Process:

1) Only parents/guardians of an individual with MPS or ML or an adult with MPS or ML who reside in the United States and have an active membership are eligible for funds from the Family Assistance Program (FAP). Membership should be active and updated annually.

2) The Society will maintain strict confidentiality regarding applications, names, and funding.

3) Funds will be available only for non-recurring, exceptional, and extraordinary costs. Ongoing expenses incurred by members are not covered under this assistance program.

4) The applicant should be willing to donate the item to another Society member when it is no longer needed.

5) Application for assistance should be made before the cost is incurred. Special consideration may or may not be made if the cost has been incurred.

6) Examples of potentially eligible costs are durable medical goods, special equipment, home modifications, and medical aids. See NOTE below regarding a subcategory of the Family Assistance Program for natural disasters titled IMPACT Disaster Relief Program. Contact the office for its separate guidelines.

7) Grants for FAP may be requested up to a maximum of $3,000 per affected individual per 12-month period, dependent on available funds and the Committee’s decision. Multiple grants can be submitted, not to exceed $3,000, funded in a 12-month period. Multiple grants for one family membership may be awarded only for single-user items.

8) A minimum of 10% of the total cost of the equipment or medical aid must be funded by the applicant.

9) All required documentation must accompany the FAP application form before the application is reviewed. The committee will review applications upon receipt of all documentation, and the Society will notify the applicant of the funding decision.

10) If the applicant has medical insurance, documentation that the applicant has requested insurance funding must accompany the application. The documentation must include either a letter of denial of coverage or the written decision indicating the amount insurance will pay. Other documentation that may be accepted would include a denial of the specific item requested in pre-printed material provided by the insurance company.

11) The Society will issue a letter to the applicant indicating whether the application has been approved or denied and the amount of funding granted, if any.

12) Funding will be paid directly to the vendor/supplier upon the Society receiving an original, scan, or photocopy of the applicant's invoice/quote/estimate. In special situations, an exception may be granted upon Committee review and authorization, allowing the individual to be reimbursed with the grant funding if the cost has already been incurred.

13) Hot tubs/spas and pools funding will be limited to a one-time grant of $1,500 per family membership. No funding will be provided for repairs, materials, accessories, and upkeep of hot tubs/spas or pools.

NOTE: The IMPACT Disaster Relief Program is available for those who have experienced a natural disaster. Separate guidelines apply. To apply for a grant through this program, please contact Leslie Urdaneta directly at leslie@mpssociety.org or 919-806-0101.
Application Review

1) The application will be reviewed once all required documentation is received.

2) The Family Support Committee will review a summarized version of the application and determine funding status.

3) Payment will be made to the vendor/supplier. This will require the applicant to supply a “quote” or invoice estimate before work is done. The Society will send payment to the vendor unless other arrangements are made in extenuating circumstances.

4) The Family Support Committee’s interpretation of the regulations outlining the FAP and any decisions made by the Committee are binding. Appeals can be made to the Board of Directors in writing within 60 days of denial. The appeal will be reviewed at the next Board meeting.

5) If funds budgeted for the current year are depleted, the Family Support Committee will not review additional applications that year. Applications will be accepted and reviewed after January 1.

6) If funding is approved, the applicant must submit receipts as appropriate and accept funds within 90 days. Items not funded within 90 days of approval will require resubmission.