

# What caused a newborn twin's badly swollen legs

By [Sandra G. Boodman](#) Reporter September 28 at 1:46 PM



Heather Ferguson was beside herself.

The 34-year-old mother of 2-month-old twin boys had just spent several days in a Charlotte hospital with one son as he underwent diagnostic tests for heart failure and other life-threatening ailments. When nothing was found, doctors resorted to an Internet search. That yielded a possible diagnosis and a recommendation that Ferguson consult a pediatric surgeon.

But the surgeon who saw Dylan Ferguson in December 2006 offered little beyond a cursory exam of the infant's badly swollen legs and groin. "Let's just keep an eye on it and bring him back in six months," Ferguson remembers the surgeon telling her.

"That was the worst moment," she recalled. "It's so horrible to know that something's wrong and to get the brushoff. I felt like we were on our own and that the medical system had just washed its hands of us." Every time Ferguson looked at the normal legs of Dylan's fraternal twin, Devdan, the contrast was upsetting.

Those early encounters with the medical system shaped Ferguson's life in unexpected ways, propelling her into a vocation far removed from her career as a dancer with the Charlotte Ballet. But the steely discipline and single-minded determination required of a ballerina, she said, proved to be "great training" for what lay ahead.

The twins were born Sept. 29, 2006, after a pregnancy Ferguson describes as “completely normal and healthy.”



*1Dylan Ferguson, right, with his twin Devdan, left, as newborns. (Courtesy of Heather Ferguson)*

Dylan, two minutes younger than Devdan, emerged with a slightly swollen groin. After he was circumcised, the puffiness disappeared.

By his one-week check-up the swelling had returned. The pediatrician chalked it up to a transitory side effect of the circumcision and tried to reassure Ferguson and her husband, Brian. There was no sign of infection, and Dylan wasn't in pain.

A week or so later, the swelling had engulfed his upper thighs and genitals, and Ferguson felt a mass on Dylan's right thigh. “At this point I thought it had nothing to do with the

circumcision,” she recalled. The pediatrician told her it might be a bug bite. She was skeptical. It was October, and her babies hadn't been outside except to go to and from the car. When the swelling failed to subside, the pediatrician suspected a hydrocele, a fluid-filled sac surrounding a testicle that causes scrotal swelling.

A pediatric surgeon who saw Dylan at 4 weeks old found hydroceles on both sides. “These are very common in little boys,” he told the Fergusons. He suggested waiting until Dylan's first birthday to see if the problem resolved naturally, as it often does. If it didn't, Dylan would need surgery.

Ferguson was relieved — briefly. Over the next few weeks she made several visits to the pediatrician as the swelling worsened and crept down Dylan's right leg. “I had his brother as a control group,” she recalled. Soon both of Dylan's legs were twice the size of his twin's, and his tiny feet were mounds of flesh. “Everyone kept telling me it wasn't anything to worry about.”

### **Abrupt about-face**

But at the twins' two-month checkup, the doctor took one look at Dylan's legs and feet, which now showed signs of [deep, pitting edema](#) — swelling where an indentation remains after flesh is pressed — and quickly left the room.

Ferguson could overhear murmured conversation in the hall as the pediatrician conferred with his partners. “I felt more annoyed than worried,” she recalled. “The kids were tired and hungry . . . and I had been pointing out this swelling for what seemed like a long time.”

The doctor reentered the room and told Ferguson she needed to take Dylan to the hospital. When she said she wanted to go home first to nurse the boys, the doctor insisted, without elaborating, that she go straight to the hospital.

Once there, the Fergusons grew increasingly frustrated. “We kept asking, ‘Why are we here?’ ” she recalled. She was shocked when a nurse revealed what doctors suspected: The pitting edema indicated that Dylan’s heart was failing.

For the next three days Dylan underwent test after test — MRI scans, X-rays and ultrasounds, some under general anesthesia — as doctors ruled out heart and kidney problems along with anything else they could think of. Every test was normal.

Just before sending the baby home, a doctor told the couple that an Internet search had turned up a disorder, [lymphedema](#), that might explain Dylan’s symptoms.



*Devdan, right, and Dylan, left. (Courtesy of Heather Ferguson)*

“That was it,” Ferguson recalled. “There was no explanation of what it was, how we could get a definitive diagnosis or how or if it could be treated.” When she asked what she should do, doctors told her to go back to the pediatric surgeon.

The surgeon advised Ferguson to “keep an eye on it” and bring the baby back in six months, she said. He seemed “uncomfortable and disinterested” and never mentioned lymphedema. The condition is caused by an accumulation of fluid in the lymphatic system, which is part of the immune system. Blockages prevent the fluid from

draining properly and cause swelling and, if not treated, infection and immobility. Ferguson said she was too exhausted and distraught to ask “focused questions” during the appointment. It wouldn’t happen again.

Skeptical of the wait-and-see approach, Ferguson turned to the Web and quickly discovered a doctor in Charlotte who specializes in treating lymphedema. If Dylan had lymphedema, her research revealed, waiting was the wrong approach.

Ferguson called [physiatrist](#) Sharon Kanelos, a rehabilitation medicine specialist, and was told the first available appointment was months away. After Ferguson pleaded with the staff, Kanelos agreed to see Dylan two weeks later, on New Year’s Day.

### **‘Not rocket science’**

Kanelos said she initially considered other causes of swelling, including a malformation of Dylan’s vascular system or a blood clot. She suspected that the most likely diagnosis was [primary congenital lymphedema](#). “It was a fairly classic presentation,” Kanelos said. Subsequent testing confirmed the diagnosis.

Primary lymphedema accounts for about 10 percent of cases of the disorder in the United States, most of which result from damage to the lymph nodes or lymphatic system during cancer treatment, particularly mastectomy. Worldwide, most lymphedema is caused by a parasitic infection. Regardless of the cause, if the disorder is untreated it can lead to [elephantiasis](#), grossly swollen and disfigured limbs. Affected skin can become rock-hard, almost like wood, or it can crack and weep fluid. Lymphedema patients, who include growing numbers of those with extreme obesity, can also develop serious bacterial skin infections, such as [cellulitis](#), which can be fatal.

Dylan's form of the disease typically surfaces in infancy and is caused by defects in several genes or by random mutations. Tests have failed to identify the genes responsible in his case, but the family is enrolled in a long-term genetics study at the University of Pittsburgh. It is possible, Kanelos said, that his twin could develop lymphedema; so far, Devdan shows no signs of the disorder.

"I see lots and lots of patients who are adults and never got diagnosed," even though they have been living with the disfiguring disease for years, Kanelos added.

"I've had doctors tell me that there's no treatment for lymphedema," which is false. There is no cure, she noted, but there is effective treatment, which includes specialized massage to disperse stagnant fluid and tight compression garments that reduce swelling.

"It's not rocket science," said Kanelos, one of about 50 U.S. physicians who manage lymphedema. Because doctors learn little about the lymphatic system during their training, she said, many fail to recognize lymphedema.

For Ferguson, Dylan's diagnosis brought "a mix of relief and doubt": How could one of her 4-month-old twins have a rare, incurable disease? She sought a second opinion at Boston Children's Hospital, where a team reviewed Dylan's records and confirmed the diagnosis. Children's also offers a program that matches newly diagnosed families with older patients. The Fergusons were paired with a law student in his 20s who is now a congressional staffer. "It was life-changing" and deeply reassuring "talking to someone who had been affected as Dylan had, and had a full and happy life," Ferguson said.

Kanelos also referred the family to a lymphedema therapist, who taught the Fergusons to perform daily [manual lymph drainage](#), a form of therapeutic massage that moves fluid out of Dylan's legs and groin to reduce swelling. That regimen was followed by swathing the baby's lower body in compression bandages, which made him look like the Michelin man.

Daily massage and bandaging the wriggling baby was an hour-long chore that Ferguson said became somewhat easier over time.

### **A new career**

When he was 7 months old, Dylan's bandages were replaced by custom-made [compression garments](#). The family's insurer covered the first set — then priced at about \$450 each, the



garments must be replaced every four to six months — but in 2008 a new insurance company refused, saying they were not covered by the family’s plan.

Ferguson repeatedly appealed the denial, an experience she channeled into her new vocation as an advocate for lymphedema patients. “I couldn’t cure Dylan,” she said, “but I could do everything in my power to close the coverage gap for my son and other lymphedema patients like him facing the same struggles,” particularly those who cannot afford to pay for the garments, which can cost as much as \$1,000.

Ferguson sought help from her state representative, who requested that the insurer’s medical director review the denial. Nine months after the first rejection, the company agreed to cover the garments, but only for a year. Ferguson, with the support of several state lawmakers, lobbied for a provision in North Carolina law that would mandate coverage.

Two months before the 2008 presidential election, Ferguson was invited to speak about her battle at a campaign rally focusing on health care that featured future Vice President Joe Biden and his wife, Jill. In 2009, a mandate requiring private insurers to cover lymphedema treatment,

including compression garments, passed the state legislature and was signed into law.

In 2010, the [Lymphedema Treatment Act, which has 133 co-sponsors and supports improved diagnosis and insurance coverage](#), was introduced in Congress. Ferguson now directs the Lymphedema Advocacy Group, a volunteer organization she founded, which lobbies for the bill.

Dylan, who has been hospitalized for cellulitis twice, is doing well. He now wears knee-high compression socks.



Ferguson says her fear that the disease would erode the bond between her twins proved to be unfounded. “We’ve always been really open with them,” she said. “Dylan has never asked me: ‘Why do I have it and Devdan doesn’t?’ And neither has Devdan.”

*Devdan, right, and Dylan, left, at age 8: Dylan wears a compression stocking. There is no cure and treatment consists of compression garments to control swelling. If not properly treated, the disease can result in permanent damage and hugely swollen limb*