

## Jonathan

There aren't many patients who are on a first-name basis with the entire All Children's Pediatric Emergency Center staff. But then, 11-year old Jonathan is pretty unique.

"I pretty much know all the doctors in the E-R," Jonathan says matter-of-factly. "I'll show up and they'll say - 'OK Jonathan, what did you do THIS time?' Normally, when I go into the E-R, it's when I break my femur (thigh bone) - which is not often, luckily - knock on wood," he adds, quickly rapping the desk in front of him.

"I have OI - osteogenesis imperfecta," Jonathan explains. "It's a brittle bone disease. It's where you can break your bones easy, so if I fall I can break a bone. Or if I hit something, I can break one."

He stopped counting how many bones he's broken when he hit 80 awhile back. But he still remembers the silliest break.

"I was hula-hooping in the garage and my big toe curled up under me and my whole foot broke. They didn't believe me for the next day or two. My foot got really big and purple and I went to the doctor and they said - 'yeah, right there.' Right where I pointed. So now they believe me!"

Jonathan knows a lot about OI and what lies ahead for him. He knows that once puberty begins, the frequency of breaking bones should decrease.

"Part of helping Jonathan to be a strong person is to empower him by giving him knowledge and understanding," says his mom Linda - who also has OI. "He needs to understand what's going on because that's really the only control we can give him over a lot of these things. And that's one thing the All Children's orthopedic group has been good about - especially Dr. Beck."

Scott Beck, MD is the pediatric orthopedic surgeon who has implanted special rods in two bones of Jonathan's left leg in the past year. Called Fassier-Duval rods, they look sort of like a café curtain rod - two metal rods, one larger and hollow that telescopes down over the smaller one. Implanting FD rods requires special training that few surgeons in the southeast have. But the benefits for growing youngsters like Jonathan are great.

In the O-R, the rod is placed down the middle of the bone. Each end of the rod assembly has threads that are sunk into the bone. In the case of Jonathan's thigh bone, Beck says the screws on the female end went into the hip-end of the femur, and the male end screwed into bone just above his knee. "So now you've attached the rod to each end in the bone. And as the patient grows - since bones grow from the end - the rod automatically telescopes out longer."

Jonathan just calls them his "growing rods".

"It grows with you. You don't have to get it adjusted or anything. They're gonna stay in me unless I feel like taking them out and I don't want to, 'caus they make your leg stronger. My tibia (shin bone) was straight, but it didn't really line up with my ankle. My femur was broken so often it looked like an "s" shape. Now my whole leg's lined up."

You'd think after all the visits to the E-R and the O-R, Jonathan would be over All Children's by now. Far from it, says this pre-teen.

"It rocks because it's so fun! They have bingo and pet therapy. If you're not feeling well and you don't want to eat, you can have food up until midnight. And you can get unlimited ICEEs."

Jonathan's parents say that's pretty typical of the way their son looks at life in general - seeking the positive in whatever comes his way.

"He's grown to accept that this is how God made me. This is WHO God made me. So I'm going to live the best life I can," Linda says with pride. "And that's pretty cool when you have an 11-year old kid that understands that, and that conveys that to other people."

