



## Sie Center for Down Syndrome Marks First Anniversary, Becomes Largest Down Syndrome-Focused Center in the Nation


**T**HE ANNA AND John J. Sie Center for Down Syndrome (Sie Center), the medical care arm of the Linda Crnic Institute for Down Syndrome, opened its doors to patients in November 2010. After just one year, it has become the largest organization with a multidisciplinary team of experts focusing solely on patients with Down syndrome. The Sie Center has served more than 13% of Colorado children younger than 21 who have Down syndrome and has seen increased visits from patients residing outside Colorado, including from Wyoming, Montana, Nebraska, Washington, California and Florida.

Renowned specialist in developmental and behavioral pediatrics, Francis James Hickey, M.D., Medical Director of the Sie Center, was recruited to establish the center and grow an unprecedented team of professionals dedicated to improving the lives of people with Down syndrome through both medical care and clinical research.

“We’re fortunate to be housed at Children’s Hospital Colorado,” says Dr. Hickey. “It is ranked fifth in the nation and has some of the best clinicians and researchers who also have big hearts for our patients with Down syndrome. Our vision is to provide the highest quality multidisciplinary medical approach to

each child who comes through the door.”

Dr. Hickey, who has a son with the dual diagnosis of Down syndrome and autism, has put together a team of outstanding professionals at the Sie Center, including nationally renowned experts Patricia C. Winders, senior physical therapist; Patti McVay, Director of Education; and Dee Daniels, program coordinator. They have more than 80 years of combined experience in caring for children with Down syndrome and developmental disabilities. A recent addition, Kristin Jensen, M.D., a physician specializing in both pediatrics and internal medicine, is developing a program for transition from youth care to adult care. The Sie Center’s team also



includes a genetic counselor, a social worker, speech pathologists, therapists and research assistants. In its first year, the Sie Center served more than 260 children with Down syndrome.

“We have always believed that children with Down syndrome deserve the best medical care and that there is a huge difference between seeing a doctor who has seen a couple dozen versus hundreds or thousands of patients with Down syndrome,” says Michelle Sie Whitten, Executive Director of the Anna and John J. Sie Foundation, the lead donor for both the Sie Center and the Crnic Institute. “It is a dream come true to see what Dr. [Edward] McCabe and Dr. Hickey are building for our children and for our future.”

For patients in the prenatal phase through age 25, the Sie Center offers multidisciplinary care, working closely

with the Children’s Hospital Colorado’s Heart Institute, Breathing Institute, Neurosciences Institute, and departments of endocrinology, otolaryngology, gastroenterology, hepatology, and nutrition. The Sie Center also offers a feeding clinic and sleep studies, which cover conditions affecting many children with Down syndrome.

“There are some wonderful doctors and clinics serving children with Down syndrome, but most organizations don’t have the institutional or financial support to really invest in clinical research that will help us address problems — for example, with the immune system or heart — to improve the length and the quality of life for individuals with Down syndrome. I believe that is what really sets us apart,” says Edward R.B. McCabe, M.D., Ph.D., Executive Director of the Linda Crnic Institute for Down

Syndrome. “Not only is the number of children with Down syndrome seen in the first year impressive, but also the impact of the care. The Sie Center identified key services required and not being provided for every child seen.”

To evaluate the needs of each patient seeking treatment at the Sie Center, an initial consultation is set up with the team over the span of one or more days, depending on the medical needs of the child. Resources and recommendations for optimizing the child’s medical care and development are shared with the family and the child’s primary care doctor. Periodic follow-up appointments are arranged as appropriate. For out-of-state patients, two days of multidisciplinary consults are highly recommended.

*Call the Anna and John J. Sie Center for Down Syndrome at (720) 777-6750 for more information.*

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