



## **International WAGR Syndrome Association Privacy and Data Protection Policy**

*Adopted May, 2018  
Updated June, 2020*

### **General**

This privacy policy sets out how International WAGR Syndrome Association (IWSA) uses and protects any information that you provide to the IWSA when you use the [wagr.org](http://wagr.org) website, respond to a survey, attend an event, or become a member of the organization. IWSA is committed to ensuring that your privacy is protected. Should we ask you to provide certain information by which you can be identified, you can be assured that it will only be used in accordance with this privacy statement.

IWSA collects personal data about our members, supporters, event attendees, the children and families we advise and support, and professionals and volunteers at organizations we work with.

We will not sell, distribute or lease your personal information to third parties unless we have your permission or are required by law to do so. We may use your personal information to send you information that we think you may find of interest. IWSA may change this policy from time to time by updating this page. You should check this page to ensure that you are happy with any changes. This policy is effective from May 1, 2018.

### **What we collect**

The [wagr.org](http://wagr.org) website will not automatically collect any personal information from visitors.

If you would like to receive information from the IWSA, or become a member of this organization, you may fill out our [Contact Form](#) or send us an email at [reachingout@wagr.org](mailto:reachingout@wagr.org). You may choose to share all or only some of the information on the Contact Form.

### **What we do with the information we gather**

We require this information to understand your needs and to respond appropriately and in particular for the following reasons:

### **Internal recordkeeping**

We may use the information to improve our communications and information delivery.

### **To send you information**

We may periodically send information such as newsletters, organizational updates, news about medical research on WAGR syndrome or new diagnostic or treatment options, or other information that we think you may find interesting or helpful using the email address or mailing address you have provided.

**We do not sell or share any information with other individuals or organizations.**

### **Security**

We are committed to ensuring that your information is secure. In order to prevent unauthorized access or disclosure, we use a customer relationship management platform called Bloomerang <https://bloomerang.co/donate-securely-bloomerang>. We have applied physical, electronic, and managerial procedures to safeguard and secure the information we collect online.

### **How we use cookies**

A cookie is a small file that asks permission to be placed on your computer's hard drive. We use traffic log cookies to identify which pages are being used. This helps us analyze data about webpage traffic and improve our website in order to tailor it to visitor needs. We only use this information for statistical analysis purposes and then the data is removed from the system.

Overall, cookies help us provide you with a better website by enabling us to monitor which pages you find useful and which you do not. A cookie in no way gives us access to your computer or any information about you, other than the data you choose to share with us.

You can choose to accept or decline cookies. Most web browsers automatically accept cookies, but you can usually modify your browser setting to decline cookies if you prefer. This may prevent you from experiencing full advantage of the website.

### **Links to other websites**

Our website may contain links to other websites of interest. However, once you use these links to leave our site, you should note that we do not have any control over other websites.

Therefore, we cannot be responsible for the protection and/or privacy of any information that you provide while visiting such sites and such sites are not governed by this privacy statement. You should exercise caution and look at the privacy statements applicable to websites in question

### **Controlling your personal information**

You may choose to restrict the collection or use of your personal information in the following ways:

When you are asked to fill in a form on the website, you may choose not to provide any/all of the information requested

if you have previously agreed to share your personal information with us, you may change your preference(s) at any time by emailing us at [reachingout@wagr.org](mailto:reachingout@wagr.org)

If you believe that any information we are holding on you is incorrect or incomplete, please email us as soon as possible at the above address. We will promptly correct information according to your direction/instruction

### **Surveys**

The IWSA occasionally produces surveys through a platform called Survey Monkey:

<https://www.surveymonkey.com/mp/policy/security/>

These surveys are designed to be anonymous. However, respondents should be aware that in responding to surveys they could be disclosing information that could make them personally identifiable to IWSA. Respondents to surveys should be aware that they alone are responsible for the content of their responses.

### **Events**

When you register for or attend one of our events we use your personal data to send you details and administer the event. We do this on the basis of the 'contract' that you have with us. We will also contact you for feedback following the event and we may contact you about similar events in the future. We will add your details to our supporters list and we may contact you by email, postal mail to tell you about our fundraising, volunteering and awareness-raising campaigns. We do this on the basis of our 'legitimate interest' as a charity. If you would like to see a fuller explanation, please ask us. We make recordings of our events in the form of audio, video and photographs. We use these on our website, on social media and in our publications. We will always let you know in advance and on the day recordings are made so you can decide not to take part or can inform us in writing to avoid including you in recordings or delete (parts of) ones where accidentally you are identifiable.

Questions, complaints, or requests to rescind consent to share information may be addressed to:

**Data Protection Officer**

Email: [reachingout@wagr.org](mailto:reachingout@wagr.org)