



# Social Support Groups *Beacons for the Future*

**Anne Shanahan**  
Regional Support Officer  
2008 -2010

Post Polio  
Support Group  
Ireland

# Social Support Groups

*Beacons for the Future*

# Anne Shanahan

Regional Support Officer

2008 – 2010

## Table of Contents

[The Post Polio Support Group.](#) 5

[The Author.](#) 6

[Introduction.](#) 9

[Objectives.](#) 11

[Evaluation.](#) 21

[Outcomes.](#) 25

[Recommendations.](#) 27

[Conclusion.](#) 31

[Appendix 1: Tables.](#) 32

[Table 1: Status of Social Support Groups - December 2010.](#) 32

[Table 2: Progression of Social Support Groups - December 2010.](#) 33

[Table 3: Review of Social Support Groups - September 2009.](#) 34

[Table 4: Social Support Groups - March 2008.](#) 35

[Appendix 2: Stories from selected Social Support Groups.](#) 36

[Appendix 3: Questionnaire - Convenors.](#) 52

[Appendix 4: Questionnaire - Members.](#) 54

[Appendix 5: Strategic Plan: PLAN TWENTY TEN..](#) 65

[Appendix 6: Strategic Plan: NEW HORIZONS Plan2015.](#) 73

The Post Polio Support Group acknowledges the support of the Minister for Community, Equality and Gaeltacht Affairs, formerly the Minister for Community, Rural and Gaeltacht Affairs, which made this valuable project viable.

## The Post Polio Support Group

---

The Post Polio Support Group (PPSG) was established in 1993 by Polio Survivors and incorporated in 2002, with the aim of providing aid, support and advice to those who had experienced paralytic Poliomyelitis at some point in the past and now experience Late Effects of Polio; formally diagnosed as Post polio Myelitic Syndrome but commonly called Post Polio Syndrome. The PPSG is a registered charity and is non-profit making, it relies on grants from both public and private bodies as well as fund raising activities to achieve its stated goal.

### **The Group works tirelessly to:-**

- Create awareness about Post Polio Myelitic Syndrome
- Provide information regarding the late effects of polio
- Ensure that the needs of Polio Survivors relating to their conditions are met to enable them to live with dignity.

### **The work of the Group is guided by the following principles:-**

- The PPSG is member led and Polio Survivors are central to its work.
- Services and supports are provided, based on needs identified through consultation with members, fairly and within the financial capacity of the Group.
- The Group will act according to best practice and in line with its Code of Conduct.
- Sensitivity, empathy and understanding are central to communication with Polio Survivors.
- Polio Survivors are encouraged and enabled to live their lives with dignity.
- The Group advocates for Social Policy change to encompass the needs of Polio Survivors.
- The Group co-operates and collaborates with other stakeholders, as appropriate.[\[1\]](#)

The Board of the Post Polio Support Group is responsible for the overall direction of the Group. It conducts regular oversight and review of all arrangements to support Polio Survivors to improve their effectiveness and efficiency.

## What choices fatally shape a life?

### How powerless is each one of us up against the force of circumstances?[\[2\]](#)

Powerlessness is indeed the experience of each and every Polio Survivor. I did not choose the polio virus; it chose me when I was a baby. I had an older brother and sister and a younger brother. We lived on a small farm about six miles from Limerick city on the Clare side. The polio virus affected my right leg with the result that it was extremely weak; was several inches shorter than the left one; my foot was several sizes smaller, deformed and useless to support me without the aid of custom made boots and a splint.

What power did I have against this force of circumstance? None, since there was no medication to combat polio. Vaccination against the illness was still in the future and didn't arrive in Ireland until the late 1950s. Unfortunately, like 60% of Polio Survivors, I now have Post Polio Syndrome which is a condition resulting in new symptoms in people who had polio years earlier. This condition presents with increased muscle weakness, atrophy of muscle, fatigue and mobility difficulties.

What supports were there in the early 1940's for my parents, not knowing where to turn or what to do? As a mother, I can imagine what they must have gone through, how powerless they must have felt, how fearful for their child. But, true to form, being of strong farming stock, they set about getting me whatever medical help they could, and so it was, that like many others, I was sent to hospital in Dublin from the age of three until the age of fourteen for spells of three to nine months to avail of physiotherapy treatment and surgery. Even today, from time to time, the pain of the frequent partings from my parents, sister and brothers is as real as yesterday, as is the joy of the home comings.

During all those years away from home I seldom had visitors. Only once was my mother able to visit and on another occasion my father. I was about eight or nine years old when my mother somehow managed the trip to Dublin. I was standing at the window of the girls' ward on the first floor, gazing down the tree line avenue, feeling like a caged bird on this warm summer day. Suddenly, a pair of legs came into view, slowly walking up the avenue. Those are like my mother's shoes I thought. Then gradually, a dress appeared. My mother has a dress like that; who could that person be? It wasn't Sunday, visiting day. Then in shock and disbelief I saw her; could it possibly be my mother! I pulled up the window and rushed out on to the fire escape and shouted, waving frantically - she saw me! Then a nurse pulled me back into the ward. Let me go I screamed, I have to go down to the hall, my mother is here! Wait, wait she said. I have to get you ready if you are having a visitor from the country. I have to get you a clean dress and brush your hair and wash your face! How I danced with impatience! But I had learned; my mother had told me many a time; it is best not to make the nurse cross, just do as you are told and be a good girl and everything will turn out alright. I held that nurse's hand as she sedately marched me down to the front hall, into my mother's arms. I don't remember having much to say to her except - take me home, please take me

home – I just couldn't stop crying.

When my father visited I was quite grown up, thirteen years old, and had just had an operation. I didn't cry any more, at least only in bed at night. I remember proudly showing off my 65 stitches and explaining to him that now my legs would both be the same length, and did he think it wasn't too late for me to start dancing lessons when I got home – all I wanted to do was learn to dance - ballet dancing, Irish dancing any kind of dancing! Well he said, you can dance out and bring in the cows!

I have had many blessings in life but the greatest has been my parents. My mother, a very resourceful, intelligent woman prepared me well for my sojourns in hospital. While I was always lonely, I never felt alone or cut off from home because my mother wrote to me every week, enclosing a stamped addressed envelope and a page of notepaper for my reply. Christy, the boiler-man posted my letters for me and he would often read aloud my mother's letters; they were read over and over again until the next one arrived. Christy became familiar with the McNamara family and life on the farm. He understood my need to talk about home. Very few children received letters – so I was special. My mother also wrote to the Matron to enquire how I was getting on. On her rounds Matron often announced; "I have had another letter Anne, what will I say to your mother?" I felt so important – I no longer envied the Dublin girls who had visitors every Sunday!

Letters were my greatest comfort and reading was my great escape.

We had a teacher, Mrs Evers, who tried to teach us the three R's. She set up a little library and I quickly offered my services as assistant librarian, bringing around books to all the children, collecting the returns, stocking the shelves, dusting and tidying. There was a great bonus attached to this job. I got first pick of the new books! I read everything from every section: Adventure, Detective, Nature and Wild Life, Travel, Myths and Legends, Facts, Fables, Children's Classics; I read them all. I escaped into my own fantasy world. I wasn't so lonely any more, just resigned to my situation and patiently waiting to be discharged. When that great day came I travelled to Limerick by train with several other children, usually arriving in the dark, and I can hear, even now, my father's footsteps as he smartly marched up the platform. I would fly into his arms and feel again the familiar rough tweed of his jacket, the smell of his hair, the bristle of his chin, the warm embrace of my father.

Regular school, when I was able to attend, was very difficult. I missed out so much; it was a struggle to keep up. I have always felt at a disadvantage. While I managed to get by at school, I had a lot of difficulty with spelling, grammar and maths. I could give the right answer – having learned it, but I seldom understood the reason behind things. I hoped one day to be able to do something about this. My opportunity came when I was in my fifties. I found myself widowed, with no job and little prospects of getting one. My children were in secondary school or college, so I decided to return to education and started as an undergraduate at UCD. This was a turning point for me, the letting go of the feelings of inadequacy and the start of four years of sponge-like absorption of knowledge, of new friendships and the pure joy of living. Graduation day came and I had made it. Then, having got the taste for learning I went on to do my MA. I don't feel disadvantaged any more. I will never stop learning.

Now, I find myself in the position of Regional Support Officer for the Post Polio Support Group. I facilitate, I empathize, I support, I try to empower, I comfort, I learn, I listen, I hear the members. Through facilitation and leadership I try to show our members that life can be good for Polio Survivors, even those with Post Polio Syndrome, for as the old saying goes: "He who wears the

shoes knows exactly where the pain is”.

Generally, we Polio Survivors are not known for our willingness to talk about our condition or share our experience with others; we want to be taken as “normal”. However, this attitude has changed since the peer support groups and telephone supports provided by the Post Polio Support Group were put in place. Now we have a support network that provides a safe, confidential and understanding place to truly express how life is for us today. We do not look back at what we have lost, but only look at what we have left. We put fresh heart into each other; we get on with life.

Most Polio Survivors that I have met while travelling around the country have, like me, been fortunate in that our physical disability was not so severe that we were unable to lead independent lives. Unfortunately, many others were more severely affected and need professional services, the help of their carers, aids and appliances, adapted homes and adapted cars to enable them to lead more independent lives. Although we have to cope with physical difficulties, we Polio Survivors seem to have been blessed with positive dispositions. We are known for our resilience, our courage, our sense of humour. We are learning how to live fulfilling lives by seeing past the labels and shackles of disability and by not allowing a physical disability to become a barrier to the talent and creativity that is in us all.

We are not powerless, we have choices to shape our lives and yes, we can overcome this force of circumstance, Polio.

*Anne Shanahan*

## Introduction

---

This report examines the role of the Regional Support Officer for the Post Polio Support Group, contracted from March 2008 to December 2010. It charts the evolution of the role throughout the period.

It shows how the psychological, social and physical lives of Polio Survivors were enriched through the formation of social support groups which provide members with a platform to address their needs. This was achieved by providing a friendly and supportive environment where matters were discussed and information shared. Most importantly, this development provided the opportunity for Polio Survivors to empathize with others in a similar situation; to form friendships; to gain support and confidence through sharing experiences and through helping each other.

It describes the concepts underlying the social support groups, their formation and development, and the impact such support groups have on the membership and the overall development of the Post Polio Support Group. The benefits of building on the experience and methodology of the existing social support groups is demonstrated as this knowledge has proved to be invaluable in the progression to new group formations.

The importance of promotional work in tandem with the formation of a new group is emphasized as it allowed the process to reach out to the many Polio Survivors who are not yet members of the Post Polio Support Group. The number of Polio Survivors in Ireland is estimated at 7,000 while less than 900 are members of the organisation.[\[3\]](#)

The report examines the effect that the development of a widespread network of social support groups has had on the aspirations of the Post Polio Support Group; on the planning and aspirations of the board of directors; on the day-to-day work of the administrative staff and on outside agencies who have been invited in to help bring a broader focus to the social support groups.

The report highlights the progressive difficulties encountered by Polio Survivors especially those 60% who have been diagnosed with Post Polio Syndrome. The progressive difficulties include lack of strength and increased muscle weakness which can lead to great anxiety and fear of losing control of their life styles. The report emphasises the importance for family, friends and careers to gain a good understanding and acceptance of the energy cost of daily living for Polio Survivors; thus enabling and informing them to be a source of support as and when the needs arise. This caring role in the lives of Polio Survivors is fully recognised, acknowledged and appreciated.

A qualitative piece of research in the form of questionnaires, conversations with groups, and individual interviews is employed to ascertain the value of the social support group concept for the Post Polio Support Group. The objective of this research is to learn from individual members, group convenors, administrative staff and directors. Such insights and knowledge will pave the way for the proper placement of the development of the social support groups in the future planning of the Post Polio Support Group.

Ultimately, the objective is, and will continue to be, to help Polio Survivors to be more confident and more active as individuals or participants in groups in their communities and especially to help them to face the challenges that Post Polio Syndrome presents.

The report shows how members of the Post Polio Support Group who are involved in social

support groups have the opportunity for building greater self-worth through developing an understanding and acceptance of their physical restrictions; through being aware of all the supports available to them; through reaching out to care for other Polio Survivors, and through developing a sense of gratitude for the positive, dynamic and happy disposition with which many Polio Survivors are blessed.

Finally, the report emphasises the importance of continuing the work started by the Regional Support Officer, focusing on sustaining those existing groups and setting up new support groups responding to requests from Polio Survivors.

### **Identifying the Need**

In 2007 the project to provide a Regional Support Officer was key to the Post Polio Support Group's forward planning preparing for the kind and extent of social support service to be delivered nationally to this ageing cohort of Polio Survivors in the coming years. The appointment of the Regional Support Officer arose from the need to deliver two of the expressed goals outlined in the Strategic Development Plan for the period 2007 to 2010. [\[4\]](#)

In general terms, delivering the Plan was to be accomplished through four programmes, the first three delivered the core objectives and the fourth enabled the Group's direction and governance of the process. The three core objectives were:

- 1) To create awareness and provide information on Post Polio Syndrome*
- 2) To support Polio Survivors.*
- 3) To advocate on behalf of Polio Survivors.*

The programme to address the first of these core objectives – awareness and information – was to design and implement initiatives to create awareness of the late effects of polio, targeting individual Polio Survivors, their families and carers, health care professionals and whole communities.

The key was to develop the volunteer base, local and regional structures and the following two goals were set:

- 1) Maintain contact programmes with Polio Survivors to ensure that their sense of isolation is minimal and that they can be made aware of the supports available to them.*
- 2) Encourage all Polio Survivors to join the Post Polio Support Group as this provides the most effective means of maintaining contact and passing on information on new developments.*

The Board set out to fulfil these tasks by appointing a Regional Support Officer. Sourcing funding for this position emerged as a priority from needs analysis conducted as part of the Group's then development programme.

The Group was awarded a Grant to cover salary and expenses from the Funding Scheme to Support National Organisations in the Community and Voluntary Sector administered by the then Department of Community, Rural and Gaeltacht Affairs, now the Department of Community, Equality and Gaeltacht Affairs.

Because of the ageing profile of the Polio Survivor population, depopulation in some areas and stresses in the community fabric, the Group was continually identifying social isolation as a problem for certain Polio Survivors. This project has assisted the Group in tackling this area of disadvantage by intervening directly and working with Polio Survivors, some of whom have neither the capacity to manage their situations nor the means to source solutions to their social support

problems. The target for the project was to directly impact all Polio Survivors and significantly reduce their isolation and their disadvantaged social situation. The emphasis has been on improving the provision of social interaction including the creation of networks; keeping in touch by telephone, email, PPSG website and through contact meetings or otherwise, thereby improving their social and community environments. The Board of Directors and the Executive Staff of the Group have also benefited from the lessons learned in the conduct of the regional development project as they continue to work with the Health Service Executive and Sectoral Departments and their agencies to refine, improve and better direct the services offered to the Polio Survivor population.

## **The Project**

Delivering PLAN TWENTY TEN<sup>[5]</sup> which was launched in September 2007 emphasised the task of developing the volunteer base, local and regional structures.

*“A well developed local structure is required to support the nationwide organisation and to invigorate it.”*

The three year target was:

*“To improve and enhance the connection amongst the Group members within local and regional areas, which will form a basis for conducting activities, encompassing social gatherings and other developmental projects.”*

Based on the stated aims of PLAN TWENTY TEN three specific targets were identified as the primary focus of this project:

- 1) Set up new support groups and invigorate existing groups.**
- 2) Seek out increased membership**
- 3) Inform Polio Survivors and the wider medical profession about Post Polio Syndrome**

These three targets are interrelated.

### **1) Set up new support groups and invigorate existing groups.**

The results of a members' satisfaction survey: *“How do we think as a Group?”* carried out in 2008, revealed that while Polio Survivors had many medical problems they also had many social and emotional needs. Listed among the Top 10 “important” items for members were:

- Going to support meetings
- Contact with other Polio Survivors
- Going on outings or attending events
- Getting booklets and information on Post Polio Syndrome.

The survey also brought to light the fact that some members feel isolated and lonely. They stated that contact with other Polio Survivors who are coping with similar issues would be of great mutual benefit.

In response to this expressed need, it was considered important to establish social support groups in both urban and rural areas. Many of these new groups were located in country towns and some members even travelled considerable distances to attend the meetings where they were able to socialise, to share experiences, to support and encourage each other.

Members were contacted by letter and telephone and invited to attend a support group meeting in their locality. Those who were unable to attend were informed of other developing telephone supports such as the Ring Ring and Phone Chat projects.

## **2) Seek out increased membership**

The number of Polio Survivors in Ireland is estimated at 7,000. It is estimated that 60% already have, or will have in the future, Post Polio Syndrome.<sup>[6]</sup> Unfortunately, less than 900 are members of the Post Polio Support Group.

Reaching out to non members, one of the key targets of the programme for awareness and information in PLAN TWENTY TEN<sup>[7]</sup> is:

*“To design and implement initiatives to create awareness of the Late Effects of Polio targeting Polio Survivors, their families and carers, health care professionals and the whole communities”.*

When starting up a new group in a particular area the opportunity was taken to avail of the local radio, free press, fliers, notices to agencies such as the local Health Service Executive (HSE), Disability Federation of Ireland (DFI), Irish Wheelchair Association (IWA) and community groups to bring awareness of the work of the Post Polio Support Group to non members and to let existing members know that they had the opportunity of coming together for mutual support.

In October 2010 a member of the Dublin south west group took part in a press conference held at the Mansion House where she discussed the everyday challenges confronted by Polio Survivors with a Government Minister and opposition spokespersons on Disability as part of the Disability Federation of Ireland’s pre budget submission to Government, and outlined the supports and services offered by the Post Polio Support Group.

In the lead up to the Group’s conference and AGM held in Limerick in 2010,

two members of the Limerick group did several radio interviews and newspaper interviews with a view to creating awareness of the Post Polio Support Group

and the needs of Polio Survivors.

### **3) Informing Polio Survivors and the wider medical profession about Post Polio Syndrome.**

The programme for awareness and information in Plan Twenty Ten also outlines the task of providing information:

*“Make information available in accessible formats to Polio Survivors and to all involved in their support and treatment, in particular those working in the medical and social care professions”.*

The key targets are:

- *To promote the publications of the organisation, in particular the newsletter, THE SURVIVOR*
- *To promote and develop the website as an information tool.*
- *To promote the booklet, “Post Polio Syndrome – Management and Treatment in Primary Care” within the medical and social care professions*
- *To promote awareness of State and other benefits available to Polio Survivors.*

Resulting from the members’ satisfaction survey (see 1 above) the organisation was aware that, in general, the medical profession had little awareness of the special needs of their Polio Survivor patients. The support groups were involved in addressing this situation through the media involvement and in particular through the information distributed at the meetings. Each member was empowered by being asked to give a copy of the booklet *“Post Polio Syndrome, Management and Treatment in Primary Care”* or a CD of same, to each of their medical carers.

#### **The aim of the project**

The broad aim was to provide the environment where the potential for independence, dignity and fulfilment could be realised for the members by facilitating and encouraging all Polio Survivors to join social support groups, thereby ensuring the most effective means of maintaining contact with each other for mutual support; of promoting awareness of current developments with regard to Post Polio Syndrome; of receiving relevant information and becoming involved, where possible, in the work of the Post Polio Support Group.

It was determined that the role of the Regional Support Officer was to reach out to all Polio Survivors and outline for them the benefits to be gained from being involved in a social support group. These benefits include:

- Friendship

- Openness
- Solidarity
- Being aware of different possibilities
- Sharing experiences
- Personal development

### **Social support groups: The rationale**

Polio Survivors help each other to cope with the challenges presented by Post Polio Syndrome. Those who are actively involved with a social support group are better informed and thus better enabled to access the necessary supports, including peer supports. Social isolation can be a problem for certain Polio Survivors because of their aging profile, depopulation in certain rural areas and stresses on the community fabric generally.

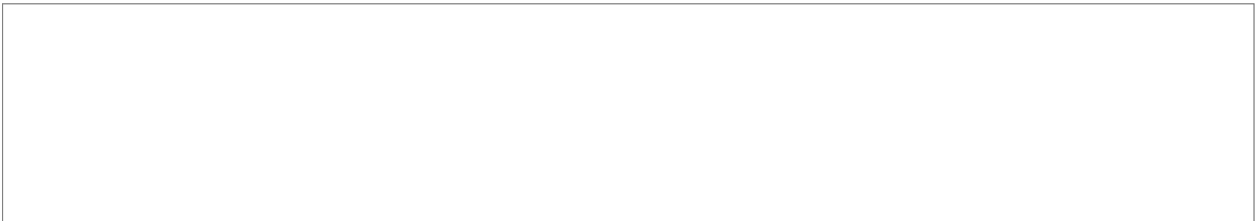
The main task for the Post Polio Support Group is to set up linkages within the more than 4,000 polio survivors expected to develop post polio syndrome<sup>[8]</sup> so that no one feels isolated and alone and that each can talk to friends who understand the condition. Social support groups provide a friendly environment and a structure within which polio survivors can meet regularly and take part in activities to help manage their conditions. A focus is provided for sharing information on Post Polio Syndrome, often with the help of specialist practitioners who attend the meetings by arrangement. Organising outings and social functions are an important part of the activity of the social support groups.

### **Building a development model for social support groups**

To assist the work of the Regional Support Officer a descriptive model showing the stages of development of a social support group was designed.

An analysis of social support group development was carried out and distinct stages in group development were identified:

**Group  
Activation**      **Facilitated  
Group  
Development**      **Assisted  
Group  
Development**      **Mature Group**



**Group Activation** describes the stage at which the group is activated in a structured way. In some cases the development takes place in a new geographical area. In others, meetings had been held only irregularly and while there were contact names on which to build there was a poor meeting formation upon which to upgrade and expand.

**Facilitated Group Development** describes the stage over which the social support group is actively managed to generate activity, to invigorate the group and to exploit positively the role of the members in the active running of the group.

**Assisted Group Development** describes the stage during which the group needs some assistance with its activity and needs oversight to ensure orderly and equitable development. It has started to design its own programme inviting and generating external inputs.

**Mature Group** describes the stage at which the group is operating with a high degree of autonomy, interacting with other organisations, conducting functional activities but under the oversight of the Social Support Committee.

**The slope of the graph** indicates the amount of input required to assist the running of the group. A steep slope indicates that considerable input is required while a flat line indicates little or no external input.

### **Social support group development plan 2008-2010**

The tables in Appendix 1 give an indication of the groups' development evolving from a comprehensive study of the population patterns for Polio Survivors throughout the country. The venues and catchments have changed in response to the wishes of the Polio Survivors and were aligned specifically to centres where appropriate activities were available. The progression and final position for social support groups can be seen.[\[9\]](#)

### **Methodology**

Orientation for the Regional Support Officer began with attendance at a training weekend

*“Developing Support in the Post Polio Support Group”* which was organised by the Social Support Committee in March 2008. This was facilitated by the Training and Support Services Team from the Carmichael Centre. The training addressed issues such as:

- Why run support group?
- Types of Support Groups – how to make them work
- Role of the Convenor
- Developing other supports e.g. telephone and Web site.

This was an important orientation activity for the Regional Support Officer. It provided an opportunity to meet with the Social Support Committee and also to meet the Convenors of the groups.

Eight social support groups were already established at this stage and the Regional Support Office was able to talk with some of the convenors and learn how their groups were structured; discussing what had worked well and what had not; how they organised and co-ordinating procedures; and

what strategies they employed in order to keep the meetings interesting and enjoyable.

During the following months, the Regional Support Officer attended all of the existing support groups meetings. The knowledge and information gained was invaluable in setting up new groups.

Some of the existing groups were working well and had consistent numbers attending meetings. The challenge was to actively reach out to Polio Survivors in the catchment area who were not members of the Post Polio Support Group.

Other existing groups had very low numbers attending meetings and they were in need of revitalisation. Various reasons for poor attendance were identified, for example, one group held meetings in a venue that was too distant for members to travel to. By simply disbanding this group and replacing it with two new groups and arranging for meetings to be held in more convenient locations, the problem was solved and the two groups are now very active.

The existing eight groups were structured on a fairly authoritarian model with a convenor having

sole responsibility for the organisation of his/her group. Most of these convenors held the position for a considerable number of years. While they had great support and help from the members of the group, active and invigorating participation by members was seldom evident. The role of the convenor and succession planning, therefore, became an important consideration in the formation of new groups.

The Regional Support Officer worked with the convenors to energise these existing groups by contacting members who did not attend meetings to involve them in the running of the meetings and in projects and activities so that they developed a sense of ownership and pride in their group.

## **New Groups**

From time to time, certain members had contacted the office to enquire about the possibility of getting a support group started in their area, but before 2008 there was not sufficient support to service stages 1-3 of the model for development of a social support group. These members were contacted and their knowledge of the locality was very useful in finding a suitable venue for the meetings, usually an accessible hotel with ample parking and reasonably priced. The meeting venue was chosen having regard for the distance members had to travel and if it was convenient to public transport. Three examples of new groups being formed in response to a request from a member are the Limerick, Kilkenny and Carrick-on-Shannon groups. Both the Kilkenny group and the Limerick group flourished and were self-sustaining after the initial two or three meetings had taken place. The Limerick group was able to take on the task of organising the annual Conference and AGM in 2010.

The first step towards setting up a new social support group began with gathering the names and contact details of members. Then, leaving out those members who already attend groups, identifying areas of the country where clusters of members could reasonably get together to form a group. An accessible hotel where a meeting could be held was chosen. Letters were sent to all members living within approx. 50/60km radius of this hotel informing them of the intention to form a support group in their area. It was quickly established that the members preferred to meet in an hotel setting in comfortable and congenial surroundings.

Arrangements for the initial meeting entailed visiting the venue to ensure that it was fully accessible both inside the hotel and in the parking area; booking the meeting room; arrange for refreshments and payment of account.

In order to advertise the first meeting the local media were contacted, e.g. local radio; local free press; fliers; church notices and community newsletters.

A letter was sent to each member in the catchment area and telephone calls were made by way of introduction to explain what the group was about, to outline how it could be of benefit to attend and to highlighting the fact that it would be an enjoyable and informative evening.

Further telephone calls were sometimes needed to encourage and assist with any problems that members might have regarding transport or other issues.

Accessible transport is a real problem for many people. The Group is not normally funded to provide transport; however, donations from philanthropic associations for accessible transport help with arrangements. These donations, together with the kindness of fellow members in providing lifts for others where possible, helps to address somewhat this major difficulty in many instances.

It is recognised that more people could attend and benefit from social support meetings should suitable transport be available.

### **Inaugural meeting**

When possible, a member of the Board or Executive Staff or a convenor from a neighbouring group attended the inaugural meeting of a new group.

For example, in the case of the Dublin south west group, ninety three letters were sent to members living in the catchment area and more than forty attended. As this was expected to be a large gathering it was valued to have key people from the organisation present to help talk to people and answer queries. A member of the Board attended this inaugural meeting and gave a short talk about the origins and development of the organisation and what it is trying to achieve. The Chair of the Social Support Committee, gave a short talk on the existing social support groups and the Services and Information Co-ordinator explained her role in the organisation. A convenor from a neighbouring group explained how his group got started and talked about the difficulties they encountered; interesting speakers that had been to their group; activities; outings and social events that made their meetings more enjoyable.

At this meeting, members voted by a show of hands to set up a social support group for Polio Survivors living in the Dublin south west area. Since then, the group has gone from strength to strength. There are 83 names on the mailing list. The attendance at meetings varies between 14 and 28. New members are always welcome, as are family and friends.

## **Second meeting**

The second meeting was usually arranged about six weeks after the first one. Where possible, the local Disability Federation of Ireland (DFI) representative in the area was invited to come along and facilitate an informal discussion on the structure of a support group and outline what would be needed by way of organisation, leadership etc. The professional facilitation and on-going support from DFI representatives was particularly valuable.

## **Third meeting**

Usually, at about the third meeting, members with special skills such as secretarial, organisational, computer, local knowledge, media knowledge or other, formed a team and various tasks were delegated to them. This team arranged to meet to discuss their plans. In due course a team leader naturally emerged who became the spokesperson for the group with the title of convenor.

The Regional Support Officer continued to be available to the new groups, to supply information, suggest projects or activities, attend meetings and help in any way until the group was mature and self-reliant.

## **The role of the Regional Support Officer in assisting policy development**

Enabling and empowering of the whole organisation, in particular those with a leadership role, emerged as an important outcome of PLAN TWENTY TEN [\[10\]](#) and seeded new developments for NEW HORIZONS Plan2015. [\[11\]](#)

## **Training weekend - Cuisle, Co. Roscommon 2009**

The Regional Support Officer attended a training weekend organised by the Social Support Committee in 2009 where she helped to facilitate training sessions for the Ring Ring and Phone Chat projects. Both of these projects are very important supports offered to members who are unable, for various reasons, to attend their local social support group meetings.

## **Training weekend – Cuisle, Co. Roscommon 2010**

In 2010 the Regional Support Officer participated in a second training weekend in Cuisle where she conducted a workshop for convenors titled *The Structure of Groups*. This workshop was chiefly concerned with giving the convenors a platform to voice their opinions, to discuss their concerns, to listen and learn for each other, to suggest ways of improving communication between the convenors and the organisation and to open up channels of communication among the convenors themselves.

A more open and approachable method of communication was said to be key to enabling the convenors to achieve a better, easier and more efficient approach to organising their social support groups.

## **Future Training and Development**

As the Post Polio Support Group is not yet in a position to run its own training courses, the Regional Support Officer briefed trainers from the Carmichael Centre to deliver further training programmes for convenors in 2011.

A long term programme to support and sustain the social support groups is incorporated in the development plan NEW HORIZONS Plan2015.[\[12\]](#)

## **Outside agencies**

The Regional Support Officer has been in contact with outside agencies so that she is informed about any training programmes which would be of interest to convenors or any of the Post Polio Support Group members.

Chief among these agencies is the Disability Federation of Ireland (DFI) and the Regional Support Officer was able to arrange for some members to attend the following training sessions held at the DFI offices:

- Media training 2010
- Sports seminar 2010

## Evaluation

---

The task of evaluating the impact of the three year project was undertaken as follows:

### 1) **Conversation between the Board of Directors and the Regional Support Officer.**

The following key points were noted:

- The need to build self-sustaining strategies to ensure that the work of the Regional Support Officer will not be wasted.
- Long term plans for social support will be secured as foreshadowed in the development plan: NEW HORIZONS Plan2015.[\[13\]](#)
- The changing focus of the Post Polio Support Group towards a member led organisation.

The work has built on the efforts of the Board of Directors over years particularly the Social Support Committee whose role is:

*“To promote and support contact and peer support among members of the Post Polio Support Group and with the wider community of Polio Survivors. To monitor the activities of the individual social support groups, and any other groups which come under this committee’s remit from the Board, to ensure that these are in conformity with the policies of the Group” [\[14\]](#)*

The Social Support Committee has discretion to spend the budget allocated to it by the Board. In 2009 expenditure on social support was some €22,000 – a significant cost, but one that produced significant outcomes.

### 2) **Individual interviews with Executive Staff.**

The Regional Support Officer held individual interviews with the Executive Staff which comprises:

- a) Chief Executive Officer.
- b) Services and Information Co-ordinator.
- c) Clerical Officer.

In their view the development of social support groups over the three year project has impacted their work as follows:

The organisation has built itself to the point that it is now well placed to undertake the challenges of NEW HORIZONS Plan2015, [15] the new strategic plan for this Group, in particular social support development and enabling and empowering Polio Survivors. The Group is certainly challenged to maintain the momentum of the development over the coming years.

The work of the Regional Support Officer has expanded the capacity of the Group to grow and develop. She was able to draw on the innovative work of the Dublin Outreach Worker from 2007 to 2009[16] and employ the lessons learned.

A significant synergy was built up between the Services and Information Co-ordinator, the Regional Support Officer and the Dublin Outreach Worker (up to mid 2009). Each worked with different aspects of the Polio Survivor's life and brought together their experiences and challenges to advance the work of the Group.

Since the number of social support groups has increased, the Services and Information Co-ordinator has noticed an increase in requests for information and services. She has also noticed that members who telephone her are no longer doing so in isolation; there is less of a sense of one person looking after his/herself and more of a sense of community, of support group and of belonging. They show concern for each other.

The Services and Information Co-ordinator saw the work of the Regional Support Officer, in many respects, as extending the range of her work. The former's contact with members is chiefly on the telephone while the latter interacted with members face-to-face (as she has attended various social support group meetings around the country). She was the outreach from the office and an important intermediary for the Services and Information Co-ordinator. The Regional Support Officer was alert to the nuances of many personal situations and able to enhance the work of the Services and Information Co-ordinator by supplementing the information already available and by alerting her to issues that might otherwise not come to notice. The two jobs complemented each other and built a synergy which helped improve services to the Polio Survivors.

The Regional Support Officer disseminates current and accurate information to members such as explaining and emphasising the importance of completing the annual questionnaire. She has facilitated those members who are reluctant to ask for help, boosting their confidence and liaising with the Information & Services Co-ordinator so that making the initial call to the office is made easier for them. This eases communication between all concerned especially assisting those members who may have literacy, hearing or other barriers to communication.

The Clerical Officer has been an important link between the new Social Support Groups and their host hotels and other activities requiring expenditure. The volume of work passing across the desk of the Clerical Officer has increased since the setting up and development of the social support groups. The need to devolve this work has become clear.

### **3) Feedback from the members:**

- a) Questionnaire[17] to the members attending selected social support meetings. This was conducted at the meetings by the Regional Support Officer and responses were recorded by the convenors.
- b) Postal questionnaire[18] to all the convenors.

a) The Regional Support Officer selected a representative sample consisting of eight of the social support groups and presented a questionnaire to members at meetings. The aim of the questionnaire was to get feed-back from members on their opinions of social support provision in general; on their level of satisfaction with their individual groups; on suggestions for improving the structure of their individual groups and on the level of commitment from members to the dynamic of their individual groups. The eight groups were chosen with regard to locations; size of group attendance and length of time established so that as wide a variety of opinions as possible was invited.

### **The key findings were:**

- Satisfaction with the concept of social support in general and especially with the development of social support groups and the work of the Regional Support Officer over the three years of the project was expressed.

- The need for improved communication between the organisation and the members to combat impressions of a hierarchical structure within the organisation.
- Personal benefits arose to members through attending group meetings, particularly in regard to availing of relevant information; getting direction on where to go for services and supports; learning from others' experiences; being in contact with other Polio Survivors.
- Development of a sense of self-worth and alleviation of feelings of isolation and loneliness, were common to all the responses. Many have also mentioned the fact that they can now be more accepting of their condition by coming to terms with their physical limitations.
- Personal resistance to seeking assistance has diminished and the quality of life has been greatly improved with suitable support.
- In general, feelings of isolation, labelling or being a burden on their families are lessened when members see how others cope; how confidence increases through sharing experiences; how achieving a more positive attitude can lift the spirits and how a better quality of life is possible through interaction with fellow Polio Survivors.
- Associates, i.e. carers, family and friends who attended meetings, expressed their appreciation for all the information to which they now have access and for the greater understanding they now have of the energy cost of everyday living for Polio Survivors.

**b)** A questionnaire titled “The Role of the Convenor” was sent to all of the convenors and generally the responses to the questions were very similar. There was a strong overall emphasis on the need for support and training, not only to bring definition and clarity to the role but also to enable the convenors to feel more confident in their leadership and facilitation skills which would make their group meetings more vibrant, positive and enjoyable for their members.[\[19\]](#)

**The key areas of concern were:**

- The need for training in people skills.

- The need for training in IT.
- The need for media training.
- The need for training on structuring and organising groups.
- The need for greater contact between convenors for mutual support.
- The need for invigorated support for convenors from the organisation i.e. the Social Support Committee.

## Outcomes

---

At the commencement of this project there were already eight social support groups in existence. Some of these were working effectively while others showed little activity. In December 2010, on completion of the project, the number of groups has increased to twenty one.[\[20\]](#)

### **Activities**

Many of the groups organise social outings, art and craft activities, sporting activities and computer courses for their members. Such activities are usually community based (partnership) or provided by a disability agency such as People with Disabilities in Ireland (PWDI), and The Irish Wheelchair Association (IWA).

### **Guest Speakers**

The groups arrange for guest speakers to give expert talks at the meetings occasionally. This brings new energy to the meetings and provides up-to date information on issues relating to entitlements, services or latest appliances and items which help to make life easier for Polio Survivors, especially those who are coming to terms with Post Polio Syndrome.

### **Media**

A significant outcome of the social support groups has been the endeavours of members to reach out to Polio Survivors who are not yet members of the Post Polio Support Group. All of the support groups put notices in local establishments, advertise in local newspapers and church newsletters and give interviews on local radio when possible.

### **Fundraising**

Many of the groups are involved in fundraising activities and all of them undertake at least one fundraising project each year.

### **General**

The personal development of the members and their sense of self-appreciation have developed in a very evident way in many of the groups. For many, indeed, the art of the possible has become a reality.

*“The convenor and committee members feel that our Dublin south west group has gone from strength to strength since our first meeting on 24<sup>th</sup> March 2009.*

*Good bonds and friendships are being cemented and whether a dozen or double that are at meetings no one is bored!*

*Our Christmas party in December 2009 and our Summer outing in 2010 were brilliant – we Post Polio Support Group members make our own fun and are all fighters of post polio problems and all support each other.*

*Many of us are prepared to work for our cause and highlight to the public a forgotten illness to try and get assistance for our members across the country in difficult times.” (Quote from “Our Stories” Dublin south west Group)*

A significant outcome of the support group meetings is the social interaction and enjoyment that members find through sharing and comparing experiences in the informal, relaxed atmosphere.

Carers and family members have also stated that they have a greater understanding of the day-to-day problems encountered by polio survivors and they have been enlightened by sharing their experiences and developing their knowledge.

The Ring Ring and Phone Chat projects have been an important extension of social support. They complement the social support groups as not all members can attend meetings and some others do not wish to.

**The major recommendations come under the following three headings:**

**1) Continue to expand the membership**

- The estimated number of Polio Survivors in Ireland is 7,000.
- The estimated number of Polio Survivors who will develop Post Polio Syndrome is 60% - some 4,000.[\[21\]](#)
- The membership of the Post Polio Support Group is less than 900.

Expand the membership to embrace the 7,000 polio survivors in Ireland, many of whom may not be aware of the existence of the Post Polio Support Group. This must continue to respect the privacy of those who do not wish to join the Group. The social support groups must play a key role in the NEW HORIZONS Plan2015[\[22\]](#) to expand the membership by undertaking local information campaigns.

**2) Increase the leadership role of members.**

NEW HORIZONS Plan2015[\[23\]](#) emphasises that the Group is member led. Innovative ways of encouraging members to participate in the Group's activities continue to be kept at the forefront of social support groups' programmes. Increased involvement of the members in running the activities will build a stronger Group.

**3) Continue to develop social support groups.**

The Regional Support Officer has observed that a social support group naturally works to develop their member participation; to look for new and innovative programmes; to be a place of sharing and caring and above all, to be a place where members can engage with each other in a climate of mutual respect and enjoyment of each other's company.

The following recommendations are offered in order to sustain existing groups; to introduce further new groups; to attract and develop a volunteer base of leaders and to provide the best possible support for members.

#### **a) Transition – long term**

A long term programme to further develop the work of the Regional Support Officer is strongly recommended. The first phase has been incorporated in the development plan: NEW HORIZONS Plan2015[24]

*“The first phase will be based on three territorial divisions to be the same boundaries as HSE Dublin Mid Leinster plus North Dublin East, HSE South, and HSE West. It is intended that seminars including representatives from each social support group should gather to point the way forward. Such divisions will elect delegates to represent them, appropriately, including progression to Board membership. The process will start in the East followed by the South and West. The Group will respond to this challenge and put the mechanisms in place to facilitate this development, including changes, as necessary, in the Memorandum and Articles of Association. A training and development programme will support the empowerment programme.*

*A programme will be put in place to gradually devolve functions such as training, social support, including telephone support, fundraising, awareness and public relations, information distribution, and growing the membership. A guiding principle will be not to overload particular people with work but to recognise that there is an untapped willingness to work for the Group amongst the membership.*

*The Group will work to ensure that its members feel that they have ownership of their lives and lifestyles and will continue its policy of providing development opportunities for members and deepening their roles in running the organisation.” [25]*

#### **b) Transition - short-term**

A vacuum must not be allowed to develop before the new structures are activated. What is needed is the establishment of means which will continue to foster good and sustained contact with the group convenors and their teams. Such a system will be the lynch pin in the social support structures by supporting and encouraging; handling queries; suggesting solutions to

difficulties encountered; monitoring and providing an invigorating response to the everyday issues arising for the social support groups. The efforts of the Social Support Committee will be key to this work.

While very little support may be required by established groups, the newer groups will have greater need for sensitive and encouraging support. This may necessitate active support at meetings.

### **c) Convenors**

It is recommended that the leadership of each group be rotated every two years. This will avoid the possibility of an authoritarian structure developing in the groups, or one person being left with all the work.

The leadership, nominated by the members, consisting of convenor as spokesperson and a team who share the tasks of running the group, is the structure preferred by members at the workshop “*The Structure of Groups*” held in Cuisle in November 2010.

Training for convenors, especially new convenors and updating skills training for all convenors is necessary and this was emphasised in the evaluation of the questionnaire “*The role of the Convenor*”.[\[26\]](#)

It is also suggested that an information pack be given to each convenor consisting of a copy of the Convenor’s Manual, relevant literature, members’ contact details, other convenors’ contact details, Social Support Committee names and contact details and stationery items.

### **d) Group Interaction**

Interaction among the groups, i.e. attending a neighbouring group’s meetings; arranging joint outings or events; exchanging knowledge and sharing ideas among convenors and their teams will foster a sense of unity of purpose. Since the purpose of the groups is to provide information; a safe environment where fellow Polio Survivors can share their experiences, good and bad; support and encourage each other: the more interaction and sharing among the various groups the broader the perspective.

## **e) Associates**

Carers, family and friends have always been welcomed at meetings; this should continue. The more informed the associates are the better they will be able to respond to the needs of Polio Survivors by understanding the condition and the limitations it imposes.

Associates play a very significant part, not just in the fundraising endeavours of the Post Polio Support Group; they are also at the forefront in supporting activities in social support groups:

*“We have a good mix of Survivors and their families and friends and these associates are always welcome and are a great help to us in many ways. For example, our convenor is a family member, and our best fundraiser is a family member”. (Quote from “Our Stories” Castleblayney Group.)*

## **f) General**

While the task of developing the volunteer base, local and regional structures has been well advanced during this three year project, it is not complete; in fact it is not a task that has an end, rather the needs of Polio Survivors for the provision of social support will remain as long as the Post Polio Support Group exists. Therefore, the following recommendations remain to be mentioned.

Continue to identify localities where clusters of members could meet with convenience and form their own local support groups. This involves using every opportunity to use the media i.e. local radio, newspapers and fliers and organising local information days to reach out to the many Polio Survivors who have yet to discover the benefits of membership of the Post Polio Support Group.

- Set up a web page for each group on the Post Polio Support Group website. This would be a very useful means of communication for members who are housebound because of their disability.

- Continue to support and encourage existing groups to grow into member led, interactive, informative, light and positive support groups.
- Manage the transition to Ring Ring and Phone Chat and other support mechanisms for those who physically cannot attend meetings.
- Encourage and assist members to avail of opportunities to update their communication, literacy and computer skills.

## Conclusion

---

Through the expansion and development of social support within the Post Polio Support Group many members are actively involved in the development and implementation of the strategic plan NEW HORIZONS Plan2015.[\[27\]](#)

There is a tangible sense among the members of the social support groups of pride in, and ownership of the Post Polio Support Group. A new vigour and enthusiastic willingness to share this sense of belonging is evident. For many, this means being part of a united family of Polio Survivors.

**Table 1: Status of Social Support Groups - December 2010**

<b>Group</b>	<b>Number On Mailing List</b>	<b>Attendance Low - High</b>	<b>Number of Meetings Per year</b>	<b>Structure</b>
Athlone	18	10 - 15	2/3	Convenor
Bray	42	10 - 18	Monthly March – Nov.	Convenor + Deputy Convenor
Carlow	18	10 - 15	4/5	New Group
Carrick-on-Shannon	13	5 - 10	3/4	New Group
Castleblayney	18	10 - 18	4/5	Convenor + Assistants
Clare	25	12 - 14	4/5	Convenor
Cork	130	40 - 80	4/5	Convenor
Donegal	35	9 - 16	3/4	Convenor
Dublin All Hallows	30	14 - 18	Monthly	Convenor + Team
Dublin south west	83	12 - 29	5	Convenor + Team
Dublin Swords	21	6 - 12	Monthly	Convenor

Enniscorthy	22	2 - 6	Monthly March – Nov.	Convenor
Galway	14	5 - 10	3/4	Convenor
Kerry	17	6 - 12	2/3	Convenor
Kildare	32	14 - 18	4/5	Convenor + Team
Kilkenny	42	22 - 26	4/5	Convenor
Limerick	47	20 - 29	4/5	Convenor + Deputy Convenor
Mayo	20	4 - 6	2	Convenor
Navan	33	14 - 18	4/5	Convenor + Team
Portlaoise	42	8 - 14	4/6	Convenor + Team
Sligo	13	6 - 8	2	Convenor
<b>Total 21</b>	<b>715</b>	<b>239 - 392</b>		

**Table 2: Progression of Social Support Groups - December 2010**

<b>Group</b>	<b>Initial area of interest</b>	<b>Activity</b>	<b>Structure</b>
Athlone	Westmeath (part) Roscommon (part) Galway (part)	Mature group	Convenor
Bray	Wicklow. Dublin S/E	Mature group	Convenor + Deputy Convenor
Carlow	Carlow	Facilitating new group	Not yet activated
Carrick-on-Shannon	Leitrim Roscommon (part) Cavan (part)	Facilitating new group	Not yet activated
Castleblayney	Monaghan Cavan (part) Louth (part)	Mature group	Convenor + assistants
Clare	Clare	Mature group	Convenor
Cork	Cork city and county Kerry (part)	Mature group	Convenor
Donegal	Donegal	Assisting new group	Convenor
Dublin All Hallows	Dublin North	Mature group	Convenor + Team
Dublin	Tallaght	Mature group	Convenor + Team

South West	Dublin south + west Kildare (part)		
Dublin Swords	Swords Balbriggan Dublin Nth. East	Mature group	Convenor + Assistant
Enniscorthy	Wexford	Mature group	Convenor
Galway	Galway (part) Mayo (part)	Mature group	Convenor
Kerry	Kerry Cork (part)	Facilitating new group	Convenor
Kildare	Kildare	Facilitating new group	Convenor + Team
Kilkenny	Kilkenny Waterford (part) Carlow (part)	Mature group	Convenor
Limerick	Limerick Tipperary (part) Cork (part)	Mature group	Convenor + Team
Mayo	Mayo (part) Roscommon (part)	Mature group	Convenor
Navan	Meath Louth (part)	Mature group	Convenor + Team
Portlaoise	Laois Offaly (part)	Mature group	Convenor + Assistant
Sligo	Sligo	Assisting group development	Convenor



**Table 3: Review of Social Support Groups - September 2009**

<b>Group</b>	<b>Initial area of interest</b>	<b>Activity</b>	<b>Structure</b>
Athlone	Westmeath (part) Roscommon (part) Galway (part)	Mature group	Convenor
Bray	Wicklow. Dublin S/E	Mature group	Convenor + Deputy Convenor
Castleblayney	Monaghan Cavan (part) Louth (part)	Assisting group development	Convenor + assistants
Clare	Clare	Assisting group development	Convenor
Cork	Cork city and county Kerry (part)	Mature group	Convenor
Donegal	Donegal	Facilitating new group	
Dublin All Hallows	Dublin North	Assisting group development	Convenor + Assistant
Dublin South West	Tallaght Dublin Sth. + West Kildare (part)	Facilitating group development	Convenor + Team
Dublin Swords	Swords Balbriggan	Assisting group	Convenor +

	Dublin Nth. East	development	Assistant
Enniscorthy	Wexford	Facilitating group development	Convenor
Galway	Galway (part) Mayo (part)	Mature group	Convenor
Kerry	Kerry Cork (part)	Assisting group development	Convenor
Kilkenny	Kilkenny Waterford (part) Carlow (part)	Facilitating new group	Convenor
Limerick	Limerick Tipperary (part) Cork (part)	Assisting group development	Convenor + Team
Mayo	Mayo (part) Roscommon (part)	Facilitating group development	Convenor
Navan	Meath Louth (part)	Assisting group development	Convenor + Team
Newbridge	Kildare (part) Carlow (part)	Facilitating group development	Convenor
Portlaoise	Laois Offaly (part)	Assisting group development	Convenor + Assistant
Sligo	Sligo	Facilitating group development	Convenor

**Table 4: Social Support Groups - March 2008**

Group	Initial area of interest	Activity	Structure
Athlone	Westmeath (part) Roscommon (part) Galway (part)	Assisting group development	Convenor
Bray	Wicklow. Dublin S/E	Mature group	Convenor + Deputy Convenor
Clare	Clare	Facilitating group development	Convenor
Cork	Cork city and county Kerry (part)	Mature group	Convenor
Enniscorthy	Wexford	Assisting group development	Convenor
Galway	Galway (part) Mayo (part)	Mature group	Convenor
Newbridge	Kildare (part) Carlow (part)	Facilitating group development	Convenor
Portlaoise	Laois Offaly (part)	Assisting group development	Convenor

## Appendix 2: Stories from selected Social Support Groups

---

This section contains original stories from the following groups:

- Castleblayney Group – *Jackie Minnock & Mairead Mathews*
  
- Clare Group – *Edwin Bailey*
  
- Cork Group – *Evelyn Wainwright*
  
- Dublin All Hallows Group – *Eddie Roycroft & Bridget Quigley O'Brien*
  
- Dublin south west Group – *Sandra Brooks*
  
- Kildare Group – *Monica Sheehan*
  
- Kilkenny Group – *Susan Dowling*
  
- Limerick Group – *Marie Boland*
  
- Navan Group – *Joan Gargan*

## Castleblayney Group

The first meeting of the Castleblayney Group took place on 20<sup>th</sup> October 2008 in the Glencarn Hotel Castleblayney. This venue was chosen as being the most convenient for the majority of members who lived in counties Monaghan, Cavan and Louth. The first two meetings were social gatherings and the theme was “sharing our stories”. People got to know each other and enjoyed the interaction over a cup of tea.

At the third meeting we were joined by Joan O’Donnell from the Disability Federation of Ireland (DFI) who facilitated a discussion on how to structure our group and planning ahead. We wanted our group to be mainly a social get-together where we could have access to information on post polio syndrome and be able to talk about matters of concern to us. Our main concerns are getting information and finding out how to access our rights and entitlements. We exchange helpful tips on keeping well and we keep in touch with each other so that no one feels left out or alone. Jim Murphy volunteered to be the Convenor for our group and Jackie Minnock and Mairead Mathews help Jim to organise the meetings.

The attendance at our meetings varies between 10 and 16. Some people have to travel a long distance; others depend on lifts so they cannot always attend. Because of this, it is difficult to organise activities. We have a good mix of Survivors and their family/friends and these associates are always welcome and are a great help to us in many ways. For example, our convenor is a family member, and our best fundraiser is a family member.

We have guest speakers occasionally and also visits from members of the Board and Staff of the Post Polio Support Group.

Guest speakers were:

Physiotherapist

Occupational Therapist

Representative from the Carers Association

We have had visits from the ex-Chair of PPSG Hugh Hamilton, the present Chair John McFarlane and the CEO Eamonn Farrell who informed us of how the organisation is run and explained the plans for the next five years as outlined in NEW HORIZONS Plan 2015. All the members agree that these visits are very informative and we all feel part of the bigger picture.

In 2010 we had our first summer gathering in Dundalk and we were joined by the newly formed Navan group. A very enjoyable evening was had by all. Members from Dublin south west, Swords and Navan groups supported our fundraising night in the Crowne Plaza in Dundalk.

We have a Christmas party every year which everyone looks forward to.

We have tried to increase our numbers by placing notices of meetings in Church Newsletters in the Cavan, Monaghan and Louth areas and also placing notices on LMFM and local radio in Dundalk, Cavan and Monaghan.

We have not as yet taken on any projects but our group would be quiet active on fundraising especially through the excellent efforts of Brendan Moore and others. We have more fundraising events planned for 2011.

*Jackie Minnock and Mairead Mathews*

## **Clare Group**

I attended an inaugural dinner in the Temple Gate Hotel Ennis with Tom Gallery as convenor. I think this was May 2008 in which I won dinner for two in Ashford Castle.

Christmas 2008 we had a Christmas lunch in the Abbey Tavern, Quin at which we had an enjoyable general knowledge quiz organised by Hugh Weir with prizes for almost everyone. Tom Lane came along to provide music and some members sang their hearts out.

Early 2009 we had a meeting in the DPOC premises in Ennis at which Geraldine Keaveny gave us a presentation on the work of the Disabled People of Clare. She is the CEO and the presentation was informative and enjoyable.

During the summer of 2009 we had an outing to Brigit's Garden in Moycullen Co. Galway. This is a Celtic Garden which takes you on a journey through the cycle of the year, Samhain, Imbolc, Bealtaine and Lughnasa. About 12 participated and enjoyed the day out.

Also in 2009 our chairperson of the time, Hugh Hamilton, paid a visit to our group, the meeting held in DPOC premises. Hugh gave us a full review of the work of PPSG and how it was funded and plans for the future.

There was one other meeting later in 2009 at which we discussed our individual problems and members told of how they coped with their situation.

Christmas 2009 we held a Christmas lunch again in The Abbey Tavern in Quin. This was again an enjoyable affair.

Our convenor Tom Gallery retired end of 2009. In 2010, I was asked to take responsibility for the Clare Group which I accepted. Our first meeting was 31<sup>st</sup> of March in DPOC at which we had a photographer make a presentation titled "Towards Better Photography". This was in view of the fact that we had a photo-competition at the AGM. The photographer was Seamus O'Donoghue, secretary of Shannon Camera Club. All enjoyed the evening and many asked questions about depth of field and exposure time etc.

Our next meeting was on the 16<sup>th</sup> of June in DPOC at which one of our members Peggy Walsh, a flower arranger, made a presentation titled “Forecourt Flowers – Achieving the Most from the Least”. Anne Shanahan attended this meeting and some group business was accomplished before we introduced Peggy. Members enjoyed her presentation and her arrangements were presented to members to take home at the end.

Members had decided not to have a summer outing as some would be away and some had other outings during the summer to attend.

In September we joined with the Limerick group in The Strand Hotel to hear Senthil Kumar, PT. MISCP, and Director of the First Step Rehabilitation Centre in Patrickswell, speak on “The Importance of Correct Exercise in a Post Polio Situation”. Senthil also spoke at the 2010 AGM.

In October we met in The Temple Gate Hotel Ennis, where Liam Toland, MD of Home Instead Senior Care made a presentation on how they provide help to seniors and their families who desire assistance to facilitate them living at home.

Our next meeting will be Christmas Lunch again in The Abbey Tavern Quin. Members like the venue as it is all one level with wheelchair access and plenty of room.

The Clare Group has 25 on the mailing list but only 20 are circulated as others are either house bound or disinterested. One or two live in east Clare therefore are closer to Limerick. The average attendance at meetings would be about 12-14 but this includes some spouses or partners. At the moment I am a one man band but know there are others who will help if required. I intend discussing the group structure in the New Year.

We recently had a large article in The Clare Champion which was aimed at attracting new members or survivors. We had no success here but a representative from Home Instead Senior Care made contact. They have a large medical mailing list and will insert our flyer into their next circular free of charge. This could be a valuable way of getting our information out there.

We do not have any activities organised in our group as we are a small group and scattered.

*Edwin Bailey*

## **Cork Group**

The Cork group is one of the longest established and it is also the largest group having 130 names on the mailing list. Members come from Cork city and county and from parts of Kerry. The attendance at meetings ranges from 40 to 80. The meetings are informal and members get to know each other well. They support each other by sharing information and experiences and they keep in touch with each other outside of the meetings.

Guest speakers have attended meetings from time to time and topics of importance to Polio Survivors such as aids and appliances and entitlements, have been discussed. Many other educational and social topics are also covered.

The Cork group organises many outings and events. The major event of the year is the Chill Out Day. This event is usually very well attended and members spend the whole day in a peaceful and relaxing venue. Another big event is the summer outing which for the past 3 years has been to Fota Island.

Fundraising is very important in the Cork group; the marathon and the mini- marathon being the major events. There are also several other fundraising events organised by the group and also by individual members.

*Evelyn Wainwright*

## **Dublin All Hallows Group**

The All Hallows group started in the spring of 2008 the attendance at meetings varies between 14 and 18 and members come from a wide catchment area: Blanchardstown, Balbriggan, East Wall, Clontarf, Finglas, Pearse St. Artane, Cabra and Beaumont. We find that All Hollows College, Drumcondra is a very good central location to hold our monthly meeting in.

### **The structure of the group which is very democratic is composed of:**

Convenor and Deputy Convenor, Secretary and Deputy Secretary, and Treasurer.

Minutes and agendas are kept.

We elect a new committee every year and we try to get everyone involved in the running of the group.

### **What we do at meetings:**

Our meetings are held on the last Wednesday of every month from 11.30am to 3.30pm. The first hour or so is given over to a “whinge hour” which means that all those present have an opportunity to talk about the ups and downs of life and we all feel better having vented our frustrations if any. The whinge hour does not go over the hour allotted to it. Then we get down to other business. We may have a speaker in or we discuss issues relating to post polio and we make plans for future events and have an enjoyable, sociable afternoon together.

We also have a “Buddy System” which means that we keep in touch with each other by telephone, home/hospital visits or cards/letters, especially if one of our members is unwell or unable to come to meetings for some reason. We also tell members about the Ring Ring and Phone Chat programmes.

### **Guest Speakers that have visited us:**

A Physiotherapist

A Yoga teacher

A person from the Patient’s Representative organisation

A person from the Mobility Care Centre

We also had visits from Hugh Hamilton and Eamonn Farrell from the PPSG.

### **Activities**

Outings are very popular with our group and we have been to the following:

Ardgillen Castle, Malahide Castle, Botanic Gardens, Collins Barracks,

Dáil Éireann and we had a great weekend away in the Hudson Bay Hotel, Athlone.

We have a Christmas party every year which is very well attended by members and guests.

### **Courses some of our members are attending:**

Computer course held in the PWDI centre in Jervis St.

Art & Craft at the Art Squad, Finglas

We are presently preparing for an Art & Craft exhibition organised by the Tolka Area Partnership.

There are no fees for these courses apart from a charge for art materials.

We source information on courses that are going on in the catchment area and see if any of our members would be interested. We then check if there is a grant available and if the venue is accessible.

The courses are very enjoyable and we hope that they will continue. We need at least seven people to attend the Art & Craft course if it is to continue.

Unfortunately, one of our members was unable to attend the Art & Craft course as the building was not fully accessible. The lift was far too small for her wheelchair and there are no disabled toilets.

A few of our members have contributed items for the newsletter

THE SURVIVOR; stories, articles, poetry and art work.

### **Interaction with other groups**

We have exchanged visits with the Dublin Swords group.

The computer classes are also attended by members from the Dublin Swords and Dublin S/W groups so we are all getting to know each other.

### **Plans for 2011**

Drama classes if a grant is available

Swimming

More outings

*Eddie Roycroft and Bridget Quigley O'Brien*

## **Dublin south west Group**

The Dublin south west group hold their meetings in the Maldron Hotel, Tallaght, usually on a Monday night from 7.30pm to 9.30pm. Occasionally they change the time to an afternoon meeting from 2.30pm to 4.30pm to facilitate those members who are unable to come to evening meetings.

The first meeting was held on 24<sup>th</sup> March 2009. Notification of the meeting was sent to 91 members living in the catchment area. 40 people attended and there were 27 apologies.

Joan Bradley, Director and Trustee, attended this inaugural meeting and gave a short talk about the organisation and what it is trying to achieve. Anne Burns, Director and Chair of the Social Support Committee, gave a short talk on the existing social support groups and Lillian McElvaney explained her role as the Services and Information Co-ordinator. At this meeting, members voted by a show of hands to set up a peer support group for Polio Survivors living in the Dublin south west area. Since then, the group has gone from strength to strength. There are 83 names on the mailing list. The attendance at meetings varies between 14 and 28. New members are always welcome as are family and friends.

### **Structure:**

The structure of the group comprises of the Convenor who is the main contact and spokesperson for the group and a team of six members who are allocated the following tasks:

- Convenor
- Deputy Convenor
- Confidential liaison
- Secretary
- Information technology.
- Hospitality and Records

On the day of a committee meeting, we book the dates for the next three group meetings with the venue, so that the secretary can inform the members before each meeting.

In December 2010 the group will have been in action for 21 months. During this time we have had eleven group meetings and also six committee meetings where plans are discussed for final decision

at the next group meeting.

The team is always conscious of the skills and talents of the members and tries to draw on this pool of expertise for the benefit of all polio survivors.

### **Training:**

Members of the team attended a training weekend in Cuisle in November when they were able to meet and get to know other group Convenors and representatives and participate in the workshops.

Three members of our group attended a media training course held in the offices of the Disability Federation of Ireland (DFI). Following on from this a media presentation by one of our members took place in the Mansion House, Dublin.

Three of our members also attended a sports seminar also organised by DFI.

### **Matters discussed at meetings:**

On the practical side the constants are:

- Aids and appliances
- Boots/shoes and callipers
- Coping with pain and fatigue
- Transport
- Entitlements - E.g. Medical card: Long term illness card: Primary Medical cert. Grants for home adaption; Heating/housing grants and many other matters.

On the social side the constants are:

- Loneliness
- Feeling isolated or forgotten

- Unable to access information
- Need for personal development and confidence building.

The group tries to address these issues by encouraging members to attend meetings; to share experiences; to pass on information; to be in contact with each other by telephone or card/letter especially when a member is ill or feeling low.

### **Guest Speakers:**

From time to time a guest speaker will be invited to a meeting. So far five speakers have given a talk on their particular subject:

- Louise McCann from DFI facilitated a discussion on the structure of groups.
- Hugh Hamilton Previous Chair PPSG spoke of plans for the future and fundraising.
- Deirdre Murray, Physiotherapist, from Beaumont hospital talked about her research into physical exercises suitable for Polio Survivors.
- Ann McEwan from the HSE explained about the NPSD Database.
- Eamonn Farrell, CEO, outlined the strategic plan – NEW HORIZONS Plan2015.
- There were two talks by our own members:

One on the occasion of *International Women's Day* and the other on

*Useful tips and ideas on how to keep warm in winter.*

### **Outings and Activities:**

- Six members attend a swimming course at the St. John of God Centre, Island Bridge.
- Five members are attending computer classes held at the PWDI centre Jervis St. and it is hoped that they will continue in 2011.
- A visit to the Bowling Alley was organised recently.
- A social night was organised at the Ballyfermot Sports Centre.
- Chess lessons are available kindly offered by one of our members.

- A summer outing to the Botanic Gardens was a huge success
- About forty members and friends attended a Christmas party in December 2009 and this year's Christmas party will be on 7<sup>th</sup> December 2010

## **AGM**

- At the 2009 AGM held in the Maldron Hotel, Tallaght, there was a good attendance from our group and we helped to man the registration table.
- A large number from our group attended the 2010 AGM held in Limerick and they manned the bookstand - meeting and enjoying the company of other Polio Survivors from all over the country.

## **Launch of NEW HORIZONS Plan2015**

Dublin south west group was well represented at the launch of the new strategic plan recently.

## **Fundraising**

- We have fundraising in the pipe line for 2011.
- One of our members who celebrated her 40<sup>th</sup> wedding anniversary recently, raised a substantial amount by requesting donations to PPSG in lieu of gifts.

## **From the Convenor and the team:**

The Convenor and committee members feel that our group has gone from strength to strength since our first meeting on 24<sup>th</sup> March 2009.

Good bonds and friendships are being cemented and whether a dozen or double that are at meetings no one is bored!

Our Christmas party in December 2009 and our Summer outing in 2010 were brilliant – we PPSG members make our own fun and are all fighters of post polio problems and all support each other.

Many of us are prepared to work for our cause and highlight to the public a forgotten illness to try and get assistance for our members across the country in difficult times.

Also, we would like to claim the following as a description our Dublin south west group:

***Our support group is for Friendship and Fun***

***Our shared support and information is for everyday living!***

*Sandra Brooks*

## **Kildare Group**

Following the dissolution of the Newbridge Group two new groups were formed; one based in Carlow town and the other in Clane, Co. Kildare.

The first meeting of the Kildare group was held in the Westgrove Hotel, Clane on 28<sup>th</sup> July 2010 and was attended by John McFarlane Chair of the Post Polio Support Group and by Anne Shanahan, the Regional Support Officer. Notification of the meeting was sent to 32 members living in the catchment area and the attendance was 14.

The second meeting was held in the same venue on 27<sup>th</sup> September 2010. Anne Shanahan presided. There were 18 members present. Anne outlined her proposal for the future of the group and this was agreed and accepted. Six members agreed to form a team to work together to organise meetings and to make plans for the future.

On 1<sup>st</sup> November 2010 the group met again. The team announced their suggestions and plans for the next few meetings and Tom Carberry was chosen to be the spokesperson and contact person for the group with the title of convenor. Eamonn Farrell, CEO of the Post Polio Support Group was the guest speaker. He talked about the strategic plan for the next five years: NEW HORIZONS Plan2015 and this was followed by a discussion and questions.

It was agreed that as the Westgrove Hotel is very convenient, accessible and has ample parking, the majority of people would like to have all further meetings held there.

It was felt that as it is so near Christmas, and everyone is busy with little time to spare at the moment that we shall have a party in the New Year instead of in December.

Monica Sheehan asked members what activities the group might like to participate in and swimming and possibly a social night was mentioned. Vincent Scully will take this on board.

The meetings so far have been very enjoyable and the cup of tea makes it possible for people to get to know each other.

This is a new group and we are only finding our feet. People don't know each other yet. However, we are hoping that the party will help us to bond and we are eager to get going and to be very productive in 2011.

*Monica Sheehan*

### **Kilkenny Group**

Living in north Kilkenny, my nearest social support group meeting was in Enniscorthy, Newbridge or Portlaoise, all of which were at least one hour's drive away: there was no group meeting in counties Kilkenny or Waterford leaving a huge gap in the national network. I mentioned this to a member of the PPSG Board who suggested that I might like to start a group in my area!

After discussions with the Regional Support Officer it was decided to hold a meeting in Kilkenny. Letters were sent to all members living in counties, Kilkenny, Waterford and south Tipperary inviting them to a meeting in Days Hotel Kilkenny on 1<sup>st</sup> September 2008. The meeting was also publicised in local newspapers and on the Kilkenny Carlow local radio station. Attempts were made to contact all members who did not respond to the letter. Some members did not wish to attend; some were unable to come and some would like to participate but did not have transport.

On the night, 19 members and 8 associates attended the meeting making a total attendance of 27 people. There was a general discussion and the majority of those present were in favour of meeting from time to time. It was suggested that the next meeting could be for a Christmas meal in November. I agreed to organise this function and contact members when arrangements have been made. The Christmas meal took place on 3<sup>rd</sup> November and was a great success. It was attended by Anne Burns, Chair of the Social Support Committee and the Regional Support Officer.

Following discussions between myself and the RSO, it was decided that the group needed to develop a structure and a plan for the future and we needed to hear the opinions of the members. We invited the DFI local representative P.J. Cleere to facilitate our next two meetings in February and April of 2009. Very useful discussions took place on how the members wanted the group structured; possible topics for discussion and suggestions for activities and outings. Since then, meetings have taken place on a regular basis in February, April, June and September with a Christmas meal in November/December. These usually take the form of a discussion followed by refreshments.

There are currently 46 members on the mailing list and the average attendance at meetings is 25 members and their guests. We have welcomed Hugh Hamilton as the then Chairman of the PPSG; Eamonn Farrell who is the CEO of the PPSG, and Deidre Murray, Physiotherapist from Beaumont Hospital who is doing a research project in connection with Post Polio Syndrome. Members living in the Carlow area have also joined us on two occasions.

Some members recently organised a very successful fundraising activity in Dungarvan, Co. Waterford.

Although I act as the group's leader, other members take an active part in the organisation of the meetings especially events like our annual Christmas meal- about 36 members attend this very popular event.

The Kilkenny group is very sociable and at each meeting time is allocated for members to share their news and views and to enjoy each other's company.

*Susan Dowling*

## **Limerick Group**

On September 4<sup>th</sup> 2008 the present social support group met in the Greenhills Hotel, Ennis Road, Limerick under the guidance of Anne Shanahan, Regional Support Officer. Evelyn Wainwright, a member of the Board of PPSG and Convenor of the Cork Group, came to lend her support and give us the benefit of her experience. Notifications of the meeting were sent to 37 members living in the catchment area, but as expected, we did not have a full complement on the night. We meet 8 times yearly and we have an average of 25 attending each meeting. The Limerick region covers north Tipperary and east Clare as well as Limerick city and county. In the interest of convenience for the members we have moved our location to the Strand Hotel, on the Ennis Road. We frequently have a guest speaker.

### **Guest speakers to-date:**

- The former chairman of PPSG Hugh Hamilton.
- Two Fire Officers who gave a slide show and talk on safety and precaution in the home.
- A representative from True Life, a Cork based company who specialize in orthopaedic aids.
- Mr. Sentil Kumar PT MISCOP Director of Feet First Rehabilitation Centre in Patrickswell. (Twice by demand),
- Mr. Liam Toland from Home Instead spoke on a nationwide programme whereby the elderly can be cared for at home.
- Mr. Derry O'Malley, Acupuncturist.
- Mr Gerard Dore, Consulting Psychologist
- Eamonn Farrell CEO of the PPSG

### **Activities and functions:**

- We have a Christmas Dinner each December.
- The biggest event was organising the Conference and AGM in May. In the lead up to this, two members of our group did several radio interviews and newspaper interviews with a view to creating awareness of the Post Polio Support Group and the needs of Polio Survivors.
- We are involved in fundraising activities such as the Limerick Ladies Mini Marathon (2009 and 2010)

- Bag packing (Supermarket) this November for the first time.

We were delighted to welcome five new members to our group recently.

We have several associates - family and friends of members - who are always welcome at our meetings and are a great support to us.

*Marie Boland*

## **Navan Group**

The Navan group was started on September 2009. There are 33 names on our mailing list. We hold meetings every second month in the Ardboyne Hotel, Navan which is accessible and has ample parking.

Our meetings are very sociable. Members like to talk about their situations especially in relation to the different aids and appliances available; problems relating to boots, shoes and callipers; entitlements; questions about the medical cert: Doctor only medical cert: primary medical cert. and hearing and other grants available from the Post Polio Support Group. Many of the problems are solved simply by listening to each other.

We particularly enjoy the chat at tea/coffee time. Members support each other by keeping in contact especially if one is not well or unable to attend a meeting.

Occasionally, we invite a guest speaker. We had a very informative talk by a representative from the Citizens Information bureau. Some of our own members have given very interesting talks, for example, one person explained about the grants for disabled drivers/passengers, others gave talks about the history of polio and about the many books and articles published on the subject of post polio syndrome.

We had a very enjoyable get-together in Dundalk with our neighbouring group from Castleblayney. It was a great experience to meet up with the members of another group for the first time.

We have not been involved in any activities or courses yet.

However, we are discussing organising swimming and bowling in 2011.

We would also like to let other Polio Survivors in our area know that we have a support group in Navan so we plan to contact our local radio station and local press.

Our next event is the Christmas party which promises to be as good a night as last year.

*Joan Gargan*

**Questionnaire: The Role of the Convenor**

**Training needs of the Convenor:**

*Q 1 What new training or skills development would enhance your role of Convenor?*

- Training in people skills
- Organising meetings
- Computer skills
- Communication training
- Recognising member's needs
- How to draw up aims, objectives and action plans
- What training is available?
- What do members need from groups?
- Inter-group visits by Convenors
- Public speaking skills training
- Knowledge of entitlements

**Ways that the PPSG can be of support to Convenors:**

*Q 2 How can the organisation better support Convenors?*

- Regular meetings of Convenors to share ideas.
- Regular training to update Convenors re Post Polio Syndrome
- Each group should have a secretary to take the minutes

- Will the organisation subsidise training courses?
- Can we trace polio survivors to encourage them to join?
- (This was mentioned by three Convenors)

**Regarding better communication:**

*Q 3 How can the Post Polio Support group improve communications with the Convenors?*

- One person to be in touch with all Convenors to plan, support and set up training.
- Communication from Convenors to members is in need of improvement
- Regular meetings of Convenors with a Board member.
- Correspondence should be more user friendly.
- How can we up-skill members who are not computer literate?
- More inter-group meetings are needed to get to know each other
- Regular contact needed between Head Office and Convenors
- Training such as Cuisle in November 2010 would enable suggestions to be made and followed up

**Involving members in their group:**

*Q 4 Can you suggest ways of identifying and encouraging members to use their skills and talents for the benefit of the group?*

- Each member should do something for his/her group. For example, take turns in organising a meeting or using whatever skills each member has for the good of the group.
- People can show their talents by organising activities
- Get an outside facilitator or someone from within the PPSG to help members to know what skills and talents they have and how to use them
- A questionnaire to all members asking what they could do for the PPSG

- Arts and crafts. Flower arranging. Story telling or recording your memories of polio – recording on tape by interviewer.
- What skills are there in each group?

**Group involvement in activities or projects:**

*Q 5 Has your group been involved in any art, craft, sporting activities or project work?*

- Six responded “No” to this question
- Art classes and preparing for art exhibition
- Held a flower arranging talk by a member
- Small group go swimming and we hope to improve this

**Anticipated changes over the next five years:**

*Q 6 How do you see you group changing over the next five years?*

- More organised social outings and especially inter-group outings
- Contacting more Polio Survivors in our catchment area
- Helping members with updated information re supports and the HSE
- We are a good strong group. Interaction and support for each other is wonderful and this will grow.
- We will work towards getting better attendance at our meetings.
- Try to get better health services for Polio Survivors.
- Our group will find out about the skills and talents of the members and have personal development courses especially computer training and arts and crafts.

**Questionnaire: Castleblayney Group, Attendance: 15**

***Q1. Why do you come to meetings?***

- I am interested in meeting other polio survivors.
- Information
- Listening to people tell their stories and learning how they cope.
- I never realised there was a support group in this area until my consultant told me about it.
- To socialise with people in the same situation as myself.
- I enjoy it. Everyone is always so cheerful.
- I realise I am not as badly affected as some others and I am grateful and would like to help others who were not as fortunate as me.

***Q2. How has coming to the group been of benefit?***

- Information
- More friendships
- It is good to see others surviving and getting on with their lives.
- Got help with my aids and appliances; physiotherapy; respite break and heating grant.
- Since getting involved with the group I feel less isolated. I have somewhere to go every six weeks or so.

***Q3 What is needed so that this group continues?***

- The group has to continue.
- Positive attitude
- Work on it.
- Attract new members
- Everyone has to say their say
- All have talents that can be used
- All talents brought to the table
- Undertake projects.
- Get involved e.g. attend the AGM; computer classes; swimming; art; other activities.
- Utilise all media to publicise the group
- Information days in local venues.

***Q4 Did the appointment of a RSO affect the PPSG?***

- Yes
- Establishment of groups and support was vital. Without the RSO this would not be possible.
- RSO gave insight into the PPSG
- RSO enabled members to get involved
- RSO enabled members' voices to be heard and acted on.

***Q5 Does this group feel they have participated in strengthening the Post Polio Support Group?***

- Yes
- Everyone is encouraged to use their voice so that the organisation can hear them and be aware of our needs and act on our behalf.
- Fund raising has greatly increased since more members are aware of the need for fundraising.
- If the organisation is to remain strong - the members need to be actively involved.
- We feel worthy of the things we get from the PPSG because we are involved, we work together, we are active and willing and happy.
- The PPSG is a very important part of a polio survivor's life. We want it to continue so that it can support members who need it especially since we are all getting older.

## Questionnaire: Clare Group, Attendance: 19

### ***Q1. Why do you come to meetings?***

- Recommended to come by physiotherapist Did not know of the PPSG before meeting with physio
- I meet people with similar difficulties. Sort out my problems with PPS, help available.
- Important to have a local linkage leading into the main organisation
- Did not know that there were so many PPS sufferers. Improved awareness

### ***Q2. How has coming to the group been of benefit to you?***

- Benefiting from loads of information
- Seeing how others cope with their condition
- Receiving advice of locations to get help with appliances
- Receive information on entitlements and grants
- Get up-to-date information on appliances and aids

### ***Q3. What is needed so that this group continues?***

- Good social side to events
- Better participation by Post Polio people
- Make meetings interesting
- Volunteer life stories – 10 minutes each night and a collection of life stories created.
- Keeping up to date with developments in treatment – main focus

- Arrange a table quiz
- Good energy in the group

***Q4. Did the appointment of a Regional Support Officer affect the PPSG***

- Good for the PPSG
- Improved contact
- Bring items to notice of organisation
- More awareness now

***Q5. Does this group feel they have participated in strengthening the PPSG***

- Certainly
- Attending the AGM's
- Participating in events – looking forward to joint meetings with neighbouring regional group
- Additional strengthening may be achieved by publicity in local newspapers and local radio.

**Questionnaire: Kildare Group, Attendance: 18**

***Q1 Why have you come to the meeting?***

- Interested to meet other survivors
- Information
- Listening to polio stories

- How we cope
- Never realised there was a support group for polio survivors
- Heard from a Consultant about the group (PPSG)
- Social aspect of those who have the same complaint

***Q2 How has coming to the group been of benefit to you?***

- Information
- More friendships
- It is good to see other survivors
- Helped with aids and appliances
- Physiotherapy
- Life is made easier
- Less isolation – somewhere to go every few weeks – something to look forward to.

***Q3 Where to go from here?***

- Positive attitude has to continue
- New members
- Work together
- Everyone has to say their say
- We all have talents that can be used
- Undertake project and bring to AGM
- All talents brought to the table
- Utilise all media to publicise the Group

- Design posters
- Information days in the surrounding counties – possibility of 9/10/11<sup>th</sup> July 2011. Posters

***Q4 Did the appointment of a Regional Support Officer affect the Post Polio Support Group?***

- Yes
- Establishment of groups and support was vital because without the Regional Support Officer this would not be possible
- RSO gave insight into the Post Polio Support Group
- RSO enabled members to get involved
- RSO enabled members' voices to be heard and acted on

***Q5 Do the members of this group feel that they have participated in strengthening the Post Polio Support Group?***

- Yes
- Everyone is encouraged to use their voice and to be heard
- Fundraising has increased
- Members feel worthy of help they get from PPSG
- Strengthening of the PPSG needs the members to be active.

**Questionnaire: Kilkenny Group, Attendance: 26**

***Q1 (a) Why do you come to meetings?***

***(b) Why do you stay?***

- To meet other polio people
- Support
- Acknowledgement of our condition
- Not alone
- Information
- Strength in numbers
- Social
- Access services

***Q2 What has been the greatest benefit for you from the group?***

- Learning a little every time
- Friendship
- Being involved
- Up-dated on post polio
- Not the only one
- Listening to others
- Surprise at meeting others with same condition

**Q3** (a) *What are your hopes for the future of the group?*

(b) *How can we make this group better?*

- Susan leader (+ Liam)
- Dedication
- Organisation strong from the beginning
- Continue to be well organised
- New members – try to attract others
- Use the media - especially local
- Social networking – attending AGM – Christmas dinner
- Share skills and talents
- Reaching out
- Sharing
- Outings

**Q4** (a) *Does our group have a voice?*

(b) *Are we listened to?*

(c) *Is the PPSG stronger?*

- Yes
- We pass on information to doctors and other medical professionals
- (After discussion the following questions were raised by the group): Should our group get involved in lobbying for improved services or should we focus on social support?
- Should we be lobbying at national level on some issues e.g. LTI recognition, VHI etc.?
- Should we link up with other organisations to do this?
- Should our group lobby at local level also?
- Liaison person to ask other groups re services
- We are listened to – read the new plan Horizon

**Questionnaire: Navan Group, Attendance: 14**

***Q1 Why do you come to meetings?***

- To learn something new in a nice group. Opinions are very broad
- I have never been with another group of polio survivors since I was in hospital years ago.
- You think you are the only one until you meet people in the group.
- You learn how little has been done by the government for polio patients.
- You got no help at the time. There was no financial help then.
- Everybody has got something from the group, like tonight, information.
- You look forward to meeting the other people.
- Collective help

***Q2 How has coming to the group been of benefit?***

- A network of contacts
- A sharing of experiences
- You know where to go if you need further help.
- Certain security in knowledge
- Interesting topics
- Raises your spirit.
- The bigger the numbers, the more say we have in getting things.
- Going to the AGM in Limerick proved that there is someone there to help.
- People need the push to look for aids, appliances and information.

- You have a national advocate to get grants or other entitlements.
- We know that we must keep writing – keep knocking at the door.

**Q3** *What is needed so that this group continues?*

- No harm to get mention on local radio say the week before the meeting is on.
- A lot of people are not members or didn't want to be members but might at a later stage of life.
- Get the word out by whatever means.
- People who want to do a radio interview can get a template of answers from the office.
- We need regular structured meetings.
- We should give out fliers.
- A lot of members are notified about the group meetings but do not come.
- Information leaflets should be in all doctor's surgeries, libraries etc.
- We should all be doing our bit to let more people know about the group.
- "Buddy System" – members of the group would watch out for each other.

**Q4** *Did the appointment of a RSO affect the PPSG?*

- Yes.
- Group are more accessible by all members.
- There is more contact
- The RSO is the conduit from the members to the organisation.
- The organisation has had a wakeup call due to the greater level of activity on the ground.

- Greater contact between different groups due to the effect of the RSO.

***Q5 Does this group feel they have participated in strengthening the PPSG?***

- Yes
- Different opinions and perspectives
- The newsletter has pieces on all the local groups
- The organisation is strengthened by the voices of the members.
- Collectively, the members, the groups and the national organisation have a greater impact on government policy.
- We are giving as well as taking
- Information from the local groups gives power to national organisation to pursue entitlement or change policy.

**Questionnaire: Portlaoise Group, Attendance: 10**

**Q1** (a) *Why do you come to meetings?*

(b) *Why do you stay?*

- To meet each other.
- Social.
- Meeting other polio people that I can relate and connect with.
- Find out about any new development in relation to the treatment of post polio syndrome
- Find out when events are taking place such as the AGM and the Christmas party.
- Update my social diary.
- I keep coming so that I meet those members who only come on nights when there is something special on.
- Friendship and bonding with others.
- Sit and chat.
- Enjoyable evening.
- Informal and entertaining.

**Q2** *What has been the greatest benefit for you from the group?*

- New friendships.
- Communicating with others.
- Social outings – Summer and Christmas.
- Getting information on services such as physiotherapy, hydrotherapy, swimming, disabled drivers issues etc.

- Exchanging information with each other.
- Become more aware.
- Encouraged to apply for different services.

**Q3 (a) What are your hopes for the future of the group?**

**(b) How can we make this group better?**

- My hope is that the group will get bigger and better.
- That people who don't come to meetings will start to come.
- Consider more social outings among the members (outside of the meetings) so that we keep up the contact and interest.
- Maybe we should target members not coming to the groups e.g. take the opportunity of meeting up with people at the AGM to bring awareness to others.
- Advertise – radio, newspapers etc.
- Share with each other.

**Q4 (a) Does our group have a voice?**

**(b) Are we listened to?**

**(c) Is the PPSG stronger?**

- We were not listened to before.
- When Mary was in charge we had a voice because they listened to her.
- We are not shy and have been successful.
- Paddy is our Regional Rep and also Convenor for a long time. We all think that these

roles should rotate every 2/3years.

- The organisation (PPSG) will be stronger if it listens to the members.
- The people in charge need to visit all the groups when they are having their meetings. We only see them at the AGM.
- We could be involved in not only social activities but also take up practical issues like reaching out to other polio survivors, becoming aware of our entitlements, having our needs met.

## **MISSION STATEMENT**

*Our Mission is to create awareness and to provide information regarding the late effects of polio among Polio Survivors, statutory agencies and the wider medical profession, and to ensure that the needs of Polio Survivors relating to their condition are met to enable them to live with dignity*

## **Guiding Principles**

The Post Polio Support Group is member led and Polio Survivors are central to its work

Services and supports will continue to be provided, based on needs identified through consultation with members, fairly and within the financial capacity of the Group

The Group will act according to best practice and in line with its Code of Conduct

Sensitivity, empathy and understanding are central to communication with Polio Survivors

Polio Survivors will be encouraged and enabled to live their lives with dignity

The Group will advocate for Social Policy change to encompass the needs of Polio Survivors

The Post Polio Support Group will cooperate and collaborate with other stakeholders, as appropriate

## **Core Objectives**

To create awareness and provide information on Post Polio Syndrome

To support Polio Survivors

To advocate on behalf of Polio Survivors

*Delivery of the Strategic Development Plan for the period September 2007 to September 2010, known as PLAN TWENTY TEN, will be accomplished through four Programmes, the first three to deliver the core objectives, and the fourth to enable the Group's direction and control of the process*

## **TARGETS for PLAN TWENTY TEN**

### **PROGRAMME Awareness and Information**

#### **TASK Create Awareness**

*Design and implement initiatives to create awareness of the late Effects of Polio targeting individual Polio Survivors, their families and carers, health care professionals and whole communities*

Three year key target

Polio Survivors, their families and carers will be aware of the Group and its services

Other targets

Promote media coverage of Post Polio Syndrome in order to increase consciousness of the condition within society

Investigate novel methods of promoting awareness

#### **TASK Provide Information**

*Make information available in accessible formats to Polio Survivors and to all involved in their support and treatment, in particular those working in the medical and social care professions*

Three year key target

Promote the publications of the Group, particularly THE SURVIVOR, and promote and develop the website as an information tool

Other targets

Promote “Post Polio Syndrome – Management and Treatment in Primary Care” within the medical and social care professions

Promote awareness of State and other benefits available to Polio Survivors

**TASK    *Research***

*Review current research on Post Polio Syndrome and developments related to the Late Effects of Polio encouraging and supporting relevant applied research*

Three year key target

Promote research in line with the Group's policy to improve the management of the care of Polio Survivors and the treatment of their conditions

Other targets

Ensure that the results of research programmes are fed back to Polio Survivors in accessible formats

**TASK    **Develop Volunteer Base, Local and Regional Structures****

*A well developed local structure is required to support the nationwide organisation and to invigorate it. Linkage to local health service delivery, as appropriate, will continue to be important*

Three year key target

Improve and enhance the connections amongst the Group members within local and regional areas, which will form a basis for conducting activities, encompassing social gatherings and other developmental projects.

Other targets

Develop structured assistance to those organising local activities

Make the necessary contacts with those in evolving health service structures

Encourage and train volunteer personnel to support and manage social

gatherings, activities and other development projects, generating sufficient funds

## **TASK    Contact and Support**

*Maintain contact programmes with Polio Survivors to ensure that their sense of isolation is minimal and that they can be made aware of the supports available to them*

Three year key target

Develop the range and types of peer support which can be made available to Polio Survivors so that each can access those most suitable to his or her needs

Other targets

Develop opportunities for social and learning activities

## **TASK    Membership Development**

*Encourage all Polio Survivors to join the Post Polio Support Group ( membership fee €10, optional ) as this provides the most effective means of maintaining contact and passing on information on new developments*

Three year key target

Increase membership by a minimum of 10%, net per annum

Other targets

Review the impact of aging on the Group membership particularly in light of the application of benefit changes at key ages in the retirement range

## **PROGRAMME    Support for Polio Survivors**

## **TASK Building Adaptation**

*Assist Polio Survivors to make arrangements to adapt their homes, working towards a quality and standard of access which supports them in their efforts to maintain a high degree of independence*

Three year key target

Make information available to members wishing to adapt their homes to maximise their independence and help them through the process

## **TASK Assistive Technology**

*Provide Polio Survivors with technological and related products and systems which can make living easier and so reduce or eliminate dependency*

Three year key target

Make Polio Survivors aware of the products and systems which can enhance independence and work with them to provide appropriate assistive technology

## **TASK Aids and Appliances**

*Provide devices designed to reduce or eliminate pain and fatigue and to increase the capacity of Polio Survivors to function as independently as possible*

Three year key target

Each Polio Survivor who feels he or she may need aids or appliances will have a prompt Occupational Therapy assessment carried out and speedy supply of the appropriate items

Other target

Provide an enhanced information stream on products available

## **TASK    Physiotherapy**

*Make arrangements for Polio Survivors to receive therapy designed to alleviate pain and ease muscle and joint problems*

Three year key target

Polio Survivors, on request, can have access to appropriate treatment to counter, as far as is possible, deterioration arising from Post Polio Syndrome

## **TASK    Occupational Therapy Services**

*Make arrangements for Polio Survivors to receive professional advice on lifestyle coping mechanisms, including advice on aids and appliances, assistive technology and adapting their living environments to maximise their mobility and independence*

Three year key target

Each Polio Survivor requesting assistance will receive one holistic Occupational Therapy assessment during the three year period or more frequently, if required

## **TASK    Counselling**

*Make arrangements for counselling support for Polio Survivors should they require it*

Three year key target

Encourage Polio Survivors to avail of appropriate counselling services when they feel they are required and assist them in developing their choice of a suitable counsellor

## **TASK    Respite Care**

*Make arrangements for Polio Survivors and their carers to avail of short periods of rest and relief where necessary*

Three year key target

Each Polio Survivor who requires a respite break to help sustain his or her living situation will be assisted with arrangements

Other target

Promote the dissemination of information about locations for suitable respite breaks

### **TASK Future Service Development**

*Continue to examine, with suitable expert assistance, the services, treatment and management options which might be made available to Polio Survivors*

Three year key target

Evaluate proposed supports and, if appropriate, work with the membership to plan future service delivery

## **PROGRAMME Advocacy**

### **TASK Advocacy**

*The Post Polio Support Group is the national campaigner for the Polio Survivor community and acts to maximise the entitlements available and to ensure that Polio Survivors both individually and as a group are treated with dignity*

Three year key target

Continue to develop a relationship with Legislators, Government Departments and their agencies and work with colleague organisations in other states to establish a presence within the European Union to improve conditions for all Polio Survivors

Other targets

Investigate the provision of a personal advocacy service in which the advocate assists in identifying Polio Survivors social service needs and needs relating to their condition

Advocate on behalf of those being infected at present in countries which are still diagnosing new cases of poliomyelitis

### **TASK Disability Sector**

*Take an active role in the development of the Disability Sector working in partnership with stakeholders in like groups in developing services and other supports*

Three year key target

Continue to work with disability and other voluntary organisations to improve supports for people with disabilities and to ensure delivery of Government commitments, particularly those under the Disability Act 2005

Other targets

Investigate the creation of linkages with Polio Survivors in Northern Ireland to promote joint working on matters of mutual interest

### **PROGRAMME Management and Systems**

#### **TASK Policy Support**

*Work in partnership with relevant Government Departments, their agencies, in particular, the Health Service Executive in developing the necessary supports to maintain the dignity and*

## *independence of Polio Survivors*

### Three year key target

Track developments within the Health Service Executive, and otherwise, as new arrangements are put in place for people with disabilities and ensure that Polio Survivors are catered for in an appropriate fashion.

### Other targets

Track appropriate legislation and regulatory and other developments assessing implications for Polio Survivors

## **TASK Service Level Agreement and Business Planning**

*Negotiate service level agreements developing constructive partnerships with the Health Service Executive and others to serve the needs of Polio Survivors. Draw up Business Plans to ensure delivery of the Group's commitments and put the arrangements in place to ensure purposeful review of the process*

### Three year key target

Enter formal agreements, as appropriate, to provide a set level of service to Polio Survivors

### Other targets

Continuously review the mechanisms to assess the needs of Polio Survivors so that the Group improves the targeting of its supports

Set up administrative systems to improve delivery of services

Improve business planning processes within the Group

## **TASK Fundraising**

*Conduct carefully planned initiatives to raise funds to complement that provided, principally by the Health Service Executive, to allow the Group more scope for its support efforts*

Three year key target

Develop the fundraising capacity of the Group both locally and nationally to augment the revenue of the Group and fund additional supports for Polio Survivors

Other targets

Examine new methods of encouraging continued donations

Encourage people to donate to the Group in their wills

### **TASK Evaluation, Monitoring and Accountability**

*Conduct regular oversight and review of all arrangements to support Polio Survivors to improve their effectiveness and efficiency, implementing assurance mechanisms, as required*

Three year key target

Assure that Post Polio Support Group systems and administration are being managed as effectively as is possible to satisfy audit requirements, in particular, those laid down by the relevant Government and other funding authorities

Other targets

Governance and Nominations Committee will monitor the progress of Plan Twenty Ten on a six monthly basis and report to the Board

Develop Terms of Reference, guidelines and reporting structures for Committees and for those members with particular responsibilities within the Group

Review policy development and work practices to improve service delivery

### **TASK Training and Development**

*Conduct an active programme of training and development encompassing the Board and Committee members, those members with particular responsibilities within the Group and the executive staff*

### Three year key target

Provide training and development for members with key roles in the organisation, and for staff to support the delivery of Plan Twenty Ten

### Other targets

Develop good practice guidance for members, including the Board and the staff

Review Board composition and development

### **Help Polio Survivors access the supports they require**

From the Group Guiding Principles Services and supports will continue to be provided, based on needs identified through consultation with members, fairly and within the financial capacity of the Group

- Promote the wellbeing and mental health of Polio Survivors
- Interact with and facilitate Polio Survivors to choose the supports they require giving them greater say in making that choice. The Group will invest the time and patience to source best solutions for Polio Survivors thus deferring the day that an individual has little option but to resort to full time residential care.
- Pursue the expanded provision of state benefits to enhance the supports available to Polio Survivors

*Enable and empower members to take increased ownership of their situations and assume a greater role in running the Group*

-

From the Group Guiding Principles The Post Polio Support Group is member led and Polio Survivors are central to its work.

- The Group will embark on a programme to devolve the running of the organisation, as appropriate, to local level under the general direction of the Board. This will be done in a graduated way with ideas being tested and proven and then developed organically.
- It will develop a structure to run a devolved organisation. The first phase will be based on three territorial divisions to the same boundaries as HSE Dublin Mid Leinster plus Dublin North East, HSE South, and HSE West. It is intended that seminars including representatives from each social support group should gather to point the way forward. Such divisions will elect delegates to represent them, appropriately, including progression to Board membership. The process will start in the East followed by the South and West.
- The Group will respond to this challenge and put the mechanisms in place to facilitate this development, including changes, as necessary, in the Memorandum and Articles of Association. A training and development programme will support this empowerment programme

- A programme will be put in place to gradually devolve functions such as training, social support, including telephone support, fundraising, awareness and public relations, information distribution, and growing the membership. A guiding principle will be not to overload particular people with work but to recognise that there is an untapped willingness to work for the Group amongst the membership.
  
- The Group will work to ensure that its members feel that they have ownership of their lives and lifestyles and will continue its policy of providing development opportunities for members and deepening their roles in running the organisation.
  
- Social support, whether face to face or by telephone, is a growing force in the lives of Polio Survivors, family members, friends and other carers. Perceptions are changing that social support is for all not just those who need help. There is a developing fellowship arising from the involvement of more people in these activities. There is huge potential for these groups to develop themselves and to be agents to help fellow Polio Survivors, drawing in non polio volunteers, as required, and to advance the work of the Group. The recruitment of non-polio volunteer support for Polio Survivor activities will be actively pursued.

***Continue to improve communication with Polio Survivors generally and with those who are members of the Group***

From the Group Guiding Principles Sensitivity, empathy and understanding are central to communication with Polio Survivors

Examine the increased use of telephone based systems to promote contact between Polio Survivors, building on the work done to date.

- Examine optional ways to get information to Polio Survivors. Look at using various media options rather than focussing exclusively on written communication.
  
- Promote awareness of Post Polio Syndrome and the work of the Group. The Group should conduct targeted public relations initiatives to focus on the activities of daily living and its challenges for Polio Survivors and divert it from telling their history, such as overcoming childhood adversity.

- Develop the website further making it more accessible to Irish Polio Survivors and keep the content newsworthy and up to date. Look at social networking media such as Twitter and Facebook to reach Polio Survivors. Examine developing initiatives in information technology to provide the necessary contact.
- Study the results of the Members Satisfaction Survey, 2010, gauging the success of the Group in meeting the aspirations of its members.
- Find ways to project successful personal solutions to post polio problems on a national basis while not specifically endorsing individual practitioners or suppliers.
- Examine the feasibility of projecting “International Polio Day” to raise awareness and to promote contact with Polio Survivors

***Monitor the policy development and the administrative environment***

From the Group Guiding Principles the Group will advocate for Social Policy change to encompass the needs of Polio Survivors

- Keep a focus on the lack of availability of certain services, particularly health related ones upon which Polio Survivors depend. Highlight where long waiting times prolong and increase the suffering of Polio Survivors
- Monitor developments such as the National Rehabilitation Strategy and the Value For Money and Policy Review and future policy documents thereby ensuring proper and appropriate care arrangements for Polio Survivors
- Respond to new administrative demands from funders, particularly the Health Service Executive.
- Influence the process for the award of the Primary Medical Certificate to take into account the particular circumstances of Polio Survivors

***Increase the knowledge base of the Group***

- The Group is increasingly aware that it is becoming an essential source of data for many concerned with the management and treatment of Post Polio Syndrome or Post polio Myelitic Syndrome as we must now learn to call it since its recent recognition by the World Health Organisation and it will continue to update its knowledge and service all requests.
- The Group will consult widely on the provision of advice on pain and pain management and will work to provide better solutions for Polio Survivors in pain.
- Study will be made of cognitive problems amongst Polio Survivors with a view to providing better support to them in this respect.
- The Group will continue to examine the provision of better shoe, calliper and brace solutions for Polio Survivors. Group research shows that many react by abandoning the appliances with consequences involving falls and, in some cases, fractures. The Group will continue to work with members, suppliers and others to improve this situation.

### ***Building linkages with other organizations***

From the Group Guiding Principles

The Post Polio Support Group will cooperate and collaborate with other stakeholders, as appropriate

- Linkages with the HSE are critical to the successful work of the Group and this partnership will deepen over the period of this plan. The Group will play a full part in the new consultative structures being set up by the HSE and looks forward to an increasingly active partnership. The Group sees its links to the Disability Federation of Ireland and the Neurological Alliance of Ireland as key supports to this relationship.
- The Group will continue to interact with a wide range of organisations, statutory, commercial, and non-statutory in the interest of developing better support solutions which can be made available to Polio Survivors.

- The Group will continue to benefit from specialist expertise in Ireland and to work with colleague organisations in the European Union countries, through its membership of the European Polio Union, to promote new knowledge and research into Post Polio Syndrome.
- The group is a member of the Carmichael Centre and continues to value its access to its supports and facilities.

*Manage finances to maintain or increase the ability of the Group to support Polio Survivors*

- The Group will continue to place a major management focus on its cost centres. It will continue to drive down costs in administrative, overhead and expenditure areas, negotiating firmly with existing and potential suppliers.
- It will continue to energise and motivate the membership to be active fund raisers and to develop this very important revenue source. The Board and the general membership will continue to be active in generating funds to enable the Group to make a comprehensive support service available to Polio Survivors

The Group will actively seek to identify and secure new sources of funding from state, philanthropic organisations and others, while still maintaining its current funding lines.

- 
- [1] Appendix 5: Strategic Plan: PLAN TWENTY TEN
- [2] Philip Roth- Nemesis. p.154
- [3] Hart, J. in A Challenge for Healthcare; Neurological Alliance of Ireland 2010: p14
- [4] Appendix 5: Strategic Plan: PLAN TWENTY TEN: 1
- [5] Appendix 5: Strategic Plan: PLAN TWENTY TEN
- [6] Post Polio Syndrome Management and Treatment in Primary Care: Post Polio Support Group: 2007: Foreword.
- [7] Appendix 5: Strategic Plan: PLAN TWENTY TEN
- [8] Hart. J. in: A Challenge for Healthcare; Neurological Alliance of Ireland 2010 p.14
- [9] Appendix 1: Table 4: 2008. Table 3: 2009. Table 2: 2010.
- [10] Appendix 5: Strategic Plan: PLAN TWENTY TEN
- [11] Appendix 6: Strategic Plan: NEW HORIZONS Plan2015
- [12] Ibid
- [13] Appendix 6: Strategic Plan: NEW HORIZONS Plan215
- [14] Terms of reference - Social Support Committee: [www.ppsg.ie](http://www.ppsg.ie)
- [15] Appendix 6: Strategic Plan: NEW HORIZONS Plan215
- [16] McCarthy, Margaret: *You are Part of this Family Now*: PPSG: 2009
- [17] Appendix 4
- [18] Appendix 3
- [19] Appendix 3
- [20] Appendix 1: Table 1
- [21] *Post Polio Syndrome - Management and Treatment in Primary Care*:  
Post Polio Support Group: 2007: Foreword.

[22] Appendix 6: Strategic Plan: NEW HORIZONS Plan215

[23] Ibid

[24] Appendix 6: Strategic Plan: NEW HORIZONS Plan215

[25] Ibid

[26] Appendix 3

[27] Appendix 6:

Published by



Post Polio  
Support Group

Ireland

Unit 319 Capel Building  
Mary's Abbey, Dublin 7

Tel: (01) 889 8920 Fax: (01) 889 8924

Email: [info@ppsg.ie](mailto:info@ppsg.ie) Web: [www.ppsg.ie](http://www.ppsg.ie)

Registered Charity No.: CHY 11356