

Pursuing our Mission

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

**PO Box 769
Hanover, PA 17331**

www.WAGR.org

2015 ANNUAL REPORT



**INTERNATIONAL WAGR
SYNDROME ASSOCIATION**

2015 was an exceptional year for the International WAGR Syndrome Association (IWSA). With nearly 300 member families located in 29 countries around the world, we continued to pursue our mission to help WAGR individuals live healthier and more productive lives. In addition to providing support and information to assist families throughout the year, we are pleased to share some highlights from 2015.



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CoRDs/IWSA Patient Registry

The IWSA was selected several years ago by the National Institutes of Health to participate in a new program to develop standardized patient registries for rare diseases. We were honored and excited to be selected from a large pool of applicants to participate in the Global Rare Disease Registry (GRDR) project. IWSA Health Consultant and WAGR parent, Kelly Trout, took the lead and worked tirelessly with the NIH and team of other rare disease organizations to bring the project to fruition. In 2015, we officially launched the IWSA Patient Registry with support from CoRDS (Coordination of Rare Diseases at Sanford). CoRDS is a not-for-profit research institution, whose goal is to connect as many patients and researchers as possible to advance treatments and cures for rare diseases. With a disorder as ultra rare as WAGR/11p deletion syndrome, it is amazing that our families now have the opportunity to participate in our own registry and to ultimately have their loved ones benefit from the data and information that will be analyzed and shared.

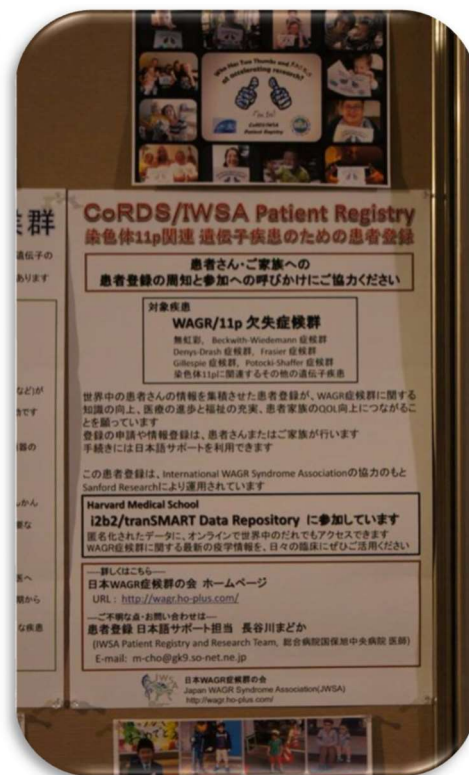
According to Kelly Trout, “Fifteen years ago, there were only 26 WAGR families in the IWSA (known at the time as Reaching Out, The WAGR Network). Doctors knew very little about WAGR syndrome, and no one seemed interested in studying it. So Catherine Luis (another WAGR parent) and I developed a simple questionnaire called “MedQuest”, and all 26 families completed it. The results were extraordinary. They led to the first-ever medical journal review article on WAGR syndrome, and also became the catalyst for a comprehensive study of the disorder at the National Institutes of Health. Today, the IWSA includes nearly 300 families. **With a state-of-the-art Patient Registry, it's so exciting to think of what we can accomplish now.**”



Japanese WAGR Syndrome Association (JWSA)



In 2015 the JWSA continued to expand its efforts to support families of children with WAGR syndrome in Japan. Under the leadership of Masayo Kamimura, President, and Madoka Hasegawa, Vice President, the JWSA won the 2015 "Brilliance of Life; Patient's Association Encouragement" Award. This award was established to support innovative Japanese rare disease patient organizations.



The JWSA also held its Second Annual Meeting in 2015. Five WAGR families from all over Japan traveled to Nagoya for the event. JWSA Leaders who traveled to America to attend WAGR Weekend 2015 in San Diego were able to share their experiences and information at this JWSA meeting.

In 2015 JWSA also made great strides toward enabling Japanese WAGR families to participate in the IWSA Patient Registry. If this effort proves successful, the translation protocol developed by the IWSA Patient Registry Team, Madoka Hasegawa, and CoRDS may become a viable model for other international rare disease patient registries.

JWSA has also made progress in having WAGR syndrome recognized as a "Designated Intractable Disease" by the Japanese government. Achieving this recognition would provide substantial medical, financial, and research support for patients and their families.

WAGR Weekend 2015

WAGR Weekend was held on the West Coast of the United States in San Diego, California in August. The Weekend was hosted by John and Leslie Volk, and Leslie's sister Karen Vaughan, with wonderful support from both of their families. Eighteen WAGR families from all over the US and two families from Japan attended the event. Guest speakers on Saturday morning included Jeffrey Dome, MD, from Children's National Medical Center in Washington, DC, who presented on "Wilms Tumor in WAGR syndrome," and Austin Letcher, a representative from CoRDS, who provided information about the IWSA Patient Registry. Dr Joan Han also joined our families, via Skype, to share updates in her research.



Thanks to local fundraising led by Karen Vaughan, attendees were treated to an afternoon that none of us will forget! The world-famous San Diego Zoo was the destination, complete with a special tour of the zoo just for our group, and a fabulously fun "tree top" meal onsite. Financial assistance for travel was provided to many of the families, and the IWSA was also able to further reduce the financial burden by covering the cost of one hotel night for every family. We are so grateful for the donors and sponsors who made it possible for these families to experience the unique combination of respite and support that is WAGR Weekend!

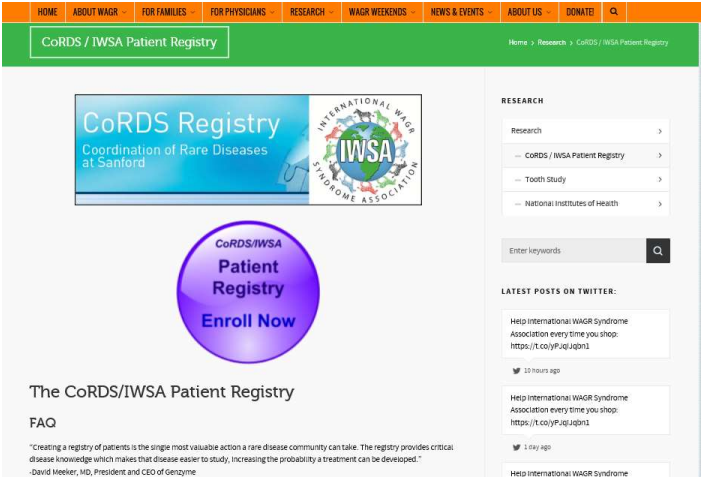
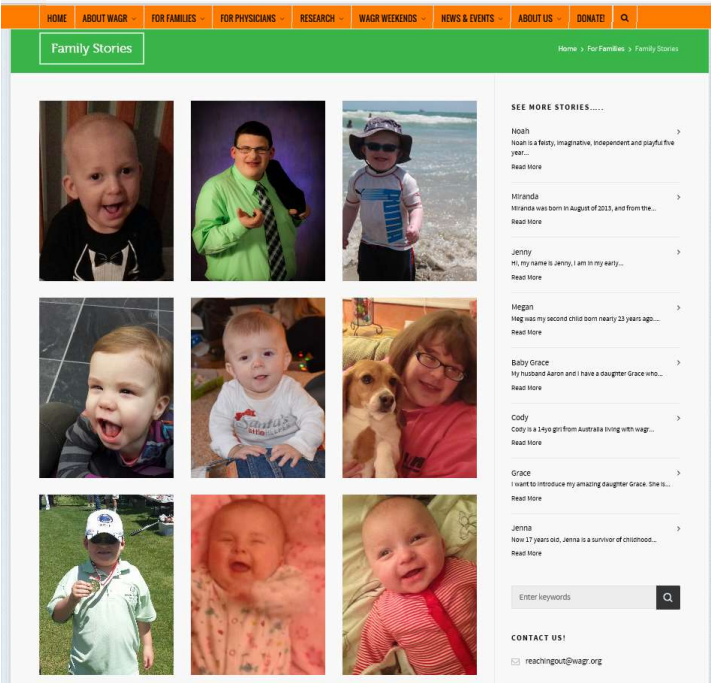


IWSA Website Upgrade

Last year we unveiled our newly designed and updated website, www.wagr.org. The time and energy devoted by our volunteer team, led by former IWSA Vice President Jason Gromek, resulted in a professional, user-friendly website that provides a broad range of information devoted to WAGR syndrome and the IWSA. Information available on the website ranges from family stories and WAGR Weekends to guidance for newly diagnosed families and published information related to WAGR/11p deletion syndrome.



As our organization grows and expands, we realize that maintaining and updating this important tool is a job that is more than one volunteer can manage. We have budgeted funds for 2016 to hire a professional webmaster as an independent contractor, representing the first-ever paid position in the IWSA.



Research Summit

In 2015, the IWSA began partnering with WAGR Warriors, a non-profit organization created by Adam and Jenny Gunckle and members of their extended family. The Gunckles have a young child with WAGR syndrome, and their organization will focus on promoting and sponsoring research. The first goal of the IWSA/WAGR Warriors collaboration is to raise funds necessary to host a Research Summit on Wilms tumor in WAGR syndrome.



More than 50% of children with WAGR syndrome develop this form of cancer before their third birthdays. Little is known about their risk for recurrence, or for long-term complications from treatment. Despite this, there has been no specific research on this tumor in children with our disorder.



The Research Summit will bring together a team of international experts to identify and prioritize the types of studies needed, and to begin the process of conducting them. Anticipated cost of the Research Summit is \$50,000. To date, WAGR Warriors has raised most of this amount, and additional fundraising efforts by both WAGR Warriors and the IWSA are planned to reach this goal.

Award Winning Electronic Newsletter



We significantly reduced the cost of producing and mailing the newsletter by going electronic. In 2015, It was a Constant Contact "ALL STAR" award winner, an award given to only 10 percent of nonprofit organization newsletters.

In 2015 our previously printed and mailed newsletter was replaced with an electronic version named the "WAGR Warrior". Under the direction of former IWSA President Tammie Hefty, the newsletter was completely redesigned and now reaches nearly 350 people per issue--including IWSA families and friends, educators, medical personnel, and others interested in our rare disease.

The WAGR Warrior

November 2015



Prepare for #GivingTuesday As we Give Thanks and Give Back

In this edition of *The WAGR Warrior* we reveal the winner of the iPad in our CoRDS/IWSA Patient Registry Contest, plus we give you some great holiday gift ideas for children with sensory issues or visual impairment. You'll learn more about what the IWSA continues to do in Japan, and we'll share some exciting news about how YOU can be a vital part of the message and the mission of the International WAGR Syndrome Association with #GivingTuesday. Grab a cup of tea or coffee, put your feet up, and enjoy!

SAVE THE DATE



#GIVINGTUESDAY

DECEMBER 1

Donate Now...

Visit Our Website

#GivingTuesday

We are excited to announce that on December 1, following Black Friday and Cyber Monday, the



The Mission of the IWSA is to promote international knowledge and awareness of WAGR(1p) Deletion syndrome and its complications and treatments, to stimulate research and to reach out those affected by WAGR syndrome in an effort to improve their lives.

The IWSA has been supporting and connecting families with WAGR syndrome for over 15 years, and consists of more than 225 families from 27 countries.

Connecting families: This year the IWSA provided more financial assistance for families to attend its annual WAGR Weekend gathering than any other year before: \$17,600.

WAGR Weekend has no registration fees, and the cost of meals, activities, and meeting space during the weekend is funded by the IWSA. In 2015, with family financial assistance included, WAGR Weekend costs totaled \$42,000.



Stimulating Research: CoRDS/IWSA Patient Registry

The first ever registry of patients with WAGR syndrome launched January 1, 2015. Thanks to Sanford CoRDS, the cost of keeping this data does not fall on the IWSA. We are so thankful for the support of Sanford CoRDS and for the families who are



Promoting International Knowledge and Awareness: Our Newsletter

The WAGR Warrior is the IWSA's electronic newsletter, which reaches over 330 people per month. This year *The WAGR Warrior* won the



Promoting International Knowledge and Awareness: Rare Disease Day

Thanks to social networking like Twitter and Facebook, the IWSA enjoys connecting on days like Rare Disease Day to celebrate people living with rare diseases like WAGR

The WAGR Warrior

October 2015



An Especially "Giving" Edition Just in time for your holiday shopping!

In this edition of *The WAGR Warrior*, you'll learn about some of the opportunities we have to GIVE BACK to the IWSA: easy things like raising money when you search on-line or shop on-line. You'll also find another family's story from WAGR Weekend 2015, and you'll learn how our families in Japan are making a tremendous difference in the lives of people living with WAGR. Don't scroll too fast, or you might miss out!

Visit Our Website

Raise \$\$\$ for the IWSA just by searching the web!

Did you know that you can use a powerful search engine called **Goodsearch** and raise money for the IWSA every time you make a new search? All you have to do is visit www.goodsearch.com to get started. Or, if you want to just immediately identify the International WAGR Syndrome Association as your charity to support, then, just click **HERE** and type in the full name of the organization. Each original search will earn a PENNY for the IWSA. If you search the internet as much as I do, that adds up FAST!



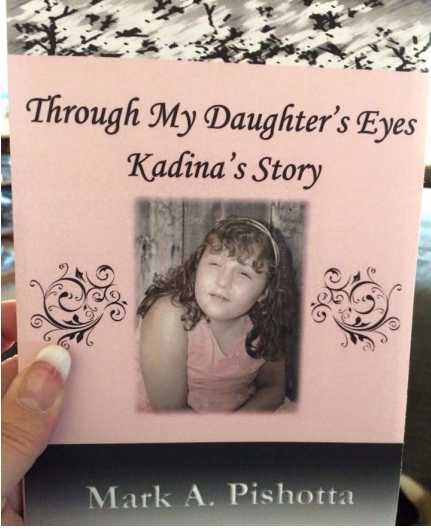
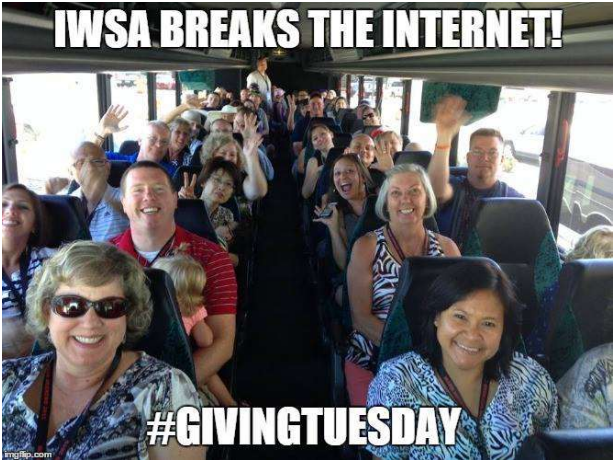
Happy searching!

IWSA Supported by Fundraising Efforts

We are strong but mighty! The IWSA depends on the generosity of others to carry out our mission. Many IWSA families conduct their own fundraising activities during the year, ranging from t-shirt and lemonade stand sales to golf outings and casino nights. During 2015, our families raised more than \$18,000 on behalf of the IWSA. The remaining donated funds of nearly \$20,000 are a combination of memorial and personal contributions, and corporate and foundation donations, including monies from the WAGR Warriors and the Saul and Theresa Esman Foundation.



The IWSA is committed to excellence in stewardship of the monies so diligently raised and generously donated to our mission. In 2015, our dedication to fiscal responsibility and transparency resulted in achievement of the Guidestar Exchange Gold Participant Award, the highest possible rating from one of America's leading reviewers of charitable organizations.



Appendix A: IWSA Leadership Team

The formal IWSA leadership group consists of two groups of volunteers: the Officers/Leaders and the Board of Directors. Both groups are elected to serve specific terms and provide all leadership services and activities on a volunteer basis

Board

Shari Krantz, Board Chair

Kelly Trout, Board Co-Chair and Health Consultant

Tom Cox, Board Member

Jeffrey Hefty, Board Member

Rhonda Sena, Board Member and Education Consultant

IWSA Registry Team

Kelly Trout

Shari Krantz

Terri Whisenhunt

Jenny Gunckle

Madoka Hasegawa (JWSA)

Officers/Leaders

Jennifer Gromek, Vice President

Jason Gromek, Vice President

Nikki Hoffman, Treasurer

Tammie Hefty, Social Media Director and Newsletter Editor

Appendix B: 2015 Income Statement

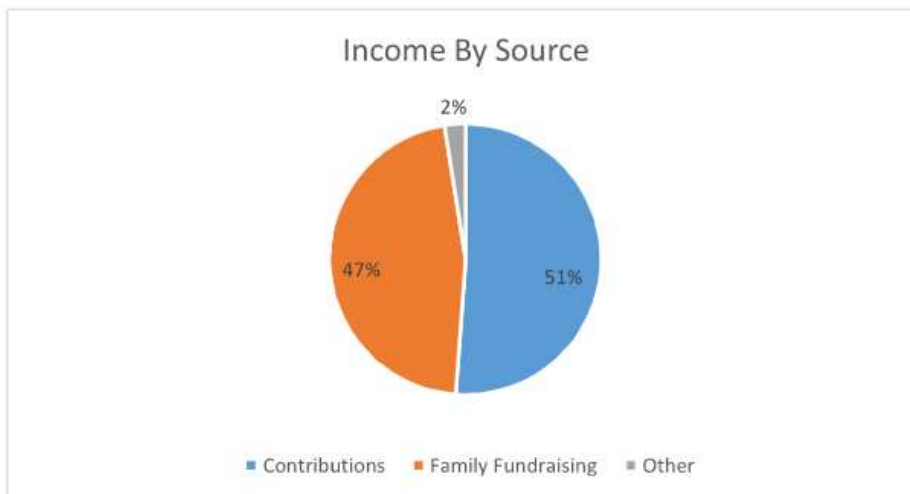
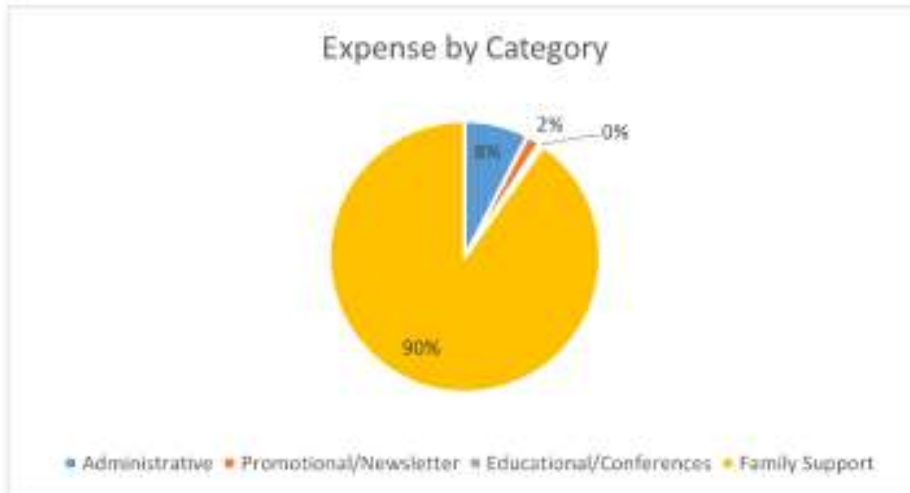
International WAGR Syndrome Association
Profit and Loss
January - December 2015

	TOTAL
Income	
Contributions	
Corporate Contributions	\$ 560.00
Esman Foundation	5,000.00
Grants	100.00
Memorial Contributions	5,690.00
Personal Contributions	3,548.00
WAGR Warrior Donations	5,000.00
Total Contributions	19,898.00
Fundraising Income	
Adalynn Davis Family Fundraising	444.00
Casual Clothes for a Cause Day	833.05
Duffy/Morris Family Fundraising	4,630.71
Give Rare Campaign	4,200.11
Book Sale Proceeds - Mark Pishotta	220.00
T-shirt Sales	798.74
Volk Family Fundraising	6,954.84
Total Fundraising Income	18,081.45
Total Income	37,979.45
Expenses	
Administrative Expenses	
Bank Charges	1.95
Computer Expenses	1,389.63
Foreign Transaction Fees	12.91
Technology - Acct. Software	317.40
Insurance	1,299.00
Leaders Group Meetings	163.24
Legal & Professional Fees	125.00
Mailing/Postage Business	80.70
Meeting Meals	134.21
Organizational Fees	25.00
PayPal Service Charge	102.64
Supplies	4.71
Total Administrative Expenses	3,656.39
Promotion/Newsletter Expenses	
Promotional - Constant Contact	232.65
Technology - website	551.90
Total Promotion/Newsletter Expenses	784.55
Education and Conference Expenses	
Associations and Memberships	50.00
Travel - Conference	189.00
Total Education and Conference Expenses	239.00
Family Support Expenses	
Gifts	759.78
WAGR Weekend - Misc Expense	9,532.33
WAGR Weekend - Family Assistance Scholarship	18,741.40
WAGR Weekend - Meals	13,843.94
UK WAGR Weekend	189.76
Total Family Support Expenses	43,067.21
Total Expenses	47,747.15
Net Operating Loss	(9,767.70)
Other Income	
Interest Earned	30.42
Miscellaneous Income	920.32
Total Other Income	950.74
Net Loss	\$ (8,816.96)

Appendix B (Cont.): 2015 Income Statement

International WAGR Syndrome Association
Profit and Loss
January - December 2015

Income	
Contributions	\$ 19,898.00
Family Fundraising	18,081.45
Other	950.74
	38,930.19
Expenses	
Administrative	3,656.39
Promotional/Newsletter	784.55
Educational/Conferences	239.00
Family Support	43,067.21
	47,747.15
Net loss	\$ (8,816.96)¹



¹ The negative income during 2015 was due to anticipated higher costs incurred at WAGR Weekend held in San Diego. Positive income in prior years allowed the IWSA to absorb those increased costs and still maintain a healthy fund balance for expenses in future years.

Can't Wait to See What We Can Do in 2016!!

