Person-Reported Ataxia Impact Scale (PRAIS)
Échelle autorapportée de l'impact des ataxies

GRIMN
Groupe de recherche interdisciplinaire sur les maladies neuromusculaires

Date: _____ / _____ / _____ (dd / mm / yyyy) **Subject number:** ☐☐☐☐

DOB: _____ / _____ / _____ (dd / mm / yyyy) **Subject initials:** ☐☐☐☐

Evaluator code: ☐☐ **A1** ☐ **A2** ☐ **A2** ☐

Self-reported questionnaire to assess the manifestations and impacts of recessive ataxia

The purpose of this questionnaire is to assess the manifestations and impacts of your ataxia on your daily life. You will be asked questions and will have to answer in general, thinking about your situation at the moment. Take the time to read the questions and the answer choices carefully. Keep in mind that we are looking for the impact of ataxia, so **disregard** any other health conditions you have. For example, if you injured yourself lately or if you have myopia (difficulty seeing from afar), this does not count in the conditions associated with ataxia.

In the questionnaire, when we say "your condition", we are referring to your ataxia.

Part 1: Questions to get to know you better

a) What walking aid do you use in your home most of the time?

☐ No aid
☐ Walls, table, counter
☐ Cane/stick
☐ Walker/rollator
☐ Wheelchair

b) Is the walking aid you use in your home different from the one you used a year ago?

(ex: switch from no help to a walker)

☐ Yes, specify: _____ ☐ Non

c) What walking aid do you use outside most of the time (e.g., to go to the mailbox, to walk to the street corner)?

☐ No aid
☐ Human aid
☐ Cane/stick
☐ Walker
☐ Wheelchair, four-wheeled scooter

d) Is the walking aid you use outside your home different from the one you used a year ago? (ex: switch from a manual wheelchair to an electric wheelchair)

☐ Yes, specify: _____ ☐ Non

Part 2: The impact of your condition

1- I find it difficult to get around in my home (with or without walking aid).

☐ I do not find it difficult
☐ I find it a little difficult
☐ I find it moderately difficult
☐ I find it very difficult
☐ I use a wheelchair

2- I find it difficult to walk short distances on the street or sidewalk/pavement in the summer (e.g., go to the street corner, go to the letter box).

☐ I do not find it difficult
☐ I find it a little difficult
☐ I find it moderately difficult
☐ I find it very difficult
☐ I use a wheelchair or a four-wheeled scooter

3- I find it difficult to walk long distances on the street or sidewalk/pavement in the summer (e.g., walk in a park, go to the store). I do not find it difficult
☐ I find it a little difficult
☐ I find it moderately difficult
☐ I find it very difficult
☐ I use a wheelchair or a four-wheeled scooter

4- I find it difficult to keep my balance when I am standing without support.

☐ I do not find it difficult
☐ I find it a little difficult (I have little or no need for adaptation or help)
☐ I find it moderately difficult (I sometimes need adaptation or help)
☐ I find it very difficult (I need adaptations or help most of the time)
☐ I am no longer able to stand

5- Because of my foot deformities, I find it difficult to stay standing.

☐ I do not have foot deformities
☐ I do not find it difficult, even if I have foot deformities
☐ I find it a little difficult
☐ I find it moderately difficult
☐ I find it very difficult
☐ I am no longer able to stand

6- Because of my leg weakness, I find it difficult to do daily tasks (e.g., get up, do transfers, support my own weight).

☐ I do not have any leg weakness
☐ I do not find it difficult even if I have leg weakness
☐ I find it a little difficult (I have little or no need for adaptation or help)
☐ I find it moderately difficult (I sometimes need adaptation or help)
☐ I find it very difficult (I need adaptations or help most of the time)

7- Because of my leg stiffness, I find it difficult to do some daily tasks (e.g., put shoes on, walk or do transfers).

☐ I do not have any leg stiffness
☐ I do not find it difficult even if I have leg stiffness
☐ I find it a little difficult (I have little or no need for adaptation or help)
☐ I find it moderately difficult (I sometimes need adaptation or help)
☐ I find it very difficult (I need adaptations or help most of the time)

8- I find it difficult to do daily tasks at home because of my condition (e.g., do housework, prepare meals).

☐ I do not find it difficult
☐ I find it a little difficult (I have little or no need for adaptation or help)
☐ I find it moderately difficult (I sometimes need adaptation or help)
☐ I find it very difficult (I need adaptations or help most of the time)
☐ I live in a residence with full service

9- I find it difficult to do sports because of my condition.

☐ I do not find it difficult
☐ I find it a little difficult (I have little or no need for adaptation or help)
☐ I find it moderately difficult (I sometimes need adaptation or help)
☐ I find it very difficult (I need adaptations or help most of the time)
☐ I do not do sports because of my condition
☐ I do not do sports for other reasons

10- I tend to choke on my saliva because of my condition.

☐ I do not choke on my saliva
☐ Rarely
☐ Sometimes
☐ Often
☐ Almost always or always

11- I tend to choke when I eat solid foods because of my condition.

☐ I do not choke on eating
☐ Rarely
☐ Sometimes
☐ Often
☐ Almost always or always

12- I tend to choke when I drink because of my condition.

☐ I do not choke on drinking
☐ Rarely
☐ Sometimes
☐ Often
☐ Almost always or always

13- Because of my <u>fatigue,</u> in general I find it difficult to do daily tasks (e.g., social activities, physical activities, tasks in the home).

☐ I do not have any fatigue related to my condition
☐ I do not find it difficult even when tired
☐ I find it a little difficult
☐ I find it moderately difficult
☐ I find it very difficult

14- Because of my <u>low energy,</u> I have to take breaks when I am doing daily tasks.

☐ I do not lack energy because of my condition
☐ Rarely
☐ Sometimes
☐ Often
☐ Almost always or always

15- Because of my pain, I find it difficult to do daily tasks (e.g., propel my wheelchair, write, do standing tasks).

☐ I do not have any pain caused by my condition
☐ I do not find it difficult even if I have pain
☐ I find it a little difficult
☐ I find it moderately difficult
☐ I find it very difficult

16- I have uncomfortable spasms (brief, painless involuntary contractions).

☐ I do not have spasms
☐ Rarely
☐ Sometimes
☐ Often
☐ Almost always or always

17- I have painful cramps (painful involuntary contractions).

☐ I do not have cramps
☐ Rarely
☐ Sometimes
☐ Often
☐ Almost always or always

18- Because of my <u>double vision or false sense of movement,</u> I find it difficult to do my daily tasks.

☐ I do not have double vision or a false sense of movement
☐ I do not find it difficult even if I have double vision or a false sense of movement
☐ I find it a little difficult
☐ I find it moderately difficult
☐ I find it very difficult

19- Because of my <u>hand weakness,</u> I find it difficult to do some daily tasks (e.g., lift objects, hold an object firmly, open a jar).

☐ I do not have any hand weakness
☐ I do not find it difficult even if I have hand weakness
☐ I find it a little difficult (I have little or no need for adaptation or help)
☐ I find it moderately difficult (I sometimes need adaptation or help)
☐ I find it very difficult (I need adaptations or help most of the time)

20- I find it difficult to write by hand.

☐ I do not find it difficult
☐ I find it a little difficult
☐ I find it moderately difficult
☐ I find it very difficult
☐ I no longer write by hand

21- I find it difficult to handle small objects because of my dexterity problems (e.g., buttons, pencil, needle, paperclip).

☐ I do not have any dexterity problems
☐ I do not find it difficult even if I have dexterity problems
☐ I find it a little difficult
☐ I find it moderately difficult
☐ I find it very difficult

22- When I feel the urge to have a bowel movement, I have to go quickly.

☐ I have no difficulty holding back
☐ Rarely
☐ Sometimes
☐ Often
☐ Almost always or always

23- When I feel the urge to urinate, I have to go quickly.

☐ I have no difficulty holding back
☐ Rarely
☐ Sometimes
☐ Often
☐ Almost always or always

24- I have difficult to do activities outside of my home because of my urinary incontinence (e.g., go on a trip, visit friends).

☐ I do not have urinary incontinence
☐ I do not find it difficult even if I have urinary incontinence
☐ I find it a little difficult (I have little or no need for adaptation or help)
☐ I find it moderately difficult (I sometimes need adaptation or help)
☐ I find it very difficult (I need adaptations or help most of the time)

25- I feel stressed about the progression of the symptoms associated with my condition.

☐ I do not feel stressed because of my condition
☐ Rarely
☐ Sometimes
☐ Often
☐ Almost always or always

26- I feel sad when I think about my condition.

☐ I do not feel sad because of my condition
☐ Rarely
☐ Sometimes
☐ Often
☐ Almost always or always

27- I feel frustrated because of the difficulties associated with my condition.

☐ I do not feel frustrated because of my condition
☐ Rarely
☐ Sometimes
☐ Often
☐ Almost always or always

28- I have difficulty remembering some important information because of my condition.

☐ I do not have difficulty remembering some information because of my condition
☐ Rarely
☐ Sometimes
☐ Often
☐ Almost always or always

29- I find it difficult to learn new things because of my condition.

☐ I do not find it difficult
☐ I find it a little difficult
☐ I find it moderately difficult
☐ I find it very difficult
☐ I am no longer able to learn new things

30- I find it difficult to pay attention or focus because of my condition.

☐ I do not find it difficult
☐ I find it a little difficult
☐ I find it moderately difficult
☐ I find it very difficult
☐ I am no longer able to pay attention

31- I find it difficult to connect with other people because of my condition.

☐ I do not find it difficult
☐ I find it a little difficult
☐ I find it moderately difficult
☐ I find it very difficult
☐ I no longer connect with other people

32- I find it difficult doing social activities (e.g., outings with friends, team sports, social clubs) because of my condition.

☐ I do not find it difficult
☐ I find it a little difficult (I have little or no need for adaptation or help)
☐ I find it moderately difficult (I sometimes need adaptation or help)
☐ I find it very difficult (I need adaptations or help most of the time)
☐ I do not do social activities because of my condition
☐ I do not do social activities for other reasons

33- I find it difficult doing leisure activities (e.g., reading, hiking, music) because of my condition.

☐ I do not find it difficult
☐ I find it a little difficult (I have little or no need for adaptation or help)
☐ I find it moderately difficult (I sometimes need adaptation or help)
☐ I find it very difficult (I need adaptations or help most of the time)
☐ I do not do leisure activities because of my condition
☐ I do not do leisure activities for other reasons

34- I often have to repeat what I say because people do not understand me.

☐ I have no difficulty with pronunciation
☐ Rarely
☐ Sometimes
☐ Often
☐ Almost always or always

35- I have difficulty fully living my sexuality due to my condition (e.g., adapt positions, use medication, assistive devices).

☐ I do not find it difficult
☐ I find it a little difficult (I have little or no need for adaptation or help)
☐ I find it moderately difficult (I sometimes need adaptation or help)
☐ I find it very difficult (I need adaptations or help most of the time)
☐ I do not have an active sex life because of my condition
☐ I do not have an active sex life for other reasons

36- I find it difficult to do some work tasks because of my condition (e.g., slower, less accurate, weakness).

☐ I do not find it difficult
☐ I find it a little difficult (I have little or no need for adaptation or help)
☐ I find it moderately difficult (I sometimes need adaptation or help)
☐ I find it very difficult (I need adaptations or help most of the time)
☐ I do not have a job currently because of my condition
☐ I do not have a job currently because for other reasons

37- I find it difficult to do some study tasks because of my condition (e.g., slower taking notes, less accurate, fatigue).

☐ I do not find it difficult
☐ I find it a little difficult (I have little or no need for adaptation or help)
☐ I find it moderately difficult (I sometimes need adaptation or help)
☐ I find it very difficult (I need adaptations or help most of the time)
☐ I am not in school currently because of my condition
☐ I am not in school currently for other reasons

38- I find it difficult to do some tasks with my children because of my condition (e.g., prepare meals, change diapers, go out).

☐ I do not find it difficult
☐ I find it a little difficult (I have little or no need for adaptation or help)
☐ I find it moderately difficult (I sometimes need adaptation or help)
☐ I find it very difficult (I need adaptations or help most of the time)
☐ I do not have children because of my condition
☐ I do not have children for other reasons, or my children are no longer at home

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Cotation sheet

The score is calculated according to the number of valid items and reported out of 100. The item is invalid if the answer is not applicable. Refer to the spreadsheet for more details.

Physical functions and activities		
Mobility and balance limitation		
1- I find it difficult to get around in my home (with or without walking aid).	I do not find it difficult	0
	I find it a little difficult	1
	I find it moderately difficult	2
	I find it very difficult	3
	I use a wheelchair	4
2- I find it difficult to walk short distances on the street or sidewalk/ pavement in the summer (e.g., go to the street corner, go to the letter box).	I do not find it difficult	0
	I find it a little difficult	1
	I find it moderately difficult	2
	I find it very difficult	3
	I use a wheelchair or a four-wheeled scooter	4
3- I find it difficult to walk long distances on the street or sidewalk/pavement in the summer (e.g., walk in a park, go to the store).	I do not find it difficult	0
	I find it a little difficult	1
	I find it moderately difficult	2
	I find it very difficult	3
	I use a wheelchair or a four-wheeled scooter	4
4- I find it difficult to keep my balance when I am standing without support.	I do not find it difficult	0
	I find it a little difficult (I have little or no need for adaptation or help)	1
	I find it moderately difficult (I sometimes need adaptation or help)	2
	I find it very difficult (I need adaptations or help most of the time)	3
	I am no longer able to stand	4
5- Because of my <u>foot deformities,</u> I find it difficult to stay standing.	I do not have foot deformities	0
	I do not find it difficult, even if I have foot deformities	1
	I find it a little difficult	2
	I find it moderately difficult	3
	I find it very difficult	4
	I am no longer able to stand	5

6- Because of my <u>leg weakness</u>, I find it difficult to do daily tasks (e.g., get up, do transfers, support my own weight).	I do not have any leg weakness	0
	I do not find it difficult even if I have leg weakness	1
	I find it a little difficult (I have little or no need for adaptation or help)	2
	I find it moderately difficult (I sometimes need adaptation or help)	3
	I find it very difficult (I need adaptations or help most of the time)	4
7- Because of my <u>leg stiffness</u>, I find it difficult to do some daily tasks (e.g., put shoes on, walk or do transfers).	I do not have any leg stiffness	0
	I do not find it difficult even if I have leg stiffness	1
	I find it a little difficult (I have little or no need for adaptation or help)	2
	I find it moderately difficult (I sometimes need adaptation or help)	3
	I find it very difficult (I need adaptations or help most of the time)	4
8- I find it difficult to do daily tasks at home because of my condition (e.g., do housework, prepare meals).	I do not find it difficult	0
	I find it a little difficult (I have little or no need for adaptation or help)	1
	I find it moderately difficult (I sometimes need adaptation or help)	2
	I find it very difficult (I need adaptations or help most of the time)	3
	I live in a residence with full service	4
9- I find it difficult to do sports because of my condition.	I do not find it difficult	0
	I find it a little difficult (I have little or no need for adaptation or help)	1
	I find it moderately difficult (I sometimes need adaptation or help)	2
	I find it very difficult (I need adaptations or help most of the time)	3
	I do not do sports because of my condition	4
	I do not do sports for other reasons	Not applicable
Dysphagia		
10- I tend to choke on my saliva because of my condition.	I do not choke on my saliva	0
	Rarely	1
	Sometimes	2
	Often	3
	Almost always or always	4

11- I tend to choke when I eat solid foods because of my condition.	I do not choke on eating	0
	Rarely	1
	Sometimes	2
	Often	3
	Almost always or always	4
12- I tend to choke when I drink because of my condition.	I do not choke on drinking	0
	Rarely	1
	Sometimes	2
	Often	3
	Almost always or always	4
Pain and sensory symptoms		
13- Because of my <u>fatigue,</u> in general I find it difficult to do daily tasks (e.g., social activities, physical activities, tasks in the home).	I do not have any fatigue related to my condition	0
	I do not find it difficult even when tired	1
	I find it a little difficult	2
	I find it moderately difficult	3
	I find it very difficult	4
14- Because of my <u>low energy,</u> I have to take breaks when I am doing daily tasks.	I do not lack energy because of my condition	0
	Rarely	1
	Sometimes	2
	Often	3
	Almost always or always	4
15- Because of my pain, I find it difficult to do daily tasks (e.g., propel my wheelchair, write, do standing tasks).	I do not have any pain caused by my condition	0
	I do not find it difficult even if I have pain	1
	I find it a little difficult	2
	I find it moderately difficult	3
	I find it very difficult	4
16- I have uncomfortable spasms (brief, painless involuntary contractions).	I do not have spasms	0
	Rarely	1
	Sometimes	2
	Often	3
	Almost always or always	4
17- I have painful cramps (painful involuntary contractions).	I do not have cramps	0
	Rarely	1
	Sometimes	2
	Often	3
	Almost always or always	4

18- Because of my <u>double vision or false sense of movement,</u> I find it difficult to do my daily tasks.	I do not have double vision or a false sense of movement	0
	I do not find it difficult even if I have double vision or a false sense of movement	1
	I find it a little difficult	2
	I find it moderately difficult	3
	I find it very difficult	4
Hand functions		
19- Because of my <u>hand weakness,</u> I find it difficult to do some daily tasks (e.g., lift objects, hold an object firmly, open a jar).	I do not have any hand weakness	0
	I do not find it difficult even if I have hand weakness	1
	I find it a little difficult (I have little or no need for adaptation or help)	2
	I find it moderately difficult (I sometimes need adaptation or help)	3
	I find it very difficult (I need adaptations or help most of the time)	4
20- I find it difficult to write by hand.	I do not find it difficult	0
	I find it a little difficult	1
	I find it moderately difficult	2
	I find it very difficult	3
	I no longer write by hand	4
21- I find it difficult to handle small objects because of my dexterity problems (e.g., buttons, pencil, needle, paperclip).	I do not have any dexterity problems	0
	I do not find it difficult even if I have dexterity problems	1
	I find it a little difficult	2
	I find it moderately difficult	3
	I find it very difficult	4
Urinary and bowel functions		
22- When I feel the urge to have a bowel movement, I have to go quickly.	I have no difficulty holding back	0
	Rarely	1
	Sometimes	2
	Often	3
	Almost always or always	4
23- When I feel the urge to urinate, I have to go quickly.	I have no difficulty holding back	0
	Rarely	1
	Sometimes	2
	Often	3
	Almost always or always	4

24- I have difficult to do activities outside of my home because of my urinary incontinence (e.g., go on a trip, visit friends).	I do not have urinary incontinence	0
	I do not find it difficult even if I have urinary incontinence	1
	I find it a little difficult (I have little or no need for adaptation or help)	2
	I find it moderately difficult (I sometimes need adaptation or help)	3
	I find it very difficult (I need adaptations or help most of the time)	4

Physical functions and activities sub-score /97

If item #9 N/A /93

Mental functions		
Affects		
25- I feel stressed about the progression of the symptoms associated with my condition.	I do not feel stressed because of my condition	0
	Rarely	1
	Sometimes	2
	Often	3
	Almost always or always	4
26- I feel sad when I think about my condition.	I do not feel sad because of my condition	0
	Rarely	1
	Sometimes	2
	Often	3
	Almost always or always	4
27- I feel frustrated because of the difficulties associated with my condition.	I do not feel frustrated because of my condition	0
	Rarely	1
	Sometimes	2
	Often	3
	Almost always or always	4
Cognition		
28- I have difficulty remembering some important information because of my condition.	I do not have difficulty remembering some information because of my condition	0
	Rarely	1
	Sometimes	2
	Often	3
	Almost always or always	4

29- I find it difficult to learn new things because of my condition.	I do not find it difficult	0
	I find it a little difficult	1
	I find it moderately difficult	2
	I find it very difficult	3
	I am no longer able to learn new things	4
30- I find it difficult to pay attention or focus because of my condition.	I do not find it difficult	0
	I find it a little difficult	1
	I find it moderately difficult	2
	I find it very difficult	3
	I am no longer able to pay attention	4

Mental functions sub-score /24

Social functions		
Social activities and relations		
31- I find it difficult to connect with other people because of my condition.	I do not find it difficult	0
	I find it a little difficult	1
	I find it moderately difficult	2
	I find it very difficult	3
	I no longer connect with other people	4
32- I find it difficult doing social activities (e.g., outings with friends, team sports, social clubs) because of my condition.	I do not find it difficult	0
	I find it a little difficult (I have little or no need for adaptation or help)	1
	I find it moderately difficult (I sometimes need adaptation or help)	2
	I find it very difficult (I need adaptations or help most of the time)	3
	I do not do social activities because of my condition	4
	I do not do social activities for other reasons	Not applicable
33- I find it difficult doing leisure activities (e.g., reading, hiking, music) because of my condition.	I do not find it difficult	0
	I find it a little difficult (I have little or no need for adaptation or help)	1
	I find it moderately difficult (I sometimes need adaptation or help)	2
	I find it very difficult (I need adaptations or help most of the time)	3
	I do not do leisure activities because of my condition	4
	I do not do leisure activities for other reasons	Not applicable

34- I often have to repeat what I say because people do not understand me.	I have no difficulty with pronunciation	0
	Rarely	1
	Sometimes	2
	Often	3
	Almost always or always	4
35- I have difficulty fully living my sexuality due to my condition (e.g., adapt positions, use medication, assistive devices).	I do not find it difficult	0
	I find it a little difficult (I have little or no need for adaptation or help)	1
	I find it moderately difficult (I sometimes need adaptation or help)	2
	I find it very difficult (I need adaptations or help most of the time)	3
	I do not have an active sex life because of my condition	4
	I do not have an active sex life for other reasons	Not applicable
Social roles		
36- I find it difficult to do some work tasks because of my condition (e.g., slower, less accurate, weakness).	I do not find it difficult	0
	I find it a little difficult (I have little or no need for adaptation or help)	1
	I find it moderately difficult (I sometimes need adaptation or help)	2
	I find it very difficult (I need adaptations or help most of the time)	3
	I do not have a job currently because of my condition	4
	I do not have a job currently because for other reasons	Not applicable
37- I find it difficult to do some study tasks because of my condition (e.g., slower taking notes, less accurate, fatigue).	I do not find it difficult	0
	I find it a little difficult (I have little or no need for adaptation or help)	1
	I find it moderately difficult (I sometimes need adaptation or help)	2
	I find it very difficult (I need adaptations or help most of the time)	3
	I am not in school currently because of my condition	4
	I am not in school currently for other reasons	Not applicable

38- I find it difficult to do some tasks with my children because of my condition (e.g., prepare meals, change diapers, go out).	I do not find it difficult	0
	I find it a little difficult (I have little or no need for adaptation or help)	1
	I find it moderately difficult (I sometimes need adaptation or help)	2
	I find it very difficult (I need adaptations or help most of the time)	3
	I do not have children because of my condition	4
	I do not have children for other reasons, or my children are no longer at home	Not applicable

Social functions sub-score	**/32**
If 1 N/A item	**/28**
If 2 N/A items	**/24**
If 3 N/A items	**/20**
If 4 N/A items	**/16**
If 5 N/A items	**/12**
If 6 N/A items	**/8**

Total score calculation

Total score if all 38 items are valid	**/153 x 100 =**
If 1 N/A item	**/149 x 100 =**
If 2 N/A items	**/145 x 100 =**
If 3 N/A items	**/141 x 100 =**
If 4 N/A items	**/137 x 100 =**
If 5 N/A items	**/133 x 100 =**
If 6 N/A items	**/129 x 100 =**
If 7 N/A items	**/125 x 100 =**