

TK2d Early Symptom Reflection Tool

This tool is here to help you understand your early TK2d symptoms and talk about them with your care team



Please think back to when **you** or the **person with thymidine kinase 2 deficiency (TK2d) you care for was a child.**

If you are a caregiver for a person with TK2d, please answer on that person's behalf.

Instructions

- 1 Answer **Yes** or **No** to show if the symptoms were noticed.
- 2 Choose the option that best describes how much the symptoms affected you or the person you care for with TK2d:
 - ☐ **Mild**
You noticed it, but it did not impact daily activities
 - ☐ **Moderate**
It made daily activities harder, and/or you needed to talk to a doctor
 - ☐ **Severe**
It stopped daily activities, and/or you needed emergency care or a hospital visit
- 3 Share the **age when you first noticed these symptoms.**
An estimate is okay. Please specify if the age is in months or years.

Questions

Think back to when you were physically active (e.g., going to the park, in gym class, on school field trips)



	Yes/No	Severity	Age first noticed
 Did you experience fatigue, weakness, or difficulty keeping up with physical activities?	☐ Y ☐ N	☐ Mild ☐ Moderate ☐ Severe	
 Did you feel that muscle weakness in any part of your body limited your day-to-day activities or physical abilities?	☐ Y ☐ N	☐ Mild ☐ Moderate ☐ Severe	



Think back to times when you were eating or drinking, such as during meals or when snacking



Did you notice any trouble or extra effort, such as coughing with drinks, choking, longer mealtimes, or needing softer foods?

☐ Y ☐ N

☐ Mild
☐ Moderate
☐ Severe



Think back to times when you had an illness or infection



Did you often struggle with unexplained breathing issues, like frequent cough, chest trouble, aspiration pneumonia, or infections that doctors couldn't fully explain?

☐ Y ☐ N

☐ Mild
☐ Moderate
☐ Severe



Did you feel unusually tired or weak, or did you recover more slowly than your peers, siblings, or parents?

☐ Y ☐ N

☐ Mild
☐ Moderate
☐ Severe



Think back to other symptoms you may have had



Did you learn to sit, crawl, walk, or climb later than other kids, or were you ever told you had low muscle tone or seemed clumsier than your peers?

☐ Y ☐ N

☐ Mild
☐ Moderate
☐ Severe



Do you remember needing to use your hands or arms to push yourself up when standing from a chair or the floor?

☐ Y ☐ N

☐ Mild
☐ Moderate
☐ Severe

	Yes/No	Severity	Age first noticed
 Did you get out of breath more easily than others, have trouble breathing when lying down, or find it harder to perform breathing-related tasks, such as blowing up balloons, blowing out candles, or whistling?	☐ Y ☐ N	☐ Mild ☐ Moderate ☐ Severe	
 Did you have difficulty sleeping as a child, such as frequent waking, snoring, or feeling unrefreshed in the morning?	☐ Y ☐ N	☐ Mild ☐ Moderate ☐ Severe	
 Do you remember your face becoming tired, so that you had trouble with opening your eyes, talking, smiling, chewing, or swallowing?	☐ Y ☐ N	☐ Mild ☐ Moderate ☐ Severe	
 Did your vision become blurry, or your eyes feel tired when watching TV, reading, or doing homework?	☐ Y ☐ N	☐ Mild ☐ Moderate ☐ Severe	
 Do you remember your speech becoming slurred, quieter, or harder to understand the longer you talked, or did you struggle to hear people during conversations?	☐ Y ☐ N	☐ Mild ☐ Moderate ☐ Severe	
 Did you experience repeated falls, notice any walking difficulties (including limping, balance issues, etc.), or need orthotics?	☐ Y ☐ N	☐ Mild ☐ Moderate ☐ Severe	
 Did you often feel very tired or low on energy, to the point that it caused you to miss school, play, or daily activities?	☐ Y ☐ N	☐ Mild ☐ Moderate ☐ Severe	
 Did you ever have seizures or episodes where you lost awareness, stared blankly, or had unusual shaking or movements?	☐ Y ☐ N	☐ Mild ☐ Moderate ☐ Severe	