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MEDIA RELEASE

New area of research into chronic childhood condition secures prestigious fellowship

A new area of ground-breaking research to provide a better understanding of the cause, treatment and prevention of Chronic Fatigue Syndrome/ME in children has secured a prestigious fellowship and funding of £730,000.

The National Institute of Health Research has awarded the Clinician Scientist Fellowship to Dr Esther Crawley, Consultant Paediatrician at the Royal National Hospital for Rheumatic Diseases NHS Foundation Trust.

This will be the first study to look at CFS/ME in children in such detail.

CFS/ME is a common childhood condition with potentially serious consequences for those affected, and is the most common reason for long-term absence from school. Despite this very little is known about it.

“I want to answer the many unresolved questions about the best ways to treat and manage the patients for whom I am responsible”. Said Esther, also based at the Centre for Child and Adolescent Health at the University of Bristol.

Esther’s research has three parts:

1) Investigate the causes of this CFS/ME in children. Esther will use the University of Bristol’s Avon Longitudinal Study of Parents and Children, also known as ‘Children of the 90s’. These children were born in the Bristol area in the 90’s, detailed information has been collected on these children since birth, they are now turning 16.

Esther will look at their data to see how many of these children had CFS/ME age 13yrs, and what factors predict CFS/ME.

2) Identify effective treatments for CFS/ME. Esther will examine the outcomes of care in children diagnosed with CFS/ME in different types of services across England to understand which are most effective in providing treatment.

3) Develop a school-based early intervention tool to prevent the development of CFS/ME in children. Esther will develop and test an education package for children who are missing school because of fatigue, to see if development of CFS/ME can be prevented. The economic impact of school absences due to fatigue will also be measured.

“This research is crucial to help us to understand the risk factors and prevalence of CFS/ME in children, and to give us an improved understanding of the most effective ways to treat and prevent the development of this condition.” She continues.

Esther's research has been prompted through her involvement in the development of the National Institute for Health and Clinical Excellence (NICE) guidance for CFS/ME

She explains

"My experience as a member of the NICE guideline development group for CFS/ME brought into sharp relief the deficits in the current evidence base.

"We do not know how common CFS/ME is in children, what the risk factors are for developing CFS/ME, whether CFS/ME can be prevented in children at high risk or what the best model for treatment is.

"Current models of care for children are based on adult evidence and there is no information on outcome, treatment or prognosis for children who are severely affected, or the very young.

"These gaps in knowledge were listed as research priority areas by the guideline development group, and this research plans to begin to address them.

"Throughout my clinical career I have aimed to base my practice on robust research evidence. This award provides an ideal opportunity for me to achieve my long-term goal is to transform the care of children with CFS/ME."

The project will begin in March 2009 and will be carried out over a five year period.

The paediatric CFS/ME service at the Royal National Hospital for Rheumatic Diseases is the largest regional paediatric CFS/ME clinical service in the UK, and has a national reputation. The paediatric CFS/ME team treats around 200 new children and young patients from across the UK and Western Europe each year.

ENDS

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Notes for Editors:

- The RNHRD NHS FT is a national specialist rehabilitation and rheumatology hospital based in Bath. Offering services to adults, children and young people the Trust has expertise in general and complex
 - Rheumatological and Musculoskeletal conditions
 - Neurological rehabilitation
 - Chronic Pain Management
 - Chronic Fatigue Syndrome/ME
 - www.rnhrd.nhs.uk
- Young people with CFS/ME, their parents and representatives of the national organisation the Association of Young people with ME, of which Esther is medical advisor, Children Missing Education Officers, school attendance officers and school assistant heads, have all been involved in the design of these study's.
- Amongst other professional bodies Dr Esther Crawley is a Fellow of the Royal College of Paediatrics and Child Health (RCPCH), Chair of the NHS Collaborative of CFS/ME services, Convener of the RCPCH CFS/ME special

interest group, and Medical Advisor to the Association of Young people with ME
<http://www.ayme.org.uk/>

- The National Health Research Clinician Scientist Award Scheme aims to fund doctors and dentists through a 5 year post-doctoral research fellowship, supporting their development as the leading clinical academics of the future. Seven previous rounds of competition have supported on average five Clinician Scientists a year. http://www.nihr.ac.uk/faculty_research_training_schemes.aspx
- The Avon Longitudinal Study of Parents and Children (ALSPAC) carried out by the University of Bristol is a long-term health research project also known as 'Children of the 90s'. More than 14,000 mothers enrolled during pregnancy in 1991 and 1992, and the health and development of their children has been followed in great detail ever since. The ALSPAC families have provided a vast amount of genetic and environmental information over the years. This resource is assisting scientists all over the world with research into a wide range of health problems. <http://www.bristol.ac.uk/alspac/>