

**"Planning Your Life in Relation to Your Kidney Function, i.e. Planning for Kidney Transplant, and Update on GI Issues."**

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Thanks to new research and treatments, people with cystinosis are living healthier lives. They might not have to deal with kidney problems until they're older teenagers or young adults. But eventually, most people with cystinosis will need treatment for kidney failure. It's helpful to track how well your kidneys are working so you can plan for the future. To do this, you need to understand what your kidney test results mean. These tests are done with routine blood work, but the results can be hard to understand. As a parent or patient, you might wonder how worried you should be about your kidney test results. What are good or bad results? Are there special things to consider if you have cystinosis compared to other people with kidney disease? We'll talk about the different stages of kidney disease, including CKD stages 1-5, and what they mean. We'll also discuss how to measure kidney function and how to use graphs to predict when you might need kidney replacement therapy. Additionally, we might talk about testing for protein in your urine to see how well your kidneys are working.

These websites are helpful:

Children, teens, young adults up to 25 years

<https://kidney.wiki/gfr-calculator/>

Adults beyond age 25

[https://www.kidney.org/professionals/gfr\\_calculator](https://www.kidney.org/professionals/gfr_calculator)

The second part of this talk will be a review of the gastrointestinal complications that cystinosis patients might experience as part of cystinosis or complications of the therapy. There is lots of new information coming out in this area.