

# Fulfilling Nemours Vision

## ONE DEVICE AT A TIME

What do a mechanical engineer, biologist, orthopedic surgeon and an industrial designer have in common? At A.I duPont Hospital for Children, they collaborate on work conducted in PERL, the Pediatric Research Engineering Laboratory, headed by Tariq Rahman, PhD. PERL has a staff of biomedical engineers and students who work with various clinicians at Nemours to conceive and develop engineering solutions to medical problems. The assistive and therapeutic devices that this diverse group of professionals develops change the lives of children with neuromuscular difficulties and orthopedic disorders.

For example, the patented Wilmington Robotic Exoskeleton (WREX) device, which PERL developed, enables children with muscular dystrophy or arthrogryposis (both conditions with symptoms of weakness in the arms) to do the simplest of tasks that most children take for granted. Now, raising their hands in school, eating a spoonful of pudding or scratching their ears is possible. When the device is worn, the child's limited power is amplified to enhance movement of the arm.

One might imagine that this anti-gravity robotic device is powered by a battery pack or other source of energy, but in fact it's the combination of rubber bands, hinges, metal

bars and unique engineering that adds the power to the child's arms. Experiencing its effect is surely analogous with what the astronauts must feel in space: one's arm is as light as a feather and floats up into the air.

"The challenge," according to Dr. Rahman, "is how to interface the device with the child in a natural way. Then, the key becomes how to communicate intent, through sensors, to the device." Children with muscular dystrophy or arthrogryposis do not have many options available to assist them with activities of daily living, but the WREX device frees them from some of the limitations of their conditions.

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"We not only seek to develop assistive or therapeutic devices, we also want to 'put smarts' into devices that already exist," says Dr. Rahman. "The Wilmington Brace is an excellent example of this." This brace was developed in the 1960's at the A. I. duPont Institute.

The Wilmington Brace is used to treat spinal curvatures resulting from scoliosis, which affects mostly adolescent girls (90% of scoliosis cases are girls). The goal of wearing the brace is to arrest the progression of the curve, although it cannot fix the curve. Should the curve worsen, surgery is required. Although much research points to the effectiveness of the brace in stopping the worsening of the curve, there is no conclusive proof and, without conclusive proof, the incentive for wearing the brace as prescribed is lessened.

Michelle Stofa, AIDHC Research Communications Manager, wore a Wilmington Brace as an adolescent. Found



Steven tried WREX for his right arm and found it helpful. He now has a device for his left arm, too. He uses them to help his acting.

to have a slight curve at the age of 8, Michelle's condition was monitored each year. Typically, and as was the case with Michelle, the spinal curve worsened as she hit her growth curve. "Imagine being a 13 year old girl, completely self-conscious and wanting to be as normal as possible, which in my case was that of a dance student and ordinary teenager, and being told that you had to wear a stiff, noticeably visible brace that made walking awkward. I was devastated," said Michelle.

"I was one of the lucky ones. I only had to wear the brace for 12 hours a day, compared to many who have to wear it 23 hours," she continued. Michelle admits that she did not always wear the brace for the full 12 hours a day, as prescribed by her physician, Shanmuga Jayakumar, MD, AIDHC Orthopaedic Surgeon. "The doctors couldn't tell me for certain that the brace would work, and as it was so uncomfortable, I avoided wearing it when I could," she admits.

Compliance with wearing the brace as prescribed is key to its effectiveness. According to Dr. Rahman, "If we can prove, definitively, that wearing the brace stops the curve from worsening, then we have increased the chance that the brace will be worn as prescribed."

Richard Bowen, MD, Nemours Orthopaedic Surgeon conceived the idea of adding a monitor to the brace. Drs. Bowen and Rahman collaborated to develop a sensor, which would serve as a data storage device and record body temperature as a measure of compliance.

"We need objective, accurate information about the length of time the brace is being worn, and sometimes we cannot trust the memories of the children who wear the braces. They tend to overestimate their compliance. The sensor provides us with the information that we need to prove our theories," Dr. Rahman stated. "And, we know if the child has 'cheated' and put the brace on the family dog—the sensor is very sensitive," he added.

A recently concluded Institutional Review Board-approved study proves that the sensor, now patented, was



Michelle Stofa holds a Wilmington Brace, while Dr. Rahman shows placement of the sensor. Michelle admits that having a brace with a sensor might have increased her compliance.

When in use, the sensor records body temperature.



very effective and reliable in providing an objective measure of compliance, and the results further demonstrated that compliance was significantly less in patients whose scoliosis worsened compared with those patients who were more compliant. "If I had a brace with the sensor when I was a teenager, I would have worn the brace for longer periods of time; I might have cheated less and worn it more," stated Michelle Stofa.

The WREX device and Wilmington brace sensor, both patented and licensed products, are just two of the devices developed by clinicians and PERL. The Nemours Associates who collaborate everyday to develop new technology carry on the legacy of Alfred I. duPont's original vision of treating children with crippling conditions. Helping to fulfill the Nemours vision of freedom from disabling conditions with every new device, the Pediatric Engineering Research Laboratory is at the forefront of applying engineering to medical conditions.