

CIDDRG

CAMBRIDGE INTELLECTUAL AND DEVELOPMENTAL DISABILITIES RESEARCH GROUP

NEWSLETTER

Welcome back to our CIDDRG Newsletter!

Our Spring edition features some exciting news and the latest updates from our team. This edition is full of community highlights and news from our study participants. We celebrated World Down Syndrome Day 2026 with many of you at our special event in March. We also share details from our recent visit to Birmingham for the meeting with the Birmingham Community Healthcare NHS team. This spring, we also attended the Cambridge Dementia Research Day. It featured a day of talks, poster presentations and panel discussions. You'll also find an article on the recent webinar, organised by the Down Syndrome and Sleep Research Network, exploring how to make sleep studies easier to understand for people with Down's syndrome and their families.





IN THIS ISSUE:

Editorial Letter	2
World Down Syndrome Day 2026	3
Team updates:	
Welcome to Sue	8
Dementia Research Day	9
Visit to Birmingham	10
Participant stories	11
Sleep research network	15
Update from the Community Advisory Group	18
Brain teaser	20

UNIVERSITY OF CAMBRIDGE

NHS
Cambridgeshire and Peterborough
NHS Foundation Trust

A letter from the Research Leader

As many of you will know, **21 March** is always a very special date in our calendar, as we come together to celebrate **International Down Syndrome Day**. We have marked this occasion for many years, and this year's event at Lucy Cavendish College in Cambridge was a wonderful success. It was heartening to see so many people involved and contributing (see the main feature).

One of the highlights for me was the short film directed by Ray Jacobs, ***Our Circle in the Storm***, which explored the impact of climate change on all of us, while shining an important light on those who are especially vulnerable.

I was also delighted to be invited to speak to the **Down Syndrome Sleep Research Network**, led by Dr Elizabeth Corcoran, Chair of the Down's Syndrome Research Foundation UK. The meeting took place at the impressive University of Surrey Sleep Research Centre. My talk focused on the importance of **recognising and treating sleep problems** in people with Down's syndrome.



These difficulties are very common, but they are also often treatable, and the right support can **make a real and lasting difference** to a person's quality of life.

Wishing you all a restful and happy summer holiday, and as always, **take good care of yourselves**.

Dr Shahid Zaman

World Down Syndrome Day 2026

On Saturday, **21st March 2026**, our team held a fantastic event in Cambridge to mark **World Down Syndrome Day**. As in previous years, people with Down's syndrome, families, researchers, and local community members gathered at Lucy Cavendish College to celebrate, spend time together, and share updates from our research and outreach initiatives.







This year's theme was **Together Against Loneliness**. Loneliness is something all of us can feel sometimes. It can affect our happiness and health.



We can feel lonely even when surrounded by many people if we don't feel **connected, included** and that we **belong**. This feeling can be particularly difficult for many individuals with Down's syndrome and other intellectual disabilities.

In discussions we held that day, we talked about what can be done so that **everyone feels included**, and how important it is to have **strong and supportive relationships** where everyone can feel **valued**.







The event was full of amazing contributions from our study participants.





We listened to a fantastic talk by **Kim Petty** entitled *I get to decide if I'm satisfied*, an inspiring story about redefining disability as well as challenging exclusion and stereotypes.

Emma Anderson presented her book, *I, Emma*, which talks about her life journey, passion for art, and making the world a better place for people with Down's syndrome and those who are different.

We watched a touching dance film, *Our Circle in the Storm,* featuring one of our study participants, **Eve Washington**. The film reflects the importance of togetherness and connection in the changing, unpredictable world.





We know that any form of **physical activity** – whether that's walking, dancing, playing sports or exercising - is good for our body but it also helps the brain and is a great way to spend time with friends and family!

Our colleagues from **Anglia Ruskin University's Cambridge Centre for Sport & Exercise Sciences** talked about their research on how movement can help people with Down's syndrome live longer, healthier lives. There was a great presentation by Professor Dan Gordon on the new Adidas trainers designed for individuals with Down's syndrome that was a highlight!



https://footwearmagazine.com/adidas-running-shoe-down-syndrome-athletes/

Finally, we created a giant poster, celebrated and enjoyed our time **together**!





Our study community members are great inspirations for us all. Their creativity and enthusiasm encourage us to find passion in art, sport, nature and cultural life, share it with others and create strong connections. We are **grateful to everyone who participated in the event** as they help raise the voices of people with Down's syndrome and show the important role they play in our communities.



Team updates

We are thrilled to welcome the new team member. Meet Sue, the team's new temporary Research Administrator.



Welcome, Sue!

Hello!

My name is **Sue Glenister** and I'll be working part-time as Administrator for the CIDDRG until the end of August 2026. My role includes booking travel and accommodation for research participants and ordering equipment supplies for the team. I'll be working on Tuesday and Wednesday mornings and am looking forward to being part of the CIDDRG team, the wider community of researchers, participants, their families and friends!

You will hear from Sue regarding transport and hotel arrangements for your study visits, new research opportunities and announcements.

Dementia Research Day

Members of the ABC-DS research team went to a meeting in Cambridge of **researchers and clinicians, social care commissioners and providers, and carers** in Cambridge and Peterborough on 28th April.



The meeting was about poor **brain health** and how we can better **support people** to keep their brains healthy. There were many interesting talks, including many about possible new treatments that might be help in delaying or preventing poor brain health.



But there was no mention of the increased risk of poor brain health and the difficulties in remembering and other problems that go with it and that affect many people with Down's syndrome and other kinds of learning disability. So we were very pleased to present our poster about the ABC-DS project and remind people: **don't forget people with learning disabilities**!



Visit to Birmigham

NHS
Birmingham
Community Healthcare
NHS Foundation Trust

On 21st May, **Shahid and Isabel went to Birmingham** to meet with our colleagues. Shahid gave a talk about Down's syndrome, that was very well received. We had the chance to talk to our colleagues to **share ideas about research**.

Before we left, we gave them a copy of a **poster** presenting the **Alzheimer's Biomarker Consortium – Down Syndrome (ABC-DS)** research project. The Birmingham team put it up in one of their team bases.

Since before Christmas, we have been meeting with clinicians at **Birmingham Community Healthcare NHS Foundation Trust**. The Trust provides a range of clinical services, including for people with learning disabilities, including Down's syndrome. We want to work with them as they support many people who are often left out of research.

Best Care
Healthy Communities

We will continue monthly meetings with our colleagues in Birmingham so that we can:

- **Make it easier for people living there to take part in our Cambridge studies about keeping your brain healthy;**
- **Plan some joint studies that include people with Down syndrome and other learning disabilities living in Birmingham.**

Participant stories

Over the spring months, our amazing study participants have been busy doing exciting things and achieving new goals. Read their stories!

Annie's visit to Lapland



I visited **Lapland** at the beginning of March and met Father Christmas, crossed into the Arctic Circle and went on a sleigh ride. I had a really great time!





Eve Washington as Madame Wardrobe



As a member of **Identity School of Dance**, we recently put on the musical ***Beauty and the Beast***. We played to a full house for every performance, and everyone loved the show.

I played **Madame Wardrobe**. My character is an opera singer who was turned into a wardrobe!

My role was to be dramatic and OTT, as you will see from my costume.

Another fabulous show from Identity where everyone has a role and **everyone shines**. It's truly magical.



MY HOBBIES by Joanne Barker

I have been talented for many years. I love to go out **walking** in the great outdoors, and with skills I am very, very hands on. I love **gardening, knitting** during the evening times, **nature, swimming, singing, dancing and acting** and many other hobbies and activities too.



I love watching films, I love to go to cinema, concerts and theatres, and operas too. I love watching musicals, museums and libraries and loads more. My **absolute passion is art**, and I dream of being a West End star.



At the moment, **planting plants** is one of those things I love at this time of year, watering them and make them grow into the sunshine.

I **can do everything** in my time and space. I have mixed feelings, emotions and full of personality.
I love reading books too, as I am very curious and very committed and a community minded person.



I go to **Phoenix Rising** group every week three days after work, where we do discuss our next show. And this year, we are doing ***Being the Pirate***, to make ourselves unique and useful, in every way possible.

I am the person who always **puts people first**, and I sponsor many charities in my life, to make peace with people that saved me and made others feel better about themselves and me too. **That's my advice**.

We would like to hear from other people with Down's syndrome about their lives.

The Down Syndrome and Sleep Research Network



The Down Syndrome and Sleep Research Network **(DSSRN)** had its **first webinar** in March 2026. Researchers and experts from many countries joined us to listen and speak with us.

The presentation focused on **making sleep studies easier to understand** for people with Down's syndrome and their families. Sleep problems are common, and many people with Down's syndrome may need a sleep study in hospital. But often, there is not enough clear and simple information about **what happens during these tests**.



The webinar showed why **good communication** matters in both healthcare and research. When information is **clear and accessible**, people with Down's syndrome can take a bigger role in decisions about their own care. **Dr Eve Hirst and her brother Joshua**, who has Down's syndrome, gave the main presentation. They shared resources that Dr Eve Hirst has been creating. These are **easy-read materials, videos, and practical tools** designed to explain sleep studies in a simple and friendly way.

These materials were created using **real lived experience**. We think they will help people feel less worried and more prepared before hospital visits.

DSSRN has also been working with a **focus group** to review these new resources before we give them out. People with Down's syndrome and carers have been taking part.





We look forward to making **improvements to the videos and resources** after we know their feedback. We'll let you know when the resources are available for anyone to use!

The full webinar recording is now available online for anyone who would like to learn more. To watch it, please use the link below:

https://www.youtube.com/watch?v=JP3rVrVGNtM

Jennie opened the GOLD Conference 2026



In February, I was delighted to be the opening speaker at the **GOLD (Growing Old with a Learning Disability) conference**. The focus of the conference was the need for **better integration in care provision**, and my speech showcased the many and varied issues which we'd faced with **my sister Liz** as she developed dementia where better integration could have really helped us on our journey.

Liz was 54 when she started to show **signs of dementia**, and now – aged 59 – she's bed bound, epileptic, doubly incontinent and unable to recognise anyone.

It has been a **rapid and disturbing journey** and one which I wanted to showcase to the conference as it is the reality which so many people are facing for and with their loved ones.

It's important to showcase the stats – **1 in 2** with Down's will have or be developing **dementia at around 50** and most will go on, as my sister did, to develop late onset myoclonic epilepsy 2 years later.



We are so very lucky that Liz is now in an absolutely amazing care home, but I am well aware others are not so fortunate.

Whilst I have to accept that I cannot bring about change for Liz I am determined to **shout out about the issues to help others** – and this was a fantastic opportunity to do just that.

I continue my battle to **raise the profile of later life care** for those with Down's syndrome and am currently chasing various individuals in government about the delay in issuing the **guidelines for the Down Syndrome Act**, a much need set of information.



Brain teaser

Find all 10 words inside the box. The words may be horizontally, vertically, diagonally and backwards.

Word Search Game

C	S	I	N	C	L	U	S	I	O	N	S	H	O
N	E	R	T	O	G	E	T	H	E	R	I	E	R
O	T	L	C	E	R	E	H	T	N	S	C	I	L
I	S	I	E	B	G	R	I	R	L	I	P	H	H
S	S	I	H	B	R	E	E	S	L	E	E	P	E
S	E	I	R	G	R	R	H	O	B	B	Y	T	A
U	B	O	L	S	N	A	E	E	N	I	O	A	U
C	S	L	H	G	T	I	T	S	S	I	I	O	R
S	S	O	D	G	H	S	R	I	E	N	C	T	E
I	P	T	T	R	O	P	S	P	O	A	A	I	P
D	B	I	R	H	B	I	S	R	S	N	R	P	O
C	R	L	T	P	N	O	L	P	R	E	L	C	R
N	H	S	S	R	T	I	C	E	I	E	H	G	H
U	S	E	I	O	T	E	O	E	H	L	I	B	S

CELEBRATION
SPRING
DISCUSSION
SLEEP
HELP
HOBBY
SPORT
INCLUSION
TOGETHER
RESEARCH

Play this puzzle online at : https://thewordsearch.com/puzzle/9725106/

This puzzle was created with **https://thewordsearch.com**