High-risk babies: It’s not enough to survive — we want them to thrive

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When it comes to pushing the boundaries of medicine, fresh approaches can bring life-saving results. “The typical research mantra I grew up with was bench-to-bedside,” says Terence Sanger, vice president for research at Children’s Hospital of Orange County (CHOC). But is the laboratory the best place to come up with new ideas? “If you are trying to cure children, you need to ask questions that are directly relevant to those children,” he says. “The only people who know those questions are the people treating them.”

Sanger joined CHOC, based in Orange, California, in January 2020. He says he was attracted by the opportunity to create a more integrated clinical research programme than most hospitals employed. With bench-to-bedside, he saw researchers focusing on the wrong problems, asking the wrong scientific questions. He prefers ‘bedside-to-bedside’ research, where questions originate with the treating physicians.

Sanger used this philosophy when redesigning CHOC's research model and working relationships with its research partners — University of California, Irvine, and Chapman University. While many hospitals partner with academic institutions, few integrate research and clinical work like CHOC. Sanger's unique educational background is one reason for this approach. He has a medical degree from Harvard Medical School, a doctorate in electrical engineering and computer science from MIT, and a master's in applied mathematics from Harvard University. He brings his graduate students into the hospital to work with patients in the movement disorders programme.

These are not medical students, however: they study computer science, data science and electrical and mechanical engineering. "It gives CHOC patients access to a kind of technological brainpower that would not typically be available — a hospital would not normally have an electrical engineering department," Sanger says. The programme's clinicians provide deep brain stimulation to improve children's movements, often in those with cerebral palsy.

That's not all that's unusual about Sanger — in addition to VP for research, he has another, less common, job title. "Why do you want a chief science officer in a hospital? Hospitals do healthcare and universities do science, right?" Sanger asks. "The reason is that it provides hope. And research provides new treatments. It has to have an impact." And CHOC is having an impact.

Supporting research and clinicians

In a hospital, a strong science focus should not come at the expense of clinical excellence. Not all doctors and nurses want to conduct research, says Sanger. "The structure that I've tried to build in the research organization is to enable people who are not scientists to do science," he says. "A surgeon may not want to conduct research, but they still may have clinical questions science can answer. They're using their skills to directly help these children, and I want to be able to leverage their brainpower."

The combination of superior clinical care with a vast network of specialists, truly integrated research relationships, and access to more than 620 human subject studies, makes CHOC a leading hospital for patients, including, for example, for the highest-risk babies — and their families.

These are qualities that helped CHOC entice neonatologist and child neurologist, Terrie Inder. She had her choice of prestigious health systems when leaving Harvard's Brigham and Women's Hospital in 2022. She chose CHOC because of its strong clinical quality and research commitment, coupled with its "immensely caring environment".

A caring environment means a focus beyond just the health of the babies; it's important to support the parents, who can feel disempowered by the traumatic experience of having a premature baby in the neonatal intensive care unit (NICU). Her team shares clinical results

with the families. “The parents are more engaged in finding solutions — although we may not have all the answers yet,” explains Inder

Inder was hired as director of CHOC’s Center for Neonatal Research, developing a research programme that, she says, ensures studies in newborns “are fundamentally designed to improve neurological and developmental outcomes”. She has already published an authoritative paper[1] on the subject in the *New England Journal of Medicine*, less than a year into her CHOC tenure.

Neonatal research

Medical advances have improved the outlook for premature babies. About 10% of babies are born premature, before 37 weeks; in the US[2], survival of extremely preterm infants (22-23 weeks) is up to 30-55%. But survival is not the only criteria, says CHOC’s chief of neonatology, Vijay Dhar. “The quality of survival is more important to that baby, to the family and to society.”

One continuing research focus, Dhar says, is treating newborns at risk of hypoxic-ischemic encephalopathy (HIE), which occurs in 1.5 per 1,000 live births[3]. In HIE, delivery complications or other factors reduce blood circulation and oxygenation, which can quickly damage the brain. Dhar’s team uses therapeutic hypothermia, a brain and body cooling technique, to reduce the baby’s body and brain temperature for 72 hours. This decreases brain cell metabolism to prevent cell damage, and reduce the risk of neurodevelopmental delays.

CHOC treats around 50 HIE babies each year, who are often airlifted to the hospital as the treatment should be initiated within six hours of birth. Dhar explains that one case he dealt with was so severe the baby was already on a ventilator. But within a day of the therapeutic hypothermia, the baby was able to breathe on its own and bottle feed. Five years later, he says, the child is neurologically normal, meeting all developmental milestones.

When it was first introduced, therapeutic hypothermia was reserved for the most severe cases. As research has progressed, including research at CHOC, doctors are now offering it to some babies with less severe conditions, Inder says.

Both Sanger and Inder came to CHOC from research-based academic medical centres, and they value scientific quality. What they believe further distinguishes CHOC is the heart of its staff and the collective commitment to the organization’s mission. “Everyone at CHOC knows they are not only going to make a difference today, but they’re going to be able to discover a way to better care for hundreds and thousands of babies and children in the future,” says Inder.

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