



Annual Report

2013

Introduction

The mission of the Post Polio Support Group 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.

The Post Polio Support Group was established for Polio Survivors by Polio Survivors. The Group was formed in 1993 and is run by a voluntary Board of Polio Survivors and friends. It is supported by voluntary committees, other voluntary workers and a small executive staff at the office in Dublin. PPSG is the only organisation in Ireland providing practical support to those unfortunate enough to have contracted Polio. The Group currently has 917 members across the country.

PPSG assists Polio Survivors by providing aids to daily living, stair lifts, callipers, bespoke footwear, electric scooters and wheelchairs. The Group also helps Survivors access Physiotherapy, Occupational Therapy and Respite Breaks, and it provides those who need it with assistance with their heating bills. The Group employs two Service & Information Co-ordinators who provide information, respond to requests for assistance from members and, perhaps most importantly, provide a listening ear.

PPSG has a network of 22 social support groups around the country and also offers a telephone support service.

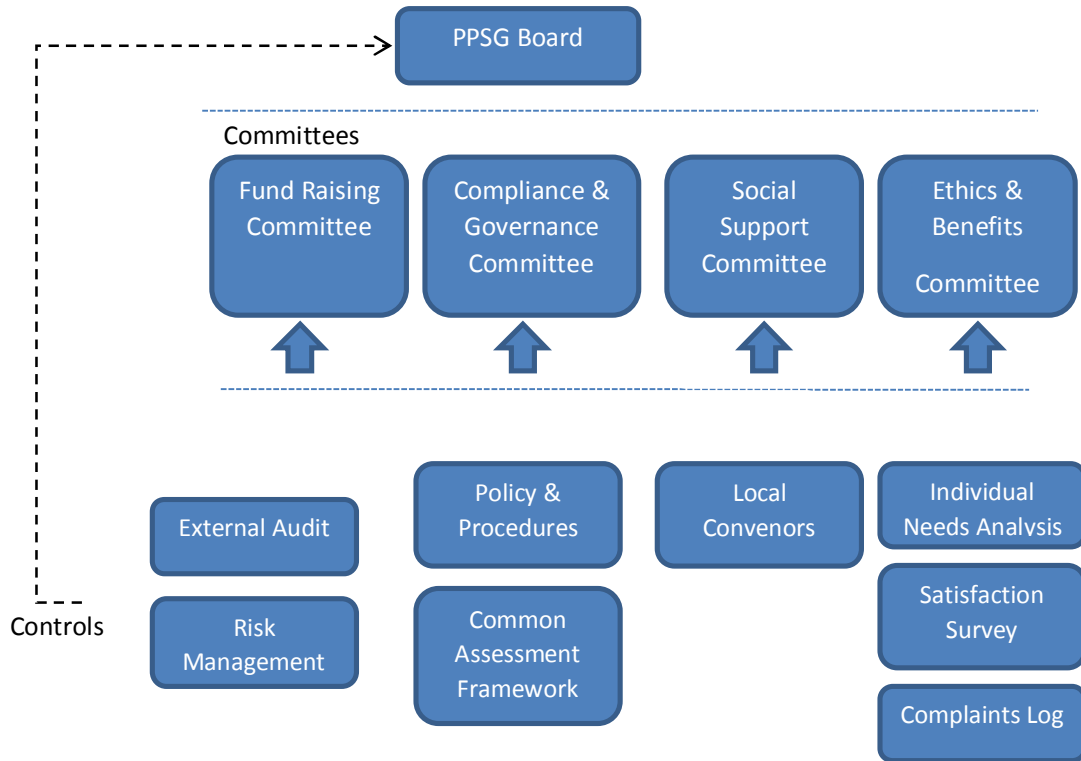
The Group works tirelessly to:

- Create awareness of Post Polio Syndrome
- Provide information on Polio and its late effects
- Ensure the needs of Polio Survivors relating to their condition are met to enable them to live with dignity

Any of the estimated 7,000 Polio Survivors in Ireland can contact the Group for support irrespective of whether they are a member or not.

Funding for the Post Polio Support Group is provided by the Health Service Executive; Department of Environment, Community & Local Government; the Polio Fellowship of Ireland; various grants from statutory and private bodies and fundraising by members, families and friends.

PPSG Organisational Structure



Chairperson's Report

The last year has seen several changes within our organisation. This has created some challenging situations but we have never lost focus of our mission - to support Polio Survivors in Ireland. This has been achieved by the unstinting support of our staff, volunteers, members, their families and friends who all helped keep the show on the road.



The first of these changes took place in January when Ruth Barror took over from Eamonn Farrell as our CEO. Eamonn was with us for 7½ years and made a huge impression on the membership and the health/disability sector. We are very grateful to him for his dedication and hard work.

Training sessions for new Leaders for the RingRing Telephone Support Service took place in Sligo in February and in Cork in March. A total of 16 new Leaders emerged from these sessions which meant that we could provide this service to an additional 32 members.

The AGM/Conference took place in Wexford in May. The main speaker was Caroline Casey of the Kanchi Foundation and the programme also included a Writers Workshop. The Conference was a tremendous success and over 200 people attended the two day event.

Another significant change occurred in September with the resignation of John McFarlane as Chairman of the Board and as a Director. Since joining the Board and then being elected Chair in 2010, John has, with the support of his wife Mary, made the most extra-ordinary contribution to the work of the Group: we thank him for all his efforts on our behalf and wish him the best of health and happiness in the future. Following John's resignation, I was appointed as Chair and Jim Barrett as Deputy Chair.

In October, we were honoured to have the European Polio Union (EPU) Conference and AGM take place in Ireland this year. Representatives from many Polio organisations in Europe attended the event in Tullamore, Co. Offaly. As October was also the 20th Anniversary of the founding of the PPSG, it was decided to have an event to celebrate this on the final day of the EPU Conference and we were delighted to welcome our European colleagues to join us for lunch on Sunday 20th October.


Our magazine, The Survivor, has always been a mainstay of our organisation. The Editorial Team of Peter Barron, Hugh McHugh and Monica Sheehan announced in the autumn that the Christmas edition would be their last. Their great work has been much appreciated by the membership and we are very grateful to them for their work.

The decision of Ruth Barror not to seek renewal of her contract as CEO at the end of the year brought about the final change of the year. We thank Ruth for her work with the Group and wish her well in the future. She was replaced by Fran Brennan in January 2014.

Apart from the many changes that occurred, 2013 was a challenging year for the Group in other ways. The ageing profile of our members and their increasing needs, especially from

the effects of Post Polio Syndrome, is well documented. Pressure on many peoples' incomes and reductions in State supports and services has meant that members increasingly need to turn to us for help. Providing the services they require has been increasingly difficult due to a reduction in our funding from the HSE. Funding from other sources is also becoming scarcer as grant programmes are either cut-back, or in some cases withdrawn, and increased competition in the sector from other organisations who are also experiencing cuts. This puts an increasing onus on us to expand our fundraising efforts as we continue to try to maintain our supports to members. We must live within our means however and we will have to examine every area of our expenditure to see where savings can be made.

During the last few months, and for a variety of reasons, a number of members have stood down from key positions within the organisation. These include 3 Board members, 1 Committee member, 3 Convenors, 3 Survivor Editors and 12 Telephone Support personnel. We thank them for their contribution: they will be sorely missed. We hope that some may be in a position to take on another role within PPSG in the future. However, they have left gaps that we now need to fill. I think this is an area where we need to "up our game" and be more proactive in the way we identify, train, mentor and support our volunteers. That is our priority for 2014 and I am confident that, having overcome significant change in 2013, a renewed PPSG will go forward and face the future with great strength and positivity.

A handwritten signature in dark ink, reading "Susan Dowling.", on a light-colored rectangular background.

Susan Dowling
Chairperson

John McFarlane – An Appreciation

We know that good voluntary bodies are successful because so many give of themselves by doing tasks which advance the welfare of their members. The Post Polio Support Group is successful and all who strive daily, weekly and monthly are deserving of the thanks of all Polio Survivors.

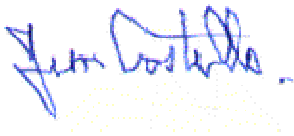


It is right, at the same time, to acknowledge exceptional people who make the PPSG the focus of their lives for many years. I would like to mention, in particular, John McFarlane. John and his wife Mary contributed massively to our organisation over a ten year period in a way which positively promoted PPSG in Ireland and throughout Europe, working with the European Polio Union. John and Mary were just as available to any member of the Group who wished to discuss symptoms of Post Polio Syndrome or the ways to import a customised vehicle, as John was to bring the concerns of Polio Survivors to Mr José Manuel Borroso, President of the European Commission, making a strong case for funds to research and tackle the problems arising from the Late Effects of Polio (Post Polio Syndrome).

John did not spare himself and we all wondered where he found the energy for his enormous workload, an energy he freely gave to make life better for all Polio Survivors. John retired as Chair of the Group last year and Mary as Occupational Health Adviser. They are missed but we are determined to continue to build on the legacy of their work. It is a great encouragement to Susan and the Board that John is still an active member of the Group, focussing principally on the European Polio Union, and we still regularly draw on his sound advice.

Thanks John for a great, productive ten years starting with your work with the team involved on the 2003 Survey highlighting the needs of Polio Survivors and finishing in 2013 as you completed a very successful period as Chair of the Post Polio Support Group.

Saol fada do'n beirt agaibh*.



**Jim Costello,
Company Secretary**

**Long life to both of you*

Annual Conference 2013

The Annual Conference and AGM took place on Monday, 12th May in White's Hotel in Wexford. 250 delegates attended the Conference which had as its theme "*Be Inspired and Inspiring*".

One of the highlights of the Conference was an address by Caroline Casey of Kanchi. Caroline is the Social Entrepreneur behind Kanchi, a not-for-profit disability organisation that works to change mindsets and behaviours. Caroline described her life journey and what motivated her to establish Kanchi and develop programmes such as The Ability Awards. Caroline's address was followed by a question and answer session where delegates had an opportunity to find out more. Delegates were extremely impressed with Caroline's vision, passion and achievements and many took the opportunity to chat with her after the session.



Another highlight of the event was a workshop on Mindfulness facilitated by Mary O'Callaghan. Mary is an experienced Mindfulness trainer and an accredited psychotherapist. Mary gave delegates an overview of Mindfulness before leading them through a demonstration of Mindfulness techniques.

Three Creative Writing Workshops were held in and around the Conference led by Geraldine Brosnahan. The workshops were proposed by Bernie O'Sullivan, Convenor of the Laois Offaly Social Support Group following suggestions from some of her Group. Geraldine is a writer and author of 10 novels and is also a member of PPSG. The workshops proved to be extremely popular with 30 members attending over the three sessions. The workshops decided to produce a collection of writing titled *How We Survived and Surprised*. The intention is that this will be a follow on from two previous publications from PPSG, *Polio and Us* and *The Arts and Us*.

New Board 2013



New Board elected at AGM in White's Hotel, Wexford

Standing L to R: Marie Boland, Jim Costello, Pat Guy, Tom Carberry, John McFarlane (Chair), Jim Barrett, Sean Breslin

Seated L to R: Evelyn Wainright, Susan Dowling, Rose Russell O'Donovan, Joan Bradley, Hugh McHugh

New Board Members

Jim Barrett

Jim had been co-opted to the Board in early 2013 and was subsequently elected to the Board at the 2013 AGM.

Jim is the third eldest born into a large family of five brothers and five sisters in a small town called Baltinglass in Co. Wicklow in December 1950. He contracted Polio at around 3 years of age. Over the next 10-12 years he spent a great deal of time in and out of several hospitals, undergoing numerous experimental operations, some thankfully he says were of some assistance.

Jim's national education was extremely limited, not unlike most people who contracted polio in or around that period. He eventually attended secondary education in Baltinglass Technical College and for a period Bolton Street College in Dublin and trained as a structural engineering technician.

Jim is married to Marie the love of his life who he met in a dance hall in Dublin they have 2 sons and a daughter. Their first grandchild Samuel is 4 year old in July 2013. Jim and Marie live in Kilkenny home of the hurlers.

In 1981 Jim was chosen from candidates from around the country to represent Ireland in architectural drawing in the first Abilympics which was held in Tokyo Japan. The aim and aspiration of this international exhibition was to show particularly to the so called able bodied people the ABILITY of people with disabilities rather than their individual disability.

He has worked in several consulting engineering firms in excess of forty years. His last employment was as office manager with a former colleague who had started his own small consulting engineering practice in Waterford where he spent approximately 20 fantastic years with some great colleagues and indeed very good friends before his retirement in December 2008. He was involved in numerous projects in Dublin such as the Bewley's Hotels Group. Jim was appointed to the Social Support Committee.

Sean Breslin

Sean had been co-opted to the Board in early 2013 and was subsequently elected to the Board at the 2013 AGM.

Sean was born in Ardara, small village in North West Donegal, and contracted the polio virus at the age of 2. The Polio Virus resulted in paralysis of his right side and left arm. While both arms recovered, his right leg was severely affected, and as a consequence it was, and still is, extremely weak and is much shorter than his left leg. Sean has used an assortment of walking aids including custom made boots, splints, calipers and crutches for support. He spent long periods of time hospitalised in Baldoyle and Cappagh Hospitals from the age of 10 until 16.

Sean secured a post as an Architectural Trainee Draughtsman in 1966 with a very reputable firm of Architects, B.F.Rathigan & Co. in Sligo. In 1969 he started working for F. Sweeney & Co. in Enniskillen, leaving there when he emigrated to New York in 1971. While there he commenced working for the Bell Corporation as a Cable Draughtsman.

Sean returned to Ireland in 1973 and started working with Dublin County Council in Parnell St. as an Architectural Draughtsman/Technician. In March 1979 he took up a similar post with Meath Co, Council. Sean retired in May 2011 after 38 years' service as an Architectural/Civil/Environmental Technician.

Sean married Kathleen in 1976 and today is the very proud father of four adult children, 3 men and 1 woman. His biggest regret however is that as the children were growing up he was unable to participate in any sporting events with them such as school outings, walks and playing football.

Sean is a relatively recent member of the Post Polio Support Group and hopes to contribute to all relevant discussions and policy issues during his time as a Board Director. Sean was appointed to the Compliance & Governance Committee.

20th Anniversary Celebrations

Celebratory Lunch

As one of a series of events and activities to mark the 20th Anniversary of PPSG, a lunch was held on 20th October in The Tullamore Court Hotel in Co. Laois. Over 100 members and friends from throughout the country attended this event which coincided with the European Polio Union AGM and Conference which was held in the same Hotel that weekend. The surviving members who founded the PPSG in 1993 were in attendance and were recognised for their enormous contribution and support.



Many others who made a significant contribution to the development of the PPSG through the years were also recognised. Polio Survivors from other European countries attended the dinner and joined in the celebrations. It was a great opportunity to share experiences. The excellent lunch was followed by an afternoon of sing song and chat which went down a treat especially with the overseas guests. The festivities went on well into the evening.

Message from President Michael D. Higgins

President Michael D. Higgins sent a message of congratulations to PPSG on achieving this important milestone:

I am pleased to send warm greetings to everyone involved in the Post Polio Support Group as you celebrate your 20th anniversary.

You can be very proud of your achievements since you embarked on this journey. You saw a need in society and you have worked tirelessly to satisfy that need. It is so important to have a body of people who are passionate and can truly relate to members of their group with empathy. This is a 'two-way street', because in giving of yourselves and your time so generously, you have also received something invaluable in return - creating a rich, diverse and caring organisation. Everybody has something to offer within a group like this and those who are Polio Survivors, are so well placed to offer support and encouragement from a first-hand perspective. You, as a group are a tremendous advocate for independent living and acknowledgement of the personal strengths evidenced in your members and you play such a key role in heightening awareness around the values of dignity and respect, in a tireless and knowledgeable manner.

I would like to commend all the members of the Post Polio Support Group for your dedication and commitment and I wish you every success in the future.

‘PPSG - The Beginning’ by Joan Bradley

Most actions are a reaction! The Post Polio Support Group was a reaction. It was the resulting of two ladies, Joan Bradley and Rosaleen Gallagher who had polio, attending the same swimming club at Belvedere College, Dublin. One had a problem and the other had part of the answer. Joan said that she was getting weaker and had pain and that there must be some explanation. She had attended a number of doctors but they could see nothing wrong and had brushed her off. Rosaleen had just been in the USA and had learned of a condition affecting Polio Survivors years after they had contracted polio - the late effects of it - Post Polio Syndrome or Post Polio Myelitic Syndrome, as it is now called officially. She had brought home literature. This information revealed all as the symptoms described exactly matched what was being experienced. Looking around we could see our fellow survivors suffering through lack of information and we could not leave them in ignorance.



The Founders: *Standing L to R: Joan Bradley; Alan Kelly (R.I.P.); Jim Costello; Ciaran Nicholson; Mary McEvoy RIP); Seated: Fr. Paddy Lewis (R.I.P.). Absent: Franton Jones (R.I.P.); Rosaleen Gallagher (R.I.P.)*

So Rosaleen and Joan began meeting in Rosaleen's home. If you like, they were the first committee meetings of the group, it was 1992/1993. In 1994 The Spiritian Community generously allowed the Post Polio Support Group Committee to hold their monthly meetings in Kimmage Manor, where Fr. Paddy Lewis gave us the benefit of his wide experience, and played an active role in committee affairs. They had no idea how many Survivors were still in Ireland, so they wrote a letter to all the papers they could find, and asked survivors to get in touch, to quantify the number still living. The letter described the symptoms asking Polio's survivors if they recognised them, but taking care not to scare them. They put a notice in 26 papers, and waited. They were overcome by replies - survivors from all over Ireland, some saying: -

'Thank goodness someone is taking notice', or words to that effect.

They were getting the 'push off' by the medical profession too. Of course the doctors, then, probably knew as little as we did about the condition.

The need for information was great. That year Jim Costello joined them and helped with setting up a registered Voluntary Organisation i.e. The Post Polio Support Group. A constitution was drawn up (and signed by Joan (Secretary) Rosaleen, Fr Paddy Lewis, Ciaran Nicholson, Aideen (Treasurer), Vera and Jim Costello as Chairman. They had no finance, so they funded it initially themselves with the help of a few sympathetic survivors and others.

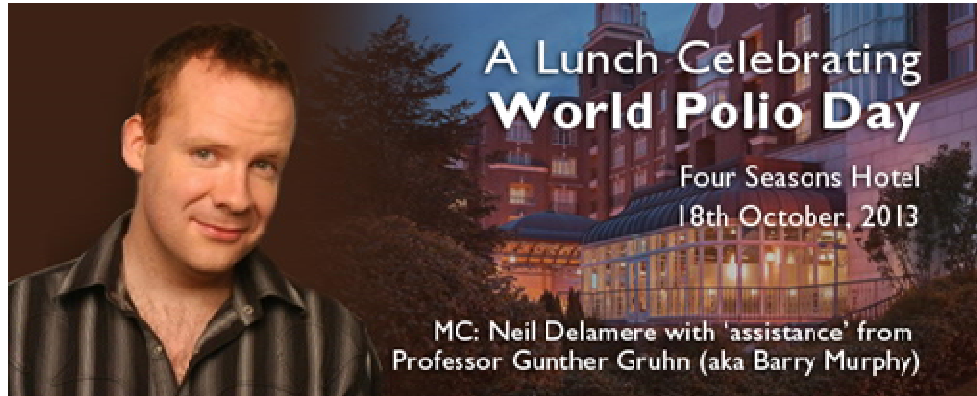
In 1993 they learned that Dr. Marinos Dalakas from USA, who had specialised in the Late Effects of Polio, was coming to Ireland in 1994. They asked him to speak, while here, at a Polio Conference they had planned. Their first grant, from the Polio Fellowship of Ireland, was used for this. It was a packed out affair and there they met Dr. Orla Hardiman, who also spoke at the Conference, and who had worked with Doctor Dalakas in USA. She was interested in setting up a Polio Clinic in Ireland, and later this came to fruition in Beaumont Hospital.

The next need was for information to be distributed to survivors, doctors, health services and the Government. A programme of lobbying, seeking media coverage, contacting health services, informing survivors and everyone they could find, who might have a part to play in assisting them.

There were many people who had input to the Group in the very early days and since - too many to record here, but the group is extremely grateful for their assistance. They had many struggles and a bit of blood sweat and tears. Sourcing funding became a daily task. What more can be said!

From there on it 'Just Grewed' as Topsy said when asked where she had come from.

World Polio Day Lunch



The second annual Post Polio Support Group Lunch to mark World Polio Day was in the Four Seasons Hotel, Ballsbridge on Friday, 18th October. 150 guests were entertained by Master of Ceremonies, comedian Neil Delamere, with additional 'commentary' from Professor Gunther Gruhn (aka Après Match's Barry Murphy).

It was an afternoon of good food, excellent company and many laughs and all in the good cause of raising much needed funds for PPSG programmes to support Polio Survivors. The event kicked off with a drinks reception in the Ice Bar before guests made their way to the restaurant. Lunch was followed by a raffle and auction.

Tickets were €100 each and some of Ireland's best known companies supported the event including Arthur Cox, Communicorp and NTR and Bord Gais.

Social Support Groups Fact Finding Exercise

By mid-2013 the PPSG had 22 Social Support Groups in place throughout the country. The Social Support Committee which supervises these groups was conscious that there were many differences in the way groups operate and in their relative strengths and weaknesses. To establish a clear picture nationwide the committee commissioned a fact finding survey of groups. Members of the Social Support Committee visited each group and spoke to convenors and members. A standard methodology was followed and topics covered included:

- When the support group was founded
- Number of members on their mailing list
- Average meeting attendance
- Venue
- Cost of meetings

Other topics explored included whether the convenor was assisted by a committee, transportation issues for members attending, guest speakers, outings and any fundraising activities.

The exercise is expected to take about 6 months as many groups meet less frequently during the winter months.

When completed the exercise will provide the Committee and the PPSG Board with a very comprehensive view of the health of the social support groups and will provide essential material for the future development of social support.

European Polio Union AGM & Conference

In recognition of the 20th anniversary of the founding of the Post Polio Support Group, the European Polio Union held their Annual Conference and AGM in Ireland this year. 30 delegates from across Europe converged on the Tullamore Court Hotel on the weekend of the 18th October.



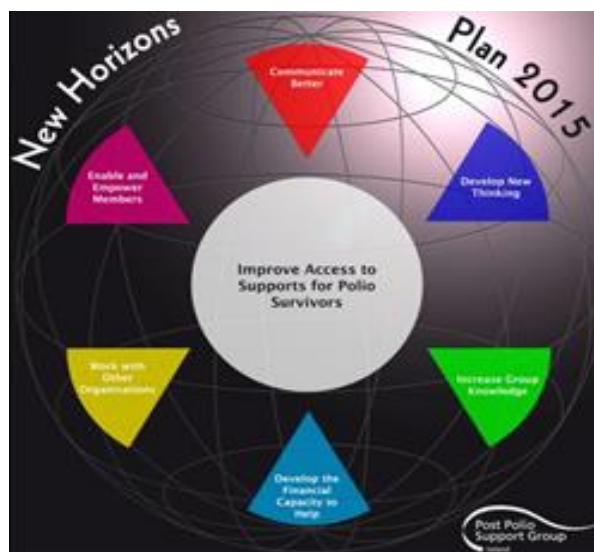
The PPSG is an active and full participant in the European Polio Union (EPU). The Group was one of the founder members and since its inception has had a member of the Group's Board serving on the governing body of the EPU. The EPU has 18 member organisations from 16 countries, which are within the European Union or Associate EU countries. All these organisations represent Polio Survivors, their families and carers. John McFarlane former Chairman of the PPSG was appointed Chair of the European Polio Union in Copenhagen in 2011.

As Telephone Support Coordinator, Susan Dowling, delivered a presentation to the Conference on the RingRing and PhoneChat Telephone Support Services. Several of the delegates were interested in adopting these successful initiatives in their own countries.

On Saturday evening the EPU invited the three surviving founder members of PPSG, Joan Bradley, Ciaran Nicholson and Jim Costello joined the delegates for dinner.

On Sunday the delegates joined their fellow Irish Survivors for the PPSG 20th Anniversary lunch and enjoyed a real afternoon and evening of Irish hospitality.

Mid-Term Review of New Horizons Plan



The New Horizons Strategic Plan was developed to chart the course of PPSG until 2015. This year we reached the half way mark in the life of the plan and this presented an opportunity to look in a structured way at how the whole organisation is functioning and how it is meeting the aspirations of Polio Survivors as expressed in NEW HORIZONS – PLAN2015. This Mid-Term Review allowed the Post Polio Support Group to redefine its objectives and look again its future policy development taking into account the changed environment within which it operates and the quality of the support it offers to Polio Survivors.

The review was led by Hugh McHugh, Deputy Chairperson of the Board at the time the review commenced. As part of the review process the members were surveyed on their views. The review looked at each of the 7 aims of the plan and their various objectives, considered progress to date and described future actions required to complete implementation of the plan.

The Mid-Term Review Report found that the three most important words for the remainder of the life of the Plan 2015 are Sustainability, Sustainability, Sustainability. The Report considered that the achievement of all the aims of PPSG requires an approach that ensures changes are sustainable and that that all aspects of the service to the Group will be sustained, adequately supported, upheld and maintained regardless of external conditions. The Report went on to conclude that sustainability in achieving adequate funding, delivering appropriate services and building systems and practices to maximise efficiency needed to be at the heart of progress for the remainder of the life of the plan. Finally sustainable leadership development will ensure that the Board evolves to ensure PPSG continues to serve its members.

The report concluded *“The service which we offer and deliver puts our member at its centre – it is the member who chooses the service best suited to him/her. This is very much in sync with the HSE which is moving from providing institutional based care to personal choice.”*

Summary of Service Provision 2013

The Post Polio Support Group provides a range of services to Polio Survivors. These include information, support with aids and appliances, a variety of therapies, Respite, stairlifts and heating grants. These supports are administered by a Service and Information Co-ordinator (SIC) and an Assistant SIC. The Post Polio Support Group would like to gratefully acknowledge the financial support of the HSE in particular, the Polio Fellowship of Ireland and a variety of other grant making trusts who make these services possible.

At the end of 2013 there were 906 members in the Polio Support Group. The Post Polio Support Group carries out a number of interventions with Polio Survivors each addressing an aspect of the deterioration in their functional abilities, in so far as is practicable. Each intervention provides incremental redress of the loss of functional ability.

The intervention originates with formal self- assessment by the Polio Survivor followed by contact assessment from the Services and Information Co-Ordinator who works on behalf of the Group. In addition the Group provides supports to those with needs arising from unforeseen circumstances and responds appropriately. The Services and Information Co-Ordinator works cooperatively with HSE frontline staff and other professionals to ensure that the intervention is appropriate to the individual Polio Survivor and arranges supply of the required supports as promptly as possible.

The Group responds to the Polio Survivor population within its financial capacity according to assessed prioritised need. Intervention costs per Polio Survivor are variable. The number of members supported each year changes but varies between 500 and 600 per year.

Post Polio Support Group encourages individual Polio Survivors to register on the NPSDD and works with the HSE Database Development Officers to promote registration of all Polio Survivors. The Group provides data to the HSE on all clients in receipt of services for the purposes of monitoring and tracking.

Direct Financial Supports to Polio Survivors during 2013

94 Polio Survivors received Aids, Appliances or Assistive Technology last year. The total expenditure was €127,224 and the average expenditure per Polio Survivor assisted in 2013 was €1,353

€48,781 was spent on Services in 2013 as follows:

41 Polio Survivors were allocated Physiotherapy,

27 Polio Survivors were allocated Occupational Therapy

97 Polio Survivors were allocated Respite care

9 Polio Survivors were allocated Chiropody and

8 Polio Survivors were allocated Counselling.

In addition to these personal services and supports the Post Polio Support Group has 22 Social Support Groups throughout the country which provide peer support to approx. 400 of its members.

Members who would like to have contact with other Polio Survivors, particularly those who have difficulty attending Social Support Groups, can avail of our Telephone Support Services, RingRing and PhoneChat. RingRing is a one-to-one telephone support service delivered by members of the Group who are trained for this role: each person receives a call once a month and 90 members benefitted from this service in 2013. PhoneChat is a group telephone support service in the form of a telephone conference where a trained host and up to 4 members participate in the call: this takes place once a fortnight and 4 PhoneChat groups were in operation in 2013.

€46,606 was spent on social, telephone, information and other support during the year

Complaints

The Group has a complaints procedure and the Company Secretary maintains a register of all complaints and actions arising. There were no complaints registered in 2013.