Fulfilling Our Mission

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
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
**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
2009
the IWSA launched

**Constant Contact**

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

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WAGR Syndrome is so rare, and we're all over the world. How can we connect?

WAGR @ **Yahoo! Groups**

186 Members in 2009

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**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
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.
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
Cost of WAGR Weekend 2009
$5,145.11

Cost of Family Assistance Scholarships
$1,265.00

WAGR Weekend 2009
July 10-12
Gaithersburg, Maryland
Attended by 25 Families
From 9 states and 3 countries

In 2009 IWSA also provided funds for meeting space for WAGR families at the Aniridia Network International Conference, held May 16 in London, England
IWSA
Oct 2009-Oct 2010

Officers
President * Tammie Hefty
Vice President * Catherine Luis
(Principle, 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...
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.
### 2009 Year End Statement

#### International WAGR Syndrome Association

**Profit & Loss**

**January - December 2009**

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<thead>
<tr>
<th>Description</th>
<th>Total</th>
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<tbody>
<tr>
<td><strong>Income</strong></td>
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<tr>
<td>Non Profit Income</td>
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<td><strong>Total Income</strong></td>
<td>13,411.83</td>
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<tr>
<td><strong>Expenses</strong></td>
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<td>Advertising</td>
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<td>Promotional - Constant Contact</td>
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<td><strong>Total Advertising</strong></td>
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<td>Bank Charges</td>
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<td>Board of Directors</td>
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<td><strong>Total Board of Directors</strong></td>
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<td>Charitable Contributions</td>
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<td>Conference Fees</td>
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<td><strong>Dues &amp; Subscriptions</strong></td>
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<td>Technology - Acct. Software</td>
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<td>Technology - website</td>
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<td><strong>Total Dues &amp; Subscriptions</strong></td>
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<td>Gifts</td>
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<td>Legal &amp; Professional Fees</td>
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<td>Office Expenses</td>
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<td>Mailing/Postage Business</td>
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<td><strong>Total Stationery &amp; Printing</strong></td>
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<td>Supplies</td>
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<td><strong>Total WAGR Weekend</strong></td>
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<td><strong>Total Expenses</strong></td>
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<td><strong>Net Operating Income</strong></td>
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<tr>
<td><strong>Net Income</strong></td>
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