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EPICure Newsletter – December 2004

We thought it was time to let you know what is happening with the EPICure Study but firstly ***we would like to thank all those who took part in the last phase of the study.*** This remains one of the best studies of outcome following premature birth in the world and nearly every publication about extremely premature babies now quotes from it. Without your help and cooperation this would not have been possible. Once again we are very grateful for your support.

We have collected a lot of information from those assessments and we are still analysing it. Our first paper has been written and accepted by the New England Journal of Medicine (www.nejm.org; a very prestigious medical journal) for publication on January 6th 2005. The two charities who funded this study – BLISS, the premature baby charity, and WellBeing of Women – are planning a press announcement to go with the publication (see the results section).

We are planning to write more papers (two more are about to go off to the journals) and we still have two papers waiting publication from the last phase of the study. Publication takes some time (for this first paper it will be 10 months) and the journals prefer us not to let the results out publicly before they get them into print. Sorry about the delay!

Some of the results have been presented at medical meetings and there is a great demand from all over the world to hear of our results – the results have or will be presented in Australia, Belgium, France, Malaysia, Portugal, South Africa, Spain, Sweden, United Arab Emirates and the

USA– and everywhere there is great interest in how well your children have done. Some of you will have contributed to the recent Panorama programme (see below) which emphasises the public interest in the study.

In view of the great interest and enthusiasm shown in our study, and the great support we have had from the families and children we are planning new studies (see the next phase)

The Results of the latest Study

Overall we saw 241 of the EPICure group which is just over 80% of those of you who were in the UK and Ireland at the time of the assessments. The age range was 62-87 months with an average of 6 years 4 months. This is a very high follow up rate – **well done** – but we hope we could see nearer to all of you next time.

In this study we also collected a group of classmates to act as a comparison group for some of the detailed testing we did in children who were at mainstream school. Where possible we wanted to compare the performance of the EPICure children and their classmates, to put the results in context of the issues faced by EPICure children in day-to-day school life.

We looked at what we termed “disability” in a similar way to how we had done it at 2½ years. Using conventional ways of classifying this, compared to our findings at 2½ years we found that a similar number of children were free of disability (just under half) and that just under a quarter had moderate or severe problems. Over 86% of those who had had the worst problems at 2½y still had major problems at 6 years. We also

found a similar number of children with cerebral palsy but in only half of these did the disability interfere badly with their day-to-day activity. These results are summarised in the chart below:

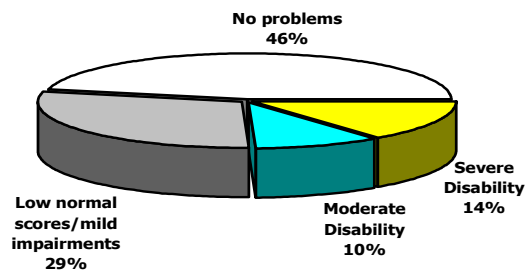


Figure 1: Proportion of children with disability out of 241 children seen at 6y defined as in most other studies

One of the problems in trying to evaluate results such as these is that most of the problems faced by extremely premature children as they grow up relate to learning and their ability in the classroom. The better comparison to do is with their classmates. This is how BBC Panorama reported the results and is considered by Professor Dieter Wolke, the psychologist working on the project, to be the correct way of looking at these results. When we do this, however, the classmates have scored better than average on the tests, which often happens with tests that were drawn up 20 years ago.

When we redo the classification using these better scores as a reference, now just over 4-in-10 EPICure children are doing significantly worse than classmates (see Fig 2) compared to 2-in-10 using the conventional test results (as in Fig 1).

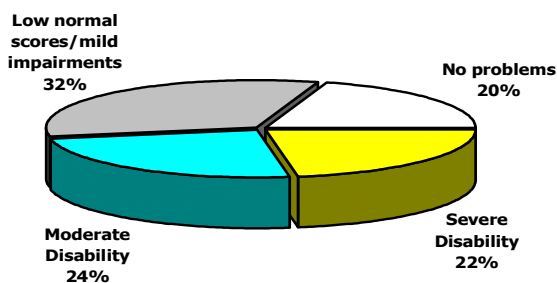


Figure 2: Proportion of children with disability out of 241 children seen at 6y defined by comparison with their classmates

Once again boys seemed to fare much less well than girls, being more prone to disability and having lower scores than the girls. We cannot explain this difference but it has been found throughout the study from its first results in the period after birth.

We only saw small differences between the children born at 25 weeks and those born at 24 or 23 weeks that were not really clinically significant.

When we looked at the detailed results of the intelligence test we did the children were achieving slightly less well than we would have predicted. It appears that being born extremely early seems to make a difference to children's ability to process a lot of information together. Doing tests in sequence was something they did better than expected but trying to do things at the same time as other tasks (simultaneously) revealed problems. Boys and girls had the same profiles here.

We also did a lot of tests to look at the fine detail of the children's hand-eye skills and of their attention. These were as we would have predicted also lower in the EPICure children and were responsible for some of the extra difficulties children were having. We are currently investigating these test results to see if they can shed more light on the underlying problems that produce children's schooling difficulties. We are also analysing the behavioural information we collected at both assessments and we will let you know what these studies come up with later in 2005.

We have looked at some of the growth outcomes as we were concerned about the height and weight of the children at 2½ years. Although the EPICure children are still small compared to their peers, their growth has been at a normal rate over the last 3-4 years. Despite this we still know very little about growth during puberty and we would expect some catch up at that time.

BUT ... Despite all these negative comments, it is important to stress that

most of the children were doing reasonably well at school and keeping up in the classroom and had normal behaviour patterns. This is something the recent press interest doesn't really bring out. Many parents have written to us or emailed to point this out and it is something which is very important for parents and professionals to keep in mind.

We are really excited by the results we have to date and they help us to think again about the aspects of our care that we need to target to help improve the outcome for children in the future. We have been looking hard at the information we collected in the neonatal nursery that happened before and after birth. We can see that some patterns of problems that we are seeing, in particular cerebral palsy and motor problems, may reduce if we can alter some aspects of our care and ensure that all mothers receive antenatal treatment with steroids to help the baby's lungs to mature and be more prepared for premature birth.



A baby born at 23 weeks gestation weighing 540 grams

Once again we could not have obtained this information without your help and we must thank you for your involvement in the study. The strength of our study is that we have included all babies born in Britain and Ireland, as it really shows the true picture for extremely preterm babies across the country.

BBC Panorama

Miracle Baby Grows Up



Layla Jane with her mum Tina.

As you know from our last letter, BBC Panorama, "Miracle Baby Grows Up" (22 September 2004) was based on the findings of the EPICure Study. The children who were featured in this programme were chosen from the EPICure Study Group. The programme generated huge interest both from the general public and the media. We received many telephone calls and emails in response to the programme including many from parents and relatives of EPICure children and we would like to take this opportunity to thank you for all the messages of support.

In general the programme was well received but the issue of how far we should take the care of this vulnerable group continues. If you want to read the interviews and comments on the programme they are available at present still on the BBC website *

The Nuffield Council on Bioethics

This important body is currently looking at the ethical issues around looking after extremely premature babies and babies before and after birth who are found to have major problems. The information we have gained from your children will help to inform the debate which will become public next spring when the Council publish a consultation document. This will eventually be published as a report. If you want to contribute to the debate look for news on their website (www.nuffieldbioethics.org).

* <http://news.bbc.co.uk/1/hi/programmes/panorama/3655050.stm>

An EPICure Parent Support Group?

One of the outcomes of this programme was that several of you contacted us to say you would be prepared to form a group to support each other, and also new parents of very pre-term infants. Many of you have suggested that it would be helpful to find out from other parents how they have dealt with a particular problem and how to access other agencies for advice and professional support. If anyone else is interested in forming such a group please contact Heather Palmer in the EPICure office.

Remember that BLISS, the premature baby charity, also provide excellent parent contact and advice (www.bliss.org.uk)

Our Website

www.nottingham.ac.uk/human-development/EPICure

We are hoping to have this revised and updated by the time the next paper is published in January, personnel changes have meant that it had to go onto a back burner for a while but we should be able to have the newsletter and more information on there early in the new year.

The Next Phase

We are hoping to see all the EPICure children again in the next school year when they are 10-12 years old; at the moment we are waiting to hear from the Medical Research Council as to whether they have approved our application for funding. We are planning to do a similar assessment to the last one, i.e., an assessment carried out at school. In addition we would like to look at how well the lungs have developed by measuring a big breath – promises to be good fun! We are optimistic that our application will be successful so hopefully we will be writing to everyone again in the New Year to make the necessary arrangements. We do hope that all of you will contribute to this important study.

Another EPICure study – EPICure-2

It is almost 10 years since you agreed to join our study. Although lots of things have changed about how we care for tiny newborn babies, we don't know whether this has caused changes in how well they do. We have also asked the MRC if they would fund a repeat of the original study and hope to hear in the next few months if we have been successful. We think it is important to see if changes in neonatal intensive care over the last decade have affected survival and outcome.

The last word!

We hope you find this Newsletter helpful and informative. We are always delighted to hear from you and how the EPICure children are getting on – several parents have even asked if they could put their children in to the study despite the fact we are only studying children born in 1995 & a few from early 1996 and we know you all ... or so we thought - we have also found a child who was lost in the original study!

Please don't hesitate to get in touch and **please let us know if you move address** – it will save Heather some work in tracing you so we can write again.

Email is becoming more popular: Heather Palmer (epicure@nottingham.ac.uk) and Neil Marlow (neil.marlow@nottingham.ac.uk) are easily contactable by this method – alternatively you can pick up the phone!

Thanks again to our two sponsoring Charities – further information on their important work may be obtained from their websites:



www.bliss.org.uk www.wellbeing.org.uk