The Princess & the PRC

Since opening its doors in 2009, the Children's Pediatric Research Center (PRC) has been thriving. Their research study participation has risen significantly, and PRC Staff Nurse Michelle Popler points out that traffic is up "more than 100 percent from our first year." In fact, Children's bedside research center has grown exponentially in just three years. In 2009, the PRC saw about 100 patients. This year, they expect to see more than 500.

The PRC is the pediatric clinical interaction research site of the Atlanta Clinical and Translational Science Institute. The center, under the direction of Howard Katzenstein, M.D., Medical Director, provides the necessary infrastructure for investigators conducting pediatric clinical research while giving patients and their families improved access to leading-edge clinical trials.

The PRC's mission statement is simple: Provide a safe, caring research environment for new technology and cutting edge treatments. Execution is a bit more complex, especially when it means creating a space that can handle the needs of both pediatric research participants and pediatric specialists. Study visits of one to six hours are the norm for participants, such as infants and children with asthma, Type 1 diabetes in teens and young adults, and children of all ages with sickle cell, liver, kidney and other diseases. In a team work environment supported by clinical coordinators, a dedicated lab, pharmacy and bionutrition services, protocol procedures are executed by a three-person staff—Nurses Michelle Popler and Emily Morrison and Nancy Ferzola, Manager, Clinical Research.

Located at Egleston, the facilities and services include a four-bed outpatient research unit, a four-bed inpatient research unit and access to amenities like exercise and laundry rooms, a library and private showers. The flexibility and comfort the space provides can support a variety of studies—at the moment there are 52 approved studies with 21 actively enrolling.

The PRC is also making a difference in the lives of our patients. For example, in the summer of 2009, a 17-year-old girl arrived at Children's with complaints of vomiting and body aches. She was found to be in acute renal failure with anemia and thrombocytopenia. A Children's physician diagnosed her with atypical hemolytic uremic syndrome (aHUS), a rare and serious clotting disorder with a 50 percent mortality rate within the first year of diagnosis. She underwent treatment, which required multiple admissions from June until December 2009, to receive plasmapheresis. Unfortunately, her body was not responding well to this treatment.

After researching her case, Larry Greenbaum, M.D., Chief of Pediatric Nephrology, had another suggestion. Dr. Greenbaum approached the patient's family to discuss a new drug that was being studied and could help—eculizumab. After careful consideration, the patient and her family consented to be a part of the eculizumab study.

The patient started receiving infusions of eculizumab every two weeks at the PRC. She responded quickly and began living on her own, attending college and traveling—all of the things she was unable to do while on dialysis—returning to the PRC every two weeks, where she earned the nickname "Princess of the PRC."

In 2009, the PRC saw about 100 patients. This year, they expect to see more than 500.

In 2011, the Food and Drug Administration approved the use of eculizumab in adults. Eculizumab can now be used to enhance the lives of patients who are living with aHUS, allowing them unprecedented freedom.

Thanks to continued trialing by Dr. Greenbaum and the PRC, eculizumab was recently approved for use in the pediatric population. Patients now have the freedom to go to any infusion facility in the United States.

This story is just one of a number of examples where the PRC has fulfilled its mission statement, providing a space for the research, as well as the participants, caring for quality of life while forwarding life-changing research.

"I've seen the good the center can do for the lives of children and their families," said Popler. "It's all so new and exciting." New, exciting and in high demand; Popler and her colleagues will certainly be busy.

Children's PRC staff members Michelle Popler, Emily Morrison and Nancy Ferzola check the vitals of one of our diabetes study participants.