Patient Perspectives Activity
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The most **challenging** aspect of living with KIF1A is _____________________
The most challenging aspect of living with KIF1A is:

- Not knowing how it will affect my child’s future
- Uncontrollable seizures
I want researchers & doctors to know ______________
I want researchers & doctors to know

I’m frustrated that I know more about KIF1A than my doctor

I’m worried about the risks of trying a new therapy on my child
If treatment could help ___________, that would make a meaningful difference in our daily lives.
If treatment could help

My child become able to tell me about her day at school

My child worry less about falling on the playground

that would make a meaningful difference in our daily lives
What matters most to me is ______________
What **matters most** to me is

- My child is happy
- My child is able to play & learn with his siblings & peers
- My child has a chance to live independently