

SUPPLEMENTARY MATERIAL

Myasthenia gravis disease burden and its impact on satisfaction with life: a qualitative survey of patients' perspectives in Japan

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Table S1. Frequency of hospital visits and commuting time to the hospital for Japanese patients with myasthenia gravis

Frequency of hospital visits, n (%)	N=452
More than once a week	1 (0.2)
Once a week	3 (0.7)
Once every 2 weeks	18 (4.0)
Once a month	127 (28.1)
Once every 2 months	176 (38.9)
Once every 3 months	115 (25.4)
Once every 6 months	8 (1.8)
Less than once every 6 months	3 (0.7)
No response	1 (0.2)
Duration of hospital commute time, n (%)	
<15 minutes	51 (11.3)
≥15 to <30 minutes	109 (24.1)
≥30 to <45 minutes	89 (19.7)
≥45 minutes to <1 hour	66 (14.6)
≥1 to <1.5 hours	90 (19.9)
≥1.5 to <2 hours	29 (6.4)
≥2 hours	15 (3.3)
No response	3 (0.6)

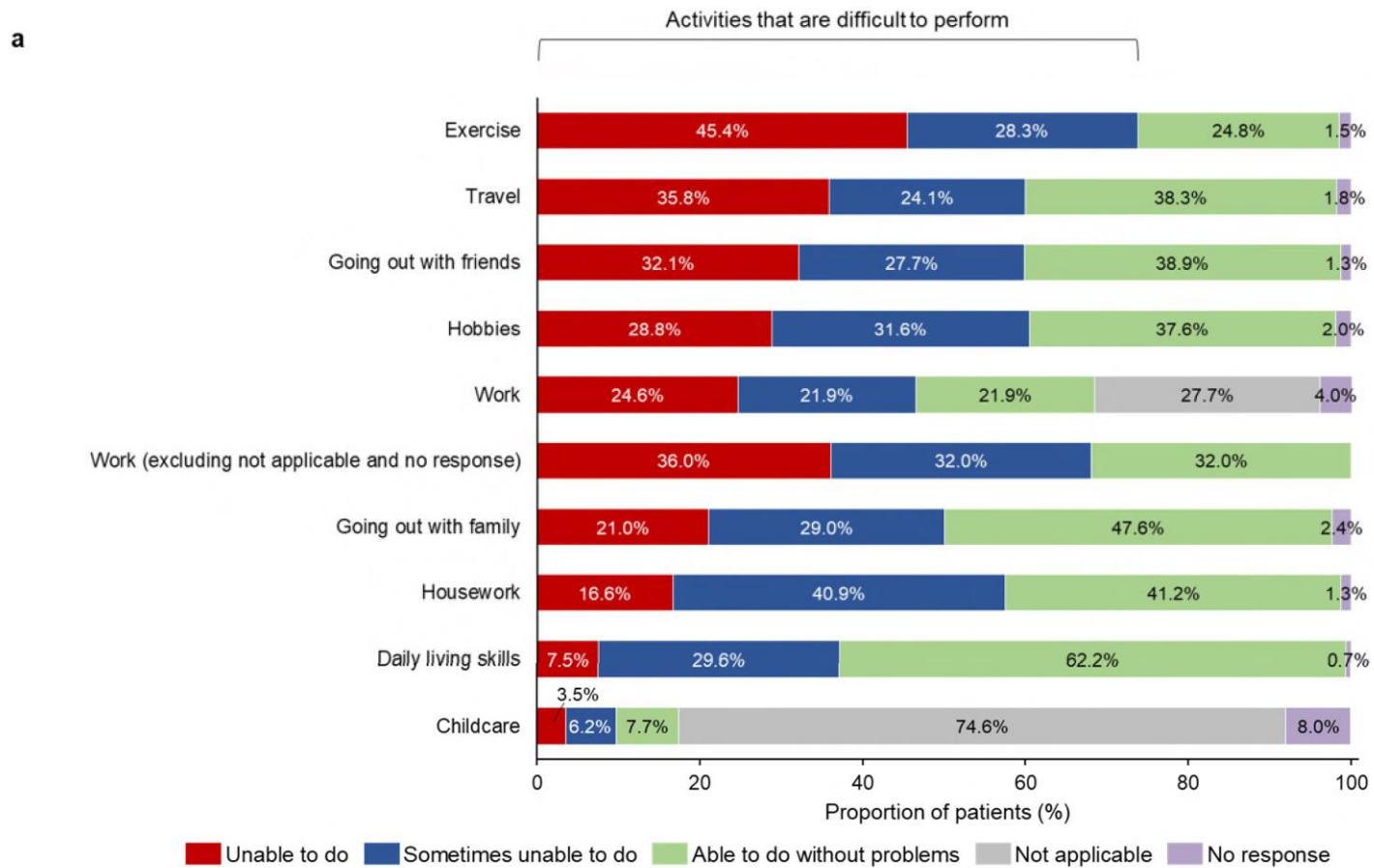
Table S2. Burden of round trip to and from the hospital and of commuting time to the hospital^a
for Japanese patients with myasthenia gravis

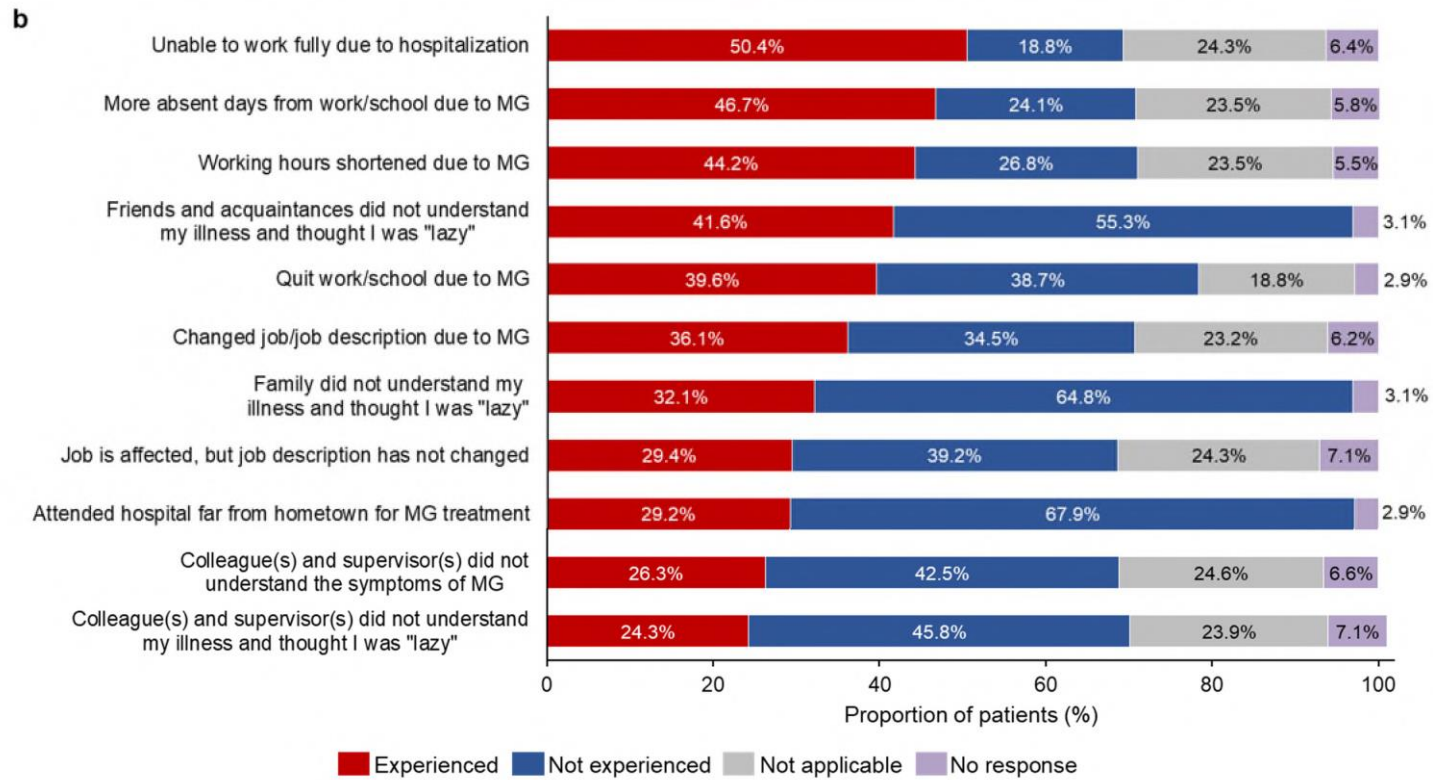
Burden of hospital visit (round trip), n (%)	N=452	
Very burdensome	26 (5.8)	
Burdensome	60 (13.3)	
Somewhat burdensome	133 (29.4)	
Neither	75 (16.6)	
Not burdensome	157 (34.7)	
No response	1 (0.2)	

Commute time,^a n (%)	Burden of hospital visit	
	Burdensome (n=219)	Not burdensome (n=157)
<15 minutes	3 (1.4)	43 (27.4)
≥15 to <30 minutes	26 (11.9)	59 (37.6)
≥30 to <45 minutes	44 (20.1)	27 (17.2)
≥45 minutes to <1 hour	41 (18.7)	13 (8.3)
≥1 to <1.5 hours	66 (30.1)	11 (7.0)
≥1.5 to <2 hours	23 (10.5)	2 (1.3)
≥2 hours	15 (6.8)	0
No response	1 (0.5)	2 (1.3)

^aRefers to one-way trip (i.e., time spent in going to the hospital).

Fig. S1. (A) Functional capability/ability and (B) personal experiences with regard to workplace/school functioning among Japanese patients with myasthenia gravis (N=452)





MG, myasthenia gravis

Fig. S2. The main reasons why Japanese patients with myasthenia gravis find it difficult to tell people about their disease

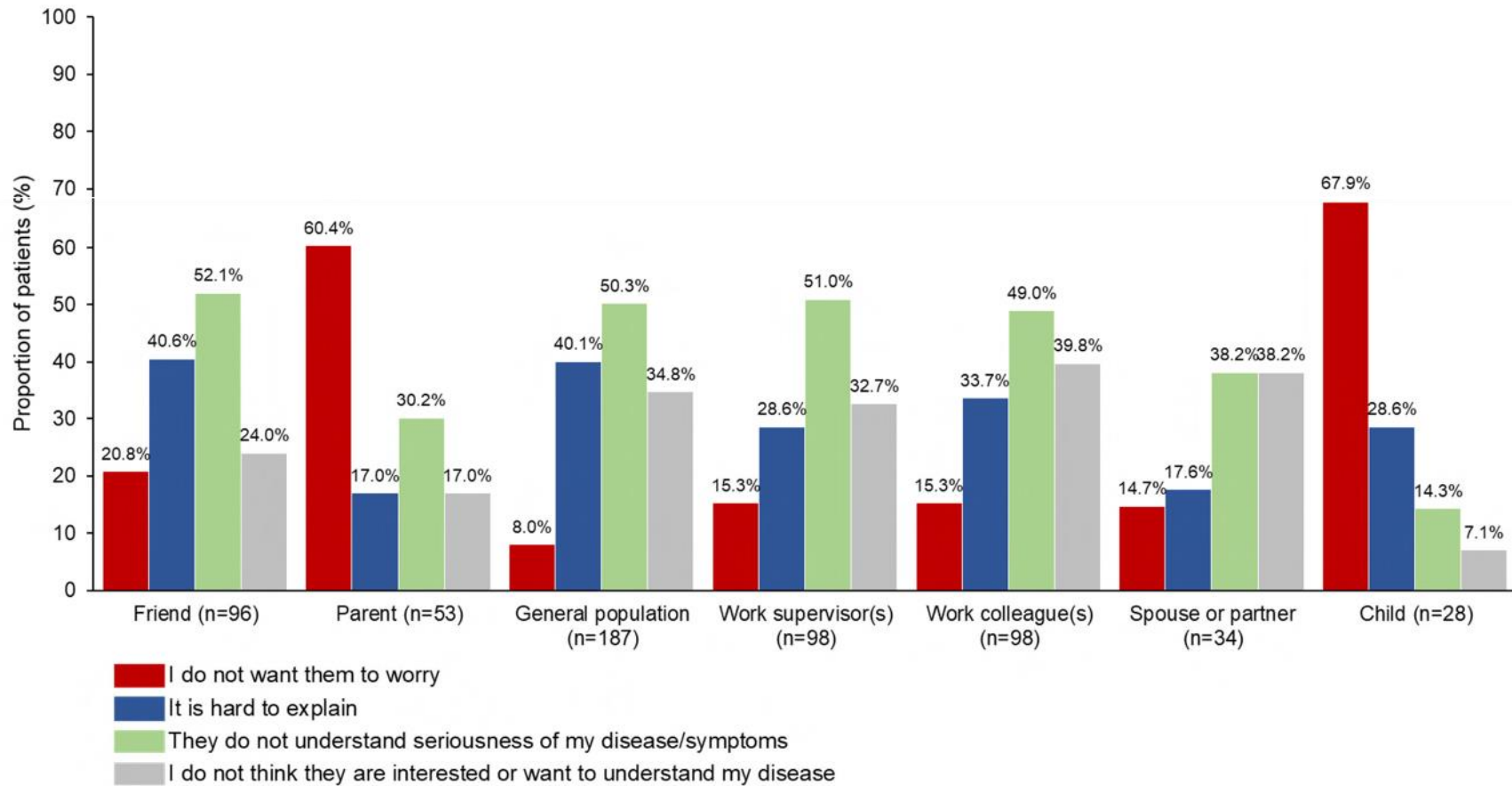


Fig. S3. Current treatments received by Japanese patients with myasthenia gravis (N=452)

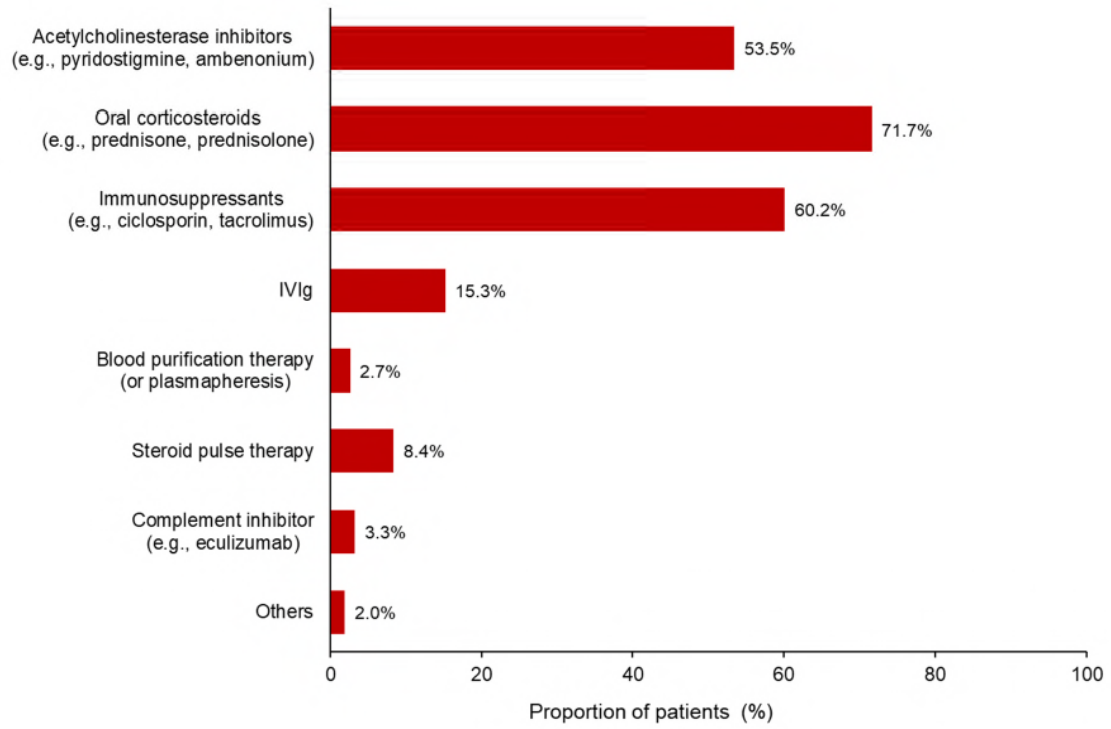


Fig. S4. Current treatment status and goals

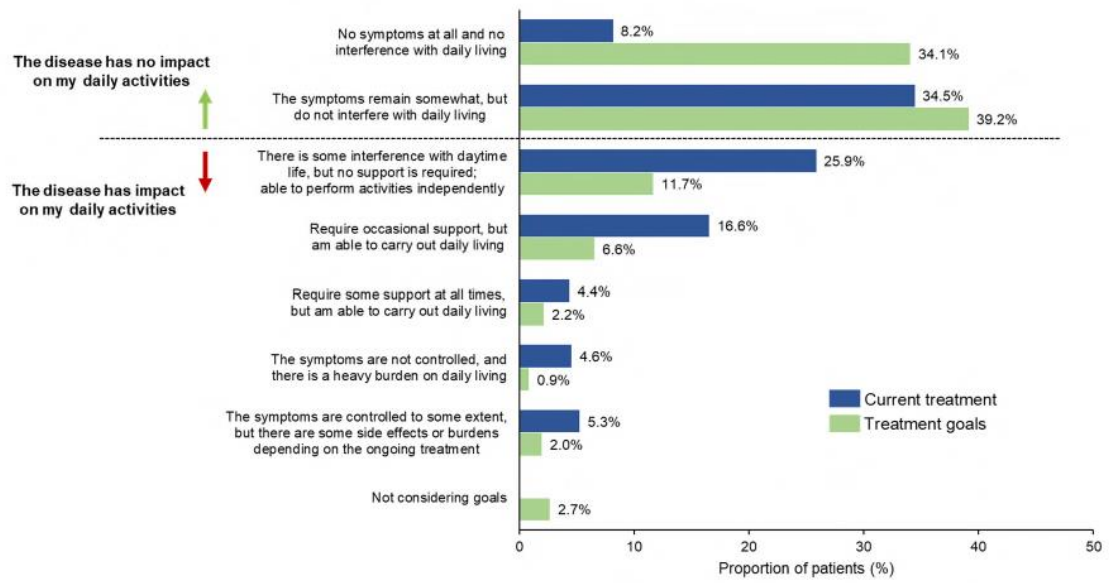
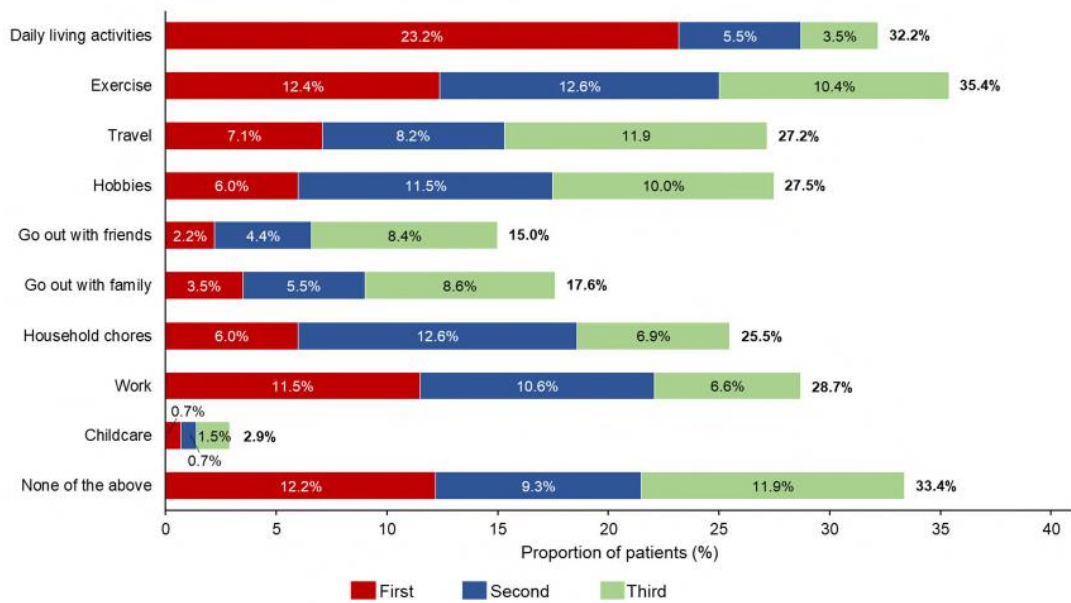


Fig. S5. The top three activities patients with myasthenia gravis wanted their treatment to allow them to perform without difficulty



Survey on Living Conditions of Persons with Myasthenia Gravis: Postal Questionnaire Form

If you answer online, you do not need to fill out this form or send it by post.

[Purpose and Request of the Survey]

We are performing this survey to understand the actual conditions of people who are suffering from myasthenia gravis, and to investigate their quality of life. We will aggregate the survey results, and use them to spread awareness in society and among the general public, regarding myasthenia gravis and its impact on these people's lives.

The key objective of this survey is to conduct public relations activities. The answers will be collected by argenx Japan and handled according to the company's privacy policy. In addition, the responses to this survey will be used in an aggregated form. No information that may be used to identify the individual respondent will be provided to any 3rd parties, unless you explicitly agree. Data may be handled outside of Japan. However, even in such cases, necessary measures will be taken to ensure the safety of the information under applicable laws and regulations.

Before filling out the survey form, please carefully read the precautions in "Notes on Filling Out the Form" below, and then start writing.

This questionnaire is intended for **adult persons who are receiving outpatient treatment for myasthenia**. We would appreciate it if those who currently and regularly visit a medical institution would cooperate with this survey.

- Please complete the form and post it (send it back) to us by **Monday, May 2, 2023**.

Notes on Filling Out the Form

- In this survey, "you" and "you, yourself" refer to the individual who has the disease.
- In this survey, we will ask you questions about "you, yourself."
 - *If it is difficult for you to answer/fill out the form yourself, a proxy can complete it for you.
 - *Please choose a proxy to fill it out who is most aware of your actual condition.
- Please circle the number of the applicable answer.
- The number of circles (○) you should write is indicated at the end of each question, such as (Circle only 1 number) or (Circle all that apply).
- This survey includes some personal questions. Please answer the questions to the extent you can.
- Please rest assured that the answers will be statistically processed and used in a manner that does not identify individuals.

S0. Are you regularly visiting a hospital or clinic for the treatment of myasthenia gravis, at present? **(Circle only 1 number)**

1	Yes
2	No

S1. Please select your gender. **(Circle only 1 number)**

1	Male
2	Female

S2. Please select only 1 item that applies to your age below. **(Circle only 1 number)**

1	15-19 years	4	40-49 years	7	≥70 years
2	20-29 years	5	50-59 years		
3	30-39 years	6	60-69 years		

S3. Please select the MGFA classification that applies to you. **(Circle only 1 number)**

1	Class I	4	Class IIIa	7	Class IVb
2	Class IIa	5	Class IIIb	8	Class V
3	Class IIb	6	Class IVa	9	No idea

Q1. How long has it been since you were diagnosed with myasthenia gravis (MG) by a doctor? Please select only 1 item that applies to you among the following, and circle the number. **(Circle only 1 number)**

1	<1 year	4	5 to <10 years
2	1 to <3 years	5	≥10 years
3	3 to <5 years		

Q2. Please select the item that applies to you for the results of autoantibody tests in your myasthenia gravis (MG). **(Circle only 1 number)**

1	Positive for anti-AChR antibody (anti-acetylcholine receptor antibody)
2	Positive for anti-MuSK antibody (anti-muscle-specific tyrosine kinase antibody)

3	Positive for LRP4 antibody
4	Positive for other antibody
5	Negative for all antibodies
6	No idea

Q3. How long did it take for you to recognize the symptoms of myasthenia gravis (MG), before you were definitely diagnosed with MG? **(Circle only 1 number)**

1	<1 month	4	1 to <3 years	7	No idea
2	1 to <6 months	5	3 to <5 years		
3	6 months to <1 year	6	≥5 years		

Q4. How many hospitals (or clinical departments) did you visit before your diagnosis of myasthenia gravis (MG) was confirmed? **(Circle only 1 number)**

1	Only 1 hospital (or 1 clinical)	4	4 hospitals (or 4 clinical departments)
2	2 hospitals (or 2 clinical)	5	5 hospitals (or 5 clinical departments)
3	3 hospitals (or 3 clinical)	6	No idea

Q5. How satisfied are you with your current treatment? **(Circle only 1 number)**

Your satisfaction with your current treatment

Satisfied	Somewhat satisfied	Neither	Somewhat dissatisfied	Dissatisfied
1	2	3	4	5

Q6. A) Please select the status of your current treatment from among the following items. **(Circle only 1 number)**

1	No symptoms at all and no interference with daily living
2	The symptoms remain somewhat, but do not interfere with daily living
3	There is some interference with daytime life, but no support is required; able to perform activities independently
4	Require occasional support, but am able to carry out daily living
5	Require some support at all times, but am able to carry out daily living

6	The symptoms are not controlled, and there is a heavy burden on daily living
7	The symptoms are controlled to some extent, but there are some side effects or burdens depending on the ongoing treatment

Q6. B) Also, please indicate your status as a goal of treatment, from among the following items. **(Circle only 1 number)**

1	No symptoms at all and no interference with daily living
2	The symptoms remain somewhat, but do not interfere with daily living
3	There is some interference with daytime life, but no support is required; able to perform activities independently
4	Require occasional support, but am able to carry out daily living
5	Require some support at all times, but am able to carry out daily living
6	The symptoms are not controlled, and there is a heavy burden on daily living
7	The symptoms are controlled to some extent, but there are some side effects or burdens depending on the ongoing treatment
8	Not considering goals

Q7. Please indicate your implementation status for each of the following treatments, from A to H. **(Circle 1 number in each row)**

		No experience	Previously performed but not currently	Currently/periodically ongoing
A	Acetylcholinesterase inhibitors (such as Mestinon and Mytelase)	1	2	3
B	Oral steroids (such as Predonine or prednisolone)	1	2	3
C	Immunosuppressants (such as Neoral and Prograf)	1	2	3
D	Intravenous immunoglobulin therapy	1	2	3
E	Plasmapheresis (Plasma exchange)	1	2	3
F	Steroid pulse therapy	1	2	3
G	Complement inhibitor (Soliris)	1	2	3
H	Other(s)	1	2	3

Q8. A) Please select all symptoms you currently have regarding myasthenia gravis (MG).

B) Then, please select the 3 items you are particularly worried about, among these.

*Please answer regardless of the degree of each symptom.

	A) Current symptoms (Circle all that apply in the column)	B) Symptoms you are particularly worried about among them (Up to 3 circles in the column)
Diplopia (double vision)	1	1
Ptosis (eyelid drooping)	2	2
Dysphonia (difficulty speaking or slurring)	3	3
Mastication disorder/dysphagia (difficulty chewing or swallowing)	4	4
Difficulty in holding head up	5	5
Weakness of arms and/or legs	6	6
Fatigability (easily fatigued)	7	7
Difficulty in walking/standing	8	8
Sleep disorder (difficulty in onset or maintaining sleep)	9	9
Dyspnea (choking/difficulty breathing)	10	10
Other(s)	11	11

Q9. Please indicate your closest frequency of visits to a medical institution for myasthenia gravis (MG). **(Circle only 1 number)**

1	> Once a week	4	Once a month	7	Once every 6 months
2	Once a week	5	Once every 2 months	8	< once every 6 months
3	Once every 2 weeks	6	Once every 3 months		

Q10. Please indicate your visiting time (one way), from the time you leave home for myasthenia gravis (MG) to the time you arrive at the medical institution you mainly visit for MG. **(Circle only 1 number)**

1	<15 minutes	5	1 to <1.5 hours
2	15 to <30 minutes	6	1.5 to <2 hours
3	30 to <45 minutes	7	≥2 hours
4	45 to <60 minutes		

Q11. How much do you feel burdened by the visiting time (round trip) from home to the medical institution you mainly visit for myasthenia gravis (MG)? **(Circle only 1 number)**

Your burden regarding the visiting time

Very burdensome	Burdensome	Somewhat burdensome	Neither	Does not feel like a burden
1	2	3	4	5

Q12. How much are you satisfied with your current life? **(Circle only 1 number)**

Your satisfaction with your current life in general

Satisfied	Somewhat satisfied	Neither	Somewhat dissatisfied	Dissatisfied
1	2	3	4	5

Q13. Please indicate your implementation status for each of the following activities A to H. **(Circle 1 number in each row)**

		Able to do it with no particular hindrance	Occasionally unable to do that	Often unable to do that	Completely unable to do that	Not applicable (for me)
A	Daily living skills	1	2	3	4	
B	Exercise	1	2	3	4	
C	Travel	1	2	3	4	
D	Hobbies	1	2	3	4	
E	Going out with my friend(s)	1	2	3	4	
F	Going out with my family	1	2	3	4	
G	Household chores	1	2	3	4	
H	Working	1	2	3	4	5
I	Childcare	1	2	3	4	5

Q14. Please select the top 3 items from the following regarding what you want to be able to do without hindrance due to treatment. **(Circle 1 number in each column)**

	1st place	2nd place	3rd place
Daily living skills	1	1	1
Exercise	2	2	2
Travel	3	3	3

Hobbies	4	4	4
Going out with my friend(s)	5	5	5
Going out with my family	6	6	6
Household chores	7	7	7
Working	8	8	8
Childcare	9	9	9
None of the above are applicable	10	10	10

Q15. Please select the applicable number of the following items the you have ever experienced since your diagnosis with myasthenia gravis (MG). **(Circle 1 number in each row)**

			Experienced	Have not experienced	Not applicable due to no work experience
Work and school	A	My family did not understand my disease and thought I was "lazy"	1	2	
	B	My friend(s) and people around me did not understand my disease and thought I was "lazy"	1	2	
	C	I visited a medical institution far away from my home to treat myasthenia gravis (MG)	1	2	
	D	I quit work or school due to myasthenia gravis (MG)	1	2	3
	E	I changed my workplace or work content due to myasthenia gravis (MG)	1	2	3
	F	I reduced my working hours due to myasthenia gravis (MG)	1	2	3
	G	Frequency of sick leave from work or school increased due to myasthenia gravis (MG)	1	2	3
	H	There is an impact on work, but the content has not been changed	1	2	3
	I	Hospitalization sometimes prevented me from working well	1	2	3
	J	People in my workplace did not well understand the necessity for my regular hospital visits	1	2	3
	K	People in my workplace did not well understand the necessity for my regular hospitalization	1	2	3
	L	My colleague(s) and supervisor(s) did not understand the symptoms of my disease	1	2	3
	M	My colleague(s) and supervisor(s) did not understand my disease and thought I was "lazy"	1	2	3

Q16. How easy it is to tell others that you have myasthenia gravis (MG). **(Circle 1 number in each row)**

		Easy to talk	Somewhat easy to talk	Neither	Somewhat difficult to talk	Difficult to talk	Not applicable
A	My friend(s)	1	2	3	4	5	6
B	My parents	1	2	3	4	5	6
C	General public	1	2	3	4	5	6
D	My supervisor(s) at the workplace	1	2	3	4	5	6
E	My colleague(s) at the workplace	1	2	3	4	5	6
F	My spouse/partner	1	2	3	4	5	6
G	My child(ren)	1	2	3	4	5	6

(If you selected "Difficult to talk" or "Somewhat difficult to talk" for Q16)

Q17. Why you feel this way about each group of people. (Circle all that apply in each row)

		Because I do not understand my disease well	Because I do not want to make the group of people worry	Because I am afraid to talk or explain	Because it is difficult to explain	Because the group of people will not understand how hard my disease and symptoms are	Because I do not feel the group of people want to hear and understand my disease
A	My friend(s)	1	2	3	4	5	6
B	My parents	1	2	3	4	5	6
C	General public	1	2	3	4	5	6
D	My supervisor(s) at the workplace	1	2	3	4	5	6
E	My colleague(s) at the workplace	1	2	3	4	5	6
F	My spouse/partner	1	2	3	4	5	6
G	My child(ren)	1	2	3	4	5	6

Q18. How much do you agree with the following items about your current myasthenia gravis (MG) doctor? (Circle 1 number in each row)

		Disagree	Somewhat disagree	Neither	Somewhat agree	Agree
A	Consultation with my doctor is essential for symptom management	1	2	3	4	5
B	My doctor selects the best treatment for me	1	2	3	4	5

C	My doctor fully understands the severity of my symptoms	1	2	3	4	5
D	I usually accept the treatment suggested by my doctor	1	2	3	4	5
E	I have been fully informed of new treatments by my doctor	1	2	3	4	5
F	My doctor fully understands and accepts the treatment I desire	1	2	3	4	5
G	My doctor provides sufficient information on myasthenia gravis (MG), in general	1	2	3	4	5
H	My doctor knows about the latest treatments	1	2	3	4	5
I	My doctor clearly explains the side effects of the myasthenia gravis (MG) treatment	1	2	3	4	5
J	My doctor is knowledgeable about myasthenia gravis (MG) treatment options	1	2	3	4	5
K	My doctor clearly explains the treatment goals	1	2	3	4	5
L	My doctor is trying to respect my intentions	1	2	3	4	5
M	My doctor tries to create an atmosphere that makes it easy to ask questions	1	2	3	4	5
N	My doctor shows empathy for my wishes	1	2	3	4	5
O	My doctor adequately addresses my concerns and consultations	1	2	3	4	5
P	My doctor takes enough time for consultations	1	2	3	4	5

Q19. How much do you agree with the following items about yourself? **(Circle 1 number in each row)**

		Disagree	Somewhat disagree	Neither	Somewhat agree	Agree
A	I want to get actively involved in my treatment	1	2	3	4	5
B	I want to actively collect information on the disease and drugs	1	2	3	4	5
C	I fully understand the explanations of my doctor	1	2	3	4	5
D	I listen well to the explanations of my doctor	1	2	3	4	5
E	I have established a relationship of trust with my doctor	1	2	3	4	5
F	I properly explain my symptoms to my doctor	1	2	3	4	5

G	I have sufficient knowledge of the disease	1	2	3	4	5
H	I select a treatment method after consulting with my doctor	1	2	3	4	5
I	I am satisfied with my communication with my doctor	1	2	3	4	5
J	I want to get actively involved in my treatment	1	2	3	4	5

Q20. Where do you obtain information or relevant information on myasthenia gravis? Please select all sources of information. **(Circle all that apply)**

1	My doctor	9	TV programs and newspaper articles
2	Websites of medical institutions	10	YouTube
3	Websites of pharmaceutical companies	11	SNS (Facebook, Instagram, Twitter, LINE)
4	Medical information sites	12	Lectures such as open seminars for citizens
5	Exchange of information with my family and friend(s)	13	Booklets and posters at medical institutions
6	Information exchange among patients	14	Other(s)
7	Patient associations	15	Nowhere in particular
8	Patient blogs and bulletin boards		

F1. Have you been diagnosed by a doctor, and are currently under treatment for any diseases other than myasthenia gravis (MG)? **(Circle all that apply)**

1	Hypertension
2	Hyperlipidemia
3	Diabetes mellitus
4	Osteoporosis
5	Cardiac disease (such as myocardial infarction and angina pectoris)
6	Glaucoma
7	Cataracts
8	Other(s)
9	Not currently under treatment for any disease other than myasthenia gravis (MG)

F2. Please indicate the type of primary medical institution you currently visit for treating myasthenia gravis (MG). **(Circle only 1 number)**

1	University hospital
2	General hospital
3	Clinic
4	Other(s)

F3. Please indicate which of the following items applies to your current work. **(Circle only 1 number)**

1	Public official	7	Freelancer
2	Management/company executive	8	Part-time worker
3	Company employee (office work)	9	Full-time homemaker (male and female)
4	Company employee (technical work)	10	Student
5	Company employee (other work)	11	Other
6	Self-employed	12	Unemployed

F4. Who do you currently live with? Please select all applicable answers. **(Circle all that apply)**

1	I live alone	6	My grandchild(ren)
2	My spouse/partner	7	My brother(s)/sister(s)
3	My child(ren)	8	My other relative(s)
4	My parent(s)	9	Other(s)
5	My grandparent(s)		

F5. Please select the prefecture where you currently live, from among the following. **(Circle only 1 number)**

1	Hokkaido	13	Tokyo	25	Shiga	37	Kagawa
2	Aomori	14	Kanagawa	26	Kyoto	38	Ehime
3	Iwate	15	Niigata	27	Osaka	39	Kochi
4	Miyagi	16	Toyama	28	Hyogo	40	Fukuoka
5	Akita	17	Ishikawa	29	Nara	41	Saga
6	Yamagata	18	Fukui	30	Wakayama	42	Nagasaki
7	Fukushima	19	Yamanashi	31	Tottori	43	Kumamoto
8	Ibaraki	20	Nagano	32	Shimane	44	Oita

9	Tochigi	21	Gifu	33	Okayama	45	Miyazaki
10	Gunma	22	Shizuoka	34	Hiroshima	46	Kagoshima
11	Saitama	23	Aichi	35	Yamaguchi	47	Okinawa
12	Chiba	24	Mie	36	Tokushima		

That's the end of this questionnaire.

We will send you a reward for your participation at a later date.

Please fill in the address where we should send it below (If no reward is necessary, you do not have to fill it in).

Address for sending the reward

Address
〒

Name
Furigana
Kanji

That is all of the questions. Thank you for your time and cooperation while you are busy.

We are sorry for the inconvenience, but please make sure that there are no omissions, and post it (send it back) to us by **Monday,**

May 2.