



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**