

A : Motor function

Please refer to the Mother and Child Handbook.
If you do not remember, you may ask your family members.

	Answers		
▶ What were your first symptoms of GNE myopathy? Check all that apply (multiple choices allowed).			
Please write the symptoms you first became aware of. Test abnormalities or genetic tests are not included as symptoms.	1 <input type="checkbox"/> tripping / falling	6 <input type="checkbox"/> difficulty running	11 <input type="checkbox"/> others (please provide details)
	2 <input type="checkbox"/> foot drop	7 <input type="checkbox"/> muscle pain	[]
	3 <input type="checkbox"/> unusual walking gait	8 <input type="checkbox"/> muscle atrophy	
	4 <input type="checkbox"/> easily getting tired	9 <input type="checkbox"/> unable to stand on tiptoe	
	5 <input type="checkbox"/> slow walking	10 <input type="checkbox"/> weakness in the hands	

▶ When did you become aware of the first symptoms?	() years old
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▶ ① How is your current walking ability?		
1 <input type="checkbox"/> unable to walk	2 <input type="checkbox"/> walk with assistive devices (sticks, orthoses, etc.)	3 <input type="checkbox"/> able to walk similar to a healthy person
	age at which it became difficult to walk	4 <input type="checkbox"/> able to walk slowly without assistive devices
	▶ () years old	
▼ For those who answered "unable to walk" or "walk with assistive devices"		
② When did you start using assistive devices?	1 <input type="checkbox"/> never used	
	2 <input type="checkbox"/> previously used or currently using → age at which started to use: () years old	
③ When did you start using a wheelchair?	1 <input type="checkbox"/> never used	
	2 <input type="checkbox"/> previously used or currently using → age at which started to use: () years old	

▶ Have you ever been treated for GNE myopathy?	1 <input type="checkbox"/> never received treatment		
If yes, please select all that apply.	2 <input type="checkbox"/> steroid therapy → → → A-5		
	3 <input type="checkbox"/> rehabilitation/orthotic treatment → → → A-6		
	4 <input type="checkbox"/> clinical trial of sialic acid supplement therapy → phase () study		
	5 <input type="checkbox"/> others (please provide details below) []		

▼ For those who have been treated with "steroids":			
① age at treatment	from () years old to () years old		
② type of steroid medication	1 <input type="checkbox"/> Prednisolone	2 <input type="checkbox"/> Predonine	3 <input type="checkbox"/> Cortril
	5 <input type="checkbox"/> Medrol	6 <input type="checkbox"/> others ()	4 <input type="checkbox"/> Decadron
③ dose per day	1 dosage forms []		2 () tablets
	(If you don't remember, please write "details unknown")		
			per day

▼ For those who have been treated with "rehabilitation or orthotic treatment":	
① age at treatment	from () years old to () years old

