

Celebrating 15 Years of INSIGHT

Let's look back at our papers!



Mental Health Among Caregivers of Children With Nephrotic Syndrome: A Prospective Cohort Study

About 1 in 3 caregivers felt stressed, and 1 in 4 had anxiety while caring for a child with nephrotic syndrome. Stress was highest when children were actively relapsing or on steroids.

Longitudinal Medication Adherence in Children With Nephrotic Syndrome and Association With Disease Outcomes

About 3 out of 10 children missed doses of their medicines at some point. Missing doses did not lead to more relapses or hospital visits.

Prolonged Remission After Cyclophosphamide or Tacrolimus Treatment in Childhood Nephrotic Syndrome: A Cohort Study

Long-term remission occurred in 29% after cyclophosphamide vs 14% after tacrolimus. Lower relapse rates before treatment strongly predicted success.

Impact of Childhood Nephrotic Syndrome on Obesity and Growth: A Prospective Cohort Study

At diagnosis, about 1 in 4 children had obesity and over half were overweight. During follow-up, almost 1 in 5 developed new obesity, especially children with many relapses.

Challenging Clinical Practice Guideline Definitions in Childhood Nephrotic Syndrome

Only 5% of children were first labelled "steroid-resistant," but almost 3 out of 4 of them improved with other medicines. Children who improved did not develop kidney failure.

Kidney Function and Mortality in Childhood Nephrotic Syndrome

For children whose disease responded to steroids, kidney failure and death were very rare (less than 3 children per 1,000 each year). Children with hard-to-treat disease had higher risk, but outcomes improved over time.

Comparative Efficacy of Nonsteroid Immunosuppressive Medications in Childhood Nephrotic Syndrome

Relapse rates were similar between treatments. Calcineurin inhibitors caused 83% more hospitalizations than cyclophosphamide.

Incidence and Risk Factors for Hypertension among Children with Nephrotic Syndrome

More than 50% of children developed high blood pressure during follow-up. This was especially common in children with frequent relapses or hard-to-treat disease.

Shared Genetic Risk Across Different Presentations of Gene Test-Negative Idiopathic Nephrotic Syndrome

Children with different types of nephrotic syndrome shared many of the same immune-related genes. This showed the immune system plays a big role, even when no single gene cause is found.



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Impact of Steroids and Steroid-Sparing Agents on Quality of Life in Children With Nephrotic Syndrome

Children taking steroids or strong immune medicines had lower quality-of-life scores. They were more tired and had more trouble with daily activities than children not taking these medicines.

Prevalence of Asthma and Allergies and Risk of Relapse in Childhood Nephrotic Syndrome: Insight into Nephrotic Syndrome Cohort

About 64% of children had allergies and 20% had asthma, but these children did not have more kidney relapses. Allergies did not make nephrotic syndrome worse.

Parental Health Literacy and Outcomes of Childhood Nephrotic Syndrome

Children had fewer kidney relapses when their parents understood medical instructions better. Families with the strongest understanding had about 1 less relapse per year and more children stayed relapse-free.

Ethnic Differences in Incidence and Outcomes of Childhood Nephrotic Syndrome

South Asian children were 6 times more likely to develop nephrotic syndrome than European children. However, frequent relapses were about 50% less common in South Asian children than in European children.



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Family Functioning and Quality of Life Among Children With Nephrotic Syndrome During the First Pandemic Wave

During COVID lockdowns, families reported better family closeness. However, children's overall well-being scores dropped, and sleep problems increased, especially in older kids.

Prediction of Short- and Long-Term Outcomes in Childhood Nephrotic Syndrome

Only 1 in 4 children never had another relapse after diagnosis, but almost 8 in 10 were disease-free by adulthood. Doctors could not reliably predict early on who would have many relapses.

Association of Low Birth Weight and Prematurity With Clinical Outcomes of Childhood Nephrotic Syndrome: A Prospective Cohort Study

Children who were born very small or early were almost 4 times more likely to have a form of nephrotic syndrome that did not respond to steroids. Each small increase in birth weight lowered this risk.

Parental Attitudes to Genetic Testing Differ by Ethnicity and Immigration in Childhood Nephrotic Syndrome: A Cross-Sectional Study

About 85 out of 100 parents said they would want genetic testing for their child. Parents who had recently moved to Canada were much less likely to want testing than parents born in Canada.

The Rationale and Design of INSIGHT

INSIGHT was created to follow children with nephrotic syndrome over many years to study genes, treatments, and family factors. Children are tracked yearly for relapses, medications, and long-term kidney outcomes