ANNUAL SCIENTIFIC MEETING

TUESDAY 1 APRIL 2014, BIRMINGHAM

INFORMATICS & TECHNOLOGY IN NEURODISABILITY

The ASM will look at how data and technology are helping to improve the lives of children and adolescents with neurodisability.

Improvements in health outcomes can result from simple strategies and the ASM will explore outcomes important to children and families and how health and allied health professionals can try to achieve them.

The ASM is aimed at all health professionals, teachers and families who are involved with the lives of children and adolescents with neurodisability.

In addition to the Polani Lecture and keynote lectures we are delighted to announce that in the afternoon session a choice of workshops will be available.

We are also calling for abstracts for poster presentation, with the best poster being awarded the Mac Keith Poster Prize - a cheque for £250!

For the first time, you can register and pay by credit/debit card online!

The meeting will once again take place at the University of Birmingham’s Medical School.

For more information about the ASM please see page 6.

WINTER EDITION 2013

IT WAS GREAT TO SEE SO MANY BACD MEMBERS AT THE EUROPEAN ACADEMY OF CHILDHOOD DISABILITY CONFERENCE AT GATESHEAD IN OCTOBER.

We plan to include a full review of this meeting in our Spring edition in order to share some of the highlights with those who were unable to attend. In addition to wide choices of personal practice workshops, an almost overwhelming array of posters and excellent posters and platform presentations from across Europe and wider afield we were treated to some truly excellent keynote lectures which put cutting edge science in to an accessible and clinically relevant format. Particularly well-received sessions included a detailed update of current knowledge of genetics in autism, advances in potential medical therapies for Duchenne Muscular Dystrophy and applications of advanced neuroimaging that are furthering our understanding of the development and integration of neural pathways.

This edition is a “Christmas stocking” of possibilities for expanding clinical or research knowledge and practice with the details of a number of forthcoming meetings and opportunities, together with a review of ‘Children with Developmental Disabilities: The Essential Guide to Assessment and Management’.

We are also offered a tour, not of Santa’s Grotto on this occasion, but of the Belnheim House Child Development Centre in Blackpool, their current services, working models and developments.

We hope to see everyone at the ASM in Birmingham in April and in the meantime wish you all very many festive and seasonal greetings!

KATHERINE MARTIN, EDITOR
BLENHEIM HOUSE CHILD DEVELOPMENT & SUPPORT CENTRE, BLACKPOOL

Dr Megan Thomas, Consultant Community Paediatrician
Blackpool Teaching Hospitals NHS Foundation Trust

Blenheim House Child Development and Family Support Centre is one of the oldest CDC’s in the country having opened in 1978 two years after the Court Report recommending the Child Development Centre model.

Originally located very close to other community services, two special schools and a respite facility it moved to specially adapted premises in 1996. This is about a ten minute walk from Blackpool Victoria Hospital. Now due to concerns about the maintenance and running of this building a further move is planned although where or how this will be achieved is not yet clear. It may yet be back to very close to its original site as part of a primary care centre.

Blenheim House offers services to predominantly pre-school children and their families across the Blackpool, Fylde and Wyre area where there is a concern about the child’s physical and/or learning development. This is a population of around 330,000 people. As Blackpool is a Unitary Authority and Fylde and Wyre are part of Lancashire there are challenges in working with two very different authorities and commissioning groups with different priorities.

The service was originally part of a community trust but when PCT’s were formed the Team was split between three PCT’s and an acute Trust. This had a negative impact on how the service was able to be managed. However, from April 2013 community services are being managed by Blackpool Teaching Hospitals meaning the Team has a unified management structure again which we feel provides some positive opportunities.

The core team consists of specialist health visitors, paediatricians, physiotherapists, occupational therapists and administrators. The team has changed considerably over the years and in common with many other CDC’s there has been a steady withdrawal of partner agencies including Educational Psychologist, Teacher, Social Worker and Nursery Officers. The speech therapists are also no longer based at the CDC but we continue to try and work closely together and with our multiagency partners. Clinics are also held with paediatric neurologists, clinical geneticists and a senior orthoptist.

There has been an increase in the number and complexity of referrals to the CDC, and this has been dramatic over the past five years with a doubling of referrals from around 150 per year to more than 300 last year.

All these changes have had an impact of the way we work and has meant we have to continually evaluate our working practices. While we consider we offered an excellent service and this has been reflected in receiving the Charter Mark in 1999 and a Strategic Health Award in 2006 changes in team structure and lack of investment means we have had to do things differently. However we hope that some of these changes are positive. Although we are no longer able to run the parent support groups we used to, we facilitate parents and a local children’s centre to do so.

We have also worked with Contact a Family to run some sibling groups. A lot of the speech and language therapy provision is through parent programmes and these are held in the evenings as well as during the day depending on parents’ preferences. We have reduced the number of formal developmental evaluations we do such as Griffiths assessments. We have clear outcomes included in therapy reports and referrals and interventions are prioritised on need. Nevertheless, it is a continual struggle to maintain appropriate waiting times and provide the necessary interventions and support.
Would you like to see your Child Development Centre featured in the BACD Newsletter?
If so, please email bacd@rcpch.ac.uk and we will be in touch!

All referrals are discussed at the weekly Team meeting. This ensures the right people are involved and the timescales for this. We also discuss information from the previous week’s patient contacts to facilitate good communication and to help provide a co-ordinated holistic service.

Where possible and appropriate assessments are joint and we also work closely with the Portage home visitors performing joint home visits. The service is offered through the CDC, home visits, children’s centres and private and maintained nurseries and schools. Having been a pathfinder for Early Support we embrace this ethos and make use of their information resources.

We also believe research and innovation are important. As well as supporting NIHR portfolio studies we are developing our own studies and trialling new innovative practices in relation to sleep management, communication and parent support. So watch this space as there are many changes in progress!

**Paul Polani Research Award 2014**

BACD is calling for applications to the Paul Polani Research Award 2014, which supports and encourages research and innovation in paediatric neurodisability in the UK.

Up to £7,500 is available to enable teams to pilot, undertake, or complete research projects based in paediatric neurodisability. Applications may be from teams or individuals (of any discipline).

The previous winning research projects are:

- Identification of behavioural risk markers for Challenging Behaviour in very young children with intellectual disabilities
- The use of taping to improve thumb and wrist posture and hand use in infants with non-progressive brain lesions affecting hand function
- Creation and validation of a tool for identifying children with functional visual impairments in children with hemiplegia
- Sleep in Children with Severe Cerebral Palsy: Objective Measurement of the Impact of Botulinum Toxin Hip Injections
- Respiratory function in children with severe motor disorders using night-time postural equipment
- Measuring the efficacy of computer communication intervention for children with cerebral palsy
- Establishing the Lifestyle Assessment Questionnaire, a measure of participation Predicting the development of intelligible speech by children with cerebral palsy: a pilot study

**Strategic Research Group Trainee representative Vacancy**

The BACD Strategic Research Group trainee representative post will be coming up soon as I have now finished training.

This is a great opportunity for someone who is interested in research or who is on a research track to get involved with the current state of play of research in childhood disability in the UK.

I have found this post extremely rewarding and I hope that we can continue to have a trainee within the group and continue to try and encourage other trainees to get more involved with research in childhood disability!

If anyone is interested in applying, please contact me.

Melissa Gladstone
M.J.Gladstone@liverpool.ac.uk
NEWS FROM CONTACT A FAMILY

WOULD YOU LIKE TO OFFER FREE INFORMATION WORKSHOPS FOR PARENTS?

Contact a Family have regional teams working across England, who can provide free information workshops for groups of parent carers on the following topics:

- coping and support
- behaviour that challenges us
- helping your child to sleep
- transition from adult to child services
- information about benefits
- bullying at school

They can also provide information sessions for professionals who work with families with disabled children, to help them understand the barriers that families face and how Contact a Family can help.

If you are interested in running any of these in your child development centre, please contact the following regional teams for more information:

- East of England eastofengland@cafamily.org.uk
- London london@southeast@cafamily.org.uk
- Midlands (East & West) westmidlands.office@cafamily.org.uk
- North East northeast.office@cafamily.org.uk
- North West northwest@cafamily.org.uk
- South East london&southeast@cafamily.org.uk
- South West southwest@cafamily.org.uk

NB Unfortunately at present we are not able to offer these in Yorkshire.

Contact a Family Guide to Developmental Delay

Contact a Family has produced the following information on developmental delay:

- Our pull out leaflet on developmental delay is useful when talking to families about developmental delay.
- Our poster encourage families to consult with you if their child is not reaching key milestones.
- Our parents guide “About diagnosis - Developmental delay” also gives parents more information about developmental delay.

For information on these and other Contact a Family guides visit:

www.cafamily.org.uk/professionals/supporting-your-work-with-families/our-work-with-health-professionals/

The Contact a Family helpline service offers information or advice on any aspect of caring for a disabled child through its national freephone helpline on 0808 808 3555, Monday to Friday, 9.30am to 5pm, or email the helpline. Or visit the website: www.cafamily.org.uk

At the meeting, the Steering Group worked through several of the survey suggestions to get a feel for how we would decide whether suggestions are in or out of scope, and how to code various interventions and generic/condition-specific topics.

The coding is now in progress and reviewing progress with this, including quality checks, are on the agenda for our next meeting in January.

www.bacdis.org.uk/research/psp.htm
This book sets out to be a comprehensive text on the assessment and management of children with neurodisabling conditions. The authors have certainly succeeded in their mission. To date no similar book exists, and is a must read for trainees, consultants and allied health professionals in the field. It fully captures the holistic approach that paediatricians should have towards children with disabilities and their families. The heart warming picture on the front speaks volumes about the passion for the specialty that exudes from this book; try not to be put off by the lurid green cover! The preface by Professor David Hall predicts that this book will become the foundation text for paediatricians specialising in this field, and we would whole-heartedly agree with this sentiment.

ICF-CY (International Classification of Functioning, Disability and Health – Children and Youth version) is the common thread running through the whole text. The book is divided into logical sections. Each chapter has key messages and case vignettes to highlight particular disorders. The learning objectives at the beginning of the chapter help you to decide if the information is relevant to you.

The first section concerns health and disability, in which the concepts of ICF-CY and quality of life are introduced. These form the underlying principles in each chapter (reminiding us that if an intervention is not going to improve a child’s quality of life, it’s probably not worth doing!). Following this are sections on child development and assessment. The next sections of the book are divided up into children’s symptoms that may present to a health professional working in neurodisability. These include disorders affecting motor impairments (including amongst others the infant with hypotonia, the child with delayed walking, the stiff child, scoliosis...), communication disorders, learning difficulties and loss of skills, behaviour disorders and sensory impairments. There is then a section on high-risk groups, including chapters on extremely preterm infants, congenital infections and toxins, and abuse resulting in disability.

The following section covers specific conditions and disorders, in which there are chapters on cerebral palsy, epilepsy, autism spectrum disorders and many other common neurodisabling conditions written by experts in the particular disorder.

Then follows a fantastic section on genetics and genetic conditions. This gives a clear guide to the assessment of a child with dysmorphic features, including which tests to do and when to seek the advice of a geneticist. Specific conditions (including Down syndrome, neurofibromatosis, William syndrome, Prader Willi and many more) and their management are covered, including what to think about at annual review. For the first time I now understand the genetics of Fragile X syndrome!

The next section is very important: Partnerships with Families. It reminds us what it is like for a family to have a disabled child, and gives practical advice on how to help families cope. Chapters include talking to families and carers (with excellent practical tips on breaking bad news), the impact of childhood disability on the family (with emphasis on financial and socio-emotional effects), supporting families during the process of adjustment (with tips for professionals on helping families cope with caring for a child with a disability), early support (with a clear explanation of why this is necessary and who provides it), cultural practices (a great chapter outlining how religious and cultural beliefs can affect a family’s attitude to a child with a disability). A chapter on ethical perspectives reminds us about ethical principles and the law, and gives practical examples of their application. Ways in which a paediatrician can help a child with disabilities access leisure facilities are outlined, and practical tips to help children being bullied.

A section on Frameworks for Family Support follows, which provides an outline of services provided by Health (in particular child development teams), social care (particularly respite), education (with advice on writing a good medical report or statement) and voluntary organisations (with an excellent index of support available to families from a variety of organisations), with additional chapters on advocacy, law and transition.

The final section concerns caring for a child with a disability. This covers symptoms experienced by many children with a variety of neurodisabling conditions, and provides information on the assessment and management of symptoms including feeding difficulties (I now have a better grasp of what “oral aversion” is, and its management), pain, drooling and sleep disorders amongst others, along with practical advice that can be given to families on bathing, oral hygiene and dressing. I thought these chapters were brilliant, with their practical tips that can really make a difference to how families manage day to day living. Following this are chapters on child abuse (and how to recognise abuse in this vulnerable population) and life shortening conditions (including advice on the writing of emergency health care plans with examples).

What the book lacks in pictures and visuals it makes up for in easy to read tables and pragmatic tips. It is a comprehensive, practical and easy to read guide which is an essential text for anyone practicing in the field of neurodisability.
ANNUAL SCIENTIFIC MEETING 2014
Tuesday 1 April 2014, University of Birmingham Medical School
Informatics & Technology in Neurodisability

Programme

08.45 Registration and Coffee
09.10 Introduction Dr Neil Wimalasundera, BACD Academic Convenor
Session one: Making data work in neurodisability
09.15 CHUMs project: meaningful outcomes for children with neurodisability
  Dr Chris Morris, Senior Research Fellow, University of Exeter
09.45 Data Matters
  Dr Karen Horridge, Paediatrician (Disability), City Hospitals Sunderland NHS Foundation Trust
10.15 Q&A
10.20 Coffee break, Exhibition and Posters

Session two: Technology in practice
10.50 Polani Award 2012 presentation: The use of taping to improve thumb and wrist posture and hand use in infants with non-progressive brain lesions affecting hand function
  Dr Anna Basu, SpR Paediatric Neurology, & Dr Jill Kisler, Consultant in Child Development and Neurodisabilities, Newcastle Hospitals NHS Foundation Trust
11.05 Strategic Research Group update
  Dr Jeremy Parr, SRG Chair
11.20 Assistive Communication Technology: iPads - what i do and what i don’t
  Mr Tom Griffiths, Assistive Technologist, Great Ormond St Hospital, London
12.00 Paul Polani Lecture: Reorganisation and rehabilitation after early childhood stroke
  Professor Janet Eyre, Professor of Paediatric Neuroscience, Newcastle University
12.40 Q&A
12.45 Lunch, Exhibition and Posters
Annual General Meeting for BACD Members

Session three
13.50 Interactive workshops – choice of 2 sessions
  Video gaming to promote the development of children with movement difficulties
  Dr Ian Maie, Consultant Community Paediatrician, Brighton
  What might Paediatricians want to know about eye gaze technology?
  Communication, Learning and Technology service, Great Ormond St Hospital, London
15.15 Reducing anxiety in children with autism spectrum disorder (ASD) through virtual reality environments
  Dr Morag Maskey, Research Associate, Newcastle University
15.50 Advances in environmental control
  Speaker TBC
16.25 Mac Keith Poster Prize Presentation Summary
16.30 Close of Meeting

To register online visit:
www.participant.co.uk/BACD2014

Mac Keith Poster Prize

The Mac Keith Poster Prize of £250 is awarded to the best poster presentation at the ASM each year.

- We are seeking posters that report innovative multi-disciplinary working for children with neurodisability and their families.
- The work should not have been presented at or accepted for any other national meeting; and it should not have been published.
- Whilst anyone can submit, some positive weighting will be given to a submission from a person in training or the earlier stages of their career.
- We encourage submissions from medical and therapy students and if their abstract is selected for presentation BACD will provide complimentary registration fees.

Abstract submission forms are available from: www.bacdis.org.uk/conferences/annual_scientific_meeting.htm

The deadline for submission is Friday 31 January 2014.

Registration Fees are as follows

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Early Bird Registration closes 4 March 2013.
Applications are invited for this MSc Paediatric Neurodisability (distance learning) 3 year course, commencing March 2014.

All Grid trainees in Paediatric Neurodisability are encouraged to undertake the course, as it complements the Grid Training programme and provides a useful framework for acquisition of the expected competences.

The course is also highly relevant to all those currently providing paediatric care for disabled children and young people who wish to extend and improve their competences.

For more information contact: mary.colclough@sch.nhs.uk
Tel: 0114 2260614

The ‘Deciphering Developmental Disorders’study-what is it?
Prof Helen Firth, Consultant Geneticist, Cambridge University Hospitals Trust

Behavioural phenotypes of neurodevelopmental disorders
Prof Tony Holland, The Health Foundation, Chair in Learning Disability, University of Cambridge

Microcephaly
Dr Alasdair Parker, Consultant Paediatric Neurologist, Cambridge University Hospitals NHS Trust

Mitochondrial disorders-when to suspect?
Prof Joanna Poulton, Professor in Mitochondrial Genetics, Nuffield Department of Obstetrics and Gynaecology, Oxford

An overview of genetic movement disorders
Dr Manju Kurian, Honorary Consultant Paediatric Neurology, Great Ormond Street Hospital, London

Neurodisability Training issues (optional)

Developing care standards for children with neuromuscular disorders
Prof Kate Bushby, Honorary Consultant Geneticist, Newcastle upon Tyne Hospitals NHS Foundation Trust and Deputy Director, MRC Centre for Neuromuscular Diseases at London and Newcastle

Autism Spectrum Conditions & Common Comorbidities: Treatments and Managements
Prof Jeremy Turk, Consultant Child and Adolescent Psychiatrist, South London and Maudsley NHS Foundation Trust

Transition from a neurodisability trainee to a consultant
Dr Amy Taylor, Consultant Paediatric Neurodisability, Nottingham University Hospitals NHS Trust

Paediatric neurodisability - into the future
Dr Karen Horridge, Consultant Paediatric Neurodisability, Sunderland NHS Foundation Trust and Chair, BACD

www.bacdis.org.uk/conferences/traineesmeeting.htm

BACD/BACCH SOUTH WEST REGIONAL MEETING, OCTOBER 2013

We held a very successful joint BACD/BACCH SW regional meeting in Exeter on the theme of childhood disability research. There were 55 participants from across the region, from Gloucestershire to Cornwall; a mix of paediatricians, therapists, parents of disabled children and academic researchers.

Presentations showcased research on a new Eating and Drinking Classification System for cerebral palsy, vision assessments in children with neurodisability, risk-taking by adolescents with ADHD, factors affecting children’s attitudes to disability, the ASD-UK database, identifying key health outcomes for children with neurodisability, long term outcome of amputation following meningococcal septicaemia, and comparing play and development in Somalia and the UK. A reflective presentation considered challenges and gains from implementing NICE guidance for management of spasticity locally in a district service.

Highlight of the day was a presentation by two parents of disabled children and a researcher that beautifully capture how parents had been involved in a research project evaluating one-to-one peer support provided by Face2Face. Dramatised as a journalist interview, the ‘play’ revealed the impact that the parents’ had in all stages of the research, and the impact this had on them and the researcher. The day closed with information on the new SW Strategic Clinical Network for Women and Children. There was much debate between presentations, and networking over lunch. Hopefully we will follow up the potential opportunities to further develop childhood disability research across the South West region.

Chris Morris, South West Regional Representative
NEWS FROM GOVERNMENT

GAIL TREML, SEN ADVISOR

CHILDREN’S CARE PRIORITIES

The priorities for the care of children and young people across the NHS next year are improving mental health services, safeguarding arrangements and outcomes for those with disabilities and long-term conditions. These measures in the NHS Mandate for 2014/15 apply to all NHS services as well as clinical commissioning groups and health and wellbeing boards.

CHIEF MEDICAL OFFICER URGES STRONG MEASURES TO BOOST CHILD HEALTH

Inspections of education and care services must put more focus on partnerships between children’s and health services, England’s chief medical officer says that Ofsted and the Care Quality Commission must “routinely ask for evidence on how well children’s and health services work together”. See https://www.gov.uk/government/publications/chief-medical-officers-annual-report-2012-our-children-deserve-better-prevention-pays

DfE SEN STATISTICS

The overall number of school pupils with SEND has remained unchanged over the past five years according. 2.8% of pupils in primary and secondary schools in England have a statement; whilst those pupils with SEND without statements has decreased from 17 to 16% from 2012 to 2013.

GOVE ADMITS ‘THINGS HAVE GONE WRONG’

Michael Gove has admitted to problems with some free schools but said the failures were now being dealt with. The Education Secretary said that he was now operating a “tighter inspection regime” for both free schools and local authority schools, and the test would be the “speed with which you deal with failure”.

VALUE FOR MONEY

A leaked DfE document shows that ministers will make struggling schools into academies even when costs are disproportionate to benefits. DfE officials planning budget cuts suggested ministers consider value for money before forcing academy conversions. Michael Gove overruled this cash-saving idea as “totally wrong”.

SHORTFALL NURSERY PLACES

Ministers pledged 15 hours per week free childcare to 130,000 two-year-olds in England from September. But the latest DfE figures show that just 92,000 children are receiving childcare, meaning only seven out of 10 of the most disadvantaged two-year-olds have been offered a place. Childcare providers said the offer was not properly funded.

SHARP FALL IN EARLY YEARS SPENDING

Local authority Sure Start spending will take the brunt of funding cuts in children’s services this year. DfE figures show a 2.73% fall in funding, before the effect of inflation is taken into account, with total funding for children’s centres and early years services showed the biggest decrease – down £190m from £1.28bn in 2012/13 to £1.09bn in 2013/14 - a drop of 14.8%.

GOVERNMENT UNVEILS PLANS TO SEND YOUNG PEOPLE TO ADULT JAILS

The government is proposing that Young offender institutions for 18- to 20-year-olds are scrapped and young people sent to adult jails instead. The Youth Justice Board strongly oppose this idea.

CHILD MAINTENANCE

The Child Maintenance Service takes over all new child maintenance cases from 26 November 2013. Charities warn that the new system, which will include charges for some parents to use the service, will result in thousands of families giving up on maintenance altogether and their children going without vital support.

EARLY SCHOOLING DAMAGES CHILDREN

More than 100 teachers, writers and academics advise that the government’s early years education policies damage children’s health and well being. They say children should learn through play. A DfE spokesman dismissed them as a ‘badly misguided lobby’.

The Association for the Professional Development of Early Years Educators (Tactyc) also believe that young children are failed by the Early Years Foundation Stage and consider that a greater focus on play-based learning would be more appropriate to their development. They warn that Government expectations of education standards for young children are “unrealistic and inappropriate”. Tactyc also criticised Ofsted chair Baroness Sally Morgan’s idea of children starting school at two years old, saying it would exacerbate the problem.

COUNCILS SIGN UP TO FURTHER TEST SEND REFORMS

The government will fund ten local authorities to test ways of helping parents understand how personalised budgets for children with SEND or disabilities will work, because of concerns that the changes, due to be introduced from September next year, have not been tested enough. SENDirect will be launched in March 2015 in Bexley, Cornwall, Coventry, Essex, Gateshead, Herefordshire, Leicestershire, Oldham, Solihull and Telford & Wrekin.

WELSH GET EXTRA £570M NHS FUNDING

The NHS in Wales will get £570m extra funding over three years, including £150m this financial year. Whilst funding for local government will be cut by 5.81% next year.

MORE MONEY FOR EARLY YEARS IN WALES

£11m additional funding has been allocated to the early years Flying Start programme. Flying Start is currently accessed by 23,579 children and the Welsh Government is aiming to extend the scheme to cover 36,000 children and their families by the end of the Assembly term in 2016. It offers eligible parents free childcare for two and three year olds, parenting support, an enhanced health visitor service and help for early language development.