



MPS and ML Extraordinary Experience Program Guidelines

Definition of the Program:

The Extraordinary Experience Program is designed to provide funding to an individual with MPS or ML for an extraordinary experience which will offer the opportunity for life enrichment. We hope to help individuals achieve a personal goal. The experience can be used to support a special trip for education purposes or for personal growth, a camp, program, or other sponsored activity that would offer the individual an opportunity to enhance their life. The focus of this program is to provide an experience that will build peer relationships, increase interactions with others, and provide an enriching opportunity for an individual. We will not fund requests that are better served for wish-granting type programs.

National MPS Society Extraordinary Experiences Program Guidelines

Process:

- 1) Individuals with MPS or ML 13 years of age and older who reside in the United States and are active members of the National MPS Society are eligible for funds from the Extraordinary Experiences Program. Parents/guardians/siblings of an individual with MPS or ML may complete the application for their child/sibling. Applicants must be a member of the National MPS Society for a minimum of three months prior to applying.
- 2) Strictest confidentiality regarding application, names and funding will be maintained by the applicant and the Society.
- 3) The applicant can receive funds from the Extraordinary Experiences Program once every 24-month period. The applicant can receive up to 2 grants in total. Preference will be given to applicants who have not previously received funding.
- 4) The applicant or parent/guardian must be willing to write a brief summary about their experience and submit a photo. The summary may be published in Society publications or our website to help show the benefit of this program to others. Applicant may request in writing to remain anonymous.
- 5) Application for assistance must be made in advance of the cost being incurred.
- 6) Examples of potentially eligible costs are summer camps, school supported trips, educational conferences (other than our annual family conference) or other sponsored activity that would be an extraordinary life enriching activity. Examples of requests ineligible for funding would be a family vacation to Hawaii, a trip to Disney World/Land and other experiences better served by wish granting organizations.
- 7) Grants for the Extraordinary Experiences Program may be requested up to a maximum of \$1,000 per qualified individual and are awarded dependent on available funds and the Committee's decision.
- 8) A minimum of 10% of the total cost must be funded by the applicant.

- 9) All required documentation must accompany the Extraordinary Experiences Program application form prior to application being reviewed. Applications will be reviewed by the Committee upon receipt of all documentation, and the National MPS Society office will notify the applicant of the funding decision.
- 10) 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.
- 11) Payments are made directly to the camp/school/or other institution upon the Society receiving an original or photocopy of a letter or invoice outlining the expenses from the applicant. In special situations, the individual may be reimbursed with the grant funding if the cost has already been incurred.

Application Review:

- 1) Applications will be reviewed once all required documentation is received.
- 2) The Family Support Committee will review all eligible applications and will select the applications for funding.
- 3) A check will be issued to the camp/school/or other institution. If applicable this will require the applicant to supply a letter from the camp/school/or other institution outlining the expenses of the trip. The Society will send the check to the applicant. The applicant will be responsible for sending the check to the camp/school/or other institution, if necessary.
- 4) The Family Support Committee's interpretation of the regulations outlining the Extraordinary Experiences Program and any decisions made by the Committee are binding. Appeals can be made to the Board of Directors in writing within 60 days of the 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 1st.
- 6) If funding is approved, applicant must submit receipts and accept funds within 90 days. Items not funded within 90 days of approval will require resubmission.