

Charity founder Jenni Thomas OBE receives honorary degree

Founder and President of the Child Bereavement Trust (CBT), Jenni Thomas OBE, was honoured at a graduation ceremony which took place at Buckinghamshire New University in September this year. Jenni's work with grieving families, while nursing on special care baby units and children's wards, and later as a counsellor, led her to develop an acute awareness of the problems faced by bereaved families and the professionals who care for them. Her career reflects her personal mission to take this work forward.

Jenni's involvement with grieving families started when she was working as a nursery nurse at Amersham hospital. In 1976 the first special care baby unit in the country designed specifically with rooms for parents to stay with their small sick children was opened at Wycombe hospital. This unit has been hugely valued by parents, although sadly it is due to close next year.

At that time when a baby died on the unit staff were deeply affected but unsure how to support the parents. Jenni began by asking parents if they would like to return to the unit to talk to one of the staff in the difficult months after their baby's death. This they did and over the years it became part of Jenni's role to see the families, finding out what mattered to them and what they appreciated from the professionals who had cared for them and their baby. Jenni also initiated training for staff about what grieving parents needed in a tragedy. She was supported in her work by her manager Jean Macdonald MBE and by South Buckinghamshire NHS Trust that had the vision to endorse what bereaved families value. She went on to train as a counsellor in 1980 and became the hospitals' Maternity and Paediatric Bereavement Facilitator, which she continues to do to this day.

To offer bereavement skills training to professionals across the country, the only option was to found a national charity and in 1994 The Child Bereavement Trust (now



the Child Bereavement Charity) was launched at the RCN with Julia Samuel as founder patron and in the presence of Diana, Princess of Wales. Since then many thousands of families have been helped as staff feel more able to provide care in what is the most difficult area of their work.

The charity started with its headquarters in a room in Jenni's house, but now has its own dedicated centre in West Wycombe. The training that Jenni has devised is requested by many hundreds of doctors, nurses, midwives, health visitors, neonatal liaison nurses, police and other community professionals across the UK and abroad. The CBT training materials include videos developed by Jenni that have received British Medical Association awards for educational merit. The charity also supports bereaved families directly through its Support and Information Line, award winning website and local CHYPS (Children Young People Support) service for bereaved children, young people and their families.

Speaking at the awards, Jenni said: "I am absolutely thrilled to receive this special award. I believe passionately in listening to bereaved families so that we can provide the best possible care in a tragedy. Having this wonderful award will help the



charity further as our training gains recognition through Buckinghamshire New University."

The Child Bereavement Trust has changed its name to Child Bereavement Charity and has unveiled a new logo to mark its thirteenth anniversary. CBC Chief Executive Ann Chalmers explained, "We realised we needed to resolve the communication difficulties we have increasingly faced around having the word "Trust" in our title, and wanted to reflect the charity's enhanced remit with a new name and logo.

"The existence of NHS Trusts and the emergence of Children's Trusts, which bring children's health, education and social care under one umbrella, has caused confusion. We also find that people mistakenly think that we are a charitable trust in possession of an endowment which finances our charitable work, and this can compromise our fundraising efforts. We hope that having the word 'Charity' clearly as part of our title will alleviate these problems."

www.childbereavement.org.uk

Special care baby units nearing breaking point

The latest report from BLISS, *Too little too late – Are we ensuring the best start for babies born too soon?*, found that in the last year only a handful of units were able to meet minimum recommended standards, meaning many are forced to refuse new admissions for considerable periods of time.

Survey responses from 195 neonatal units countrywide revealed that many units had average occupancy levels significantly above those recommended by BAPM. One in eight of the most specialist units had an average occupancy of 100% or more for a whole year and over half of these units operate at or below 50% of minimum staffing levels. The service is still 2,600 nurses (37% of the workforce) short of the number needed to meet recommended standards.

BLISS found that units were forced to refuse new admissions for an average total of two weeks in a six month period, and 10% of units refused new admissions for eight weeks or more in a six month period. Babies are being moved across the country in potentially risky transfers to find a unit. The report found that no consistent dedicated transport service is in place to deal with these transfers, which often happen in an *ad-hoc* way.

As many as 35% of twins and triplets needing special care were separated and treated in different hospitals, putting a strain on parents.

The report concludes that the system is being kept together by the goodwill of staff working above their agreed capacity.

Full report at www.bliss.org.uk



Transporting children on ECMO across Europe

KITS – Kids Intensive Care Transport Service – has been developed by the air rescue alliance TEAM DRF, working in collaboration with the ECMO Center of the Children's Clinic Mannheim, to provide an effective transport service for critically ill newborns, infants and children who need extracorporeal membrane oxygenation (ECMO) treatment. Patients come from all regions of Germany as well as Holland, Sweden, Russia, Switzerland and Austria.

A team consisting of a paediatric surgeon and an intensive care nurse from the University Clinic of Mannheim picks up children at the clinic of origin and flies them back to an ECMO centre. If there is no treatment available in Mannheim, patients can be transported to the ECMO center in Bremen or further afield. The transports are carried out by Bell

helicopters which are ideal because of their size and 24 hour availability. TEAM DRF in Germany, Austria and Italy operates 44 Helicopter Emergency Medical Service bases with more than 50 helicopters for rescue and intensive care transport between hospitals at eight locations.

Donations enabled KITS to acquire a new transport unit for children's transport which is adapted to enable high frequency oscillatory ventilation, inhaled nitric oxide therapy and ECMO to be performed during transport. ECMO therapy can begin in the clinic of origin and continue during the flight to an ECMO centre.

ECMO therapy is a staff intensive and costly method. Between 1987 and the beginning of 2007 University Clinic of Mannheim ECMO centre has treated 320 children and developed into a centre of excellence.

Yellow Alert campaign for childhood liver disease

Children's Liver Disease Foundation (CLDF) has launched the Yellow Alert campaign to help community healthcare professionals recognise and take action on the signs and symptoms of potentially life-threatening neonatal liver disease.

CLDF Chief Executive Catherine Arkley explains: "For more than 25 years we have been supporting families whose child has died or needed an early transplant due to a failure to identify the signs and symptoms of liver disease and initiate prompt referral. This is nothing short of a tragedy.

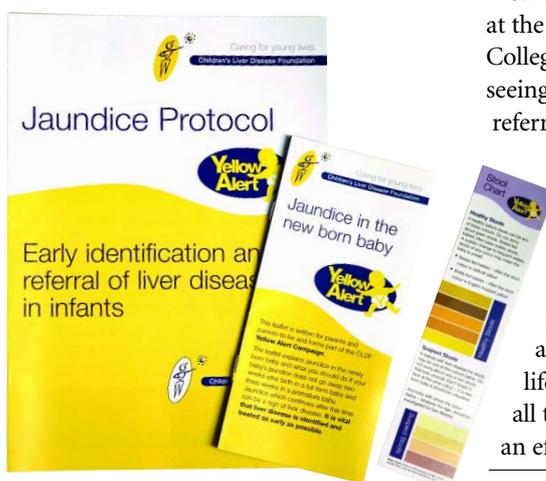
"The signs of neonatal liver disease are simple and visual but they are often overlooked, particularly as the baby can look and feed well. Yellow Alert aims to fill this knowledge gap and has the indisputable potential to save lives."

Research conducted on behalf of CLDF among health visitors highlights a need for greater understanding of the key signs and symptoms:

- Less than 50% knew the definition of prolonged jaundice – jaundice of the skin and whites of the eyes beyond two weeks in term babies and three weeks in pre-term babies should be investigated
- Only 10% identified yellow urine as a sign – babies' urine is usually colourless
- Only 35% identified pale stools as a sign – Normal baby stools are daffodil yellow (breast fed babies) or English mustard yellow (bottle fed babies)
- Less than a third recognised that yellowing of the sclera of the eyes is a sign of jaundice – a key tool in detecting jaundice in all ethnic and racial groups
- 2.2% of community healthcare professionals knew that a split bilirubin blood test costing £1.50 would identify the cause of prolonged jaundice as liver disease.



A yellow tinge to the whites of the eyes is a typical sign of jaundice but can also indicate liver disease.



CLDF is providing a free pack of resources to health professionals including a jaundice protocol, the care pathway algorithm for early identification of liver disease, a stool colour chart bookmark for easy reference, a poster for health centres and surgeries and a leaflet aimed at parents and parents-to-be.

Sarah Tizzard, Clinical Nurse Specialist at the Paediatric Liver Centre, King's College Hospital London, says: "We are seeing more examples of babies being referred late for treatment, which can lead to irretrievable liver damage and early liver transplant against a backdrop of an increasing shortage of donor organs. The devastating effects on the youngsters and their families are sadly becoming all too common in our practice. This life-saving campaign is underpinned by all the information needed to implement an effective jaundice protocol."

Resources packs available from yellowalert@childliverdisease.org or 0121 212 3839

New online 'safe sleep for babies' video

Cot death and infant health charity the Foundation for the Study of Infant Deaths has teamed up with www.videojug.com and child sleep specialist Andrea Grace to bring parents the best advice on safe sleep for their baby. Visit the website www.fsid.org.uk to watch the video.

FSID has also updated its award-winning BabyZone leaflet which can be viewed at the website. BabyZone is a colourful, easy-to-understand booklet for parents, with advice to help them keep their baby safe and healthy. The leaflet has been updated with the latest research-based baby safety advice, including new advice about settling babies to sleep with a dummy.

www.fsid.org.uk

Prize fund aims to promote breastfeeding research

Philips AVENT has announced the first worldwide Philips AVENT Prize for Breastfeeding Research, in partnership with the international scientific community. The prize was launched during the 8th World Congress of Perinatal Medicine in September.

The prize is open to healthcare professionals worldwide who are committed to promoting, protecting and supporting breastfeeding. It aims to develop international cooperation with the objective of developing a richer dialogue to promote the health and wellness of individuals. It will reward outstanding unpublished research in:

- Breastfeeding: education and dissemination
- Breastfeeding: basic and clinical research

The winning submissions in the two areas will be awarded funds to support further research and study. Papers must be submitted by 30th September 2008.

For more information and enquiries about research paper submission, email philipsaventworldprize@philips.com