

MSUD Family Support Group Policy Regarding Support for Individuals

The MSUD Family Support Group is a small nonprofit volunteer organization with the following goals:

connecting and engaging MSUD families and professionals

progressing research to improve the lives of those with MSUD

advocating to meet the needs of our community.

Our organization is funded by donations which allow us to perform basic operations, conduct a biennial symposium, and support research projects.

We recognize that there are many MSUD families in the US and internationally that do not have the financial resources or government support to assist with expenses for vital MSUD treatments such as medical formulas, low protein foods, supplements, laboratory tests or expenses associated with liver transplantation. We are empathetic to the challenges these families face each day to care for their MSUD loved ones with limited resources. However, the scope of this problem is too large for us to make a meaningful impact in a way that is fair to all in need. Therefore our policy is to not provide individual assistance with expenses. We believe that we can best serve our entire community through our advocacy efforts, encouraging access to newborn screening and medical care including medical formula throughout the world.

We encourage MSUD families to connect with other families via our social support network and increase their knowledge of MSUD via our website.