The following survey will ask you questions about your family history of MS, your MS diagnosis and history, your symptoms, and your treatments. You may find it easier to fully answer these questions if you have your records on hand.

Note: This PDF version is for your information only and does not accurately reflect the order of the questions. To view the questions as they are meant to be asked, you must complete the online survey.

MS Family History

Do you	ı or did you have	any family me	mbers who	have been o	diagnosed v	with MS?
□ Yes	□ No □ I Don't K	Know				

Please list each family member who has been diagnosed with MS:

Family member		Blood relative? Indicate yes, no, or "don't know"	Date of birth (month / day / year or "don't know")
Mother			
Father			
Sister	Your twin? ☐ Yes – identical ☐ Yes – not identical ☐ No		
Brother	Your twin? □ Yes – identical □ Yes – not identical □ No		
Grandmother	Maternal side / Paternal side		
Grandfather	Maternal side / Paternal side		
Great-grandmother	Maternal side / Paternal side		
Great-grandfather	Maternal side / Paternal side		
Aunt	Maternal side / Paternal side		
Uncle	Maternal side / Paternal side		
Cousin – male	Maternal side / Paternal side		
Cousin – female	Maternal side / Paternal side		



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Niece	Maternal side /		
	Paternal side		
Nephew	Maternal side /		
	Paternal side		
Daughter			
Son			
Granddaughter	Daughter's side /		
<u> </u>	Son's side		
Grandson	Daughter's side /		
	Son's side		
Other	Maternal side /		
	Paternal side		
☐ Yes ☐ No ☐ I'm not sure If yes If no If	f I'm not sure If no or I	'm not sure	
□ Blood tests □ Evoked potentials Are you confident that your □ Yes	as part of the diagnostice ord land land land land land land land lan	c process? Check e/spinal tap)	all that apply.
New diagnosis:	ed a new diagnosis that ons about whether I acti		nave MS.
The following questions withat your diagnosis has char experiences leading up to the following questions with you are unsure of your diagnosis to learn more about your experiences.	nged; however, it is extrained in the second	remely helpful to lee answer to the be tory and sympton as; however, it is s	learn more about your est of your ability. / ns. We understand that still extremely helpful
Please elaborate:	agnosed, but I believe I l	nave MS.	

☐ I have not been diagnosed, and I'm not sure whether I have ☐ I have not been diagnosed, and I do not believe I have MS.	MS or not.
Please elaborate ☐ I am not sure if I have received a diagnosis, but I believe I h ☐ I am not sure if I have received a diagnosis, and I'm not sur not. ☐ I am not sure if I have received a diagnosis, and I do not be	e whether I have MS or
Are you in the process of being tested to find out if you have MS? □ Yes □ No	
Have you experienced symptoms that led you to believe you have MS ☐ Yes ☐ No	5?
Have your symptoms ever met the definition of an MS relapse or exa	cerbation?
Have your symptoms ever met the definition of an MS relapse or exact A relapse or exacerbation is defined as a development of new symptom old symptoms that lasts longer than 48 hours. * In a relapse or exacerbation, MS symptoms generally worsen over a several weeks. * They then improve partially or completely over several weeks or maken a relapse or exacerbation can be associated with several different symptoms at the same time. * Symptoms that occur in the context of an infection or fever do not relapse or exacerbation.	oms or worsening of a period of days to nonths. Symptoms getting
A relapse or exacerbation is defined as a development of new symptoold symptoms that lasts longer than 48 hours. * In a relapse or exacerbation, MS symptoms generally worsen over a several weeks. * They then improve partially or completely over several weeks or maken a relapse or exacerbation can be associated with several different several the same time. * Symptoms that occur in the context of an infection or fever do not maken.	oms or worsening of a period of days to nonths. Symptoms getting
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A relapse or exacerbation is defined as a development of new symptoold symptoms that lasts longer than 48 hours. * In a relapse or exacerbation, MS symptoms generally worsen over a several weeks. * They then improve partially or completely over several weeks or m * A relapse or exacerbation can be associated with several different sworse at the same time. * Symptoms that occur in the context of an infection or fever do not relapse or exacerbation.	oms or worsening of a period of days to nonths. Symptoms getting meet our definition of a odiagnosis and up

Date of onset	Symptoms (check all that apply)				Degree of recovery	
	Vision	Weakness	Balance	Sensory	Other	See list below



□ I have not had any exacerbations.					
 Degree of recovery: I made a nearly complete recovery (> 90%): Following recovery from this relapse, I had minimal remaining MS related symptoms or problems that did not already exist prior to the relapse. I made a partial recovery (50-90%): Following recovery from this relapse, I had moderate persistence of MS related symptoms or problems that did not already exist prior to the relapse. I made very little recovery (10-49%): Following recovery from this relapse, I had significant persistence of MS related symptoms or problems that did not already exist prior to the relapse. I made no significant recovery (<10%) from this relapse. I am unable to recall my recovery from this relapse. 					
Have you developed symptoms that have gotte ☐ Yes ☐ No	en progr	essively	worse over	time?	
Indicate which of the following symptoms have MS. Please tell us if: You have ever experienced this symptom. This symptom occurred during your first exact You are currently experiencing this symptom. You have never experienced this symptom. You do not recall whether or not you have experienced that apply.	erbation	or at or	ıset.	t you mi	ght
Symptom	Ever	First	Currently	Never	Don't Recall
Weakness in arms/hands					
Weakness in legs/feet					
Difficulty walking / dragging a foot					
Loss of coordination in arms / hands					
Loss of coordination in legs / feet					
Stiffness / spasms					
Difficulty with balance					
Shaking or tremors					
Paralysis of half or whole face (i.e. facial					
drooping with altered smile, difficulty closing an eye tightly or wrinkling forehead)					
Facial twitching					
		1			



3				
		П		П
		П		
_				
	П		П	
7				
-				
	П			П
		- 		
ou may	y have M	AS?		

Which of the following best characterizes your form of MS? (check one)

Note: A relapse or exacerbation is defined as a development of new symptoms or worsening of old symptoms that lasts longer than 48 hours.

- * In a relapse or exacerbation, MS symptoms generally worsen over a period of days to several weeks.
- * They then improve partially or completely over several weeks or months.
- * A relapse or exacerbation can be associated with several different symptoms getting worse at the same time.
- * Symptoms that occur in the context of an infection or fever do not meet our definition of a relapse or exacerbation.



$\hfill\Box$ Clinically isolated syndrome (CIS) - You have experienced only one exacerbation with or without significant recovery.
□ Relapsing remitting (RRMS) - You have experienced two or more exacerbations, separated by more than 30 days, of being worse for a period of time followed by an improvement in condition. In between exacerbations your MS is stable.
☐ Secondary progressive (SPMS) - Your disease began with at least one exacerbation (usually more) separated or followed by periods of stability and has changed to the point where symptoms have been getting progressively worse even when not having an exacerbation.
At what age did this change take place? You may answer approximately years old
□ Primary progressive (PPMS) -Your initial MS symptoms came on too slowly to be considered an exacerbation. Since then, your symptoms have continued to steadily get worse. You may also have experienced one or more exacerbations after onset, or you may never have had an exacerbation.
Have you ever had any MS exacerbations that meet the definition above? $\ \square$ Yes $\ \square$ No $\ \square$ Don't know
□ Radiologically isolated syndrome (RIS) - Your MRI shows evidence that you may have MS, but you have not had any symptoms that are typical of MS (for instance, a doctor obtained an MRI scan for a reason other than MS and found abnormalities that look like MS).
□ Not sure/don't know

We're interested in your early experiences with MS. Use the table below to list the exacerbations you experienced prior to diagnosis and up through the first two years following your diagnosis, starting with your first exacerbation. Only list exacerbations you can recall with great accuracy.

Date of onset	Symptoms (check all that apply)				Degree of recovery	
	Vision	Weakness	Balance	Sensory	Other	See list below

☐ I have not had any exacerbations.



Degree of recovery:

- I made a nearly complete recovery (> 90%): Following recovery from this relapse, I had minimal remaining MS related symptoms or problems that did not already exist prior to the relapse.
- I made a partial recovery (50-90%): Following recovery from this relapse, I had moderate persistence of MS related symptoms or problems that did not already exist prior to the relapse.
- I made very little recovery (10-49%): Following recovery from this relapse, I had significant persistence of MS related symptoms or problems that did not already exist prior to the relapse.
- I made no significant recovery (<10%) from this relapse.
- I am unable to recall my recovery from this relapse.

We're interested in your more recent experiences with MS. Use the table below to list any additional exacerbations you experienced in the last two years. Only list exacerbations you can recall with great accuracy. (Please enter the date in MM/YYYY format)

Date of onset	Sympto	Symptoms (check all that apply)				Degi	ee of	recovery
	Vision	Weakness	Balance	Sensory	Other	See l	ist ab	ove

☐ I have not had any exacerbations in the last two years.

Before your first exacerbation or diagnosis, did you experience any symptoms that you feel were due to MS but did not meet the definition of a relapse or a doctor did not consider these symptoms consistent with MS? \Box Yes \Box No \Box I Don't know \Box Not applicable	
How old were you when you had your first symptom? You may answer approximately years old	

Indicate which of the following symptoms you have experienced as a result of your MS. Please tell us if :

You have ever experienced this symptom.

This symptom occurred during your first exacerbation or at onset.

You are currently experiencing this symptom.

You have never experienced this symptom.

You do not recall whether or not you have experienced this symptom.



Check all that	t apply.
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Symptom	Ever	First	Currently	Never	Don't Recall
Weakness in arms/hands					
Weakness in legs/feet					
Difficulty walking / dragging a foot					
Loss of coordination in arms / hands					
Loss of coordination in legs / feet					
Stiffness / spasms					
Difficulty with balance					
Shaking or tremors					
Paralysis of half or whole face (i.e. facial drooping with altered smile, difficulty closing an eye tightly or wrinkling forehead)					
Facial twitching					
Speech articulation (speech sounds slurred or slowed or loses normal rhythm)					
Difficulty with swallowing					
Blindness or blurry vision in one eye or both					
Disturbed vision e.g. double vision, objects moving, etc.					
Sensory symptoms: Loss of feeling, painful feeling, unable to feel position of fingers/arms/legs, swollen feeling, numbness, tingling, feeling of pinpricks					
Vertigo					
Sharp, painful feeling in face not due to trauma or injury (trigeminal neuralgia)					
Electric shock-like feeling when bending neck					
Itching, not due to other causes e.g. psoriasis, insect bites, etc.					
Burning sensation in feet					
Cognitive difficulties, e.g. memory problems					
Sexual dysfunction, not caused by medication					
Urinary problems, e.g. unusual urgency or hesitancy					
Trouble with bowel movements					
Fatigue					
Changes in mood or depression considered out of the ordinary					
Total paralysis of legs					
Total paralysis of arms					
Need for mechanical ventilation					
Other:					



Are you currently or have you ever been on any of these therapies to manage your MS or prevent disease activity? **Note: Do not check "Yes" if you have only received the treatment for relapses.**

Therapy	Yes, currently	Yes, in the past	No
EDA annuavad MC disassa mas	difring the area is a	but not now	
FDA-approved MS disease mod	unying therapies) :	
Aubagio (teriflunomide)			
Avonex (interferon beta-1a)			
Betaseron (interferon beta-1b)			
Copaxone (glatiramer acetate)			
Extavia (interferon beta-1b)			
Gilenya (fingolimod)			
Novantrone (mitoxantrone)			
Plegridy (peginterferon beta- 1a)			
Rebif (interferon beta-1a)			
Tecfidera (dimethyl fumarate)			
Tysabri (natalizumab)			
Therapies that suppress/mod	ulate the immun	e system:	
Campath (alemtuzumab)			
CellCept (mycophenolate			
mofetil)			
Cytoxan (cyclophosphamide)			
Imuran (azathioprine)			
Leustatin (cladribine)			
Myfortic (mycophenolate sodium)			
Rituxan (rituximab)			
Trexall (methotrexate) Zenapax (dacliximab,			
daclizumab)			
daciizuiiiabj			
MS relapse treatments that are	also used as dis	sease-modifying t	heranies:
(Do not select therapies that you			_
that you have used on a long-ter			
Acthar (adrenocorticotropic			
hormone)			
Decadron (dexamethasone)			
IVIG (immunoglobulin)			
Methylprednisone			
(methylprednisolone),			
Prednisone, Solu-Medrol			
(methylprednisolone sodium			



succinate)					
Other:					
Low-dose Naltrexone					
Other					