

International WAGR Syndrome Association



IWSA is a non profit,
501(c) (3) organization.
Tax ID# 20-1947169

All donations are tax deductible.

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.

**IWSA
P.O. Box 392
Allen Park, MI 48101
www.wagr.org**

WAGR Syndrome is a rare genetic disorder caused by a chromosomal deletion at 11p13. It is sometimes called "11p Deletion Syndrome."

With good medical care, early intervention, and the support of family and friends, people with WAGR Syndrome can lead full, happy, and productive lives.

It is important to remember that a given individual with WAGR Syndrome may or may not have or develop all of the conditions listed.

WAGR is an acronym, which stands for the following:

W—Wilms' Tumor
(malignant tumor(s) of the kidney)

A—Aniridia (absence of the iris, colored part of the eye causing a wide range of visual impairments including blindness, glaucoma, low vision, and sensitivity to light)

G—Genitourinary
abnormalities

R—Intellectual Disability or
Developmental/Cognitive delays

Individuals, families, and caregivers are encouraged to join our international online discussion group.

<http://health.groups.yahoo.com/group/WAGR/>

The opportunity for our families to communicate with one other is invaluable. With more than 150 members in 22 countries around the world, there is always someone available to provide support and information.

"...had the pleasure of attending a WAGR Weekend, which words cannot do justice to. I always know there will be someone to receive my e-mail and join in my sorrow or joy. My WAGR family never lets me down. I know I'm never alone. No matter how far apart we are, we are never forgotten." — Vicky, Kent, UK

"At two months, we got a diagnosis of WAGR...there were no families to talk to...no experience or firsthand knowledge...no one to speak for our child. Those dedicated to giving all of this to others have made it possible for IWSA to exist. Words will never tell you what is in my heart." — Grandma B, Washington, US

"When my daughter was diagnosed with Wilms' Tumor, I was able to call one of our tenured moms and find out right away what types of questions to ask the doctors. I felt empowered, comforted, and well-informed because of our group." — Tammie, Wisconsin, US

"Our doctor referred us to IWSA when my daughter was diagnosed with WAGR Syndrome at 11 years. I became part of this wonderful group and was relieved to find I was no longer alone. I have received overwhelming personal and medical support and information." — Shari, Maryland, US

Donations and Community Awards help fund the following:

- Our free "WINGS" newsletter (published twice yearly)
- Website
- Gifts to hospitalized children
- General operating expenses
- Annual WAGR Weekend family event
- The promotion of medical research

Our website includes information for parents, guidelines and resources for physicians and educators, as well as information about ongoing research projects.

For more information about the IWSA, to print a copy of our newsletter, get information about our annual event, make a donation or learn how you can help, please visit our website at www.wagr.org

Through research, support and the sharing of information our hope is to improve the quality of life for individuals with WAGR Syndrome.