



6 monthly e-newsletter

Issue 2 – April 2015

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). **See our new webpage for more information:** tinyurl.com/optcareneuro

OPTCARE Neuro will open for recruitment to the main trial on Tuesday 7th April!

London, Nottingham and Liverpool will be the first sites to open, with patients being consented to the study from this date. Cardiff will open once final approvals are in place and Brighton will open in the Autumn as initially planned.

Being a part of OPTCARE Neuro

“When I was asked to join this study and met my co-members I had two immediate responses; their dedication in the face of their personal challenges across many neurological conditions, in my case Multiple System Atrophy (MSA); and the importance that the system now is prepared to place upon the premise that early palliative care intervention creates benefits, and to study potential outcomes. I wholly support the notion that patient benefits will arise.

I am particularly interested in its approach and application to MSA as it affects such a relatively small population and is notoriously difficult to diagnose. Now that the project is live it will become even more relevant. I look forward to sharing progress through our MSA support groups”.

Colin Fellows

*PPI Committee member
MSA Patient representative*

OPTCARE Neuro in the last 6 months Committee meetings

A Study Steering Committee (SSC) has been established to ensure the project is being undertaken in an effective manner, as well as an independent Data Monitoring and Ethics Committee (DMEC), to check the quality of our results and to ensure the trial is running according to the protocol. Both have had their first meetings.

The Patient and Public Involvement (PPI) Committee has met twice to discuss the study from the perspectives of those who have experiences of living with the conditions OPTCARE Neuro is trying to address.

Training

On 8th December 2014, Caty Pannell led a training day for research nurses involved in the study. This was to ensure that the processes of recruitment, consent and data collection are standardised across all sites involved. Dr Vincent Crosby and Marsha Dawkins have also delivered training for the intervention to the palliative care teams at the 3 sites opening on 7th April to standardise the SIPC delivered in the trial.

Piloting

From January to the end of March, patients participated in piloting our study questionnaires to ensure that they are asking the right questions. The pilot has now closed in preparation for the main trial opening on 7th April at our Nottingham, Liverpool and London sites!

New Trial Manager/ Research Associate

Sadly we have had to say goodbye to Dr Liesbeth van Vliet, Trial Manager and Research Associate for OPTCARE Neuro.

After a 3 week handover, Dr Nilay Hepgul (pictured below) has taken on this role.

Nilay, we welcome you to the project and Liesbeth we are sad to see you go!



For more information on the study, visit our **NEW** webpage:
tinyurl.com/optcareneuro

OPTCARE Neuro in Liverpool

The Liverpool site is a collaboration between [the Walton Centre NHS Foundation Trust](#) and [Queenscourt Hospice](#), Southport.

The Walton Centre specialises in Neuroscience, and clinicians from the Trust will identify eligible patients to refer to the study. A research nurse from the Trust will consent patients to the study and complete the research interviews with them.

The Queenscourt Hospice palliative care team (pictured below) will deliver the intervention of Short term Integrated Palliative Care (SIPC) at the location of the patient's choice. It is this service that is being assessed in the trial as to how effective and cost-effective it is for those with long-term neurological conditions.



Above: *The Queenscourt Hospice palliative care team.*
Top, left to right: *Helen Birch, Dr Tim Jones, Laura Webster, Dr Mary Bunn, Dr Karen Groves,* Bottom, left to right: *Dr Shorna Warren, Sandra Leyland, Louise Charnock, Dawn Garlick*

The importance of OPTCARE Neuro to the Walton Centre NHS Foundation Trust

“The MS, MND and movement disorders specialist teams at the Walton Centre are delighted to be taking part in this important study. We have always aspired to caring for our patients from diagnosis through to the late stages of their illnesses. For years we have been promoting community neurology and a hub and spoke model, so care is delivered close to the patient's home. OPTCARE Neuro weaves together the strands of integrated care and community delivery and we hope it will offer evidence for how we can better help our patients in future”.

*Professor Carolyn Young
Liverpool Site Principal Investigator
and Co-applicant*



Above: *The Walton Centre NHS Foundation Trust*

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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