Survey: GBS-CIDP Survey

GBS/CIDP Survey Information

If you suffer from or have had Guillain-Barré Syndrome (GBS) or Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) or other related disorders, please spend 10 minutes filling in this survey to help others!

I am an individual who suffers from CIDP, which has taken over my life. It took around 3-4 months for CIDP to be diagnosed during which time the information available was vague/non-existent and the diagnosis variable (depending on who you see and where you live?). If I could have been diagnosed earlier, my symptoms would not have been so bad, so I have created this survey to try and get more information on GBS/CIDP, how it effects people, what works and how people are coping. This information I will collate and publish via a web site for all to see.

This is an independent survey into GBS/CIDP, I am not a doctor or consultant or affiliated to any GBS/CIDP support groups, I will not use this information other than for this survey and have no axe to grind, just someone who wants more information to assist others. I have paid for this survey so the information gathered is mine and I will NOT use it for any profit.

This GBS/CIDP survey is intended to be available for about 1 year. The survey will commence from, the middle of March 2012. I will start collating results around 3 months later and will publish the results page via my blog: mycidp.blogspot.com (hopefully around July/August 2012 the first results will be available - provided enough valid information is gathered)

I hope to get the OK of various support groups to publicise it as and independent survey, by them putting a link to this page into their newsletters/forums. As I would like as many details/answers as possible, if not I'll have to try myself. Please if you feel able, pass the details onto anyone else you know with these conditions.

Here is a link to my blog: http://mycidp.blogspot.com

It should take no more than 10 minutes to complete the GBS/CIDP survey. The results are important to me and hopefully will be of benefit to others. There are no mandatory questions - please be as complete as you can.

The default question is a single answer (Radio Button), text by the side of the question (or answer) denotes multiples/text.

If you have any questions, please put a comment on my blog or fill in the comment box at the end of the survey.

Thank you very much for your time and support. Please start with the survey now by, ticking "I Agree" and clicking on the Continue button below. If you do not wish to participate, then close this window. Thank you for your interest

☐ **I Agree**

General Information

What is your age?

-- Select --

What is your gender?

- ○ Male
- ○ Female

Country of Residence?

-- Select --

Region/State/County?

(free text)

How Fit were You?

○ Active ○ Fairly Active ○ Fairly Passive ○ Passive

Diagnosis Information

Date Issues First Noticed?

Month Day Year

-- -- --

Date of Correct Diagnosis?

Month Day Year

-- -- --

What Illness was Diagnosed?

- ○ GBS
- ○ CIDP

○ Other

What other Illnesses were Considered/Diagnosed - Prior to GBS/CIDP?

(free text - please separate answers with a comma)

How many Doctors/Consultants were Seen?

○ One ○ Two ○ Three ○ Four ○ Five ○ Six ○ More Than Six

Have you any Idea how you Got the Illness?

○ Don't Know ○ Flu/Virus ○ Vaccination ○ Blood Infusion ○ Other

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What Other illnesses do you Currently suffer From?

(free text, please separate answers with a comma)

Which Parts of the Body were Affected?

	No Feeling	Minimal Feeling	Some Feeling	Reasonable Feeling	Not Affected
Fingers	○	○	○	○	○
Hands	○	○	○	○	○
Wrist	○	○	○	○	○
Lower Arms	○	○	○	○	○
Upper Arms	○	○	○	○	○
Head	○	○	○	○	○
Neck	○	○	○	○	○
Chest	○	○	○	○	○
Stomach	○	○	○	○	○
Back	○	○	○	○	○
Upper Legs	○	○	○	○	○
Lower Legs	○	○	○	○	○
Ankles	○	○	○	○	○

Feet	○	○	○	○	○
Toes	○	○	○	○	○

Where did it Start? (select All that apply)

- ☐ Fingers
- ☐ Hands
- ☐ Wrists
- ☐ Lower Arms
- ☐ Upper Arms
- ☐ Head
- ☐ Neck
- ☐ Chest
- ☐ Stomach
- ☐ Back
- ☐ Upper Legs
- ☐ Lower Legs
- ☐ Ankle
- ☐ Feet
- ☐ Toes

How Did it Spread?

○ Inwards (towards the centre) ○ Outwards (away from the centre) ○ Random ○ Did Not ○ Other

Were the Symptoms more or less Symmetrical?

- ○ Yes
- ○ No

Which Side is Worse?

- ○ Left
- ○ Right
- ○ Other

Treatment Information

What Treatments were Recommended? (select All that apply)

☐ IVIG ☐ Steroids ☐ Plasma ☐ Immuno-Suppressants ☐ Other

What Treatments Worked? (select All that apply)

	IVIG	Steroids	Plasma	Immuno-Suppressants	Other
Major Difference	☐	☐	☐	☐	☐
Some Difference	☐	☐	☐	☐	☐

Minor Difference	☐	☐	☐	☐	☐
No Difference	☐	☐	☐	☐	☐

What Treatments are you now On? (select All that apply)

☐ IVIG ☐ Steroids ☐ Plasma ☐ Immuno-Suppressants ☐ None ☐ Other

How Often are you having the Treatments?

○ Daily ○ Every Other Day ○ Weekly ○ Fortnightly ○ Monthly ○ Other

Did/Do you have any Physical treatments? (select All that apply)

☐ Physiotherapy ☐ Hydrotherapy ☐ Exercise Program ☐ None ☐ Other

After Care Information

How is it affecting your Life Now?

○ I can Run
○ I can Walk Unaided
○ I can Walk with Assistance
○ I use a Cane/Stick
○ I use a Frame/Walker
○ I use a Wheelchair
○ I am Bed Bound
○ Other

Do you need External Care - Others to Look After You?

○ Yes
○ No

How Much Extra Care is Required?

○ For Everything ○ Cooking Meals ○ Mobility ○ Other

Do you have any Nerve Pain?

○ Yes - Severe
○ Yes - Mild
○ No

Where Do you Have Nerve Pain? (select All that apply)

- ☐ Fingers
- ☐ Hands
- ☐ Wrist
- ☐ Lower Arms
- ☐ Upper Arms
- ☐ Head
- ☐ Neck
- ☐ Chest
- ☐ Stomach
- ☐ Back
- ☐ Upper Legs
- ☐ Lower Legs
- ☐ Ankles
- ☐ Feet
- ☐ Toes

When do you have Nerve Pain? (select All that apply)

- ☐ Morning
- ☐ Afternoon
- ☐ Evening
- ☐ Night
- ☐ All The Time
- ☐ Other

Do/Did you Suffer from Fatigue

- ○ Yes - Severe
- ○ Yes - Some
- ○ Yes - A Little
- ○ No

Are you able to Return to Work?

- ○ Yes - Fully
- ○ Yes - Limited
- ○ No

How Healthy are you Compared to Before?

- ○ 10%
- ○ 20%
- ○ 30%
- ○ 40%
- ○ 50%
- ○ 60%
- ○ 70%
- ○ 80%
- ○ 90%
- ○ 100%

Comments/Further Information?

(free text)