



**Post Polio Support Society  
of New Zealand (Inc)**

[www.postpolio.org.nz](http://www.postpolio.org.nz)



**REPORT ON  
POST POLIO SUPPORT SOCIETY OF  
NEW ZEALAND QUESTIONNAIRE  
2009/2010**

**Data and statistics compiled by  
SUSAN KERR AND ANNE MACE**



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<b>NUMBER OF QUESTIONNAIRES COMPLETED ON EXTRACTION OF DATA</b>	<b>388</b>
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<b>PERSONAL DETAILS</b>		<b>Percentage</b>
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<b>Ethnicity</b>	European - NZ Pakeha	<b>345</b>	<b>89%</b>
	Maori	<b>6</b>	<b>2%</b>
<b>Internet Access</b>		<b>175</b>	<b>45%</b>

<b>1. PERSONAL POLIO DATA</b>
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<b>Average Age 2009</b>	<b>71</b>
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	<b>Age</b>	<b>Number</b>	<b>Percentage</b>
<b>Age had polio</b>	0	19	<b>5%</b>
	1	31	<b>8%</b>
	2	24	<b>6%</b>
	3	23	<b>6%</b>
	4	29	<b>7%</b>
	5	20	<b>5%</b>
	6	26	<b>7%</b>
	7	20	<b>5%</b>
	8	17	<b>4%</b>
	9	20	<b>5%</b>
	10	16	<b>4%</b>
	11	14	<b>4%</b>
	12	10	<b>3%</b>
	13	11	<b>3%</b>
	14	12	<b>3%</b>
	15	4	<b>1%</b>
	16	7	<b>2%</b>
	17	9	<b>2%</b>
	18	7	<b>2%</b>
	19	4	<b>1%</b>
	20	5	<b>1%</b>
	21	3	<b>1%</b>
	22	9	<b>2%</b>
	23	6	<b>2%</b>
	24	6	<b>2%</b>
	25	6	<b>2%</b>
	26	3	<b>1%</b>
	27	6	<b>2%</b>
	28	3	<b>1%</b>
	29	29	<b>7%</b>
	30-39	8	<b>2%</b>
	53	1	<b>0%</b>
Polio Age not given		3	
<b>Average Age Polio</b>		<b>10</b>	

<b>Year Polio</b>	<b>Year</b>	<b>Numbers</b>	<b>Percentage</b>
	1919	1	0%
	1920	2	1%
	1923	1	0%
	1924	2	1%
	1925	5	1%
	1926	2	1%
	1927	2	1%
	1928	1	0%
	1929	1	0%
	1930	3	1%
	1932	4	1%
	1933	6	2%
	1934	2	1%
	1935	4	1%
	1936	18	5%
	1937	*32	8%
	1938	1	0%
	1939	7	2%
	1941	7	2%
	1942	10	3%
	1943	8	2%
	1944	3	1%
	1945	9	2%
	1946	11	3%
	1947	17	4%
	1948	*40	10%
	1949	18	5%
	1950	12	3%
	1951	6	2%
	1952	*40	10%
	1953	13	3%
	1954	9	2%
	1955	31	8%
	1956	*40	10%
	1957	5	1%
	1958	6	2%
	1959	3	1%
	1960	2	1%
	1961	1	0%
	1962	2	1%

**Note: These figures include people from outside NZ who are now resident.**

**\* Peak years within our survey.**

Country where those surveyed contracted Polio	Out of 388	Percentage <sup>1</sup>
New Zealand	333	86%
UK	30	8%
Australia	6	2%
South Africa	4	1%
Canada	2	1%
India	2	1%
Ireland	2	1%
Ukraine	1	0%
USA	1	0%
Pacific Ocean	1	0%
Papua New Guinea	1	0%
Egypt	1	0%
Ceylon	1	0%
Chile	1	0%
Germany	1	0%
Kenya	1	0%

		Out of 388	Percentage
Hospitalised		297	77%
Average of Months Hospitalised	Out of 266	8	
In an iron lung*		29	7%
Considered for Iron Lung		43	11%
Not hospitalised; Kept at Home		36	9%
Average of months at home above	Out of 36	6	

\* No-one as far as we know remained in an Iron Lung at best recovery, or returned to one later.

<sup>1</sup> Percentages do not make much sense with these figures where only one person is involved.

## 2. ABOUT YOUR POLIO ILLNESS

		<b>Out of 388</b>	<b>Percentage</b>
<b>Bulbar Polio</b>		52	<b>13%</b>
<b>Too sick to remember first weeks</b>		170 <sup>1</sup>	<b>44%</b>
<b>Kept still for months</b>		104 <sup>2</sup>	<b>27%</b>
<b>Immobilised for years</b>		32	<b>8%</b>
<b>Had Kenny Hot Packs</b>		153	<b>39%</b>
<b>Regular Physio treatment after Polio</b>		248	<b>64%</b>
<b>Hydrotherapy</b>		175	<b>45%</b>
<b>Return to Outpatient treatment years</b>		154	<b>40%</b>
<b>No treatment for Polio</b>		63	<b>16%</b>
<b>Others in family had Polio</b>		61	<b>16%</b>
<b>Surgery to stop leg growing</b>		14	<b>4%</b>
<b>Radiation to stop leg growing</b>		1	<b>0%</b>
<b>Polio-related Surgery</b>		Most	

<sup>1</sup> This is not an accurate figure. Some were too sick and some too young and this does not accurately reflect the difference.

<sup>2</sup> There may be some confusion between *being still* and *kept still*.

**3. PARTS OF BODY AFFECTED DURING POLIO AND PRESENT PROBLEMS**

All figures out of 388

Face at sickest			At best		Now	
NM 14	W 16		NM 1	W 10	NM 1	W 17
Neck at sickest			At best		Now	
NM 43	W 37		NM 1	W 30	NM 2	W 30
Right Arm sickest			At best		Now	
NM 61	W 61		NM 3	W 68	NM 2	W 113
Left Arm sickest			At best		Now	
NM 56	W 63		NM 1	W 62	NM 3	W 103
Breathing			At best		Now	
Iron Lung 29	W 42		NM 0	W 25	NM 0	W 60
Abdomen at sickest			At best		Now	
NM 39	W 37		NM 2	W 34	NM 1	W 64
Back at sickest			At best		Now	
NM 78	W 69		NM 3	W 76	NM 5	W 139
Right Leg at sickest			At best		Now	
NM 121	W 85		NM 17	W 105	NM 18	W 176
Left Leg at sickest			At best		Now	
NM 138	W 88		NM 21	W 107	NM 23	W 181

- NM = NO MOVEMENT and W = WEAK
- Those surveyed seemed to find this the most difficult to fill in.
- Some ignored at best.
- Some could not remember their condition during polio and could not fill that in.
- It must be remembered that people were usually affected in more than one body part.
- In paralytic polio it seems to be true that the whole body was affected in the initial stages.
- Many of those surveyed still had residual weakness at their best.
- The total of those with no movement now and weakness in an affected part, is often akin to the total of no movement and weakness during polio, except that there is more weakness than no movement in each case now.
- In the case of limbs, legs were affected more than arms.

<b>4. BODY CHART (Analysis difficult)</b>		<b>out of 388</b>	<b>Percentage</b>
<b>Body chart filled out</b>		<b>315</b>	<b>81%</b>

<b>5. PRESENT MOBILITY AND AIDS</b>		<b>out of 388</b>	<b>Percentage</b>
<b>Can Walk<sup>1</sup></b>		<b>303</b>	<b>78%</b>
<b>Special Shoes</b>		<b>79</b>	<b>20%</b>
<b>In-shoe orthosis</b>		<b>92</b>	<b>24%</b>
<b>Walking Stick(s)</b>		<b>129</b>	<b>33%</b>
<b>Walking Frame</b>		<b>64</b>	<b>16%</b>
<b>Crutches</b>		<b>46</b>	<b>12%</b>
<b>Calliper(s) half</b>		<b>20</b>	<b>5%</b>
<b>Calliper(s) full</b>		<b>28</b>	<b>7%</b>
<b>Knee brace/bandage</b>		<b>34</b>	<b>9%</b>
<b>Corset (surgical)</b>		<b>11</b>	<b>3%</b>
<b>Manual Wheel Chair</b>		<b>48</b>	<b>12%</b>
<b>Electric Wheel Chair<sup>2</sup></b>		<b>42</b>	<b>11%</b>
<b>Breathing Help day</b>		<b>14</b>	<b>4%</b>
<b>Breathing Help night</b>		<b>25</b>	<b>6%</b>
<b>Iron Lung</b>		<b>0</b>	<b>0%</b>

<sup>1</sup> Since the emphasis of this section was on mobility aids, many omitted to tick this box, even if they could walk. In most cases we were able to establish whether or not the person could in fact walk by checking data from the rest of the questionnaire. Complete accuracy therefore is hard to verify.

<sup>2</sup> We did not make a category for mobility scooters, and some of the figure for electric wheel chairs may include these.

6. RESPIRATORY AND SLEEPING	Out of 388	Percentage
shortness of breath when doing normal activities e.g. bed making	132	34%
Shortness of breath when talking	63	16%
Asthma	46	12%
Hayfever	79	20%
Allergies -drug/ food	88	23%
Dermatitis/ psoriasis	50	13%
Difficulty breathing through your nose/ either nostril	56	14%
Difficulty swallowing/ choking	95	24%
Wake short of breath	35	9%
Wake with a start for no obvious reason	96	25%
Snore	Most	
Often have restless sleep	222	57%
Legs restless/ jumping at night	175	45%
Wake a lot during the night	188	48%
Nightmares of drowning/ suffocation	29	7%
Often wake with a headache in the morning	78	20%
Wake even more tired in the morning	126	32%

7. Physical	Out of 388	Percentage
Permanent paralysis (little or no movement)	95	24%
Permanent weakness (for a long time)	178	4%
Increasing muscle weakness noticed over last few months/years	207	53%
Increasing muscle weakness noticed over last 5 -20 years	240	62%
Permanent muscle wastage (thinner, less muscle seen)	197	51%
Increasing muscle wastage (more or new last few years or so)	107	28%
Increase in size of (1) leg (2) ankle (3) foot (swelling)	117	30%
Muscle twitching/jumping/ spasm	123	32%
Numbness or tingling	144	37%
Camps	166	43%
Sweats	82	21%
Increasing difficulty climbing stairs	249	64%
Tire more quickly now when walking	269	69%
Falling/stumbling/ tripping over more	186	48%
Increasing tendency to drop things/difficulty using hands	162	42%
Increasing difficulty rising from chairs	223	57%
(1) Painful joints (2) Arthritis	(1)175 (2)79 both 43	(1)45%(2)20%(3)11%
Sharp pain	60	15%
Nagging/ aching pain	151	39%
Constant pain	69	18%
Back-ache	217	56%
Unusual chest pain that is not indigestion or heart	66	17%
Excessive tiredness or fatigue	198	51%
Urinary problems	126	32%
Bowel or stomach problems	121	31%

<b>8. DAILY LIVING</b>	<b>Out of 388</b>	<b>Percentage</b>
Can use public transport. <sup>1</sup>	197	51%
Do you have a car for transport? <sup>2</sup>	313	81%
Have hand controls to drive a car.	38	10%
Have paid employment.	72	19%
Have sheltered employment.	2	1%
Have an invalid pension. <sup>3</sup>	41	11%
Have National Superannuation. (old age pension) <sup>4</sup>	274	71%
Have other superannuation.	58	15%
Housewife (unpaid job).	135	35%
Due to health struggling to maintain your job.	24	6%
Due to health struggling to maintain your gardening. <sup>5</sup>	229	59%
Due to health struggling to maintain your housework. <sup>6</sup>	177	46%
Due to health have had to reduce or stop work. <sup>7</sup>	98	25%
Due to health have had to reduce/adjust daily activities.	212	55%
Have to/ feel you should take a rest during the day now	262	68%
Have home alterations/handrails/ramp etc	157	40%
Need home alterations.	33	9%
(1) Shoes (2) calliper (3) brace etc not quite right.	60	15%
Lack of finance preventing use of needed aids.	35	9%
One leg/ arm shorter than the other	186	48%
Walk with a limp.	231	60%
Have had a hip replacement.	39	10%
One foot shorter than the other.	130	34%
(1) Wheelchair suitable (2) Cushioning comfortable supportive?	(1) 53 (2) 47 out of 90 users	(1) 59% (2) 52%
Would like a support group in your area. <sup>8</sup>	56	14%

<sup>1</sup> Some did not answer yes to this question if there was no public transport. Some interpreted it as meaning that they would have been able to use it if it was available.

<sup>2</sup> Some of these cars were only driven by spouse.

<sup>3</sup> We presume that these people qualify because they are not old enough to get National Super.

<sup>4</sup> This figure is surprisingly low given that most would qualify.

<sup>5</sup> Some people did not answer yes if they had to get help for the garden and were, therefore, no longer struggling.

<sup>6</sup> Same applies as above for housework.

<sup>7</sup> The answer to this seemed to depend upon how recent this was.

<sup>8</sup> Some indicated that they would like a support group in their area when there was in fact one close by. We presume that lack of transport kept them from attending. Some areas had no support group.

## **Comments**

The comments section allowed all respondents to indicate what was bothering them or to tell their story, an opportunity which has obviously been lacking in their lives previously.

The fact that 90% responded within 3 weeks of receiving the survey clearly indicates their need to have a voice for their concerns and to speak out about their challenges and needs.

Several people indicated that that all known polio survivors are fighters and this 'can do' attitude is clearly reflected by the majority of respondents.

One person mentioned that in 1946 when she got polio almost every house in their street had a child affected and the doctor made house calls from one end of the street to the other every day.

One person mentions that she is 1 of 3 with post polio syndrome in her doctors' practice, a lucky doctor to have a point of comparison for understanding.

One person was already in hospital for an unrelated condition when she contracted polio; one was a ward sister in the polio ward; and 5 were pregnant when they got polio.

## **Associated medical conditions**

People with post polio syndrome may also be affected with other medical conditions as well. The most frequently mentioned included

- ◆ Cancer
- ◆ Cardiac conditions such as bypass, atrial fibrillation, stroke
- ◆ Chronic fatigue
- ◆ Degeneration
- ◆ Diabetes
- ◆ Fibromyalgia
- ◆ Guillain–Barré syndrome
- ◆ Osteoarthritis
- ◆ Parkinson's
- ◆ Rheumatism
- ◆ Spinal stenosis

We did not have a question on the survey which allowed people to name other conditions, so this information is volunteered rather than an accurate statistic.

## **Cold/heat intolerance**

4% mentioned this as a significant problem.

## **Chiropractor and natural supplements**

3% find regular treatment from a chiropractor to be most useful, while a significant number use natural supplements to relieve their symptoms. Those using natural supplements have clearly tried several kinds before settling on the most appropriate for them.

## **Depression**

2 people mentioned having severe depression in the past, but we believe those with depression currently are among the people who have not filled in their forms, as their situation stops their taking action.

## **Doctors**

Several people mentioned that doctors do not know about post polio, show very little interest and therefore make little effort on behalf of those with this condition. While education of doctors, other associations, the public and family members is part of the Board's work, it is on-going, and specific instances should be brought to our attention, so that we can supply information where it is needed most.

One person mentioned that her niece has just qualified as a doctor, and during her training 1 half day was all that was devoted to the effects of disability in the entire training..

## **Family**

Family support and understanding is mentioned by numerous people as being a significant factor in their ability to remain functional.

## **Home alterations**

40% have home alterations

9% need home alterations

2% have financial challenges which prevent them from getting home alterations and required aides.

Several people mentioned that they had had to pay personally for their aids and their home alterations. One person indicated that she and her husband had spent \$200,000 to make their home and vehicle wheelchair friendly. They did this to get what she **knows** she needed, rather than be supplied with what was *thought* she needed.

## **Lucky**

7% mentioned they are lucky to have been able to lead such a full life even though they had polio. One of our members was "capped" at 50 despite having being hospitalized with polio for 3 months when she was 6. These people who are counting their blessing make us all smile, and we hope you are one of them.

## **Knee replacements**

While 39 people have hip replacements, we did not ask about knee replacements. However 3 people mentioned that they have had knee replacements.

## **Medical alarms**

One member asks how many PPS people use medical alarms, a question we cannot answer at this time.

## **Newsletter**

Several people indicated the importance of the information and education that was supplied through the newsletter, and its importance and relevance to their continuing ability to cope with their post polio situation. Several people talked about how important their contact with the Association is for the provision of understanding, education through conferences, and web links where appropriate.

## **Orthotics**

As a group we are extensive users of orthotics.

- 20% have special shoes
- 24% use in-shoe orthoses
- 33% use walking sticks
- 16% use a walking frame
- 12% use crutches
- 5% use ½ callipers
- 7% use full callipers
- 9% use a knee brace
- 3% have a surgical corset
- 12% have a manual wheelchair
- 11% have an electric wheelchair

A total of 258 people use orthotic device in any combination

- 77 people use one orthotic device
- 85 people use two orthotic devices
- 39 people use three orthotic devices
- 32 people use four orthotic devices
- 25 people use five orthotic devices

So 150 respondents do not require to use orthotics of any kind.

It appears that this is the area where most people find the waiting time for equipment very time consuming and frustrating, (although not very many people filled in that part of the form near the end which asked for what services they were waiting). This also appears to be the area where people are given what is thought to be necessary, rather than what is necessary. Further information is found in the separate orthotics report.

## **Skype**

Susan and Anne spent 7 months extracting this data from the surveys, and spoke to each other from separate parts of New Zealand for an hour and a half each week day on Skype, the computer to computer communication system which created no cost to the Association.

While both Susan and Anne probably separately each doubled that time commitment on the project, Anne would particularly like to acknowledge the extra work and time that Susan put in while using her programme to input all the statistics.

## **Support groups**

14% would like a support group, even though some of them live in areas where active support groups are operating, and the lack of transport provision to these groups is mentioned.

However as 45% of our members now have internet connections, Susan Kerr is happy to start and run an internet support group, either on an individual or group basis depending on the need. Susan has connections to American internet support groups, so is well experienced in this type of activity. She can be contacted on [susanvrm@clear.net.nz](mailto:susanvrm@clear.net.nz) for further information

## **Wilson Home**

Several people mentioned spending considerable periods of time in Wilson Home after discharge from hospital. However as this was not asked as a specific survey question we are unable to indicate the length of time spent there or the number of people involved.

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