

Privacy Policy

Effective Date: February 10, 2022

Association for Glycogen Storage Disease's goal is to provide trusted and current information about Glycogen Storage Disease to assist patients in making informed decisions about their own medical care. For purposes of this Privacy Policy, "we," "us" and "our" refer to Association for Glycogen Storage Disease. "You" refers to any user of the Association for Glycogen Storage Disease website ("Site"). This policy applies to all information on the Site, whether developed or posted by us or by other users, including text, graphics, informational materials, surveys, audio, or other content in any form or medium ("Content").

Please review this policy in full so you understand how we use and protect your information.

By using the Site, you understand and agree to the terms of the Privacy Policy as well as the website Terms of Use. If you do not agree, please exit the Site.

I. Changes to Privacy Policy

We may update the Privacy Policy at any time and without advance notice to you. We encourage you to frequently review the Privacy Policy. If we make changes, we will post the updated effective date so you are aware that the policy may have changed.

II. Children Under Age 13

This Site is intended for use by adults over the age of 18. Users under the age of 18 should get the assistance of a parent or guardian to use this site. We do not knowingly use, collect, or disclose information from children under the age of 13. Parents/guardians are responsible for any information they may release about their minor children. If we learn we have unknowingly collected personal information from a child under age 13, we will make reasonable efforts to delete such information from our records.

III. Collection of General Information

It is important to us to understand who is using the Site and for what purposes to ensure we are providing helpful information and reaching our intended audience. Because of this, we or our affiliates may collect general information about users, such as IP addresses, device information, location, frequency of visits to individual pages and similar general information. We use this information to make sure we can support the volume of Site traffic and for other statistical purposes.

IV. European Union Users/Users Outside the United States

Under the General Data Protection Regulation ("GDPR"), you must expressly consent to the collection and use of your personal information, except in certain limited cases. Please access the consent form here. You have the right to request a copy of any data collected and processed as well as ensure the accuracy of your personal information. You may also ask that your information be removed or forgotten. Your data may have been processed in a country, including the United States, where laws regarding

processing of personal data may be less stringent than the laws in your country. We abide by the laws in the United States and adhere to the GDPR.

If you wish to exercise your GDPR rights, please contact us.

V. Collection and Use of Personal Information

In using the Site, you may have opportunities to share personal information about yourself or individuals for whom you are providing care. You are not required to share personal information about yourself or others as a condition of using the Site. If you are concerned about the privacy of your health information, or you do not wish to identify yourself, we encourage you to limit the sharing of personal information. If you voluntarily provide such personal information, we cannot guarantee the privacy of this information or how other participants may use it. Please do not share any demographic or personal health information that you wish to keep private.

If you contact us through the Site, we may use your email address to respond to you and/or add you to our contact list. You may “opt out” of receiving future messages from us at any time.

We use the data you provide on the Site to facilitate the creation of your account, secure your account, send administrative notifications, respond to comments or messages that you post, respond to your inquiries or questions, respond to volunteer requests, send thank you notifications for donations, respond to your submission of your experiences, create content to benefit the public, and provide general health education. By submitting questions or providing information, you are consenting to our use of this data in all content, including educational materials, print, fundraising case studies, and in any/all media. If we do so, we will use the content but not your personally identifiable information (such as your name, username, or address), unless you agree to allow us to identify you.

We also use the information you provide for marketing and targeted advertising. If you prefer to not receive targeted advertising, you can opt out of certain network advertising programs through the [Network Advertising Initiative \(NAI\) opt-out page](#). Options are Device-specific, so if you use multiple Devices, you may need to opt out on each one. You can also opt out of certain targeted advertising programs by clicking on the “AdChoices” icon that may appear on some of our advertising. We may use more than one third party company for placing this advertising, which would require you to opt out of each company’s program. Please note that even if you opt out you will still see advertisements while you’re browsing online. However, the advertisements you see may be less relevant to you and your interests. Additionally, many network advertising programs allow you to view and manage the interest categories they have compiled from your online browsing activities. These interest categories help determine the types of targeted advertisements you may receive. The NAI opt-out page provides a tool that identifies its member companies that have cookies on your browser and provides links to those companies.

In using the Site, you will have the opportunity to participate in surveys or other research efforts conducted by us or third party providers. If you choose to participate, we or the other party will provide you with information regarding the use and disclosure of any data you submit. Each survey or study may have different goals and ways of using and disclosing your data, which may differ from how we use and disclose your information.

VI. Retention and Deletion of Data

We will retain your personal information for as long as your account is active or as needed to provide you services and as necessary to comply with our legal obligations, resolve disputes, and enforce our agreements. If you wish to cancel your account or request that we no longer use your personal information to provide you services, contact us at [info\[at\]agsdus.org](mailto:info[at]agsdus.org). We do not control certain privacy settings and preferences maintained by third party sites. If you wish to make changes to those settings and preferences, you may do so by visiting the settings page of the appropriate third-party site.

We may delete certain personal information submitted on our Site, particularly if requested to do so by a user. However, it may not be possible to remove this data completely because of legal or technical reasons.

VII. Cookies

We use “cookies” which are data files placed on your web browser when you visit our Site to help you with Site navigation and personalize your experience. Cookies may also be used to enable your activities on other third-party Sites.

If you do not wish to accept cookies, you can adjust your browser settings; however, some functionality and personalization from the Site may be lost.

VIII. California Users and “Do Not Track” Signals

California law requires website operators to disclose when tracking information is used across websites. We or our affiliates may obtain and use such information about your browsing habits, but we do not knowingly use or share personal information about you.

We do not take actions to respond to “Do Not Track” signals, which would prevent such tracking when you use our Site.

IX. Security

We maintain reasonable safeguards to protect personal information against loss, unauthorized use, disclosure, or destruction and when transferring information for processing, and require third parties providing services on our behalf to do the same. However, no electronic data transmission or storage of information can be guaranteed to be 100% secure. Please note that we cannot ensure or warrant the security of any information you transmit to us.

Personally identifiable information that is non-public, such as your account information, is protected via encryption.

X. Links to Other Sites

This Site and Content may have links to websites owned or operated by third parties. Any such links are provided for your convenience and reference only and not because we endorse the content of anyone else’s website. We do not guarantee that materials and information on other websites are accurate or secure, particularly if these website links were provided by other users. This privacy policy only covers our website, and other third-party websites may have policies that differ from ours. Users should review

the privacy policies of the third-party websites to learn more about how they collect and use personal information.

XI. No Warranties and Limitation of Liability

The Content of the Site is provided on an “as is” and “as available” basis without warranties of any kind, express and/or implied, including, but not limited to non-infringement or fitness for a particular purpose. AGSD does not represent or warrant that use of the Site will be uninterrupted, or the Site will be error-free.

If you are unhappy with the Site or Content, you understand that your only remedy is to stop using or reviewing the Site or the Content. You are responsible for determining the accuracy and usefulness of the Content, and you understand that we are not responsible for any loss or damage caused by your reliance on information contained in the Content of the Site.

Because of this, we will not be legally liable for any direct, indirect, incidental, special, punitive or any other damages or losses resulting from your use of (or inability to use) the Site, or any losses that result from mistakes, deletion of information, omissions, interruptions, errors, defects, delays in operation or transmission, or failure of performance of the Site or any Content, whether based in tort, contract, or other legal basis.

XII. Indemnification and Hold Harmless

By using this Site, you agree to defend, indemnify, and hold AGSD and its directors, officers, employees, agents, and affiliates from and against any and all claims and expenses, including reasonable attorneys’ fees, arising out of your use of this Site, including, but not limited to, your violation of this policy.

XIII. Governing Law and Statute of Limitation

The laws of the state of Iowa, United States of America, govern this policy and any claim or cause of action arising under or relating to your use of the Site, without reference to choice of law principals. You agree that any dispute with us or that relates to your use of the Site or Content will be brought only in the State or Federal courts of the State of Iowa, USA You consent to the personal jurisdiction of these courts in connection with any such disputes.

Before you take any legal action for any harm you believe you have suffered related to the Site or Content, you agree to notify us in writing and give us thirty (30) calendar days to cure the harm. You agree that you must take legal action within one (1) calendar year after the claim has arisen or you will be barred from seeking any legal recourse. This does not supersede your other legal rights under Federal or State law that is unrelated to your use of the Site or Content.

XIV. Severability and Entire Agreement

This policy represents the entire agreement between us and you regarding your use of the Site and Content as far as privacy is concerned. If any portion of this policy is considered illegal, invalid, or unenforceable, that portion will be interpreted to, as best as possible, reflect the intent of both parties, or

removed from this policy if this is not possible, and the remainder of the policy will continue in full force and effect.

XV. Contact Information

If you have questions or comments, or you would like to notify us of an error in Content or a suspected violation of the privacy policy, please contact us at: [info\[at\]agsdus.org](mailto:info[at]agsdus.org)