EDINBURGH BRANCH
PARKINSON’S UK
Branch History Appendix

A principal aim of the Edinburgh Branch has always been to try and achieve the best possible health and care services for people with Parkinson’s in Lothian. How we tried to achieve this over the past 20 years is described below.

The introduction of Parkinson’s Disease Nurse Specialists (PDNS) to the National Health Service in Britain transformed the level of care that could be provided for PwPs. The appointment of Alison Stewart as Lothian PDNS in 1999 was a vital development for us. Her excellent work rapidly demonstrated the huge benefit of a PDNS Service but her workload of over 1500 clients was impossibly large.

The Branch soon recognised the need to introduce additional resources and staff, including secretarial support but it seemed to us that NHS Lothian did not share this view. To shore up the PDNS Service the Branch agreed to fund the provision of a part-time secretary for Alison allowing her to focus her skills on helping people.

Whilst it was clear that obtaining additional Parkinson’s Nurses for Lothian must be the number one priority for the Branch, how to achieve this was not obvious. The Parkinson’s Disease Society (PDS) claimed to be lobbying the NHS, but as time went by the Branch concluded that we needed to take ownership of the problem. Dr Conor Maguire the senior Parkinson’s physician in Lothian was entirely supportive of our view and over several years submitted business cases to NHS management arguing for additional staff. However, it was impossible to identify who in NHS Lothian was really responsible and able to act.

To make the NHS more aware of our concern, the then Branch Chair, Patrick Mark, took every opportunity to attend meetings about nurses or provision for the elderly and always ask the same question: “What is NHS Lothian’s plan for developing Specialist Parkinson’s Nurses, and why does Lothian only have one PDNS yet Glasgow has six?”

Eventually in 2009, Dr Maguire had an unexpected positive response to his submissions, and two additional nurses were appointed, together with secretarial support. This was a huge welcome surprise for everyone and a major step forward for Parkinson’s Services in Lothian. We surmised that someone in the hierarchy was both sympathetic to the issue and knew how to find the funding.

After many years focussing on getting more Nurses, the Branch needed to review its policy and objectives. At a special Branch meeting in 2009 we discussed what the important issues might be and settled on the following:

Edinburgh Branch Priorities for Parkinson's Services in Lothian

1. Access to Parkinson's Services should be clear, structured and easily available to all.

2. The Parkinson's Nurse Specialist Team (a change of title from PDNS Team) should be supported and developed to achieve universal access.

3. Services should be provided by multi-disciplinary teams structured to focus on patient needs. Team members including Physiotherapy, Speech and Language, and Occupational Therapy professionals should all have specialist Parkinson‘s training and experience.

These priorities remain Branch policy but trying to achieve them in the last decade has been a challenge.

We asked ourselves: What does a good Parkinson’s service look like? What is world best practice?

We did not know, but fortuitously the World Parkinson Congress 2010 in Glasgow provided an opportunity for us to hear acknowledged world experts on the subject. The most inspiring was Professor Bastian Bloem who developed ParkinsonNet, a comprehensive Parkinson’s patient centred structure based on specialised and focused therapy teams.

At a special Branch Meeting in Edinburgh in February 2014, Branch Members learned more about ParkinsonNet principles from a recorded video conference involving Professor Bloem and other leading Parkinson’s experts. We discussed what we had learned and there was universal enthusiasm for the ideas and a vision that it might be possible to apply them in Scotland but particularly in Lothian. You can read a review of the Branch Meeting and descriptions of the various neurological groups mentioned below in the Branch Newsletter March 2014.

As part of Branch strategy to achieve this, we invited Professor Bloem to deliver the Edinburgh Parkinson’s Lecture in 2016. We had hoped that this would inject some much needed interest and enthusiasm into the Scottish Government and NHS Lothian but there is little evidence that it did. Meanwhile, ParkinsonNet is increasingly recognised as world best practice for Parkinson’s.

Attention to neurological issues in general in NHS Scotland was increased by the publication of “Quality Improvement Scotland Neurological Standards 2009”. These set out rules for Health Boards to follow in dealing with neurological issues and with specific conditions such as Parkinson’s. One requirement was that each Health Board should produce a service improvement plan for neurology.

In 2013 Patrick Mark became a member of a group formed as Lothian Neurological Voices. This was part of a project funded by the Scottish Neurological Alliance and the Scottish Government to improve patient involvement. Neurological Voices included people involved with various conditions such as MS, Huntington’s Disease and Parkinson’s. The purpose was to provide a focus group to advise Lothian Health Board regarding neurological service policy. The group met with senior NHS Lothian management for this purpose. Patrick became Chair of Lothian Neurological Voices and the group developed a set of priorities.

This led to Patrick joining, as patient representative, another group tasked with developing the Lothian Neurological Improvement Plan. It was led by NHS Lothian General Manager Jane Hopton. Other group members were clinicians and managers from the NHS so Patrick was effectively the only non-professional, enabling him to offer opinions freely without being constrained by hierarchical considerations.

In practice, attendance at the group was variable, but Patrick made sure of consistently being there and as a result, we suggest, achieved a considerable influence on some of the policies proposed. The Plan was subsequently published as NHS Lothian Neurological Improvement Plan 2014 and adopted by the NHS Lothian Board.

An Improvement Group to supervise the application of the Plan’s proposals was set up with Patrick again becoming a member. The chairmanship of the group changed several times, discussion was unfocussed and attendance at the meetings was poor with little being achieved. Meetings stopped and in an attempt to stimulate action, Patrick corresponded with the Chair of NHS Lothian, but to no avail. The Plan seemed to have died.

On behalf of the Branch, Patrick also became involved with the Neurological Alliance of Scotland which represents all neurological conditions. The Alliance was involved with the development of the Scottish Government Neurological Services Improvement Plan which has been published but there is as yet no structure for local implementation of it.

And so, on it goes . . . . . the Branch will keep striving within the limits of our capabilities for better care and health services for PwPs in Lothian.
