

I Wish My Doctors Knew That...



- It means so much to me when they take the time to learn more about cystinosis.
- I know so much about cystinosis and I would welcome the opportunity to share my knowledge and experiences.
- Transitioning from my pediatric doctors has been difficult because I was comfortable with them and they really knew me.
- I would appreciate them being more understanding about how hard my life can be sometimes.
- I appreciate being looked in the eyes when I ask questions.
- I worry about fertility issues.
- Sometimes I don't feel well even when it may look like things are going well.
- I would like them to ask more questions about my physical and emotional well-being.
- I need more than a few minutes to discuss how I am doing.
- I am sometimes afraid to get my white blood cell cystine test results back because I am worried I might get bad news.

