

CHILDHOOD NEPHROTIC SYNDROME

WHAT IS IT?

Kidneys normally filter waste and water from the blood



In nephrotic syndrome, the cells that make up the filter barrier in the kidney become “leaky”

Think of it like a colander with big holes. Because the holes are large, protein in the blood spills through

When protein spills into the urine, this can cause:



Swelling



Tiredness



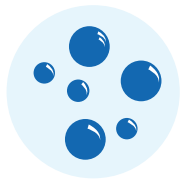
Loss of appetite



Stomach pains



Low urine output



Frothy urine

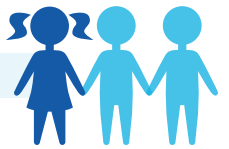
Currently we do not know exactly what causes nephrotic syndrome

Studies suggest a complex set of factors are involved, in particular the immune system



Your child is not alone

100,000
It occurs in 5 per 100,000 children



It is almost twice as common in boys than girls with the peak age between 3-4 years

WHAT CAN WE EXPECT?

93%

of children respond to steroids

85%

of children become disease-free during childhood

Relapses are common

74% of children who respond will relapse within

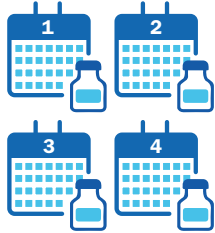
Infections are a common trigger for relapses



HOW IS IT TREATED?

The most effective treatments are those that act on the immune system

Steroids (Prednisone) are the initial treatment



Your child will be on steroids initially for at least 12 weeks

Other medications that suppress the immune system may be needed in 48% of children

HOW CAN I BEST HELP MY CHILD?



Keep a healthy diet



Regularly exercise



Stick to the steroid treatment and contact clinic if concerned



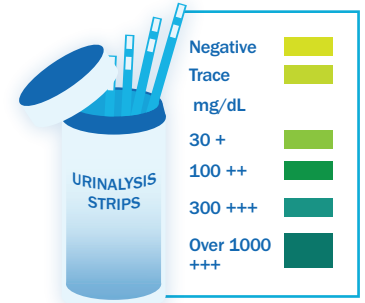
Regularly monitor and record your child's protein in the urine using the first morning urine when possible:



Do not add salt to your child's food (no added salt diet)

- 1 Collect fresh urine specimen in a clean, dry container
- 2 Dip test area of one strip in urine and remove immediately
- 3 Tap edge of strip against a clean, dry surface to remove excess urine
- 4 Compare test area to chart after 60 seconds

*Store strips in dry cool place in an airtight container



22%

Have no further active disease after initial treatment

30%

Receive steroids only
On average, have 3 relapses in childhood

31%

Receive steroids & another medication
On average, have 5 relapses in childhood

17%

Receive steroids & 2 or more medications
On average, have 12 relapses in childhood

9%

Receive ongoing care as an adult

1%

Have progressive kidney disease

WARNING SIGNS

Seek medical help if:



Fever while spilling protein



Severe headaches



Visible blood in urine



Vomiting and abdominal pains



Significant weight gain

With regular monitoring, serious events are rare.

HELPFUL RESOURCES

- 1) kidney.ca/childhood-nephrotic-syndrome
- 2) kidney.ca/document.doc?id=330
- 3) nephcure.org/livingwithkidneydisease/raising-a-child-with-nephrotic-syndrome/
- 4) infokid.org.uk/nephrotic-syndrome
- 5) lab.research.sickkids.ca/parekh/research/insight/



INSIGHT is an observational study devoted to a better understanding of nephrotic syndrome. If you have any questions regarding the information included in this fact sheet, please contact: insight.study@sickkids.ca

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