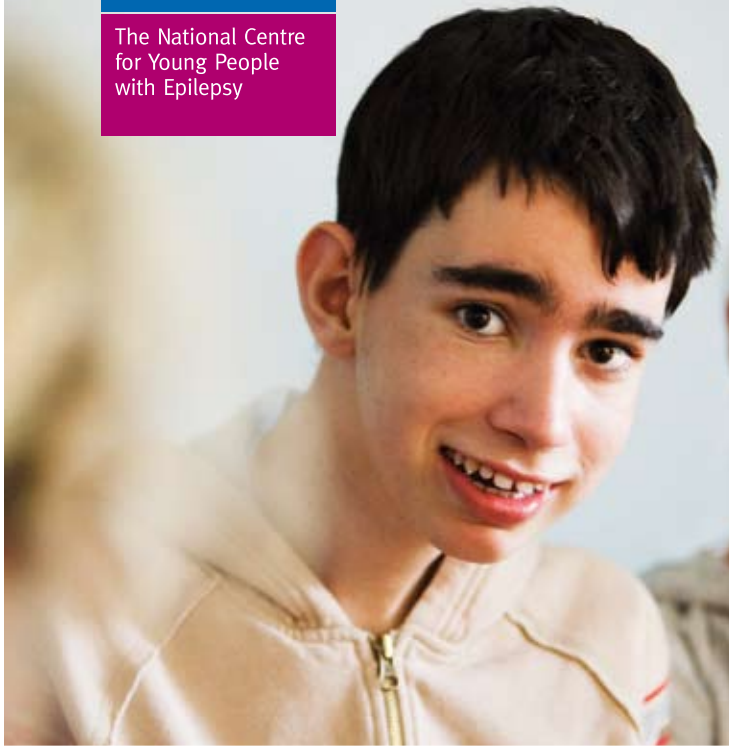


NCYPE 

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Professor Helen Cross

**The Prince of Wales's
Chair of Childhood
Epilepsy**

Annual Report 2008/9

Great Ormond Street
Hospital for Children

NHS Trust

NHS



Introduction

It is with great pleasure that I introduce the first of our annual reports in my current position of The Prince of Wales's Chair of Childhood Epilepsy. I have now been in post for a little over 12 months in what has proved to be a very exciting time with great promise for the future.

The post was initially taken on by Professor Brian Neville, who through foresight has laid the groundwork for epilepsy research across UCL-Institute of Child Health, Great Ormond Street Hospital and The National Centre for Young People with Epilepsy. The premise on

which much of the research is based is that we aim for a better understanding of the underlying mechanisms in childhood epilepsy and the natural history of associated behaviour and learning difficulties. Expertise within the Unit translates findings from basic science, and epidemiology, to clinical evaluation and intervention, with collaboration within our own Institute, across the University, nationally and worldwide.

Over my first year the aim has been primarily to consolidate research that is ongoing as well as working towards the development of a strategy for moving forward. Coordinated working across the University and The National Centre for Young People with Epilepsy alongside Great Ormond Street Hospital enables us to examine all facets of childhood epilepsy from basic mechanisms looking at underlying cause through intervention and ultimate outcome. My own research contributes to this through a focus on intervention and improved outcomes in childhood epilepsy. This was consolidated with my inaugural lecture in May 2009 at The Royal College of Physicians, in Regents Park, London. This was attended by 120 people, professional colleagues, fundraisers as well as employees and friends of the respective organisations. It was also actively supported by Professor Andrew Copp and Dr Jane Collins, Director of the Institute of Child Health and Chief Executive of Great Ormond Street Hospital respectively.

In addition to consolidating our progress within our own institution and in collaboration with others, I have maintained my national and international profile. Certainly one of the roles of the Chair is representation of our respective institutions within national and international bodies and contribution to their perspective on childhood epilepsy. Nationally I have been appointed Clinical Advisor to the review of the NICE guidelines on the diagnosis and management of adults and children with epilepsy. I have also undertaken a number of media interviews about epilepsy and its treatment over the year. Within the NCYPE we continue to advocate services for all children with ongoing epilepsy and how we can improve the situation, emphasised with the NCYPE campaign for a consistent approach to childhood epilepsy by primary care trusts. Internationally, I and other members of the team continue to be invited as guest speakers at meetings and conferences overseas. I have participated in two international consensus groups resulting in publication and I have just completed my term as Chair of the Commission of Paediatrics for the International League Against Epilepsy (ILAE). For the next four year term I have been appointed to the Commission for European Affairs.



Further Principal Investigators in epilepsy at UCL-Institute of Child Health & NCYPE

Dr R Chin

Richard Chin is a Walport Lecturer at the UCL-Institute of Child Health, working jointly across the Neurosciences Unit and the MRC Centre of Epidemiology for Child Health. His research focuses on the epidemiological aspects of epilepsy, with the overall objective of improving the scientific basis for the prevention and management of childhood epilepsy. His epidemiological study of childhood status epilepticus, the North London Convulsive Status Epilepticus in Childhood Surveillance Study (NLSTEPSS) is largely considered the seminal study on the subject and he has recently completed a study on the long-term outcomes of childhood epilepsy utilising the 1958 British Birth Cohort. His current research projects include investigating the short and medium term outcomes of childhood status epilepticus and the development of a comprehensive, international, population-based programme on childhood epilepsy.

Professor B Neville

Professor Brian Neville was the first Prince of Wales's Chair of Childhood Epilepsy, stepping aside from this post only to continue with research in December 2007. He was the first Professor of Paediatric Neurology in the UK appointed in 1989, and developed the unit at Great Ormond Street Hospital for it to become the largest combined clinical and academic department in the country, with collaborative links across Africa and India. He was also key to the development of the epilepsy surgery programme. He took the Chair of Epilepsy in 2004, with a vision to considerably expand the academic research between UCL, GOSH and NCYPE. His research interests involve the early onset epilepsies, with a focus on mechanisms involved in the comorbidities of cognitive and behaviour impairment, and interventions available to minimise these. He has been a principal driver in highlighting the possible extent of problems encountered by these children in education, and is developing research to determine the true extent of the problem as well as the possible role of intervention in the community. He is also a principal investigator on a large project funded by the EU on rare disorders of the nervous system.

Professor Charles Newton

The Tropical Neuroscience programme is primarily based in Africa, in particular at the Kenya Medical Research Institute/Wellcome Trust Collaborative Programme in Kilifi, Kenya and at the Muhimbili University of Health and Allied Sciences, Dar-es-Salaam, Tanzania. In Kilifi they investigate the causes, consequences and burden of neurological conditions in a rural tropical area, particularly those affecting children. Children with neurological conditions are assessed, either on admission to hospital or in epidemiological surveys in the community. Clinical pathophysiology studies are conducted on children admitted with acute seizures, malaria, bacterial meningitis and neonatal conditions such as sepsis, jaundice and tetanus. Outpatients with HIV infection and epilepsy are studied. Further studies on the genetic susceptibility and immunological basis of these conditions are being conducted. The neurocognitive consequences of these conditions are assessed by cultural appropriate psychological assessment and event related potentials. The follow up of cohorts of children with these conditions





and epidemiological surveys allow us to assess the burden of neurological conditions in this community. In Dar-es-Salaam we are conducting studies on Sickle Cell Disease and epilepsy, in particular plan to use the neuroimaging facilities that are available in this city. More recently they have been examining the burden of neurological disease in adults, and are funded to conduct studies of epilepsy in five demographic surveillance sites in Africa (Ghana, Kenya, South Africa, Tanzania and Uganda) to determine the prevalence, risk factors and treatment gap associated with epilepsy.

Dr R Scott

Dr Rod Scott leads a clinical and basic science research program evaluating the nature and mechanisms of brain damage and dysfunction associated with childhood epilepsy. There are ongoing clinical studies evaluating brain abnormality and associated learning impairments following very long seizures (status epilepticus), and investigating long term outcomes from status epilepticus. A randomised controlled trial assessing the role of multiple drugs in impaired quality of life is in progress at NCYPE. He also leads animal model projects investigating the role of inflammation in brain injury associated with status epilepticus and in collaboration with Dr Gregory Holmes (Dartmouth College, USA) he is investigating the relative impacts of early life seizures and developmental brain abnormalities on long term cognitive outcomes.

Epilepsy research at UCL-ICH, Great Ormond Street Hospital & National Centre for Young People with Epilepsy

We have ongoing programs lead by respective members of our unit as outlined above; Professor Helen Cross (JHC), Professor Brian Neville (BN), Professor Charles Newton (CN), Dr Rod Scott (RS) and Dr Richard Chin (RC). The themes of these research programs and the people leading individual projects are outlined below.

1. Epidemiology:

We continue to have thriving epidemiological projects which are carried out in north London. These projects aim to describe long term outcome following epilepsy onset in infancy (led by JHC) and following status epilepticus (RS). In addition there is a major epidemiological study in Africa investigating the burden, outcomes and the treatment gap of epilepsy (CN). Further epidemiological studies are planned evaluating the effect of epilepsy on school age children (BN) and on evaluating the outcomes of epilepsy and the genetic substrates for childhood epilepsy using international birth cohorts (RC). A very long term follow up study of children born in 1958 has recently been completed (RC).

2. Basic mechanisms:

Collaborative studies with Melbourne, Florence and Glasgow have enabled participation in genetic studies, and contribution to the discovery of genes associated with epilepsy and its treatment (JHC). Further evaluation has recently been funded in collaboration with UCL-Institute of Neurology of defined populations of children with epilepsy (JHC). The epilepsy surgery programme has also allowed the examination of pathological specimens

to enhance our understanding of malformations of the brain as a cause for complex epilepsy (JHC in collaboration with neuropathologist Dr Thomas Jacques). We also have plans to conduct genetic studies of epilepsy in Africa, where we will have brought together a cohort of 3000-5000 patients with epilepsy and similar number of controls (CN).



We have a longstanding track record of studies and advances in neuroimaging.

Over this year we have completed a study to examine the role of quantitative analysis in assessment of magnetic resonance imaging in childhood focal epilepsy, and published correlative EEG and MRI studies to examine electrical activity in relation to underlying structure (JHC). Imaging is also used to evaluate possible mechanisms involved in initial damage from prolonged seizures (RS). Electroclinical studies are being further utilised to examine possible mechanisms of later impairments following early onset epilepsies (BN). We also have basic science projects in which animal models are used to study the role of inflammation in brain injury associated with status epilepticus (RS). Dr Scott has just completed his second sabbatical in the USA where he is establishing collaboration with Dr Gregory Holmes (Dartmouth College, USA) in order to investigate the relative impacts of early life seizures and developmental brain abnormalities on long term cognitive outcomes.

3. Intervention studies:

Our group has interests relating to interventions for childhood epilepsy. Last year saw the publication of the first randomised controlled trial of the ketogenic diet (a high fat diet) in drug resistant epilepsy in children 2-16 years of age. This has established the unit as a leading authority in the area, with participation of members of the unit in the first international conference in April 2008 and organising the next in October 2010. This work is now being taken further to examine the efficacy of the diet in a younger population (JHC).

A major European grant led by Great Ormond Street Hospital neurophysiologist Dr R Pressler has been awarded for a multicentre study to examine the efficacy of a new treatment in neonatal seizures (onset in the first 4 weeks of life) which is very controversial and about which little has been investigated to date.

A further European funded project is underway aiming towards better identification and management of rare disorders including rarer forms of epilepsy (BN)

Although antiepileptic drugs are useful for treating seizures the side effects may lead to important reductions in an individuals quality of life (particularly if more than one drug is used at a time). The impact on quality of life of drug minimisation in children with more complex epilepsies is being studied with a drug withdrawal study at the NCYPE (RS).

We are also examining the role of education and traditional healers in Kenya to reduce the treatment gap in this area (CN).

4. Outcome:

In addition to the epidemiological projects outlined above, outcome of surgery for epilepsy is also being evaluated. We have been leaders and active participants in a major international collaborative study of outcome of epilepsy surgery undertaken internationally in 2004 (1124 patients) currently undergoing analysis (JHC). Longer term review of our own surgical cohort is also feeding important cognitive information about outcome and appropriate expectations (JHC).



Work in sub-saharan Africa, centred on the Wellcome Trust unit in Kilifi, Kenya continues on causes and prevention of disability associated with acute infections and seizures (CN).

Following on from the work in Sub Saharan Africa led by Professor Charles Newton, he and Brian Neville were privileged to meet Mr Nelson Mandela last year at his home in Johannesburg. They talked about the new programme of research in 5 centres (Kenya, Uganda, Tanzania, Ghana and South Africa) on the causes of epilepsy and closing the treatment gap for epilepsy which approaches 90% in many places. Mr Mandela agreed to be the patron of the international paediatric epilepsy work that links our UK centre with work in 5 countries in sub-Saharan Africa and also with colleagues in Chandigarh and Dhaka. We are very grateful for Mr Mandela's support and interest in childhood epilepsy and his agreement to continue to give his support and advice.

Over the twelve month period our research has resulted in 47 peer reviewed publications, 14 book chapters, 23 reviews and secured £430,000 of funding (with a further £5.8m for the European project on neonatal seizures and £2.1m from the Wellcome Trust for the study in sub-saharan Africa). We have also recently appointed a research coordinator to enhance coordination of projects across the three institutions. A database is being established to track ongoing projects.

As we move forward with respective programmes, the year has culminated in the completion of The Neville Childhood Epilepsy Centre at the NCYPE. This is the previously named Medical, Assessment and Research Centre (MARC building), for which fundraising has been undertaken over the past few years. This is a very exciting time as the Centre incorporates facilities for health care and video EEG as well as for assessment, research and conferencing. The unit also continues active collaboration both within UCL, as well as outside both nationally and internationally (USA, Italy, Norway, Finland, Canada and Australia). Our focus now has to be to consolidate our position with regard to childhood epilepsy research by looking outside the medical model towards integration with education, therapy and care to formulate research programmes within these areas, diversifying and completing our programme

Over the next 12 months we aim to consolidate further funding for research across our priority areas in childhood epilepsy. In this current economic climate, the acquisition of funding remains a challenge but we continue to bring together projects across UCL-The Institute of Child Health, Great Ormond Street Hospital and The NCYPE alongside national and international collaboration to enhance the treatment and outcome of children with epilepsy.

Publications 2008-2009

Chapters in books

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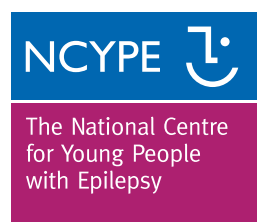
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Reviews

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