Sample letter for family and friends

Dear

As you know our son/daughter_____ has a rare genetic condition called Maple Syrup Urine Disease. MSUD affects 1 in every 185,000 babies born. In contrast, Downs Syndrome affects 1 in 1000 and Cystic Fibrosis affects 1 in every 2500 babies born.

______follows a strict low protein diet and drinks a special metabolic formula which provides the majority of his/her nutrition. Careful monitoring of his/her daily intake is essential for him/her to remain healthy. Illnesses, even mild, can upset his /her delicate protein balance resulting in a need for increased care.

______ and others with MSUD would benefit from new treatments and ultimately a cure for MSUD. Unfortunately, rare diseases have not received much attention from researchers in the past. Recently, though, there has been an interest in finding alternative treatments and cures for rare diseases. The MSUD Family Support Group is currently funding several research projects and is proactively looking for researchers interested in studying MSUD to improve the lives of affected individuals, like _____. To make this a reality, the MSUD Family Support Group needs your help.

Please consider sending a tax deductible contribution. You can donate by mailing a check to: Dave Bulcher, MSUD Treasurer, 958 Medinah Terrace, Columbus, OH 43235, or by credit card through PayPal on the MSUD website (www.msud-support.org). Make the check payable to the MSUD Family Support Group.

Thanks in advance for considering my request,

The MSUD Family Support Group is a tax exempt 501(c)3 organization with no paid staff. All donations are tax deductible. Tax exempt ID # is 54-1556981