



Society for the Study of Inborn Errors of Metabolism (SSIEM)
PO Box 3375
South Croydon
CR2 1PN
United Kingdom
Email: admin@ssiem.org

FUNDING APPLICATION FORM FOR NON-PROFIT PARENT/CARER SUPPORT ORGANISATIONS 2025

Please complete this application in English, however if this creates any difficulty please contact the SSIEM.

The SSIEM is offering modest financial support for non-profit organisations such as associations, patient organisations and support groups who represent in general more than 50 families with a rare IEM.

€10,000 will be made available twice per year with a maximum award of €5,000. Submission dates for application in 2025 will be 1st January closing 1st March and 1st July closing date 1st September.

Applications for funding will be considered by an award panel. The applicants will be informed of the SSIEM decision within 30 days of the closing date for application.

The event cannot be within two months of the award decision dates of 1 - 30th March or 2 - 30th September to acknowledge the support of the SSIEM for the event in your publicity material & website.

Association / Patient Organisation or Support Group submitting application for financial support:

[National Association Familias GA](#)

Title of meeting or activity:

[GA1 in Adult Life: Facing the Motor Disorder and its Challenges, latest advances in nutrition"](#)

Date of meeting or activity:

[June 2025](#)

How much funding is requested? € 5000

How will the funds be used?:

The requested funding will be used to cover essential costs for organizing and conducting a dedicated event for young and adult individuals affected by Glutaric Aciduria Type 1 (GA1) and their families. Specifically, the funds will be allocated to:

- Accommodation and meals for affected individuals and their families, including a lysine-restricted diet, which is crucial for managing the disease.
- Fees and travel expenses for invited professionals, ensuring the participation of experts in key areas for the comprehensive management of GA1:
 - Neurologist specializing in movement disorders, who will address motor challenges associated with the disease and their management.
 - A dietitian specialized in GA1, who will provide practical guidance on dietary management and strategies for adherence to a lysine-restricted diet.
 - A psychologist specialized in rare diseases**, who will lead emotional support sessions and provide coping strategies for affected individuals and their families.
- **Recording of lectures and educational content** for later dissemination, allowing the information shared during the event to reach a wider audience, including those unable to attend in person.

This budget breakdown ensures that the event fulfills its purpose of providing specialized information, emotional support, and practical strategies to improve the quality of life of individuals affected by GA1 and their families.

Please continue on a separate sheet or include details in the covering letter requested below.

Signature of Applicant: _____ Date signed: 13/02/2025

Print name: HELENA CARPIO ANGUITA

Position within organisation/association/support group etc:

PRESIDENT OF THE ASSOCIATION

Please attach a letter briefly describing the function of the Association / Patient Organisation or Support Group signed by the person making the application. Please forward this application and letter to admin@ssiem.org

Should this application be successful the SSIEM requires acknowledgement of support on the event's publicity material.