The Association for Glycogen Storage Disease in the U.S. is comprised of members mostly from the United States and Canada, although there are members from other parts of the world. We were established in 1979 for the purpose of supporting parents of and individuals with any type of glycogen storage disease.

Our focus is to share successes and concerns when dealing with every type of glycogen storage disease, sharing useful findings, providing support, creating an awareness of this condition to the public, stimulating research in the various forms of glycogen storage disease and then communicating the results to the parents, affected individuals, and the public as soon as possible.

Our newsletter, *The Ray*, which is published four times a year, includes articles about families and individuals that they wish to share, new research findings, and articles written by or about individuals and professionals dealing with the various types of glycogen storage diseases through research and care. In the last few years we have restarted the practice of printing synopses from the professionals that attend and present at our yearly conference.

We are proud of the active involvement that our professionals take in our organization. We have fourteen professionals that are part of our Scientific Advisory Board and others that are just involved personally with the organization. Each is as willing to attend and present at our yearly conference and are wonderful about giving of their time to mingle with parents and GSD affected individuals to discuss individual issues, research findings, or just lend encouragement and support.

For the last few years, we have given monetary support towards care guidelines for the various types of GSD with the outcome of publishing them for all professionals who are treating GSD individuals to see and learn through the American College of Medical Genetics. Our hope is that care will become more similar in treatment but also individualized for each individual. We have recently updated our GSD brochure and Patient-Parent Handbook for use in promoting glycogen storage disease.

The Association for Glycogen Storage Disease is an organization that takes pride in how we work together to support each other regardless of which type of GSD is involved, and give our support to all the doctors and professionals treating and/or involved in research for the better care of our GSD members.

Kathy Thelen,

AGSD President Ex-Officio