

INNOVATIVE NEONATAL PALLIATIVE CARE PROJECT GOES NATIONAL

First-of-its-kind project transforms neonatal palliative care in London and is rolled out across the UK

London, 22 March 2021 - Today, Chelsea and Westminster Hospital NHS Foundation Trust, its charity CW+ and the True Colours Trust announce the national roll-out of their pioneering regional *Lead Nurse for Neonatal Palliative Care Project* after a successful five-year London pilot. The work will continue to be spearheaded by Alex Mancini, who will become the country's first National Lead Nurse in Neonatal Palliative Care.

Neonatal palliative care is an emerging specialism, which emphasises the comfort of the baby and quality of life for the family, however long their time together may be. It improves the experience and outcomes for families during a time of crisis, specifically when their baby is not expected to survive, or when a baby has multiple complex health needs with an uncertain future.

Alex Mancini says: "When I was first talking about palliative care on neonatal units about 15 to 20 years ago, many of my colleagues said there's no such thing as neonatal palliative care, there's either death or there's survival. Thankfully, neonatal palliative care is now recognised as essential in supporting babies with life limiting conditions, end of life care and supporting his or her family during this devastating time."

The *Lead Nurse for Neonatal Palliative Care Project* is part of the CW Innovation programme - jointly led by the Trust and CW+ - which facilitates the development of innovative models of care within the Trust, and then supports the national roll-out at scale to deliver improved patient care and experience.

In response to the COVID-19 pandemic, the *Lead Nurse for Neonatal Palliative Care Project* has rapidly and innovatively evolved with the introduction of new technologies to enable Alex Mancini to provide virtual training and mentorship sessions to neonatal and children's palliative care colleagues, facilitate a weekly virtual peer support group for neonatal nurses in London and adapt the multi-disciplinary training programme for digital learning.

The success of the project and its digital transformation during the pandemic will greatly strengthen the national roll-out, enabling Alex Mancini's work in London to be easily replicated in other neonatal Operational Delivery Networks across the UK to train and develop the neonatal workforce in this unique field.

Lucy Sainsbury, Chair of Trustees at the True Colours Trust explains: "The national roll-out of this project realises a long-held dream we share with Alex Mancini to ensure high quality and equitable access to neonatal palliative care across the country. We hope this project will ensure that any baby that needs neonatal palliative care can receive the best possible care and that neonatal staff are supported to help families at an incredibly difficult time. We are very proud to be working with Alex Mancini, the Chelsea and Westminster Hospital NHS Foundation Trust and CW+ on this critical project which we hope will transform the neonatal palliative care landscape."

The news of the national roll-out coincides with the publication of an independent evaluation of the *Lead Nurse for Neonatal Palliative Care Project* in London, which can be read in full [on the CW+ website](#). New data extracted for the evaluation by the Neonatal Data Analysis Unit at Imperial College indicates that out of approximately 60,000 babies admitted to neonatal care in London during 2014-2018 inclusive, 7% (over 4,000 babies in this five-year period) met the BAPM (British Association of Perinatal Medicine 2010) criteria for palliative care in the London region alone. Although this is only a snapshot figure, the data and evaluation prove the need for the project and its expansion across the country. Palliative care is crucial to babies and their families, as it:

- Opens up discussions on the best individual care pathway for a baby who meets the criteria for palliative care
- Directly prioritises the baby's needs and the family's needs
- Provides a multi-disciplinary approach, supporting the whole family through a variety of services
- Supports and enables choice for families, facilitating advance care plans and improving continuous bereavement care and support after the baby has died
- Provides staff with the training and knowledge in recognising and identifying babies who meet the criteria, to have those difficult and sensitive conversations with families, to think of and suggest additional supportive specialist services such as hospice care, sibling support, and support within the home setting.

This project is endorsed by the Neonatal Nurses Association.

- ENDS -

For more information, photos, and interviews contact:

Rachel Vrettos rachel.vrettos@cwplus.org.uk

Deepa Lalwani deepa.lalwani@cwplus.org.uk

About CW+ www.cwplus.org.uk

CW+ is the official charity of Chelsea and Westminster Hospital NHS Foundation Trust, including its hospitals and clinics. The charity's generous supporters and partners enable it to:

- Build and enhance clinical facilities to create an outstanding healing environment for patients and staff
- Deliver a unique art and design programme to transform the experience and wellbeing of our patients
- Invest in health innovation to deliver exceptional patient care

CWPLUS Registered Charity No.1169897

About The True Colours Trust www.truecolourstrust.org.uk

True Colours is a small independent funder working in the UK and Africa. Our work is focussed on:

- improving access to pain relief and palliative care in Africa
- improving access to palliative care for children and babies in the UK
- enabling disabled children to live their lives to the full.

True Colours Registered Charity No. 1089893