

## OVERVIEW

The purpose of this Strategic Plan is to address the goals and objectives of the International WAGR Syndrome Association, to ensure a solid infrastructure, quality programming and services, and effective marketing and fundraising strategies.

The goals and objectives outlined in this Strategic Plan will help to ensure that the mission of the International WAGR Syndrome Association remains clear and focused, and that our vision for the future becomes a reality.

### ABBREVIATIONS USED IN THIS DOCUMENT

GA - IWSA Global Alliance

IWSA - International WAGR Syndrome Association

JWSA - Japan WAGR Syndrome Association

MSAB – Medical and Scientific Advisory Board

NIH – National Institutes of Health

WAGR - Wilms tumor, Aniridia, Genitourinary abnormalities, Range of developmental delays

WW - WAGR Weekend

COE-Center of Excellence

RDI-Rare Disease Institute

CNMC-Children’s National Medical Center

### REVISION HISTORY

<b>Date Submitted</b>	<b>Version #</b>	<b>Author(s)</b>	<b>Board Approval / Notes</b>
10/15/2020	1	S. Krantz K. Trout J. Morris	Draft
11/19/2020	2	S. Krantz K. Trout J. Morris	Revisions, to Board for review
11/23/2020	3	Board	Approved

## TABLE OF CONTENTS

### Organization Overview

History of Organization .....	3
Mission .....	6
Vision .....	6
Values .....	6
Stakeholders .....	6
IWSA Team .....	7
SWOT Analysis .....	8

### Programs and Goals

Strategic Goals Summary .....	9
Evaluation and Management .....	11

### Appendices

Appendix #1: IWSA Initiative Analysis .....	12
Appendix #2: Future Initiatives .....	13

## HISTORY OF ORGANIZATION

Prior to the late 1990s, support for WAGR Syndrome did not exist. Then, in **1997**, the mother of a child with WAGR syndrome started a single page newsletter for families affected by aniridia. Soon after, a mother in Michigan expanded the newsletter and called it “Reaching Out, The WAGR/Aniridia Network.”

In **1999**, a handful of families created an email discussion group, leading to the first in-person gathering. Dubbed “**WAGR Weekend**,” it brought together seven families from the US and Canada in the summer of **2000**.

A website and Facebook pages soon followed, and the group began to grow. The newsletter, originally printed and mailed, became digital. In **2004**, the families applied for US 501(c)(3) nonprofit status, and the **International WAGR Syndrome Association (IWSA)** was born.

One of the IWSA’s first efforts was the “MedQuest,” a questionnaire that attempted to establish a more accurate characterization of the features of WAGR syndrome. This simple survey led to the first-ever review of the disorder in a medical journal. “**WAGR syndrome: a clinical review of 54 cases**” was published in the journal *Pediatrics* in **2005**.

Publication of the review article generated interest in the research community, and from **2006-2014** the **National Institutes of Health (NIH)** conducted a study of WAGR syndrome. This research resulted in a variety of important clinical findings and numerous publications, including a seminal article on the BDNF gene in the *New England Journal of Medicine*.

In **2012**, the IWSA was selected to participate in the NIH Global Rare Diseases Registry and Data Repository (GRDR) project. This project enabled the IWSA to build an online **WAGR Syndrome Patient Registry**, which launched in **2015**.

In late **2017**, a leadership retreat was held to create a roadmap for the future of the organization. As a result, the IWSA hired its **first Executive Director**, and began the process of expanding its Board of Directors and increasing and developing its base of volunteers. In this same year, the **first ever WAGR Awareness Day (WAD)** took place on November 13.

#### 2018

- Hosted the PCORI-funded “Conference on Wilms Tumor in WAGR Syndrome,” attended by 17 researchers and 11 parents
- Began planning a WAGR Syndrome Center of Excellence Clinic at the Rare Disease Institute, Children’s National Hospital, Washington, DC
- IWSA representatives of the IWSA attended the 4th European Aniridia Conference in Paris, France and hosted a meeting of leaders of European Aniridia patient organizations
- IWSA delegation met with researchers and clinicians at the Prinses Maxima Centrum for Pediatric Oncology, Netherlands. One member of this delegation later joined the Board of Directors
- Created a CRM-type database with Bloomerang to manage contact information, donations and donors, and organizational communications to all stakeholders
- WAGR Weekend conferences were held in North America, Europe, and Asia

#### 2019

- Celebrated 3rd annual WAGR Awareness Day and raised \$14,700 with 367 donors
- Created a Strategic Research Plan
- Translated one-page information sheets into 12 languages
- Launched the New Family Welcome project
- Appointed first-ever international Board member
- Created an Emeritus Board
- Joined EURORDIS, the European Organization for Rare Diseases
- Sent a team to attend the Global Genes Summit
- IWSA representatives returned to the Prinses Maxima Centrum for Pediatric Oncology, Netherlands, and met with clinicians and researchers at Great Ormond Street Hospital, London, UK
- IWSA representatives attended the 2019 John F. Anderson Symposium: “Aniridia-PAX6 and Beyond” at the University of Virginia, Charlottesville
- WAGR Weekend conferences held on three continents
- Continued work on the WAGR Syndrome Center of Excellence Clinic at the Rare Disease Institute, Children’s National Hospital, Washington, DC

#### 2020

- Celebrated 4th annual WAGR Awareness Day, raising \$15,388 with 303 donors
- IWSA representatives met with researchers at MD Anderson Cancer Center, Houston, Texas to support the project, “Chemo-Preventive Agent for Wilms Tumor in Children with WAGR Syndrome”
- Executed Memorandum of Understanding with Miranda’s Mission
- Began collaborating with researchers and Aniridia-related patient groups to facilitate creation of an umbrella organization to be called Aniridia North America
- Began collaborating with the Very Rare Cancer Consortium of the New York Genome Center on a project involving Wilms tumor in adults
- Began collaborating with Jenn Kalish, MD, Children’s Hospital of Philadelphia on publishing data from the WAGR Syndrome Patient Registry
- Continued collaboration with the Inter-regional Support Center for Patients with Aniridia, Russia
- Conducted a video-based campaign to increase enrollment in the WAGR Syndrome Patient Registry
- Redesigned and launched the WAGR.org website
- Served more than 206 families in 42 countries, and networks with more than 30 Aniridia and related-disorder organizations around the world
- Due to COVID19 - Converted WAGR Weekend Conference from in-person events to a single virtual event via Zoom, attended by 167 registrants from 25 countries

## ORGANIZATION PURPOSE

### MISSION

To promote awareness, stimulate research, and support families affected by WAGR syndrome.  
*Adopted October 2017.*

### VISION

To be the world's respected source of help, hope, and information for those touched by WAGR syndrome.  
*Adopted April 2018.*

### VALUES

Our values: Respect and Compassion. Ethics, Trust, and Transparency. Stewardship and Fiscal Responsibility. Commitment to Learning, Collaboration, Innovation, Research and Privacy. Membership and access to information and support will always remain free.  
*Adopted May 2018.*

### STAKEHOLDERS

Our stakeholders include:

- Individuals diagnosed with WAGR syndrome and their families, friends, and caregivers
- Physicians and allied health professionals
- Researchers
- Therapists
- Teachers
- WAGR syndrome-related foundations and nonprofit organizations
- Individuals with aniridia and related disorders and their associated support organizations



## IWSA TEAM

### BOARD OF DIRECTORS

Kelly Trout, Chair (Texas)

John Morris, Secretary (Pennsylvania)

Tom Cox (North Carolina)

Nikki Hoffman, Treasurer, financial and nonprofit advisor (Pennsylvania)

Jenny Gunckle (Michigan)

Cathryne Cansler (Michigan)

Linda van de Sande (Belgium)

### EMERITUS BOARD

Rhonda Sena (New Mexico)

### STAFF

Shari Krantz, Executive Director (Maryland)

### VOLUNTEER TEAM LEADS

Beth Morris, Communications and Marketing (Pennsylvania)

Cathryne Cansler, Fundraising (Michigan)

Kelly Trout, Research and Medical Advocacy (Texas)

Linda van de Sande, European Representative (Belgium)

## SWOT ANALYSIS FOR IWSA

### STRENGTHS

- The only global organization focused solely on WAGR syndrome
- As primary source of information and support for WAGR syndrome, IWSA can:
  - Lead in elevating awareness of the disorder
  - Stimulate interest and facilitate participation in research
  - Lead in connecting stakeholders to each other
  - Empower, train, and develop new organization leadership
- Organization leadership includes individuals with diverse backgrounds including medical, legal, financial, business management, educational, and marketing expertise
- Involved in multiple rare disease umbrella organizations, including NORD, Global Genes, Eurordis
  - These organizations provide resources for rare disease NPOs and training on research collaboration, working with regulatory agencies, and maximizing funding opportunities
  - Membership in these organizations extends the reach of the IWSA by providing opportunities to learn from, contribute to, and collaborate with other stakeholders across the landscape of rare disease patient advocacy
- Leadership desires to ensure organizational Operations, diversity, and programming expansion
- Host of the WAGR Syndrome Patient Registry

### CHALLENGES

- Organization board is led by volunteer members with varied levels of commitment to the practical needs required to fulfill organization's mission
- Limited pool of volunteers to engage due to small size of patient population
- Lack of focus/support in leadership could lead to frustration, sense of "being overwhelmed"
- Loss of "older" (age and longevity) leaders could lead to loss of historical knowledge
- Expanding programs and activities too widely with limited resources and capacity are diluting efforts
- Lack of a focused fundraising plan
- WAGR syndrome involves multiple and significant medical conditions. Our challenge is how to cover all of these, and to prioritize our efforts
- Many leaders/volunteers are caregivers for children with significant medical and behavioral conditions
- International language and cultural differences



### OPPORTUNITIES

- Use of virtual platforms to enhance connectivity/collaboration with stakeholders
- Current high level of interest in rare and genetic diseases increases potential for funding and for increasing diagnostic and treatment options

### THREATS

- Representation of an ultra-rare syndrome with limited knowledge, research, and resources globally

## STRATEGIC GOALS AND PROJECTS SUMMARY

### GOAL #1: PROMOTING AWARENESS

Engage WAGR community, healthcare and professionals, and the public through communication and education to foster awareness and enhance quality of life

- Website
- Public social media (Facebook/Instagram)
- News and Events
- Annual Impact Reports
- Videos for Communication and Education
- Webinars
  - Presentation templates on IWSA/WAGR syndrome
- WAGR Awareness Day
- One-page information sheets
- Global access to information through language translation

### GOAL #2: SUPPORTING FAMILIES

Be responsive to the needs of the WAGR community around the world with support and information, and community building opportunities

- Optimize communication and engagement with families
- New Family Welcome
- WAGR Weekend Conference and Meetups
- Facebook Private Group
- Educational and social/supportive webinars
- Information translation

### GOAL #3: FACILITATING RESEARCH

Engage WAGR and related-disorder researchers to seek opportunities and to enable and monitor ongoing research, recommendations, and clinical studies

- Strategic Research Plan
- Patient Registry
- Medical and Scientific Advisory Board
- Monitor and track ongoing research
- Educate families about participating in clinical studies
- Conferences
- Collaborative relationships with scientists and researchers
- Resources and support for researchers
- WAGR syndrome Clinical Center of Excellence

### GOAL #4: OPERATIONS

Ensure that IWSA is a financially secure, smoothly functioning organization, and that broad initiatives that advance the mission are developed and implemented

#### Administration

- IWSA Strategic Plan
- Executive Director
- Annual Budget
- Bloomerang database of all stakeholders
- Volunteer program
- Donor relations

#### Organizational initiatives

- Collaborative relationship development and management
- Board development
- Strategic Fundraising Plan
- International affiliate organization relationships
- Partnerships with related-disorder organizations
- Global Alliance/international outreach

### EVALUATION AND MANAGEMENT

Evaluation and management must go hand-in-hand with implementation of the IWSA Strategic Plan. Ongoing assessment is vital for several basic reasons: accountability, quality improvement, and predicting future needs and resources. Evaluation and management of the strategic plan will help to provide a clear understanding of the strengths and effectiveness of the organization's management and programmatic strategies and will help identify areas that need to be addressed and improved.

IWSA will take the following steps to ensure implementation and evaluation of the IWSA Strategic Plan:

- **Every 6 months:** Board Chair, Executive Director, and Board Secretary to review and update the Strategic Plan and share results with Board
- **Every year:** Entire Board to thoroughly review, assess, and update the strategic plan, either in person or virtually
- **Every 3 years:** Create new Strategic Plan

**IWSA INITIATIVE ANALYSIS**

Proposed Initiative:

Description of Planned Activity:

Criteria	Yes	No	Comments
1. Directly supports IWSA mission			How does it support the mission?
2. Leader identified to lead this initiative			Who? Time commitment?
3. Meets organizations strategic goals			Which goals will be met and how?
4. Has measurable objectives			What are they?
5. Requires partners and/ or collaborators			Who?
6. Project obligations and expectations			What are they?
7. Commits IWSA's financial or other resources			How much? Provide budget
8. Commits additional IWSA staff or volunteer resources			Who, how much and in what way?
9. Involves legal risk			If yes, explain:
10. Project Timeline			Provide timeline:
11. Similar activities attempted previously			If yes, what, when and by whom?

Additional comments:

Rationale:

Potential Audience:

Summary – Overall estimated impact on the organization:

Submitted by: \_\_\_\_\_ Date: \_\_\_\_\_

**FUTURE IWSA INITIATIVES**

PROGRAM	DESCRIPTION	RESPONSIBILITY	ADDITIONAL NOTES
<b>Family Support</b> WAGR Dads Program WAGR Siblings WAGR Parent Mentors Adults with WAGR Create support networks/connections for families			
<b>Education</b>			
<b>Empowerment</b> Parent Advocacy Training			
<b>Resources</b> Parent's Guide (lay version of Physician's Guide)	A single document of everything-you-need-to-know... Or perhaps a life stages list of questions to ask, referrals to consider		
<b>Meetings</b> Leadership Retreat		<b>Leadership Retreat</b> (budget dependent)	Consider doing every 3 years, starting 2023