

### Dup15q Syndrome Caregiver Global Impression of Severity Questionnaire

In the following questions, “your child” refers to your child or to the person you care for with Dup15q syndrome. We are going to ask you about the impact Dup15q syndrome may have had on your child **over the past 7 days**. Please **choose the response** for each question that most accurately describes your child. Try to answer each question based on your first impression.

<p>1. Over the past 7 days, how difficult was it for your child to <b>communicate</b>? For example, speaking words, babbling, pointing, gesturing, using picture boards or technology to aid communication, etc.</p>	<input type="checkbox"/> Not at all difficult <input type="checkbox"/> A little difficult <input type="checkbox"/> Somewhat difficult <input type="checkbox"/> Quite difficult <input type="checkbox"/> Very difficult
<p>2. Over the past 7 days, how difficult was it for your child to <b>coordinate their hand movements</b>? For example, picking up or holding a small object such as a block or crayon, picking up coins, having hand tremors, etc.</p>	<input type="checkbox"/> Not at all difficult <input type="checkbox"/> A little difficult <input type="checkbox"/> Somewhat difficult <input type="checkbox"/> Quite difficult <input type="checkbox"/> Very difficult
<p>3. Over the past 7 days, how difficult was it for your child to <b>walk</b>*? *If your child is not walking yet then rate their difficulty with crawling or moving around unassisted. If your child uses a wheelchair then please select “Very difficult.”</p>	<input type="checkbox"/> Not at all difficult <input type="checkbox"/> A little difficult <input type="checkbox"/> Somewhat difficult <input type="checkbox"/> Quite difficult <input type="checkbox"/> Very difficult
<p>4. Over the past 7 days, how difficult was it for your child to <b>concentrate, follow instructions, or learn new things</b>?</p>	<input type="checkbox"/> Not at all difficult <input type="checkbox"/> A little difficult <input type="checkbox"/> Somewhat difficult <input type="checkbox"/> Quite difficult <input type="checkbox"/> Very difficult

<p>5. Over the past 7 days, how difficult was it for your child to <b>participate in self-care activities</b>? For example, eating, dressing, bathing, toileting, etc.</p>	<input type="checkbox"/> Not at all difficult <input type="checkbox"/> A little difficult <input type="checkbox"/> Somewhat difficult <input type="checkbox"/> Quite difficult <input type="checkbox"/> Very difficult
<p>6. Over the past 7 days, how difficult was it for your child to <b>behave appropriately</b>? Consider behaviors such as self-injury, hitting, biting, pinching, pulling hair, acting aggressively, hyperactivity, refusing to move, etc.</p>	<input type="checkbox"/> Not at all difficult <input type="checkbox"/> A little difficult <input type="checkbox"/> Somewhat difficult <input type="checkbox"/> Quite difficult <input type="checkbox"/> Very difficult
<p>7. Over the past 7 days, how difficult was it for your child to <b>sleep throughout the night</b>? Consider difficulties falling asleep, staying asleep, waking too early, problems with sleep pattern, daytime sleepiness, etc.</p>	<input type="checkbox"/> Not at all difficult <input type="checkbox"/> A little difficult <input type="checkbox"/> Somewhat difficult <input type="checkbox"/> Quite difficult <input type="checkbox"/> Very difficult
<p>8. Over the past 7 days, how impacted were your <b>child's social behaviors and/or social interactions</b>? For example, nonverbal communication (eye contact, gestures), interacting with others at home or at school, or during play with others, etc.</p>	<input type="checkbox"/> Not at all impacted <input type="checkbox"/> A little impacted <input type="checkbox"/> Somewhat impacted <input type="checkbox"/> Quite impacted <input type="checkbox"/> Very impacted
<p>9. Over the past 7 days, how much has your <b>child's life been impacted by seizures</b>?</p>	<input type="checkbox"/> Not at all impacted <input type="checkbox"/> A little impacted <input type="checkbox"/> Somewhat impacted <input type="checkbox"/> Quite impacted <input type="checkbox"/> Very impacted

10. Over the past 7 days, how much has your **child's life been impacted by Dup15q syndrome overall**?

Not at all impacted

A little impacted

Somewhat impacted

Quite impacted

Very impacted

### Dup15q Syndrome Caregiver Global Impression of Change Questionnaire

In the questions below, we are going to ask you to rate how much change in different symptoms associated with Dup15q syndrome you may have noticed in your child (or person you care for) **since the start of the clinical study**. Please **choose the response** for each question that most accurately describes your child (or the person you care for). Your child or the person you care for with Dup15q syndrome will be referred to as “your child” below. Try to answer each question based on your first impression.

<p>1. How would you rate your child’s <b>seizures</b> now <b>compared to the start of the clinical study</b>?</p>	<input type="checkbox"/> Very much improved <input type="checkbox"/> Much improved <input type="checkbox"/> Minimally improved <input type="checkbox"/> No change <input type="checkbox"/> Minimally worse <input type="checkbox"/> Much worse <input type="checkbox"/> Very much worse
<p>2. How would you rate your child’s <b>difficulties communicating</b> now <b>compared to the start of the clinical study</b>?            For example, speaking words, babbling, pointing, gesturing, using picture boards or technology to aid communication, etc.</p>	<input type="checkbox"/> Very much improved <input type="checkbox"/> Much improved <input type="checkbox"/> Minimally improved <input type="checkbox"/> No change <input type="checkbox"/> Minimally worse <input type="checkbox"/> Much worse <input type="checkbox"/> Very much worse
<p>3. How would you rate your child’s <b>difficulties coordinating hand movements</b> now <b>compared to the start of the clinical study</b>?            For example, holding a small object such as a block or crayon, picking up coins, having hand tremors, etc.</p>	<input type="checkbox"/> Very much improved <input type="checkbox"/> Much improved <input type="checkbox"/> Minimally improved <input type="checkbox"/> No change <input type="checkbox"/> Minimally worse <input type="checkbox"/> Much worse <input type="checkbox"/> Very much worse

<p>4. How would you rate your child's <b>difficulties walking*</b> now <b>compared to the start of the clinical study?</b>          *If your child is not walking yet, rate their difficulty with crawling or moving around unassisted.</p>	<input type="checkbox"/> Very much improved <input type="checkbox"/> Much improved <input type="checkbox"/> Minimally improved <input type="checkbox"/> No change <input type="checkbox"/> Minimally worse <input type="checkbox"/> Much worse <input type="checkbox"/> Very much worse
<p>5. How would you rate your child's difficulties <b>concentrating, following instructions, or learning new things</b> now <b>compared to the start of the clinical study?</b></p>	<input type="checkbox"/> Very much improved <input type="checkbox"/> Much improved <input type="checkbox"/> Minimally improved <input type="checkbox"/> No change <input type="checkbox"/> Minimally worse <input type="checkbox"/> Much worse <input type="checkbox"/> Very much worse
<p>6. How would you rate your child's <b>difficulties with self-care activities</b> now <b>compared to the start of the clinical study?</b>          For example, eating, dressing, bathing, toileting, etc.</p>	<input type="checkbox"/> Very much improved <input type="checkbox"/> Much improved <input type="checkbox"/> Minimally improved <input type="checkbox"/> No change <input type="checkbox"/> Minimally worse <input type="checkbox"/> Much worse <input type="checkbox"/> Very much worse

<p>7. How would you rate your child's <b>disruptive behaviors</b> now <b>compared to the start of the clinical study</b>? For example, self-injury, hitting, biting, pinching, pulling hair, acting aggressively, hyperactivity, refusing to move, etc.</p>	<input type="checkbox"/> Very much improved <input type="checkbox"/> Much improved <input type="checkbox"/> Minimally improved <input type="checkbox"/> No change <input type="checkbox"/> Minimally worse <input type="checkbox"/> Much worse <input type="checkbox"/> Very much worse
<p>8. How would you rate your <b>child's social behaviors and/or social interactions</b> now <b>compared to the start of the clinical study</b>? For example, nonverbal communication (eye contact, gestures), interacting with others at home or at school, or during play with others, etc.</p>	<input type="checkbox"/> Very much improved <input type="checkbox"/> Much improved <input type="checkbox"/> Minimally improved <input type="checkbox"/> No change <input type="checkbox"/> Minimally worse <input type="checkbox"/> Much worse <input type="checkbox"/> Very much worse
<p>9. How would you rate your child's <b>sleep problems</b> now <b>compared to the start of the clinical study</b>? For example, difficulties falling asleep, staying asleep, waking too early, problems with sleep patterns, daytime sleepiness, etc.</p>	<input type="checkbox"/> Very much improved <input type="checkbox"/> Much improved <input type="checkbox"/> Minimally improved <input type="checkbox"/> No change <input type="checkbox"/> Minimally worse <input type="checkbox"/> Much worse <input type="checkbox"/> Very much worse
<p>10. a. How would you rate your child's <b>Dup15q syndrome overall</b> now <b>compared to the start of the clinical study</b>?</p>	<input type="checkbox"/> Very much improved <input type="checkbox"/> Much improved <input type="checkbox"/> Minimally improved <input type="checkbox"/> No change <input type="checkbox"/> Minimally worse <input type="checkbox"/> Much worse <input type="checkbox"/> Very much worse

b. Would you consider this change in your child's <b>Dup15q syndrome overall</b> to be meaningful?	<input type="checkbox"/> Yes, a meaningful improvement or worsening in my child's Dup15q syndrome
	<input type="checkbox"/> No, not a meaningful improvement or worsening in my child's Dup15q syndrome
	<input type="checkbox"/> Not applicable – My child has had no change in their overall Dup15q syndrome