Born prematurely in 2003 with a hole in his heart, Shawn Warczak spent all but a handful of days in the first 11 months of his life in Advocate Hope Children’s Hospital. His prognosis was grim until he was implanted with an experimental patching device that had an almost miraculous effect; Shawn went home four days later, never again to be hospitalized.

Shawn had access to this life-transforming treatment because his pediatric cardiologist, Alex Javois, MD, was participating in a clinical trial of the Gore® HELEX Septal Occluder device. This multi-center trial demonstrated that the device was safe and effective for use in small children—in fact, in children much smaller than anyone had dared to imagine. “Shawn was too tiny to formally qualify for the trial, but we requested a humanitarian exemption because his situation was so dire,” says Dr. Javois. “At almost 1 year old he still weighed only nine pounds.”

Today, though still smaller than most boys his age, Shawn is doing well both physically and intellectually. And he has not been the only beneficiary of the procedure he underwent seven years ago: Dr. Javois published an article about the case in a medical journal to share lessons learned with other doctors caring for
infants like Shawn with atrial septal defects. That was just one example of the many different research studies that doctors and nurses at Advocate Health Care’s children’s hospitals are actively involved in—often giving patients access to leading-edge treatments that may offer them their best chance at recovery while helping to advance understanding and treatment of children with a variety of complex conditions.

“Survival rates for children with congenital heart defects have dramatically increased thanks to applied medical research,” says Dr. Javois. “Twenty years ago, most children who were born with hypoplastic left heart syndrome died, for example; today 90 percent of them survive.”

New hope for newborns

Research has delivered equally remarkable gains for extremely premature babies—the incidence of which has increased in recent years. “When I first started practicing neonatology, it was truly amazing if a baby that was born at 28 or 29 weeks’ gestation survived,” says Bhagya Puppala, MD, who directs the neonatal research program at Advocate Lutheran General Children’s Hospital. “Today we see babies born as young as 24 weeks, or even 23 weeks, survive and go home to their parents.”

Over the past 20 years, the neonatal intensive care units (NICUs) at Advocate’s children’s hospitals have been active in a number of clinical trials of novel therapies designed specifically for premature infants. One of the most significant studies evaluated the effectiveness of a new treatment for premature infants with respiratory distress syndrome—a frequent and potentially fatal complication. “Surfactant is a natural protein that keeps small air sacs in the lungs from collapsing, but preemies lack this protein,” says Dr. Puppala. “When we gave infants the synthetic surfactant, we saw tremendous improvement almost immediately, right before our eyes. It was so exciting to stand at the bedside and know that our patients were among the first to benefit from this important new therapy.”

The clinical trial of surfactant that Lutheran General Children’s Hospital participated in showed that surfactant reduced mortality from early lung disease, decreased the use of mechanical ventilation and oxygen, and reduced the risk of blindness, among other benefits. Now surfactant is routinely administered to premature infants, as was the case for Jack Alesia. “Our son was born at 27 weeks’ gestation, and he never even had to be on a ventilator,” Cheryl Alesia says. “That used to be unheard of.”

Improving care and long-term outcomes

Because research has helped save so many children’s lives, it has increased the need for another kind of research—research to improve their quality of life and the quality of care children’s hospitals provide. Dozens of studies are currently underway across Advocate to do just that. For example, physician investigators at The Heart Institute for Children, based at Hope Children’s Hospital, are pioneering the use of 3-D echocardiography to enhance the positioning, and in turn the functioning,
Likewise, Dr. Puppala and her colleagues are evaluating the air quality in the plastic incubators that house fragile newborns in the NICU. Advocate nurse researchers are evaluating parents’ perceptions of family-centered care and family presence when children need to undergo invasive procedures or resuscitation. And Advocate pediatric cancer specialists are involved in research studies designed to reduce the side effects and long-term complications (such as learning difficulties) that can result when young children are treated with chemotherapy and radiation.

“We have helped decrease mortality rates, so now our goal is to reduce complications and improve the quality of children’s lives,” says Denise Angst, PhD, RN, director of the Advocate Center for Pediatric Research. “We want all of our patients to lead long, happy and productive lives.”

You can make a difference

You may be surprised to know that the vast majority of medicines and devices used in pediatric settings have never been tested in children. Most research has been done on adults, and then the medicines are used “off-label” in children. Federal initiatives and rules over the past 10-15 years have now mandated that research include children to understand the distinct benefits and risks they can experience. “Children are not merely small adults,” says Denise Angst, PhD, RN, director of the Advocate Center for Pediatric Research. “They have diseases that are unique or experienced differently than those in adults, and can metabolize medications in unpredictable ways, among other things.”

The Center leads and supports clinical trials and other studies within Advocate’s children’s hospitals to provide children with access to the latest treatments and medications, offer alternatives to standard therapies, and enhance the care given to children and their families. Research is currently underway in the fields of cardiology, critical care, cystic fibrosis/pulmonology, gastroenterology, general pediatrics, infectious disease, neonatology, neurology, nursing and oncology. To expand opportunities for children to participate, the Center is seeking charitable gifts in order to hire a full-time coordinator to further support Advocate’s pediatric physician and nurse researchers.

“Advocate cares for more children than any other health system in Illinois, and we have the state’s largest network of pediatricians and pediatric subspecialists,” says Dr. Angst. “The presence of clinical research in our hospitals is critically important to our primary mission of delivering the best care possible to our patients—and donors can help advance that mission.”

For more information or to make a gift, please call 847.384.3494.