OPTCARE Neuro aims to determine the effectiveness and cost-effectiveness of Short-term Integrated Palliative care (SIPC) for people severely affected by long-term neurological conditions (Multiple Sclerosis, Parkinsonism and related disorders, and Motor Neurone Disease).

For more information on the project and how to get involved, visit our webpage: tinyurl.com/optcareneuro

**Trial extension**
The trial has been granted a no cost extension by NIHR. As such we will continue recruiting new participants until end of June 2017 so that we can ensure we meet our overall targets.

**New trial administrator**
We have a new OPTCARE Neuro trial administrator Zaynah Sheikh who joined us in May. Debbie Tonkin has been promoted to Business manager for the Cicely Saunders Institute. We welcome you Zaynah and congratulations to Debbie!

**Sheffield site now open!**
The site opened for recruitment in September, led by site PI Dr Ellie Smith; making it the 7th in total.

**Training**
On the 30th August the Cicely Saunders Institute hosted a Qualitative Interviewing training day for researchers and research nurses. We had attendees from the King’s, Nottingham and Brighton sites.

**Cicely Saunders Institute Conference 2016: Palliative care in Neurology**
On Wednesday 4th May 2016, the OPTCARE Neuro team hosted a one-day conference on Palliative care in Neurology at the Cicely Saunders Institute, London. The event was a great success, with over 100 registrations. The day included presentations from clinicians, PPI members, researchers as well as charitable organisations. A post conference survey revealed that 70% of attendees felt that the topics covered in the conference were extremely important to them professionally and 88% felt that the conference was likely to influence their practice.

The day before the conference we also held a closed meeting for all the OPTCARE Neuro teams. We had representation from all trial sites with a mixture of PIs, research nurses, clinicians and PPI members attending.

It was extremely productive to have all the teams together to exchange ideas, learn from each other and celebrate the success of OPTCARE Neuro so far.

**RECRUITMENT UPDATE**
OPTCARE Neuro is aiming to recruit 356 patients by the end of June 2017. The graph shows progress to date at each of our sites. Congratulations to the team at King’s College Hospital who have recruited the most participants to date!
OPTCARE Neuro in Cardiff

The Cardiff site has been open for recruitment since July 2015. The team is led by Principle Investigator Dr Anthony Byrne (pictured) and research nurses Mim Evans and Rebecca Cloudsdale. To date the team have recruited 16 patients and 9 caregivers.

Pre study meetings were set up with the three specialist neurology and rehabilitation teams at the University Hospital of Wales and Rookwood Hospital with positive feedback on the importance of the study for their patient groups.

There are two community based specialist palliative care teams providing the intervention across Cardiff and the Vale of Glamorgan. The George Thomas Hospice Care team cover a predominantly urban population in Cardiff.

The Marie Curie Hospice team cover a mixed urban/semi-rural population including the Vale of Glamorgan.

The work involved as a research nurse

The research nurses attend a variety of MS, MND and Parkinson’s clinics, both consultant and nurse led on hospital sites. They also attend Nursing Home based clinics with the Parkinson’s team.

Each clinic has a different format and has required a different approach to screening and patient access. As with other sites, the clinics are extremely busy and pressured for space and the research nurses have worked with the clinic co-ordinators as well as the nursing and medical teams to try and minimise disturbance to clinic function. The recruitment of Parkinson’s patients has accounted for the majority of recruitment to date.

After patients have their consultation, the research nurse is introduced by the consultant and explains the research project to the patient and their relatives/careers. This is a great opportunity for the research nurses to meet with the patients and talk about the trial face to face rather than having telephone conversations where communication can be difficult with these patient cohorts. Patients are given the Patient Information Leaflet to take away. If patients prefer to discuss at another time, the research nurses offer home visits to further discuss the study.

If you have any queries regarding any of the information in this newsletter, please do not hesitate to contact us via:

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