

Healing broken hearts

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Credit: University of North Carolina at Chapel Hill School of Medicine

During each of her two pregnancies, Jennifer Solms Nelson studied the results of her ultrasound a bit more intensely than other expectant mothers. Whereas most might scan the grainy black-and-white images for ten fingers and ten toes, or the presence (or absence) of certain gender-identifying parts, Nelson focused on the heart of her unborn child. She checked that the heart was beating, and at the proper rate; that it was positioned on the left side; that it had four chambers; that the arteries and veins were all in the right place.

Nelson is a congenital heart surgeon, and she knows the statistics all too well. Congenital [heart defects](#) are the most common type of birth defect, affecting eight out of every 1,000 newborns. Because surgical treatment for heart defects has improved tremendously over the past 30 years, most patients with heart defects can now live long, fulfilling lives. In the

United States, more than 1 million adults are currently living with a [congenital heart defect](#).

Two years ago, Nelson approached NC TraCS about creating a research program focused on understanding such defects. The result is the UNC Children's Heart Collaborative, a multi-disciplinary team of researchers who, like Nelson, are determined to improve the care of children and adults born with a heart defect.

"I absolutely love what I do, and I wanted to bring together other people who are also passionate about making a difference in these patients' lives," said Nelson, an assistant professor of pediatrics and surgery at the UNC School of Medicine.

When Nelson was in medical school, she recalls many people trying to dissuade her from going into [congenital heart surgery](#). Classmates argued that it would be a rough life, that she would never have time for herself, that she would never be able to have a family of her own. Professors in other specialties remarked that she was "too nice to be a surgeon" and that "female cardiac surgeons have a tough road." Ever thorough, Nelson gave other specialties a chance, flirting with ophthalmology, dermatology, and radiology, but admits that she wasn't passionate about anything else.

Congenital [heart surgery](#) involves repairing heart defects in any patient, regardless of age. As a result, Nelson might operate on a one-week-old one day, and a 60-year-old the next. Because up to a third of heart defects are detected during fetal ultrasound, she often begins her relationship with patients before they're even born. Her job demands mastery of procedures running the gamut from routine to risky, and the ability to remain calm under pressure.

"Congenital heart surgery has very high highs and very low lows," said

Nelson. "I think doing the job requires a certain personality, and even a different philosophy on life and death, especially when you're dealing with newborns. When I decided to focus on congenital heart surgery as a career, I was determined to pursue the best possible training available."

Nelson believes she did just that. After medical school at UNC, Nelson did a general surgery residency at UNC, followed by fellowships in cardiothoracic surgery and then pediatric cardiac surgery at the University of Michigan in Ann Arbor. There, she discovered the Michigan Congenital Heart Outcomes Research and Discovery program or MCHORD, a successful multi-disciplinary group focused on research around [congenital heart disease](#). The group included a statistician, an analyst, a database manager, and clinicians across many different areas of medicine. When Nelson returned to UNC in 2013, she decided to recreate that model.

Team science experts at NC TraCS, home of UNC's Clinical and Translational Science Award (CTSA), told her how to get started. At first, she contacted everyone she could think of at UNC that did anything remotely related to congenital heart disease. Nelson set up a Sakai website, and invited them to a meeting. That led to a host of new projects and a symposium with a roster of nationally recognized speakers, and then another symposium, now an annual event. In 2015, the members of the UNC Children's Heart Collaborative decided to launch a research project together, evaluating the feasibility of starting a tetralogy of Fallot patient registry in North Carolina. Tetralogy of Fallot is the most common complex heart defect, caused by a combination of four anatomical anomalies of the heart.

Up until the 1960's, newborns with this defect – known as "blue babies" because they suffered from a lack of oxygen in their blood – rarely survived infancy. Thanks to advances in surgery, well over 80 percent of treated patients now live to adulthood. Nelson is trying to figure out how

best to care for these patients with repaired hearts, who are facing a whole new set of problems the world has never seen before. She and her team received pilot funding from TraCS to get in touch with UNC's older tetralogy of Fallot patients and inquire about their progress.

The treatment of congenital heart defects is not always straightforward. Nelson recently completed her Master's of Science in Clinical Research from the UNC Gillings School of Global Public Health. She wrote her master's thesis on the geographic distribution of births in North Carolina with tetralogy of Fallot, and uncovered an alarming statistic that 15 percent of infants born with that diagnosis between 2003 and 2012 in North Carolina have died. Through the UNC Children's Heart Collaborative, she and her team plan to look at factors that can help improve neonatal survival with tetralogy of Fallot.

The Collaborative is creating new opportunities for a variety of different projects that reflect the interests of its members. For example, basic scientist Frank Conlon has spent years studying the genetics of congenital heart disease, but he has conducted most of his work in model organisms because human samples are so difficult to come by. Through the patient registries developed by the Collaborative, Conlon hopes to uncover new knowledge relating to the origins and inheritance of heart defects. UNC medical student Eric Jernigan has dedicated an entire year to being the Collaborative's first official research fellow. He now directs half a dozen research projects run by several UNC medical students, including Audrey Lan and Luma Essaid, with the financial support of private donors, philanthropists, and the Carolina Medical Student Research Program. Another medical student has already approached Nelson to ask if she can take over Jernigan's post next year.

"We want to mentor and educate future physician scientists, and improve exposure to congenital heart surgery," said Nelson. "I think, for many students, it sounds exciting, but the work we do is still kind of a mystery.

For me, it's the best job in the world and I want to share what we do with the next generation of caregivers."

Provided by University of North Carolina at Chapel Hill School of Medicine

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