

Follow-up Study of premature babies born at UCH



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Contents:

- Research Findings so far
- Ongoing Research Projects
- Story of Ann Stewart
- Fun Stuff
- MRI Information
- Contact Details

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- The Wellcome Trust
- March of Dimes
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- PPP
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Thank You

Thanks to the invaluable participation of yourself and others we have managed to see people during their childhood and teenage years and currently adulthood, making this one of the largest studies of its type in the world. However without your participation and the support from your family none of this would have been possible.

The history behind the Study

In 1979 work began on a follow-up study of babies born prematurely under the overall supervision of Professor Robin Murray and Dr Ann Stewart. A team of specialist paediatricians and psychologists followed up all premature and high-risk babies admitted to the neonatal unit at University College Hospital.

To date over 1,500 children have taken part in the project and it is now arguably the most detailed long term study of premature babies to be carried out anywhere in the world.

The primary aim of the study is to examine the effect of prematurity and to increase the understanding of the factors that might influence the health and development of people born prematurely.

The study has produced some exciting results from the data collected during the stages of



*Larry Rifkin
Lead Researcher*

childhood and adolescence, with a pleasing finding that most premature babies do very well. Our ongoing research is now looking at how the brain naturally grows and changes through adolescence into adulthood.

Our aim is to give an overview of our findings and to keep you informed of our future plans.

We hope you find the newsletter interesting and that it provides you with an insight into what your participation is helping to achieve.

Research Team

The research team in October 2003 comprised of Matthew Allin, Marion Cuddy, Sonya Frearson, Elena Giouroukou, Elaine Healy, Antigone Lebessi, Nadia Micali, Chiara Nosarti, Larry Rifkin, Theresa Ruse and Muriel Walshe. Recently however, Adele Fern and Colin O'Carroll have joined the team to help further the research.

The project is in collaboration with the Paediatrics Department at University College Hospital and is based at the Institute of Psychiatry, Kings College London, which is where you will have had your previous assessments.



*FROM LEFT TO RIGHT:
ROBIN MURRAY, MURIEL WALSHE, MARION CUDDY, ADELE FERN, ELENA GIUROUKOU, MATT ALLIN*



Research Findings So Far

The Development of Preterm Babies



Marion Cuddy

Advances in neonatal intensive care made during the 1960's have greatly improved the survival chances of premature and low birth weight infants, with smaller and younger babies surviving.

It is estimated that 5-8% of babies in Europe are born preterm, that is, before 37 weeks of pregnancy and weighing under 2,500grams.

Most follow-up studies of children born preterm end once the children reach school age. This is unfortunate, as some parts of the brain continue to mature into late adolescence, and some outcomes of prematurity not detectable in childhood may appear during the teenage years.

This study looked at the functioning of 14 and 18 year olds who were

born very premature. The participants were born between 1979 and 1985 in University College Hospital (UCH) or where transferred from other London hospitals.

The 14-year-old participants had a brain scan and were examined by a neurologist and a psychologist. Additionally, a child psychiatrist also interviewed their parents.

The 18-year-old participants received detailed neurological and psychological assessments and were interviewed about their current state of health. Both groups were then compared to age-matched controls born at full-term.

The most surprising finding of this study was how well the preterm adolescents did, despite the effects caused by preterm birth.

Marion Cuddy



Emotional, Social and Behavioural Development of Preterm Adolescents



Elaine Healy

This study looked at 112 adolescents aged between 14 and 16 years old who were born prematurely at University College Hospital in London or transferred from other London hospitals. Additionally, 71 full-term adolescents were asked to participate as a comparison group.

On the day of assessment the participants and one of their parents/carers came to the Institute of Psychiatry where they completed a number of questionnaires and assessments.

The aim of this study was to look at the emotional and behavioural

development of the individuals using self-report questionnaires along with parent questionnaires and interviews.

In this group of preterm adolescents, there was no difference in the degree to which the adolescents themselves reported problems with emotions or behaviour.

Preterm-born adolescents saw themselves as equally competent in extracurricular activities and in social relationships as their full-term born peers, but did acknowledge a slight difference in academic difficulties.

The parents of the preterm-born adolescents reported that they were no more concerned about their child's well-being than any other parent and parents of both the preterm group and the full-term group reported their children having similar levels of emotional or behavioural difficulties.

Additionally, parents of both the preterm born adolescents and full-term born adolescents reported similar levels of competence in

extracurricular activities and in social relationships in their children.

In summary, the study found that on a whole there was little difference between the full-term and the preterm born adolescents with regards to the adolescent's self-perception of their emotional, social and behavioural difficulties and the parent's perceptions of any emotional, social and behavioural difficulties their child may experience.

Elaine Healy

Follow-up Study of Preterm Young Adults Born Between 1979-1982

Very few studies exist that have managed to follow-up preterm individuals to adulthood. The reason this particular study is of great significance is that it provides a picture of how preterm individuals develop.

Our interest was to assess memory, attention and language ability. In addition, we asked participants to fill in questionnaires about how they rate their memory and attention in everyday life and if they have problems. Finally, we examined if individuals who are born prematurely are at a greater risk of developing mental health problems.

A group of full-term individuals were also enrolled in the study and used as a comparison group.

We did not find any differences in memory performance between those born preterm and those born at full-term. Participants of the study will probably remember the tests used in the memory assessment: the story recall test and the reproduction of three pictures. We found that preterm participants scored as highly as full-term controls in these two tests.

However, we found small differences between those born

preterm and those born full-term in the language assessment. Particularly, preterm participants produced fewer words in the word production test that required the participants to produce words that started with letters F, A, S, although no differences were found in the production of words that belonged to semantic categories (either objects or animals).

In the attention tests, preterm participants did not perform differently compared to the full-term group, which means that most preterm adults have no problem performing efficiently on attention tasks.

As for the questionnaires, we found that the preterm participants did not report more attention and memory problems. Finally, we did not find that the preterm participants have a higher risk of developing mental health problems.

In summary, we found that the preterm group performed very well in the assessment, with small exceptions. Our findings show that preterm birth has no major effect on cognitive functioning of young adults.

Elena Giouroukou



Elena Giouroukou





Ongoing Research Projects



Chiara Nosarti

Brain Function and Preterm Birth

We are investigating whether the brain organisation of individuals born very preterm is altered in early adult life.

We use a technique called functional magnetic resonance imaging (fMRI). This enables us to see which areas of the brain are working while participants give certain responses to a computer screen, while their brain is being 'photographed'.

The brain areas that are 'activated' during the task that the participant is completing appear as coloured blobs on a brain map.

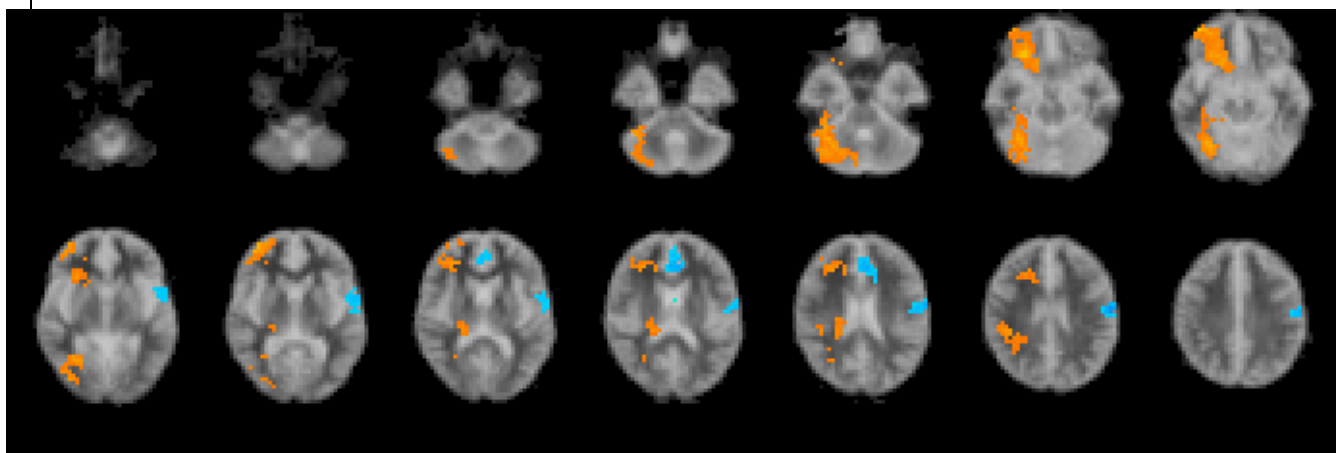
The example given below of an fMRI output shows brain regions of decreased (blue) and increased

(yellow) activation in preterm individuals compared to full-term controls during a test involving attention. It is important to note that despite these different activations, young adults who were born very preterm carried out the task as accurately as the comparison group.

This study uses a range of cognitive tests including language, memory, attention and motor-coordination.

So far we have seen 51 people as part of this study and hope to be able to report on some of the findings early next year.

Chiara Nosarti



*This picture shows you what an fMRI output looks like.
This was taken during a test involving attention.*

Structural MRI Study

We are very interested in how the brain develops - and particularly in the changes that happen in the brain between the ages of 14 and 20. This is because this is an important period during which our brains mature, just as we ourselves mature as people.

To look at the physical changes going on in the brain we have done MRI brain scans at age 14, and again at age 18-20. Using a large computer we can then compare the scans taken at the two different ages and see which bits of the brain are changing in size and shape over this

period.

We have scanned two groups of people - some born premature, and some born at 'term', so we will be able to see if being born too early affects the way the brain develops in adolescence.

The other part of the study is to ask questions about health and well-being, and test abilities such as reasoning, learning and memory. This will enable us to look at how the development of the person into adulthood is connected to the development of the brain.

Matt Allin



Matt Allin



In Memory of Dr Ann Stewart (1930-2004)

Ann qualified in medicine at Bristol University. Her first post was in Paediatrics during which she was encouraged to make a career in the subject.

In 1965 she moved with her husband, Dr Duncan Hutchison, to Edinburgh. Her work there led to her life-long interest in the follow-up of vulnerable infants.

In 1968 she came to work at UCL. At that time intensive care for premature babies was developing rapidly and the Neonatal Unit at UCH was pioneering new methods of caring for tiny babies. Ann was one of the first people in the world to realise that it was essential that long-term follow-up studies were carried out on the premature babies who were now surviving.

Ann's first study of premature babies started in the late 1960's. In 1979 she started the current follow-up study, which is still in existence

25 years later. In 1995, Ann joined up with Professor Robin Murray and the team at the Institute of Psychiatry, to ensure that the follow-up study would continue into adulthood. She retired in 1997 but continued to play an active role, until illness made this impossible.

Ann was acknowledged as a leading international expert on the development of premature babies, and her pioneering work is continuing to produce results today. But she was not only an influential scientist; she was a caring and sensitive doctor who loved the daily interaction with the children and families in the study. Her example, and her insistence that the care and welfare of children should always come first, was a major influence for many junior doctors at UCH. She will be greatly missed. It was a real privilege to know her and to learn from her.



Ann Stewart

John Wyatt





Fun Stuff!

Picture of Your Brain!

Participation in this study may have involved an MRI scan, which I'm sure you'd remember as it involved you having to lie still for 50 minutes listening to a selection of questionable music provided by our MRI department. The outcome of this however, was that we were able to gain a black and white picture of the structure of your brain which will be used in this study along with all the other participants.

As it was you that had to listen to the music, and lie there for the 50 minutes, we thought that it would only be fair if you got something back from this as well. Therefore, along with this newsletter we have sent you a picture of your brain that was taken during your scan.

Below we have also provided a model picture that labels each of the different structures of the brain, with a key that describes what each of these structures are responsible for.

KEY

Cerebellum-

This co-ordinates the movements of your arms and legs and allows you to keep your balance.

Corpus Callosum -

This is a big band of nerve fibres that connects the left and the right side of the brain and allows them to communicate with each other.

Frontal Cortex -

This is the part of the brain that deals with Decision making.

Occipital Cortex -

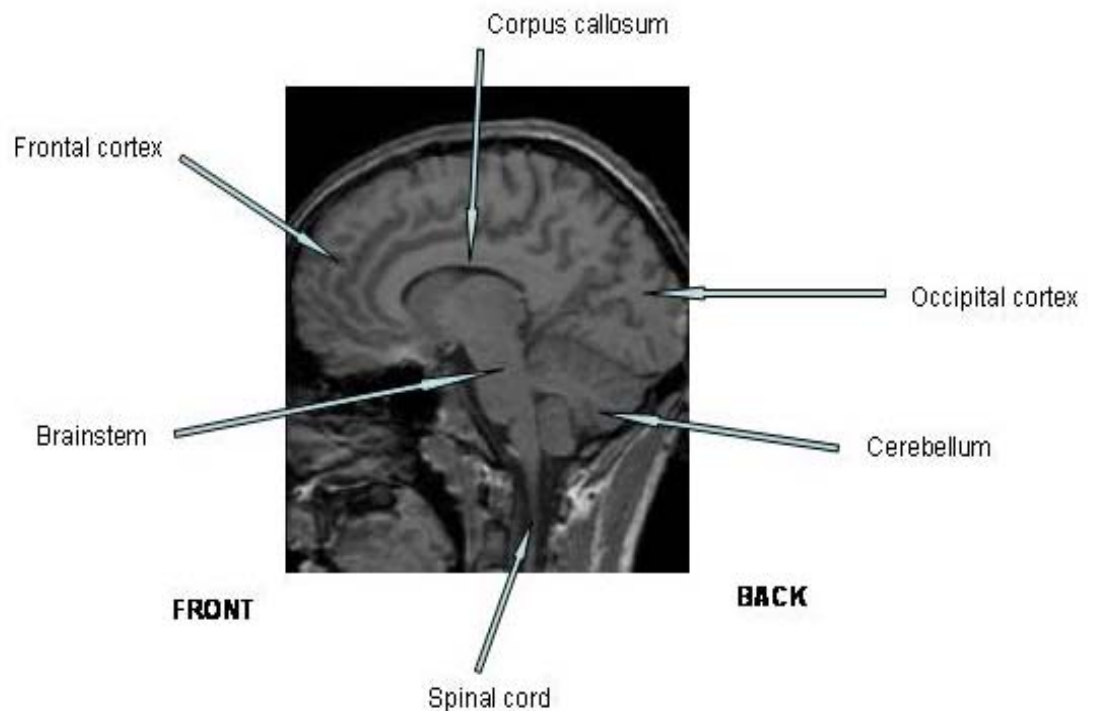
This is the part of the brain that deals with vision.

Spinal Cord -

This is made up of nerves that carry information between the brain and the body.

Brainstem -

This controls your heart rate and breathing pattern and blood pressure.



A side-on picture of the middle of the brain



Famous Premature Babies

Although modern technology is able to help premature babies to survive today, in the past some babies who were born prematurely managed to

survive despite the lack of technology and went on to make a huge difference to the world we live in today.



Winston Churchill: Born November 30th 1874.

Not expected to be born until sometime in January, Winston Churchill was born 2 months premature. Despite this he went on to become one of the most prominent leaders of the 20th Century. Best known for his leadership as British Prime Minister during World War II and his speech in the House of Commons, June 1940 "We shall fight on the beaches, we shall fight on the landing grounds ... we shall never surrender".



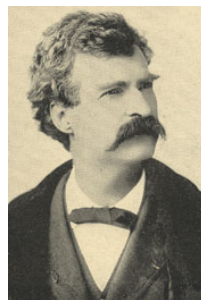
Sir Isaac Newton: Born January 4th 1643.

Born weighing just 3 pounds, the midwives present thought that he was as good as dead. Nevertheless this premature baby went on to be known as one of the greatest scientists of all time, with an estimated I.Q. of 170.



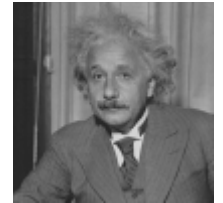
Stevie Wonder: Born May 13, 1950.

Born prematurely he spent his first 56 days of life in an incubator, during which time complications caused him to lose his sight. Despite this he went on to make music that won him many awards such as OSCARS and GRAMMYS and made him one of the world's most influential musicians.



Mark Twain: Born November 30th 1835.

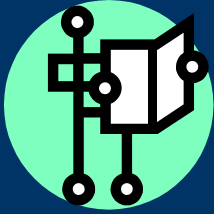
Mark Twain entered the world 2 months early weighing only 5 pounds. It was 1835, when premature babies could not be expected to live. Despite his premature birth, Mark Twain would live to become one of the most famous personalities in American literature, writing novels such as "The Adventures of Tom Sawyer" and "The Adventures of Huckleberry Finn".



"There are two ways to live your life. One is as though nothing is a miracle. The other is as if everything is."

Albert Einstein. Born prematurely. March 13th 1879





Contact Details and Scan Information



Picture of an MRI scanning machine.

MRI and fMRI Information

What is an MRI scan?

An MRI scan is a process used to take a detailed picture of the structure of the brain. This image is then displayed on a computer just like with a digital camera, which can then be used by researchers to study the brain.

How should I prepare for the procedure?

Before you have your scan the radiologist will make sure that you are safe to have the MRI scan. You will be asked to remove anything that is metallic before the scan such as, hairpins, jewellery, eye glasses, metallic make up, and any removable dental work.

It is also important that you let the radiologist or researcher know if there is a chance that you could be pregnant before the scan takes place.

Additionally, you will be able to listen to a CD during your scan (this only applies to MRI scans and not fMRI scans) you are therefore

welcome to bring along one of your own CDs to listen to.

Are there any risks?

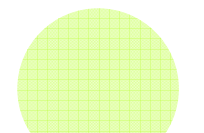
There are no risks associated with MRI scans. They are painless and generally quick with no lasting effects.

What is an fMRI scan?

Researchers know the general area of the brain where speech, sensation, memory, and other functions occur. fMRI (Functional Magnetic Resonance Imaging) not only provides a picture of the brain but it also helps to determine precisely which part of the brain is handling critical functions such as thought, speech, movement, and sensation.

How does the procedure work?

The procedure is carried out in the same way as an MRI scan. However, you will be asked to perform a number of tasks while the imaging is taking place.

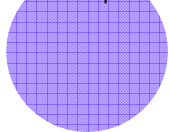


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Getting in Touch

We welcome any feedback or input that you might like to provide in regards to the project or newsletter. Our contact details are listed on this page and we are willing to talk to you about any of the things that have been discussed in this newsletter.

If there is something you think we could help with or if you want to talk to anyone then please call Muriel Walshe on telephone number 020 7848 0057, or email her at m.walsh@iop.kcl.ac.uk.

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