EUROPEAN MULTIPLE SCLEROSIS SURVEY 2005

Questionnaire to be completed by a person with multiple sclerosis (MS) or their carer.

The purpose of this questionnaire is to investigate the cost of care and the quality of life of people with MS in a number of European countries. The research is being conducted by Heron Evidence Development Ltd on behalf of Biogen Idec UK Ltd. We would appreciate your time to answer these questions, as only you are aware of all the health care resources and services that you require, and only you can assess the effect of the disease on your quality of life and daily activities. Your contribution to our research to better understand the personal and financial costs associated with MS is therefore very important.

Please complete the whole European Multiple Sclerosis Survey using a ***black pen*** and return it to us in the reply paid envelope by ***Tuesday 8th March 2005***.

All information in the questionnaire is strictly confidential and anonymous. The information that you provide will be pooled with a large number of other respondents in a database and used to produce a scientific report. Please sign and complete this questionnaire only if you agree to these terms. If you are completing the questionnaire on behalf of a person with MS, please sign on their behalf only if you have their authority to do so.

Consent Statement:

I understand that the data I have provided will remain anonymous and entered into a database held by Biogen Idec and those under contract with Biogen Idec. The data will be analysed with all other data collected. This analysis will be carried out by Biogen Idec and those under contract with Biogen Idec. The data may be held in databases outside the European Union. I understand that if I do not agree to the above then I should NOT return this completed questionnaire.

Date ☐☐ ☐☐ 2005
D D M M

I am a ☐ Person with MS ☐ Carer

signature

When answering the questions, please note that the time period for which we establish costs differs between the different questions. Most questions refer to information regarding the past three months, but some questions, e.g. the questions concerning the use of medication refer to the past month, while others, e.g. major investments, refer to the past year.

Only indicate those expenses and situations that refer directly to your multiple sclerosis. For instance, if you have visited a doctor or taken drugs because of another disease (e.g. a cold), do not include this visit. This is very important.

Please use a black pen and write clearly in the space provided. Please note also that we will be unable to respond to individual queries regarding your health or care and suggest that you contact your doctor with such questions.

Thank you for your contribution.

If your reply paid envelope is mislaid, please send completed survey to:

Personal Data (please put a cross in the appropriate box and write clearly)

Please indicate your year of birth(e.g.19 7 6) 19 ☐☐

Are you? ☐ Male ☐ Female

Are you? ☐ Married ☐ Single

Are you living? ☐ Alone ☐ With Others

What is your highest level of education?
☐ Secondary School ☐ University/Polytechnic
☐ College/Sixth Form ☐ Post-graduate Degree

Employment and Activity Data (please put a cross in the appropriate box and write clearly)

Are you currently in paid work? ☐ Yes ☐ No

If Yes: How many hours per week do you normally work? ☐☐ hours

Did you have to reduce working hours because of your MS, e.g. by changing from full-time to part-time work? ☐ Yes ☐ No

If Yes: Reduced by how many hours per week? ☐☐ hours

Did you have to change the type of work you do because of your MS? ☐ Yes ☐ No

If Yes: Did this change lead to a reduction of income? ☐ Yes ☐ No

If Yes: How much (in %) ? ☐☐☐ %

Did you have to take sick leave during the past 3 months because of your MS? ☐ Yes ☐ No

If Yes: How many days in total in these 3 months? ☐☐☐ days

If you are not currently employed or self-employed:

Are you on permanent sick leave (disability allowance)? ☐ Yes ☐ No

If Yes: Since what year? ☐☐☐☐

Is this due to your MS? ☐ Yes ☐ No

Are you on long-term sick leave (not permanent)? ☐ Yes ☐ No

If Yes: For how many months ? ☐☐☐ months

What is your current activity?
☐ Home maker ☐ Retired
☐ Student ☐ Unemployed

Hospitalisations (please put a cross in the appropriate box and write clearly)

Inpatient admission

Have you been admitted to a hospital during the past 3 months because of your MS? ☐ Yes ☐ No

If Yes: How many times? ____ times

For how many days in total? ____ days

In which hospital wards(s)? Neurology ____ days

Other ____ days

Day admission

Have you been admitted to the hospital for a day, i.e. without spending the night, because of your MS during the past 3 months? ☐ Yes ☐ No

If Yes: How many times? ____ times

To which hospital department? Neurology ____ days

Other ____ days

Rehabilitation and Rest (please put a cross in the appropriate box and write clearly)

Rehabilitation

Have you spent time in a re-habilitation department because of your MS during the past 3 months? ☐ Yes ☐ No

If Yes: How many days as an inpatient? ____ days

How many visits as an outpatient (day visits)? ____ visits

Nursing home

Did you spend time in a nursing home or a similar institution because of your MS during the past 3 months? ☐ Yes ☐ No

If Yes: How many days as an inpatient? ____ days

How many visits as an outpatient (day visits)? ____ visits

Consultations (please put a cross in the appropriate box and write clearly)

Doctors, Specialists

During the past 3 months, did you visit a doctor or a nurse because of your MS? ☐ Yes ☐ No

If Yes: Please indicate whom you have seen and how many times:

	At the hospital or GP surgery	At a private practice
Neurologist	____ times	____ times
Junior doctor	____ times	____ times
Urologist	____ times	____ times
Ophthalmologist	____ times	____ times
Psychiatrist	____ times	____ times
General practitioner	____ times	____ times
Nurse	____ times	____ times

Other health care specialists

During the past 3 months, did you use any other services from health professionals because of your MS? ☐ Yes ☐ No

If Yes: Please indicate which services, the number of sessions during the past 3 months and the amounts that you have spent:

	Number of sessions	Did you pay?	If yes, how much did you pay yourself per session?
Physiotherapist	____ sessions	☐ Yes ☐ No	£ ____
Social worker	____ sessions	☐ Yes ☐ No	£ ____
Occupational therapist	____ sessions	☐ Yes ☐ No	£ ____
Speech therapist	____ sessions	☐ Yes ☐ No	£ ____
Acupuncturist	____ sessions	☐ Yes ☐ No	£ ____
Chiropractor / Osteopath	____ sessions	☐ Yes ☐ No	£ ____
Counsellor / Psychologist	____ sessions	☐ Yes ☐ No	£ ____
Chiropodist	____ sessions	☐ Yes ☐ No	£ ____
Reflexologist	____ sessions	☐ Yes ☐ No	£ ____

Investigations, Tests (please put a cross in the appropriate box and write clearly)

During the past 3 months, did you undergo special investigations or tests due to your MS? ☐ Yes ☐ No

If Yes: Please indicate which tests:

MRI (brain)	☐ Yes
MRI (spine)	☐ Yes
CT scan	☐ Yes
Lumbar puncture	☐ Yes
Evoked potential	☐ Yes
Ultrasound	☐ Yes
Electrocardiogram (ECG)	☐ Yes
Blood test	☐ ☐ times

Medication (please put a cross in the appropriate box and write clearly)

MS Drugs

During the past month, did you use a specific MS treatment? ☐ Yes ☐ No

If Yes: Please indicate which one(s):

Aimspro (Goat serum)	☐ Yes
Avonex (Interferon β-1a)	☐ Yes
Betaferon (Interferon β-1b)	☐ Yes
Copaxone (Glatiramer)	☐ Yes
Imuran (Azathioprine)	☐ Yes
Intravenous immunoglobulin (IVIG)	☐ Yes
Intravenous steroid treatment	☐ Yes
Methotrexate	☐ Yes
Novantrone (Mitoxantrone)	☐ Yes
Rebif 22 (Interferon β-1a 22 µg)	☐ Yes
Rebif 44 (Interferon β-1a 44 µg)	☐ Yes

Other Prescription Drugs (please put a cross in the appropriate box and write clearly)

During the past month, did your doctor prescribe any other drugs in relation to your MS? ☐ Yes ☐ No

If Yes: Please indicate the number of days you were taking each drug them during the past month:

Drugs	Number of days during 1 month		Drugs	Number of days during 1 month	
Baclofen (eg Lioresal)		days	Amantadine (eg Symmetrel)		days
Clonazepam (eg Rivotril)		days	Methylphenidate (eg Ritalin)		days
Dantrolene (eg Dantrium)		days	Modafinil (eg Provigil)		days
Diazepam (eg Valium)		days	Prochlorperazine (eg Stemetil)		days
Gabapentin (eg Neurontin)		days	Bisacodyl (eg Dulco-lax)		days
Tizanidine (eg Zanaflex)		days	Docusate (eg Docusol)		days
Amitriptyline (eg Elavil)		days	Glycerol		days
Citalopram (eg Cipramil)		days	Ispaghula husk (eg Fybogel)		days
Escitalopram (eg Cipralex)		days	Lactulose		days
Fluoxetine (eg Prozac)		days	Milk of Magnesia		days
Fluvoxamine (eg Faverin)		days	Nitrofurantoin (eg Furadantin)		days
Imipramine (eg Tofranil)		days	Oxybutynin (eg Ditropan)		days
Mianserin (eg Bolvidon)		days	Senna (eg Senokot)		days
Mirtazapine (eg Zispin)		days	Sildenafil (eg Viagra)		days
Nortriptyline (eg Allegron)		days	Tolterodine (eg Detrusitol)		days
Paroxetine (eg Seroxat)		days	Botulinum toxin A (eg Botox)		days
Sertaline (eg Lustral)		days	Carbamazepine (eg Tegretol)		days
Venlafaxine (eg Efexor)		days	Phenytoin (eg Epanutin)		days

Non-Prescription Drugs

During the past month, did you buy any non-prescription medicines (for example vitamins, pain killers, homeopathic medicines, etc) for your MS? ☐ Yes ☐ No

If Yes: Please indicate approximately how much you spent on such drugs during the past month: £

Aids and Appliances (please put a cross in the appropriate box and write clearly)

During the past year (12 months) have you made changes to your house, flat or car, or required any special equipment or aids because of your MS? ☐ Yes ☐ No

If Yes: Please indicate for each of the items what the total cost was, and how much you had to pay yourself:

	Total cost	How much did you pay yourself?
Stair lift, elevator	£	£
Bed lift, ramps, rails	£	£
Other modifications to your house/apartment (kitchen, bathroom, bedroom, alarm, etc)	£	£
Walking aids (sticks, walking frame, etc)	£	£
Wheelchair	£	£
Electric wheelchair, scooter	£	£
Modifications to your car	£	£
Special utensils and devices (for writing, cooking, personal hygiene, getting dressed, etc)	£	£
Special glasses (e.g. prisms)	£	£

Assistance (please put a cross in the appropriate box and write clearly)

Community and Social Services

During the past month, did you require assistance because of your MS? ☐ Yes ☐ No

If Yes: Please indicate what type of help and how much (if any) you had to pay yourself during the past month:

	Hours per day on average	Number of days in the past month	Did the NHS pay?	How much did you pay yourself in the past month?
Nurse (home visits)	hours	days	☐ Yes ☐ No	£
Social care worker	hours	days	☐ Yes ☐ No	£
Transportation	average miles per trip	number of trips per month	☐ Yes ☐ No	£

During the past month, were there days when you required help from a member of your family or friends to perform your usual activities because of your MS? ☐ Yes ☐ No

If Yes: For how many days in the past month? days

On average for how many hours per day? hours

Your own health state today

By placing a tick in one box in each group below, please indicate which statement best decribes your own health state today.

Do not tick more than one box in each group.

Mobility

I have no problems in walking about ☐

I have some problems in walking about ☐

I am confined to bed ☐

Self-Care

I have no problems with self-care ☐

I have some problems with washing and dressing myself ☐

I am unable to wash or dress myself ☐

Usual Activities
(e.g. work, study, housework, family or leisure activities)

I have no problems with performing my usual activities ☐

I have some problems with performing my usual activities ☐

I am unable to perform my usual activities ☐

Pain/Discomfort

I have no pain or discomfort ☐

I have moderate pain or discomfort ☐

I have extreme pain or discomfort ☐

Anxiety/Depression

I am not anxious or depressed ☐

I am moderately anxious or depressed ☐

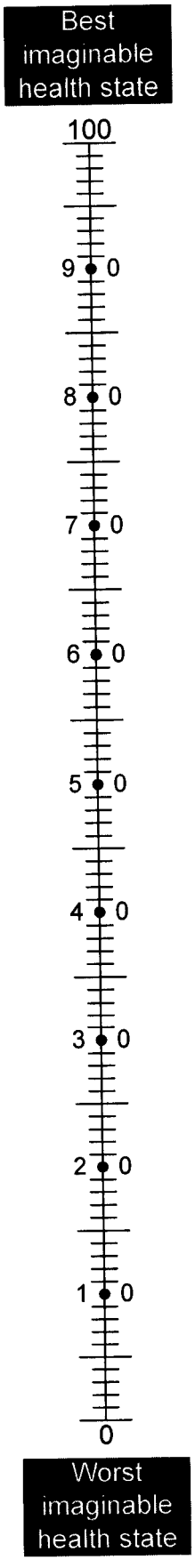
I am extremely anxious or depressed ☐

Your own health state today

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked at 0.

We would like you to indicate on this scale how good or bad your health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is.

Your own health state today



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Fatigue (please put a cross in the box that corresponds best to your current situation)

On a scale of 0 to 10, how do you judge your fatigue during the past 48 hours?

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Not at all tired — Extremely tired

Questions about your MS (please put a cross in the appropriate box and write clearly)

In which year were you diagnosed with MS? ☐☐☐☐

In retrospect, how old were you when you first experienced symptoms that you believe were due to MS? Age ☐☐

What type of MS do you currently have?

Please read the description and select the one that is closest to your current status:	(Please cross only one)
Relapsing-remitting MS Relapses happen from time to time, with new symptoms, but recovery after the relapse is almost complete. Between the relapses, the condition is stable.	☐ Yes
Secondary progressive MS After initial relapsing/remitting disease, the disease causes increasing limitations and physical disabilities, both during a relapse and between relapses.	☐ Yes
Primary progressive MS Relapses were infrequent or not at all from the beginning and symptoms have slowly and steadily increased without clear attacks.	☐ Yes
Not known.	☐ Yes

Did you experience any relapses (see note below) during the past 3 months? ☐ Yes ☐ No ☐ Unsure

A relapse or an exacerbation of MS is defined as the development of new symptoms or worsening of old symptoms that last longer then 48 hours. In a relapse/exacerbation, MS symptoms generally worsen over a period of a few days to several weeks. Symptoms then disappear partially or completely for several weeks, months or years. During a relapse/ exacerbation, several different symptoms can get worse at the same time.

(For our purposes here (to be called a relapse / exacerbation), the change in symptoms cannot be due to heat or illness (e.g. flu, cold, urinary tract infection, etc).

If Yes: How many relapses during the past 3 months? ☐☐

How many of these happened during the past month? ☐☐

How would you describe the severity of your disease <u>at the moment</u>?

Please read the choices listed below and choose the one that best describes your own situation. These choices focus mainly on how well you currently walk. Not everyone will find a description that reflects their condition exactly, but please mark the <u>one</u> category that most closely describes your situation. (Please select only <u>one</u>).

I have no problems and no limitations	☐ 0
I may have some mild symptoms, mostly sensory due to MS but they do not limit my activity. If I do have an attack, I return to normal when the attack has passed.	☐ 1
I have some noticeable symptoms from my MS (e.g. some muscle weakness, slight difficulties in walking, slight visual disturbances) but they are minor and have only a small effect on my lifestyle.	☐ 2
I have symptoms as described above, but I don't have any limitations in my walking ability. However, I do have significant problems due to MS that limit daily activities in other ways.	☐ 3
MS does interfere with my activities, especially my walking. I am able to walk for at least 300-500 metres without help or rest, and I can work a full day, but athletic or physically demanding activities are more difficult than they used to be. I usually don't need a stick or other assistance to walk, but I might need some assistance during an attack.	☐ 4
I can walk 100-200 metres without help or rest, but often use a stick or some other form of support (such as touching a wall or leaning on someone's arm), especially when walking outside. I always need some assistance (stick or crutch) when walking more than 200 metres. Many of my daily activities are limited, and I may need assistance.	☐ 5
I need a stick or a single crutch, or someone to hold onto, to walk up to 100 metres. I can get around the house or other building by holding onto furniture or walls for support. I may use a wheelchair for longer distances. My activities are limited.	☐ 6
To be able to walk as far as 20 metres I must have 2 canes/crutches or a walker. I may use a wheelchair or scooter for longer distances.	☐ 7
My main form of mobility is a wheelchair, and I am able to move with the chair without help. I may be able to stand and/or take one or two steps, but I can't walk 10 metres, even with crutches or a walker.	☐ 8
I am restricted to a bed or a chair. My main form of mobility is a wheelchair, but I need help to move with the chair.	☐ 9
I am bedridden and unable to sit in a wheelchair for more than one hour.	☐ 10