Home of the Lincolnshire Post-Polio Library

Polio Survivors Network

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Registered Charity No. 1064177

21st October 2011

Dear Recipient,

Polio Survivors Network Members Survey October 2011.

Attached is a copy of our Survey which is being distributed as widely around the country as it is possible for us and already we have had some very positive responses in particular from researchers who wish to work with us.

By distributing the data that has arisen in the survey we hope to stimulate discussions and research in to some of the issues that the polio survivors are coping with on a daily basis.

I would like to finish by saying if you know of any person who you think would be interested in our survey perhaps you could either pass it on or provide an email address for electronic delivery or name /address so we can send a copy.

We are always interested as to who has had a copy to update our list so if we could be kept informed it would be useful.

We would be interested in hearing any comments you may have.

Yours faithfully,

Secretary and Newsletter Editor

Polio Survivors Network
Survey of Members

Please answer all questions that are relevant to you. Tick or write as appropriate
Please do not identify yourself.

I am a Polio Survivor ..... Male .... Female ..... Age .....

I am a carer of a Polio Survivor ..... Male..... Female ..... Age .....

1. Do you live alone ... or with a partner/spouse ..... friend ....

2. Age when you or the person you care for had Polio ..... in .....
(please state which year)

3. What type of polio did you or the person you care for have? paralytic .... non-paralytic ....

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4. Have you or the person you care for received a diagnosis of post polio syndrome?

Yes ..... No.....

5. What were the first symptoms you or the person you care for reported?.....
.....
.....
.....
.....

6. Did you discuss these symptoms with your GP? Yes .... No....

If yes, what advice were you given?.....
.....
.....

7. Do you think your GP has a good understanding of Post Polio Syndrome Yes... No....

8. How long did it take from first symptoms to diagnosis?

.... months ..... years don't know ....

9. Who gave you the diagnosis?

GP..... Neurologist ..... Respiratory Consultant ..... Other.....

10, When you or the person you care for was first diagnosed was a full assessment of health needs done?

Yes .... No ..... Not sure ....

11. If yes who did the assessment? .....

12. What happened?.....
.....
.....

Medical Support

13. Do you or the person you care for see any or all of the following on a regular basis, for example, once a year? (please tick as many as necessary).

	12 months	6 months	Other	Never see
Consultant Neuroulogist	.....	.....	.....	.....
Physiotherapist	.....	.....	.....	.....
Speech & Languaage Therapists	.....	.....	.....	.....
Psychologist/Counsellor	.....	.....	.....	.....
Other	.....	.....	.....	.....

(please state)

If you have answered Yes to any of the above: what are your experiences at consultation?.....

.....

.....

.....

14. Do you think any of the professionals above have a good understanding of Post Polio Syndrome?

Yes.... No... Not sure.....

15. If you or the person you care for has answered No to any of the above. have you asked to be seen by any of the above for your symptoms? Yes.... No....

16. Were you seen? Yes.... No....

If No what reason was given?.....

.....

If Yes were you or the person you care for satisfied with the outcome Yes.... No....

If No, why not.....

.....

17. Were you or the person you care for in an iron lung Yes.. No....

If yes how long for ..... years months .....

18. Do you or the person you care for have respiratory/breathing problems now?

Yes... No....

If yes how long for? .....years months .....

what treatment/therapy do you receive?.....

.....

.....

19. Do you or the person you care for use a ventilator? Yes... No....

If yes: night time only ..... day time only ..... all the time .... days per week .....

Bi-level .... cpap ....

20 How often do you see any of the following:

	12 months	6 months	Other	Never see
Respiratory Consultant	.....	.....	.....	.....
Respiratory Nurse	.....	.....	.....	.....
Respiratory Team	.....	.....	.....	.....

21. Are you satisfied with the support you receive with regard to your ventilation needs?

Yes..... No...

If no what are your resaons?.....

.....

.....

Information provision:

22. When you or the person you care for was first diagnosed were you given any information about Post Polio Syndrome?

Yes ... No ... Not sure.....

If yes, Who gave you the information? Doctor .... Nurse ....

Other (please explain).....

.....

.....

23. Would you have liked more information at diagnossis Yes..... No..... or Later .....

If later, how much later? .....

24. How was the information given? Verbally.... In writing ... Not sure....

25. Did you ask for some information but not given any? Yes .... No .... Not sure.....

26. Were you referred to a website Yes .... No.... Not sure .....

If yes which website.....

27. Were you referred to a patient organisation/support group? Yes .... No.... Not sure ....

If yes which .....

28. What other sources of information are available to you ?

.....

.....

29. If you need information in a particular format, e.g. large print, braille, CD,

Have you asked for information to meet your requirements? Yes.... No....

Was it provided? Yes.... No...

If No what was the reason given?.....

.....

Respite care and Neuro-rehabilitation

30. Have you or the person you care for received respite care? Yes.... No...

31. Do you or the person you care for need respite care?

Yes..... No...

32. If you or the person you care for receives respite care, do you think it helps to improve the quality of your life?

Yes.... No...

33. Have you or the person you care for received neuro-rehabilitation? Yes... No..

If yes, was it in-patient rehabilitation ..... or .... community rehabilitation ....

What happened? .....

.....

34.Were you satisfied with the outcome Yes.... No....

35.Do you think the staff understood your needs? Yes.... No... Not sure.....

Mobility

36. Do you or the person you care for use a wheelchair ? Yes... No....

If Yes: what type of chair ? electric ..... manual .....

is it provided through the local Wheelchair Service Yes... No....

is the service easy to contact Yes.... No....

are repairs done to a good standard Yes.... No....

do you think the staff understand your needs Yes.... no....

If Not provided by your local wheelchair service who provides it

.....

37. What other experiences, good or bad, of your Wheelchair Service do you have?

.....

.....

.....

.....

38.Do you or the person you care for need either an electric or manual wheelchair but been refused by the NHS

Yes... No....

If yes, what reason was given?.....

.....

39. Did you buy your own? Yes.... No....

40. Do you use a scooter Yes.....No...

41. Can you use public transport Yes.... No....

If No what are your difficulties.....

.....

.....

42. Do you have a “disability friendly” taxi service in your area Yes.... No.....

42. Do you use orthotics/calipers/walking aides, hand/arm aides etc? Yes... No.....

If yes, what do you use?.....

.....

.....

If Yes: is this supplied through your local orthotics service? Yes... No...

is the service easy to contact Yes.... No....

are repairs done to a good standard Yes.... No...

do you think the staff understand your needs Yes.... No...

43. What other experiences, good or bad, of your Orthotics Service do you have?

.....

.....

.....

44. Do you or the person you care for need a particular type of orthotic but been refused Yes... No....

If yes, what reason was given and what do you need?.....

.....

.....

.....

45. Did you buy your own? Yes.... No....

Employment

Are you currently working? Yes... No....

Have you had to stop working or reduce your working hours due to Post Polio Syndrome or because you care for someone with Post Polio Syndrome?

Yes... No....

Equipment

46. Do you or the person you care for need any equipment at home? Yes... No ....

If yes, what do you need.....

.....

.....

47. Have you received an assessment of what equipment you need? Yes.... No....

If yes, who did the assessment?

Adult Social Care ..... Community Occupational Therapy ..... Other .....

48. Where did the assessment take place ? .....

Please describe what happened.....

.....

.....

49. Do you think the person doing the assessment understood your needs? Yes... No....

50. How long after the assessment did you wait for the equipment to arrive?

weeks ..... months..... Years.....

51. Did you get what you needed? Yes.... No....

If No, what reason was given?.....

.....

.....

.....

Other medical conditions

53. Have you been diagnosed with any other medical condition, e.g., diabetes, asthmas, cardiovascular, etc.

Yes.... No....

If yes, what is the condition?.....

.....

.....

Complementary Therapies

54. Do you use a complementary therapy? Yes.... No....

If yes what do you use?.....

.....

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Thank you for your help and please return to

Polio Survivors Network in the envelope provided

Anecdotal Evidence

(optional)

This page is for additional information to any of your answers. If you wish to do so just put the number of the question and write whatever you think would be useful for us to know. This page can also be used for any other issues you think we should know about.

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