



# Seeking Genetic Information

As researchers learn more about human genes (DNA), they are better able to understand how mutations (errors) in our genes can cause or contribute to different diseases. Nephrotic Syndrome researchers have identified dozens of genes that may contribute to Nephrotic Syndrome diseases. On-going research is focused on understanding the effects of these gene mutations. More genetic research is needed to develop safer and more personalized treatments. Sometimes, genetic information can be used to help the doctor understand or treat Nephrotic Syndrome. However, because most patients do not have a known gene mutation related to their nephrotic syndrome, doctors do not yet routinely perform genetic testing.



## Genetic testing may be considered in people who:

- Have congenital Nephrotic Syndrome (are diagnosed in the first few months of life)
  - Do not respond to steroids
- Have a family history of similar kidney diseases

Genetic testing requires a blood draw, saliva sample, or cheek swab. Your DNA is then analyzed to identify specific gene mutations that may be contributing to your disease.



## The results of a genetic test may:

- Help with treatment decisions
- Provide additional information for patients and families about the likely clinical course of disease
- Help with the selection of appropriate transplant donors
- Help you understand your family members' risk of developing the same disease



## Things to Keep in Mind

- Test results can sometimes be distressing, so your doctor should help you set up a meeting with a genetic counselor to discuss your results.
- Not all health insurance plans pay for genetic testing. So, before you have a genetic test, check with your insurance provider to see what will be covered. It may help to have your doctor write a letter describing why they are recommending the test.