



Europe's Children Our Concern asbl

supporting children and young people with learning difficulties

Under the Patronage of Her Royal Highness Princess Mathilde

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"Together we can make a difference"

ECOC News No. 68 – May 2008

If you have news that you would like us to pass on, or if you would like us to publicise an event or mention a resource that you have found useful, please send us the details.

ECOC News

ECOC Annual General Meeting

You are invited to attend the ECOC Annual General Meeting on 19 June. It will be held at Autoworld in the Cinquantenaire Park and will be followed by a dinner. The meeting will begin at 19.00.

More information from www.ecoc.be

ECOC Conference

ECOC will be holding its annual conference on 8 October. Please make a note of the date. Details will follow!

New website

ECOC has a new website! Take a look and let us know what you think. www.ecoc.be
In fact, in future we will be posting this newsletter on the web rather than sending it out so do make regular visits.

News

UK National Epilepsy Week 2008 - 18-25 May 2008

For National Epilepsy Week 2008, Epilepsy Action will be highlighting the lack of awareness about epilepsy that exists in society and encouraging supporters to help educate more people, from MPs and other key decision makers to the general public.

- [Epilepsy facts and stats](#)

More information: mmiller@epilepsy.org.uk or + 44 113 210 8877

Research into rare gene mutation that causes epilepsy in women

Scientists have discovered the link between a mutant gene and a rare condition that causes epilepsy and mental impairment in women. The condition, known as EFMR, whose cause

has hitherto been a mystery, has now been linked a large family of genes known as protocadherins.

Girls with the condition appear normal at birth but start having seizures at about one year of age. Their development then becomes slowed and they grow up disabled, with some unable to feed or dress themselves.

The study, published in the journal *Nature Genetics*, shows that although men carry the mutant gene, only women are affected.

The research was led by Dr Leanne Dibbens and Associate Professor Jozef Gecz from the Women's and Children's Hospital in Adelaide and the University of Adelaide. They collaborated with experts from around the world, including scientists at the Sanger Institute and the Wellcome Trust in Britain, and other researchers in Melbourne, the US, Ireland and Israel.

Dr Dibbens said their discovery would enable families affected by EFMR to benefit from genetic counselling, including screening for the genetic mutation at pregnancy. She said the gene involved is important for cell-to-cell communication in the brain, and could also hold the key to better understanding of related issues such as autism and obsessive disorders.

High-fat, low-carb diet shown to curb epileptic seizures

The first clinical trial of a ketogenic diet - high in fats and low in carbohydrates and protein - has shown that it sharply curtails seizures and is an effective tool for managing children who are resistant to anti-epilepsy drugs.

The diet mimics the effects of starvation and induces the body to produce chemicals called ketone bodies rather than glucose as an energy source for the brain. Ketone bodies appear to reduce seizures but the reason for it is unclear.

In the new study, Dr. J. Helen Cross of Great Ormond Street Hospital in London and her colleagues enrolled 145 children, aged 2 to 16, who were having at least seven seizures per week and who were not responding to anti-epileptic drugs. They were randomly assigned to receive the ketogenic diet or a normal diet for three months, after which those on the normal diet were switched to the treatment diet.

The team reported in the journal *Lancet Neurology* that the number of seizures dropped by more than a third in the group receiving the ketogenic diet, while the seizures rose by more than a third in the control group.

The researchers concluded that "the diet should be more widely available as a treatment," but cautioned that it "should only be undertaken on medical advice and under medical and dietetic supervision."

La Dyslexie a la radio

La Première, radio de la RTBF, consacre une émission de deux heures à la dyslexie: "Quand les jeunes s'en mêlent" samedi 31 mai de 15h à 17h, avec des témoignages de jeunes dyslexiques et des réactions d'adultes du monde éducatif et associatif.

Xtraordinary People assesses the cost of neglecting dyslexia

Delay in providing specialist educational support to children with dyslexia is needlessly costing the UK £1.8bn a year, a charity has warned. Dyslexic children are not identified early

enough and therefore suffer difficulties in school, leading to expensive knock-on effects for individuals and society.

The report by dyslexia charity Xtraordinary People suggests the UK's estimated two million children with dyslexia and other learning difficulties would flourish at school if identified and given access to trained specialists. The report also says that the government could avoid the wastage if each school had a teacher trained as a dyslexia specialist, able to recognise and support dyslexic children. Dyslexia awareness training should be mandatory for all other teachers, it continues.

Earlier this month, ministers announced an [independent review](#) into the identification and teaching of children with dyslexia, in addition to the allocation of £3m to pilot and review specialist support over the next three years.

Kate Griggs, the charity's founder, said dyslexic children were being denied the opportunity to be successful. "This is having a costly effect for everyone. But even more worryingly, the report also finds that by depriving children of specialist help, the UK is wasting the potential of one fifth of its children."

More information: <http://www.xtraordinarypeople.com/>

Launch of the PMLD Network website

The PMLD Network is a group of people and organisations working together to improve the lives of people with profound and multiple learning disabilities (PMLD). They have just launched their new website www.pmldnetwork.org. Take a look!

Researchers report improvements in brain power

University of Michigan at Ann Arbor (UM) researchers report that a specific memory exercise may improve so-called [fluid intelligence](#)—the capacity to succeed at new cognitive tasks and in new situations. If confirmed, the finding could lead to new therapies and prevention of [learning disorders](#) and [age-related memory loss](#).

[The study](#), published in the journal *Proceedings of the National Academy of Sciences USA*, contradicts earlier research showing that attempts at crossover training effects, known as far transfer, do not work well. Previous research has shown that improving on one kind of cognitive task does not improve performance on other kinds—for example, memorizing long strings of numbers does not help people learn strings of letters.

"This is the first time it could be shown that [cognitive training](#) leads to improvement on an untrained task, so we can say it's a far-transfer task," says study co-author Martin Buschkuhl, a U.M. psychologist. He and his colleagues are hoping to extend the work beyond the healthy 20-something adults they studied to other groups, such as [older people in the throes of cognitive decline](#) and [youngsters diagnosed with attention-deficit disorder](#).

"It's a little oversold, but it is certainly interesting," says Earl Hunt, a psychologist at the University of Washington in Seattle, who researches individual differences in cognition but was not involved in this study. "It will be important in education and a number of other things—*if* these results prove to hold up."

More information : <http://www.sciam.com/article.cfm?id=study-shows-brain-power-can-be-bolstered>

Heart investigation advised before prescription of ADHD drugs

Children should be screened for heart problems with an electrocardiogram before being prescribed drugs like Ritalin to treat hyperactivity and attention-deficit disorder, according to the American Heart Association.

Stimulant drugs can increase blood pressure and heart rate. For most children, that is not a problem. But in those with heart conditions, it could make them more vulnerable to sudden cardiac arrest and other heart problems.

Medication on the rise for US and UK children

Anti-psychotic medication use is rising on both sides of the Atlantic with research suggesting that the drugs are being over-prescribed for both US and UK children. Among the most commonly used drugs were those to treat symptoms of autism and hyperactivity.

In the UK study, anti-psychotics were prescribed for 595 children at a rate of less than four per 10,000 children in 1992. By 2005, 2,917 children were prescribed the drugs at a rate of seven per 10,000 — a near-doubling, said lead author Fariz Rani, a researcher at the University of London's pharmacy school.

By contrast, an earlier US study found that more than 23 per 10,000 used the drugs in 1996 versus nearly 45 American children out of 10,000 in 2001.

The study is released in the May edition of the journal *Pediatrics*.

Possible mercury-autism link

A study of Texas school district data and industrial mercury-release data, conducted by researchers at The University of Texas Health Science Center at San Antonio, shows a statistically significant link between pounds of industrial release of mercury and increased autism rates. It also shows — for the first time — a statistically significant association between autism risk and distance from the mercury source.

"This is not a definitive study, but just one more that furthers the association between environmental mercury and autism," said lead author Dr Raymond F. Palmer, associate professor of family and community medicine at the UT Health Science Center San Antonio.

Dr Palmer, Dr Stephen Blanchard, of Our Lady of the Lake University in San Antonio and Robert Wood of the UT Health Science Center found that community autism prevalence is reduced by 1 per cent to 2 per cent with each 10 miles of distance from the pollution source.

"This study was not designed to understand which individuals in the population are at risk due to mercury exposure," Dr Palmer said. "However, it does suggest generally that there is greater autism risk closer to the polluting source."

More information: Palmer, R.F., et al., Proximity to point sources of environmental mercury release as a predictor of autism prevalence. *Health & Place* (2008).

UK government to calculate the number of adults with autism in England

Announcing the £500,000 project, Care Services Minister Ivan Lewis said autistic adults are too often abandoned by health and social services. The National Autistic Society welcomed the move, saying it hopes it will mark a turning point in the way the needs of adults with autism are met.

The statistics will be used to form a national strategy.

Geoffrey Maddrell, chairman of the charity Research Autism added: "This is an important first step towards understanding the scale of autism in the UK and will help to decide what next steps need to be taken to ensure people with the condition are supported and signposted toward approaches that will enhance their quality of life."

Award-winning stair-climbing aid

A young woman from Sheffield, UK, has turned a school project into an award-winning stair-climbing device for older and disabled people. Ruth Amos has launched her StairSteady handrail at Naidex 2008 - the annual disability exhibition in Birmingham.

The StairSteady is a horizontal rail at 90 degrees to the wall or banister that people can hold on to as they go up or down stairs. A friction device inside the handrail enables the user to move it up or down but it locks when weight is applied in order to give added support. Ms Amos says her invention will enable people who have difficulty with stairs to remain active - something that she says is not the case when a stair lift is fitted. "Our product will fit any width of stairs and it's also low-cost," she said.

Resources

Books

Making Sense of Sex

A Forthright Guide to Puberty, Sex and Relationships for People with Asperger's Syndrome by Sarah Attwood

Paperback, ISBN: 978-1-84310-374-5, 320pp, 2008, £12.99, \$19.95

Puberty is a time of huge change in the body, in emotional experience and in social relationships. Having an understanding of these developments and learning how to deal with them is essential, and for people with Asperger's Syndrome it can be a challenge to get to grips with the social and emotional aspects of puberty, sex and relationships.

This book is ideal for those who need clear, detailed explanations and direct answers to the many questions raised by puberty and sexual maturity. Sarah Attwood describes developments in both the male and female body, and explains how to maintain hygiene and personal care, and to promote general good health. She examines emotional changes, including moods and sexual feelings, and provides comprehensive information on sex, sexual health and reproduction. She looks at the nature of friendship, how it changes from childhood to adulthood and its importance as a basis for sexual encounter. She also offers coping strategies for different social experiences, from bullying to dating, and includes essential tips on the politics of mature behaviour, such as knowing the difference between public and personal topics of conversation.

Making Sense of Sex is a thorough guide written in unambiguous language with helpful diagrams, explanations and practical advice for young people approaching puberty and beyond.

Reaching and Teaching the Child with Autism Spectrum Disorder Using Learning Preferences and Strengths by Heather MacKenzie

Paperback, ISBN: 978-1-84310-623-4, 272pp, 2008, £15.99, \$24.95

Reaching and Teaching Children with Autism provides a positive approach to understanding and educating children on the autism spectrum. The book gives greater insight into the perspective and behaviour of a child with autism and explores how the child's learning preferences, strengths and interests can be used to facilitate learning and enhance motivation.

Based on well-researched theory and extensive clinical experience, the author provides a comprehensive model for developing lifelong independent learning skills in children with autism between the ages of 3 and 12 years old. The book describes the underlying principles, learning preferences and strengths typical of children with autism and offers a detailed but flexible program structure based on these concepts. Easy to follow activities and approaches are described in each chapter, along with clear examples and illustrations.

This accessible and practical book is an essential resource for parents, teachers, support workers, therapists and others concerned with learning and development in children with autism.

The First Six Weeks of School by Paula Denton and Roxann Kriete

Paperback, ISBN 978-1-892989-04-8, 232 pp, 2000, \$22.00

Learn how to structure the first six weeks of school to lay the groundwork for a productive year of learning. Discover how taking the time to build a solid foundation in the early weeks of school can pay off all year long in increased student motivation, cooperation, responsibility, and self-control.

This comprehensive guidebook for K-6 teachers features:

- Daily plans for the first three weeks and commentary about these plans at three grade levels: primary (K-2), middle (3-4), and upper (5-6)
- Detailed guidelines for:
 - Building community
 - Creating rules and teaching routines
 - Introducing engaging curriculum
 - Fostering autonomy
 - Integrating social and academic learning
 - Establishing high expectations for learning and behavior
- An extensive collection of games, activities, greetings, songs, read-alouds, and resources especially useful during the early weeks of school

The Tipping Points by Phil Anderton

Retired police officer Phil Anderton looks at how young people with poorly managed ADHD are at risk of following a path into crime, substance misuse, anti-social behaviour and personal danger, and outlines ways to reduce those risks with easy to follow and pragmatic text and checklists. The book, the first of its kind, also has advice for magistrates and the police when coming into contact with these young people.

You can buy it online now. Just [click here](#)

Conferences and events

17 May 2008

Dyspraxia and maths problems

Farnham, Surrey, UK

A presentation with Amanda Kirby, author of *Dyspraxia: The Hidden Handicap*.

More information: courses@arkellcentre.org.uk

19 May 2008

ADHD – talk by Diane Zaccheo

ISB, Brussels, Belgium

A second evening with Diane Zaccheo on practical strategies for those with ADHD

22 mai 2008

Traitement du TDA/H avec la participation d'un médecin spécialisé

Brussels

Contactez info@tdah.be

9 June 2008

[Improving the skills of children with Aspergers syndrome](#)

The Ibis Hotel, 3, Cardington Street, London UK

More information: www.concept-training.co.uk

12 June 2008

[Autism 2020 Conference](#)

Prior's Court School, Thatcham, Berkshire, UK

This one-day conference will feature internationally-renowned experts who will present their perspectives on the future of autism research, understanding, interventions and provision. This is the inaugural conference in the annual Dame Stephanie Shirley lecture series.

More information: www.priorscourt.org.uk

12 & 13 June 2008

International Conference and NIPPA AGM 2008

Derry City Hotel, Northern Ireland

The theme will be "Enjoyment of Learning". The keynote speakers are Professor Guy Claxton and Dr Larry Schweinhart.

More information: www.early-years.org

14 June 2008

Epilepsy Action 2008 National Conference and Annual General Meeting

[Novotel London St Pancras](#).

The conference will explore the many different ways we understand epilepsy from medical research, in-depth social studies, focus groups and from individual experiences.

More information: www.epilepsy.org.uk

14 June 2008

Special Educational Needs training day – Dyspraxia Foundation

London Voluntary Resource Centre, 356 Holloway Road, London, UK

For more information: [Download a booking form now...](#)

19 June 2008

ECOC Annual General Meeting

Autoworld, Cinquantenaire Park, Brussels, Belgium

More information: www.ecoc.be

19 June 2008

[A voice of their own – good practice in advocacy](#)

Ramada Plaza, Wrexham, UK

More information: [Download leaflet](#)

30 June 2008

Practical solutions for students with dyslexia in the normal classroom

Wimbledon, London, UK

The first in a series of conferences offering practical solutions for classroom teachers, this concentrates on reading. Subsequent conferences deal with spelling and writing.

More information: www.bdadyslexia.org.uk

14-18 July 2008

Understanding Dyslexia and ADHD

San Jose, California, US

More information: <http://www.dys-add.com>

17-18 July 2008

[Autism & Asperger's syndrome: an outstanding online conference](#)

More information: +1 800489 0727

8-19 September 2008

Children's Rights in a Globalized World: From Principles to Practice

Ghent and Antwerp

An international study session.

More information: www.iccr.be

27 September 2008

Dyspraxia

Sheraton Hotel, Heathrow, London, UK

Spanning the years: A joint approach to dealing with dyspraxia. A one-day conference for health, education professionals and anyone working with children and adults with dyspraxia.

[Call for Abstracts: Dyspraxia Foundation Professional dyspraxiaConference 2008](#)

6&7 October 2008

Autism neuroscience

London, UK

The Autism Research Centre at the University of Cambridge will be hosting an autism neuroscience conference.

The conference will include lectures summarising the latest international research on the nature and causes of autism. Abstracts are invited on these topics for both oral presentations and poster displays at the conference.

For further information, to register and to download the abstract submission form visit www.arc-conference.com

8 October 2008

ECOC conference

Brussels, Belgium

Tip of the month

The Council for Exceptional Children introduces AT packages

CEC has two new assistive technology packages available. The first groups Technology Supports for Young Children, Using AT Accommodations in Assessments, and AT Considerations for Academic Success in one package. The second package is AT Consideration Quick Wheel and TAM Technology Fan (AT Considerations for Academic Success). [Find out more.](#)