

Disclaimer – For Member Portal & Social Media Platforms

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. Among the methods we use to help achieve this goal is a membership portal for registered members of our organization (note that you must be 18 or older to become a member and use our portal). We also share information about Glycogen Storage Disease via several platforms, including social media.

We understand that you may review or share personal information about yourself or others in the member portal or on our social media channels. You are not required to share personal information about yourself or others as a condition of using the member portal, or to share information on our social media channels. 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 in the portal or on our social media channels, we cannot guarantee the privacy of this information. Nor can we control how other portal users, social media users, and/or social media platform providers may use it.

Please do not share any demographic or personal health information that you wish to keep private.

We will retain your personal information for as long as your membership 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. We may delete certain personal information submitted on the member portal, 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. If you wish to remove information submitted on the member portal, contact us at info@agsdus.org.