A qualitative look into Diffuse Intrinsic Pontine Glioma (DIPG):

Implications for advocacy, education, and research

Acknowledgements

The Marc Jr. Foundation would like to thank and acknowledge all the parents who participated in this study (January, 2010 to July 2010).* The experiences and insights shared have been invaluable to our current knowledge base of DIPG, and we thank you for sharing your journey and your child with us.

We would also like to thank the following individuals for their valuable and professional assistance with this project:

Jack Finch, M.S. – Colorado Department of Public Health
Nicholas Foreman, M.D., Denver Children's Hospital
Paula Hagar - WheelerTriggO'Donnell, LLP
Jennifer Madden, RN, MSN, CPNP –Denver Children's Hospital
Talitha McGuinness - Carolina Consulting Company
Brad Neiger, Ph.D., CHES - Brigham Young University

Research was funded in part by the Marc Jr. Foundation.

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*Names of participating families and children are not disclosed to protect their anonymity.

Dedication

This research is dedicated to Maryn Cella who was diagnosed with DIPG June 17, 2009. She earned her angel wings on January 25, 2011.

Maryn Cella

2005 - 2011

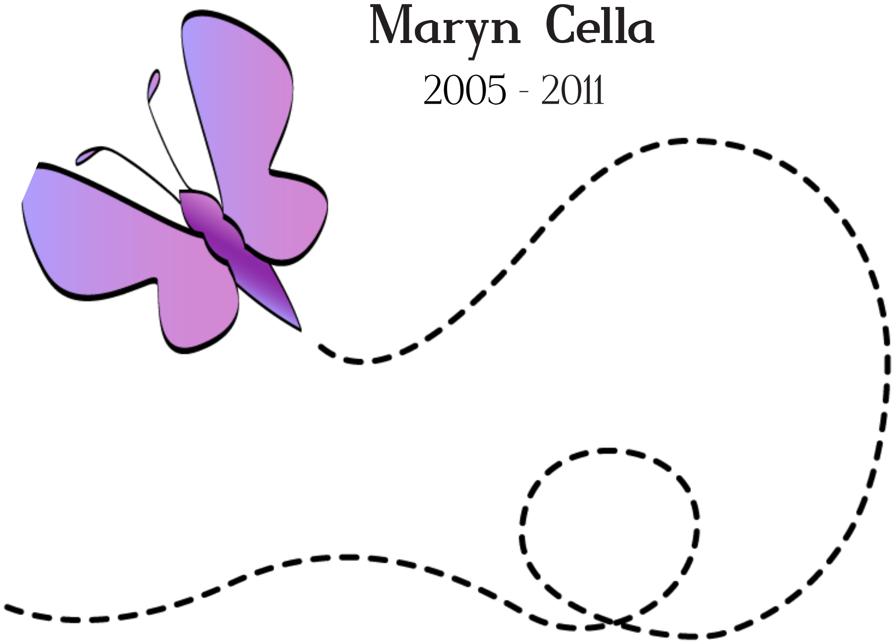


Table of Contents

Introduction

"How could this have happened? What did we do wrong? This is the worst news a parent could ever get!"

According to the National Cancer Institute (NCI), cancer is now the leading cause of death by disease among U.S. children ages 5 to 14, and ranks fourth in leading cause of death for children ages 1-19, who account for 20% of the U.S population. [1-4] Of the 12 major childhood cancers, brain tumors are the second most common type behind leukemia, accounting for approximately 17% of all pediatric cancer cases. Among the most common primary brain tumors in children, brain stem gliomas account for approximately 10% of all cases, the most common type being Diffuse Intrinstic Pontine Glioma (DIPG). [5-8]

DIPG is a high-grade, aggressive tumor affecting the pons area of the brainstem in children ranging in age from 2-11 with a typical age range of 5 to 9 at diagnosis. Symptoms include inability to control eye movement, double vision, dropping one side of the face, weakness in the arms and legs, impaired balance and coordination, and difficulty chewing and swallowing. According to recent Surveillance Epidemiology and End Results (SEER) data, there are approximately 211 new cases of DIPG reported in the United States each year for children 0-14, and over 90% of these children will die within 24 months of diagnosis (see Note 1). [9-13]

DIPG is diagnosed using radiologic imaging tests, e.g., computerized tomography (CT) and magnetic resonance imaging (MRI), and is typically treated initially with steroids followed by radiation therapy. It is one of the most resistant of all cancers to chemotherapy treatments, and due to the location and the diffuse characteristics of the tumor, surgical removal is nearly impossible. No treatment to date, including external beam radiation in the form of both standard and in escalated dose trials, or chemotherapy at either standard or high doses, has shown any long-term survival benefits. [14] Among pediatric neurologists in the United States, there is a growing consensus that the lack of progress with regard to understanding the etiology, progression, and treatment of this disease warrants a novel and innovative change of direction. [15-18]

In summary, there is a dearth of information available with regard to prevention and causation of DIPG, and successful treatment alternatives are few. Combined with unknown causation, limited

treatment options, and poor prognosis, medical professionals and health educators are rendered helpless in providing successful preventive, therapeutic, and curative measures making DIPG one of most baffling and difficult tumors in pediatric oncology.

"I was told that there is no research or funding for any type of help with this type of cancer because it is very rare, and I was like, 'Are you kidding me? We live in the United States of America and they are just going to let my son die?!?' I was like, 'I don't live in a 3rd world country!' I couldn't believe that you know, there wasn't anything they could do for us. I was so disgusted."

Purpose of the Study

"Doctors need to think outside their box. We just can't assume that a drug is going to be the salvation....If what we've been doing conventionally isn't working, shouldn't we be doing something completely different?"

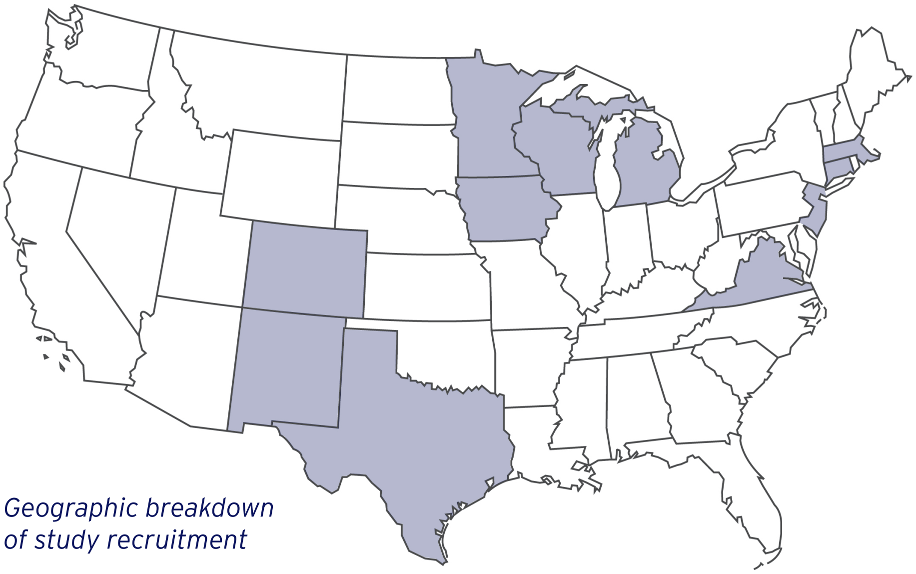
Over the last 20 years, the majority of research related to DIPG has focused on testing various targeted therapeutic protocols, e.g., chemotherapies, enhanced radiation therapies, alternative steroid use, and alternative therapies such as the controversial antineoplaston therapy developed by Stanislaw Burzynski. [19-20] Furthermore, the majority of etiological studies have been less than conclusive. Although there have been studies to examine possible causes of childhood cancer in general, no studies to date have specifically targeted DIPG or the families of DIPG to explore in-depth the commonalities of DIPG with regard to environment, nutrition, and genetic history, etc. According to the National Cancer Institute, childhood cancer is determined by an interaction of many factors, or multiple- causation. Factors that have been linked to childhood cancer include: biological (genetic and immunological deficiencies), environmental (exposure to toxic chemicals, radiation and magnetic field exposure, pollution, fluoridated water, pesticides), behavioral (lifestyle, exposure to cigarette smoke), nutritional (excessive sugar, processed food, and fat intake), and psychological (personality characteristics and emotional vulnerabilities) factors. [21] Although demonstrating causation is a long and difficult process, providing information on commonalities and differences among DIPG patients and families could provide valuable insight into possible relationships which can then be tested and correlated through empirical research. It has been suggested that a cure for DIPG might result in a cure for almost every other type of cancer. [22]

The purpose of this study was to explore possible common factors among DIPG families and children and to better understand what families experience in dealing with a child who has been diagnosed with this cancer. Due to the exploratory nature of this study, there was no hypothesis that was used to guide the study, but rather, the overarching research question for this study was, "What are the commonalities among the children and families affected by DIPG?" Implications of these findings and recommendations for future research are discussed.

Methods

Recruitment

Parents who had lost a child to DIPG were recruited in the United States through an online DIPG support group and through word-of-mouth purposive sampling. Parents living outside the United States were excluded primarily for cultural and logistical reasons. Where possible, both the mother and father were recruited in order to explore the health and diet history of both parents. Single parent households, divorced or separated parents, widows and widowers, and non-biological parents including step-parents, guardians, non-married significant others, as well as children and other children still battling DIPG were excluded from the study. There were no exclusionary criteria with regard to age, race, religion, socio-economic status, or geographical location within the United States.



Geographic breakdown of study recruitment

Procedures

A total of at least three and no more than five interviews were conducted with each participant that included an introductory intake interview which collected pertinent family information and information relevant to the child who was diagnosed with DIPG, and up to 4 follow-up interviews (See Note 2). Interview questions included family history and lifestyle prior to and after diagnosis, prenatal experiences, as well as specific questions pertaining to diagnosis, treatment, support, and loss. All interviews were conducted and recorded via ReadyTalk [23] audio conferencing services and stored on the principal investigator's personal computer. Recorded interviews were then sent electronically within 24 to 48 hours to a professional transcriptionist, who signed a confidentiality agreement. Participants were given a copy of each interview transcript via email prior to their next interview to verify and edit

responses [24-25] (See Note 3). Each interview lasted between 60 and 90 minutes. Upon completed and verified transcription, all recorded interviews were deleted from Ready Talk audio conferencing storage, the transcriptionist's personal computer, as well as the principal investigator's home computer. Upon completion of the study, all hardcopies of transcriptions were shredded.

In addition to the interviews, participants were also asked to voluntarily provide relevant medical and nutritional information as well as stories, art work, newspaper articles, blogs, etc in order provide greater understanding of the experience of DIPG.

Analysis

Reponses from interview data were coded and analyzed using descriptive statistical analyses and thematic analysis, i.e., a process of immersion in the data in order to identify categories, patterns, and consistencies in the data and in the participant responses. [26]

Table 1. Parent Demographics

Study Size:	N=26 (11 couples and 5 parents with no participating spouse) (See Note 4).			
Location:	The majority of families were from mountain and central time zones states and included: Colorado, New Mexico, Texas, Minnesota, Iowa, Wisconsin, Michigan, Virginia, New Jersey, Connecticut, and Massachusetts.			
Home:	Families reported moving 1 to 4 times prior to DIPG diagnosis, averaging 2 homes per child.			
Age at Study:	Range: 30-53 with mean age of 41			
Age at child of DIPG birth:	Range: 24-43 with mean age of 32			
Family Size:	The majority of families reported 3-4 members in their household.			
Race/Ethnicity:	The majority of parents (N=22) were Caucasian, 4 reported being of either Hispanic/Latino, Italian, or Greek descent.			
Education:	9 had high school diplomas 1 had a Master's Degree 1 was currently in undergraduate school		11 had Bachelor Degrees 3 had Associate Degrees 1 had a Juris Doctorate	
Income:	The majority of families reported a household income of $70,000 or higher.			
Occupations included:	Administration Computers Nursing/Medical	Homemaker Construction Bus./Retail/Sales	Banking Non-profit Food Service/Restaurant Mgmt.	Legal Services Engineering
Religion:	The majority of families reported being Catholic, with others reporting Lutheran, Greek Orthodox, Baptist, Latter-Day Saint, or non-religious/agnostic.			

Results

A total of 26 parents (15 mothers and 11 fathers) of a child who was diagnosed with DIPG participated in the study. Parents ranged in age from 30 to 53 years of age at the time of the study (See Table 1 for demographic breakdown).

Information collected from the intake and follow-up interviews were grouped into the following categories and subcategories:

1. Overall Household: home and environment.
2. Paternal Characteristics: demographics, occupation and employment history, family history of cancer, health, diet, and coping and support.
3. Maternal Characteristics: demographics, occupation and employment history, family history of cancer, health, pregnancy history, diet, and coping and support.
4. DIPG Child Characteristics: demographics, birth, health and development pre-diagnosis, diet pre-diagnosis, diagnosis, and treatment.

Overall Household

Home

Parents reported having moved up to five times, with an average of two times prior to their child's diagnosis of DIPG. When asked about the interior and exterior conditions of the homes, as well as environmental concerns, many reported that their homes were at least 20 years old and that exposure to asbestos, lead, radon and other hazardous chemicals were a concern. One parent reported having asbestos in the insulation and in the roof's shingles. Many had done extensive remodeling to the home including wall paper removal, floor and carpeting replacement, re-painting, extensions, and complete makeovers. The majority of parents reported that their homes were painted with non-lead, i.e., water or oil-based paint. Others reported experiencing some flooding, breaking pipes, basement mold, problems with termites, ants, and cockroaches. One home was a prior methamphetamine lab and there was concern for toxicity of carpets and other hazards associated with methamphetamine production. Others reported severe damage from hail or hurricane, and the majority of parents believed they had lived on a prior vegetable or fruit, dairy, or horse farm.

The majority of water coming into homes was city water with two reporting use of well water. Ninety-four percent of the counties in which the child of DIPG was born had fluoridated drinking water and 88% of the counties where the child was diagnosed had fluoridated drinking water. (See Note 5). A total of 81% of parents reported

drinking filtered or bottled water due to concerns about the safety of their tap water, including fluoride, lead, and arsenic.

Twenty-four of the 26 families reported having at least one pet, e.g., dog, cat, bird, hamster, fish, or crabs in their home prior to their child's diagnosis. Of these 24, nine reported some sort of condition or abnormality with their pet including intestinal flipping, scorpion bite, internal parasites, kennel cough or dermatomyocitis, an immune disease characterized by inflammatory muscle and skin lesions. Three reported that their dog died of a brain tumor or cancer. One family reported that their child was allergic to their pet. All reported that their pets were indoors the majority of the time. Some parents voiced concern about pet parasites, fecal contact, or pet illness including cancer and a connection to DIPG.

Environment

All of the participants reported living within 1 to 10 miles of a major freeway, business, or metropolitan district. The majority reported living near power lines, a power substation, or nuclear plant. One reported having fuzzy cell phone coverage in his neighborhood.

The majority of parents reported living within 1 to 5 miles of a pond, lake, river, stream, or wetland. One parent, who reported living in a communal type of living environment, was diagnosed with breast cancer the same week her son was diagnosed with DIPG. One father reported a high rate of cancer within his zip code and another reported that there were three children in his cul-de-sac that were diagnosed with cancer although less than half of the participants reported living in a cul-de-sac. One reported experiencing a major natural disaster that shut down a portion of the freeway in their area.

Most common characteristics prior to DIPG diagnosis:

- *Moved an average of 2 times*
- *Lived on either a current or prior vegetable, fruit, dairy, or animal farm*
- *Main water source was fluoridated city water*
- *Owned a pet which was kept indoors*
- *Lived within 10 miles of freeway and metropolitan district*
- *Lived within 5 miles of major water source, e.g., lake, river*
- *Lived near power lines*

Paternal Characteristics

Demographics

Eleven fathers, ranging in age from 30-53 with an average age of 41 at the time of the study, were included in this study. At the time of the birth of their DIPG child, fathers ranged in age from 25-43 with an average age of 32. Fathers were predominantly Caucasian (n=9), college-educated (n=6), of Christian faith (n=8), and reported an annual household income of $70,000 or higher (n=8).

Occupation and Employment

With regard to type of employment, the majority of fathers had been in their current job prior to their child's DIPG diagnosis. Areas of employment included: engineering, law, medical, construction,

Results

Most common paternal characteristics prior to DIPG diagnosis:

- *Exposure to work-related chemical/electrical/medical hazards*
- *Family history of cancer*
- *Health condition or history prior to DIPG child conception*
- *History of experimentation with or use of cigarettes, alcohol, and other drugs*
- *Diet high in processed foods, sugar, dairy, and red meat, and low in fruits and vegetables*
- *High use of microwaves*
- *Fast food consumption at least 2 times per week*

computer technology, business management, and sales.
When asked about possible exposure to hazardous or toxic chemicals, power source or electromagnetic fields, or unusually stressful circumstances at work prior to their child's diagnosis of DIPG, nine of the 11 fathers reported experiencing one or more of the following: high usage of work-related cell phones and/or computers; daily exposure and use of salon chemicals; radiation, blood transfusion, and exposure to other chemicals and treatments related to hospital and emergency room care; daily exposure to construction materials including asphalt, cement, drywall, tile, etc.; daily exposure to chemicals, gases, and air within an oil refinery; daily exposure to excess second-hand smoke from bar ownership; and daily exposure to aircraft computers and technology. Two of the fathers reported nothing unusual. Only two of the 11 fathers reported flying on a regular basis, e.g., 1 to 2 times per month prior to the conception of their child with DIPG.

Family History of Cancer

Seven of the 11 fathers reported some family history of cancer. Three reported cancer on the maternal side and included bladder, breast, lung, colon, and bladder. Five reported cancer on the paternal side and included lung, prostate, leukemia, breast, and esophageal. To their knowledge, none of the fathers knew of any neurological cancer or illness in their family history.

Health

Four of the 11 fathers reported having had no health issues prior to the conception of their child with DIPG. Seven reported having experienced one or more of the following in their lifetime: toxic shock syndrome, immunotherapy, low sperm production requiring use of Clomid, hernias, high stress and anxiety with the use of Zoloft or Alprazolam, prior concussions, broken bones, high blood pressure, and equilibrium problems. Seven of the 11 fathers had experimented with illicit drugs including marijuana, cocaine, LSD at some point in their younger lives. Five reported high alcohol use prior to conception of their child with DIPG, and three reported regular cigarette use prior to conception.

Diet

Fathers were asked to recall to the best of their ability their typical diet one year prior to conception of their DIPG child. The majority of fathers reported having had a high consumption of processed, high sugar foods, and dairy products. Red meats and poultry were also high with pork and seafood being lower. Fruit and vegetable consumption was also low and the majority of fathers reported

preferring enriched breads. The majority of fathers reported drinking bottled, canned or filtered water. Seven reported coffee use and nine of the 11 fathers reported eating fast food two or more times per week. High use of microwaves was also reported.

Coping and Support

When asked about how fathers dealt with and continue to deal with the death of their child with DIPG, responses included; support from family and friends, their faith or religion, working with their non-profit organization, helping others, professional counseling, use of antidepressant medication, and acceptance of the disease and death. One father reported that nothing has helped. In terms of support, four of the fathers reported utilizing online support such as DIPG, Yahoo, and CaringBridge support sites, creating their own personal blog, or the use of online social media sources such as Facebook and Twitter.

With regard to changes in their life, some said their faith or religious convictions were stronger. Others had become healthier, more social, more outgoing and proactive with other families and in the fight against DIPG. Others reported the opposite and had become introverted, less social, more withdrawn, angry, and disenfranchised with religion. Six of the eleven reported a strained marriage as a result of the DIPG experience.

Maternal Characteristics

Demographics

Fifteen mothers participated in this study and ranged in age from 31 to 48 with an average age of 42 at the time of the study. At the time of the birth of their DIPG child, ages ranged from 24 to 41 and averaged 32 years of age. Mothers were predominantly Caucasian (n=13), college-educated (n=10), homemakers (n=8) and reported a Christian religious background (n=11).

Occupation and Employment

With regard to type of employment among mothers who worked prior to the birth of the child with DIPG, seven reported working in the following areas: administration in a law office or college campus, salon services, bakery and food service, nursing, banking, education, and aircraft maintenance. When asked about possible exposure to hazardous or toxic chemicals, power sources or electromagnetic fields, or unusually stressful circumstances at work prior to birth of the DIPG child, 11 of the 15 mothers reported experiencing one or

Results

Most common maternal characteristics prior to DIPG diagnosis:

- *Average age of pregnancy of DIPG child was 32*
- *Exposure to work-related chemical/electrical/medical hazards*
- *Family history of cancer*
- *Health condition or history prior to DIPG child conception*
- *Average of 3 pregnancies*
- *History of atypical, difficult, or traumatic pregnancy or delivery*
- *Use of epidural during labor*
- *Stress during pregnancy*
- *Prior use of prescribed birth control*
- *History of experimentation with or use of cigarettes, alcohol, and other drugs*
- *Pregnancy diet high in sugar, dairy, red meat, poultry, fruits, vegetables and whole grains*
- *Use of microwaves*
- *Fast food consumption at least 2 times per week*

more of the following: worked full-time up until birth of child with DIPG, working on the top floors of a high rise building using recycled air, working daily with salon chemicals including dyes, nails and shampoos, working in a hospital environment with high exposure to X-rays and other medical devices, cleaning aircraft, working in army barracks built in the early 1900s, and high exposure to computer equipment. Only four of the 15 mothers reported high usage of work-related cell phones and/or computers during pregnancy. Thirteen of the 15 mothers reported experiencing one or more of the following: radiation due to excess ultrasound x-rays, exposure to a person being treated with oral radiation, chemical spill, salon chemicals, power lines, high pollution from manufacturing plants, living within one mile of an airstrip, living near farmlands, pesticides, second-hand smoke, asbestos and lead.

Family History of Cancer

Thirteen of the 15 mothers reported a family history of cancer. Ten of the 13 were on the maternal side and seven were on the paternal side. On the paternal side, the following cancers were reported: lung, breast, prostate, bladder, esophageal, colon, uterine, and brain. On the maternal side, cancers included: breast, stomach, ovarian, lymphoma, lung, spine, colon, liver, and brain. In total, four mothers reported some form of brain cancer in their family history. One mother was diagnosed with breast cancer the same week her child was diagnosed with DIPG. Another mother reported being highly concerned that her child was exposed to a family member who was taking oral radiation medication for a thyroid condition.

Health

Nine of the 15 mothers reported some form of pre-existing condition prior to the pregnancy of the DIPG child including: broken bones, clinical depression and anxiety requiring medication, trouble breathing, irritable bowel, scoliosis , removal of appendix or gall bladder, extreme migraines, difficulty conceiving, or involvement in a severe car accident. One mother had Harrington rods put in her spine to treat her condition of scoliosis.

Pregnancy history

Mothers reported having 2-4 pregnancies with an average of three children. Six of the 15 mothers either had a miscarriage, delivered a stillborn child or experienced both. One mother lost a child to Sudden Infant Death Syndrome, three of the 15 mothers had had abortions. Twelve of the 15 mothers had difficult pregnancies or births that included: required bed rest, premature labor, gestational diabetes, low iron count, steroid injections, severe illness, long and

traumatic labor, and c-section due to position of baby. Four of the mothers had amniocenteses and of these 4, 3 had miscarriages in a previous pregnancy. Thirteen of the 15 mothers had an epidural and seven were induced with Pitocin. Eight of the mothers had two or more ultrasounds. Nine of the 15 mothers used birth control and nine of the 15 exercised including walking, light running, or yoga. Pregnancy weight gain with DIPG child ranged from 6 to 60 pounds and averaged 32 pounds. Four of the 15 mothers had tried cigarettes in their lifetime but only one mother smoked during pregnancy. Three of the 15 drank alcohol during pregnancy including one during lactation. Nine mothers had experimented with marijuana or other drugs at some point in the lifetime, but none of the mothers were using drugs one year prior to conception or during pregnancy. The majority of mothers (n=12) reported experiencing moderate to high amounts of stress during pregnancy related to work, travel, home and family, illness, or financial stress.

Diet

Mothers were asked to recall to the best of their ability their typical diet during pregnancy. The majority of mothers reported having had a low consumption of processed foods and medium to high consumption of high sugar foods and dairy products. Red meats and poultry were also high with pork and seafood being low. Fruit and vegetable consumption was also medium to high and the majority of mothers reported using whole grains. The majority of mothers preferred bottled, canned or filtered water. Four of the mothers reported use of coffee during pregnancy and 11 reported going out to fast food two or more times per week. Eleven mothers reported medium to high use of microwaves and 13 of the 15 mothers reported using prenatal vitamins with folic acid. Six of the mothers took additional multivitamins during pregnancy, and of these six, 2 used additional antioxidants. Four mothers reported eating an organic or partial organic diet before or during pregnancy.

Coping and Support

When asked about how mothers dealt with and continue to deal with the death of their DIPG child, responses included; starting a foundation in their child's name, faith and religion, family and community support including friends, helping other DIPG families, professional counseling, use of antidepressant medication, or online support. One mother reported that nothing has helped.

With regard to changes in their life, some said their perspective in life had changed, some said it was difficult to be around other children,

others reported loss of friendships, anger at God, and depression. Others had become proactive with families in the fight against DIPG. Nine of the 15 reported a strained marriage as a result of the DIPG experience.

DIPG Child Characteristics

Demographics

A total of 16 children who died from DIPG, including 11 boys and 5 girls from the central/mountain, great lakes, and east coast regions were included in this study. Children ranged from 20 mo. to 11 years of age with a mean age of six years of age at time of diagnosis. (See Note 6). The length of time from diagnosis to death ranged from 4 months to 25 months, averaging 13 months.

Birth

Birth weight ranged from 4.11 pounds to 11.07 pounds with an average of 7.41 pounds at birth. None of the children were born with any known birth defects. Although considered a benign condition, one child was born with Mongolian birth marks, a congenital skin condition thought to be most common among children with rare metabolic conditions. This same child later developed shingles, which is a painful skin condition caused by the varicella virus.

Five of the children were either the first or the third child and three of the children were either the second or the fourth child in the family. Four of the children were born early, four were late, and eight were born near the projected due date. Of these eight children, five were either induced or c-sectioned.

Health and Development Pre-diagnosis

None of the children were born with birth defects; however all of the 16 children in the study were reported as having had either a difficult, traumatic, or unusual birthing circumstance or as having developed a condition prior to their DIPG diagnosis. These experienced included:

1. Premature labor a month early and later developed ticks due to anxiety.
2. A combination of retinitis pigmentosa, scoliosis, and peripheral sensory neuropathy by the age of two. The parents were convinced these conditions were directly related to an undetected DIPG at birth.
3. ADHD and anxiety and the use of anti-depressants prior to diagnosis, also later developed ticks due to anxiety.
4. Hematoma during birth.

Most common characteristics of DIPG child pre-diagnosis:

- *Average age at diagnosis was 6 years*
- *Average length from diagnosis to death was 13 months*
- *All of the children experienced unusual birthing circumstance or condition prior to DIPG diagnosis*
- *All were immunized*
- *None were drooley or colicky as infant*
- *All were above average in intelligence*
- *Pre-diagnosis diet high in processed foods, sugar, diary, juice, fruits, vegetables, and red meat*
- *Fast food consumption at least 2 times per week*
- *No exposure to toxic or hazardous chemicals*
- *Hit head prior to diagnosis*

5. Two children were born with the umbilical cord wrapped around their neck or body.
6. Asthma pre-DIPG.
7. Skull fracture and brain injury from a car accident.
8. Born breach.
9. Contraction of Respiratory Syncytial Virus (RSV) as an infant.
10. Eczema.
11. Born to a drug-addicted mother.
12. Placental eruption.
13. Low Apgar score post birth.
14. Oxygen deprivation during delivery.
15. Malrotation of the intestines at birth.
16. Diagnosed with anaplastic astrocytoma prior to the diagnosis of DIPG.
17. Hyper sensitive to light or sound
18. Traumatic birth and violently suctioned causing broken collar bone and inability to use arms for two weeks.
19. Roaming eye from birth.
20. Hitting head hard or taking hard fall. (See Note 7)
21. The use of medications pre-diagnosis including antibiotics, anti-anxiety or depression medications, or other medication for a preexisting condition.

Diet

The majority of DIPG children were breastfed ranging from two to 18 months with an average duration of seven months. The time of first whole food ranged from three months to 14 months, averaging six months for first solid food. Parents reported that 11 of the 16 children were not particularly picky eaters. Only four of the 16 children were on a regular regimen of multivitamins prior to diagnosis.

The majority of parents reported that prior to diagnosis, the typical diet was fairly high in processed foods, sugar, diary, juice, fruits, vegetables, and red meats and low in fish and whole grains. Eleven of the 16 children ate outside the home at restaurants or fast food establishments a minimum of two days per week. Parents reported that the majority of children drank filtered or bottled water.

Exposure

The majority of children were not exposed to toxic chemicals; however five children were reported as having been exposed to second-hand smoke, pesticides, drugs and alcohol, and radiation prior to the DIPG diagnosis. One child was given formaldehyde by a dentist to treat a tooth infection. Ten children were reported as having 1-2 dental x-rays, and two children had high exposure to x-rays due to a pre-existing condition. With regard to airplane travel, children traveled an

average of 2 times prior to their diagnosis. None of the children were reported as spending more than 1-4 hours a week on a computer, including video games.

The first medical provider was either a pediatrician or optometrist/opthamologist.

Diagnosis

All the children were initially diagnosed via computed tomography (CT) or magnetic resonance imaging (MRI) scan. MRI scans were then used to track the progression of the tumor over time. The number of scans per child, ranged from 1 to 15 post initial diagnosis and were taken at an average of 3 month intervals (see Note 8).

Most common first symptom of DIPG was eye or facial changes, e.g., roaming eye, eye turned inward, blurriness, facial droop followed by:

- *Changes in balance and coordination*
- *Headaches*
- *Dizziness*
- *Nausea*
- *Drooling*
- *Lethargy*
- *Cold or flu-like symptoms*

When asked what the first symptoms were leading up to diagnosis, the overwhelming majority of children first experienced eye or facial changes such as a roaming eye, an eye turned inward, blurriness, or facial droop on one side, followed by changes in balance and coordination, headaches and dizziness, nausea, drooling, and lethargy. After symptoms first appeared, many parents assumed that the symptoms were related to a lingering cold or sinus/ear infections.

The time from first symptom to diagnosis ranged from two days to six years averaging 2-5 months before taking the child to a medical professional. The majority of parents first took their child to either a pediatrician or eye specialist followed by an oncologist, neurologist, family doctor, or radiologist. The majority of children were diagnosed in the winter (Dec/Jan/Feb) followed equally by fall (Sept/Oct/Nov) and spring (Mar/Apr/May). Two children were diagnosed in the summer (June/July/August).

Due to unusual or unclear symptomatology, two of the children were biopsied in order to confirm a diagnosis of DIPG (see Note 9).

Treatment

The uses of traditional versus alternative treatments were divided equally, i.e. eight children were treated with traditional treatment and eight were treated with alternative treatment. Of the eight children using traditional treatment, six used either oral or intravenous chemotherapy treatment. Two children did not use any form of chemotherapy. (See Table 2 for a complete listing of treatments used).

All 16 of the children were initially treated with Decadron to reduce swelling of the tumor, while two children were additionally treated with another hydrocortisone steroid. Fourteen of the 16 treatments included a six-week radiation therapy to shrink the tumor. The most common chemotherapy treatment was Temodar followed by various combinations of the following chemotherapy agents:

- Thalidomide (Oral)

- Vincristine (IV)
- Carboplatin (IV)
- Lomustine or CCNU (IV)
- Oxaliplatin (IV)
- Fluorouracil or 5FU (IV)
- Peg Interon (Injection)
- Gefitinib or Iressa (Oral)
- Bevacizumab or Avastin (IV)
- Irinitecan (IV)
- Motexatin Gadolinium (IV)
- Nimotuzumab (IV)
- Temsirolimus or Torisel (IV)
- Etopacide or VP 16 (Oral or IV)
- Nexavar or Sorafenib (Oral)
- Tarceva or Erlotinib (Oral)

Of the six who tried alternative treatments, the most common treatments were Boswellia, Ruta 6/Calcium Phosphate [27-28] (see Note 10). Two families chose to be treated with sodium phenylbutrate/antineoplaston therapy, a controversial therapy founded by Stanislov Burzkynski, which claims to destroy cancerous cells without harming the normal cells through the use of naturally occurring peptides found in human blood and urine. [29-30]

All of the children were first treated with Dexamethasone.

"You want to believe that something is going to work."

"Why did I do chemo? If I didn't and then she died, what would I say? If we did and she died, what would I say. That's the problem. Why do we have to make these decisions? It's not fair!"

Results

Table 2. Treatment Protocols Used

Child	Traditional	Alternative	Diet	Biopsy
1	Decadron Radiation	Footbath (6 months) Ruta-5 months Boswelia Chiropractor OncoPLEX Pro Omega Pre Que, Vit D, Vit C	Organic No Flouride Artificial sweetners Carbohydrates Processed meats Low sugar Low salt	No
2	Decadron Vincristine (IV) Zantac Miralax Bactrim Temodar (oral chemo) Radiation Carboplatin (IV) Nupragen Paxil Thalidomide (oral)	None	Xango Juice Juice Plus Limited sugar first 2 mo.	No
3	Decadron Temodar Irinitegan CCNU (Lomustine) (chemo) Radiation Avastin Ondansetron	None	Kushi/ Macrobiotic/organic Ganoderma Xango Juice	Yes
4	Decadron Motexalen Gadolinium (NYU Clinical Trial) Radiation	None	None	No
5	Decadron/Solumedral Radiation Pentamadine-infection Oxiplatin (IV Chemo)/5FU Florofox Zofran-anti nausea Temodar (Clinical Trial)	None	Low salt, sugar, fat	No
6	Decadron Iressa (Oral Chemo) Radiation	None	None	No
7	Radiation Zofran-anti nausea Decadron Prevacid	Mushroom	None	No
8	Decadron Peg Interferon-NIH Phase II Radiation	None	None	No
9	Decadron Temozolomide/CCNU Radiation Nimotuzumab (Chemo)	Boswellia Melatonin Reglan Miralax Bactrim Thiamus Astragalus Probiotic Poly MVA (liquid) Primadophilus Nystatin Selenium Ruta 6 Zantac Muriocin Calphos Echinacea	Organic Diet/Raw Vit C, D, Zinc Green Tea Shark oil Fish oil	No

Table 2 (contd). Treatment Protocols Used

Child	Traditional	Alternative	Diet	Biopsy
10	Decadron Radiation Metafax (Clinical Trial) Gadolinium Bactrim Temsurolemis (Clinical Trial)	Antineoplasm-Burzynski (9 mo.) Potassium	None	No
11	Decadron Radiation Accutane Itopacide Nimotuzumab NIH Peg Interfon (7 months) Temodor (oral chemo) Irinotecan CPT 11 and Avastin	None	None	No
12	Radiation Temodar (oral chemo) Irenotecan (port chemo) Carboplatin (IV) Thalidomide (oral) VP16 (chemo) Decadron/Hydrocortizone	None	More organic	Yes
13	Steriods/Radiation	Reiki	Vit. K Mushroom Extract Organic Diet Protocel (4 months)	No
14	Decadron Prevacid Radiation Temodar Irinotecan and Avastin Nexavar Tarceva Etopiside and Carboplatin (chemo) Vincristine/Irinotecan/Temodar	Burzynski/Sodium phenylbutrate Lithotripsy (kidney stones) Boswellia Coriolus PSK Ruta6 Calc Phos	Vit D2 D3	No
15	Decadron Radiation	Ruta 6 Calphosphate Berberine Lycopine	Vit C, K	No
16	Decadron Radiation	ipc/inisotol Miralax Zantac Zofran Mercurius X-ray 12 Baryta Carb AHCC Boswelia Glutamine Barberine Curcumin Cats Claw Bromelain Acidopholus Melotonin Religious healer Host defense/AHCC Ruta 6 Calphosphate Integrated Manual Therapy VIBE machine (cell energy enhancer)	Less sugar/ processed Vit K,A,E	No

Discussion

"We need to find out about this tumor."

The purpose of this research was to explore common factors among DIPG children and families that can be used as a stepping stone toward new and innovative research toward prevention and a cure. Because this research was primarily exploratory, strong conclusions cannot be made, but clearly important questions and the need for a new direction in research was made evident.

Although clinical trial research and testing new treatment therapies for tumor reduction and elimination is important, we have yet to make progress in understanding the nature and etiology of this tumor. This research supports the idea that we need to look outside the box and consider other areas of research in order to add to the knowledge base of DIPG and possibly other pediatric cancers. One parent commented:

"When I talk to a doctor about what causes this, I don't want to hear, 'I don't know.' You have been trying to figure this out for 30 years! That's not an answer a parent wants to hear. I mean you go to these doctors because this is what they go to school for and this what they do, and you go to these so-called best hospitals in the world, and they have nothing."

Another parent said,

"Doctors need to think outside their box. We just can't assume that a drug is going to be the salvation. If what we have been doing conventionally isn't working, shouldn't we be doing something completely different?"

Next Steps-Biopsy?

When asked what the next steps in DIPG research should be, the majority of parents suggested that more research dollars need to be allocated to understand the genetic makeup of the tumor, to find out what is causing the tumor. One parent said,

"I really don't see the medical and the pharmaceutical industries really trying anything outside of the box. So for me, it really comes down to getting a better idea of what is the genetic makeup of this tumor."

The subject of whether to biopsy or not continues to be a topic of debate and controversy in the pediatric oncology community. This

study was no exception. The majority of parents were supportive of biopsy research to learn more about the tumor itself:

"I see it as by not doing biopsies, you're saying well, we've got to let these kids die. Ethically, we owe it to our future kids. We owe it to our grandkids...to me it's unethical to let these kids just keep dying."

"We need to get neurosurgeons to do a biopsy when they first go in... When my son was first diagnosed, they told us it was too dangerous, but the problem with giving a portion of the tumor AFTER they have died is that they can't tell you how it starts."

However, some were not supportive of the idea and felt it was too risky or that it served no purpose:

"We were told that to biopsy was like taking a handful of sand, throwing it on the grass and then trying the pick the sand out without touching the grass."

"It isn't going to save my child....it's too risky...if all they can tell me is that the tumor is growing, and it is a stage 3 or 4, there is still nothing you can do."

"I guess that is the fear of doing biopsies...that once you poke at it, it is going to grow bigger or it is going to go somewhere else in her body. I didn't want my daughter's tumor to metastasize into something bigger."

"It's about quality of life. I don't know how you'd be able to biopsy that portion of the brain without destroying something else. The risk is too great."

The overall consensus from parents was that if biological research, i.e., doing biopsies at diagnosis rather than post-mortem, could be done without further impacting quality of life, prove to be non-invasive and non-threatening, as well as be able to provide new information on the cause of the tumor or directions for successful treatment therapies, they would be supportive. Ultimately, the choice has to be theirs.

Next Steps-Diet and Nutrition?

The general feeling among most of the parents was that diet and nutrition are not related to the etiology of the tumor, especially since these children are quite young at diagnosis and have not had time to be affected by poor nutritional habits or choices.

"I have 3 other kids who are healthy who are on the same diet and lived in the same environment. It has be a combination of genetics and environment. I don't think diet makes a difference."

However, many parents felt that diet made a difference in the progression of the tumor post diagnosis or in prognosis and in their child's comfort and quality of life.

"You want your child to eat feel better and you want to feed them all this healthy, nutrition stuff, but then again, going for ice cream with their friends can do them a world of good too. We just want the quality of life for as long as we can with our child…to gain an extra day."

Many parents made changes to their child's diet post-diagnosis including: eliminating fluoride and other minerals found in city water, eliminating red and blue dyes found in certain juices and beverages, and reducing sugars and artificial sweeteners, dairy products, carbohydrates, processed meats, and salt from the diet. A few parents chose to incorporate a completely organic or macrobiotic diet regime for their child and family, and some parents reduced microwave use and barbequing as a method of cooking. However, further research is needed to better understand when diet IS critical in cancer prevention as well as in treatment.

Next Steps, Pre-natal Screening?

Some parents were of strong belief that their child was born with the tumor.

"I feel like the tumor was probably with her from birth and the traumatic brain injury from the accident ignited it to start erupting and start growing."

"I think my son had it from the beginning. He was a difficult child and had sensory issues. DIPG is in the brain stem, which controls all the sensory nerves. So it had to have been there since he was baby."

"So our doctor suggested that perhaps the DIPG tumor can grow in infancy or when you are little and then lay dormant for years, then due to puberty and growth, it could explode…We asked 'Are you born with it?' and he said that there is so little research on it that I really can't tell you. That's when I started realizing the need for research and support for this type of tumor."

If this is the case, the question remains, what triggers its growth, and why are children within a certain age-range more susceptible to this tumor? Is there the possibility of screening for tumors in utero with advanced ultrasound technology? Could there be blood indicators that can be used in early detection?

Next Steps – Genetic Testing?

It was interesting that the overwhelming majority of both parents reported some type of health history either in pregnancy, illness, accident, genetic disease, or family history of cancer, although neurological cancers were rare. Further research is needed to understand whether there is a genetic link passed on by the mother or the father that makes a child more susceptible to the tumor. If there is a genetic link with the mother or the father, which link is stronger, the mother or the father? Other questions that were raised included:

- Is there a genetic link with other rare disease in families?
- Is the genetic link stronger with a maternal or paternal family history of cancer?
- Does the parent's early lifestyle pre-conception play a role, e.g., diet and exercise habits, drug experimentation, prescription drug use, etc.?
- Is parental use of antidepressants use linked to this cancer?
- Does the mother's pregnancy and pregnancy history including, prior pregnancy experience, stress, the difficulty of the pregnancy, diet, physical health of the mother, exposure to environment, etc, have something to do with the development of the tumor?
- Is there a link with the maternal use of birth control?
- ALL of the children were described as above average in intelligence. Is there a connection with intelligence and tumor development?
- Is there a connection between childhood immunizations and tumor development?

Next Steps-Environment?

With regard to environment, further research is needed to determine a connection with the home environment, such as location of home, type of materials used in paint, carpet, heating and cooling as well as in home and lawn maintenance. Additionally, is the link to cancer transmitted through the air through electromagnetic fields, pollution, power stations, computers and cell phones? Does proximity to large bodies of water that carry disease-carrying insects have a role? Can pets transfer a link to cancer to their human hosts?

Discussion

Most common affect of DIPG:

- *Financial strain*
- *Changes in family and friend relationships*
- *Depression/withdrawal*
- *Change in life perspective*
- *Change in religious or spiritual perspective*
- *Comfort and connection in blogging or online group support*
- *Helping others/common cause*

Other areas for environmental research that were suggested included: looking at common denominators with zip codes with high incidence rates of cancer, as well as air, soil, and water testing within those zip codes.

Next Steps – Other Research?

Other areas of suggested research included: researching a possible vaccination against DIPG; more research to evaluate the effectiveness of alternative therapies; and research to evaluate effective alternatives to drugs like Decadron and other steroids that cause quality- of-life altering side effects such as extreme hunger, weight gain, and moodiness.

In addition to further research, families of DIPG need resources to better help them cope with the devastating diagnosis. Parents said,

"I wish someone would have handed me a binder and at least given me a starting point and would have said, we can't guarantee we are going to heal your child, but this is the information that was helpful... None of this information was introduced to us at all other than me researching it online and trying to find information on my own."

"When I heard the news, I felt like was suffocating. You can't believe what you are hearing. You are in a state of shock and you can't believe what you are hearing. ...It would have been nice to have something to refer to later."

"I wish I was given some information...all I was given was a piece of paper with the word DIPG on it. I didn't even know what that was."

"I remember taking a lot of notes. There were pamphlets but nothing specific to DIPG."

"After we were given the diagnosis, they just left us there. We had no information."

"We need to make sure parents have as much information as possible from the beginning so they can make the best decisions for their family."

"There was information but it was scattered all over and we had to find it on our own."

The lack of information propelled most parents into a frenzied internet search, looking for anything they could find about the tumor,

e.g., what it is, what causes it, how it's treated, success stories and survival rates, payment options, etc. Unfortunately, for some, all the time spent researching left a feeling of regret:

"If I could do it all over again, I would have spent more quality time with my son."

"I regret not spending more quality time with my son. It's about finding a balance. We spend all this time fighting instead of tickling our kid and having fun. They just simply want to be cared for. They don't appreciate you running around doing all this research and if you tell them that, they don't care. They just want to be snuggled with and hugged. They feel like crap and they just want you to sit with them and read them a book."

Next Steps – Parental Support?

Additionally, financial as well as deep emotional strain and stress of dealing with and watching their child suffer negatively impacted several marriage relationships, and one ended in divorce.

"The highs never seem to get quite as high and the lows are not a lot lower in a lot of ways. There are days when you feel almost guilty for feeling good."

"There is no normal anymore. This is your new normal."

"My tolerance has gotten much smaller for things."

"Things don't mean as much to me anymore."

"The biggest struggle is adjusting to a whole new normal of what we call life."

"I could care less if your kid has a skinned knee. I found myself not wanting to talk to my friends. I think I kind of alienate them."

"I went from being the type of person that really plans things out to the type of person who was very spontaneous, was very in the moment and who could literally care less about the future.

"There was no future for me during that time; there was only the moment."

"I regret lying to my son. I didn't want to tell him that after all the treatments he would die. I wanted to tell him he would get better."

Discussion

"My spouse and I are roommates at best. The intimacy is gone."

"We lost everything and we are still paying the medical bills."

"You blame yourself as a mom when you can't save your child."

"We had to declare bankruptcy."

Parents and couples who had a strong belief in God or in their faith, sought the support of other DIPG families and friends, channeled their energy toward helping other families of DIPG or in a cause such as creating a foundation in their child's name or working with other pediatric cancer organizations, had a better outlook on life during and post DIPG and were better able to cope than parents who did not.

"The morning our son died, we woke up and had our hands both on his chest...I told him that I don't know what happens when you die, but I believe that getting to spend eternity with our family sure sounds like heaven and that is enough of a belief for me and if that is what you want to call heaven that's is as good as it gets to me."

"Starting a foundation in my child's name gave me a new purpose... gave me a reason to get up every day."

Recommendations

"No parent should have to bury their child. Period."

In summary, parents recommended that future efforts to help understand, prevent, and treat the DIPG tumor as well as to better help families cope with the devastating cancer, should be directed toward:

1. Understanding the genetic makeup of the tumor.
2. Developing means of earlier and more conclusive detection.
3. Better education about DIPG symptoms for health care providers including ObGYNs, pediatricians, optometrist/ opthamologists, nurses, and dentists.
4. Improved education and support for parents at diagnosis.
5. Improved coping resources for families of DIPG.
6. Research effectiveness of alternative therapies.
7. Better options for treatment including alternatives to Decadron and other quality of life inhibiting drugs.
8. Examine environmental factors and cancer incidence.
9. Additional funding allocation for DIPG and pediatric brain tumor research.

Summary of Recommendations:

- *Biological research to understand the genetic makeup of the tumor*
- *Earlier and more conclusive detection*
- *Better education about DIPG symptoms for health care providers*
- *Improved education and support for parents at diagnosis*
- *Improved coping resources for families of DIPG*
- *Better options for treatment*
- *Alternative therapy research*
- *Examining environmental relationships*
- *Funding for pediatric brain tumor research*

Limitations

The following limitations should be considered when interpreting these results:

1. Self-selection of participants and small sample size preclude the ability to make large generalizations or definitive conclusions.
2. This research was exploratory in nature and further empirical research is needed in order to make strong inferences with regard to the etiology, treatment, and prevention of DIPG.
3. In order to provide the BEST overall picture of DIPG results of the study reflected the responses of the participants as a WHOLE, and not the individual participant.
4. This study relied primarily on the recall and memory of the participants, their personal experiences and subjective perspectives, as well as the interpretation of the researcher.
5. The timing of the study as well as the emotional difficulty of recalling their journey of DIPG and loss of their child may have also influenced the ability to accurately recall or share information.

Notes

1. These numbers are likely an underrepresentation of the true incidence of DIPG. Ninety-five percent of cancer classifications in SEER data are histologically confirmed through molecular data. However, DIPGs are typically not biopsied due to its tendency to infiltrate normal, healthy tissue, making it virtually impossible to isolate the DIPG tumor and to provide reliable and accurate diagnosis.
2. The number of interviews for each participant varied due to response length and time allowance.
3. Accurately reflecting participant responses increases the trustworthiness and authenticity of interview data.
4. Five of the husbands of the mothers chose not to participate, and one father was remarried so the birth mother was not available for the study.
5. Data regarding counties with fluoridated water were obtained through the National Center for Chronic Disease Prevention and Health Promotion, Division of Oral Health Resources. http://apps.nccd.cdc.gov/MWF/Index.asp
6. Seven of the children were diagnosed in a different state than the state in which they were born. Six were diagnosed in a different city, but the same state in which they were born, and three were diagnosed in the same city and state as their birth.
7. Twelve of the 16 children were reporting as having hit their head or taking a hard fall prior to the DIPG diagnosis.
8. All of the tumors decreased significantly in size, averaging an 80% reduction after the initial diagnosis and treatment. By the second MRI scan, the majority of tumors had shown progression again, regardless of treatment protocol used.
9. For one child, the oncologist felt that the tumor was not intrinsic and did not agree with a diagnosis of DIPG. He recommended a biopsy and afterwards determined it was a grade 3 anaplastic astrocytoma, but categorized it as a diffused pontine glioma. Another child, who was diagnosed with other neuropathies prior to DIPG was biopsied in order to confirm a diagnosis of DIPG since she had "no traditional characteristics to support this tumor." Results of the surgery confirmed a high grade DIPG. Both tumors were considered atypical.
10. Boswellia and Ruta 6 combined with Ca3 calcium phosphate are common homeopathic remedies used to reduce inflammation of the brain and block progression of brain tumors.

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We would like to recognize the artwork provided in this document as the work of the children affected by DIPG in this study.