



## **International WAGR Syndrome Association Facebook Private Group Policy**

*Adopted: June, 2015*

The purpose of the IWSA private Facebook group is to provide an online environment for parents of children/adults with WAGR syndrome to support each other. This support is accomplished by parents sharing their concerns, experiences, and questions, and by interacting with each other in a sympathetic and encouraging manner. Due to the sometimes sensitive nature of the topics discussed, the IWSA private Facebook group is open to **parents or legal guardians only**. In rare cases, exceptions to this policy may be made for the following:

- Persons who were members of the IWSA email listserv before the advent of the IWSA private FB group
- If one/both parents are members of the group, they must request the exception
- Exceptions will not be granted if one of the child's parents/legal guardians objects
- The person for whom the exception is requested must provide 50 percent or more of the daily care of the child/adult with WAGR syndrome

It is the intent of this policy to specifically exclude professional caregivers, physicians, researchers, therapists, teachers, and family members (immediate or extended) who do not serve as primary caregivers in a parental role. All exceptions to this policy must be approved by the IWSA Board of Directors

In addition, participants in the IWSA private Facebook group agree to abide by the following rules of conduct. *Failure to comply with these rules may result in removal from the IWSA private Facebook page:*

- Respect the privacy of others in the group. ***Messages, comments, and photos should not be shared outside the group in any form without the express written permission of the person(s) who posted them***

- Refrain from posting messages regarding products or services for sale or links to products or services for sale which would result in personal financial gain
- Sharing personal experience with medications or medical procedures is encouraged, but please refrain from offering medical advice
- Refrain from soliciting funds for self, other individuals, or other organizations
- Respect the views and opinions of others