



Your child has been diagnosed with diffuse intrinsic pontine glioma, diffuse pontine glioma, or brain stem glioma. You don't know much about the disease other than what the doctors have just told you. Now what do you do?

Like you, our children were given this same diagnosis and like you, we scrambled for information.

## We Can Help

The Marc Apodaca Jr. Children's Glioma Cancer Foundation ("Marc Jr Foundation") was formed by the families and friends of children treated for diffuse intrinsic pontine glioma at The Children's Hospital of Denver. We have put together a gift for you ... this binder of information that will help you obtain and sort the information throughout you and your child's journey. This binder includes:

- General DIPG information
- A terminology sheet
- A listing of some additional foundations to consider contacting
- DIPG Registry
- Marc Jr Grant Application
- General discussions on "Quality of Life" issues
- Stories about our children & our experiences with DIPGs.
- A Health Guide & Diary
- Some suggested questions for your doctor
- A single place to keep track of appointments, medications, MRI results, gifts and donations.

Upon contacting us, we will provide you with information to assist with your expenses during your child's treatment. You can also go to [www.marcjr.org](http://www.marcjr.org) for additional information on resources and support.

### **Marc Jr. Foundation**

Marc & Lynette McCarty Apodaca

720-840-4995

[lapodaca@marcjr.org](mailto:lapodaca@marcjr.org)

[www.marcjr.org](http://www.marcjr.org)

# What is Marc Jr's Foundation?

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Marc Apodaca Jr., who the Foundation is in memorial of, was diagnosed in 2007 with a diffuse intrinsic pontine glioma (DIPG). As parents, we realized how little help there was in the form of treatment, information, and support for the families facing glioma cancer. Much of the information we found from online research or medical journals was very difficult to understand.

From our experience, we found many families who are facing, or who have faced this dreadful disease to be a wealth of information. We found that once parents and the community are faced with this type of cancer, each unknowingly foster a spirit of compassion, wisdom, charity, and a willingness to share.

We created the Foundation to help support families in their search for answers and to utilize the support of families fighting this insidious disease.

## Disclaimer

We are not medical doctors. The information contained herein is provided strictly from parents who are offering the information they have found beneficial from their own independent research. They offer you this information as a form of support, which they hope will be viewed as help given to you about things they believe have given their child hope of healing and a better quality of life.

When Marc Jr. was first diagnosed with a DIPG, I didn't want to believe that my child had this serious illness; therefore, I didn't want to talk to my friends or family about this. I was hoping it wasn't true. I wish I would have had the information in this binder and I believe I would have been open to talking to family and friends who were willing listen.

-Marc Apodaca

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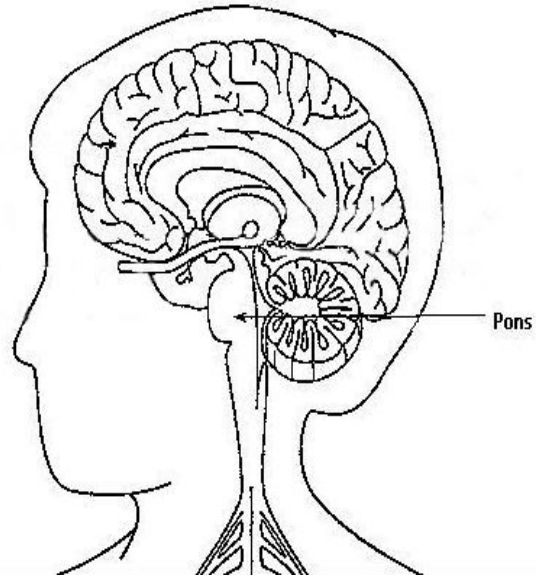
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# What is Diffuse Intrinsic Pontine Glioma?

Your child's doctor can give the full, medical description of diffuse intrinsic pontine glioma (DIPG), all of the treatments that are available, and your child's overall prognosis. This guide is designed to provide high-level introductions to these areas to assist with the decisions that you will be making along with your doctor.

Simply put, DIPG is a cancer of the pons - the area directly above the brainstem - and is considered one of the most dreaded forms of childhood cancer due to the historically poor prognosis. DIPG is very rare and affects approximately 300 children per year in the United States. There is no known cause; it affects girls and boys equally; spans all social, racial, and religious groups; and has a peak incidence around 6 to 9 years of age.



Cancerous tumors are classified and named based on their pathology and location. This tumor is diffusely spread throughout the pons and initially forms in the glial cells that support the central nervous system. DIPG is also called diffuse pontine glioma, diffusely infiltrative brainstem glioma, and brainstem glioma. The Marc Jr Foundation, and most of the organizations that we collaborate with use the name diffuse intrinsic pontine glioma (DIPG).

Having your child diagnosed with DIPG is earth shattering. Everything in your life has been reprioritized. When it comes to the health of your child, you know them better than anyone else in the world including your doctor. Trust your judgment, ask questions, and don't be afraid to seek second opinions.

## Prognosis

Survival times vary from child to child with the majority of children dying within one year of diagnosis. Fewer than ten percent of children survive for more than two years.

Don't hesitate to ask your doctor for a second opinion. Ours gladly sent Sam's scans to St. Jude's Hospital and they gave us their opinion.

-Pete Walsdorf

## Symptoms

The initial symptoms of DIPG build gradually for as much as six months prior to diagnosis and include clumsiness, weakness of an arm and/or leg, double vision, tilting of the head, mood changes, and headaches. The gradual buildup of the severity of these symptoms allows them to go unnoticed for months.

## Treatment

Treatment plans for DIPG are usually designed to relieve the symptoms of the cancer as well as reduce the size and growth rate of the tumor.

### Radiation or Radiotherapy

Radiation is the primary treatment plan for most children as it has shown positive results in reducing the size of tumor. Radiation therapy is given in low doses over approximately six weeks to the exact portion of the brain that is affected. The first few sessions are used to create a targeting mask for the treatments and will include another CAT scan or MRI. Your child will wear the mask during subsequent treatments to ensure that the radiation is being delivered to the correct portion of the brain to maximize the effectiveness. Common side effects of radiation include decreased energy and hair loss to the radiated areas.

We found radiation fairly easy to manage once Ben got used to the routine. I'd help him onto the table and hold his hand while they adjusted his mask before the five-minute treatments.

-Dean Steadman

### Chemotherapy

Chemotherapy and other cancer fighting drugs are constantly being evaluated for use in treating DIPG. Traditionally, chemotherapy has shown little impact on the treatment of DIPG due to the blood brain barrier that protects the brain from infections. Improvements have been made in recent years, but to date there is no commonly accepted chemotherapy plan for DIPG. Many of these newer treatment plans are designed to increase the effectiveness of radiation therapy. Your doctor will present you with information on any of these programs that are currently available. We recommend reviewing page 87 of the Moss Report for details on how clinical trials are designed and operated as well as asking your doctor for details on the side effects of the treatment, how the drugs are administered, and what the expected outcomes are.

### Steroids

Decadron (Dexamethasone) is a very powerful steroid commonly prescribed to reduce the swelling of the tumor and relieve many of the initial symptoms associated with DIPG. Most children are slowly weaned off if it during or after radiation. Many doctors prescribe it as part of palliative care as well due to the speed at which it can

Decadron can cause sleeplessness. Sam watched "Chicken Run" five times in a row one night.

-Hope Walsdorf

relieve swelling and the accompanying symptoms. Side effects include decreased energy, sleeplessness, irritable mood changes, food cravings, weight gain, puffiness of the face, high blood pressure, and an increased risk of infection. We recommend patience and love when dealing with your child while they are taking Decadron.

### Neurosurgery

Surgery is not a common option for DIPG due to the way that the cancer diffusely grows between the normal cells of brain. Surgery can be used to place shunts into the brain to relieve pressure, but this is uncommon.

### Experimental Therapies

In addition to the standard therapies, there may be new/experimental therapies available for your child.

These treatments are considered experimental because they have not been given to many children and we do not know if they are going to be helpful in the treatment of DIPG. These treatments may be available through participation in a clinical trial or study. If you are interested in possible alternative treatments, you should ask your doctor to see what options may be available for you. Important questions to consider asking in addition to what trials are available: What are the risks and side effects? Has this trial shown any effectiveness in DIPGs? Is there a reason it should be tried in DIPGs? How often do we have to be in the clinic for this study? You can also visit [www.clinicaltrials.gov](http://www.clinicaltrials.gov) for additional information.

### Progression after Treatment

Most children experience a relief from the symptoms of DIPG after radiation treatment. This "honeymoon" period can last for weeks or months as each child's tumor, responsiveness to radiation and treatments, and general health are different. We recommend using this time to enjoy your child and explore any additional treatment options that may be available.

Unfortunately, most children will experience a recurrence of the tumor and a return of their symptoms. For most, the symptoms will return at a faster rate and with greater severity than they originally appeared. We recommend focusing on palliative care - health care focused on reducing the severity of the symptoms rather than to halt or reverse their progress - and on being together as a family.

Your job as a parent is to remain focused on keeping your child feeling safe and loved. This time is no different.

Dealing with the side effects of Decadron was a challenge. Ben's face swelled, he was constantly hungry, tired and surprisingly crabby. We never left home without his favorite snacks.

He also regained much of his facial muscle control, balance, and strength. We were anxious to cut it out of his treatment, but grateful for the results.

-Dean Steadman

# Helping Hands

The news of your child's diagnosis is going to bring out the support and generosity of everyone you know and everyone who hears. Unfortunately, no one knows how to really help and their efforts often end up as well intentioned sympathetic gestures. To make matters worse, many parents have no idea what help they need or even how to ask.

This section outlines some of the things that our member parents found helpful. Share this information with your family, friends, church congregation, coworkers, or anyone else who can help.

**"How can I help?"** were usually the first words out of everybody's mouth and without a doubt, the hardest to answer. I had no idea how to help Ben, myself or even what challenges were ahead.

-Melinda Steadman

## Accept Charity

Our first bit of advice is to accept the love and generosity of those around you. Accepting charity does not come easily to many people and is often looked down upon in our society. The simple fact is that this is the time to focus on your child and the needs of your family. You'll find assistance coming in many forms and from surprising sources. Graciously accept it.

## Delegate to Others

For many, the daily struggles of normal parenting can be a challenge. Dealing with everything from getting your kids dressed, fed, off to school, to soccer practice and into the tub at night is a fulltime job not to mention managing your relationships, career, and wellbeing. Suddenly adding the challenge of childhood cancer into the mix is overwhelming as the priorities of yesterday are now trivial compared to the health of your child. Delegate as many of these "trivial" tasks as possible, focusing instead on the tasks that directly impact your family.

Examples of tasks that can be delegated:

- House cleaning
- Laundry
- Cooking meals
- Yard work
- Running errands

A few moms from Sam's preschool cleaned our house from top to bottom. Cleaning was the last thing on my mind - what a wonderful gift.

-Hope Walsdorf



## Assign Organizers

Assign someone to be in charge of coordinating these mundane tasks to ensure that your well-wishers efforts are most effective. For example, specify one family member to organize all meal deliveries to ensure that you're not suddenly overwhelmed with several meals at the same time or have the same meal several nights in a row.

## Fundraisers

Fundraisers are a great way for your community to rally around your child and relieve some of the financial pressures of their treatment. Successful fundraisers require masterful organization and should be delegated to others to arrange.

Additionally, several foundations offer financial assistance to the parents of cancer patients. The social workers at Children's Hospital of Denver can direct you to many of these foundations and assist with the application process.

## Start a Blog or Journal

For many people, this recommendation may seem like the hardest to undertake, but it has several advantages. Keeping a written history of your thoughts and feelings is wonderfully therapeutic whether you choose to create a public blog or simply keep a private journal. A blog or online journal is a fantastic method for keeping everyone updated on your child's fight with DIPG. Coworkers, church members, distant relatives and friends of friends all want to know how your child is doing, but are either too afraid to ask or are trying to respect your privacy. A website is an excellent, non-intrusive method for keeping everyone updated. Blogs are also a way to discover and share information with other families battling DIPG.

There are several free blogging sites available such as [blogger.com](http://blogger.com). These sites are simple to setup and many online help resources are available. Sites such as [caringbridge.com](http://caringbridge.com) offer more privacy and focus on providing services to patients and their families. This is great option for sharing your story and maintaining a level of privacy.

We have experience with all of these options and will help get you started.

## Seek Counseling

Your child has been diagnosed with a very serious form of brain cancer - you're going to need some help. Please turn to someone to focus on your mental and spiritual well-being. Seek assistance from the social workers at Children's Hospital, a professional counselor or clergy.

# Marc Jr Recommended Resources

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## Butterfly (Denver Only)

Children and their families enrolled in The Butterfly Program are able to access supportive services including nursing, social work, chaplaincy, and expressive therapy while receiving curative and therapeutic medical interventions aligned with their goals of care. The focus of the program is solely on the quality of life for the child, and their families.

## Children With Limited Life Waiver (Denver Only)

The CLLI program provides Health First Colorado benefits in the home for children with a life limiting illness. This waiver allows you to seek curative treatment while your child is receiving palliative care.

Services offered with this waiver supplement the services that you already receive through regular Health First Colorado benefits and other federal, state, and local public programs, as well as the support that you get from your community.

Children who receive services through the CLLI waiver are also eligible for all Health First Colorado covered services except nursing facility and long-term hospital care.

## The Child and Family Wellness Center (Denver Only)

The Child and Family Therapy Center of Denver is compassionately dedicated to improving the lives of each family we serve.

Kelly Curnalia - Executive Director: [kelly@childfamilytherapyofdenver.com](mailto:kelly@childfamilytherapyofdenver.com) (720-442-2720)  
[www.childfamilytherapyofdenver.com](http://www.childfamilytherapyofdenver.com)

## Kids Mobility Network, Inc. (Denver Only)

Kids Mobility Network is a 501(c)3 non-profit organization providing children with disabilities with durable medical equipment such as wheelchairs, walkers and other medical equipment. We operate our organization with caring and integrity.

Through hard work, effective use of adaptive technology, and comprehensive service, Kids Mobility Network is changing the lives of children with disabilities and their families.

Peter Kopp - Co-Founder: [Peter.kopp@kidsmobility.org](mailto:Peter.kopp@kidsmobility.org) (303-242-8281)  
[www.kidsmobility.org](http://www.kidsmobility.org)

## Children's Brain Tumor Foundation

The Family 2 Family (F2F) Mentor Program connects caregiver, survivor, and bereaved caregiver mentors to families who are seeking peer support.

## Super Sibs

Sibling Comfort and Care – Our SuperSibs Comfort and Care Program provides tools to help siblings during and long after this life challenge.

## ACCO Free Books

Offer quality materials for children and families who are dealing with childhood cancer.

Recommended book- *Understanding the Journey: A Parent's Guide to DIPG*

## DIPG Warrior

DIPG Warrior is The Cure Starts Now's way to help your family and friends through: awareness, support, fundraising, and more than anything, honoring your DIPG Warrior.

## DIPG Registry

The International Diffuse Intrinsic Pontine Glioma (DIPG) Registry is a collaborative effort by physicians and researchers from North America, Europe, and Australia to centralize and standardize the collection of clinical data and tumor samples from DIPG patients. The goal of this effort is to support innovative research and ultimately find a cure for DIPG.

## The Children's Brain Tumor Tissue Consortium

Bringing together leaders in pediatric brain cancer research through cutting-edge technology to innovate, collaborate and share data.

## Mealtrain

mealtrain.com simplifies the organization of meal giving around significant life events. We strive to simplify and promote interpersonal relationships between friends, families, and neighbors through meals.

## Cancer Support Community

Providing comprehensive care - including counseling, support groups, nutrition, exercise and education - for cancer patients and their loved ones.

## Caringbridge

A CaringBridge website is a personal health journal, rallying friends and family during any type of health journey. Start a free CaringBridge website today.

## Clinicaltrials.gov

ClinicalTrials.gov is a registry of clinical trials. It is run by the United States National Library of Medicine (NLM) at the National Institutes of Health, and is the largest clinical trials database

## DIPG.org

Offer facts regarding dealing with a Diagnosis of DIPG



## Monkey In My Chair

Monkey in My Chair is a program originally developed in honor of Chloe Watson Feyerherm for pre-school and elementary aged children who are away from school because of a cancer diagnosis. As a result of Chloe's experience, her mother, teachers and community got together to develop the Monkey In My Chair program through the efforts of their newly established charity, the Love, Chloe Foundation. In 2011, in an attempt to have the program complement cancer research efforts, the Love, Chloe Foundation partnered with The Cure Starts Now Foundation to offer the program to a wider audience, thus increasing both awareness and donations to not only support the program but also fund the cure for cancer.

## The Bunting's Tale

Capture your Family's Story: A voice left on an answering machine, candid moments on video clips, memories of lazy afternoons. For some of us, these are all we have left of loved ones.

Memories fade. My aim is to capture the family folklore, the detailed history and the essence of the storyteller with an audio recording to preserve and revisit for years and years.

Erin Schneiderman - Owner: [Erin@thebuntingstale.com](mailto:Erin@thebuntingstale.com) (303-669-3191)  
[www.thebuntingstale.com](http://www.thebuntingstale.com)

## There with Care

Our mission is to provide a wide range of thoughtful and fundamental services to families and children during the critical phase of a medical crisis. We serve families referred by medical agencies, by building a network of services and people who ease the burden of life's day-to-day obligations with compassion and care.

Mary Beth Appel - Program Director: [marybeth@therewithcare.org](mailto:marybeth@therewithcare.org) (303-447-2273)  
[www.therewithcare.org](http://www.therewithcare.org)

## Hope Kids

HopeKids provides ongoing events, activities and a powerful, unique support community for families who have a child with cancer or some other life-threatening medical condition. We surround these remarkable children and their families with the message that hope can be a powerful medicine.

Lisa Sweeney - Program Director: [lisa@hopekids.org](mailto:lisa@hopekids.org) (720-366-9833)  
[www.hopekids.org](http://www.hopekids.org)

## Double J Foundation

Emotional & spiritual support for families after a cancer diagnosis

Ashley Andrews - Founder: (719) 564-2772

\*no website yet



## Quite Strength

Quiet Strength is a 501(c)(3) charitable nonprofit committed to supporting families battling pediatric cancer. When a child has cancer, the entire family is in pain. We want to make life more bearable for all members of these brave families. We are a small group, with big ideas and high hopes... inviting and welcoming fellow travelers on this journey.

Supporting courageous children with cancer, their parents and siblings is a big undertaking. Quiet Strength is just beginning, so we're starting out slowly with two projects ~~ our Gift Photography Program and a Gift Card Program.

Mary Sharrenberg - Founder & Executive Director: [mary@quietstrength.org](mailto:mary@quietstrength.org) (408-706-6287)  
[www.quietstrength.org](http://www.quietstrength.org)

## RECOMMENDED

### Google Calendar

Google Calendar application allows users to create personal or public calendars and share calendars. Calendar sharing means that it's easier to share information such as doctor appointments and invitations with family members across their devices.

### One Note

OneNote is your digital notebook for capturing and organizing everything across your devices. Jot down your ideas, keep track of doctors and meeting notes, clips from the web, or make a to-do list, store voice files to refer to later as well as draw and sketch your questions or ideas.

### Office Lens

Office Lens allows you to scan and import business cards from your iPad or mobile phone to OneNote. It will save as a picture and read the business cards and have them converted into digital contacts in your address books- great for when you're going between appointments and you do not want to misplace a business card.

### Facebook Groups

DIPG Parents Only Sanctuary  
DIPG Awareness for Family and Friends  
DIPG Research  
Marc Jr Foundation - DIPG

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The Marc Jr Foundation Board of Directors and Volunteers hope you find this information helpful in your quest to navigate a DIPG diagnosis.

The Marc Jr Foundation offers this information because we know and understand that you have a very important role to play and we hope that you find the information provided useful, timesaving and beneficial.



## Providing Support

Through the hard work and dedication of DIPG parents and volunteers this information has been provide to you in the hopes of offering “social support”. Some apps will offer informational support while others will be gathering data or the latest news on DIPG. And others will give practical help like driving to and from doctor appointments, cooking, cleaning, grocery shopping and child care. We offer you this information in the hopes it will be viewed as help given to you about things we believe have given our child hope for a better quality of life and we hope it makes you feel loved, cared for and understood.

## Taking Care of Yourself

Watching your child battle cancer can, in so many ways, be as hard as fighting it yourself. It can be painful to see them struggle and you may hide your feelings of anger, fear or helplessness because you don’t want to upset them. As members of your DIPG community, we encourage you to talk about your feelings. Connecting with other DIPG families can be a huge source of support, so we encourage you to please consider visiting and/or joining the suggested DIPG/cancer supporting communities (see above).

# Terminologies and Descriptions

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**Astrocyte** - Glial cells that anchor neurons to their blood supply that regulate the external chemical environment of neurons. These may be the predominant building blocks of the blood-brain barrier.

**Astrocytoma** - A tumor developed in astrocyte glial cells.

**Blood-brain barrier** - Separation of circulating blood and cerebrospinal fluid that restricts the passage of substances from the bloodstream to the brain.

**Brainstem glioma** - The broadest term to describe all histological grades of glial tumor that are located in any part of the brainstem. Brainstem gliomas can be classified more specifically by particular location (e.g. pontine glioma) and by certain descriptive terms (e.g. diffuse, intrinsic).

**Diffuse** - Tumors with an infiltrative nature. Diffuse tumors are usually also intrinsic. These tumors cannot be removed without severely disturbing the surrounding tissue. Diffuse tumors can be thought of like 'sand in grass'.

**Diffuse brainstem glioma** - This is an infiltrative tumor of glial origin located anywhere in the brainstem. Most, but not all, diffuse brainstem gliomas can be more specifically called diffuse pontine gliomas or diffuse intrinsic pontine gliomas.

**Diffuse intrinsic pontine glioma (DIPG) or diffuse pontine glioma (DPG)** - A glioma (usually an astrocytoma) located in the pons, which intermingles with and infiltrates normal pontine tissue.

**Glial cells (glia)** - Non-neuronal cells that maintain homeostasis providing support and protection for neurons.

**Glioma** - A tumor arising from glial cells. Different adjectives can be applied to the term glioma to convey a more descriptive, specific understanding of the tumor.

**Intrinsic** - A tumor that originates or is included wholly within an organ.

**Pons** - The area of the brainstem that deals primarily with sleep, respiration, swallowing, bladder control, hearing, equilibrium, taste, eye movement, facial expressions, facial sensation, and posture.

We had so many friends and family that wanted to help in the search for information. We were constantly describing and spelling Ben's tumor to everyone. A handout like this would have made things a lot easier.

-Melinda Steadman

# Quality of Life

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A DIPG diagnosis is often considered to be terminal. Having your child diagnosed with a terminal illness is completely devastating and often leaves you with a feeling of shock and disbelief. Immediately you begin to weigh all of your options and search for a way to beat the odds. Leaving no stone unturned, you consider everything from conventional radiation and chemotherapy, to clinical trials and maybe even leaving the country. It's natural to feel like every waking moment needs to be spent on finding a cure, finding a "miracle" to save your child's life. We are their parents after all, and that is our job.

Minimizing the stress and anxiety often associated with various cancer treatments is extremely important and should always be a factor when considering them.

-Melinda Steadman

While there is no denying that anyone of us would do anything to save our children, there needs to be an awareness of the price both you and your family could pay in this "quest for a miracle." All too easily, the full focus of the family's energy can be spent chasing after promises of a cure, or at the very least, for more time. When this is the case, we can forget about the time we have now and how important it is to live in the present. Equally important is the realization that you may never find the "miracle" you so desperately pray for and your time with your child may be measured in only weeks or months. Try to make your child's remaining time with you both meaningful and fun, while making as many special memories as possible.

A good quality of life often means different things for different people, including children. You know your child best and therefore, what can be done by everyone to help them to maintain the quality of life that they want, and that you want for them.

I've focused so much energy into fighting Ben's cancer and losing just plain sucks.

The fight isn't over, but it's changed. I'm fighting to keep Ben comfortable, secure and feeling as loved as *he is*. *That's what I've always* done for him – from his first cries to today. Preparing yourself to lose a child is impossible, but just being Dad is easy.

-Dean Steadman

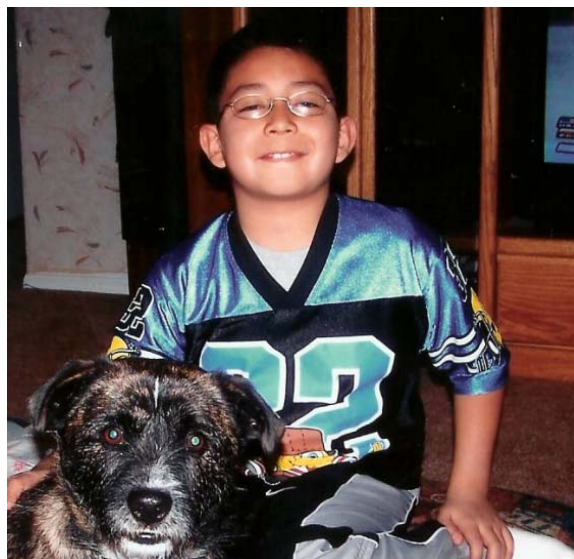


# Our Stories

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## The Apodaca Family

My husband's eulogy was titled "Our Brave and Courageous Champion," because that's what Marc, Jr. ("MJ") was to all who knew him. When MJ was diagnosed in April of 2007 with diffuse intrinsic pontine glioma (DIPG), our family's life entered a state of desolation. Our only son was diagnosed with an inoperable, incurable, and terminal brain tumor that strikes children usually between the ages of 5 and 11.



Marc was not only our son, but he was our friend. Marc cherished his family very much. He loved to play with his sisters, he loved to goof off and laugh with his mom, and he loved to hang out and tag along with his dad. Marc had a variety of hobbies. He studied Taekwondo in which he was a redbelt. He enjoyed the outdoors where he loved to fish and snowboard. He enjoyed playing basketball and envisioned himself one day playing in the NBA. Throughout the duration of Marc's sickness he never gave up. He never complained once and was all about courage. He displayed an awesome amount of determination and will. He loved life to the fullest. In this we are so very proud of him. Marc is our family's inspiration to live on. We loved to care for Marc, to watch him laugh and have fun. We thank God each day for allowing Marc to be a part of our life.

About a month after being diagnosed with the DIPG, Marc started to suffer from weakness and headaches, so it was decided to start radiation. According to his doctors, Marc's symptoms would dramatically improve (after the radiation), and they did. However, the symptoms recurred six months later and we were told that Marc would not survive longer than 12 to 14 months. (Incredibly, even saying it and having gone through it, I am wondering how does a parent handle this kind of news). After a difficult, courageous and heartbreaking struggle, Marc peacefully passed away on February 8, 2008.

The months to follow were filled with heartache and a complete sense of emptiness not only for ourselves but for our entire family and our circle of friends. We questioned our faith; went to grief counselors; tried to talk about it, but nothing made a difference because Marc was still gone and nothing was ever going to change that!

Please join us in getting the word out about the deadly childhood cancer that DIPG is and help us to help others in fighting and surviving this devastating and horrific disease.

## The Steadman Family

Melinda and Dean Steadman's son Ben was born on August 11<sup>th</sup>, 1999, the same day as the last total solar eclipse of the millennium. Our journey as a family had finally begun and, like the eclipse, Ben overshadowed everything else, becoming the center of our world. Eighteen months later, his little sister was born and our family seemed complete. They became best friends who constantly looked out for each other. Madie was willing to play Power Rangers and Ben was often seen dressed up as a princess. We looked on with wonder and amusement, always amazed at how lucky we had become to have this beautiful family.

We noticed changes in Ben in the fall of 2005. He stumbled into walls. His speech became slurred and he could no longer write his name. On September 8<sup>th</sup>, 2005, our world crumbled when we were given the diagnosis. Ben had a brain tumor called a diffuse intrinsic pontine glioma and it was terminal.



We couldn't comprehend it at first. Ben was going to die and there was nothing we could do to save him? The most we could hope for was a good response to radiation treatment, hopefully buying us a few more months. We were sent home with a few handouts and little hope. We scoured the internet looking for any information. Wanting to find anything that would help us, not only to save our son's life, but to help us know what to do now.

With little to go on, we decided on radiation treatment and several homeopathic medicines. Ben handled all of it with complete trust and courage, always willing to do what was asked of him. We also decided to do as much "living" as possible with whatever time we might have left. We managed several trips including a Make-A-Wish trip to San Diego. Ben was given a puppy we named Peaches. We were even allowed to feed the elephants at the Denver Zoo. Treatment brought us an additional 7 months which we spent doing our best to live life to its fullest.

On March 29<sup>th</sup>, 2006, our son Ben died peacefully in our arms at home lying in bed between us. Shortly thereafter, we discovered there had been a total solar eclipse that same morning. Ben's uncle Neal said it best, "that the sun itself was willing to stand aside to make way for both the arrival and passing of Ben."

Our goal is to support and educate the families battling DIPG until a cure can be found. One way for us to facilitate this goal is to share our treatment plan and our experiences.

## The Walsdorf Family

Hope and Pete Walsdorf's son Samuel was a typical 5-year-old boy. His passions were baseball, hockey, motorcycles and playing with his younger sister and brother. He was excited about starting his kindergarten year and especially about learning to read. Sam had an infectious laugh and a caring heart. He dreamt of being a professional baseball player - he wore his baseball pants almost daily and slept with bats, gloves, or baseballs instead of teddy's.

In late July 2005, Sam started tripping, talking slower, and losing strength in his right arm. On July 26th, he was diagnosed with diffuse intrinsic pontine glioma, a tumor in the brain stem.

Our lives were turned upside down.

Sam seemed to regress daily -- having difficulty eating, sleeping, needing help walking, and slowly losing basic motor skills. Eventually, he gave up talking but learned to communicate with his eyes. The only medical treatment options given to us were steroids and 6 weeks of radiation, both which Sam endured and barely survived. In our desperate attempts to save our son's life, we reached out to alternative therapies -- herbal supplements, homeopaths, energy, and light therapy. Through all this, Sam showed strength, courage, faith, and willingness to play and laugh. Without his speech, he was unable to tell us what his thoughts were. He accepted his disease and lived the best he could.

By Thanksgiving, Sam's tumor began to grow again. We were given a few weeks left with Sam. Sam died February 2nd, 2006 ... 19 days before his sixth birthday ... 6 months and 7 days after his diagnosis.

Samuel is and always will be our hero. He gave our family strength and faith that we never knew we had. He pulled people together. He made us smile in very, very hard times. He is a true champion.



## The Lucius Family

Our daughter Kayla was diagnosed with DIPG on August 23, 2005 on her first day of kindergarten at age 5. She had been drooling, seeing double, and clumsy for several weeks. After her first day of kindergarten, our eye doctor recommended an MRI and we found out later that day that she had a mass in her brain stem.

We took the advice of our doctors and started treatments immediately. First, Kayla had an unusual surgery to remove a piece of bone in head to allow room for swelling during radiation. Then we did 33 treatments of standard radiation therapy concurrently with Temodar chemotherapy. She regained her abilities by the end of radiation. We continued the chemotherapy for two months following the radiation therapy and then stopped.

We used many alternative therapies and diet changes and by God's grace, Kayla lived a very normal and fairly symptom-free life for over 4 years. She was in ballet and piano and at the top of her 4<sup>th</sup> grade class in school when her tumor came back or possibly a new tumor occurred very unexpectedly in January 2010 when she was 10 years old. She passed away June 18, 2010. She survived for nearly 5 years with a DIPG and we are so thankful.







Flowers on a Sunny Day  
Ben Steadman

# Health Journal Guide

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Good health care is largely dependent on organization. This can help you maintain an open and honest communication with your child's doctor and health care team. Remember that you are all working together to provide the best quality of care for your child and you.

Use the Health Care Diary as a way of charting your child's physical and emotional well-being. This is key in allowing you and your doctor to know what's helping and what isn't. Especially important is to note any changes that occur and to share those with the health care team.

Use the Appointment Diary to keep track of all of your child's appointments, and there will be many. Keeping track of the appointments all in one place helps you to be prepared for each one and to plan for the others.

The Question and Answer section will help you initially with finding out as much information as possible from your child's doctor and health care team. Once treatment has begun, it will also provide you a place to write down your questions for every appointment and record the answers for you to refer to at any time.

The Medications List is similar to the Health Diary. Use it to keep a record of medication your child is taking, from conventional to holistic. This will not only aid you and the doctor in knowing what's effective and what isn't, it will also help to insure that nothing is mixed with anything it shouldn't be. Most important is to write down any side effects that you see and share those with the doctor and health care team.

We recommend that you make copies of these pages.

I would have found something like this to be a big help, especially in the beginning. When Ben was first diagnosed, I was in such a state of shock that I barely remembered anything the doctor had to say. I also had no idea what to ask him, let alone any way to remember any of the answers.

-Melinda Steadman

# Health Diary

Name:

[illegible]

Tip: Make copies for future use and to give to the health care team. Keep entries short and to the point.

# Health Diary

Name:

[illegible]

Tip: Make copies for future use and to give to the health care team. Keep entries short and to the point.



# Health Diary

Name:

[illegible]

Tip: Make copies for future use and to give to the health care team. Keep entries short and to the point.



Robots  
Ben Steadman

# Appointment Diary

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

Date	Time	Care Provider	Reason for Appointment	Next Appointment

Tip: Make copies for future use and to give to the health care team. Keep entries short and to the point.

# Appointment Diary

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Name:

Date	Time	Care Provider	Reason for Appointment	Next Appointment

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Date	Time	Care Provider	Reason for Appointment	Next Appointment

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Best Bird Ever  
Sam Walsdorf

# Initial Questions to Ask Your Doctor and Health Care Team:

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What are all of the treatment options available currently?

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How are the side effects of treatment managed?

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What can we expect after treatment?

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# Questions to Ask at Appointments:

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## Questions for the doctor or health care team:

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Tip: Go over your list of questions right before the appointment so they'll be fresh in your mind.

## Answer/Notes:

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Tip: If you don't understand the initial answer given, ask the team to give you the answer again, maybe in a different way.

## Treatment Plan:

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Tip: Make sure you understand and agree with the treatment plan. If not, then ask for it to be explained again and/or get a second opinion.

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[illegible]



Watercolor Reflects #8  
Ben Steadman

# List of Medications

Name:

Medication	Date Prescribed	Dosage	Prescribing Doctor	Reason for Medication	Medication Directors	Side Effects Experienced

Tip: Bring this list to all of your child's appointments. This will let the doctors know about every medication your child is taking, who is prescribing them, and how they might affect each other.

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Name:

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# Donation Tracker

Date	Name/Organization	Gift/Donation	"Thank you" Note Sent

Tip: This is a great task to assign to one of the many loved ones who will be asking what they can do to help. Have them go down the list and fill out "Thank You" cards accordingly.

# Donation Tracker

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Tip: This is a great task to assign to one of the many loved ones who will be asking what they can do to help. Have them go down the list and fill out "Thank You" cards accordingly.



# Important Phone Numbers

<b>Name:</b> Lynette McCarty Apodaca <b>Organization:</b> Marc Jr Foundation <b>Phone:</b> 720-840-4995 <b>Phone:</b> <b>E-mail:</b> lapodaca@marcjr.org	<b>Name:</b> <b>Organization:</b> <b>Phone:</b> <b>Phone:</b> <b>E-mail:</b>
<b>Name:</b> <b>Organization:</b> <b>Phone:</b> <b>Phone:</b> <b>E-mail:</b>	<b>Name:</b> <b>Organization:</b> <b>Phone:</b> <b>Phone:</b> <b>E-mail:</b>
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Man in Hat  
Ben Steadman

# Register With The DIPG Registry

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The International Diffuse Intrinsic Pontine Glioma (DIPG) Registry is a collaborative effort by physicians and researchers from North America, Europe, and Australia to centralize and standardize the collection of clinical data and tumor samples from DIPG patients. This goal of this effort is to support innovative research and ultimately find a cure for DIPG.

The registry is a database collecting basic information about DIPG patients as well as their medical history, imaging (scans), and any available biopsy results to link to a another database of results from testing available tumor samples. The registry is run by an international network of experts studying and treating DIPG. The data collected form a research continuum from basic biology to clinical practice to address our primary goals of:

1. Better understanding the biology of DIPG
2. Developing more effective therapies
3. Developing new approaches to diagnosis, response assessment and multidisciplinary treatment and follow-up that will improve patient outcomes

Specifically, the work of the registry includes:

1. Recruiting patients diagnosed with DIPG to enroll in the International DIPG Registry
2. Collecting and maintaining a repository of clinical, demographic, radiologic, and pathologic data for patients with DIPG enrolled on the registry, with annual follow-up of all cases
3. Developing a bioinformatics repository of new and existing molecular data on DIPG that can be linked to de-identified clinical information in the registry
4. Establishing and supporting collaborations among investigators for hypothesis-driven research studies using registry data that will ultimately lead to better classification of these tumors and more effective treatments

The long-term goal of the registry is to establish and maintain a highly collaborative, international, hypothesis-driven research infrastructure that can support a wide spectrum of interdisciplinary and translational projects related to DIPG.

## For More information

- **Call the Registry at**  
1 (513) 636-2799
- **Email the Registry at**  
[dipgregistry@cchmc.org](mailto:dipgregistry@cchmc.org)





Ryan Mott  
Beautiful Day

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