



“Drew’s team at the hospital called him the ‘miracle kid.’”

*Drew’s mom, Jennifer D’Auteuil*

# Mom POWER

WHEN HER SON WAS STRUCK WITH A POTENTIALLY FATAL ILLNESS, JENNIFER D'AUTEUIL FELT SO ALONE. THEN A GROUP OF WOMEN SHE'D NEVER MET CAME THROUGH FOR HER.

BY PAULA DERROW • PHOTOGRAPHED BY BRIAN DOBEN

**I**n the spring of 2009, Jennifer D'Auteuil noticed a rash and unusual bruising on her youngest son, Drew. Doctors quickly diagnosed the 10-year-old with an acute case of aplastic anemia (AA), a rare disease that affects only 500 people in the U.S. each year. Drew hadn't responded to drug therapy, so six months after his diagnosis, Jen, 47, of Amherst, NH, sat at a computer Googling "aplastic anemia," "kids" and "New Hampshire," looking for anyone who'd been through what her family was experiencing. Nothing. Then she searched every single state in the country.

As his mother combed the Internet, Drew lay in a germ-free room in Boston Children's Hospital, recovering from a bone marrow transplant—the only other treatment for aplastic anemia. With AA, the bone marrow stops producing platelets and blood cells, and the immune system crashes. Drew was at high risk for uncontrolled bleeding, infection and multiple organ failure. "This is a boy who played soccer and never missed school!" says Jen, a nurse.

Even more than information, Jen, who also has twin boys, Kevin and Ryan, then 14, with her husband Pete, craved support. The cause of AA is not known, and there were no online support groups or social

networks, let alone colored ribbons or survivor walks. "It was brutal not having anyone beyond my husband to cry with, to say, 'Yes, I went through that too.'"

The day-to-day of families facing AA is exceptionally lonely. Patients are in and out of the hospital with infections and must be confined to rooms with interlocking doors and negative air pressure to keep germs out. When Drew was home, Jen had to create

similarly sanitary conditions. That meant no visitors. "No friends, no relatives, no one except for a tutor, as long as she was masked and washed her hands frequently," Jen says. The family stayed in their rooms if they came down with colds and ran their toothbrushes through the dishwasher nightly.

All she did, Jen says, was clean obsessively. "I'd get up in the middle of the night, worried that I'd missed something, and start all over again. It was horrifying," Jen recalls. "If someone used a towel, it had to go right into the wash to prevent Drew from touching it. I literally scrubbed the numbers and letters off our computer keyboards." The loneliness and anxiety, and the



guilt of not being able to pay much attention to Kevin and Ryan, she says, “was overwhelming.”

## CONNECTION MADE

Which is why Jen’s heart leapt when her Internet search finally turned up another mom, Alaina Palomino, who lived in California and had a son with AA. Jen reached out, asking if they could connect. “I told her I felt so lonely.” Alaina emailed right back: “Oh, my God—you are not alone,” she wrote. Then she gave Jen the names of two more mothers of AA kids.

One of those was Jennifer Barrios of Los Angeles, whose son Ethan had had a bone marrow transplant eight days before Drew. “The boys were so closely aligned. I couldn’t

believe I’d found another family going through this.” Over the next few days, the two Jennifers batted emails and texts back and forth. “It doesn’t seem possible to love someone you’ve never seen, but I felt as though I loved this woman,” Jen recalls. “She had an amazing ability to call me at the exact moment I needed support—night or day.”

The two Jennifers helped each other through the grueling waiting period after their sons’ marrow transplants—for a year, the patient lives in isolation to avoid infection. When Drew’s white blood cell count rose above 500 (a sign that the body is producing its own blood cells and the transplant is working), Jennifer Barrios was the first person Jen

texted. “Ethan was already beyond that and doing great—and she texted me right back, ‘We knew this was going to happen! Now our boys are both on their way. I love you—I told you we’d get through this!’” Jen says.

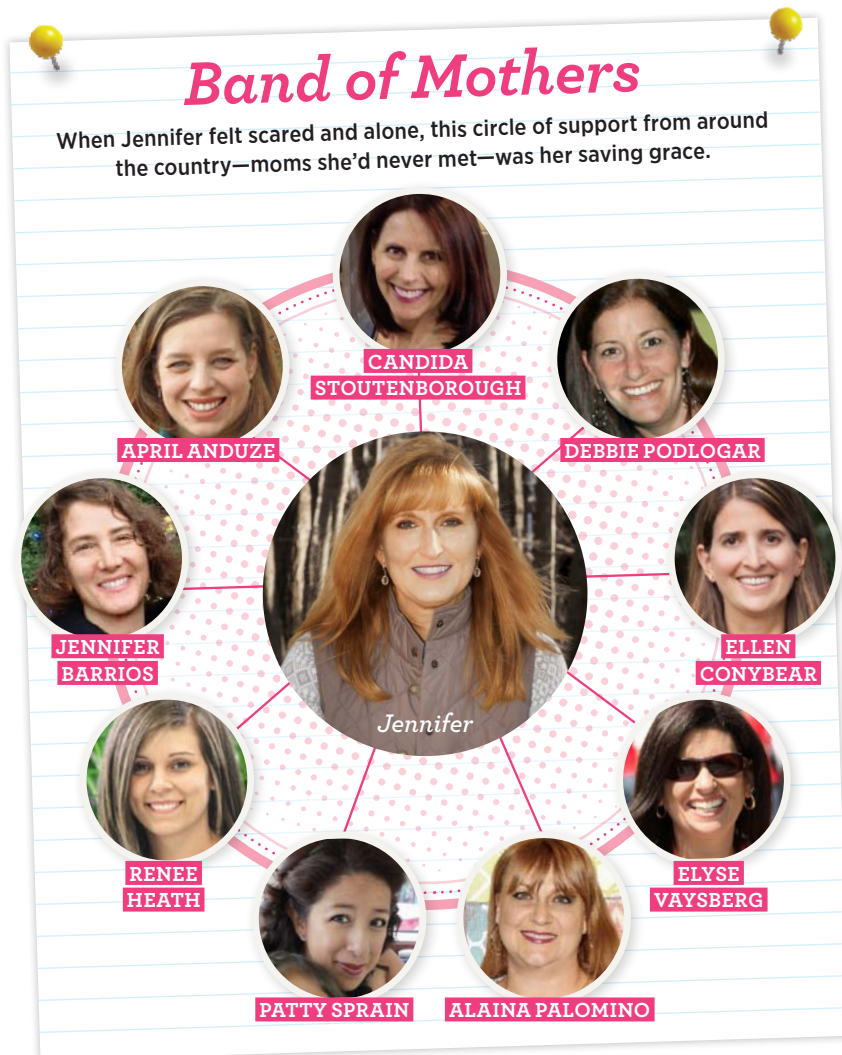
## GROWING GROUP

All told, including Jen, there were 10 AA moms—several in California, one in Texas, one in Kentucky, one in Louisiana—and the women connected on Facebook multiple times a day. “It felt important to have validation that our kids were getting the right treatment,” Jen explains. “We’d compare drug reactions, talk about next steps. It was huge.”

Jen dubbed her crew the “Band of Mothers.” “We’d get into these states where we’d fantasize about leaving our husbands at home, meeting up and drinking margaritas,” Jen laughs. “Maybe it was the stress of being cooped up and all the cleaning or maybe it was the fear, but we liked to get snarky and make one another laugh. Without them, I would have become a raving lunatic.”

But just when things were looking up, Drew’s health took a bad turn. On April 10, 2010, Jen and Pete went out for dessert with friends—the first time they’d socialized since Drew got sick. When Jen came home and heard Drew coughing, she wasn’t too worried. “He looked fine. It had been five months since the transplant. We had only seven months before we could start living normally again.” Still, the doctor suggested she bring Drew in the next day, just to be safe.

At the hospital, all hell broke loose. Drew was taken to the ICU, his lungs failed and he began losing consciousness. “Basically, he was crashing. They had to put him on a ventilator—that’s the hardest thing for a parent to watch,” Jen says with tears in her voice. The team of doctors couldn’t explain why.





By Tuesday morning, Drew was in total organ failure. “One doctor asked me if I believed in God. I said I did, and she told me to pray.” Jen called in a priest and let the twins see Drew for what might be the last time. “He had tubes everywhere. Ryan couldn’t look at him; Kevin just burst into tears.” Jen fired off an email to Jen Barrios telling her how sick Drew was, then stayed by his side. “I wanted to talk with her in the worst way,” says Jen, “but I knew that all I would do is cry.”

## VIRTUAL PRAYERS

Messages of support queued up in Jen’s powered-off phone, and gifts also began arriving. One mom sent an “angel of hope,” which Jen pinned to Drew’s pillow; another sent a stuffed dinosaur in a Boston Red Sox shirt (Drew’s favorite team); one mailed written prayers; and another overnighted a box of spa products for Jen.

In the end, the moms’ collective will seems to have made all the

difference. A few days later, one of Drew’s doctors came into his room smiling. Drew’s lungs had improved overnight. “The chief of the ER told us, ‘We don’t know why and we don’t care, but he’s getting better,’” Jen says. The team at Boston Children’s told the D’Auteuils that Drew’s recovery was unlike anything they’d seen.

When Jen finally saw the days’ worth of messages, she was floored. “All these women had children with AA. I wouldn’t have been surprised if what happened to Drew caused them to back away in fear. Instead, they were all there for me.”

Over the next months, the moms discussed how to help others dealing with AA. The result was a Facebook group Jen created in 2012, “Band of Mothers in the Fight Against Aplastic Anemia.” It now has more than 800 members in 16 countries. Thankfully, all 10 kids in Jen’s circle are thriving, and some of the families gathered in Los Angeles in person last year. “When we all met at the airport, the waterworks started immediately,” Jen laughs. “It was surreal, being able to hug, seeing all of our beautiful, healthy kids together.”

Perhaps the most amazing thing about the trip, says Jen, is just how normal it was. “At one point I realized that Jennifer and I had been together for hours and that we hadn’t mentioned aplastic anemia at all,” she says. “We were talking like regular people.” Jennifer is thankful for those ordinary moments. “You appreciate the little things so much more,” she says.

## BECOME A BONE MARROW DONOR

If you’re 18 to 44 and in good health, go to [bethematch.org](http://bethematch.org), the largest bone marrow registry in the world, and click on “Donate bone marrow” to learn about eligibility. The procedure doesn’t hurt, and you can be back at work in a matter of days. All proceeds of Jen’s book, *Anatomy of a Miracle: Drew’s Story* (Amazon), benefit various charities, including Be the Match.