

Down Syndrome CEN: working to support children and adults who have Down syndrome.

# **SUMMER 2022** NEWSLETTER

## **Events and CPD**

## **DS CEN Summer Term Meeting**

We had a very interesting summer meeting in July, with two excellent presentations: Lauren Newman shared the work of Barts Health NHS Trust 'Developing an integrated NHS therapy pathway for supporting babies and young children with Down syndrome'.

Dr Silvana Mengoni, University of Hertfordshire, presented regarding research on 'Feeding and eating in children with Down syndrome'.

DS CEN members can access recordings of Lauren and Silvana's presentations via Basecamp. Minutes from the meeting are available here: <a href="https://tinyurl.com/DSCEN-Summ-22-Minutes">https://tinyurl.com/DSCEN-Summ-22-Minutes</a>

Following the presentation and discussion around care pathways, please take a few minutes to tell us about your local care pathways:

https://forms.gle/tdSHBSjR7JVARxe7A . Many thanks in advance for taking the time and sharing this information.

### **Autumn DS CEN meetings for members**

The Autumn Term DS CEN online meeting is on 21st November 13:00-15:00. The topic is: 'What SLTs working with children and adults with Down syndrome need to know' (agenda to be announced). If you have any requests for topics/information you would like covered in future meetings, please email dscen@letsgouk.org

Autumn Term DS CEN supervision group, research group, working group and journal club meetings
Dates for all supervision group, research group, working group and journal clubs meetings can be found our website: www.ds-cen.co.uk/upcoming-events

## Resources

## **DS CEN Website**

We are pleased to announce the launch of the DS CEN website: www.ds-cen.co.uk. You can access information about the CEN, upcoming events, how to join and a members area.



## The Down Syndrome Act

The Down Syndrome Association has resources and a webinar on the Down Syndrome Act and the call for evidence (deadline 8 November): https://www.downs-

syndrome.org.uk/our-work/campaigning/the-downsyndrome-act/

## The Oxford Handbook of Down Syndrome and **Development**

The Oxford Handbook of Down Syndrome and Development (2020) is available online and includes chapters on language development, interventions, working memory, attention and many more: https://academic.oup.com/editedvolume/35415

# Research updates



Launch of PACT-DS research project

A new ESRC-funded research collaboration between the University of Manchester and University of Reading aims to adapt the PACT early language teaching programme for parents and young children with Down Syndrome. Recruitment of project steering group members and families is

Exploring the communication methods and experiences of children and young people with Down syndrome: Parent perspectives

https://sites.manchester.ac.uk/pct/pact-ds/

Contact: Kelly.Burgoyne@manchester.ac.uk

currently underway. Visit:

#### **London Down Syndrome Consortium**

This multidisciplinary team based at UCL is currently recruiting infants and adults with Down syndrome for a number of research studies: https://www.ucl.ac.uk/london-downsyndrome-consortium/study-information

## New study on word learning in children with Down syndrome

Dr Kelly Burgoyne and colleagues at the University of Manchester are currently recruiting children with Down syndrome aged 8-12 years and typically developing children aged 4-6 years for an online study looking at the effects of retrieval on word learning in children with Down syndrome. Contact: Kelly.Burgoyne@manchester.ac.uk

#### Feeding and eating project

Dr Silvana Mengoni and colleagues at the University of Hertfordshire are currently recruiting parents of 1-4 year old children with Down syndrome for a study on feeding and eating in early development. Contact:

I.k.hielscher@herts.ac.uk

#### **Caregiver perspectives of communication**

Elaine Scougal, University of Dundee, is seeking the view of parents of children and young people with Down syndrome (3-18 years) about communication methods and experiences. To complete the survey or find out more visit:

https://dundee.onlinesurveys.ac.uk/caregiver-survey

# Keep in touch

Email: dscen@letsgouk.org Website: www.ds-cen.co.uk Twitter: @DownSynCEN

Closed Facebook Group: For Members & Associate Members (the group is not for Friends of the DS CEN): www.facebook.com/groups/5837910309557009

Basecamp: The RCSLT DS CEN Basecamp has been set up

for full & associate members.

Become a DS CEN member: Please visit: https://www.ds-

cen.co.uk/jointhedscen