

All PNE patients should now only be prescribed the oral forms of desmopressin; tablets or DesmoMelt (desmopressin oral lyophilisate 120mcg and 240mcg).

Since April 2007, desmopressin nasal spray (both Desmospray and the generic products) have no longer been licensed for Primary Nocturnal Enuresis. Communications informing healthcare

professionals of the MHRA decision to change have been sent to all UK GPs, enuresis clinic services, paediatricians, urologists, and medicines management directors of PCTs.

Ferring now recommend that all children should be transferred to DesmoMelt 120 mcg at bedtime increasing to 240mcg only if necessary. For those who prefer to take a conventional tablet, Desmotabs (desmopressin 0.2mg desmopressin acetate) continues to be available. The cost of treatment is the same for Desmotabs and DesmoMelt.

If you would like further information including copies of the communications already sent, please visit the website www.urinecontrol.co.uk, and follow the "Desmospray licence change" link.

Alternatively e-mail: medical@ferring.com, or call 01753 214800.



ferring news

Childhood Continence News and Views

Issue 1 October 2007

Urology calendar

Conference	Date	Venue
ERIC's 5th International Conference Challenging for Change in Childhood Continence: Engaging, Educating, Empowering.....	3 - 4 Oct 2007	University of York
RCN Continence Care Annual conference and exhibition: A global perspective	31 Oct, 1 Nov 2007	York racecourse
International Children's Continence in Society (ICCS) International Enuresis Symposium: Latest Advances on Children Bedwetting and Incontinence Care	30 Nov - 2 Dec 2007	Hong Kong
Royal College of Paediatrics and Child Health (RCPCH) Annual Spring Meeting	14-18 April 2008	University of York

News and resources

News from the 37th Annual meeting of the International Continence Society (ICS), Rotterdam, Netherlands 20-24 August 2007.

A poster entitled Desmopressin Response in the Treatment of Primary Nocturnal Enuresis in the United Kingdom was presented at the recent ICS meeting held in Rotterdam. It showed that in the treatment of PNE the efficacy of desmopressin and an enuresis alarm is similar but that patients showed poorer compliance to the alarm treatment. The lead author, Dr Jonathan Evans Consultant Paediatric Nephrologist, Nottingham City Hospital, reported that there was a high rate of early withdrawal from the study among patients being treated with the alarm and that, among those patients who did stay to the end of the study, compliance rates were consistently higher in the desmopressin group than in the alarm group. It was suggested by investigators that early withdrawal and low compliance rates in the alarm group may be attributed in

part to the disruption to sleep caused by enuresis alarms.

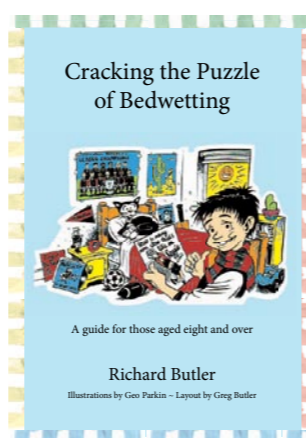
The study was funded by Ferring Pharmaceuticals.

Reference:
DRIP UK: an Open-Label, Randomised Comparative Study of Oral Desmopressin Versus Enuresis Alarm. Abstract 225

To view the abstract go to:
<https://www.icsoffice.org/publications/2007/PDF/0225.PDF>

Useful websites

International Children's Continence Society: www.i-c-c-s.org
Royal College of Paediatrics and Child Health: www.rcpch.ac.uk
Ferring's healthcare professional website: www.urinecontrol.co.uk
Ferring's patient website: www.stopbedwetting.org



'Cracking the puzzle of bedwetting' A new illustrated booklet produced by Richard Butler to help children discover ways of solving many of the issues they encounter as a result of bedwetting is now available to download from: www.urinecontrol.co.uk

Date of preparation: October 2007
DE 677/09/07

Welcome to the first issue of Childhood Continence News and Views, a publication designed for healthcare professionals under the guidance of an independent expert advisory panel and sponsored by a grant from Ferring Pharmaceuticals.

In this issue June Rogers, Team Director of PromoCon, answers some of the frequently asked questions regarding how to treat children

aged between 5 and 7 years who suffer from bedwetting, and Dr Fiona Cameron, Community Paediatrician, reports on the recently formed Scottish Enuresis Interest Group. Regular columns will include news from Ferring Pharmaceuticals along with forthcoming conferences and useful resources.

We hope that you find this and future issues of this publication useful.

in this issue:

- Treating 5-7 year olds
- Setting up a nocturnal enuresis interest group
- ERIC News
- Ferring News
- Urology Calendar
- News and Resources

Treating 5-7 year olds with bedwetting



June Rogers MBE, Team Director of PromoCon, at Disabled Living NW, Manchester

In the first of a series of 'Ask the expert' features which will be running in Childhood Continence News and Views, June Rogers answers some of the questions that she is commonly asked in her role as a Paediatric Continence Advisor.

Q. Bedwetting is a common problem in 5-7 year olds - what should I do regarding treatment for this age group?

A. We know the impact of bedwetting on children and families can be significant. It can affect a child's self-esteem and interpersonal relationships with peers and parents, with increased risk of physical abuse. One study found that 23 to 36 percent of parents had used punishment as their primary means of dealing with bed-wetting.¹ Children with bedwetting are often teased by siblings and friends and are reluctant to participate in school trips requiring an overnight stay or to attend sleepovers. Recent data in the UK found that around only 32% of families of children with bedwetting seek professional help.²

The attitudes of the child and the parents to bedwetting (desire and motivation to change) influence the likelihood of treatment success.³ Hence, family education is crucial. Parents and the

affected child need to know that bedwetting is a common problem, and parents should be instructed not to blame or shame the child.



The age at which parents seek treatment for their child's wetting problems is often influenced both by the severity of symptoms and by parental and/or child concerns. Therefore parents who present with a child with bedwetting, regardless of the child's age, should be offered appropriate advice and support. Often parents want reassurance that there is nothing seriously wrong with their child. Once reassured they are often happy to go away to follow basic advice. For other parents and children the bedwetting is causing significant distress therefore active treatment should always be offered, regardless of age, to those families that seek it.

Editorial advisory panel:

Dr Melissa Bracewell, Consultant Paediatrician, Child Development Centre, Chichester

Dr Fiona Cameron, Community Paediatrician, Motherwell Health Centre, Motherwell

Dr Jonathan Evans, Consultant Paediatric Nephrologist, Nottingham City Hospital

Dr Victoria McGregor, Community Paediatrician, Central Health Clinic, Southampton

June Rogers MBE, Team Director of PromoCon, at Disabled Living NW, Manchester

Dr Anne Wright, Consultant Paediatrician, Sheldon Centre, Camberwell

Editorial liaison

We hope that you enjoy reading the first issue of Childhood Continence News and Views. If you have any comments on this issue, or suggestions for topics that you would like to see covered in subsequent issues, please send them to: carrie@helenlawn.co.uk

This publication is produced by Helen Lawn and Associates.

Treating 5-7 year olds - cont'd...

Q. What treatment is available for this age group?

A. It is important that any child presenting with bedwetting has an holistic assessment to both exclude any underlying pathology and identify the potential cause of the bedwetting. There are a number of assessment tools available, including the Clinical Management Tool (CMT),* which will help individualise treatment, taking into account both the underlying cause of the bedwetting and any significant comorbidity, including family dynamics and motivation.

Treatment for all children should include adjustment of fluid intake and encourage complete regular daytime voids. Any constipation should be treated and bladder retraining undertaken if necessary. We encourage all children over the age of 5 years to remove night time nappies if worn and the families are given advice regarding bed protection and ensuring easy access to the toilet at night.

If these basic interventions do not lead to significant improvement then formalised treatment programmes including

medication, such as desmopressin, or an alarm need to be considered, (although alarms can be offered at any age they are commonly only used for children over the age of 7 years).

Q. Is it true that desmopressin is only for short term use, such as going away on holiday?

A. No, desmopressin can be given from age 5 years and can be taken for as long as symptom control is required. All that is suggested is that the need for continued treatment should be reassessed every 3 months by stopping the medication for a week and only recommence if the wetting recurs.

Desmopressin is the synthetic analogue of the antidiuretic hormone vasopressin and is now also available in the form of DesmoMelt® (desmopressin acetate 120mcg or 240mcg as the acetate) . It has been demonstrated that children under 12 years of age prefer to take DesmoMelt rather than ordinary tablets⁴.

A number of studies have supported both the efficacy and safety profile of taking desmopressin long term.⁵

References

1. Miller K. Concomitant nonpharmacologic therapy in the treatment of primary nocturnal enuresis. Clin Pediatr [Phila] 1993;July(spec. no.):32-7.
2. Butler R J et al (2005). Nocturnal Enuresis : a survey of parental coping strategies at 71/2 years. Child care, health and development, 31, 6, 659-667.
3. Morison MJ. Parents' and young people's attitudes towards bedwetting and their influence on behaviour, including readiness to engage in and persist with treatment. Br J Urol 1998; 81 Suppl 3: 56-66.
4. Persson B-E et al. 15th European Urology Winter Forum, Davos, Switzerland, February 11-15 Poster 13
5. Snajderova M et al (1999) Long-term treatment with desmopressin in children with primary nocturnal enuresis. An international multi-center study. Cas Lek Cesk; 138(14):429-435.

Additional information:

* Clinical Management Tool (CMT) Available for download from the internet at: www.urinecontrol.co.uk

across Scotland attend RHSC Yorkhill. SPRUN is trying to establish direct links to a lead clinician in each NHS trust with regular teleconferencing.

In the first meeting of SEIG we wanted to establish who does what, where and how. This took some time but we now have a list of services available and one area is looking at their service provision as a result. Children moving from area to area should now have an identifiable point of contact. This established, we looked at what we each expected from SEIG. We need to justify time spent away from work and make it useful. We are still learning about each other and a balance will need to be found to accommodate the various needs of the group.

SEIG has decided to meet again, one day every six months divided into two distinct parts. A business type meeting with two representatives per trust will discuss

how the group will progress; business plans, provision for investigations and paperwork have all been suggested as topics for discussion. An educational session following the group meeting will be open to all. This will initially be on how we have set up our current continence services, with urology and psychology in later sessions.

In between meetings electronic communication makes keeping contact easier. A contact list of e-mail addresses is available and communication is only a click away. We have circulated minutes and the good news that SPRUN has secured funding from Kidney Kids for training and equipment.

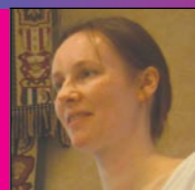
Our next meeting is on 31st of October.

In the meantime let's keep in touch. fiona.cameron@lanarkshire.scot.nhs.uk



Communication - the key to success: forming a new interest group for nocturnal enuresis

Dr Fiona Cameron, Community Paediatrician, Motherwell



Communication, according to Wikipedia, is a process that allows beings - in particular humans - to exchange information by several methods. Communication requires that all parties understand a common language that is exchanged. Between parties, communication includes acts that confer knowledge and experiences, give advice and commands, and ask questions.

Anyone who practices the art of medicine will know how important communication is. Good communication, especially in areas such as continence, is essential to ensure understanding, co-operation, and consequently success. Those of us that work in paediatric continence know how rewarding success can be and that we need the right audience to share it with!

We enjoy meetings as a time to learn and to discuss, to meet colleagues, and share thoughts and ideas. Through this process we build communications hoping to keep in touch between meetings - but do we?

In reality we often return to work and contact becomes lost, until the next time, and it's finding the next time that can be hard.

We all have obstacles that prevent us from keeping in touch with our colleagues. Consider Scotland, it has a population of 5.1 million in an area of 30,341 square miles, compared with London's population of 7.5 million over 609 square miles. This population is unevenly distributed with about 70% of the country's population living in the Central belt. Even meeting in the same area can be a challenge. Despite this Scotland has a feeling of national identity with a health care, educational and legal system and government structurally different to the rest of the UK.

So geography and health politics aside, how do we ensure that we meet those working in other areas? If we want to set up a service or improve what we do, how do we go about it? These questions were

often talked about among ourselves. The answer was found in a simple idea which came from our Ferring Pharmaceuticals representatives, and that was to set up more established communication by forming an interest group for nocturnal enuresis. Invitations were sent out and we met for the first time on the 2nd May 2007 to form SEIG, the Scottish Enuresis Interest Group.

We have 14 NHS Trusts in Scotland and had positive replies from 10 of these authorities. The meeting attracted a broad spectrum of people from across Scotland; School Nurses, Continence Advisors, Community Children's Nurses, Paediatric Staff Nurses, Health Visitors, Staff Grade Community Paediatricians, Acute and Community Consultant Paediatricians and the manager of MCN (Managed Clinical Network). The MCN were invited as they have assisted in establishing SPRUN (Scottish Paediatric Renal Urology Network). Children with chronic renal and urology conditions

News from ERIC

Penny Dobson, Director



ERIC (Education and Resources for Improving Childhood Continence) provides information and support to children, parents and health and social care professionals on all aspects of childhood continence including bedwetting, daytime wetting, soiling and constipation and special needs.

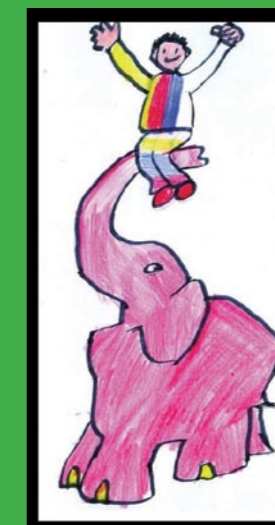
ERIC welcomes the Department of Health request that the National Institute for Health and Clinical Excellence (NICE) 'develop a clinical guideline for the management of bedwetting in children'.

The NICE Topic Selection Panel recognised that there were wide variations in practice between geographical areas, there was need for a different style of service and there were high social costs in terms of impact on the quality of life of patients and their families; with a recommendation that guidelines should incorporate a consideration of both diagnosis and management of nocturnal enuresis.

ERIC has striven to provide support and information to children, parents and health professionals to bridge the gap between need and service provision, fully recognising the impact upon patients and their families. The development of clinical guidelines will help place bedwetting in the mainstream of the NHS agenda.

Further information and details of how to register as a stakeholder can be found at www.nice.org.uk.

For further information from ERIC: Tel: 0117 9603060 Helpline: 0845 370 8008 Email: info@eric.org.uk Websites: www.eric.org.uk & www.trusteric.org



There has been cause for celebration for the young winners of the recent "Design a Character for ERIC" competition. Judges from ERIC and Aardman Animations, famous for Wallace and Gromit and donors of prizes for this competition, spent a long time selecting a winner from the many imaginative and inspiring ideas sent in.

The winning entry 'Eric the Elephant' was created by 12 year old India from Worcestershire. Her design was chosen for its simple

idea and because it is easy to recognise and has a wide appeal. Due to the high standard of entries it was decided to give a runner up prize to 15 year old Nick from Kent for his great creation, 'Billy the Bladder'.

It is now all steam ahead as ERIC prepares for its 5th International Conference to be held in York on October 3rd & 4th. The Conference, entitled 'Challenging for Change in Childhood Continence: Engaging, Educating, Empowering...' is an exciting opportunity for delegates to disseminate the most recent research and share clinical practice.

ERIC update