

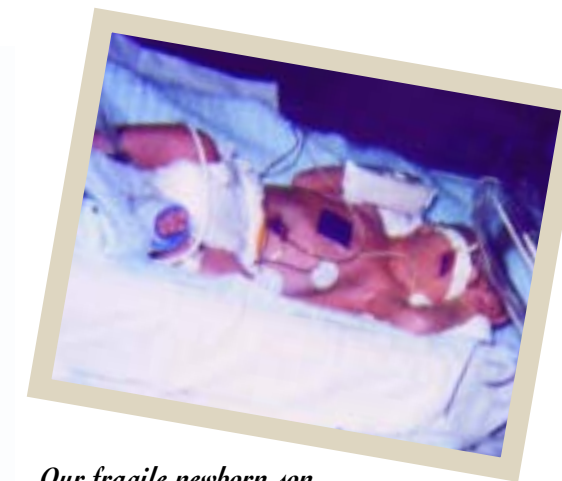
# I'm DJ's mommy

## How a special needs child saved me

By Joan Graves

What kind of mother is ashamed of her child? Six years after my son was born, it still hurts to think about my initial attitude. The official term used for my baby's condition was "special needs." But neither DJ nor I found anything special about it.

Prior to DJ's birth I had only one thought regarding special needs children, "Lord, please don't let me have one!" Although I greatly admired the parents of special needs children, I thought I wasn't strong enough for the job. In fact, I could imagine nothing worse. I thought any life less than what I lived wasn't life at all. Then DJ burst onto the scene, turned my world upside down and taught me more than I could ever teach him.



Our fragile newborn son

With the piercing wail of a premature baby, DJ announced his misery. As I looked into his haunting blue eyes, I thought he hated the world and everything in it. He was a tiny, screeching almost translucent being and even I said that he looked like an alien.

A year later there wasn't much of a difference. DJ rarely slept. He refused to eat and cried more often than not. Worst of all, no one knew why. At age one, he was the size of a newborn with equally underdeveloped muscles. He'd been tested for every condition imaginable (and a few I think someone made up). Every doctor, every time, in every field ended up frustrated.

My husband Steve and I literally worked in shifts, one caring for DJ while the other one slept. I had never known such desolation. Emotionally, I wasn't ready to accept that this was my child; so I

latched onto the idea that if I had a diagnosis, there would be treatment and it would lead to improvement.

Naturally, people wanted to ooh and ah over my baby, but DJ was so small he wasn't fully visible in his infant carrier. And when I'd uncover him, I saw the onlooker's shock register. DJ looked like the sick child that he was. Every time someone found out he was a year old they'd scurry away as if they feared my child was contagious. After a few episodes of this, I followed my answer of his age with a quick run-down of his medical history.

One day DJ and I waited at the pharmacy for his prescriptions. DJ, in his infant carrier, was sitting in a chair between me and another lady when a third lady asked if I was DJ's mommy. My eyes flicked to the stranger beside him and I wondered what she'd say if I tried to pass her off as DJ's mommy. Instead I dropped my gaze and muttered a "yes," hoping it would slam the door on any further conversation. It didn't. This time before revealing DJ, I began with his medical report. Meanwhile, a sign was hanging in front of me advising customers and staff that a patient's medical condition was confidential. Yet that sign was totally lost on me. Indeed the pharmacist cared more

about my son's privacy than I did.

I left the pharmacy more determined than ever to find a cure for DJ. I spent countless hours on the computer and in the public library, scouring for any crumb of information. I began carefully charting his food intake, height, weight and any other medical details. Showing DJ affection didn't occur to me. I was too busy trying to survive him. After all, I wasn't sure he had the cognitive ability to comprehend love and any guilt from neglecting him was easily justified by the promise to bond as soon as I got him fixed.

Furthermore, holding DJ was a wrestling match. He wriggled and squirmed as if every touch inflicted pain. Steve and I called him our "little touch me not." How relieved I was every day when my husband came home. At nearly two years of age, DJ's head still wobbled unsteadily as he lifted it to look at his daddy. One day, like a newborn foal climbing to its feet for the first time, DJ stretched his frail little arm towards Daddy. Steve and I stared at each other transfixed. Until then, our son had shown no response to the world around him and yet he was reaching for his dad. As we stood still digesting this moment, DJ mustered up all

DJ at age one





*DJ talks to his brothers with a DynaVox*

his strength and nearly flipped out of my arms towards his father.

I cried and Steve assumed I was crying tears of joy. But as I handed him our son, I was crying because my heart was shattered—shattered because my son preferred his father to me. And it was shattered because I realized why. Steve had handled the bulk of caring for DJ while I had invested my time searching for a cure. Suddenly, I looked at DJ and knew what I'd lost.

### **DJ saved my life**

As day turned to night I sat in the stillness of the early morning hours rocking my son. The moonlight cascaded through the window onto the small patch of downy hair that didn't come close to covering his head. By the light of the moon we studied one another as if for the first time. Silently my tears dripped one by one onto his precious little face and soaking into his hair. At last I confessed to DJ how I'd let him down. Once I opened up, I could no longer contain my emotions and I poured out my soul.

I cried until I had nothing left. I promised DJ that never again would I be ashamed of him. I

promised to do what I should've been doing all along—I promised to love him unconditionally. I realized that DJ wasn't the one who suffered a poor quality of life—it was me. I had chosen prejudice and shame whereas DJ made the best of his condition. Then, in the silent aftermath of my true remorse, he blinked up at me with his penetrating blue eyes and ever so slightly the corners of his mouth turned up into his first smile. It was as if my child had tried to teach me about love from the beginning and he was pleased that at last I learned.

As miserable as DJ once was, now he is happy. No one has diagnosed his condition, but he radiates pure joy. I left my job to care for

him full time and he has thrived in my attention. Financially, the strain has been enormous but the tradeoff is incomparable.

He laughs, plays and has a way of making you understand what he wants. He loves NASCAR and zips around on his little walker. He rolls right up to people and jabbars in a dialect that only he understands, yet he evokes a response.

He is not to be pitied; he is to be celebrated. He's not the one with a handicap; society is handicapped because we've placed restrictions on happiness. The world has decided to determine when life begins and what its value is. We hear "persistent vegetative state" and assume all hope is gone. Six years ago, DJ was classified as being PVS—but you wouldn't guess that now. One doctor even referred to him as a blob, telling me that any rehabilitation attempts would be futile. Had I subscribed to that erroneous opinion, I would've missed the greatest blessing of my life. Now hear this: I'm DJ's mommy and proud of it!

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*The entire Graves family*

