

# Unexpected Gifts from a Cruel Monster: Caring for Children with DIPG

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**Unexpected Gifts from a Cruel Monster: Caring for Children with DIPG** Megan R. Schaefer, PhD<sup>1-2</sup>

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Dear Diffuse Intrinsic Pontine Glioma (DIPG),

You are a terrible and cruel disease. You are rare and aggressive, developing in a critical part of a child's brain, often limiting the ability to biopsy, resect, or treat. You cheat children of the life they deserve. Because of you, the world loses out on future firefighters, scientists, teachers, and presidents. Hearing about your existence is unimaginable to a parent as you limit a child's life expectancy to less than a year on average. Given your aggressive nature, children gradually lose parts of themselves, bit by bit. Weakness, difficulties breathing, confusion, unable to swallow, loss of speech. You trap children in their bodies, and they report feeling as if their body is an unrecognizable, foreign object. You wreak havoc on family's lives as they try to comprehend the news that their sweet child will not live to graduate high school, become an engineer, get married, have children, and likely not play their next baseball game.

The grief starts from the moment families hear your crushing acronym. Parents immediately begin to question their identity and how they will navigate life without their child. Will they be able to parent their other children? Who are they if not a parent to this special child? It becomes impossible not to imagine burying their child and planning their funeral. Siblings feel as if they lost their playmate at diagnosis and also their caregivers as they watch them slowly cocoon in a shell, enveloped with immense grief. Life becomes a ticking time bomb, and the pressure to make every birthday and holiday celebration perfect becomes crippling.

You tear the hearts of pediatric neuro-oncologists around the world as they enter the room to be the bearer of excruciatingly painful news. You make families and healthcare providers feel helpless as no treatment has yet been found to fight against your awfulness. Your existence is unfair. You have turned the worlds of families upside down such that the order of the world no longer makes any sense and families feel they are constantly living in a nightmare. You are equivalent to the “D word” in invoking fear and panic, as of right now, you are a death sentence. But, I would like to remind you, you have not won, and you will not win. Despite how powerful and almighty you feel you are, our patients, families, and pediatric neuro-oncology community are stronger.

As a pediatric psychologist who specializes in seeing children with brain tumors, I have walked alongside many children and families impacted by you. Despite the immense physical and emotional pain you have imposed on children and families, I have truly witnessed unexpected beautiful gifts along these journeys. While I could continue on sharing how much I hate your existence, I want to thank you for the beautiful, yet unexpected, gifts you have provided. You have taught us that joy, beauty, and love can co-exist with fear, distress, and grief. As you significantly limit life expectancy, you teach us to cherish every little moment and to find joy in the small things. You have shown us what is truly important in life, time with family and friends and following our dreams. You have reminded me to hug my loved ones a little tighter and to take the trip, chase the experience as responsibilities can always wait. You have shown us how to weather the storm and taught us about a level of faith and strength many of us never knew existed. You have strengthened our motivation and persistence to show up every day at our jobs and give 110% effort to finding a cure because no child or family ever deserves to hear the heart-wrenching news that their child has you.

Many times, I have left the hospital after a day supporting children and families affected by you and felt defeated, helpless, and angry. As a helper, I want to alleviate children and families of the emotional pain and worries they are carrying. Caring for children and families impacted by you often leads to secondary trauma. It is bravely walking into situations day in and day out, expressing vulnerability and opening yourself to love on a child who we know will not survive because of you. And each clinic visit, we watch the patient’s functioning slowly fade away, and as this happens, we witness the heartache of families as they desperately seek options to prolong time together while prioritizing their child’s quality of life. Even though the child loses their ability to communicate or move their arms to give a hug, I find comfort in still seeing the sparkle in their eye, the small smirk, the head nod, the blink; the love is always there. It may be expressed differently but the room remains filled with love. Although you are pervasive and hard to ignore, I do not give my attention or memory to all the changes and losses you unfairly force on children. I remember the bell ringing after radiation, the Make-A-Wish pictures and videos, the winks, the celebration of small moments where smiles and laughter were shared through the tears. You have made us all cry more times than we would like to share, but you have also made us smile because life is messy and hard, but it is also beautiful. My heart is heavy, but it is not just filled with grief. In between the dark and torn spaces, there is love and appreciation for the children who have selflessly given me unexpected gifts through their tumultuous journey with you, and for that, I will forever be thankful. If I did not let down my walls and love on these children, I may save myself from heartache, but it would come at the cost of not getting to witness the lives of extraordinary children, so the grief is worth every ounce of pain.

With a 0% cure rate, you may think you are winning this battle, but we will not give in. We will continue fighting the good fight until no child, parent, and sibling ever has to hear the devastating news that shatters their heart in a million pieces that their child is diagnosed with you. We will rise up to the challenge because the world is a much better place with our children growing up to achieve their wildest dreams. To everyone in the neuro-oncology community, thank you for your courage, persistence, and dedication to destroy DIPG. One day, we will prevail. I hope it is in my lifetime, but if not, I will continue to express my gratitude to the patients, families, and colleagues who have touched my heart and inspired me to face insurmountable obstacles with humility and grace. **D**iffuse **I**ntrinsic **P**ontine**G**lioma or **D**etermination, **I**nspiration, **P**assion, **G**ratitude. The first is you, the terrible monster who has placed heavy emotional burdens on my heart. The second is the gifts I have received from you. Not all cruel things are pure evil. There is goodness in the hard. So as I grieve the lives of change-makers whose time was cut way too short, I will find gratitude

for the unexpected gifts.

From a grieving yet grateful and hopeful pediatric psychologist, Dr. Megan