The following are recommendations for families of those newly diagnosed with Glycogen Storage Disease 1b. These ***guidelines do not substitute for medical advice*** *and* ***all interventions should be approved and decided by your child's doctors.***

1. **Understanding Glycogen Storage Disease 1b (GSD1b)**
   Glycogen Storage Disease 1b is a rare, genetic metabolic liver disease. While every case differs, those with GSD1b are at risk of hypoglycemia, neutropenia and inflammatory bowel disease. Some information on the disease and treatment can be found under the resources tab here: https://curegsd1b.org/gsd1b-overview/

2. **Consider registering in the Family Contact Registry** (https://curegsd1b.org/family-contact-registry/)
   The Family and Patient Registry is 1-minute questionnaire using Google forms to help capture some very basic demographics and contact information. This data will not be shared with anyone and will give cureGSD1b a more effective way to communicate with the GSD1b community about events, research updates, etc. By filling out this form you will be added to the CureGSD1b organization and be assured of receiving important updates. We currently have the forms available in English, Spanish, Italian, Portuguese, German, and Turkish.

3. **Consider participating in the Rare X Data Collection Program**
   (https://curegsd1b.org/data-collection-program-w-rare-x/)
   Rare-X is a collaborative platform for global data sharing and analysis to accelerate treatments for rare diseases. It is critical for GSD1b that we get our data online and make it accessible to researchers for these very important reasons:

   1. Attract new research and researchers by making our data easy to find and study
   2. Provide existing researchers and drug developers easy access to relevant and up to date data
   3. Prepare ourselves for future clinical trials

4. **Set up a team of doctors**
   GSD1b affects multiple organ systems in the body. Your child's medical team may include a geneticists, hematologists, endocrinologists, gastroenterologists and nephrologists, depending on their needs and how care is managed where you live.

5. **Review Glycogen Storage Disease treatment guidelines**
   (https://www.agsdus.org/docs/Type_I_GSD_Guidelines.pdf)
   You or your doctors may be interested in treatment guidelines for patients with Glycogen Storage Disease Type 1. The most recent treatment guidelines were published in 2014 and were developed by leading experts in the field of metabolic disease.

6. **Gather emergency letters from appropriate doctors**
   People with GSD1b are more sensitive to physiological stressors. This means minor illnesses, dehydration, fever, temperature extremes, surgery and anesthesia can be particularly dangerous, and fasting must be avoided. Avoiding these situations is very important, but when your child is having a sick day, it is of critical importance that emergency room doctors have the most up-to-date recommendations for patient care.

Reach out if you would like to view an example emergency letter. Patients can also use the following website, created for GSDs and Fatty Acid Oxidation Disorders (a different metabolic disease), to generate their own emergency protocol guidelines: https://www.emergencyprotocol.net

7. **Connect with other families**

   Connecting with other families living with a GSD1b diagnosis can provide emotional support and a wealth of useful information. If interested, request to join the Facebook group "Glycogen Storage Disease 1B" or follow this link: (https://www.facebook.com/groups/130620537072144) The GSD1b Facebook group has members from around the world and is an excellent source of information and support. The group is moderated by GSD1b patients and caregivers. If you would like to be connected with other families directly, please contact Sophie's Hope Foundation Director of Patient Outreach and Engagement at blair@sophieshopefoundation.org.

8. **Join efforts to find a cure**

   Research is necessary to better understand how to treat GSD1b, and is a major source of hope for those suffering from this disease. If you are interested in working with us to help find new therapeutic approaches and a cure for GSD1b, please contact us at jamas@sophieshopefoundation.org or blair@sophieshopefoundation.org