

## Learning from Patients and Parents Living with Nephrotic Syndrome

It can be difficult for a patient or a parent to hear that they, or their child, has nephrotic syndrome. It is often at this difficult moment that patients are also given an overwhelming amount of information, including what nephrotic syndrome is, the treatment options, about relapses and remissions, diet, and more.

Along with a multidisciplinary research team, Heather Beanlands wanted learn what would make it easier for patients and parents of children to understand nephrotic syndrome, so they talked with patients and parents. When patients know more about their condition, they can become a partner with their health care provider and be a voice in discussions about disease management, treatment options, and their care.



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## What we learned

Everyone is different. It is important for health professionals to understand patient concerns, what information they need, when they need it, and in what form. For example, some patients want to know a lot of information at once, while others want information in small pieces. By taking this time, health professionals can provide information and support in a way that best suits each individual patient, parent, and family.

As part of this study, patients were also asked about their experiences and challenges living with nephrotic syndrome. The team found that soon after their diagnosis, patients wanted to understand nephrotic syndrome, what to expect, and the different medications available. Later, they wanted to learn strategies to manage their disease, such as preventing and managing relapse, diet, and medication side effects. This information needs to be available at the right time and provided in a way that is understandable so that patients and parents can relate it to their own situation and circumstances.

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Please address any questions/suggestions to your coordinator to give to the NEPTUNE R&R Committee

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