C:\Documents and Settings\nnde\Local Settings\Temporary Internet Files\Content.Word\NHS-header2.gif

**Support for parents who have suffered the loss of a baby in a multiple pregnancy**

**Information for parents about the Butterfly project**

We have given you this short information leaflet because you have suffered the loss of one or more babies in your pregnancy. We would like to express our sincere condolences for your loss, and tell you about some of the work we are developing here in Newcastle to help parents through this difficult time. We are still in the early stages of this work, and recognise that we still have a lot to learn from parents. We are therefore keen to hear your views.

Over the last few years, we have been involved in a research study where we spoke to parents who had suffered the loss of a baby, either before or after birth. We have also spoken to NHS staff such as midwives, neonatal nurses and doctors. We wanted to find out whether there was anything we could do to make things better for parents. Some of those things may seem quite simple, but however ‘small’ we still want to see if they will help.

One of things parents said they found difficult was that some staff looking after them did not appear to know what had happened, or forgot that their pregnancy was a twin or triplet pregnancy. Parents understandably found that quite upsetting. Most of the parents we spoke to had a surviving baby on the baby unit. However, we know these issues also arose for parents whose surviving babies did not have problems, and went home soon after they were born.

On the baby unit, some parents had suffered the loss of a baby before birth. However, for some parents the baby had been born sick or premature and later died on the baby unit. In both situations, some parents felt that staff treated the surviving baby (or babies) as if they were from a singleton pregnancy. Many parents told us they would have liked us to continue remembering the twin (or triplet) nature of the pregnancy.

We have been developing information leaflets for staff education, and are making an educational film for staff. In the future we will develop other resources that might help parents. At present, we have found that most parents value using a Butterfly cot card as it seems to help remind staff about what happened during the pregnancy or after birth. We will only do this if you, as parents, would like us to. Most parents have wanted to write the name of the baby who they lost on the front of the cot card. Some parents may not, and we understand some babies may not have been named, so the choice is for you as parents.

Whilst other parents will not see your medical notes, a butterfly on the cot or incubator will be visible to other parents on the baby unit. Many parents will not know what it means, but some may ask. For parents who have suffered a similar loss, they will recognise the butterfly logo and may approach you. We do not know if all parents would feel happy with this. However, many parents told us they would have found it helpful to know other parents on the baby unit who had also experienced a similar loss.

Please let the member of staff who gave you this information leaflet know what you would like us to do. If you would like to give us any feedback on the butterfly project, please tell a member of staff, or contact a member of the team via email. You can also tell us what you think by contacting Tiny Lives, the baby unit charity who funded the project, or at our website [www.neonatalresearch.net/butterfly-project](http://www.neonatalresearch.net/butterfly-project) below.

**Butterfly project team**

Sarah Stephenson, Claire Campbell (Sisters, Neonatal Unit Ward 35 SCBU)

Dr Nicholas Embleton (Consultant Neonatal Paediatrician Ward 35 SCBU)

Email: [nicholas.embleton@ncl.ac.uk](mailto:nicholas.embleton@ncl.ac.uk)

Tiny Lives charity: [www.tinylives.org.uk](http://www.tinylives.org.uk)

Buddy Volunteers and Bereavement Buddy group

[*www.tinylives.org.uk/support-and-information/buddy-group/*](http://www.tinylives.org.uk/support-and-information/buddy-group/)

Project website: [www.neonatalresearch.net/butterfly-project](http://www.neonatalresearch.net/butterfly-project)

Example of Butterfly cot card

