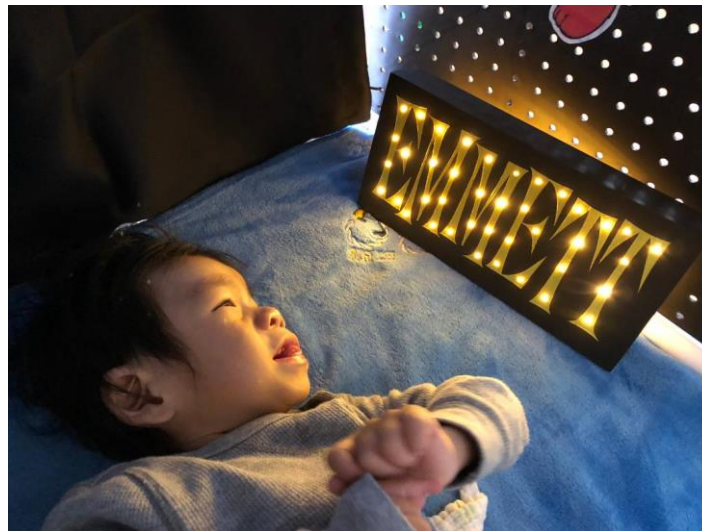




**CDG CARE is excited to announce that we are now accepting applications for the  
2024 Emmett's Legacy Fund grant program!**

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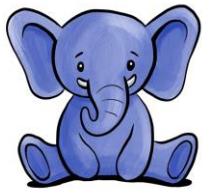
*Emmett's Legacy Fund was created in 2021 to remember and honor the life of Emmett Nguyen. Emmett was born in April 2016 with PIGA-CDG, a rare and devastating genetic metabolic disorder. He was loved by everyone around him, and fought through multiple illnesses and hospitalizations during the course of his short life.*



*In February 2020, Emmett lost his battle with PIGA-CDG and passed from respiratory complications. His memory lives on and continues to inspire friends and family who followed his story throughout his life.*

*Emmett's parents created this fund as a celebration of his life, and as a way to make a meaningful impact in the lives of other children diagnosed with CDG & NGLY1-deficiency. For more information about Emmett and his life, visit [www.lifebyemmett.com](http://www.lifebyemmett.com). For information about PIGA-CDG, please visit <https://www.piga-cdg.org/>*

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EMMETT'S  
LEGACY FUND



### **Overview:**

Life with Congenital Disorders of Glycosylation (CDGs) is tough. We understand the many challenges (expected and unexpected) that arise on a daily basis, and our aim is to alleviate some of these hardships. Through Emmett's Legacy Fund, we hope to help improve the quality of life and activities for individuals diagnosed with CDG/NGLY1 and their families.

**Grant Eligibility:** We work directly with families around the world who have received a confirmed diagnosis of Congenital Disorders of Glycosylation (CDG) or N-glycanase deficiency (NGLY1).

### **Grant Guidelines:**

- Types of items considered for this program include: seating, mobility, transport, comfort, positioning, bathing, therapy and feeding. Specific ideas are detailed on Page 3.
- All requests require a letter of medical necessity from a licensed physician/specialist, therapist, or social worker who works directly with the patient.
- All grant requests must be more than \$150 USD and grants will be awarded up to \$2,000 USD.
- You may submit requests for equipment/items >\$2,000; however, please provide explanation of supplemental funding. No more than **two** separate items may be included in one grant application.
- Applicants may apply in consecutive years; however, funding will be determined based on the funds available in a given year and priority will be given to applicants who have not yet received an Emmett's Legacy Fund award.
- Grants will be awarded either as reimbursement for purchase (with proof of purchase) or paid directly to the vendor. Grants will not be awarded in the form of cash or check made payable to the patient/family prior to acquisition of the item.
- Grant award recipients will be required to submit an update on how the grant support has made a positive impact on their child/family.

### **Application Deadline**

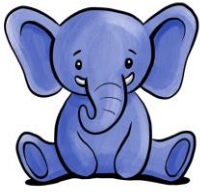
March 31, 2024

### **Recipients Announced**

April 11, 2024

### **Checklist:**

- 1) Completed application with parent/guardian signature.
- 2) Equipment request details including where to purchase, size, color, etc.
- 3) Letter of medical necessity from a licensed healthcare provider who works directly with the child/family.



**Examples of Eligible Items:**

Types of items considered for this program are (but are not limited to): seating, mobility, transport, comfort, positioning, bathing, therapy and feeding. We would urge you to consult with your healthcare professional team and/or therapist(s) on which items might be beneficial for your child(ren).

Items for safety: Special needs car seats, feeding chairs, bath chairs, floor sitters

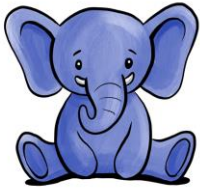


Items for Therapy: Adaptive tricycles, therapy benches, mats, wedges, swings, speech communication software/devices, sensory supplies/equipment, gait trainers, standers



Medical: Cooling vests, mattresses, seizure helmets, orthotics (and shoes to go with orthotics)





**EMMETT'S  
LEGACY FUND**



**2023 Medical/Therapy Equipment Grant Application**

Return this form by email or mail to:

Email: [grants@cdgcare.org](mailto:grants@cdgcare.org)

Address: CDG CARE, PO Box 38832, Colorado Springs, CO 80937

All fields and forms are required to be filled out completely for application to be considered.

**Patient Information:**

Last name \_\_\_\_\_ First name \_\_\_\_\_

Male  Female

Patient's Date of Birth (MM) \_\_\_\_\_ (DD) \_\_\_\_\_ (YYYY) \_\_\_\_\_

**Parent/Legal Guardian Information:**

Last name \_\_\_\_\_ First name \_\_\_\_\_

Address/City/Zip: \_\_\_\_\_

Address Line 2 (include Country): \_\_\_\_\_

Home phone \_\_\_\_\_ Cell phone \_\_\_\_\_

Email \_\_\_\_\_

Does the household speak English? Yes \_\_\_\_\_ No \_\_\_\_\_ If no, what is the primary language? \_\_\_\_\_

**Financial & Household Information:**

Item Requested: \_\_\_\_\_

Amount Requested (\$ USD): \_\_\_\_\_ Have you received previous CDG CARE funding? YES \_\_\_\_\_ NO \_\_\_\_\_

Has funding been requested from additional sources? YES \_\_\_\_\_ NO \_\_\_\_\_

If funding has been received, from whom? \_\_\_\_\_ Amount \$ \_\_\_\_\_

Household Income (circle one):

<\$30,000

\$30,000 - \$60,000

\$60,001 - \$100,000

>\$100,000

Number of dependents/children in household (circle one):

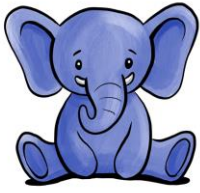
1

2

3

4

5 or greater



EMMETT'S  
LEGACY FUND



**Healthcare Professional Information:**

Pediatrician \_\_\_\_\_ Medical Specialist \_\_\_\_\_ Therapist \_\_\_\_\_ Case Manager \_\_\_\_\_ Other \_\_\_\_\_

Name: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Medical Organization: \_\_\_\_\_

Address/City/Zip: \_\_\_\_\_

Address Line 2 (include Country): \_\_\_\_\_

***\*Please attach a signed Letter of Medical Necessity from the Healthcare Professional describing why the requested equipment is needed.***

**Equipment/Item(s) Requested (please attach additional pages if needed):**

Describe the item(s) you are seeking funding for. Applications not providing exact brand and model number will not be considered. (You may attach website address or catalog pages for additional descriptive information).

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Describe the child's medical condition and the hardships, *in detail*.

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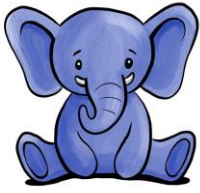
Describe, *in detail*, what ways this grant award will contribute to an increased quality of life for the child and/or family?

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EMMETT'S  
LEGACY FUND



Describe, *in detail*, how this item will be used (how often, medically necessary, therapy advancements, etc.)

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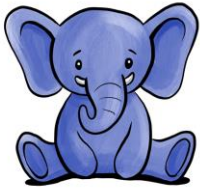
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Has this requested item been submitted to an insurance company and/or Medicaid in the past? If so, when, and what was the outcome?

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**Follow up Requirements:** CDG CARE asks that that all grant award recipients submit an update on how the equipment and/or item(s) have made a positive impact on their child/family within 45 days of receiving the equipment/item(s). CDG CARE will list grant awards on website, social media and other printed materials. Please specify if you do NOT want this information shared.



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LEGACY FUND



**Disclosure/Signature:**

\_\_\_\_\_ (initials) I declare that the information provided in this application for financial assistance is true and complete to the best of my knowledge.

\_\_\_\_\_ (initials) I understand that I may be required to provide evidence of submitted information and that CDG CARE may contact the healthcare professional listed in this application for verification purposes.

\_\_\_\_\_ (initials) I agree to allow CDG CARE to use my name and photographs, if provided, in announcements and related publications.

\_\_\_\_\_ (initials) I understand that I will be notified by email as to the status of this application and have provided a valid email address.

Parent/Legal Guardian Signature: \_\_\_\_\_

Parent/Legal Guardian Name Printed: \_\_\_\_\_

Date: \_\_\_\_\_