



# Newsletter

Issue 17

September/October 2005

## Editorial

KEEA had its fourth Annual General Meeting on Friday 19 August, our first without Shirley at the helm and we all took time to reflect on what a wonderful person she was. Also at the AGM was Val Colley a colleague of Shirley's who will be taking on the role of KEEA Coordinator in February 2006. She will answer calls to our 0800 number and reply to emails etc. More details later. I was officially given the title of Chairperson at our AGM along with Andrea and Fiona retaining the important roles of Treasurer and Secretary respectively. Gwen will still be answering phone calls and emails until Val is able to start early in 2006. We all appreciate the feedback and support we also get from the readers of our newsletters and to those who take time to email, send letters and cards with support and contributions for the Newsletters. In this Newsletter we have included two letters from Parents re encopresis problems. Also in this newsletter we have got the start of a series of exerts from a Pamphlet produced by ERIC on soiling and wetting for Parents of children with Learning Disabilities.

Karen Lane  
Chairperson KEEA Trust

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## Deciding when to start toilet training

For any parent, choosing the right moment to start potty or toilet training is not easy. Many feel under pressure from family, friends—or the local preschool—to have their child trained by the age of three. Yet we know that the age when a child is “naturally ready” to start toilet training varies a lot—and for children with learning disabilities this may be later than the average age of 2-3 years. The key is to be positive, whatever the degree of ability, and to be aware of the best time for child and your family. The following checklist may help you to decide when to make a start. On the whole the best time is when:

- Your child is beginning to show an awareness when wet or soiled and an interest—and a willingness—to sit on a potty or toilet (you could perhaps take her to choose a new potty or toilet seat).
- She can understand simple instructions, such as “put your mug on the table”, “go to the toilet”.
- She is able to sit on, and get up from the potty with only a little help from you.
- The gap between wetting is about 1 1/2 hours (otherwise it will be very hard work!). Cont page 2.....

# LETTERS FROM PARENTS

As a parent of a child with Encopresis I would like to comment on the letter in the last newsletter from Adair Simkin. I felt very glad to hear that she has found a helpful strategy for her child and we should all celebrate this. However, I also feel her letter may raise the expectations of other parents a little too high or put them off seeking help from the more conventional sources i.e. Public Health Nurse (or a Doctor who has expertise in Soiling problems). After prolonged constipation and Encopresis, it is very common for improvement to take many months or even years. We also need to recognise that for many children, a change of diet will not be the answer. My own son has needed a range of strategies with different things being more important at different stages. We do monitor his diet but he also needs a small amount of daily lactulose. We try take him off it periodically but he then just 'stops' passing bowel motions. After more than a year without a soiling 'incident' he recently had to take antibiotics and we also missed a few lactulose doses. Before we knew it, he lost the ability to 'know when to go'. He was really distressed to realise encopresis was still a problem. Early on it also seemed a waste of time to practise sitting on the toilet after meals. But 18 months through the healing process, he triumphantly reported he had "actually been doing poos in the morning". Looking back to the awful time when we did not understand our sons Encopresis I know I should have sought help much earlier. First stop should have been the Public Health Nurse when he started school with a 'occasional soiling accidents'. At that time, however, I believed it was a toilet 'training' issue and therefore something to do with my lack of parenting skills. I felt I needed to try harder. In complete ignorance of Encopresis I also had never recognised that constipation was the cause. He managed to hide many of the little accidents and the infrequent 'disasters' that I witnessed, were definitely not suggestive of constipation. It was over a year later when he had spiralled downwards to the point of several 'accidents' a day that I finally took him to our GP. A friend had mentioned Encopresis and I realised I couldn't help my son any more. The Doctor was great, offered practical treatment for the constipation and lots of reassurance for our son. Through the KEEA website we are also now armed with better understanding of the condition. His improvement has been slow but we are thrilled to have a healthy confident eight year old. I feel very sad now that I didn't know what Encopresis was. I would like to support KEEA in widely publicising Encopresis so that no child has to wait as long as my son for effective help.

Sue (Nelson)

I thought I would give your readers an update on our toileting and constipation problems. Our desperate plea for help was in your last newsletter. Thanks for the replies. You may recall Hayley has Down syndrome and is a extremely fussy eater. Well I'm pleased to report our feeding problems are improving and our episodes of constipation are becoming much less frequent. So what changes have we made, firstly we ditched the brown bread as I noticed she always seemed uncomfortable after eating this and started her on Tip Top Hi Fibre bread, the paediatrician prescribed her Fortini Multi Fibre supplement drink in which she likes the chocolate flavour and she loves Uncle Toby's date porridge, all this is given on a daily basis. We are currently trialling Movicol for children daily as well and I'm pleased to report it is the first medication that completely dissolves and tastes okay and Hayley will drink it. Now that's saying something because she wont even drink juice! As for the toileting, when she finally clicked onto the sensation of needing to go, there was no turning back, we have had to be cruel to be kind as she had become rather lazy over the years and no amount of rewards/treats/ etc was working so we as a last resort starting removing items (mostly her books which she loves) for every poo in the pants. Funny how she clicked onto this rather quickly and suddenly the toilet seemed more attractive! She has now earned all her books back and I'm pleased to say there seems to be light at the end of the tunnel. I hope this gives some of your readers hope. Bronwyn Rydon

From page 1....

- There is no sign of constipation—this will have to be sorted out first.
- You have a 'clear run' with no major upheavals for your child or family, such as moving house or going on holiday.

See back page for What to do first.....

*The next few newsletters will have further excerpts from the ERIC booklet. This organization is a British based organization similar but much bigger to KEEA Trust.*

# KEEA Trust AGM Report August 19 2005

I feel very privileged to be able to give this report at KEEA's fourth AGM and to take time to remember the wonderful contribution, support, encouragement and leadership given to all those involved in KEEA by Shirley Reid who sadly passed away on the 23 April.

It has been very encouraging for the KEEA committee to receive so many wonderful tributes about Shirley and KEEA which we have shared with her husband John and their adult children Lucy and James

We all feel we have some very big shoes to fill and will endeavor to continue to support and provide information for Parents and Health Professionals dealing with Soiling and Wetting issues in children.

Our committee remains small and dedicated. We have all taken on a number of different roles to maintain the functions of KEEA. I thank everyone for their commitment and effort. We look forward to having Val Collie as a paid Part time Coordinator early in 2006.

Our first achievement for this year was the circulation in February of a Pamphlet for Schools re Soiling and Wetting in school aged children. This Pamphlet was sent out to all schools in New Zealand. We have received a lot of positive feedback and more copies have been asked for.

The Continece Association has funding for a more detailed brochure for schools re Soiling and Wetting and KEEA is currently involved in the writing of this Publication and it is hoped that it should be in Schools early next year.

Shirley and I attended a Nocturnal Enuresis National Guidelines group meeting in February to finalise the draft of the Guidelines. The Guidelines are now completed. I am currently involved with other member of the Guidelines group in the writing of supporting Patient Information Leaflets. These will be distributed as part of the Guidelines package to all Doctors etc throughout NZ. It is quite exciting to think that there should be a lot more consistent and appropriate advice given by the Medical Profession after the Guidelines are distributed.

We have applied to the JR McKenzie Trust and to COG's for funding and as yet haven't heard if our applications have been successful. Money from these grants will be used to maintain our 0800 number and email services and to try and reach families who are not aware of the support and help they can get through KEEA.

We are also very grateful to Ferring Pharmaceuticals and Dry nites who continue to sponsor our Newsletters.

I would also like to thank Dr Pat Boulton for her ongoing support of KEEA. Pat is also able to provide us with up to date information and appropriate medical advice for concerned parents and Health professionals.

Karen Lane  
Chairperson

# Information on quilted underpads

Just thought I could help out the parents who have children suffering from bedwetting or soiling in the beds. I have come across these 'LITENEED QUILTED UNDERPADS'. There are two varieties and one has 2 flaps that tuck in and the other without. I have these on my boys beds as I have bedwetters and they are 9 and 11. The 9 year old is everyday and the other is maybe once a week. I was very frustrated with the washing the next day. I have 2 on the bed ,one on the bottom mattress which has been positioned properly, the other one doesn't have flaps ,but I have sewn this to a top sheet. Double protection for the whole bed. Every morning I just pick up this pad off the bottom mattress and top sheet one and throw them in the washing machine, put out to dry or throw in dryer. These pads absorb all his urine during the night. Bed underneath dry. I would still put a plastic mattress protector underneath as they may miss the pad. This pad has to be in the right place ,trial and error. The single bed is 84 cm long and the width goes around a single mattress which tucks in. Comes in different sizes. I have ended up buying 5 .Just incase you didn't get the washing dry that day. Back up). These are the details of the people who make them. INTERNATIONAL MEDICAL LTD>POST OFFICE BOX 1000.NAPIER NEW ZEALAND.TELEPHONE 06 834 4202,Hope this helps you out. You maybe able to get help with these through WINZ if you are a low income, or on a benefit and the children are able to get disability allowance. Enuresis is a disability. Debra Sentor.

## What to do first

### Start keeping a record

Keep a chart of wetting and soiling over a 2-3 week period (the chart sample below can be adapted). A pattern may become clear, which will help you to design your toilet training plan.

	Day 1		Day 2		Day 3		Day 4	
Time	Pants	Toilet	Pants	Toilet	Pants	Toilet	Pants	Toilet
7.00								
8.00								

**To:**

*If undelivered please return to: P O Box 1123, Nelson*