

## Polio Survivors Network

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### Polio Survivors Network

Name:- [.....]

I am a Polio Survivor from ..... Year.

I am a Relative/Friend [.....]

I am a Health Professional [.....]

Signed:- [.....]

Date:- [.....]

Address:- [.....]

.....

.....

..... Post Code:- .....

Tel:- [.....]

Mobile:- [.....]

Email:- [.....]

.....

Please Return to:- Polio Survivors Network,  
P.O. Box 954, Lincoln, LN5 5ER

## Campaigning messages

**Better understanding** by health and social care professionals of post polio syndrome and how it affects individual's, their partners and families.

**Appropriate assessment** of respiratory and swallowing problems.

**Appropriate assessment** of physical abilities

**Better listening to Polio Survivors** experiences of the symptoms of post polio syndrome.

**Better focus** on the needs of people with rare conditions by health and social care professionals and researchers. Post Polio Syndrome is classed as a rare condition.

**Better orthotics and wheelchair services.**

**Full implementation of the Eleven Quality Requirements** - published in March 2005 in the National Service Framework for Long Term Neurological Conditions for anyone living in England with a neurological condition - by the new NHS Quality, Innovation, Productivity and Prevention (QIPP) programme.

**Polio Survivors Network** is a member of the Neurological Alliance, [www.neural.org.uk](http://www.neural.org.uk), National Voices, [www.nationalvoices.org.uk](http://www.nationalvoices.org.uk), Rare Disease UK, [www.raredisease.org.uk](http://www.raredisease.org.uk), European Polio Union, [www.europeanpolio.eu](http://www.europeanpolio.eu) Post-Polio Health International [www.post-polio.org](http://www.post-polio.org)

**Polio Survivors are still here**  
**Please take our**  
**Campaigning Messages Seriously**



## Polio Survivors Network

[www.poliosurvivorsnetwork.org.uk](http://www.poliosurvivorsnetwork.org.uk)



Home of the

**Lincolnshire Post-Polio Library**

Containing information about  
**Post Polio Syndrome,**  
**causes and treatments and**  
**the life experiences of Polio Survivors**

**Our Newsletters**

### **POST POLIO MATTERS**

### **Polio Survivors Network**

**P.O. Box 954,**

**Lincoln, LN5 5ER, U.K.**

**Tel:- 01522 888601**

**Email:-**

**[info@poliosurvivorsnetwork.org.uk](mailto:info@poliosurvivorsnetwork.org.uk)**

Polio Survivors Network is the registered working name of the Lincolnshire Post-Polio Network.  
Registered Charity No. 1064177

## Polio Survivors Network

Polio Survivors Network is a support network for Polio Survivors experiencing and coping with the effects of Post Polio Syndrome. [PPS]

Polio is now almost forgotten due to an effective vaccine that was developed in the Nineteen Fifties. Until then an average summer polio outbreak would result in 5000 -7000 cases. After the vaccine people sighed with relief and got on with their lives.

Polio survivors recovered to varying degrees and got on with their lives. Many, believing Polio was part of their past, were determined to live a normal life, have careers and families. Many Polio Survivors who struggled to overcome initial problems caused by the polio virus are now being hit by post-polio syndrome, which can occur after a stable period of 10 to 50+ years following best recovery.

Post Polio Syndrome is the name given to polio survivors new symptoms of:- fatigue often overwhelming, both physical and mental: loss of muscle strength and/or use also in muscles below the line of clinically evident weakness at the time of the original infection; new pain in muscles and joints; trouble breathing and/or swallowing; problems sleeping and intolerance of cold.

Other symptoms can affect us more because of the way the polio virus changed how we function.

Many of our members are approaching their older years and some have had to retire early due to Post Polio Syndrome.

The Polio Survivors Network has no paid workers and is run for and by Polio Survivors, their families and friends and people with other disabilities. All money raised is used to support our work.

## Aims

**To represent** the concerns of the members of the Polio Survivors Network and their families

**To promote** understanding of the experiences of those living with the long term effects of polio and post polio syndrome among health and social care professionals, service providers and the general public. See PatientPlus article on PPS.

[www.patient.co.uk/doctor/Post-Polio-Syndrome.htm](http://www.patient.co.uk/doctor/Post-Polio-Syndrome.htm)

**To encourage** health and social care service providers to include polio survivors and families in the consultation and planning of local services.

**To promote** the provision of good quality and appropriate respite care and rehabilitation for polio survivors.

**To promote** the provision of good quality information that enables and empowers Polio Survivors and their families to make decisions about their daily lives.

**To promote** better research of, treatments, therapies and quality of life issues that concern Polio Survivors and their families.

## By

Consulting the members of the Polio Survivors Network to identify their concerns

Raising awareness of Post Polio Syndrome

Encouraging working relationships between our members and health and social care services at national and local levels

Educating and informing

Networking with others who share similar concerns

## Membership

Full membership including voting rights is available to polio survivors, their partners, families and friends health and social care professionals complementary therapists and any individual working in the interests of polio survivors

### Membership Fees

Individual	£ 12.50 per year
Life membership	£ 150.00 or
Life Membership by SO.	£ 5.00 x 30 month

Anyone wishing to pay by Standing Order, Yearly or Life Membership, will find a copy on our Website. Alternatively you can email [membership@poliosurvivorsnetwork.org.uk](mailto:membership@poliosurvivorsnetwork.org.uk) or write or ring and we will post you a copy.

We welcome members living in other countries and details will be sent upon request. Please note for overseas members the majority of information will be sent via the Internet.

Further details over-leaf

**Website:-**

[www.poliosurvivorsnetwork.org.uk](http://www.poliosurvivorsnetwork.org.uk)

**Email:-**

[info@poliosurvivorsnetwork.org.uk](mailto:info@poliosurvivorsnetwork.org.uk)

**Phone:-**

**01522 888601**