

RIGHT (left to right) APNs Judith Wilson, Kathleen Einarson and Paula Pereira-Solomos.

Tending to tiny hearts

Advanced practice nurses at Sick Kids Hospital in Toronto are part of innovative multidisciplinary teams in pediatric cardiology—a Canadian first—dramatically reducing emergency admissions

By **Lucianna Ciccocioppo**/Photography by **Carolyn C.**

It was supposed to be an idyllic summer trip back to her Hungarian homeland, with her four-month-old son and mother in tow. But for Suzanna Deak, “It was two weeks of hell.”

Two summers ago, Julian Finkelstein was a rather sweaty baby, suffering from diarrhea and vomiting, but his pediatrician assured Deak it would pass. The long and tiring plane ride to Hungary was marked with a one-hour crying and screaming match by baby, and Deak’s mother’s intuition kicked into high gear. “This isn’t right,” she thought, and promptly got a doctor to make a house call upon arrival in Europe.

He detected a heart murmur and transferred Julian to the central heart clinic. An x-ray diagnosed a very sick little boy, the nurses started IVs, and doctors told Deak to expect the worst—he wasn’t going to make it.

Deak’s travel insurance offered a medical plane to return to Toronto, and Julian was immediately taken to Sick Kids Hospital, where staff cardiologist Dr. Paul Kantor confirmed the diagnosis: dilated cardiomyopathy. This is the most common form of cardiomyopathy, a chronic and sometimes progressive disease that causes the heart muscle to abnormally enlarge, thicken or stiffen, eventually weakening it to perhaps cause heart failure.

Days later, Julian was recovering and slowly got better. “We didn’t need to be on a transplant list,” says Deak. It turns out, Julian’s case was caused by a viral infection, not genetics. He still has regular follow ups with his cardiologist and with Judith Wilson, MN oT1, an advanced practice nurse at Sick Kids’ Labatt Family Heart Centre.

Wilson is one of nine APNs who subspecialize in pediatric cardiology. These APNs bring their expertise to six areas: surgery, single ventricle, cardiomyopathy and heart function, pulmonary hypertension, cardiac transplant and lipid disorders. While heart failure teams are established in hospitals for the adult population, they are new to pediatrics—and The Hospital for Sick Children was the first to implement them in Canada.

Wilson started in this unit seven years ago. She runs an outpatient clinic with Dr. Lee Benson, head of the cardiac diagnostic and interventional unit, for children with hypertrophic cardiomyopathy. She determines if genetic screening is required, disseminates information on the genetics of the disease, ensures they have the proper medications if diagnosed, and presents at weekly rounds with the multidisciplinary team.

With an increasing expertise in this area, she helps keep patients from re-admission into Sick Kids. “If the physician is tied up in a catheter lab, or doing other

procedures, and the patient needs medical attention, I can triage the situation. I’ll ask to have the child brought into emergency, assess the patient and send him or her home if everything is ok, or call in the team if not,” says Wilson. Sometimes it’s a matter of tweaking their medications. “The patient, or the family, may call in with a blood pressure reading, and I can advise to go up on this medication. Or if they seem to be doing much better, and don’t require so much diuretic therapy, I’ll advise to back off on the medication.”

Her passion for nursing has grown since working in this area of pediatrics. “This has been the most rewarding part of my career, working with this population, because it covers the whole spectrum of their illness, from being acutely ill in the intensive care unit, newly diagnosed, to meeting the patients and their families and teaching about the disease, through managing them as they start to get better on the ward, and following them as an outpatient,” says Wilson.

Using advanced practice nurses in the division of cardiology makes perfect sense, says cardiologist and clinical head, heart failure service, Dr. Paul Kantor, “because of the complexities of the patients and because it promotes a closer patient-caregiver relationship, which continues after discharge, and which is able to continue more readily than if it were run solely through a physician.”

Parents, such as Suzanna Deak, can’t thank Wilson enough for being that one contact person who truly knows their child. “We had her direct number,” says Deak. “She walked us through everything, and told us how other families were dealing with this disease. She helped us get back to a normal life.”

The cardiology unit is busy. Most patients end up on the transplant list. A new heart, however, means new medical issues, and that means advanced nursing support, says APN Kathleen Einarson (ACNP oT3). She works in the post-operative care and management unit, reviewing charts, tests and results, examining patients to make the necessary adjustments to their treatment plans and medications, and ordering investigations to prepare the patients for discharge. Like her other APN colleagues, Einarson collaborates with the multidisciplinary team, and presents to the cardiologist on rounds.

New to her practice is a one-month rotation in the critical care unit, where many post-operative patients could remain for months. “The staff nurses need support on how to provide interventions with families who are under a lot of stress,” says Einarson. “They need advice on how to move the care forward in the critical unit. Things like getting patients out of bed because they don’t need to be on the monitor all the time, or taking the invasive monitoring lines out in children who would normally be on the ward in 4D, but aren’t, because





there isn't an available bed yet."

This support means overall hospital stay isn't unduly prolonged. It also means increasing family and staff nurse satisfaction. The educational support extends to the staff nurses on the ward, who have "numerous questions" about the many issues surrounding cardiac surgery, says Einarson. "We advise on strategizing and prioritizing testing in terms of what should be done first. We also teach chest tube removal and pacing wiring removal to the general staff, so a patient doesn't have to wait for an APN or physician to be available." Adds Wilson: "A lot of staff nurses don't remember a time when there weren't APNs. Helping the RNs problem solve takes some pressure off them."

Consistency to care is a recurrent theme. "Being a teaching hospital, we work with a lot of residents, fellows and trainees, who come and go on a frequent basis. The APNs, however, are here on a regular basis; they understand our routines and protocols, and have, in fact, helped up to develop those protocols," says Dr. Jennifer Russell, program director, pediatric cardiology, and section head, inpatient cardiology. "They know it's our policy to minimize blood work," she says. Russell explains since pediatric residents don't do a lot of cardiology, they tend to be "very test-oriented." That means cancelling the overabundance of lab tests or x-rays by morning that residents, unfamiliar with the patient, or insecure about their cardiac skills, may have ordered on an overnight shift. "Lab utilization is a big focus at the hospital," says Russell, "and I think APNs have bought into that very early on."

Russell says APNs have been instrumental in developing care maps, the critical pathway for decision-making from diagnosis, pre-operation and discharge. She co-chairs the care map committee with APN Paula Pereira-Solomos (BA 9T3, BScN 9T4, MN 9T9). The maps prevent needless testing, and ensure certain procedures are in place at appropriate times. "We can track for quality purposes whether certain procedures are happening, or not, and if not, why not, so that we can track the root cause of the lapse," explains Pereira-Solomos.

She is credited with essentially carving out the advanced practice role in the Labatt Family Heart Centre almost nine years ago, and with Einarson, launched the APN-driven out-patient clinic as well. "It was met with lots of resistance at first, from the cardiology team, but now they've embraced the role quite well," she says. "The cardiologists wanted people with expertise to see the patients." Those experts are now APNs who have developed a strong working relationship with the medical team. "We help move the program forward to provide better care for families and their children."

The results of this better care? "Anecdotally, I can tell you we've noticed a dramatic reduction in emergency admissions of patients with heart failure," says Kantor, a U of T associate professor. "The cardiomyopathy and heart function service is essentially run by two APNs, and it's that continuum at the outpatient level that results in adjustments of care and ultimately averts deterioration which would otherwise mean readmission."

The single ventricle unit, where Pereira-Solomos works, has experienced the same trend. The unit has an APN-driven clinic and staff cardiologist which has translated to fewer emergency admissions. It also staffs a hotline by APNs during the day, fellows at night, to help triage situations. If patients need to come to emergency, "then the admission is much more coordinated, anticipated," says Pereira-Solomos. "We can prevent a crisis."

Their APN expertise is now reaching out prenatally, linking with mothers whose fetuses have been diagnosed with single ventricle disease. The nurses are connected with Mount Sinai Hospital's fetal alert network. "We meet with the parents prenatally and provide a lot of anticipatory guidance about what they can expect with caring for their child after birth. We walk them through the experience of this type of heart disease and outline resources they're going to need, if they require help with other children. We ensure collaboration with social workers because of the complexity of the disease," says Pereira-Solomos. The APNs follow the families from diagnosis to what they call "graduation," after second stage palliative surgery, because this is the time the children require the most intense care. It's also a time of educating the parents extensively about life with a child who has a diseased heart.

The education continues after discharge, where APNs empower parents to take advantage of available community partnerships to help them develop an expertise in taking care of baby at home. "Together with Community Care Access Centres, we're stepping up in-home monitoring of these families, so parents take more of a leadership role," says Pereira-Solomos. "We give them a binder full of information, prepared by nurses, to keep them on top of medical issues, such as feeding and weight, so they don't have to come back to Sick Kids unnecessarily, especially if it's a long drive."

While it's not a long drive back to Sick Kids for Julian Finkelstein and his parents, the Toronto-based family would like to keep the emergency admission a distant memory. Today, Julian is a healthy 17-month-old little boy, "super active and super fast," laughs his mother. "You'd never think he was so close to death two summers ago," says Deak. 卐