

Tami C. Gaines tells of the joys and challenges she faced with premature twins

Mom is an advocate for her children's rights and has written a helpful book for other parents

BY JANE RIDLEY / NEW YORK DAILY NEWS

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TONY TURNER/

Tami Gaines

[Tami C. Gaines](#) got increasingly mad as the strangers in the hospital elevator stared at her son.

The man and woman were transfixed by the tubes coming out of his throat.

Usually she wouldn't react, but 13-month-old Trey, an extremely premature baby who had a tracheostomy, was about to get heart surgery and she was feeling anxious.

"What are you looking at?" she snapped at the gawkers.

The woman flushed red and mumbled that she was sorry. Seconds later, the couple reached their floor of New York's Columbia Presbyterian — the neo-natal intensive care unit — and were gone.

"I was under stress all day that I'd yelled at them," recalls Gaines. .

"When I saw they were headed to the NICU, I realized they must have a baby in there."



TAMI GAINES/

Tami Gaines with her premature babies Bria and Trey in the NICU.



TAMI GAINES/

Tami Gaines' children Hailli (in white hood) with (from l.) Trey, Bria and Shane

If anyone knew how bewildering it was to be in that position, Gaines did.

"Trey had his surgery and I went to go find the parents in the NICU," she says. "I described them to a social worker who took me to meet them and apologize.



TAMI GAINES/

Tami Gaines' children (from top) Bria and Trey in the NICU

"It turned out their baby was getting a trach [tracheostomy] that day. That's why they'd been staring at Trey."

Tami sat down with them and told Trey's story.

"I did my best to reassure them about their own situation," she says.

The conversation was a turning point for Gaines because she identified the best way she could help other parents of premature infants.

She decided to write a book about her roller-coaster experiences with twins, a boy and girl, born at just 25 weeks' gestation.

Titled "Premie Parents: 26 Ways to Grow With Your Premature Baby" (Sellers, \$15.95), it gives first-hand advice on navigating the intimidating world of the NICU.

It motivates readers to become emotionally strong and offers tips on being the best possible advocate for your child.

"There was a gap to fill because hardly anything like this exists for parents of preemies," explains Gaines, now 43. "When I was in the NICU, I had a lot of time to think.

"I'd taken notes and kept a journal about everything that happened so the actual writing of the book took only four days."

One of the key messages is to look on the trauma of having a premature baby, not as a tragedy, but an opportunity for mental and spiritual growth.

While it might be tempting — and much easier — to crack up, you have to keep it together for the sake of the child and the rest of the family.

And, of course, yourself.

"You never know how strong you are until you get through an experience you never thought you would," says Gaines, who lives in northern New Jersey. "No matter how dark things get, you have to find that little piece of light to hold onto.

"That little piece of light will guide you out of the darkness.

"For me, it was the fact that, no matter what was thrown at them, my twins held on. They were so strong. I thought: 'If they can fight, then so can I.'"

The journey began in early 2006 when she unexpectedly became pregnant at the age of 37.

"The twins were, to me, a very happy surprise," she says. "But not to my husband."

The marriage imploded. Gaines, a high-flying career woman who runs her own business coaching entrepreneurs, faced life as a single mother of four.

The stress took a toll on her pregnant body. She went into premature labor. At 20 weeks' pregnant, she was admitted to Morristown Memorial Hospital.

While on bed-rest to keep the babies in utero for as long as possible, she developed a near-fatal blood infection. Her so-called micro-preemies were delivered, via emergency C-section, five weeks later.

Trey weighed 1 pound 13 ounces and his sister, Bria, was 1 pound 12 ounces. So tiny and underdeveloped, they had a range of health problems.

It was unlikely they would survive one week.

Gaines vividly recalls the moment when she snapped out of her despair and summoned up the strength to cope.

"I was staring blankly out of the window, at absolutely nothing, and my then 8-year-old daughter, Haili, looked at me and started crying," she remembers. "She was waiting for me to fall apart.

"That's when I knew I had to very quickly embrace this new normal. I talked to Haili and her younger brother, Shane, but I really was talking to myself. I said: 'Listen, everything is going to be fine. No matter what happens — and I don't know what will happen with these babies — everything will be fine. This is what my plan is. This is what the universe intended for me'.

"Whether the babies lived or they didn't live, over time, I knew that eventually we would be okay."

For the following 18 months, [Gaines](#) stationed herself at the hospital. Bria battled the same blood infection as her mom and, after gaining weight, was discharged, on a ventilator, after four months.

Trey, the weaker twin, was less fortunate. Among other critical conditions affecting his heart, he had acute respiratory problems which warranted the tracheostomy.

The family was repeatedly told to "make their calls" in case he didn't pull through.

But somehow, he always did.

"He is incredible," Gaines says. "Children like Trey and Bria are so much more resilient than we think they are.

"They don't have the same baggage as adults — this perception of the bad things of the world — and are fearless."

She has lost count of the number of times Trey has been resuscitated — literally brought back from the dead.

"No matter what he has been through — from turning blue with one foot in the grave — he opens his eyes and is usually a little bit dazed," says Gaines.

"But he always smiles a big smile, as if to say: 'I'm back again!'"

Recalling the twins' time in the NICU, she believes it was a period of personal growth.

She worked on basic coping skills like living in the moment, not thinking too far ahead and celebrating even the smallest goals.

Standing up for their rights was a huge challenge, especially when the specialists had a different perspective to hers.

"The hardest thing for a preemie parent to understand is that your main job is not to be their mom or dad, it's to advocate for your babies," she explains. "You have to separate yourself from being a parent who wants to have a nervous breakdown and cry your eyes out and being an advocate who needs to learn how to ask the right questions."

Tami rarely clashed with the medical staff, but, when she did, she chose her battles carefully.

She was insistent about so-called "kangaroo care," where NICU preemies, no matter how many wires and tubes are attached to them, are given regular skin-on-skin contact with their parents.

"Everything heals faster," says Tami. "Every day, I would lay Bria and Trey on my chest and their breathing would slow down.

"Some of the neonatologists don't want to do it because of all the equipment and it can be a stressor for the kids to be out of their isolette.

"But most of the nurses know it's the best thing you can do for them."

She describes the NICU staff at Morristown Medical Center as phenomenal and only had one major disagreement with an insensitive neonatologist who railed at her for nursing Trey.

Tami even manages to turn that negative experience into a positive.

"It's part of the reason I wrote the book," she says. "The NICU is very busy. It's high pressure. Babies' lives are in the balance.

"The doctors often don't have time to be courteous and I wanted to help parents deal with that."

Today, despite ongoing health issues, 5-year-old Trey is a calm little boy who faces every challenge with courage.

He can't yet speak but is undergoing a range of therapies to help him reach his next goal.

Bria, meanwhile, has overcome her developmental delays and was recently declassified as a child with special needs.

This fall, she began regular kindergarten.

Gaines is clearly proud of all four of her children.

"I could never have taught Shane and Haili what they've learned from our family's experience in the NICU," she says. "They've developed this amazing sense of humanity."

Gaines, too, is continuing to unearth new life lessons.

"I'm still on this journey," she concludes. "I am still growing."

BOX:

Tami Gaines is a parent advocate for The March of Dimes, the charity which has designated November National Prematurity Awareness Month.

She regularly addresses groups of preemie parents with the message that accepting the challenge and learning a more positive way to look at it can make it much easier to handle.

Here are some of her strategies:

1. Meditate. Pray or meditate each day to gain spiritual or emotional strength for the challenge. Feel your physical strength building each day.
2. Be honest. Be open and honest with yourself and others about the fears you have. Talk through them and then make the decision not to live your life around the "what ifs."
3. Find and celebrate joys. Find something to celebrate each day, even if it's something small, so you remember to be joyful.
4. Help others. By reaching out to others, you're putting your own challenges into perspective. It also temporarily takes your mind off your own challenges, which can be healing relief in itself.

For more information, visit www.preemieparents.com