

Script – Print - Normal Heart, Normal Life

Thirty years between operations, an OSF congenital heart patient has new lease on life

"OSF saved my life at eight months and again at (age) 31."

That's how Kristy Nielcen sums up her three decades of experience with congenital heart disease (CHD).

She's part of the one percent of infants born with congenital heart problems, the most common of birth defects. Nielcen is also among the more than 90 percent of those patients who become adults. Many of them, like Kristy, need to have another operation.

For her it started as a pulmonary valve that was not working properly and it was leaking. OSF HealthCare Children's Hospital of Illinois surgeons repaired it with a cow valve. Better. But for Kristy it meant some limitations to an active childhood that now, as an adult, became increasingly unmanageable.

"Made it harder for me to do things, like walking up the stairs," says Kristy Nielcen, a congenital heart disease patient. "A couple of steps I would just get tired and couldn't do it anymore. Or, like, walking through the store to go grocery shopping. It just made it harder on me."

Kristy's last annual check-up found increased leaking and swelling of her heart. It was time for another valve surgery.

Now in cardiac rehab, Kristy says she is seeing signs of improvement - up to 20 minutes on the treadmill from a starting point of eight. Her surgeon, Dr. Marc Knepp, Division Head of Pediatric Cardiology for OSF HealthCare Children's Hospital of Illinois and a specialist in adults with congenital heart disease, says she's doing great.

"Her last visit in the office here her heart was remodeling, it was shrinking back to normal size," says Dr. Marc Knepp, Division Head of Pediatric Cardiology for OSF HealthCare Children's Hospital of Illinois. "The heart was squeezing very well. And that brand new valve looks beautiful. So, overall, she's doing terrific."

"With it now with two valves, I'll be able to do a lot more and it'll work a lot better," says Kristy Nielcen, a congenital heart disease patient. "The swelling has already gone down, so that's like a big plus.- we didn't want it to get any worse. And I can do a little more. But, once I'm fully healed, I should be able to do a lot more than I could before."

Dr. Knepp, says because survival rates are good today there are more adults with CHD than children. Additionally, providing good treatment and care of these patients through their teens allows of a better medical determination of their needs when they become adults.

"Valve replacements. They may need pacemakers and other things along those lines," says Dr. Marc Knepp, Division Head of Pediatric Cardiology for OSF HealthCare Children's Hospital of Illinois. "The other thing that we really are concerned about is Mom's with congenital heart disease. If the woman wants to have a pregnancy, it's very important that we take care of the Mom and then the future baby as well. So that both of them get great care and have a good outcome."

Calling Dr. Knepp and her OSF congenital heart team her heroes, Kristy says she's grateful and thankful. She's also excited for what's ahead in her life.

"It's like a whole new world for me," says Kristy Nielcen, a congenital heart disease patient. "I just want to try everything. I don't want to be 'no I don't want to do that'. I want to go snowboarding and go do a ton of things that I couldn't do before. Running, maybe a marathon - work on that, not right away. But do something that I just couldn't do before and now I'll have the luxury of doing."

To learn more about the OSF HealthCare Children's Hospital of Illinois congenital heart program, visit www.osfhealthcare.org/childrens/services/heart/