**Welcome to the EPRC Newsletter Summer 2010**

Prof Barbara Jack has received international recognition for her work with the terminally ill at Hospice Africa Uganda by being made a Visiting Professor. Prof Jack said of the award that ‘It formalises this international collaboration and shows that Edge Hill is working with this charity to the benefit of a developing country.’

It has been an exciting year with the EPRC holding national conferences, as well as an ongoing programme of national and international research. For further information please see [www.edgehill.ac.uk/eprc](http://www.edgehill.ac.uk/eprc).

**Congratulations to the Dr Lucy Bray and Jacqueline McKenna from Edge Hill University who along with Erica Pritchard and Dr Caroline Sanders were awarded a prize at the RCN International Research Society Conference in May 2010. The presented paper which focused on a project exploring how sexual health is discussed with young people within the context of acute paediatric care was judged by the RCN Research Society’s Scientific Committee as a paper they believed ‘people would still be talking about in 12 months time’. The study is a collaborative project with Alder Hey Children’s NHS Foundation Trust, funded by the Burdett Trust for Nursing and is currently involved in the design and implementation of an e-learning resource to equip health care staff to discuss sexual and relationship health with young people.**

**Evaluation of children and young people’s weight loss interventions and healthy life style programmes offered in the Burnley area.**

This project was commissioned by the Public Health Department of the NHS East Lancashire PCT and aimed to identify the basic features of children and young people’s weight loss interventions and healthy lifestyle programmes offered in the Burnley area. Included were the Obesity Support for Children And Relatives (OSCAR); Mind, Exercise, Nutrition, Do it (MEND); and the Burnley Food and Fitness Aimed at Lowering Obesity (BUFFALO) programmes. The objectives of three programmes range from obesity treatment for children with complex needs and their families (OSCAR), treatment programmes for obese and overweight children (MEND) to obesity prevention for children and their teachers (BUFFALO). Using framework given by the National Obesity Observatory (NOO 2009) the basic characteristics of each of the programmes were compared and details of such things as recruitment profiles, core staff delivering the programmes, programme costs and the types of outcome measures deployed were identified. It is concluded that the OSCAR, MEND and BUFFALO programmes comprise of a tiered approach to providing services for children and young people spanning the ‘at risk’ to the obese. Thus a crucial finding of the study undertaken is not that one programme is more cost effective or produces better health outcomes than another but that the programmes have different emphases all of which are necessary in combating the significant risk childhood obesity has for the future health of the population in the Burnley area.

A copy of the report is available at [http://www.edgehill.ac.uk/eprc/research/reports](http://www.edgehill.ac.uk/eprc/research/reports)

Prof Annette Jinks

**Optimisation of services for people with Motor Neurone Disease (MND)**

This was a qualitative study carried out collaboratively by the EPRC and Preston Motor Neurone Disease Care and Research Centre, led by Dr Mary O’Brien. The study explored the experiences of people living with Motor Neurone Disease (both patients and carers) using narrative interviews and identified to what extent their needs were being met by health, social and palliative care services. This study was funded for 30 months by the National Institute for Health Research (NIHR) Research for Patient Benefit programme (RfPB). The study, one of the first RfPB projects to be funded in the North West, has been completed both on time and within budget.

The project made a number of interesting findings, for example problems with diagnostic delays and poor communication of the diagnosis were common; delays in referrals to specialist care were prevalent and there was little integration of health and social care services. Additionally, there was limited availability of psychological/emotional support for patients and carers.

The findings from the study will be further disseminated amongst service providers in the form of conferences and publications. A number of resources to support people with MND have been recommended in the form of care pathways for specific times in the illness trajectory which are currently being developed. Further research studies will follow on from this project and a number of subsequent applications are currently under review by the RfPB and Marie Curie Cancer Research UK.

Dr Mary O’Brien and Bridget Whitehead

**Of Sound Mind and Body? A Case Study**

Prof Barbara Jack, Pat Hosgood, Julie Devereux, Jennifer Kirton

Despite the increasing legislation surrounding disability and guidance from the professional regulatory bodies regarding health care students, the issue that universities face, is the need for students to disclose any health needs or disability before the commencement of their course. This enables anticipatory adjustments to be made, particularly in the practice environment, to support their progression and retention throughout their programme. This case study which was a collaborative venture with the HEA was accepted as a poster presentation at the Higher Education Academy Conference in Edinburgh. Several key themes emerged from the data relating to pre admission information and guidance requirements that have informed the development of a new web zone;

[http://www.edgehill.ac.uk/health/f2p/goodhealth](http://www.edgehill.ac.uk/health/f2p/goodhealth)

Prof Brenda Roe of the EPRC has been made an Honorary Fellow with the PSSRU (Personal Social Services Research Unit) at the University of Manchester (see [www.pssru.ac.uk](http://www.pssru.ac.uk)) in recognition of their collaborations related to services for older people, in particular work related to carers, services and dementia.
Congratulations to Dr Lucy Bray who has recently completed her PhD at the University of Manchester which explored the experiences of children, young people and their parents of living with, and managing a continenta stoma. Her research interests include the information needs and preparation of children, young people and their parents relating to surgery and interventions. She also has a keen interest in the education and clinical skills of children’s nurses. She leads the local Research in Child Health group, organises the annual national RICH study day and is actively involved in the continuing professional development of nurses.

Prof Barbara Jack is one of the Nursing Academy mentors, some of the aims of which are to:

- Identify nursing, midwifery and health visiting research leaders of the future
- Help nurses, midwives and health visitors who are navigating new territory
- Help people influence the wider health research agenda
- Facilitate a sustainable programme in an environment of economic pressure

For further information please see http://www.researchacademy.co.uk/mentors

Prof Barbara Jack has also been appointed to the editorial board of Nurse Researcher, the International Journal of Research Methodology in Nursing and Health Care.

Bridging the Gap: The Impact of a Generic Neurology Nursing Service on Patients and Carers.

The evaluation of the generic neurology nursing service, a novel development to provide additional support for patients with neurological conditions highlighted the value of this service. The findings from this project were presented at the RCN 2010 International Research Society conference at Gateshead. Full report available at http://www.edgehill.ac.uk/eprc/research/reports

Communication: the key to success

The 4th international conference, held in collaboration with Pontville School in Ormskirk, addressed the needs of young people with high functioning Autism/Asperger’s Syndrome and was held at Edge Hill University in May. Dr Gary Mesibov, Director of Division TEACCH at the University of North Carolina was the keynote speaker at this highly successful conference which attracted over 300 delegates. Dr Emma Ashwin, Research Officer at Bath University, presented the Fetal Testosterone Theory of Autism and Paul Hughes, a former pupil at Pontville School, gave his personal perspective on what it is like to be diagnosed with Asperger’s syndrome. Derek Paravicini, who is blind, autistic and a gifted musician enthralled the audience with his fantastic piano playing which included his own composition of the ‘Ormskirk Blues’.

Dr Jeremy Brown

The EPRC team presented at the following national and international conferences:

- RCN International Nursing Research Conference, Gateshead
- The Higher Education Academy Conference, Edinburgh
- 20th International ALS/MND Symposium, Berlin
- Exploring the Challenges of an Ageing Population of Drug Users, Liverpool John Moores University, Liverpool
- 38th British Society of Gerontology Conference. University of Bristol and University of the West of England, Bristol
- European Head and Neck Oncology [EHNS] Conference, Athens
- 7th International Conference on Head and Neck Cancer (San Francisco)

Prof Ben Shaw works at Liverpool Women’s Hospital as a consultant neonatologist and has since 2005 been an Associate Postgraduate Dean for Mersey Deane. During the past five years he has developed individual and multidisciplinary collaborations with the EPRC at Edge Hill University. These have facilitated his research activity, particularly in the field of educational research on a wide range of topics, including portfolio reflective practice, workplace based assessments and educational interventions to improve patient care (the latter resulting in collaborative experience being gained in performing Best Evidence Medical Education (BEME) reviews). In his role as Visiting Professor at Edge Hill he hopes to develop a research programme incorporating both clinical and educational research collaborations.

Research funding for the Patient and Carer Burden Project

Over 40 patients, family, and staff from the Regional H&N Cancer Centre joined in the 10K Liverpool run to raise money for charity. This charity event is raising money towards funding a head and neck chemoradiotherapy project. The tunnel run is because it is a major part of a lot of patients’ cancer journey travelling to and from the regional centre and Clatterbridge. The ‘team’, through the support of patients, carers and others are aiming to raise £40K over the next 18 months for this research into those with the most advanced form of head and neck cancer where treatment side effects are most severe. Further information can be accessed on: www.headandneckcancer.co.uk

Prof Simon Rogers

Goodbye and Good Luck

The EPRC team wish a fond farewell to Carol Wright, the EPRC administrator. After over two years with the EPRC Carol is retiring from Edge Hill University to take a part-time position with a local independent assessment and development centre for children with communication difficulties.

For further information on any collaborative projects or copies of reports please contact carol.wright@edgehill.ac.uk