



IWSA Country Representatives

The purpose of this position is to have an IWSA representative in countries where there are IWSA/WAGR families. The representative should be a person or persons who are familiar with the medical, social, educational, and cultural challenges of raising a child with a rare disease in their specific country. The person should have an interest in learning about WAGR syndrome and its complications, supporting other families, and engaging in activities that positively reflect the mission and vision of the organization.

Expectations

Representing the IWSA and IWSA families in a way that is respectful, knowledgeable, and collaborative. Respecting privacy and confidentiality are also required.

- Be a member of the IWSA
- Meet with and work together with representatives of other countries
- Share ideas with IWSA Board
- Adopt and follow IWSA mission, vision, values

Engagement Opportunities and Activities

Listed are possibilities for representatives to consider; none are mandatory nor is this a complete list of possible items.

- Collaborate with the IWSA Director of Research and Medical Advocacy to represent the IWSA in research and awareness activities in their country
- Contact, welcome new families
- Plan, coordinate, lead special day/event activities
- Manage/coordinate translations/interpretations
- Share new ideas for new programs, activities, ways to support families
- Attend meetings
- Promote, participate and/or encourage fundraising activities
- Attend workshops and conferences
- Encourage others to participate in activities including fundraising and awareness
- Serve on IWSA committees/teams

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