Premature babies are very vulnerable to infection. GM-CSF is a medication that increases the number of blood cells that are important in fighting infection. The purpose of the PROGRAMS study was to find out whether GM-CSF would reduce the number of infections in very small premature babies.

With your help 280 babies were enrolled into the PROGRAMS study. This makes the PROGRAMS babies one of the largest groups of very premature, very small babies ever studied. We are very pleased that the main results of the PROGRAMS Study will shortly be published in the Lancet, one of the leading medical journals in the world.

The results show that a fifth of babies enrolled had a very low number of blood cells that fight infection. These babies were at particularly high risk of infection. Babies who received the GM-CSF medication rapidly increased the number of these blood cells, but surprisingly this did not seem to reduce the number of infections. The number of infections was the same in babies who received GM-CSF and those who did not. The same number of babies in the group who received GM-CSF and the group that did not, went home, and their health was similar.

What does this mean?

Giving GM-CSF to very small premature babies does not provide any benefit in the short term nor does it do any harm. Using GM-CSF will not reduce infections and so it should not be used unnecessarily in small babies. The information gathered from the PROGRAMS study does not provide a solution for the problem of infection, but has pointed the way to other lines of research. Each of these small achievements is a small but important step towards ultimately being able to prevent infection in the future.

Why are we seeing children again at the age of 2 and 5 years?

Infection can affect long term health. We are reviewing PROGRAMS babies at 2 and 5 years to find out whether GM-CSF influences later health and development. We have now seen almost all PROGRAMS babies who have reached 2 years of age and the 5 year assessments are well underway.
We were very pleased to see over 90% of children at 2 years and would be thrilled to see the children again at 5 years. The results of the assessments have been made available to parents as well as to the paediatrician providing ongoing care. If your child is 5 years old and you haven’t heard from us, please give us a call so that we can make the necessary arrangements.

What is the 5 year assessment?

A PROGRAMS trained researcher will visit your child at school. S/he will be given a selection of activities designed to test understanding, language, memory and balance. This involves, for example, catching a bean bag, walking on tip-toe and recognising objects from pictures. The researcher will be with your child for most of the morning but they will be able to join their classmates at play-time and take any other breaks they might need. They will re-join their class in plenty of time for lunch. Like the assessment at age 2, most children will find these activities enjoyable.

We realise that not every child will be attending a mainstream school and may have difficulties or be unable to undertake the assessment. We hope to be able to speak to parents to discuss each child’s individual situation and make appropriate arrangements.

PROGRAMS Economic Evaluation

This month, the PROGRAMS economics team will post out their final 2 year follow-up economic questionnaire. We would like to send our grateful thanks to all parents who have been able to complete these 6 monthly questionnaires over the past few years. The analysis of the questionnaires will provide the National Health Service with information about the cost to families caring for babies born prematurely. We will send you the results of our economic study when they are ready.

PLEASE HELP US

Unfortunately, not everyone has replied to our letters or telephone messages. Some of you may have moved house or changed telephone numbers. If you have received a letter from us, please do return the consent form and contact details up-date so that we can make the necessary arrangements to see your child or telephone us with your new contact details.

If you would like to have a chat about the follow-up study in more details, please feel free to call me on 01865 289746.

Anne Smith
PROGRAMS Co-ordinator
National Perinatal Epidemiology Unit, University of Oxford,
Old Road Campus, Headington, Oxford, OX3 7LF
T: 01865 289746 F: 01865 227002
Email: programs@npeu.ox.ac.uk Website: www.npeu.ox.ac.uk/programs