

Comments (23) |  Recommend (5)

Buzz up!

- [Print](#)
- [Reprint or License](#)
- [Share](#)

# Weddington embraces Grace with love and faith

**Grace McGrath, 7, has a very rare, inoperable cancer - and a town lifting her on butterfly wings.**

By Amanda Chan  
achan@charlotteobserver.com  
Posted: Monday, Jul. 26, 2010

WEDDINGTON It started with a butterfly.

Grace McGrath, 7, was diagnosed with a rare, inoperable brain stem cancer last November. Weeks later, she was undergoing daily radiation treatments while in first grade at Weddington Elementary.

Friends wanted to show Grace and her family that people at the school were thinking of them, so they hatched the idea of pink butterfly magnets to stick to the backs of cars. Grace and her 9-year-old brother Nate could see the magnets when being picked up at the school carpool line.

Grace shouted "Butterfly, butterfly!" whenever she saw the magnets. Nate would count them. Mom Jennifer and Dad Sean would see them as they drove around the Union County town. It's helped.

Things have not been easy for the McGraths. Grace's cancer, diffuse intrinsic pontine glioma, is entwined with the nerves that control all of her functions. Today, she can't chew, sit up, flex her feet, walk or speak.

Grace communicates with her eyes, looking up for "yes" and down or to the side for "no."

The family doesn't have deep roots here. They moved to Weddington just four years ago from Pennsylvania. They've been stunned by the outpouring from neighbors and people they don't even know.

"It's the community supporting us, because I know we're not doing this on our own strength," said Sean, who works in the Charlotte home-building industry.

Every day, friends from school and Bethany Church drop by to read and draw with Grace. Donations online and from a June fundraiser, organized in two weeks by friends and teachers, raised more than \$50,000 for medical expenses and alternative medications not covered by insurance.

And to date, 750 of the butterfly magnets have been given away or sold.

A frustrating illness

Grace's cancer, which usually strikes between the ages of 5 and 9, is extremely rare. It affects 200 to 300 children a year, said Keith Zesserich, chairman of brain cancer foundation The Cure Starts Now.

Because the tumor is diffused into the brain stem, most surgery is impossible. Dr. Gerald Grant, a pediatric neurosurgeon at Duke University, said radiation is the first line of treatment, but there's not much else beyond that.

"In the past 20, 30 years, there's been absolutely no improvement in treating these kids," Grant said.

Most children with DIPG don't survive more than a year past diagnosis.

"It's frustrating to doctors ... I could see it in their eyes, the genuine disappointment ... that there's nothing proven to be effective," said Sean, who plans to start a foundation in Grace's honor. "But we're a faith-based family, and we have a lot of faith."

### **Her journey**

Before last November, Grace was a running, dancing, active first-grader who loved things like chocolate swiss rolls and bothering her brother.

She was diagnosed at Levine Children's Hospital in Charlotte more than eight months ago, the day after her seventh birthday and after Jennifer realized Grace couldn't move her left arm normally one day while getting dressed for church.

Grace underwent six weeks of radiation after her diagnosis. With treatment, she got better and even returned to school full-time. But in mid-May, her condition worsened. She couldn't speak and resorted to writing on a whiteboard.

Grace stopped going to school and by late May, she could only communicate with her eyes. Her family keeps her mobile by pushing her in a wheelchair that looks like a jogging stroller.

She had a feeding tube put in, Jennifer said, and she receives consults on supplements and homeopathic treatments from a brain-tumor nutritionist in Utah. Right now, Grace is undergoing low doses of chemotherapy coupled with an alternative drug from Canada - in addition to daily prayer.

Her mom tries to give back her freedom of choice by using boards with colors and pictures on them. When Grace stares hard at a picture, like of a TV or food, her family knows what she's asking for. On a recent Friday, Grace picked out a purple tank top and white skirt using the color board.

"Seven-year-old girls like to choose what they wear, and we wanted to give her that part of her life back," Jennifer said.

### **'We have a lot of faith'**

These days, Grace enjoys spending time with her pets, going to her brother's football games, sitting on the porch and going to the pool. But what she likes most are visits.

On a typical day, a teacher, neighbors and a school friend might come read to her, paint her toenails and trade Silly Bandz. Friends bring dinner for the family twice a week.

When she was still able to go to school, Grace's first-grade teacher Pam Murray said the kids would always fight to hold the door for her.

"There'd be 20 kids sitting around Grace (at recess) with whiteboards and markers, just wanting to play and write with her," she said.

Even people the family didn't know before Grace's illness stepped in to help. Chi Omega sorority at Wingate University sponsored Grace's Make-A-Wish trip to swim with dolphins in Florida this April.

The June fundraiser, "Soaring with Grace," had volunteers from all the area schools, and food donations from local restaurants. And local charity Kids First of the Carolinas has accepted more than \$20,000 in donations for Grace, said cofounder Sharon Sanders.

"We felt the meals and the prayers were what we needed, seeing people bring that light in Grace's eyes," she said. "But (close friend) Jennifer Lassiter said to me at the fund-raiser, 'You don't understand, people have been waiting for this. People have been waiting to help.'"



[Subscribe to The Charlotte Observer.](#)