

Hope Begins in the Dark

Mother and Daughter Learn To Live with Nephrotic Syndrome

by Ricka McNaughton

If you are the parent of a child stricken with a critical illness, once the initial stun factor of the diagnosis subsides, you move to the stock-taking questions. What do I know? How can I find out what I don't know? What constructive thing haven't I thought of? The questions run on a nattering, near-continuous loop through your head. They are still on the mind of Montpelier resident Dawn Seibert. She is the parent of a child with a rare and serious kidney condition.

Dawn wants to share her medical saga as a means to do more to fight her daughter's disease, and, lately, she has found more energy for public engagement. That's because her daughter, Loretta, now 4 years old, has come a long way since the onset of her illness a little over three years ago.

Loretta is currently in remission. To all outward appearances, she's a normal, fizzy-spirited little girl. And for all she knows, her regimen of meds, shots and close medical surveillance are as much a part of normal life as brushing her teeth. Getting to this welcome plateau was a rough haul plagued with radical medical trials and failures. Loretta was 9 months old when the first medical crisis struck. It was shortly before Christmas.

Dawn knew that something was amiss with her baby girl. It was nothing overt at first, but there were symptoms of the sort that trip a wire in a mother's early warning system, however low grade they may appear. Dawn took Loretta for an exam, and some tests followed. "Then I got one of those [doctor's office] messages on my phone," said Dawn, "that makes your blood run cold. It included the words 'kidneys . . . urgent . . . go immediately to Fletcher Allen Health Care in Burlington . . . and don't speed.'" So, of course, Dawn drove like a madwoman, throwing panicky glances at her child in the back seat all the way.

Loretta was admitted to intensive care on the verge of kidney failure. She turned out to have a condition known as nephrotic syn-

drome, caused by a very rare and so-far-incurable disease called focal segmental glomerulosclerosis (FSGS). "With FSGS," Dawn explained, "the immune system tells the millions of protective filters of the kidneys, called glomeruli, to stand down, in effect, and just let the blood pass unfiltered." This leads to all kinds of life-threatening bodily mayhem. The search began, in a world with few answers, for something to rein in Loretta's rogue immune system.

Loretta came home from the hospital on Christmas Eve. Dawn, a single parent with a full-time job, had to take a leave of absence and immediately master some daunting home-care tasks, which included using and keeping antiseptically clean a central-line catheter that protruded from her frail, 9-month-old baby's chest. Enter Rhonda Desrochers, a nurse with Central Vermont

Profile

Home Health and Hospice, whom Dawn described as "God's gift to people like me who have children with very special medical needs." Dawn said, "Rhonda was there on Christmas Eve when we first got home, and she didn't miss a beat on Christmas Day." All told, Rhonda shepherded mother and daughter through a lot. Still, the next few years would be grueling.

Author Anne Lamott once wrote, "Hope begins in the dark, the stubborn hope that if you just show up and try to do the right thing, the dawn will come. You wait and watch and work: You don't give up." And that's pretty much what Dawn did.

"There was that period before things stabilized," she said, "when I just kept getting bad news. She wasn't going into remission. We'd try one thing, then another." Early on she had to give her daughter what was essentially a powerful cancer treatment regimen to counter the immune response. "I was giving my baby something so toxic that I was warned not to come in contact with it barehanded," Dawn recounted. "I found myself sitting in my kitchen one day, sobbing."

That was then. This is now: Loretta, said Dawn, is a "little social bon vivant . . . she has a passion for talking, eat-



Dawn Seibert with 4-year-old daughter Loretta, who has a rare kidney disease. Dawn is now joining, in her own way, the race to find a cure. Photo by Ricka McNaughton.

and riding her bike." She's proud of having ridden in Montpelier's Fourth of July parade along with the Onion River Sports gang. She is reportedly a caring "little mama" to the other kids at day care. But even in this good time, a sober reality hovers.

The likelihood that Loretta will one day face end-stage renal disease is great. Keeping that day at bay through all achievable means is a main thrust of Dawn's life. Another priority is to simply love the life that she and Loretta have together now. "This is my time to recharge," said Dawn, "and I know I'll need those stores . . . for later. We'll be dealing with this disease the rest of our lives."

Dawn, who is tall, lithe and seems to move everywhere with a brisk stride, calls herself a "lapsed runner," largely due to cartilage problems in her ankle. The pain will

only let her go so far now. But she thinks she's good for seven miles. That's the length of an upcoming race in Falmouth, Massachusetts, which will raise funds for an organization called NEPHCURE, a research organization devoted to finding a cure for nephrotic syndrome and FSGS. Dawn helped organize the Falmouth race and intends to go the distance as well. "If I have to," she declared, "I'll walk the course."

Dawn Seibert can be reached at negriart@yahoo.com. If you would like to contribute to the effort to find a cure for nephrotic syndrome, if you are confronting similar medical issues, or if you have some information, ideas or fundraising experience to share, she would welcome your e-mails.

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