramatically increased its fundraising efforts. Despite the weakened economy, these efforts allowed the IWSA to end the year in the black. 2009 fundraising initiatives included:

- **Partnering with Network for Good and iGive.com.**  
Network for Good makes it quick and easy to make online donations, and to learn more about the IWSA and its mission. Online shopping and web searches through iGive.com result in automatic donations to the IWSA.
- **Encouraging IWSA members to hold local fundraising events.** This year, these events included Gorilla Giving jars, special occasion donations (in lieu of gifts), a Sub Sandwich sale, and a home jewelry party.
- **Ask Letter Campaign.** End of year donation letters were sent to previous donors and to every member of the group. Members were encouraged to send these or a personal request to their family and friends. Thanks to the efforts of board members Tom Cox and Shari Krantz and all those who participated, this campaign raised nearly \$2000.

# Fiscal Responsibility...

## 2009 Year End Statement



International WAGR Syndrome Association	
Profit & Loss	
January - December 2009	
	Total
<b>Income</b>	
Non Profit Income	13,411.83
<b>Total Income</b>	<b>\$ 13,411.83</b>
<b>Expenses</b>	
Advertising	
Promotional - Constant Contact	126.00
<b>Total Advertising</b>	<b>\$ 126.00</b>
Bank Charges	45.00
Board of Directors	
Board Meeting	524.20
<b>Total Board of Directors</b>	<b>\$ 524.20</b>
Charitable Contributions	183.47
Conference Fees	175.00
Dues & Subscriptions	
Technology - Acct. Software	253.80
Technology - website	119.50
<b>Total Dues &amp; Subscriptions</b>	<b>\$ 373.30</b>
Gifts	351.42
Legal & Professional Fees	275.00
Miscellaneous	151.41
Office Expenses	15.59
Mailing/Postage Business	782.37
<b>Total Office Expenses</b>	<b>\$ 797.96</b>
PayPal Service Charge	1.95
Rent or Lease	38.00
Stationery & Printing	701.00
Newsletter	1,265.00
<b>Total Stationery &amp; Printing</b>	<b>\$ 1,966.00</b>
Supplies	26.64
WAGR Weekend	1,690.40
Family Assistance Scholarship	1,297.20
Meals	2,157.51
<b>Total WAGR Weekend</b>	<b>\$ 5,145.11</b>
<b>Total Expenses</b>	<b>\$ 10,180.46</b>
<b>Net Operating Income</b>	<b>\$ 3,231.37</b>
<b>Net Income</b>	<b>\$ 3,231.37</b>