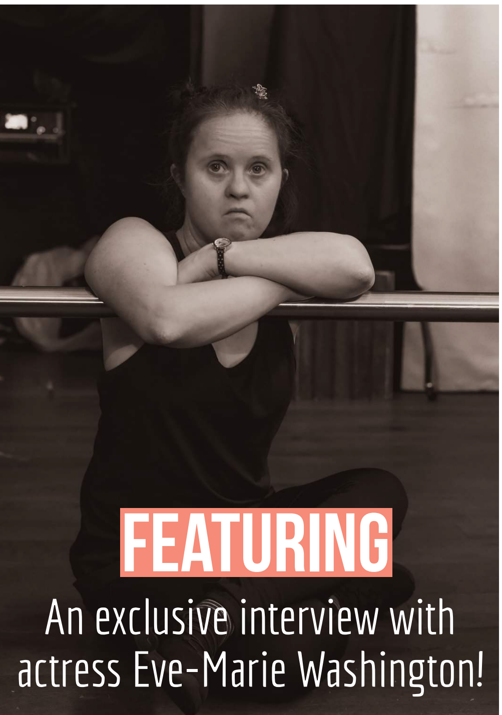
Winter 2025

DEFEATING DEMENTIA IN DOWN'S SYNDROME (DIDS) GROUP NEWSLETTER

Happy New Year from the DiDS Team!

As we step into 2025, we're thrilled to share our latest newsletter with you. This edition is packed with exciting updates and inspiring stories from our community. Over the holiday period, our team took some well-deserved time to rest and reflect on the wonderful progress we've made together, read more about the festivities we got up to! We also catch up with a former team member, Monika, on her career achievements since leaving the team 4 years ago. We shine a spotlight on one of our amazing participants, Eve, whose talents in the acting and artistic world are truly inspiring. You'll hear about the fantastic discussions from our first Community Advisory Group meeting, held just before Christmas. Finally, we're thrilled to announce that our World Down's Syndrome Day event will take place on March 22nd - save the date, we can't wait to see you there!

Thank you for being part of our journey. Here's to a joyful and succesful year ahead!



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CIDDRG
CAMBRIDGE INTELLECTUAL AND DEVELOPMENTAL DISABILITIES RESEARCH GROUP

UNIVERSITY OF CAMBRIDGE

NHS
Cambridgeshire and Peterborough
NHS Foundation Trust

A LETTER FROM THE RESEARCH LEADER

Dr Shahid Zaman

Happy New Year!
The Christmas and the New Year period was a great opportunity for us to reflect on our achievements. We have continued to scan and assess participants, and on behalf our research team I would like to thank you all, including families and paid carers, for your tremendous effort in supporting our research. I say “our research” because all people involved should feel that it belongs to them too. We hope this newsletter keeps you informed of all these achievements.

We are very grateful for the research funding which we receive from the National Institutes of Health (NIH) in the USA. The good news is that this funding has been extended!

Our congratulations go out to Carol Boys, the Chief Executive Officer of the Down’s Syndrome Association, who last year was honoured by His Majesty the King with an OBE for all the work she has undertaken for people with Down’s syndrome. A truly well-deserved honour.

We are looking forward to be moving towards starting cycle three of the ABC-DS project, which is set for renewal in 2026.

Best wishes,
Shahid

TEAM NEWS !

Sarah enjoyed a snowy christmas with friends!

Last Christmas, I had the most amazing time with friends in the Austrian Alps. We spent the day snowboarding in festive Christmas onesies, with Santa, the Grinch, and me as Rudolph the Reindeer hitting the slopes together. In the evening, we came together to prepare a cosy Christmas dinner, sharing stories and enjoying the festive spirit. It was such a special way to celebrate, especially being far from home during the holidays. I hope you all had a fun and memorable holiday as well! - Sarah

Jess's son, George, made personalised gift cards!

This Christmas was filled with joy, activity, and creativity! We ended up having two Christmas Days, making the most of time with loved ones in Cornwall. George got creative, designing Christmas cards that were printed at the Burwell Print Company to send out to our friends and family. It was a Christmas that left us with many cherished memories. I'm very much looking forward to getting back to the research studies in the New Year and hearing how our participants spent the festive period!
- Jess

TEAM NEWS !

Zhiyuan enjoyed some restful time with his furry friends!

During the holidays, I enjoyed a peaceful time at home with my cats, Aslan and BoBo, taking things slow and catching up on rest. The highlight was celebrating Christmas Eve with my friends at Cambridge. It was nice to have a simple but meaningful break. - Zhiyuan

Shahid was in charge of the Christmas Turkey!

I was not keen on cooking a whole turkey this year but settled on the crown instead as it takes a lot less time and it’s less messy! - Shahid

Isabel's little pirates went hunting for Halloween gold!

Here are my three eldest grandsons (Nathaniel, and twins, Sammy and Danny) dressed up as pirates for Halloween, on the lookout for treasure. - Isabel

TEAM NEWS !

Natasha took a brave festive splash!

I spent Christmas in Devon last year. We started the day with the Christmas morning tradition of a refreshing dip in the sea followed by a warm hot-tub session with hot chocolate. The sunny weather made the day even more magical!
- Natasha

Stephanie welcomed a new puppy!

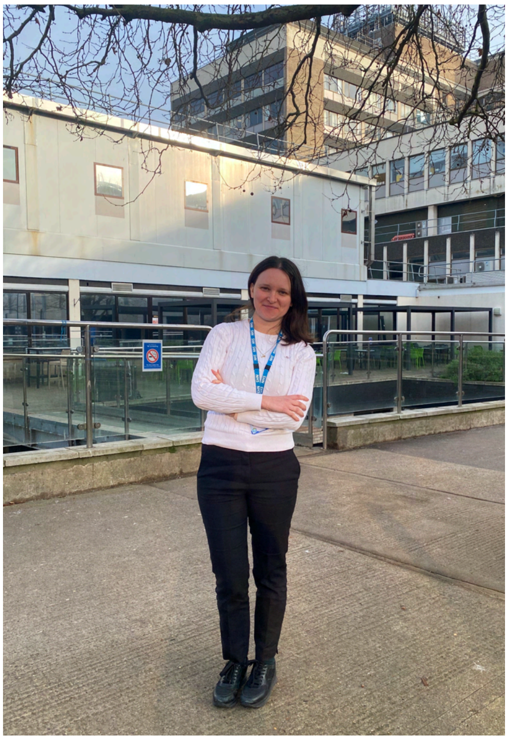
Happy New Year and thank you very much to everyone who has taken part in our study looking at sleep using brain scanning! I got a new puppy just before Christmas, his name is Charlie.
-Stephanie

Don't miss our Study Spotlight where we dive deeper into Stephanie's Sleep Study!

HELLO FROM MONIKA!

Catch up with a previous lab member, Monika, to hear what she's got up to since she left the team!

Some of you might remember me from the NiAD study! I worked as a Research Assistant and Coordinator on the study between October 2018 and July 2021.



During that time, I supported participants as they completed the many quizzes and puzzles, and I went with them to the scanner where pictures of their brains were taken. Thanks to everyone's hard work—both in Cambridge and the USA—we even published a paper with some of the study's findings. Working on the NiAD was such a rewarding experience. I learned so much from all the amazing participants and their families, as well as my wonderful colleagues at the Defeating Dementia in Down's Syndrome (DiDS) Team.

In September 2021, I moved to London to train as a Clinical Psychologist. The past three years were very busy with work placements and research. But now, I'm delighted to say that I've returned to Cambridge!

I've just started my new role as a Clinical Psychologist in an eating disorders service. My new workplace is right next to where we ran the NiAD study at Addenbrooke's Hospital - what a lovely coincidence!

I'm sending a big warm hello to everyone I met during my time with NiAD!
With warmest wishes,
Monika

RECENT NEWS

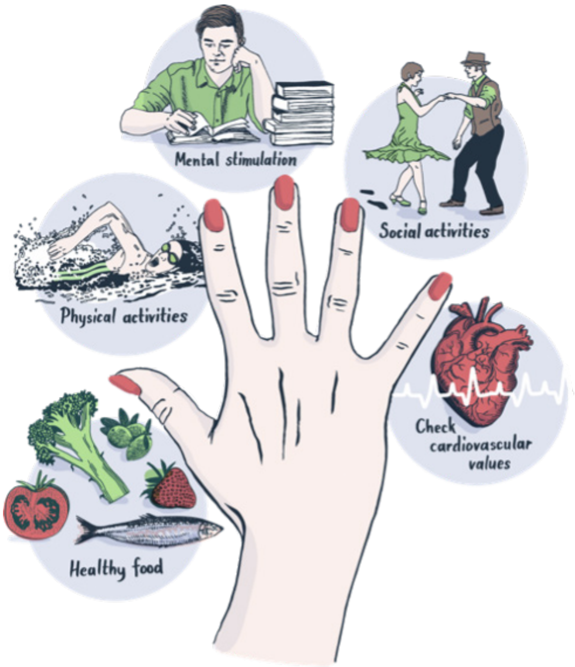
In recognition of

CAROL BOYS OBE

We were delighted to hear that Carol Boys OBE, the Chief Executive of the Down's Syndrome Association, was presented with her OBE at Buckingham Palace. She was honoured by His Majesty King Charles at a ceremony just before Christmas, following her inclusion in the King's Birthday Honours List in June last year, in recognition of her contributions to special educational needs, disability and research.

A letter from Dr Ruma Raha-Chowdhury

STAYING HEALTHY IN THE WINTER



People with Down's syndrome (DS) have a weakened immune system, (the body's defence system against infections). This means they can become seriously unwell when they catch an infection such as pneumonia or flu. We know that lifestyle changes such as eating well, physical activities, and using your brain (through workshops, volunteering, socialising etc.) can slow down the start of dementia. The FINGER study tells you more.

\- Ruma

PARTICIPANT STORIES

JOANNE'S MUSICAL SHOW

- JO BARKER

Joanne's activity group called Phoenix Rising enjoys performing a musical show every year. In December 2024, the young people and the group members have staged their own musical version of Matilda, writing songs including music and acting, rewriting our story lines, just like our own, themselves and ourselves. It was called 'We are the future, rebellious and revolting!'

The musical is the best place I've even been in.

Being in a production like Matilda is the greatest version that we've put on. My character was a firm character called Miss Bee, a teacher who knows what she is doing with her students. She took pity on Matilda herself, especially Peter as well. Taking and facing challenges, taking part in a musical, and any other musicals, they all helped me by being a family member of their team. Just like you, we are more like a team, expressing our feelings and knowing this musical always means a lot.

Miss Bee and others are absolutely witty, fun, funny and sometimes serious, because of Ms Punchball, the Head. She was trying to get students to be perfect. And they all came in for the Finale.

JO'S SPONSORED WALK FOR BBC CHILDREN IN NEED

Joanne did a sponsored walk in November and December 2024, to raise money for BBC's Children in Need. When she was younger, her special needs gym club "SNUGS" received a grant from Children in Need, so this cause has always been dear to her heart. In spite of the best efforts of Storms Bert and Darragh, Jo walked 100 TIMES round the block where she lives, so she walked around 25 miles - pretty good for someone with arthritis! She managed to raise around £2,000!

RESEARCH FACT SHEET

People with Down's syndrome (DS) are more likely to develop the symptoms of Alzheimer's disease earlier than others. Our research team explores what is happening inside the brain so that we can help people with DS to *live a healthy, long life.*

What is Alzheimer's disease?

Alzheimer's disease is a condition that affects the brain. It can cause problems with memory, thinking, and daily tasks.

Why are people with Down's syndrome more likely to develop Alzheimer's disease?

People with Down's syndrome are born with an extra copy of the chromosome 21. A chromosome is like a tiny, special instruction manual inside every cell in our body. There are 23 different chromosomes. This extra copy has instructions that can make changes in the brain happen earlier.

What are the symptoms of Alzheimer's disease in people with Down's syndrome?

Some common symptoms are:

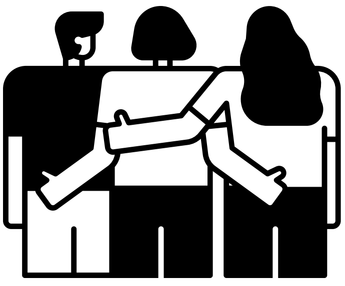
- Changes in memory or thinking skills
- Difficulty with daily activities
- Changes in behaviour or mood
- Trouble communicating

How do we study these changes in the brain?

Our research projects use tools like brain scans, memory tests, blood processing, and physical health checks. We also run separate studies that look at things such as the role of sleep or imaging the brain through the eyes.

Who can take part in our research?

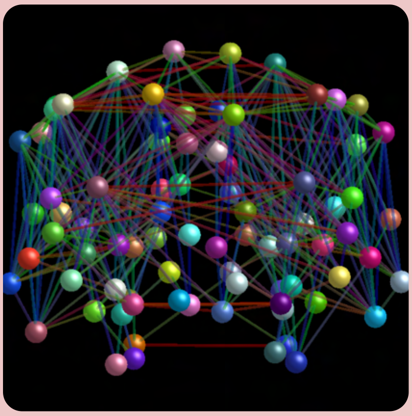
People with Down's syndrome aged 25 years or older can take part in our research, with a parent or caregiver. We also recruit siblings controls who have a sibling with Down's syndrome.



STUDY SPOTLIGHT

THE SLEEP STUDY - DR STEPHANIE BROWN

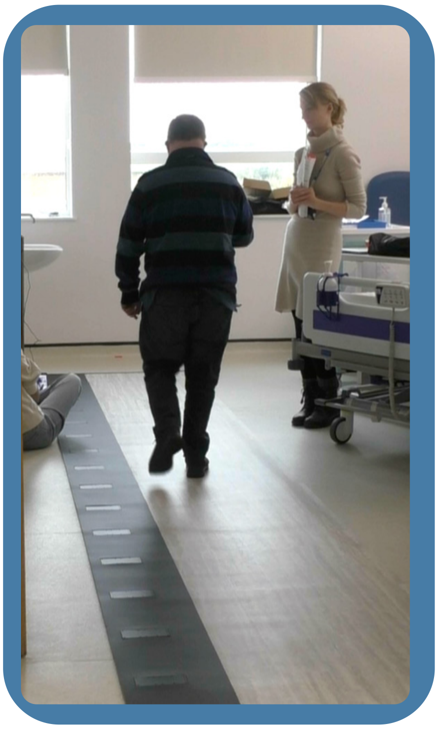
Thank you very much to everyone who has taken part in this study looking at sleep using high-resolution brain scanning! Participants who have come to see Stephanie have had blood tests, done puzzles and quizzes, used a fitbit and had an MRI brain scan. Some have even spent a night at the Royal Papworth sleep clinic! We have also welcomed participant siblings, and everyone has been fantastic at giving their time to help us understand more about how sleep might affect our brains and memories.



We are now looking at the information we have gathered for this study, and will share with you soon what we have found out. The picture above is a brain picture which shows which brain cells are communicating which each other!

ABC-DS STUDY UPDATE

We have started a new quiz! In addition to quizzes and puzzles, our participants who come for their 2nd and 3rd visit will have a chance to take part in the new walking test. We will ask you to walk on the 16-foot-long foam carpet with sensors that measures different features of your walk. This is also an exciting opportunity to help scientists understand whether how you walk is a measure of your brain's health! Thank you to those who already tried our new walkway (they said it was fun) and we hope everyone will enjoy it!

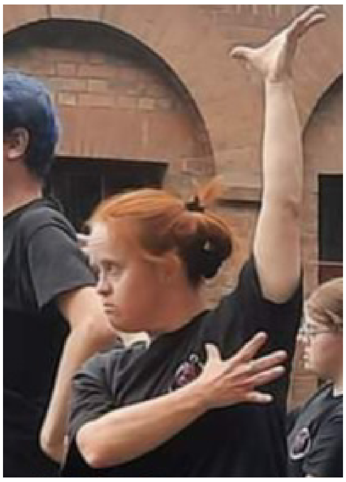


EXCLUSIVE INTERVIEW

A Star Among Us: Meet Eve-Marie Washington

This month, we spoke to Eve-Marie Washington, an actress, dancer, writer, and proud member of our community, about her incredible journey as an artist and her experiences in our research. Eve's story is a testament to her hard work and the power of dreams.

A Dream Come True

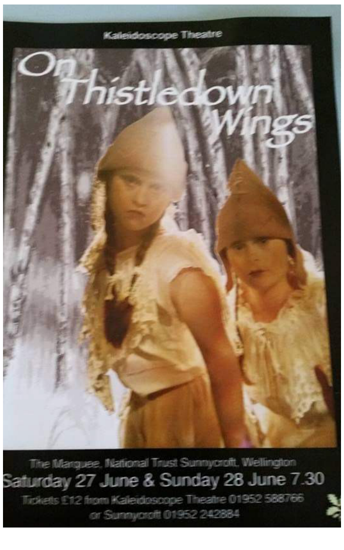


Eve always wanted to be an actress. When she was 16, she joined Kaleidoscope Theatre, an integrated theatre group where core members lived and worked together. Eve said, "I saw an advert for Kaleidoscope Theatre, auditioned, and got to perform with them at the Edinburgh Festival. When we came back, I was offered a contract and moved to Walsall, then Shropshire and was part of the theatre company for 25 years."

Eve has performed in many places, like the RSC Swan Theatre and the Jersey Opera House. She was also in movies such as *Shooting Fish* and *Titanic Town*, which starred actors including Kate Beckinsale, Julie Walters and Stuart Townsend.

When asked what Eve wanted to be when she grew up, her answer was always the same: "A star."

Becoming 'Moonflower'



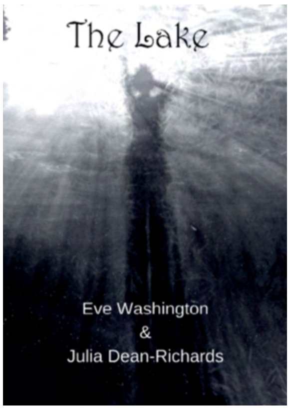
Eve's favourite role was Moonflower, a magical girl who lived in a forest and cared for animals. Eve played Moonflower for over 10 years and loved playing this character because she was "kind, caring, and strong". Moonflower then became the main character in Eve's book, *The Lake*.

When preparing for an acting role, Eve highlighted the importance of "practice, rehearse, practice, rehearse", but most importantly, "enjoy it!"

EXCLUSIVE INTERVIEW

Beyond Acting

Eve's creativity extends beyond the stage. She works as a class assistant at Identity Dance School and enjoys crafting, puzzles and meeting friends. Eve is also an author. Her novel, *The Lake*, tells the story of a family curse and its impact on people's lives. The heroine, Moonflower, brings together Eve's acting past and artistic abilities. "I wrote the book with the support of my friend Julia. It took us 2 years."



Joining the DiDS Research Community

Recently, Eve joined our research study in Cambridge. Despite initial nerves, she faced the visit head-on. "I was nervous about the tests, but everything was explained, and the team was friendly and kind. I felt proud that I was helping other people", she said. Eve shared with us she reflected on the visit, thinking about her friend who has been diagnosed with dementia, and she was proud she was making a difference.

Eve and her mother, Andrea, and now active members of our Community Advisory Group, sharing their insights and experiences to improve the outreach of our research.

Life in Lockdown

At the peak of the pandemic, times were very scary for many people. During lockdown, Eve and her family found the light in dark times through "Dress Up Saturdays", where they dressed in costumes and shared pictures online to make people smile.

Advice for Aspiring Performers

Eve's advice for others pursuing acting or any dream is simple and profound:

- Look for opportunities
- Be brave and give it a go
- Work hard, listen, and learn
- Enjoy it and have fun
- Be proud of whatever you do.

Eve's story is a beautiful reminder that with passion, perseverance, and a little magic, dreams can come true. Thank you, Eve, for sharing your journey with us and for being a treasured member of our community.

An update from our Community Advisory Group!

OUR COMMUNITY-LED GROUP AIMS TO SHAPE RESEARCH AND OUTREACH FOR PEOPLE WITH DOWN'S SYNDROME

On the 6th of December 2024, our new **Community Advisory Group** met for their first meeting! The conversations were deeply insightful and members shared their ideas, experiences, and feedback with the purpose of making our research more effective and inclusive.

WHAT DID WE DISCUSS?

- What makes the study visits **enjoyable**.
- Why our research is **essential** to the Down's syndrome community.
- The lack of general **publicity** about dementia and Down's syndrome.
- The importance of **clear language** and **consenting**.

YOU SAID, WE DID...

Building on the conversations had in this group, our research team are:

- Planning to create a new information video to be part of the consenting process.
- Continuing to work with NHS services, local learning disability groups and organisations to raise awareness of our research.

INTERESTED IN JOINING THE GROUP?

Contact Natasha at nmd36@cam.ac.uk or CIDDRG@medschl.cam.ac.uk to find out more and get involved!

Celebrate

World Down's Syndrome Day

with Cambridge Intellectual and Developmental Disability Research Group

Saturday, 22 March 10:30am-2:00pm

Featuring keynote speakers

Research exhibitions

Mini-science experiments

& lots of fun activities

Book tickets for free !

Address: Lucy Cavendish College Cafe | Lady Margaret Rd | Cambridge | CB3 0BU

Image credit: Hilary Gauld @oneforthewall

UNIVERSITY OF CAMBRIDGE

CIDDRG

CAMBRIDGE INTELLECTUAL AND DEVELOPMENTAL DISABILITIES RESEARCH GROUP

NHS 75
Cambridge
University Hospitals
NHS Foundation Trust

HEALTHY BRAIN AGEING WORKSHOPS

Offered by the University of Cambridge's 'Defeating Dementia in Down's Syndrome' Research Group

Bring our expert-led session to your community!

Our team is offering tailored sessions into the connection between Down's syndrome and Alzheimer's disease, early detection of dementia, and strategies for promoting lifelong brain health. Sessions can be adapted to meet the specific needs of your group, charity, or organisation.

Interested in Hosting a Session?

Contact Natasha to arrange this event for your group: nmd36@cam.ac.uk

Important research needs important people.

Adults with Down's syndrome are invited to join the ABC-DS study.

This research study will look to identify early signs that may indicate Alzheimer's disease. Help make a difference.

ABC-DS

The Alzheimer Biomarkers Consortium-Down Syndrome (ABC-DS)

We welcome participants who:

- Have Down's syndrome and are 25 years or older.
- Are accompanied by parent, caregiver, or legal guardian.

Participants will:

- Make visits to Cambridge to complete thinking tests, brain imaging, and other medical tests.
- Complete questionnaires at each visit.
- Be compensated for their travel, stay and time.

We can recruit participants from anywhere in the UK!
Learn more about the study here: abc-ds.org

To learn more about taking part, contact:
Natasha Duggan - email: nmd36@cam.ac.uk

Or scan the QR code below to register your interest!

Our Community Partners

Alzheimer's Research UK

DOWN'S SYNDROME ASSOCIATION

Brain Teasers

Riddles

Answers

1. What is white and fluffy and covers the ground in white?
2. What keeps your hands warm in chilly air?
3. What do people give each other on Valentine's Day to show they care?

1. Snow
2. Gloves/mittens
3. A Valentine's card

Word Search

Find the word in the puzzle. Words can go in any direction.

N	E	W	E	L	H	O	S	I	R	G	A	A	C
E	L	G	O	L	M	G	G	M	G	E	H	I	N
O	A	V	T	I	T	L	I	G	H	T	S	S	A
N	E	G	T	H	O	S	E	N	I	S	N	O	W
S	V	V	S	T	F	I	G	M	S	O	C	S	T
A	E	H	V	A	L	E	N	T	I	N	E	A	G
C	H	R	I	S	T	M	A	S	V	W	L	N	V
I	S	E	A	N	T	N	E	A	I	I	E	T	T
N	V	R	O	G	S	E	A	E	L	N	B	A	I
T	E	G	D	I	R	B	M	A	C	T	R	I	S
S	I	H	E	C	I	I	A	B	I	E	A	E	A
B	L	H	G	I	E	L	S	S	T	R	T	E	S
T	A	A	B	I	L	I	T	I	E	S	E	E	W
B	H	L	C	C	D	B	N	I	M	O	T	S	E

WINTER
CHRISTMAS
SANTA
VALENTINE
LIGHTS
ABILITIES
GIFTS
SLEIGH
LOVE
SNOW
CELEBRATE
CAMBRIDGE

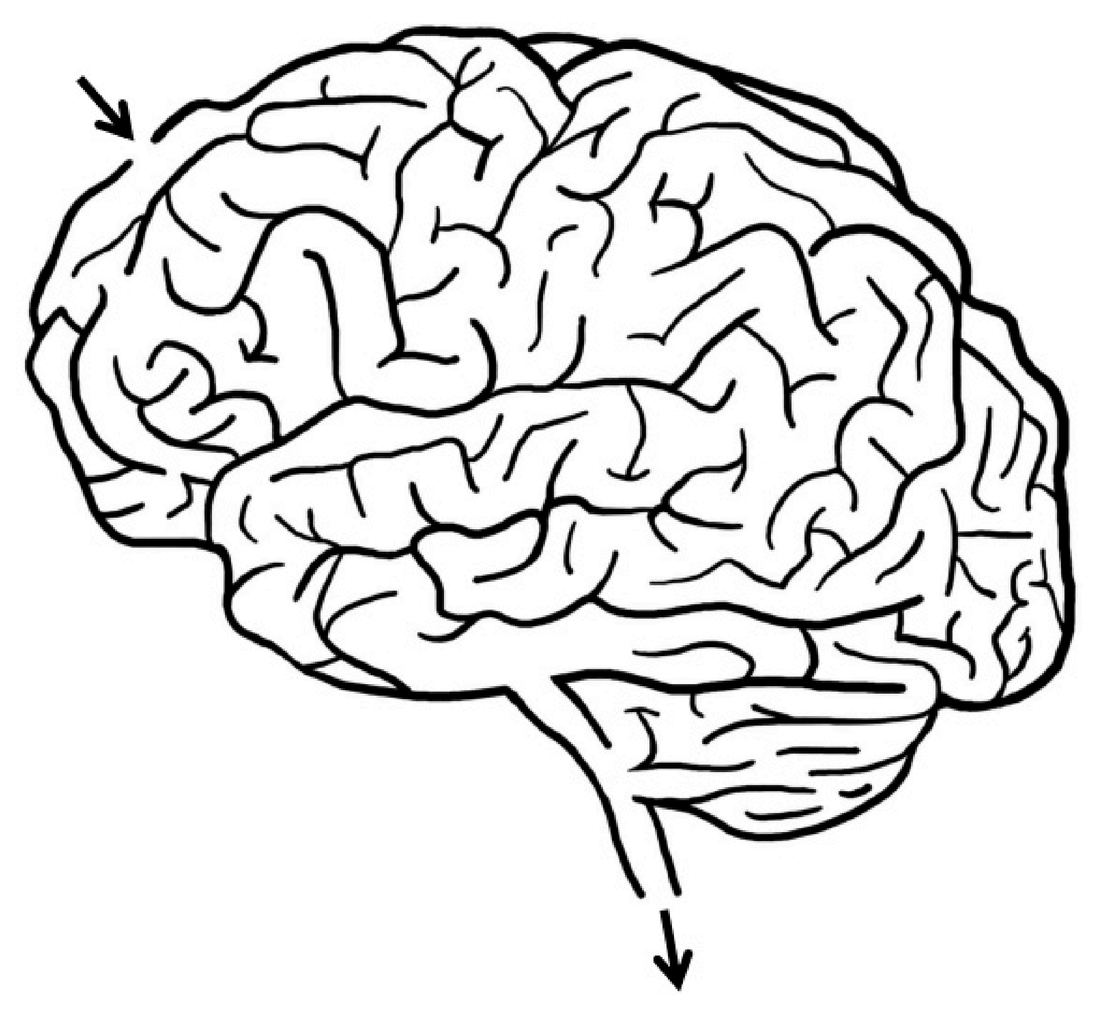
Spot the difference

There are 8 differences between the two pictures. Can you spot all of them?

Wishing you a happy start to 2025. See you in the Spring!

Brain Maze!

Can you find your way out of the brain?



Thank you to everyone who supports our studies! You're helping to make a big difference for those with Down's syndrome. Please share this newsletter with friends and family who might be interested in our research. If you would like to contribute to our next newsletter, please reach out!

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