



The Marc Jr Foundation works to bring DIPG Families Assistance by joining forces with Amazing Foundation's that are doing Amazing work!

What is Financial Assistance from the Marc Jr Foundation

- The Marc Jr Foundation offers financial assistance to assist with the cost of any issue for families who have a child diagnosed with a DIPG;
- Financial assistance can be used to cover basic travel expenses, including transportation and food.
- **Once the Marc Jr Foundation reviews your application it will be submitted for final approval.**

Who is eligible?

To be eligible for financial assistance, your child must:

- Have a DIPG diagnosis of cancer as certified by an oncology healthcare provider from your child's Children's Hospital.

How do I apply?

In order for an application to be considered, please fill out the application in the appropriate section(s) and it **MUST BE SUBMITTED and COMPLETED**:

- Your child's social worker or health care provider **MUST** submit a completed Financial Assistance Application.
- Please PRINT clearly: illegible applications will not be processed.
- Use 'no', 'none', or '0' as appropriate; do not leave a blank response.
- A medical oncology professional must complete all sections of the Medical Information Section and provide a signature and date. **You or your family member MAY NOT complete this section!**
- **ACCO:** Please select the items you would like to receive and submit along with your Marc Jr Grant application to receive the selected items.

Note: You can submit this application by:

- E-mailing your application to migrants@marcjr.org

***Please note: Submission of an application is not a guarantee of receiving funds.
Funds are limited and based on eligibility and availability of funds.
We will not process incomplete applications.***



Marc Jr Foundation
PO Box 33042
Denver CO 80233

APPLICATION

PATIENT INFORMATION (please print clearly)				Date:
Patient First & Last Name:				
Parent/Guardian First/Last Name:				
Street Address:				
City, State, Zip:				
Home Phone:		Mobile:		
Patient (Child's) Date of Birth:				
Primary Language		Secondary Language (if applicable)		
Email Address:				
Schools Name				
Teacher's Name				
Grade				
<input type="checkbox"/>	Monkey in My Chair [check if you would like the Marc Jr Foundation to order your kit] http://www.monkeyinmychair.org/get (there is ONE kit per family)			
<input type="checkbox"/>	HopeCam – please check if you would like an iPad for your DIPG child. [note the Marc Jr Foundation will send a \$350 iTunes gift card for a medical speaking app upon request]			
SEE PAGE 5 IF TRAVEL IS NEEDED				

MEDICAL INFORMATION			
***THIS SECTION MUST BE COMPLETED BY YOUR ONCOLOGY NURSE, DOCTOR, SOCIAL WORKER OR HOSPITAL ACS PATIENT NAVIGATOR ONLY ***			
Date of Diagnosis:			
Primary Cancer:			
<input type="checkbox"/> New Diagnosis	<input type="checkbox"/> Recurrence	Is patient in active treatment? <input type="checkbox"/> Yes <input type="checkbox"/> No	
HEALTHCARE PROFESSIONAL INFORMATION (please print clearly)			
MD Name:			
Hospital/Clinic:			
Phone Number:			
MD Email			
Social Worker First & Last Name:			
Social Worker Email:			
Business Phone:		Mobile:	
Your relations to person applying for help: <input type="checkbox"/> Doctor <input type="checkbox"/> Nurse <input type="checkbox"/> Social Worker			
<input type="checkbox"/> Medical providers recommend a clinical trial and would like help with travel and housing from the Marc Jr Foundation (please provide the name, email, and phone number of the social worker we should contact (see above).			
Name of Medical Professional Signing (please print):			
Signature of Medical Professional:			



FREE --- The items listed below are being offered free of charge by the ACCO. Please select the items you would like to receive and submit along with your Marc Jr Grant application to receive the selected items.

☐ **Medical Play Kit**

The ACCO's Medical Play Kit is a free resource designed to familiarize children battling cancer with many of the medical instruments they will encounter during their hospital stays. We hope to empower children by helping them become more comfortable in a hospital environment and giving them the opportunity to play the role of doctor/caregiver rather than be forced into the role of patient. Please note that Cozy the Port-a-Cat is requested separately.

☐ **Along the Way, Documenting My Child's Cancer Journey**

A parental resource that provides a way to document medical treatments, hospital contact information, treatment expenditures, and local resources. This logbook also contains information about clinical trials, treatment procedures, blood counts, side effects, a journal section, and a place to take notes.

☐ **Paul and the Dragon DVD**

Now available online! <https://www.acco.org/paulandthedragon/>

This 25 minute animated cartoon is for children diagnosed with cancer, their family, school, and friends. The child with cancer is seen as a hero who battles the evil cancer-dragon with the help of medications and family support. The story can be personalized to the child's individual cancer type and treatment. Created, directed and animated by Albert 't Hooft and Paco Vink of Anikey Studios and produced by il Luster Films Foundation, ACCO is the sole U.S. distributor of this important visual resource. One free copy per child diagnosed with cancer ages 2-12. Additional copies available for purchase through ACCO's web store.

☐ **Dance in the Rain – Teen Journal**

A Teen journal that allows adolescents a place to write out their thoughts and feelings throughout their cancer journey. Includes a wooden pen and pencil set.

☐ **Cozy Cares Journal**

This 122 page full color journal features ACCO's mascot, COZY the Port-a-Cat. It encourages children with cancer to express their feelings by writing and drawing. Text prompts assist children with identifying people in their lives who they can talk to about their cancer diagnosis and treatment. Written to empower children to find their inner strength, this journal will also be a treasured keepsake for years to come.



☐ **Journal Pen**

Each Cozy Cares Journal comes with a fun pen in the shape of hand gestures like "thumbs up" and "I love you." Select your desired color.

- ☐ Yellow
- ☐ Green
- ☐ None

☐ **Cozy the Port-a-Cat**

Cozy the Port-a-Cat is not your everyday stuffed animal. He is a companion that children with cancer can relate to, and he is a teaching tool for parents and healthcare professionals. Children are able to learn about cancer treatments by identifying and practicing them on Cozy, who has endured many cancer related treatments as seen by the patches on his fur. Cozy also proudly displays the gold ribbon symbol over his heart and ACCO's logo on his foot. Children will want to take Cozy with them everywhere.

☐ **Marvelous Marleigh**

A 31 page book for preschoolers diagnosed with cancer (ages 1 to 5 years). Through real-life photos, preschool children are able to identify with Marleigh's treatments and hospital stays. The last page of the book includes a mirror so that children can see themselves and reflect upon the thought that Marvelous Marleigh is "just like them."

☐ **La Fantastica Hannah, Miren todo lo que puedo hacer!**

This 28 page picture book is written for the Spanish-speaking preschool child who has been diagnosed with cancer. Through real-life photos, children will be able to identify with Hannah's hospital stay, special friends, tests, treatment and germ care.

☐ **Oliver's Story: For "Sibs" of Kids with Cancer**

40 page illustrated book targeted for the 3 to 8 year old sibling of children diagnosed with cancer. Illustrated by Mike Dodd and written through the eyes of his six-year-old son Oliver, this resource focuses on the many questions that siblings have when their brother or sister is diagnosed with cancer, and offers constructive ways on how they can provide support.

☐ **La Historia de Oliver, Para los Hermanos de Niños con Cancer**

Oliver's Story (above) for Spanish-speaking siblings.

☐ **Chemo, Crazyness, and Comfort**

200 page resource that provides practical advice for children diagnosed with cancer between 6 and 12 years of age. Warm and funny illustrations and easy-to-read text help the child (and parents) make sense of cancer and it's treatment.



☐ **Educating the Child with Cancer, A Guide for Parents and Teachers - Personal Copy**

An essential resource for families who have faced the childhood cancer diagnosis. Written by top researchers in the field, and balanced with parent's personal experiences, this 322 page resource covers learning issues from infancy through adulthood. A good education provides hope for the future.

☐ **A Parent's Guide to Enhancing Quality of Life in Children with Cancer**

An essential resource for families who have a child diagnosed with cancer. Written by experts in the field, and balanced with parents' personal experiences, this 261 page resource focuses on improving the quality of life of the child through an understanding of pain and symptom management, enhanced communication skills and practical ways to simply help sick kids be kids.

☐ **Color Me Cozy!**

This is an inspiring 25 page book filled with wonderful pictures to color, word activities to complete and words of encouragement for kids with cancer.

☐ **A Parent's guide to clinical trials**

Is a concise reference guide which explains what clinical trials are, which defines a clinical trials process and structure.



TRAVEL / FINANCIAL FORM

Leaving From

Going To

Departure Date

Returning Date

Number of Travelers

Name of Clinical Trial

Name of Hospital

Do you have housing
arranged for clinical trial
(please describe)

Do you have air arranged
for clinical trial
(please describe)

Do you have transportation
arranged for clinical trial
(please describe)

Other

Gas Card Gift Cards
(please describe)

Meal Gift Cards
(please describe)

Additional Information:

NEW BEST PRACTICES TO KNOW UPON DIPG DIAGNOSIS

Dr. Sabine Mueller

- The most important first step is radiation to start relatively quickly (to preserve as much function as possible during the honeymoon period that many patients have, or to improve any functional loss before its permanent) – for some children with less symptoms this might be less critical.
- There is no documented difference between proton or photon radiation for DIPG/DMG, so whatever can be offered sooner should be considered. Radiation is standard of care used for many years and can generally be performed at most hospitals safely.
- Steroids should be weaned as quickly and safely as possible – when and how much to use depends heavily on the clinical presentation and should be discussed with your team. Consider with your team whether it is necessary to start steroids proactively. Steroids do not inhibit the tumor from progressing, steroids help alleviate symptoms caused by inflammation surrounding the tumor. Learn the pros and cons of steroids early.
- Biopsy should be performed by someone who has experience with the procedure. If a patient is critically ill and needs to start radiation therapy quickly, a biopsy can also be performed after completion of radiation therapy. Biopsies are necessary to confirm the diagnosis and determine the specific DIPG subtype. Having tissue available is becoming more and more important as many trials require information from the biopsy or actual tissue for enrollment. Be sure that the tissue is used for relevant testing – often the tissue is fairly limited. Data generated from the tissue can easily be shared with others.
- Some clinical trials start WITH radiation, but most clinical trials start after radiation – all trials are listed on clinicaltrials.gov but be sure to discuss these options also with your team. It is challenging to sort through the different options alone.
- Ask for a second opinion if you want to – it is highly recommended to get second opinions from different centers with experience treating DMG, as centers have different options to offer. Some trials are only available in certain places and providers have variable levels of comfort taking care of ALL diagnoses, including DIPG.
- If your insurance is not covering all needs, talk to your social worker about secondary insurance options (i.e. Medicaid).
- Palliative care is often a helpful resource in the beginning to coordinate care, provide emotional support, etc. and palliative care can be activated WHILE on therapy in pediatric and plays a different role than classic “HOSPICE” end of life care in adults. Palliative care teams can really make your life much easier.
- We will make more progress when working as a team– data sharing for a rare disease like DIPG is critical. One example is the DMG ACT. This group combines researchers around the globe to develop the best next therapies for children with DIPG. Anyone can join and we aim to make data available as soon as possible to enhance research further. Consenting to share data with the Children's Brain Tumor Network allows researchers to learn from DIPG patients to drive treatments.