

## **Disclaimer and Privacy Statement**

### **Disclaimer:**

The medical information on this website is adapted from the Association for Glycogen Storage Disease's handbook, "Glycogen Storage Diseases, A Patient-Parent Handbook," and is endorsed by the Scientific Advisory Board of the AGSD. The Scientific Advisory Board of the AGSD is a group of physicians, scientists, and other medical professionals who have graciously volunteered to share their expertise and knowledge of glycogen storage diseases.

The materials and other information provided on this website are for educational purposes only; and are designed to support, not replace, the relationship that exists between a patient/site visitor and their physician. Please consult your doctor for specific medical advice, diagnoses, and treatment.

This website includes links to a variety of other Internet sites that are not maintained by the Association for Glycogen Storage Disease. These links are provided as a starting point to explore related resources on the Internet. The presence of a link to an on-line resource does not represent an endorsement of that site. The AGSD is not responsible for the content or for the privacy practices of any site to which [www.agsdus.org](http://www.agsdus.org) is linked.

This website does not use any advertisements whatsoever. The site is funded solely by the Association for Glycogen Storage Disease; no outside contributions were used to fund this site.

### **Privacy Statement:**

You do not have to provide any personal information to visit this website. If you choose to provide us with information about yourself through an e-mail message or a PayPal-system supported purchase, we will only maintain your personal information as long as needed to respond to your question or to fulfill the stated purpose of the communication. The Association for Glycogen Storage Disease does not give, sell, or share this information with any outside parties.

### **Traffic Data**

In general, you can browse the AGSD website without telling us who you are or revealing any personal information about yourself. The only information we gather during general browsing is from standard server logs. We use software to keep track of traffic to our site and acquire such information as the location from which the traffic originates and which particular pages within the site are being viewed and for how long. We do not know visitors' names, addresses, or other personal information.

## Cookies

Your Internet browser has a feature called "cookies" which store small amounts of data on your computer about the websites you visit. Our site does not use cookies to keep track of your movements through the AGSD website.

## Use of electronic mail

Email communication that you send to us via the email links on our site may be shared with a medical expert or an AGSD director that is most able to address your inquiry. We make every effort to respond in a timely fashion once communications are received.

We may, unless you indicate otherwise, store, edit, and excerpt your email for use in Q&As, presentations, analyses, and other similar purposes. In these cases, we will delete any content that would specifically identify you as the writer of the email.

The email functionality on our site does not provide a completely secure and confidential means of communication. It's possible that your e-mail communication may be accessed or viewed by another Internet user while in transit to us.

## Collection of personally identifiable information

If you make a donation, register for membership, order merchandise from us, request information, or provide feedback, you will be asked to provide personal information such as your name, e-mail address, and, in some cases, your postal address. This information is collected only with your knowledge and permission, and is not kept in any database or mailing lists - unless you have registered for membership. Our membership database is maintained and stored off-line. If you are purchasing something or making a payment through our website, you will be asked to provide your PayPal or credit card details to the PayPal payment service. These details are not accessible to us.

## **Guidelines for the Association for Glycogen Storage Disease's Facebook Page:**

The purpose of the Association for Glycogen Storage Disease's Facebook Page is to facilitate an online meeting place for individuals and families who are affected by the glycogen storage diseases and/or are interested in the AGSD.

Opinions expressed on our Facebook Page may periodically contain inaccurate information. The viewpoints, opinions and actions expressed in comments are those of the individuals themselves, and may not reflect the AGSD's policies or positions.

Do not rely on our Facebook Page for important health care questions. Always consult your own physician or healthcare provider with any questions you may have regarding your/your family member's medical condition.

The minimum age for the use or participation in our Facebook page is 13 years.

### Authority

Our forum is moderated on a weekly basis. The moderators and administrators are volunteers. The moderators and forum members are not regarded as health professionals.

### Medical Disclaimer

The information provided on this forum is designed to support, not replace, the direct relationship between patients and health professionals.

### Privacy

We remind you that any message can be read, used, reproduced, and cited by all.

You do not have the option to delete your messages. However, under exceptional circumstances, you can contact the moderators to do so. The references you provide for your posts cannot be deleted. Thus, please take care regarding the information that you post.

### Messages

The moderators and members should conduct themselves at all times with respect and honesty.

By using our forums, you agree to post information that is true and correct to the best of your knowledge and is of your personal experience. If the information you post is not personal experience, we request you to provide sources (references, links, etc.) whenever it is relevant and possible.

Don't say anything online that you wouldn't be comfortable "seeing quoted on CNN," being asked about by your mother, or having to justify to your boss. You are not allowed to post advertisements, whether in the form of text links or banners, for example.

We welcome constructive feedback, but we reserve the right to remove any comments that are inappropriate due to foul language, unsupported accusations, attacking of a single person or group, or spam that explicitly promotes a product or service. If contact information is available, we will notify comment authors personally to let them know their comments have been removed. We reserve the right to ban repeat offenders.