Nephrotic Syndrome
Not as simple as expected!
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Q. We were told that this problem would resolve with regular treatment with steroids. Our child has had many attacks in spite of treatment with steroids. What do we do?
A. Some children may initially respond well to steroids but later can have frequent relapses when the steroid dose is reduced. This is termed as frequent relapses or steroid dependence. Apart from steroids there are other drugs that can be useful in reducing the protein leak and swelling.

Q. Our child is not responding to steroids. Do you have any alternative drug?
A. In a small group of patients, in spite of giving adequate doses of steroids there is no reduction in protein leak or swelling. In such situations the child may need additional medication like diuretics to reduce the swelling and may even require hospitalization. Usually these children have to undergo a minor procedure called “Renal Biopsy”. Thereafter we need to use other medication for a longer duration to control the protein leak. While using the alternative drugs the child will require frequent and regular check ups for specific side effects.

Q. Are the other drugs safe?
A. The drugs we use instead of steroids do have specific side effects. If used cautiously and judiciously with prompt monitoring by the doctor the drugs could be used safely and effectively.

Q. What is a renal biopsy? Is it compulsory to undergo the test?
A. Renal biopsy is a procedure that will be done after hospitalization. Under the guidance of an ultrasound scan, the kidneys are visualized. The child is sedated well and a tiny piece of the kidney tissue is taken with the help of a needle. This kidney tissue is then examined under the microscope for the details on the kidney disease. This test becomes a necessity when the child has not shown adequate response to steroids and needs other alternative drugs. Understanding the details of the type of the disease would make it easier to predict the course of the disease and the response to treatment.

Q. How long will our child be on the alternative medication?
A. It depends on the specific medication used. Usually the average duration ranges from 3 months to 3 years, may be longer.

Q. Is there a risk for the kidneys to get damaged?
A. Children who respond well to steroids do not have a risk for renal damage. However a very small proportion of children who do not respond to steroids and other alternative medication can have a risk to develop kidney failure. Your treating doctor will monitor this.
Parents please note: Regular follow up is absolutely necessary!

Diet: A child with nephrotic syndrome should have a diet with normal protein intake and calories. It would be preferable to restrict oily food and high calorie food till the child completes the treatment course.

Your child should have: No restriction on sweets, fruits, snacks and meat | No extra proteins or restricted proteins | No additional salt or fat | Normal fluids

Consult your doctor if your child needs a special diet chart

Vaccines: As steroids affect the child’s immune system, he or she should not be given any “live vaccines” like oral polio drops, measles, MMR, varicella and BCG. Regarding other vaccines parents need to consult their doctor. Your child may require special vaccines in order to prevent serious infections for which your doctor can be consulted.

Infections: Your child may be at risk of infections while they are on steroids or even otherwise when they have swelling. If your child has fever or stomach ache or appears unwell PLEASE CONTACT YOUR DOCTOR IMMEDIATELY.

Avoid self-medications | Do not use diuretics for a long duration without consulting your doctor | Take the opportunity to meet the medical social worker who could help you with clarifications.