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## AHS researcher leads national study on nephrotic syndrome

CALGARY – A researcher at Alberta Children’s Hospital is spearheading a national study aimed at identifying best practices in treating nephrotic syndrome, a rare childhood kidney disorder in which blood protein ends up in the urine.

Nephrologists at 13 pediatric centres across Canada will pool information on their patients’ responses to treatment. When the five-year project is complete, it’s expected the patient registry and data repository will have information on more than 600 cases.

“It’s a challenge to generate high-quality evidence about rare illnesses like childhood nephrotic syndrome,” says Dr. Susan Samuel, an Alberta Health Services (AHS) pediatric nephrologist and researcher with the Alberta Children’s Hospital Research Institute at the University of Calgary Cumming School of Medicine.

“There are very few research studies that involve significant numbers of children, meaning we don’t know with a high level of certainty what the most effective course of treatment is,” Dr. Samuel says.

Steroids have been the standard treatment for nephrotic syndrome since the 1950s but there is wide variation in the total dose and duration of therapy prescribed for relapses of nephrotic syndrome. Variations in the length of treatment range from six weeks to six months.

Many children eventually outgrow the condition, but others stay in a cycle of relapse and remission and must undergo a course of steroid treatment every few months. Some even progress to have kidney failure and require dialysis or kidney transplant.

“Steroid treatment can have negative side effects, such as obesity, slowed growth, high blood pressure, cataracts, poor bone health and behavioural issues,” Dr. Samuel says.

“One potential benefit of the study would be to determine the minimal amount of steroids that can be prescribed while still remaining effective in preventing relapses of disease,” she says.

Researchers also hope the findings could lead to the development of targeted therapies in their patients, as well as help doctors predict the course and severity of illness in their patients.

The cause of childhood nephrotic syndrome is unknown and there is no cure, although it can go into remission later in a person’s life. It’s estimated 16 children per 100,000 are affected. There are almost a 100 cases in southern Alberta.

Nephrotic syndrome affects boys more than girls and can be difficult to diagnose. Urine output decreases, with fluid entering the tissue instead. Children show up at the doctor’s office with a puffy appearance and decreased volume of urine. Eventually, fluid can collect in the abdomen and between the lungs and chest wall.

Children can also get very sick with infection, and also have clots in their brains and lungs while they are leaking protein in the urine. Prompt recognition and management of these complications is very important to prevent severe illness, disability or death.

Laura Roberts and her husband, Adam, first suspected their daughter Hazel might have a problem when they noticed she was waking up with puffy eyes.

“At first, the family doctor thought it might be an allergy,” Laura says. “We changed her pillows and changed the detergent we were using.”

But Hazel’s condition worsened. Then two years old and living in Fort McMurray, she wound up undergoing treatment co-ordinated through the Stollery Children’s Hospital in Edmonton.

Her story is not uncommon, Dr. Samuel says. Most children eventually diagnosed with nephrotic syndrome are initially diagnosed to have allergies and given the wrong treatment.

Today, Hazel is five years old and one of the first children to be enrolled in the national study.

“She has about three or four relapses a year, and then each time has to go back on the steroids daily for about 10 days, and then every other day for about two months,” says Adam. “Hopefully getting involved in the research will help out. It would be nice to find a better treatment for this.”

Alberta Children’s Hospital recently hosted a national symposium on nephrotic syndrome, bringing together researchers and affected families from across the country. During the symposium, the pediatric nephrology clinic staff hosted a Patient and Parent Forum during which a panel of experts answered patients’ and families’ questions regarding the latest advances in nephrotic syndrome research and how best to care for children with this disease.

The study is funded by the Canadian Institutes of Health Research and the Kidney Foundation of Canada. To date more than 150 patients have enrolled.

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Alberta Health Services is the provincial health authority responsible for planning and delivering health supports and services for more than four million adults and children living in Alberta. Its mission is to provide a patient-focused, quality health system that is accessible and sustainable for all Albertans.

The [Alberta Children’s Hospital Research Institute](http://www.research4kids.ca) (ACHRI) is a multi-disciplinary research institute partnered with the University of Calgary, Alberta Health Services and the Alberta Children’s Hospital Foundation. Through excellence in research, innovation, knowledge translation and education, the institute aims to foster healthy biological and psychosocial trajectories for babies, children and youth.  
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