Daniel Kietz tries balancing with Julienne as he checks on her muscle strength and coordination in July.

A DOCTOR WITH “HIGH TOUCH”

IT’S THE LAST DAY OF SCHOOL AND THE 11TH NIGHT IN THE HOSPITAL

STORY AND PHOTOGRAPHY BY ELIZABETH ANNE MAY

It’s not the last day of school we wanted. No ice cream social at the neighbor’s to commemorate the start of summer. No Silly String celebration at the bus stop. Instead, I pick my 9-year-old up straight from school.

As she hugs friends, teachers, and the school secretary goodbye, we realize this day is a big deal. It’s her last day of third grade and her final day at this school. Next year, she moves up to the big fourth- to sixth-grade elementary.
Today also marks the 11th night my daughter will spend in the hospital. The 12th time in the past 18 months she’ll have an IV inserted. The 11th time she’ll receive intravenous immunoglobulin. The 20th time she’ll be treated with pulse steroids.

The milestones for me are less dramatic: It will be the 11th night I get to sleep fitfully on a hospital foldout, waking what feels like every few minutes to the symphony of beeps and vibrations and chimes of monitoring alarms. It will be the 11th time I leave the hospital feeling confident I am not tired, only to find out the opposite the minute I walk through my front door.

Quiet pervades the admissions suite at Children’s Hospital of Pittsburgh of UPMC when we arrive—not much going on here on a gorgeous June Friday at 4:30 p.m. After we’re all checked in, the woman working the desk looks at me shrewdly: *You don’t need an escort?*

Our records have given us away.

A few moments later, Julianne and I roll past the security guard near the inpatient-floor elevators like the pros we are. It’s a dubious honor, to be this familiar with a hospital.

My daughter is one of a relative handful of children with juvenile dermatomyositis (JDM), a somewhat mysterious inflammatory muscle disease related to autoimmune dysfunction. In JDM, the immune system sets off an inflammatory response in the body’s blood vessels. Two or three children per million have an inflamed system.

JDM shows up in two key ways: a distinctive rash and weakness. The pinkish-purple heliotrope rash can appear on the eyelids, face, hands, and around the joints. Muscle inflammation causes fatigue: weakness near the body’s trunk (thighs, upper arms, neck) and the torso itself.

There is no known cure for JDM (though we families hope for remission), and no one knows for certain what causes it. Experts speculate that genetic predisposition, along with an environmental trigger, can activate JDM. We certainly match the hereditary description, with autoimmune diseases on both sides of the family, including lupus, polymyalgia rheumatica, and psoriatic arthritis. (Even our dog has immune-mediated hemolytic anemia; Jasper has been in remission for the past few years.

Our human family members have not been so lucky and still need medication to control their symptoms.

While we can’t know exactly what clicked Julianne’s autoimmune system to this aggressive “on” position, getting it to switch off has proven elusive.

As the golden light of the late afternoon filters through our window in Unit 7B, I bustle around—getting Jules settled into her hospital bed, seeing if there are linens or pillows for me stowed in the cupboards, figuring out where the family pantry is and putting away our little insulated bag with favorite foods from home, and generally organizing myself for the long night ahead.

It’s a mom thing, wanting to feel helpful; and in the hospital—and with this disease—I feel powerless.

It won’t be long before we see Dr. Kietz, clinical director of the Division of Rheumatology, director of the hospital’s rheumatology fellowship program, and an associate professor of pediatrics and medicine in the School of Medicine. A slim, neat man with slightly gray hair, glasses, and a faint German accent, Dr. Kietz always greets us with a smile, a handshake, and a little head bob, almost like a tiny bow. He’ll examine Julianne, listen intently to our questions, ask us how things are going. He’ll stay as long as it takes to answer everything—without a hint of impatience—laughing off my apologies. *I know I should let you go now, I say, but I just have one more question . . .*

The residents often scare us when they check in: *Who knows, they say as if it’s a long shot, Dr. Kietz might stop by.* And my heart drops. What if he can’t make it?

I should know better. We could be here on a Monday night or a Friday night, and Dr. Kietz is always here. It could be 6 p.m. or 9 p.m. or 8 a.m., but he shows.

The first time we met him, in the rheumatology clinic in October 2012, he immediately gravitated to Julianne, kneeling so he could be at her eye level, speaking with kindness and concern. He said: *I know you feel bad, and I know you’re probably worried, but we’re going to figure out what’s going on and get you feeling better again.*

We ended up in his clinic a short two weeks after I first called our pediatrician, Stephanie Sussman (Res ’11), with a perplexing set of symptoms. Feeling foolish, I said: *I’m calling about two unrelated issues. First, my daughter seems depressed. Second, she gets up off the floor funny.* I went on to explain how my then-7-year-old daughter seemed vaguely lethargic and unhappy, though she couldn’t tell me why. I talked about how she got up off the floor like an old lady, turning around, getting on her knees, and slowly, almost arduously, pushing up to stand—yet, she said nothing hurt.

Dr. Sussman had us come in for an exam. The blood work she ordered put us on the fast track here. The markers that appeared in Julianne’s blood painted a picture of significant inflammation.

My husband and I came to Children’s armed with notes: Julianne was running a slight fever every day. She woke up tired, even after 12 hours of sleep. She couldn’t sit “criss-cross applesauce.” Climbing in and out of our low-slung van had become an issue.

Dr. Kietz examined Julianne. He looked with particular interest at the tiny, red-dotted rash at the base of her fingernails and her eyelids (where we saw nothing unusual). He rubbed his thumbs across some faint red patches on her knees and elbows. He had her push her weight against his with her arms and legs.

Only about 15 minutes into the appointment, he gave us the diagnosis. We were shocked. We expected more blood work, additional tests, time to prepare ourselves. Dr. Kietz had seen this disease often enough to know its signs well. An MRI would later confirm his diagnosis.

He went on to explain the disease, the treatment, the prognosis. And, though we understood the potential outcomes—the disease course could run chronic; could be on-again, off-again, with flares or relapses; or could go into remission—the uncertainty fell hard. The intense path of treatment we would have to follow took weeks to really sink in. Dr. Kietz recommended a treatment plan of inpatient infusions once a month every month for seven months.

And, now, on this June day in 2014, we have been there and done that. From October 2012 to April 2013, we paid our dues in full with monthly hospital overnights. We expected to be done or, at the very least, progressing. It seemed we were—our girl was
Julianne at a dance recital. When she came out of remission earlier this year, her treatments allowed her to tap across the stage.

suddenly able to ride a bike without training wheels. And now, a relapse.

A light knock at the door interrupts my thoughts; the IV team is here. She's an ace, this nurse, and takes her time, looking for a nice, juicy vein. She offers Jules some freezy spray to help numb the arm. We say, Why not? Let's try it.

Another knock, and Dr. Kietz peeks in. I smile as he greets me and Julianne. You can see I have no pull here, he says in mock apology, gesturing to our view of a brick wall, instead of the picturesque Allegheny Cemetery or the city views our windows usually frame.

Next thing I know, he’s rolling up his sleeve and grabbing the bottle of freezy spray we just told him about. Watch as I heroically demonstrate on myself, he says, and sprays the inside of his forearm. Here, touch.

I laugh and feel. It’s cold.

I n early April, when Julianne’s JDM symptoms came raging back, she sat on the couch and cried. She knew exactly what would happen this time, and she dreaded it. She didn’t want to go back to the hospital; she was especially nervous about the IV. She didn’t want to feel weak and tired and miss school constantly. She didn’t want to have to sit out gym or not play tag with her friends at recess. She didn’t want to have to explain when her classmates asked, Why?

I didn’t want to go back either. I wasn’t ready for Plan B, because I liked Plan A: weaning Julianne off steroids and then, slowly but surely, lowering her once-weekly maintenance med (methotrexate) until she could quit it completely. The plan was remission with medication—and then remission without. The plan was not going back to a series of six hospital overnights, twice-daily steroid doses, once-a-week injections, plus a new medication. No thank you.

I sat next to Julianne on our worn chenille couch and said what I was supposed to say: I said I’d be there with her. I said we knew how to do this hospital thing now. I said she was so brave; the IV didn’t even bother her anymore. I said it wasn’t fun, but we had to do this to get her feeling better again.

I’m not sure what else I told her, but, mostly, I wasn’t even buying it.

T his evening, at the hospital, Dr. Kietz asks us if we want to walk down to the little overlook area on 7B; it’s a favorite of his. It gives him a chance to see Julianne’s gait and for us all to chat.

As we gaze out over the streets of Pittsburgh’s Lawrenceville neighborhood (where Julianne’s grandparents and great-grandparents grew up), Dr. Kietz muses about how the city comes alive in summer. When the weather warms up, he says, everyone comes outside again. There are block parties and festivals—always something going on.

He notices.

It reminds me of something nonfiction author Daniel Pink says. Pink tells us success in today’s world depends not only on scientific or technical know-how but also on authenticity, connection, and creativity.

We long for someone to come along and do a job with excellence and empathy.

Pink calls this “high touch”—the ability to understand the subtleties of human interaction, to find joy in oneself and elicit it in others.

Tonight, we three stand still for a moment, here at this busy hospital. It’s a place I’ve always assumed I’m unlikely to find joy and beauty and meaning, a place I rush to get into and out of as quickly as possible so we can get on with the rest of our lives. And I wonder if I’ve gotten it wrong.

Look! Dr. Kietz calls. He’s noticed a little girl down below, twirling on the sidewalk. The tiny braids all over her head fly out, and she is dancing, spinning, a neon-orange blur of brief, pure, concentrated joy.

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Arthritis and other rheumatic conditions affect more than 300,000 children in America—making them among the most common childhood diseases—yet only about 300 pediatric rheumatologists currently practice in the United States. Many states have only one or two board-certified pediatric rheumatologists; eight states have none.

But Daniel Kietz, an MD/PhD—among the first recruits of Children’s fledgling rheumatology service in 2003—has seen the landscape change dramatically in Pittsburgh. “Patients used to wait months to get an appointment,” he recalls of the program’s early days. “Now, we promise new patients an appointment within 72 hours.” Children’s division has seen exponential growth; it’s now one of the country’s most robust programs, with five full-time faculty members, basic and clinical research programs, a fellowship program, and a dedicated rheumatology social worker.

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DOCTORS NEEDED

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