PART 4 FOLLOW UP 6,12, 24, 36M ETC.

This part of the database will look at how arachnoiditis affects people over time to give us a clearer picture of the natural history of the condition.

Section 1

Do you think your condition is progressive? Yes/No

What is the pattern of your condition?

1. Constant
2. Fluctuating
3. Plateau
4. Deteriorating

Section 2

The next 10 questions are specifically about pain. We are looking at pain over the past week or so.

1. What is the average level of your pain on a scale of 1-10, 0= no pain, 10= worst pain imaginable?

2. what is the worst level of pain you have had in the past week?

3. where is your pain (include as many as you need to): (a) back (b) neck (c) head (d) limbs (e) chest (f) abdomen (g) pelvis

4. what type of pain is it (include all relevant descriptions) : (a) sharp (b) stabbing (c) burning / hot+cold together (d) aching (e) other (please specify)

5. do you have (a) pins & needles (b) numbness (c) pain in a numb area (d) pain with light touch (e) odd sensations e.g. insect bites, electric shock (f) muscle cramps? (include all relevant)

6. do you have any of the following associated with your pain: (a) shortness of breath (b) palpitations (c) less/more awareness of bladder sensation (d) sensitivity to light/ noise/ startle easily (e) anxiety/panic (f) sweating (g) weakness?

7. do you have fatigue? If so, on a scale of 1-10 (0=no fatigue, 10= worst you could imagine) what level do you experience?

8. does sleep affect your sleep? If so, do you have (a) difficulty falling asleep, (b) wake because of pain (c) wake early in the morning? (include all that apply to you)

9. does pain limit what you can do (activities) E.g. (a) sitting (b) standing (c) walking (d) lifting (e) bending? Are you wheelchair or bedbound?

10. does pain make you (a) irritable (b) tearful (c) depressed (d) anxious (e) have difficulty concentrating (f) have memory difficulties?

Section 3

Here are some questions about other symptoms that may be related to arachnoiditis:

1) bladder dysfunction (needing to go urgently, inability to initiate passing water, incomplete emptying, incontinence)
2) bowel dysfunction: incontinence, loss of rectal sensation
3) sexual dysfunction
4) muscle spasms/cramps
5) weakness/paralysis
6) balance problems
7) excessive sweating
8) other (please specify)

Section 4

The next questions are about other general health problems.Please answer Yes or No. If you answer Y (yes) to a question, please put some brief details, including how long you have had the problem.

1. do you have any difficulty breathing?
2. do you have any heart problems?
3. do you have any bowel problems, e.g constipation or indigestion?
4. do you have any liver disease?
5. do you have any kidney disease?
6. do you have any joint problems?
7. do you have any endocrine disease e.g. diabetes, thyroid?
8. do you have any skin problems? In particular do you have psoriasis/eczema?
9. do you have any hearing or sight problems?
10. do you have any problem with chronic infections/immune deficiency?
11. do you have cancer?
12. if you are a woman, have you had any gynae problems such as irregular periods?
13. do you have any psychiatric or emotional problems?

Section 5

Have you any other illnesses?

Note degenerative spinal disorders including stenosis are not specified on this list:

1. Osteoarthritis
2. Fibromyalgia
3. Chronic fatigue syndrome
4. Depression
5. Diabetes
6. autoimmune condition: Lupus, Rheumatoid etc.
7. Thyroid disorder
8. Cancer
9. Cardiac incl. Hypertension
10. Respiratory
11. Genitourinary
12. Gastrointestinal
13. Skin
14. eye
15. gynaecology
16. haematology
17. complication: syrinx/hydrocephalus
18. neurology e.g. stroke, neuropathy, headache, Multiple Sclerosis, Chiari
19. Cauda equina syndrome
20. Failed Back Surgery Syndrome
21. Other

Section 6

These are some questions on your current treatment.

For each, please indicate how long you have been having this treatment and whether it is effective in (a) reducing pain and (b) improving function (allowing you to do more).

Are you taking any of the following:

1. paracetamol/acetaminophen; aspirin
2. anti-inflammatories
3. morphine-related medication including codeine, cocodamol, morphine, tramadol etc.
4. antidepressants such as amitriptyline, fluoxetine etc. (please indicate dose) FOR PAIN
5. anticonvulsants such as gabapentin, pregabalin (Lyrica) , lamotrigine etc.
6. muscle relaxants such as diazepam, clonazepam, baclofen
7. treatment for bladder problems
8. other including treatment of constipation, sleeping tablets (please list all) related to arachoiditis problems
9. antidepressants for depression/anxiety
10. other : for unrelated conditions e.g. hypertension

Other treatments:

1. herbal/homoeopathic
2. vitamins/supplements including cod liver oil etc.
3. acupuncture
4. TENS
5. Physiotherapy
6. Hydrotherapy
7. Epidural steroid injection/ facet joint injection (please indicate number)
8. surgery
9. intraspinal pump
10. spinal cord stimulator

Section 7

Side effects:

Please indicate if you have any of the following side effects and which medication you think is causing the problem:

1. constipation
2. nausea
3. dry mouth
4. indigestion/ ulcers
5. skin rash
6. sleepiness/fatigue
7. poor concentration/memory

8. loss of balance/falls
9. tremor
10. addiction
11. Other (please specify)

Do you need to take additional medicines to counter these side effects?

Have you had any allergic reaction to medication?

AGAIN, MANY THANKS FOR YOUR TIME!