

Family Support Guidelines & Policies

Project Name

Family Support Fund –DupMECP2 - Lasst Uns MDS Heilen (LUMH)

Purpose

To provide financial assistance to children affected by MECP2 Duplication Syndrome and their families for therapies, medical treatments, and necessary equipment not fully covered by insurance, as well as psychological assistance for affected families.

Eligibility Criteria

- The child must have a confirmed MECP2 Duplication Syndrome diagnosis via the international platform REMEDS (www.remeds.org)
- The family must reside in Europe, defined as countries that are members of the European Union, the European Economic Area (EEA), or otherwise geographically located in Europe (list on Annex E).

***For application from USA, there is an existing family support program provided by the MECP2d foundation. Click here to access the form and conditions: [LINK](#)**

You are anyway very much invited in filling out the form so that we understand better your needs for future extension of the program to worldwide support.

****For application from the rest of the world, we will surely extend this program to outside of Europe in early 2027. To evaluate the type of funding needed and the urgency, you are invited to fill out the application form available in REMEDS. We will do our best to constitute further budget to support you.**

- The requested support is for costs directly connected to the child's care (therapy, treatment, equipment, etc.) or its family (restricted to psychological support and travel support).
- Families may apply once per calendar year, per affected individual. (e.g. a family with two children affected by MDS may submit two applications; however, a single application may be submitted if the request concerns shared equipment or support benefiting more than one individual, such as a Galileo vibration plate).
- Application form is available only in English, but you may fill it out in your own language.
- Application is restricted to parents, grandparents, legal guardians, siblings or close relatives.
- The maximum support amount per family depends on the total amount of the invoice (see Payments paragraph).

Payments

- DupMECP2 - LUMH does **NOT** transfer money directly to families (with the exception of travel support)
- DupMECP2 - LUMH pays invoices directly to service providers (such as therapy centers, medical suppliers, clinics) after reviewing and approving the costs.
- Only original invoices and official cost estimates addressed to DupMECP2 – LUMH, and clearly referencing the benefiting individual and the corresponding treatment, therapy, or service, will be considered.
- Reimbursement for already paid invoices by families **is not possible** under this program.
- Max support amount:
 - Invoices up to 500€: 100% of the invoice will be paid = max 500€
 - Invoices 501€ - 1.000€: 80% of the invoice will be paid = max 800€
 - Invoices 1.001€ - 2.500€: 60% of the invoice will be paid = max 1.500€
 - Invoices 2.501€ - 5.000€: 40% of the invoice will be paid = max 2.000€
 - Invoices over 5.000€: the amount will be decided by the DupMECP2 – LUMH reviewers.

Eligible Costs (non-exhaustive list)

- Therapy bills (e.g., physiotherapy, occupational therapy).
- Medical devices (wheelchairs, communication aids, etc.).
- Travel expenses **related to transport to treatment/therapy** (public transport tickets, mileage, expenses for a patient and a maximum of 1 caregiver).
- Special nutritional products prescribed by a doctor.
- Prescribed medical treatment.
- Medical procedures
- Life support (eg: car seat, adapted highchair)

Non-Eligible Costs

- General living expenses (rent, food, utilities).
- Travel to conferences (family meetings*, scientific conferences, etc)
- Private leisure activities.

***specific grant are already covering such event**

Application Process

Step 1: Access form via REMEDS

To apply, you must first log in to **REMEDS.org**.

- If a patient is already successfully registered, you will be able to access the Family Support application form.

- If not, you are invited to **sign up and register a person first** and wait for confirmation before applying.

Step 2: Complete the Online Application Form

Families will be asked to fill out a simple, secured online form

Step 3: Submit the Required Documents

The following documents should be sent immediately after the form application to office@dupmecp2.eu. **Please add as subject: “Family Support + your name”:**

- Quotes or cost estimates for the services or products you are applying for.
- Any documents that show partial coverage or no coverage of the cost by any other fund (organization, health insurance, private insurance, etc.)

Step 4: Review by DupMECP2-LUMH Board & Eligibility Check

All applications are reviewed confidentially by the reviewers of DupMECP2-LUMH. (*Current board members in charge: David Covini (President), Caroline Covini (Vice-President), Gerald Molnar (Treasurer), Susanne Molnar (Vice- Treasurer).*)

The following topics will be first checked:

- The child has a confirmed diagnosis of MECP2 Duplication Syndrome and is registered at REMEDS
- The family currently resides in Europe, defined as countries that are members of the European Union, the European Economic Area (EEA), or otherwise geographically located in Europe (list on Annex E)
- The requested support fits within the project scope, such as therapy, assistive equipment, travel for medical reasons, etc.
- The support requested is not or only partially reimbursed by insurance or other sources.
- The requested support benefits the affected child and/or its family

A scoring system will be used to prioritize applications. A scoring grid and its use is explained in **Annex A**.

The review and decisions are made within a timeframe of 1 to 3 months. It may vary, depending on the urgency of the application but also the availability of the reviewers, the availability of funds, and the size of the project.

In some cases, we may ask for clarification or additional documents to complete the review. It might extend the timeline for final decisions.

Final decision will be sent via email:

- In the case of positive decision: Approved amount and liable contract will be provided for signature
- In case of negative decision: An explanation will be given by the board in all cases. **If the DupMECP2 – LUMH budget is exhausted, the application may remain valid until additional funding becomes available.**

Step 5: Invoice Submission & Payment

Important: DupMECP2-LUMH does **not** transfer money to families.

- The family must not pre-pay or incur costs.
- After the support amount is confirmed, applicant will be asked to submit a final invoice. The unpaid balance should match the approved support amount confirmed by DupMECP2-LUMH.
- Bank details of the supplier/vendor/service provider should be clearly stated on the invoice.
- The applicant should sign a contract with DupMECP2-LUMH

Example:

If the total invoice is 1,000€ and DupMECP2-LUMH approves support covering 80%:

- The family must pay and submit proof of payment for 200€ (20%).
- The final invoice should show an outstanding balance of 800€.
- DupMECP2-LUMH will then pay the remaining 800€ directly to the service provider/vendor.

Step 6: Feedback & Follow-Up

- DupMECP2 – Lasst uns MDS heilen values hearing how the support has made a difference for your family. If you agree, we may contact you after your support has been provided to invite you to share your experience (for example, feedback, a short testimony, photos, or videos).
- Sharing images or videos that illustrate how the support was used can help raise awareness and support other families. Any materials you choose to share may be used in our communications, (eg: social media, website, YouTube channel, newsletter, etc), always either anonymously or not, depending on your wish.
- Sharing images and/or videos is entirely voluntary. You can indicate your preference by answering Question 29 in the application form. Whatever you decide, you are free to change your mind at any time, and nothing will be published without informing you and confirming your agreement beforehand.
- Feedbacks help us improve the family support project and raise future funds to support more families.

Important Notes

Funds are limited. Not all requests may be fully granted. Application that cannot be granted will be kept on a waiting list for an undetermined period. Families that are on the waiting list (eligible but funds are required) will be informed. If in the meantime the family found funds in a different way, DupMECP2-LUMH appreciates to be advised so that the application can be removed from the waiting list.

- The decision of DupMECP2-LUMH's reviewers is final.
- All data is processed under GDPR regulations.
- DupMECP2 is not responsible for the misuse of the funded project

Family support project aligned with DupMECP2-LUMH statutes

Legal conclusion

Based on DupMECP2-LUMH statutes:

- DupMECP2-LUMH is **legally allowed** to financially support families
- DupMECP2-LUMH **may pay directly** for therapies, devices, or services
- DupMECP2-LUMH **may operate internationally**
- DupMECP2-LUMH **do not need income verification**, as long as eligibility is medically and ethically justified

Annexes

Annex A – Scoring Grid (Internal)

Total: 100 points (approval guideline \geq **60 points**, subject to funds)

Anchor definitions: 0–3 = low, 4–6 = moderate, 7–8 = high, 9–10 = critical/exceptional

1. **Medical relevance & necessity (0-10) factor 2,5x**

- Direct medical necessity; evidence-based; aligns with clinician recommendation.

2. **Expected impact on child/family (0-10) factor 2,5x**

- Likely to improve function, communication, comfort, or care burden.

3. Urgency & timing (0-10) factor 2x

- Time-sensitive therapy/device; deterioration risk without support.

4. Alternative funding coverage (0-10) factor 1x

- Not covered/only partially covered by insurance or other sources (documentation provided).

5. Cost-effectiveness (0-10) factor 1x

- Reasonable price vs. benefit; durable or multi-year use.

6. Completeness & clarity of application (0-10) factor 1x

- Clear documents, quotes, provider details.

Annex B – Reviewer enrollment, Conflict-of-Interest (COI) Declaration & Handling

Who signs: All Review Committee members

Declaration (to sign each year):

- I will **not** access or review files where I have a conflict and will **recuse** from discussion and voting.
- I will keep all information **confidential** and use it only for this program.
- The form to be signed is available

Handling:

- If a COI is declared or suspected, the DupMECP2 – LUMH president assigns an alternate reviewer (if available) or proceeds with reduced reviewers.

NOTE: The number of reviewers should be at least 2.

- All recusals are **documented** in the decision record

Annex C – GDPR Data Notice & Consent (for Applicants)

Data Controller: DupMECP2 - LUMH – (contact: office@dupmecp2.eu)

Purpose: Assess eligibility, decide on support, coordinate approved payments, and report (un)anonymized program metrics (depending on consent)

Data types: Parent/guardian contact details; child’s identification (initials/DoB), health

data (needs), provider details, invoices/quotes, payment references.

Legal bases:

- **Consent** (Art. 6(1)(a) GDPR) and explicit consent for health data (Art. 9(2)(a) GDPR).
- **Legitimate interests** (Art. 6(1)(f)) in fraud prevention, audit, and program administration (limited to non-health data).

Recipients: Internal Review Committee; accounting and bank/payment processors

Transfers: Data stored/processed within the EEA where feasible; if external transfers are needed, appropriate safeguards apply.

Retention: Application data kept **5 years** after decision (or last payment) for audit;

Rights: Access, rectification, erasure, restriction, portability, objection, and withdrawal of consent at any time (withdrawal does not affect prior lawful processing).

Consent text (included in the form):

“I confirm I am the parent/legal guardian and I give my consent for DupMECP2 - Lasst uns MDS heilen to process my personal data and my child’s **personal and medical data** contained in this form and in follow-up emails (including prescriptions/quotes/cost estimates) for the sole purpose of assessing, deciding and administering my Family Support application, including payment coordination with providers. I understand I may withdraw consent at any time by contacting **office@dupmecp2.eu**”

Consent 1 (Mandatory):

Consent to Process Personal and Health Data for the Family Support Fund

Data Controller: DupMECP2 – Lasst Uns MDS Heilen (LUMH), contact: **office@dupmecp2.eu**

Purpose: Assessing eligibility, reviewing and deciding on the application, communicating with you, and coordinating any approved payment directly to providers under the Family Support Guidelines.

What data this covers:

- **Personal data (non-medical):** applicant/guardian contact details; provider and quote details; application metadata.
- **Health data (special category):** any information in the form or email exchanges that **reveals or implies** the child’s health status or disability (e.g., *descriptions of medical/assistive device needs, therapy needs, functional limitations, diagnosis if provided*), as well as health-related details contained in quotes/cost estimates.

Who will access the data: Only authorized LUMH reviewers involved in eligibility review, decision-making, and payments; accounting/banking/payment processors as necessary to execute approved payments.

Legal bases:

- **Art. 6(1)(a) GDPR – consent** (personal data)
- **Art. 9(2)(a) GDPR – explicit consent** (health data)
- **Art. 6(1)(f) GDPR – legitimate interests** (limited to fraud prevention, audit, and program administration for non-health data).

Transfers & retention: Data stored/processed primarily within the EEA

Your rights: Access, rectification, erasure, restriction, portability, and withdrawal of consent at any time (withdrawal does not affect lawful processing carried out before withdrawal). Contact office@dupmecp2.eu.

Consent 2 (Optional):

Optional Consent to Provide and Use Pictures/Video and Testimony (If Funded)

When applicable: Only if the application is approved and funded and you choose to share material.

Purpose: Communication about the Family Support Fund, awareness-raising and fundraising for DupMECP2-LUMH (website, social media, reports). Publication will follow your preferences (anonymous or named). **This is not a condition for funding.**

What this covers: Any pictures/videos related to the funded support and a written or recorded testimony describing impact. No health data beyond what appears in the media/testimony you choose to share will be processed. You may request blurring/cropping, or use of initials only. DupMECP2-LUMH will confirm content and your anonymity preference with you before publication. You can withdraw at any time; future use will cease upon withdrawal.

Annex D – Waiting-List Rules

- If funding is temporarily unavailable, eligible applications enter a **waiting list for up to 1 year. Applicants are likely requested to notify if any changes occurred on the application (no longer needed, partially funded, etc)**
- Order: by **date of eligibility confirmation.**
- Priority can change if **urgency** significantly increases

Annex E – List of eligible countries for application

European Union (27)

Austria, Belgium, Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Ireland, Italy, Latvia, Lithuania, Luxembourg, Malta, Netherlands, Poland, Portugal, Romania, Slovakia, Slovenia, Spain, Sweden

EEA (non-EU)

Iceland, Liechtenstein, Norway

Other Western Europe

Switzerland, United Kingdom

Western Balkans

Albania, Bosnia and Herzegovina, Kosovo, Montenegro, North Macedonia, Serbia

Eastern Europe

Ukraine, Moldova, Belarus

Caucasus

Georgia, Armenia, Azerbaijan

Other European states

Andorra, Monaco, San Marino, Vatican City

Additional

Turkey (partly in Europe)