



BRACE
Dementia Research

SPRING 2023
MAGAZINE



“She could squeeze my hand and tell me she loved me, and I believe right then she knew who she was...”

Together We Will Defeat Dementia

www.alzheimers-brace.org

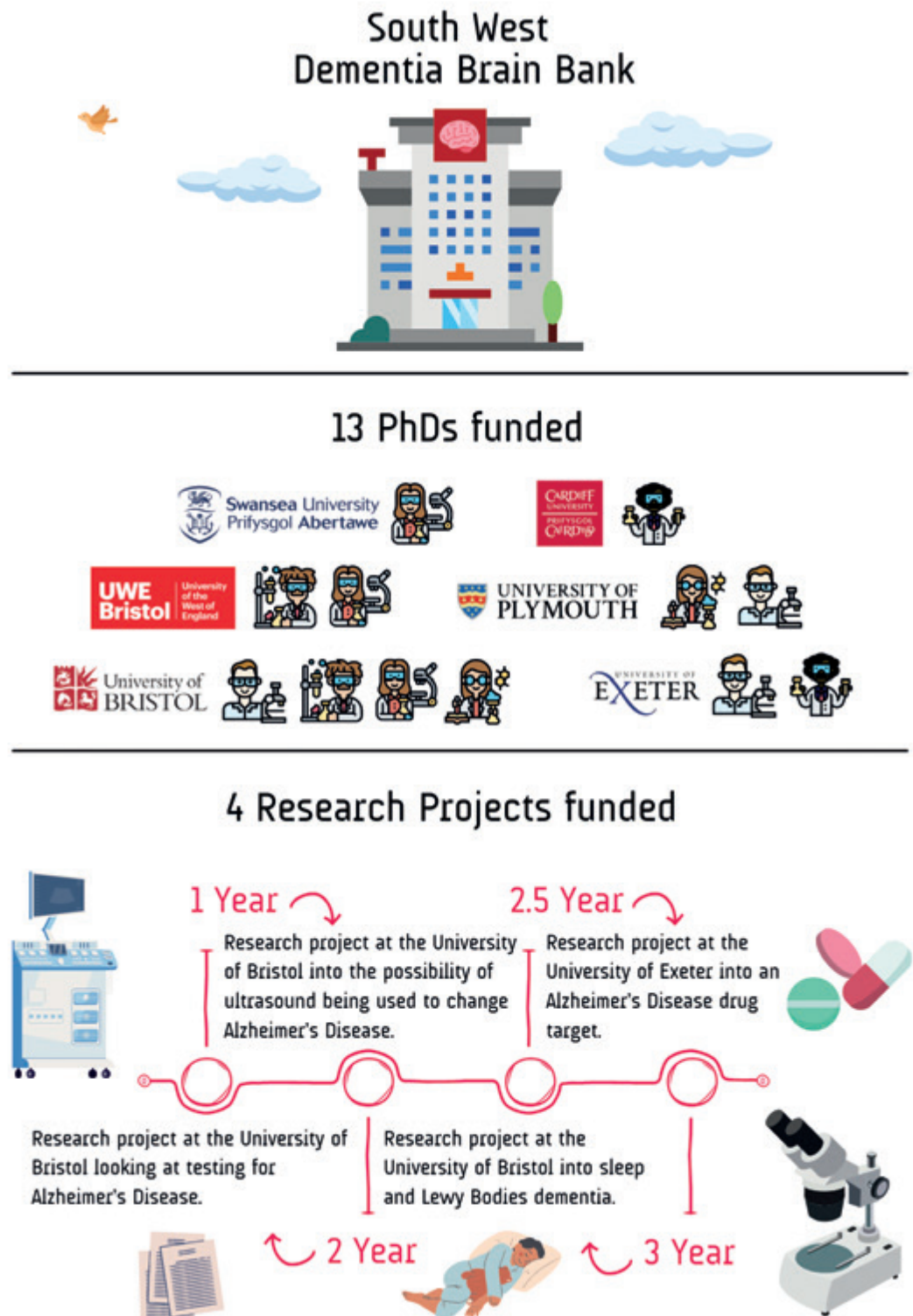
Dementia Research in 2022

BRACE was able to achieve a great deal for dementia research in 2022. Thank you to our incredible supporters and the dedicated researchers for making this possible.

In 2022 the charity funded the work of 13 PhD students, four at the University of Bristol, two at the University of Exeter, one at Swansea University, two at Plymouth University, two at the University of the West of England, two at Cardiff University and one at the University of Bath.

The charity was also funding:

- 1-year research project at the University of Bristol into the possibility of ultrasound being used to change Alzheimer's Disease
- 2.5-year project at the University of Exeter into an Alzheimer's Disease drug target
- 3-year research project at the University of Bristol into sleep and Lewy Bodies dementia
- 2-year research project at the University of Bristol looking at testing for Alzheimer's Disease
- Ongoing support for the South West Dementia Brain Bank.



The Vision for BRACE and Dementia Research

After a challenging 3 years, now is the time for BRACE to re-build!

Real progress has been made in the past 30 years and BRACE has played an important part in improved understanding of the causes of dementia and the ability to treat people living with dementia.

But even in the face of such progress, one of our greatest medical challenges remains unsolved. A cure for dementia.

BRACE is striving for a world free from dementia and I am confident this can happen in my lifetime.

To transform the lives of people with dementia and their families, we must tackle the condition on four fronts. By confronting public misunderstanding, creating a dementia friendly world, bringing together more people and organisations to work on research, and investing in the most cutting-edge research to find a cure.

But it won't just be scientists in labs who take us there.

It will be the people with dementia and their loved ones whose voices will be heard loud and clear so that we can all truly understand why dementia needs to be stopped.

It will be the families who support and care for loved ones with dementia, the people taking part in research and those who selflessly donate their brains.

It will be politicians whose decisions shape the research environment and charities like BRACE that drive improvements forward.

But most importantly it will be people like you who speak out and help us fund this critical research.

2022 saw a new direction for BRACE, with you, our supporters, at its heart. It's an exciting time for the charity, with ambitious plans for BRACE to be a £1,000,000 organisation by 2028.

This wouldn't be possible without supporters like you, who have so generously given to make research happen.

Here's to aiming higher and to supporting even more research over the next few years. Together we will defeat dementia.

Best Wishes,



Chris Williams
Director of BRACE
Dementia Research

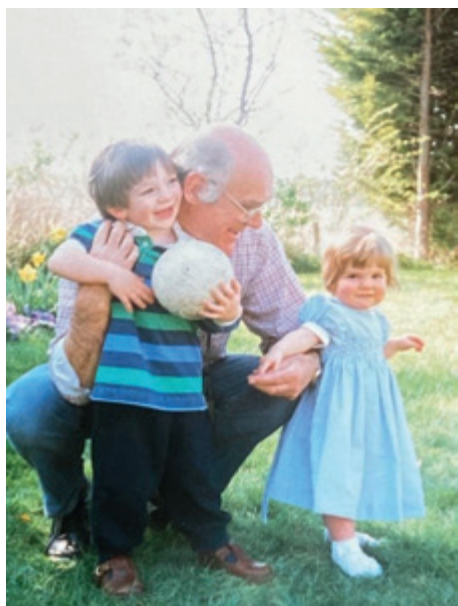
How you can help BRACE to re-build

- Follow on social media
- Sign up to our email newsletter
- Attend an event
- Donate
- Book a speaker
- Talk to friends and family about dementia research
- Host a Cuppa 4 a Cure
- Share your story



My Story: Grandad and Me

“My grandfather was a uniquely intelligent and active man. He was a successful engineer and businessman. But also with such a love of literature he went back to university as a mature student to study it. He was a skilled painter, singer, actor, gardener, writer and sailor. He was still going to the gym and skiing in the French alps, a place he adored, well into his late 70s.

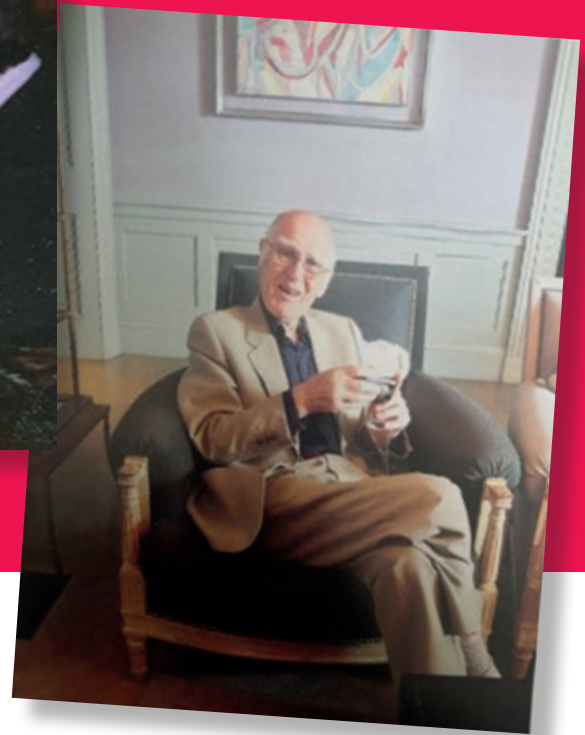


My grandma and he dedicated enormous amounts of time and effort to helping my mother raise myself and my brothers. He was, in many ways, a father to us. He picked us up from school, took us on long walks, drove for hours on holidays, played with us, talked with us for hours about books and history and built us toys from scratch - including a full doll's house for myself.

Despite keeping an active mind and body throughout his life, by his mid-80s he was suffering with many conditions, kick-started by heart problems. Eventually, vascular dementia took hold of him. The granddad I knew slowly started to

change. He couldn't understand or remember his new limitations or the medical advice he had been given and resisted it defiantly. He could no longer make his limbs do what he wanted them to and became weak. He rapidly lost his balance and autonomy. He had always been stubborn, particularly around ageing and his health, but his stubborn independence had never been a risk to his health before.

His personality changed too. He began saying things he would never have previously said. He began swearing aggressively. I had never heard him swear once in my life - not even a 'damn'. He lost his



ability to talk coherently and find the words he wanted to use. He became vulnerable to telephone and computer scammers. Then he lost his ability to recognise and empathise with the emotions of others. It was extremely hard for my grandma, my mum and my aunt who were with him most during this time. My mum became so exhausted from caring for him that she passed out in the shower, hitting her head and being hospitalised herself.

He had at home care for a while, but it wasn't enough and was too expensive. Eventually, nor was the care home. Poor care is the subject of an ongoing inquest into his death - almost two years on. The first time I visited him in his care home, I did nothing but cry. But he didn't seem to notice. He just smiled vacantly. He didn't say much but as I left that day he kissed my cheek and said 'God bless you'. Something he hadn't done since I was a young child. He seemed to have forgotten that while religious for much of his life, he had pulled away from it in the last decade or two. He had told us

during one of our long philosophical talks some years before that he thought perhaps 'god' wasn't a man or institution at all, but simply present in the trees and flowers and mountains and lakes. I wondered if he had forgotten that or was in fact returning to religion in his final weeks. Either way, as I held his hand throughout the week he spent unconscious and slowly slipping away, I kept repeating 'God bless you' to him. Just in case he could hear me. Just in case it brought him comfort at the end of his fight.

My granddad lost his personality to Dementia, creating a prolonged, anticipatory grief for his family. But today, by connecting with the things he loved - writing, reading, the French mountains, nature, music, singing, painting etc - who he truly was before dementia remains alive and with us. And he really was completely wonderful."

If you would like to read more stories, please go to the following page on the BRACE website: www.alzheimers-brace.org/my-story/

Today, by connecting with the things he loved - who he truly was before dementia remains alive and with us. And he really was completely wonderful."

If you would like share your story with BRACE, or learn more, please get in touch with: jed@alzheimers-brace.org or call the office on 0117 414 4831.

Thank you.

Meet the Researchers



Dr Katie Lunnon

I am a Professor of Dementia Genomics at the University of Exeter. I have always loved science since a young age, and as both of my grandmothers developed dementia, this was naturally the research field that I felt myself drawn to.

Being a Scientist is one of the most rewarding jobs I can imagine, as you can learn something completely new about a disease you are passionate about, working out small parts of the puzzle, together with the rest of the research community.

My team are interested in studying the role of epigenetic mechanisms in dementia, and we look at brain and blood samples to identify new disease mechanisms and potential biological markers (biomarkers).

Epigenetics is a growing area of interest in dementia as it refers to the additional chemical tags to DNA, which switches genes on and off, and can be influenced by external factors such as the environment. As there are well recognised genetic and environmental risk factors for Alzheimer's disease, we are studying whether this may be mediated by epigenetics.

Excitingly, as these epigenetic tags are reversible, they could potentially represent new places for drugs to target.

Due to advances in technology we are now at a stage in dementia research where my team can simultaneously measure epigenetic levels in the brain in nearly 1 million sites in the genome, in nearly 400 people in a single week!

Our team undertake both the lab work and bioinformatics, which is the analysis of the large datasets we generate. Given that we can generate such vast quantities of data, our team spend a large proportion of their time developing and using computational methods to analyse this, so we can identify genes that may be altered in disease.

The focus of much of our research has been on Alzheimer's disease, and we have identified really robust epigenetic changes in different brain regions (affected at different stages of disease) as well as blood.

Much of this research has been supported through BRACE, who have funded two exceptional PhD students in our group over the years, who have been instrumental in identifying specific epigenetic changes in Alzheimer's disease.

Our team are all naturally curious and incredibly passionate about dementia research, and we are fortunate to collaborate extensively with other leading teams around the world; sharing data and working together to uncover the mechanisms underlying disease.

No two days are ever the same as a Dementia Researcher; in addition to generating and analysing data, we also are involved in research-led teaching at the University of Exeter on both undergraduate and postgraduate courses, helping train and nurture the next generation of scientists, and public and scientific networking engagement events to broaden the outreach and impact of our work. We are also fortunate to be able to travel to international conferences to present our exciting findings and to foster further collaborations with world-leading experts.

I love my job as a Dementia Scientist, there is truly nothing else I would rather do!

Thank you, Katie, for your dedication to dementia research.



Since the early noughties, BRACE has been investing more and more funds into PhD students to ensure there will always be highly skilled dementia researchers. But what happens once a PhD is completed?

Dr Adam Smith

In 2019, Dr Adam Smith completed his BRACE funded PhD at Exeter University. During his studies he worked with Dr Katie Lunnon and Professor Jonathan Mill in a Complex Disease Epigenetics group.

Adam has gone from strength to strength as a dementia researcher in the last 4 years.

The University of Exeter awarded Adam an Above and Beyond Silver award at the start of 2023 in recognition of his achievements. He is currently co-supervising 3 PhD students and in 2021 became a Fellow of Higher Education Academy, which is a qualification in teaching and learning support in higher education.

Adam also teaches on several of the undergraduate programs at Exeter, alongside his role as Laboratory manager and Research Fellow

Last but not least, Adam has had 20 peer-reviewed articles published, showcasing his expertise.

It's incredible to see how much Adam has achieved in such a short space of time, thank you Adam for your dedication to dementia research.

A big thank you to BRACE supporters who have made it possible for BRACE to fund more than 40 PhD studentships in the last 20 years. Together we are defeating dementia.



In Memory of Brandon Lush



It is with sadness that we share that Brandon Lush, one of the founders of BRACE, passed away on 2nd November 2022 at the age of 102. Our thoughts are with his family and friends.

Brandon was one of the charity's four founding trustees alongside Professor Gordon Wilcock, the late David Pockney and the late John Rogan, when BRACE was founded in 1987.

During his retirement he continued to serve as an active trustee and offered his incredible knowledge and support to the charity until 2009.

The charity owes a lot to Brandon. We are so grateful that his life's work had such a positive impact on dementia research. He leaves behind a strong legacy and one we will continue to honour in every grant we award.

31/06/1920 - 2/11/2022

My Story: Pete and Eve

“I support dementia research because I have a dream that, one day, no one will have to suffer what Eve did when she lost herself.”



“We talked about her illness over the six years, changing the emphasis as time progressed and the worse she got, and discussed what it all meant. What was consistent, though, was our agreement none of it was what we wanted or had planned for, but it was what we had, and we needed to make sure we made it work because we were magic together and could conquer the world if we set our minds to it, but it had to be the two of us together.

She could be quite lucid at times, right up until four or five days before she died. Well, that’s subjective too. By lucid I mean she could answer questions like Are you in pain? She could squeeze my hand and tell me she loved me, and I believe right then she knew who she was, who I was and where we were.

For most of the time I don’t think she knew what she wanted, except to be with me, but by late 2021 she was too far gone to understand she couldn’t be with me if she were dead.

At a minute to midnight on Wednesday, July 6th, 2022, I sat on a chair and held Eve’s hand while she lay dying on the bed we’d shared for more than twenty-five years.”

Pete Elverhøi, writing about his wife Eve in his book ‘Goodbye Forever, Again.’

Superstar Supporters

We are so grateful to each and every one of our incredible supporters who help make dementia research possible. Our supporters help BRACE in all kinds of ways, from running marathons, to baking cakes, to volunteering in the office, inviting speakers to their community groups and encouraging loved ones to learn more about BRACE and dementia research.



Five incredible years of support!

Rich Ford has been a force to be reckoned with when it comes to raising funds for BRACE. Since 2018 he has taken part in cycling events, hosted several quiz nights, sweepstakes, a 12-hour gym challenge and secured countless, top quality event tickets for free, to be 'sold on' in return for donations to BRACE amongst other fundraising activities.

Rich's unrelenting drive has raised more than £10,000 for dementia research! We can't thank him enough for all his efforts. After 5 years, Rich is stepping down from his unofficial role as a BRACE fundraiser.

Here are a few words from Rich:

"I can't exactly recall the moment I became aware of BRACE but when I did something just clicked. I had already been supporting the Alzheimer's Society, following a diagnosis of the condition to my mum and whilst the time raising funds for them was successful, the desire to support a local charity took over and a close link and friendship was formed.

"I wanted to learn more about BRACE and help champion a small charity who are helping to tackle a big problem. I would like to think some of the events I have done, have done just that. I always felt that the people I approached for help would now be aware of BRACE even if they couldn't help. The last quiz couldn't have gone any better and record numbers helped to raise over £1,500. I'm massively grateful for all the support and will still be supporting, but just from afar."

Running the London Marathon for my loved ones

Dawn O'Connor took on the London Marathon in October 2022 for BRACE and raised more than £2,000, which is an incredible amount, thank you so much. Here are a few words from her:

"When I watched my daughter, Ashleigh Molton, running the London Marathon for BRACE in 2017, I could not have been prouder. It had seemed an impossible feat but after discovering running in my sixties a few years later, I wanted to know whether I could rise to the challenge too. Like my daughter, I wanted to run for BRACE in memory of my much-loved Mum, Patricia O'Connor, but also for my dear university friend, Sheila Reynolds, who was living with early onset Alzheimers. With the fantastic support of friends and family, I not only achieved my goal but also had the experience of my life! Thank you BRACE!"



If you would like to get involved in a fundraising event, such as Cuppa 4 a Cure or entering a race please email fundraising@alzheimers-brace.org
We'd love to hear from you!



BRACE has been awarded more than £100,000 from the Medical Research Council (MRC). This is incredible news for dementia research. The grant will be used to support up-and-coming researchers at the University of Bath, University of Bristol, Plymouth University and Swansea University.



BRACE secures £100k for up-and-coming dementia researchers

In recent years the pandemic has limited the amount of research BRACE has been able to support, with requests for funding far outweighing the resources available.

Thanks to the MRC grant the following research will go ahead:

- An investigation into cell changes in Alzheimer's
- Understanding the impact of sleep on vascular dementia and Alzheimer's
- Exploring new ways to slow down vascular dementia with different medicines
- A new approach to stop plaque build-up in Alzheimer's
- Investigating if an early Alzheimer's test can be used to diagnose other types of dementia.

BRACE funded research has recently had an incredible breakthrough with Dr George Stothart's work at the University of Bath, where he developed an early Alzheimer's test called Fastball. The test is now being investigated by the NHS.

One of five researchers benefiting from the MRC grant is PhD student Oliver Hermann. Thanks to the grant from MRC, Oliver will be funded for a full year to work alongside Dr Stothart on the Fastball test. A dementia test which has the potential to transform how people are diagnosed with dementia in the UK and around the world.

Dr Stothart says:

"The support from BRACE to build on our early success with developing Fastball is so valuable. BRACE funded the essential pilot work in 2019 to show that the technique worked with Alzheimer's disease, Oliver will now focus on adapting Fastball for use in other forms of dementia, such as Lewy Body and Vascular dementia. It is critical not only to diagnose early, but to diagnose accurately, and Oliver's work will contribute to this global effort."



Supporting researchers in the early stages of their careers is vital for dementia research and ensures there will always be highly qualified researchers, now and in the future. BRACE has supported more than 40 PhD students over the years, and this grant from the Medical Research Council could not have come at a better time for the charity to continue its support of up-and-coming researchers.

Huge thanks to the MRC, our committed dementia researchers and all our supporters who have stuck by BRACE through our recent challenges.



Together 4 Dementia

On Tuesday 1st November 2022, we were delighted to host the charity's first ever hybrid conference, welcoming guests and speakers in person and, online. Broadcaster and presenter Ali Vowles generously gave her time to chair the event for the 4th year in a row.

Dr George Stothart, from the University of Bath, kicked off the conference with his talk on a new dementia diagnosis hope called 'Fastball'. Followed by dementia campaigners Willy and Gerald, from Ecredibles and Deep, talking about life with dementia and the importance of peer support.

Professor Deborah Sturdy, Chief Nurse for Adult Social Care, spoke about the need for more funding and support for people living with dementia and their carers.

Dr Emma Richards and PhD student Chloe Tulip, from Swansea university, shared their BRACE funded Vascular Dementia research stories. Chloe's research focuses on the role of sleep and dementia - **who knew a nap as short as 6 minutes could boost memory!?**

Author and dementia campaigner Wendy Mitchell, gave insight into her experience of the reality of living with dementia. She said,

"Imagine the brain is like a string of fairy lights - each light a different part of the brain, and with dementia, lights start to slowly go out... All we've got is this moment - we don't know what's round the corner - Live Life!"

Closing the day we had a talk on detecting and monitoring behaviour patterns to diagnose dementia, from Weisong Yang of the University of Bristol. And gained insight into how we can better support Black, Asian and minority ethnic people living with dementia from Jes Phillips, of the Race Equality Foundation.

Thank you to all who attended - we hope you found the updates, stories and personal experiences interesting and inspiring. In 2023 we will be hosting Let's Talk Dementia...



BRACE

Lets Talk Dementia

Join us on **Saturday 30th September**, 10am - 5pm for this free event in Bristol.



Let's Talk Dementia is a one stop event for families to learn more about dementia.

Knowing where to turn when supporting loved ones with dementia can be a minefield. If you, or loved ones are given a dementia diagnosis in the future, what would you need to know?

The chance to meet dementia experts in an informal setting, seek free advice, ask questions, and learn more about the practicalities of life with dementia.

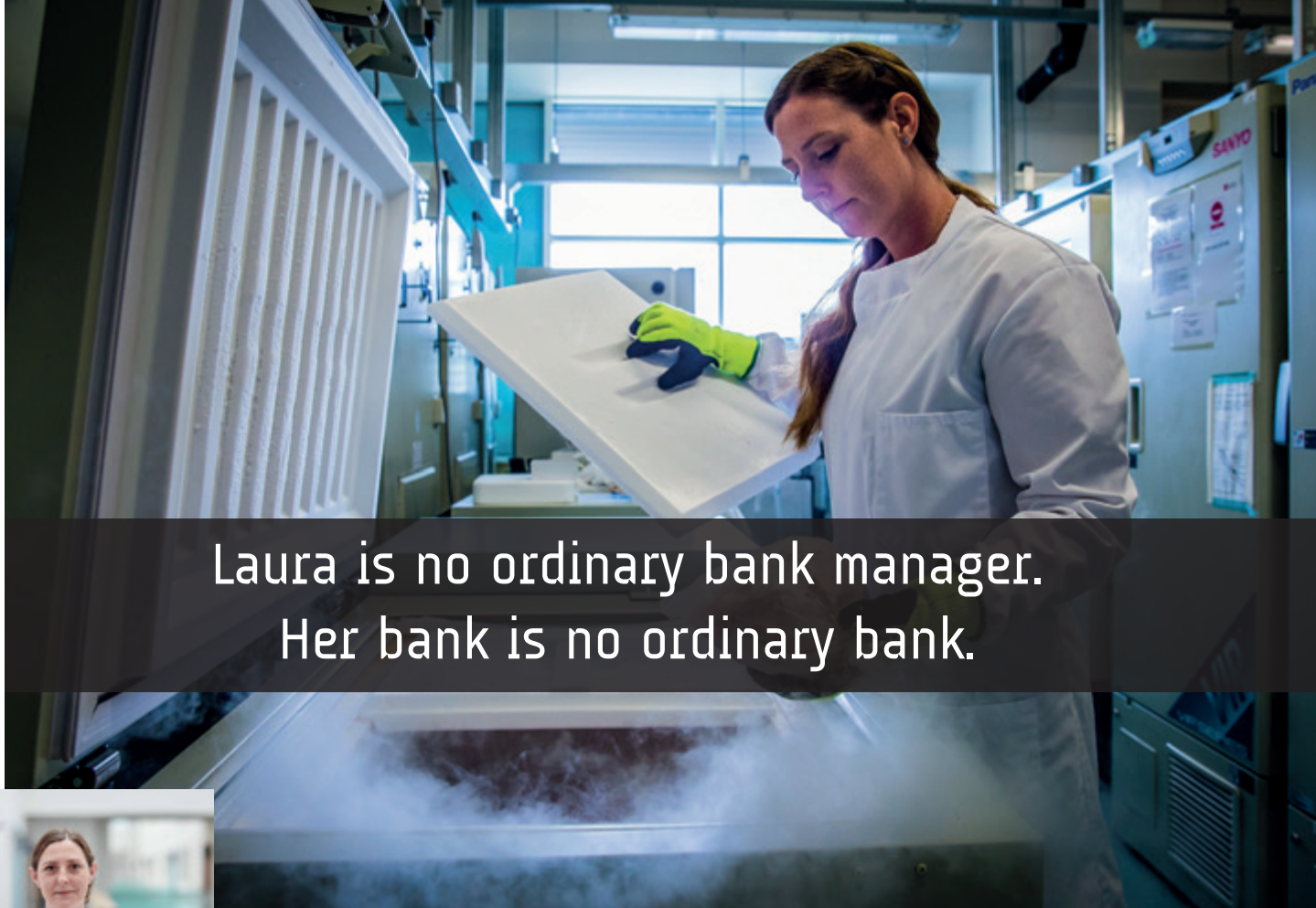
We recommend booking free tickets to guarantee your place.

www.alzheimers-brace.org/event/lets-talk-dementia

The event is taking place at The Paintworks, Bath Road, Bristol, BS4 3EH. (The event space is next door to The Boca Bar).

The venue has some free parking and is a short walk from Bristol Temple Mead Station, there are also two bus stops less than a five-minute walk away.

We hope to see you on the day!



**Laura is no ordinary bank manager.
Her bank is no ordinary bank.**



Dr Laura Palmer is the Bank Manager at the South West Dementia Brain Bank. One of just

six such dementia research centres in the UK. The bank stores donated brains for use in dementia research. In 2022 alone the Brain Bank provided 11,696 samples to researchers across the world. That's one sample sent globally every 44 minutes!

Despite every breakthrough in dementia research using donated tissue provided by researchers like Laura, she is facing redundancy.

It costs more than £2,000 to retrieve and store one brain. The tissue must be stored at minus 80 degrees and each freezer costs £12,000. Each donated brain can be stored for decades, supporting research for 10, 20 years or more. Storing one brain for just five years costs more than £9,500.

These prices and the unpredictability of funding means that every 12 months, Laura and her colleagues are put through a redundancy process.

This Bank cannot apply for a loan or an overdraft. When the money is gone, so is the dementia research.

They do not receive government funding, so it's thanks to people like you that BRACE was able to sponsor Laura's PhD. And support more than 18 remarkable years of her work at the Brain Bank.

But researchers like Laura need continued funding to make their work possible. One in three people born in the UK this year will develop dementia in their lifetime. The need for dementia research is greater than ever.

During this period of instability, please can you help us secure Laura's work, and the South West Dementia Brain Bank for another 12 months?

If you would like to support Laura and the Brain Bank please visit:
www.alzheimers-brace.org/laura/
or call the office on 0117 414 4831 to donate over the phone.

Thank you for your support.



"The only way we can end dementia is through research and lots of it.

Please support BRACE Dementia Research in whatever way you can and help to defeat dementia once and for all."

Alan Titchmarsh

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