



MPS and ML Extraordinary Experiences 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 one of their goals. The experience can be used to support a special trip for education purposes or for personal growth, a camp or program, or any other activity that would offer the individual an opportunity to enhance their life. Special exceptions may be made as determined by the Family Support Committee.

National MPS Society Extraordinary Experiences Program Guidelines

Process:

- 1) Affected individuals 13 years of age and older who reside in the United States and are active members are eligible for funds from the Extraordinary Experiences Program. Parents/guardians of an affected individual may complete the application for their child.
- 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. 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 *Courage* 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 any extraordinary life enriching experience.
- 7) Grants for the Extraordinary Experiences Program may be requested up to a maximum of **\$1,000.00** per qualified individual, and may be awarded dependent on available funds and the Committee's decision.
- 8) A minimum of 10% of the total cost, up to a maximum of \$100, must be funded by the applicant or by other sources.
- 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 NMPS 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) If applicable, funding will be paid 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 of the 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) In the event that 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.