A Few Words from the Research Team...

It’s been a hectic few months for the research team. A very important milestone for us has been completion of the ‘Research Impact Report’ which looks at how research at LOROS has developed during the period 2011-2014. The report highlights our successes and reflects on some of our challenges. If you would like to see a copy, it can be viewed from our website:

Many of our newsletter readers are research colleagues who have worked with LOROS, and we want to thank them for helping LOROS to move forward as a research active Hospice.

We have taken great strides in achieving many of the recommendations suggested in the Hospice UK commissioned report: ‘Research in Palliative Care: Can hospices afford not to be involved? A report for the Commission into the Future of Hospice Care 2013’:

In view of this, a particular highlight of our forthcoming Research Awareness week (June 22nd - 26th), will be the guest speaker at this year’s LNR event… Dr Nancy Preston, co-author of the report. The LNR is open to everyone (not just medical professionals), and we hope that you will be able to join us, and have an opportunity to meet Dr Preston, and share any questions you might have about research within Hospice settings.

Research Awareness Week June 22nd – 26th 2015

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<th>Monday 22nd June</th>
<th>Tuesday 23rd June</th>
<th>Thursday 25th June</th>
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<td>All Day</td>
<td>1.30pm – 5.00pm</td>
<td>9.30am – 12.30pm</td>
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<td>Venue: Frizelle 1, LOROS</td>
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<td>Keynote Speaker: Dr Nancy Preston</td>
<td>MS Publisher Training</td>
<td>A Beginners Guide to Research Study Day</td>
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<td>Co-Author of Research in Palliative Care: Can hospices afford not to be involved? A report for the Commission into the Future of Hospice Care 2013</td>
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To book a place at any of the above events, please email: research@loros.co.uk /phone: 0116 231 8455
Last November I set out, with poster in hand, for this day conference held at the Cicely Saunders Institute at King’s College London. I had been encouraged by Professor Christina Faull to submit a poster on ‘Soul Space’ and was delighted to receive a research bursary from LOROS to fund my participation in this fascinating conference.

I was one of 100 delegates from many European countries, as well as the USA and India, and my poster was one of 12 presented. Subjects ranged from Silence in Spiritual Care at the End of Life, to Understanding Spirituality at the End of Life in India. The conference began and ended with a Mindfulness Meditation which helped us to become fully present to ourselves and each other. A common thread running through the 8 presentations was an understanding that Spirituality is about what it means to be human and that listening with ‘authentic interest’ is essential in order to address spiritual needs. Dr Lucy Selman’s research has shown a high prevalence of spiritual distress in cancer patients seeking ‘peace of mind’ ‘hope’ and ‘meaning in life’. While globally, palliative care guidance mandates spiritual care, still spiritual needs are often neglected because of lack of staff confidence and lack of evidence to inform care provision. There is a need for a robust international research agenda.

LOROS Physiotherapists

Hannah, Kathryn & Isabel, ‘inspired’ by study day to undertake evaluation of breath stacking techniques

The day has inspired us and helped us continue the discussion of best practice in this area. We are now hoping to evaluate our use of ‘breath stacking techniques’ with some of our Motor Neurone Disease patients”

More information about breath stacking techniques is available:
Feedback from the December 2014

26th International Symposium on ALS/MND

Held at ‘The Square’ Meeting Centre, in Brussels

Professor Christina Faull

Brussels is a vibrant city and in December the Christmas Markets are wonderful. So more than Belgian chocolates to entice me! Every year the ‘world’ gets together to discuss research about Motor Neurone Disease. The UK Motor Neurone Disease Association is the major lead in this conference and the programme has sessions ranging from genetics, drug development, services to all aspects of clinical care. The big buzz was the ‘Ice bucket challenge’ which has swept the world and raised millions of pounds. It was great that many at LOROS were a part of this.

For the first time since I’ve been attending this conference there was an afternoon session discussing aspects of end-of-life care. We heard about Netherlands and the experiences of euthanasia and physician assisted suicide. Baroness Ilora Findlay argued strongly about the British position and the dangers that might be an unintended consequence for patients in changing law in the UK. A palliative care consultant from Switzerland talked of how palliative care supports patients in discussions about the use of ventilation support and how knowing they can ask to stop it is liberating for patients. This led on to a presentation of work from a team in Berlin who described the technical aspects of their experiences of withdrawing assisted ventilation from patients who were ventilator dependant. Finally it was my turn. I discussed our findings of the ethical, practical and emotional challenges in the experiences of 17 families and 50 professionals who have withdrawn assisted ventilation at the request of a patient with MND.

One of the great things about this conference is that it is attended not only by professionals but also some patients and families. My talk was well received. My lasting memory will be my conversation with a woman from America, whose father has MND, who was so grateful that such choices can be discussed openly and that she can now support her father, whatever his choices are as his disease progresses.
In February, Christina Faull was delighted to accept, on behalf of LOROS, a donation of £4,000 from 3M’s Loughborough based Health Care in recognition of its support for research into tackling chronic oedema. The care pathway project, being run in partnership by LOROS, LPT, 3M and the University of Nottingham, could result in significant improvements in the treatment of patients who have swollen legs with fluid retention, often caused by cancer but also heart disease and circulatory and lymph system problems.

Lymphoedema affects approximately 200,000 people in the UK and approximately 3,000 people in Leicestershire. About 1 in 5 women develop lymphoedema after breast cancer treatment. Without the valuable service provided by LOROS at its lymphoedema clinics, almost all of Leicestershire’s patients would have to travel to a different county to get treatment. Lymphoedema, and many other conditions, fall under the umbrella term ‘Chronic Oedema’. There is limited research detailing the number of people affected by “Chronic Oedema”, and the introduction of the care pathway will investigate the numbers in the region.

Whilst not life limiting, lymphoedema can be severely debilitating resulting in limited movement and often severe cosmetic issues such as cracked and inflamed skin. Collaborative work in developing a community based care pathway will help to provide care to a broader spectrum of chronic oedema patients, alleviating some of their current challenges including; “identification at general practice level... (not enough) specialist nurses....and also the communication factor... (professionals) not being able to talk to each other because of different trusts, or whatever it may be”, explains Mark Smith, LOROS Patient and project stakeholder.

"There is no cure for lymphoedema, but it is usually possible to control the main symptoms using techniques to minimise fluid build-up and stimulate the flow of fluid through the lymphatic system", said Professor Christine Moffatt from Nottingham University, “These new developments may help to further control the symptoms and reduce the suffering for cancer patients.”

"3M is committed to improving patients’ lives through innovation in care and technology", said Martin Arrowsmith from 3M’s Critical and Chronic Care Solutions division.

“We recognise the invaluable, specialist service that LOROS provides to Leicestershire’s lymphoedema patients and we are proud to be able to help support this service.”

For the past 18 months, the Palliative and end of life care Priority Setting Partnership has been asking patients, current and bereaved carers, health and social care professionals - to tell them their most important unanswered questions in palliative and end of life care that research should address. Please find attached a copy of a report revealing the Top 10 unanswered questions. Identifying the best ways of providing care and support to terminally ill people, their families and carers outside of ‘working hours’ has been rated the top priority for the future of palliative and end of life care research.

This was followed in second place by a question about how access to palliative care services can be improved for everyone regardless of where they are in the UK, and what are the benefits of Advance Care Planning? – in third place.
Professor Irene Higginson, Director of The Cicely Saunders Institute at King’s College London, inspired all who attended the annual LOROS-DMU Centre for the Promotion of Excellence in Palliative Care (CPEP) lecture. Saunders’ vision for improving the care of patients with advanced illness and their families always focused on research and education. Professor Higginson gave detail to this vision discussing how the care of dying patients in intensive care had been developed by the joint endeavours of clinicians and researchers and not just off the press (Lancet Respiratory) findings that early, holistic management of breathlessness in advanced disease improves patients’ lives and in doing so increases their survival too.

CPEP Award Winners

The LOROS-CPEP award winner for postgraduate student excellence in palliative care is Elaine Wright. Elaine has a consistently high standard of work on the Masters Programme and has shown how she was using this to transform the care of young people with cancer. The RCN-CPEP pre-registration nursing award winner is Holly Smith who demonstrated how she made a difference to the care provided to a patient on an admissions ward through application of holistic palliative care.

The applications for the awards were of a very high standard and we congratulate the very worthy winners.

Six senior managers from LOROS attended the annual Hospice UK Conference which in 2014 was held in Leeds from 25 - 26 November.

The overall theme was “Demonstrating the Value of Hospice Care” and about 400 people attended.

One of the main plenary sessions was on “Building Energy for Change across the Hospice Movement”. This was led by Helen Bevan, NHS Chief Transformation Officer, and provided a good stimulus for debate around culture and approaches to making change effectively.

Other sessions included commercial collaboration case studies; highlighting the value of research in improving End of Life Care; maximising the potential for volunteering; the leader’s role in facilitating change; the principles of good evaluation and the need for better outcome measures in palliative care; the way forward for Personal Health Budgets and demonstrating value to Commissioners.

These sessions provided added impetus for, and input to, the current LOROS Strategic Workstream activity. Some specific ideas to follow up have been identified e.g. with respect to an apparently successful volunteer hospice neighbours model in Suffolk which might help to inform and optimise the LOROS recently reconfigured home visiting service.
Good Clinical Practice (GCP) Training
17th June 2015
9:30-11:30am, Frizelle 2, LOROS
Session to be facilitated by Anne Moore,
Clinical Trials Monitor & Trainer, UHL
Cost: FREE

A Beginners Guide to Research, Study Day
26th June 2015
9:30-4:30pm, room PC1, LOROS
Cost: Subsidised rate £25 (students £15)
This event is part of a series of activities planned for
Research Awareness week at the Hospice (June 22nd - 26th)
For more information, contact:
Zoebia Islam: zoebiaislam@loros.co.uk

A Cup O’ Learning
& A Slice O’ Cake:
Palliative Care/Mental Health Research
29th June 2015
Dr Manoj Kuma
Mental Health Action Trust (MHAT)
Institute of Palliative Medicine in Calicut,
Kerala

Transition in Palliative Care
21st July 2015
Simon Hardcastle
Diana Service Team Leader
(12:00 - 1:00pm), Frizelle 1 LOROS Hospice
Cost: FREE

Bursaries Are Back for 2015!
We are excited to announce that the LOROS research bursaries are back for a second year!
If you are a member of LOROS staff who would like to become involved in research to improve
LOROS services for the benefit of patients and families that we care for, you are eligible to apply.
It may be that you want to attend, or present at, a conference; go on a research training course;
secure funding to backfill your time so that you can develop an idea or a project; or are looking for support with fees to
support a research qualification. If you would like further information, please speak with a member of the research team, or
email: research@loros.co.uk

The closing date for applications is October 1st 2015 and ALL
staff are eligible to apply.

Leicestershire, Northamptonshire & Rutland (LNR)
Research & Audit Half-Day
23rd June 2015
1:30-5:00pm (lunch 1:00pm)
Keynote Speaker: Dr Nancy Preston
Senior Lecturer
International Observatory on
End of Life Care,
Lancaster University
Co-Author of ‘Research in Palliative Care: Can hospices afford not to be involved? A
report for the Commission into the Future of Hospice Care 2013’
Cost: FREE

The LOROS/DMU Centre for the Promotion of Palliative Care (CPEP)
Annual Lecture 2015
The Meaning of Afterlife: What archaeology & anthropology can teach us about life after death
6:30pm, Thursday 12th November
Cost: FREE
Details TBC...but if you would like to be kept on the mailing list for information, please
ring the LOROS Education Team on: 0116 231 8455 /Email: education@loros.co.uk

A final note...If you are aware of patients or family members visiting the Hospice, who might also have
questions about research at LOROS, we have now developed a leaflet which we would like to encourage you
to share.
Copies of these can be found in the patient information boards (located in main reception and near the
patient social area), and they cover many of the key questions that patients and their families may have.