

Childhood dystonia

Parents and Carers Conference

In October, the Society held a conference for parents and carers of youngsters with dystonia. Staged at the Wellcome Centre in London, the eighty people who attended were treated to a varied day that included presentations from leading clinicians and key support organisations as well as candid reports from parents.

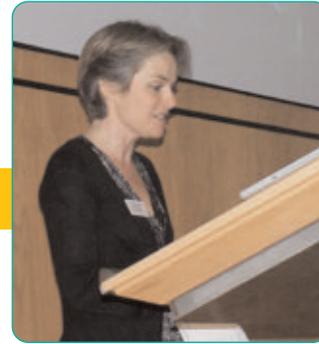


● Dr Jean-Pierre Lin

What is dystonia? was the subject of Dr Jean-Pierre Lin's talk. A consultant paediatric neurologist at Evelina Children's Hospital, Dr Lin drew attention to an intriguing similarity between the movements that we all see in very young children and those of an adult with dystonia. As babies develop, they go through a range of abnormal postures which require the use of all their muscles. This process is part of developing the economical movements and fine motor skills of later life.

Dr Lin suggested that, in developing dystonia, the brain may again act as if it has too many options. Instead of choosing one option for muscle control it wants them all, resulting in a 'pile up of motor strategies'. The brain seems to revert to the child's earliest state, with all muscles turned on, resulting in the postures and movements that we see in dystonia.

Dr Lucinda Carr, consultant paediatric neurologist at Great Ormond Street Hospital, presented the Robert Surtees Memorial Lecture, and discussed treatments for childhood dystonia. She drew attention to the big question concerning clinicians: *How (if at all) should you treat the dystonia?* Doctors try to balance the positives and negatives of each treatment and consider the daily impact that dystonia has on the child; what having the treatment will mean for the family; whether there are any side effects to consider, and the time and cost implications of treatments. Only by considering how the condition affects the child's overall quality of life, taking note of particular problems, say with



● Dr Lucinda Carr



● Hortensia Gimeno

communications, education or other medical conditions, can the clinician be confident they have come up with the best combination of answers.

Hortensia Gimeno, Senior Occupational Therapist Team at the Evelina Children's Hospital talked about the importance of enabling children with dystonia to develop and learn the life skills that others take for granted. Otherwise they face the double disadvantage of living with the symptoms and lacking the opportunities to develop skills and confidence.

Children learn through their everyday experiences and opportunities and children with dystonia often do not get opportunities to 'learn through doing'. Occupational Therapists will now try and empower children by providing the family with equipment and strategies to develop independence and life skills. This may be by providing equipment, or by modifying tasks to make them more accessible. She stated that one of the most important things a parent can do is to set up a daily activity that is accessible to the child.

Before lunch there were especially poignant contributions from two parents of youngsters with dystonia as well as from Amy-Belle, 18, who was diagnosed with dystonia aged 4.

Ruth King spoke about her son, Mattie, now 14, who has been severely disabled since birth, with dystonic atheroid cerebral palsy. A couple of years ago, Mattie was told he would need rods put in his back due to problems with his spine; however the severity of his dystonia meant this surgery would not be possible. Mattie was put forward for an Intrathecal Baclofen pump to help reduce his dystonia spasms and this has had a positive impact on Mattie's quality of life – he is now in less pain, happier, more communicative and his personality has blossomed.

Childhood dystonia (continued)

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● *Ellie Logue*



● *Mattie King*

Jackie Logue's daughter Ellie is 16 and has had a severe form of dystonia since birth. Ellie uses a communication aid and is totally care dependent; however, she has full cognitive ability. Jackie talked about the importance in seeing Ellie as a child first – she is given every opportunity to enjoy life, going on holidays and pop concerts like any 16 year old. She

emphasises the importance in having fun with your children and not letting a medical label overshadow their lives. "You need to think about what your child can do, not what they can't," she said.

Amy-Belle was 4 when she found she couldn't lift her right arm. She had DBS surgery earlier this year. Before the DBS her arm was moving uncontrollably, which she found incredibly frustrating. Although she says it was a difficult decision to have the DBS surgery, the surgery was very successful and she said that she would recommend it to anybody.

In the afternoon there were very informative presentations from representatives of four leading support organisations that provide support for children with health conditions: *Contact a family*, *Parent Partnership* and *Abilitynet*. Those who attended the event were enthusiastic, as comments on the evaluation forms showed: "It was incredible. I had thought I was alone – meeting other parents helps me to see the future and understand there are people who have been through it and can help me get some answers"; "I really enjoyed the talks from the professionals and the parents/individuals" and "which part did I find most useful? – All of it!"



Conference for parents of children with dystonia

Saturday, 9th October 2010, London

Location: Wellcome Conference Centre, London NW1 2BE (2 minutes walk from Euston station)
 You are invited to a FREE conference for parents of children with dystonia.

The special conference offers:

- Presentations from leading paediatric neurology specialists
- Workshops from leading organisations
- Other parents and children talk about their experiences
- A chance for you to find answers and meet other parents

There will be a supervised programme of activities (age appropriate) for children/teenagers during the day. Places may be limited.

Morning session 10.30 – 12.30

- **Dystonia – what is it?**
Dr Jean-Pierre Lin, Evelina Children's Hospital
- **Treatments – what are the options?**
Robert Sartorius Memorial Lecture
Dr Lucinda Carr, Great Ormond Street Hospital
- **Life options – putting you in charge**
Hortensia Gimeno, Evelina Children's Hospital
- **Lessons learned**
Other parents and youngsters speak honestly about their journeys

Lunch 12.30 – 14.00

For children/teenagers with dystonia...
A programme of activities is planned in adjoining rooms with supervision from...



Afternoon session 14.00 – 16.30

A choice of workshops from each group:

GROUP 1

- **Where do I get support?**
Representative from: Contact a family
- **Mobility matters**
Wheeler/ir / mobility expert
- **The educational statement**
Representative from: Parent Partnership
- **Adapting computers to change lives**
Representative from: Abilitynet

GROUP 2

- **Adapting computers to change lives**
Representative from: Abilitynet

Finish 16.30