

# 2022 REVIEW

1st January - 31st December 2022



## Major health discoveries thanks to twins

Our members can be very proud of their contributions to health discoveries through their participation in studies in 2022, two of which have run over a decade. We share some of the highlights:

### Multiple insights in a decade of twin research

The decade-long ground-breaking [Academic Development Study of Australian Twins](#) at the University of New England is helping us to better understand what factors impact children's learning and how to achieve the best outcomes for all Australian students.

The project uses data from the *National Assessment Program: Literacy and Numeracy* (NAPLAN) and involves 2,762 twins pairs, 40 triplet sets and 1,485 non-twin siblings. Among the major project findings to date are that:

- Genetic differences among students are the single biggest influence on differences in literacy and numeracy
- The home environment that twins share has an unexpectedly modest influence on NAPLAN results
- Identical twins learning in different classrooms with different teachers perform almost as

similarly in literacy and numeracy as pairs sharing the same classroom and teacher, indicating that the influence of individual teachers may have been overestimated

- Students attending private schools make no more progress in literacy and numeracy from Year 3 to Year 9 than students attending public schools

"We hope our findings can inform educational policymakers looking to design and deliver interventions that can help struggling children to reach their potential," the researchers say.

"As one example, we have suggested that any financial assistance available to students struggling with reading development be directed to individual students rather than to the school or even classroom."

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## Striving for higher wellbeing and resilience for all

For over 13 years, Dr Justine Gatt and her team at Neuroscience Research Australia have led a large twin study investigating how people's genes, environment and neural factors affect their mental wellbeing and resilience.

Dr Gatt began her *Twin-E Emotional Wellbeing Study* in 2009, recruiting over 1,600 adult twins to undertake a series of assessments and procedures including cognitive tests, emotional regulation questionnaires, brain imaging and genetic analyses.

Her results led to the development of a wellbeing scale called [COMPAS-W](#) which provides an accurate measure of overall mental health and wellbeing.

It also allowed her team to identify various factors associated with higher wellbeing and resilience, such as lower depression and anxiety, better working memory and attention to certain tasks, even differences in brain structure and function.

More recently, she re-tested the twins after 10 and 12 years as part of her next phase *Twin-10 Resilience Study*. She is looking at how their wellbeing has changed over time and ideally determining how different life experiences may have affected participants' resilience or vulnerability to mental health issues.

In 2022, Dr Gatt invited a new cohort of twins to join *Twin-10*. This research is focusing on how the brain, and its structure and functioning, affects wellbeing and resilience. Study participants undertake an online emotional regulation survey and complete a brain imaging scan.

Undoubtedly, there will be many novel and important findings for us to report over the coming year or two from *Twin-10*.

## Environmental factors significant in Alzheimer's disease

The [Older Australian Twins Study](#) at the University of NSW has revealed new insights into one of the hallmarks of Alzheimer's disease, amyloid plaques, with the help of twins.

Amyloid is a protein that accumulates in the brain very early in the development of the disease. Researchers looked at the brains of identical and non-identical twins using a special type of imaging called amyloid PET, or *position emission tomography*. Their aim was to determine what proportion of amyloid accumulation is determined by genes in comparison to the environment, or modifiable risk factors such as high blood pressure and high cholesterol.

They found the heritability of amyloid is moderate—meaning genes play only a moderate role in amyloid build-up in the brain. While the study did not find an association between vascular risk factors and amyloid, larger studies are required.

"Our findings are significant, because they tell us that while genes are important, there is actually a major environmental contribution that may respond well to intervention," the researchers say.

"Identifying modifiable risk factors will lead us to interventions that reduce the risk of amyloid accumulation—and ultimately risk reduction of developing Alzheimer's disease."



HRH Crown Prince Mary met multiple-birth families in Sydney in 2013 as Patron of Twins Research Australia

## TRA Patron celebrates her 50th birthday

TRA joined in global celebrations for the 50th birthday of our International Patron, HRH Crown Princess Mary of Denmark, earlier this year.

A TRA video message featured in a special televised gala by Danish TV to celebrate her milestone birthday and incredible global philanthropic work.

TRA Director, Professor John Hopper, passed on congratulations from all at Twins Research Australia: "We are not only immensely grateful for the generous contribution that HRH has made to our work over the past decade, but also her amazing contribution to causes around the globe and to benefit all humanity. What remarkable achievements in the first 50 years of the Crown Princess's life – and we are excited to share in what is to come."

## DIRECTOR'S MESSAGE

While we continued to live with the ongoing effects of COVID, 2022 allowed greater freedom of movement and a resurgence of research opportunities. Our volunteer twin members continued to shine, responding to approaches for seven studies ranging from the twins and sisters' mammographic density study to the diet and fertility health study. With your ongoing help and commitment, Twins Research Australia once again enabled researchers within Australia and around the world to undertake extremely valuable health and medical research studies.

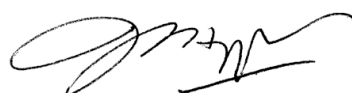
This year's highlights (below) illustrate the strength of our collaborations, with both the *Academic Development Study of Australian Twins* and the *Twin-10 Resilience Study* celebrating significant milestones. This lovely message from Associate Professor Gatt, Senior Research Scientist of the Twin-10 Resilience Study, reinforces our invaluable partnership:

*"I have worked with the TRA team for quite a number of years on our twin resilience project. From my experience, it has always been a pleasure to work with TRA and I have never had any doubts regarding their work efficacy, efficiency (particularly in demanding times) and attention to detail. Their professionalism, dedication and time commitment to*

*the project deadlines has always exceeded my expectations, and has enabled us to reach our many projected and often challenging recruitment goals. I would highly recommend working with the TRA team to anyone interested in twin research and I hope to maintain a long-term collaboration with them for years to come."*

There will be a number of new studies to kick off next year – and we thank you in advance for considering them. Without your generous and enthusiastic support none of these projects would be possible. We look forward to your continued involvement in 2023.

Best wishes



Professor John Hopper AM  
Director, Twins Research Australia  
Director (Research), Centre for Epidemiology and Biostatistics  
Melbourne School of Population and Global Health  
The University of Melbourne

### 2022 highlights

Nearly  
**6,000** study  
invitations sent to  
members

Launch of a significant  
new study to understand  
the **impact of diet** on male  
fertility, and the potential  
impact on child health

Findings from  
twin studies contribute new  
insights into **Alzheimer's  
disease** and **dementia**

**1,890** twins and  
**1,038** multiple-birth  
families participate  
in studies

Two landmark  
studies reach their **10th**  
and **13th** year of research  
investigation respectively  
– *Academic Development  
Study of Australian Twins*  
and *Twin-10 Resilience  
Study*

TRA advocates for  
increased financial, social  
and health support for  
multiple-birth families as  
part of a major nation-wide  
public campaign,  
**Multiples Matter**



# RESEARCH IMPACT

TRA's research impact reaches around Australia and the world. We conduct and enable research involving twins through our expertise in study design, twin and family recruitment, managing membership and study data, and data analysis.

## Studies by the numbers 2022

- Seven actively recruiting studies in 2022: diet and fertility health (Deakin University), financial decision making (University of Technology Sydney), GenV (Murdoch Childrens Research Institute), mammographic density follow-up (TRA/University of Melbourne), mental health (Monash University), neurodevelopmental disorders (University of Adelaide), and the TWIN-10 resilience study (University of NSW/ Neuroscience Research Australia)
- 5,779 study invitations sent to members
- 1,890 individuals and 1,038 families participated in studies
- Biggest studies:
  - 739 participants joined the [Australian Twins and Sisters Mammographic Density Study Follow-Up](#)
  - 561 joined the [Mental Health Study AKA the Brain Behaviour Project](#)
  - 289 joined the Financial Decision Making Study
  - 159 joined the TWIN-10 Resilience Study (a 10-year follow-up of prior participants)
- TRA studies conducted in 26 institutes around Australia as well as 10 international institutes
- View papers published in 2022 [here](#)

## A simple eye test could predict dementia

A study mapping the thickness of the layers of the retina in twins at midlife, led by researchers at Monash University's [National Centre for Healthy Ageing in Australia](#), has found that it could be a marker of future dementia risk.

Currently potential biomarkers of future dementia risk are based on complex brain scans or testing of specimens involving blood or cerebrospinal fluid (found within the tissue surrounding the brain and spinal cord) – procedures which are often complex, expensive, or invasive.



Researchers with twin study participants at the National Centre for Healthy Ageing

In comparison the retina at the back of the eye, which can be relatively simply visualised, has been advanced as a potential surrogate of brain health given that its blood vessels and nerves are an extension of that of the brain.

Our great appreciation to the 18 pairs of TRA twin members who undertook cognitive testing and MRI scans in support of this research.

The study found that the greater thickness of a particular retinal layer, the ganglion cells (the cells that connect the eye to the brain), was strongly associated with better cognitive function, and greater grey and white matter, and brain blood flow.

"Ganglion cell layer thickness showed consistent associations with a range of brain measures suggesting it may have utility as a midlife marker for future neurodegeneration and dementia risk," the researchers reported.

## FEASST of a study for male twins



FEASST study participants, Royden and Pierson Budge

A new study, launched mid-2022, is investigating whether changes occur to male sperm as a result of differences in diet, and whether this can impact the health of future offspring. The *Introducing the Food Intake and Epigenetic Alteration in the Spermatozoa of Singletons and Twins (FEASST)* study involves male twins, identical and non-identical, aged 18-45 from Melbourne and surrounds.

As part of the study, each twin in a pair is given a different diet to follow for three weeks, with all meals and snacks provided for free. The twins are monitored via clinic visits and provide sperm samples before and after the dietary intervention. The study aims to better understand the impact of diet on men's fertility and the potential impact on child health. It is hoped the findings will lead to the development of dietary guidelines for fathers-to-be.

# OUR MEMBERS

Our volunteer members are an integral part of Twins Research Australia, and member management and engagement are core TRA services.

We manage a database of twins and Higher Order Multiples (HOM) and their parents (if the twins and HOM are under the age of 18) who have expressed interest in volunteering for health studies.

Twins and HOMs – including triplets, quadruplets and quintuplets - of all ages, sex combinations and zygosity – are eligible to enrol with TRA.

## Highlights 2022

- 38,069 active twin pairs (or 76,138 individual twins) on our database in 2022
- 402 active sets of triplets and HOM
- Of this total, there are 26,957 adult pairs/sets (18-plus years of age) and 11,514 children (under 18 years of age)
- Of those twins, 43% are identical, 54% non-identical and 3% unknown zygosity
- TRA recruited a total of 379 new twin and HOM sets in 2022, 375 of whom were twin pairs

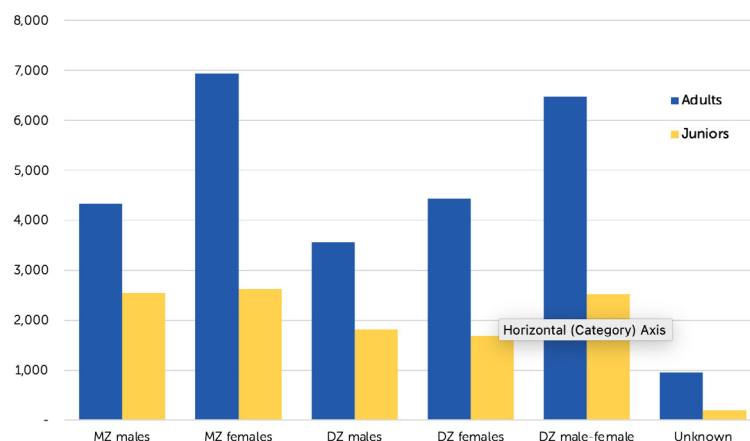
## Active<sup>1</sup> twins and HOM members 2022

| Active status of set     | Twin pairs | HOM sets | Total pairs/sets |
|--------------------------|------------|----------|------------------|
| Both <sup>2</sup> active | 38,069     | 421      | 38,490           |
| One active               | 5,428      | 17       | 5,445            |
| None are active          | 6,620      | 46       | 6,666            |
| Total                    | 50,117     | 484      | 50,601           |

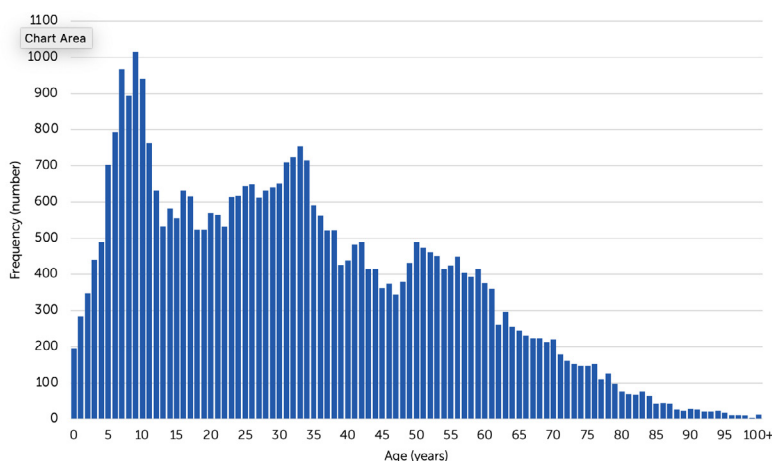
<sup>1</sup>Active means they are currently recorded on the registry as willing to be approached for studies (including those only willing to complete questionnaires)

<sup>2</sup>Both twins in a pair or at least two members of a HOM set

## Active twin pairs by sex and zygosity



## Age distribution of active twin pairs



## KNOWLEDGE EXCHANGE

Twins Research Australia prioritises knowledge exchange and translation in its work to enable twin research to have impact in society. We aim to maximise the transfer of twin research outcomes to broader health policy and practice.

As part of this work, TRA continues its close partnership with the twin community, especially the [Australian Multiple Birth Association](#) and [International Council of Multiple Birth Organisations](#), to support research and resources to address health issues of particular concern to them.

### TRA supports nationwide campaign: Multiples Matter



*Federal Assistant Minister for Health and Aged Care, Ged Kearney, meets multiple-birth families as part of AMBA's campaign*

TRA is supporting a major nationwide public campaign launched by the Australian Multiple Birth Association in 2022 with the release of the report, [Multiples Matter: Investigating the Support Needs of Multiple Birth Families](#). The AMBA report outlines how multiple-birth parents are significantly more likely to have premature babies, experience mental health challenges, severe exhaustion, financial stress and medical complications. It recommends key areas where parents need more support including accessing affordable childcare and greater financial support.

The report reflects many of the previous key findings of TRA and global researchers that are collated at [Multiple Perspectives: What Do Multiple Birth Families Need to Live Happy and Healthy Lives](#). TRA encouraged its many stakeholders, including 75,000 members, to support the campaign; and TRA representatives contributed to media stories and attended an event at Parliament House in Canberra to raise awareness of the unique challenges of multiple-birth families.

"Our long-term and ongoing research supports the key issues raised by the campaign," TRA Director, Professor John Hopper said. "All of us involved must work together to bring urgently needed change to policies and practices that hinder equality for parents of multiples."

### Twins can face risks before and just after birth



The AMBA campaign was further strengthened with a widely distributed media article by TRA researchers, [Twins Can Face Unique Risks Before and Just After Birth](#)

The article explains: "Twin pregnancies, births and early-life care commonly require extra attention and resources from medical carers, clinics and hospitals. This is because multiple-birth babies are much more likely than singletons to be born preterm and with low birth weight, which are risk factors for higher infant mortality. TRA researchers are calling for specific healthcare guidelines in Australian hospitals to increase specialist care and reduce early-life inequities faced by these babies."



## Inaugural multiple birth symposium for health professionals

TRA was pleased to support, and encourage its stakeholders to attend, the Inaugural Multiple Birth Symposium presented by the Australian Multiple Birth Association in November this year. The symposium was designed as a day-long professional development workshop to support health professionals to provide the best possible care for multiple-birth patients and their families.

Attendees included midwives and general practitioners as well as maternal, child, family and mental health service providers. Presentations were made by specialists from obstetrics, gynaecology, neonatology, mental health, genetics and multiple-birth research. TRA researcher, Dr Lucas Calais Ferreira, spoke on *Improving the Health of Twins, Multiples and their Families through Science and Evidence*.

## National TV series to showcase twin research



Filming for a new Channel 9 series about twins with hosts Scott Cam and Jana Pittman

TRA assisted in finding twins and researchers for a new two-part TV series being produced by Helium Limited for Channel 9 Australia. Nearly 100 twin pairs joined a variety of scientific and entertaining challenges to find *Australia's Most Identical*. Channel 9 hosts, Scott Cam and Dr Jana Pittman (both parents of twins) are joined by two TRA researchers, Professors Jeff Craig and Sarah Wilson, who supervise and assess the results.

TRA is supporting the series to raise public awareness of the unique role of twins in health research which, ultimately, benefits all Australians. The series is expected to be broadcast sometime in 2023.

## Increasing awareness

Other activities undertaken by TRA to increase awareness of twin research and its contribution to public health included:

- Updating and uploading new content to its central communication platform [www.twins.org.au](http://www.twins.org.au)
- Continuing diverse communications to reach as broad an audience as possible e.g. social channels ([Facebook](#)), emailing ([Member eNews](#), study invites and feedback questionnaires), and 1800 phone-assist service
- Media campaigns to raise public and twin awareness. Issues that gained widespread attention in 2022 included:
  - [Researchers find resilience is written in the brain](#)
  - [Simple eye test could predict dementia](#)
  - [Why are we so fascinated by identical twins?](#)
  - [I'm a mirror twin with opposite traits to my sister](#)
  - [NAPLAN analysis shows no difference between public/private schools](#)
  - [You can't bake the same cake twice](#)
  - [Environmental factors significant in Alzheimer's](#)
  - [What Happens When One Twin Exercises and the Other Doesn't?](#)

# BUILDING RESEARCH CAPACITY AND CAPABILITY

TRA conducts its own research as well as enabling twin research across Australia and the world. It openly promotes the twin registry and associated resources to all researchers, across all disciplines.

TRA provides researchers with an established infrastructure and access to a rapidly growing network of twin researchers, statisticians and administrative staff who are experienced in establishing and conducting studies. Further information on resources and access are available at our [website](#).



## Research supervision, training and education

A key to the increasing success of TRA is its training and upskilling of researchers from many disciplines and of varying skillsets across the country and internationally. In 2022, TRA continued to build capacity and capability in twin research through the following educational training, professional development, and mentoring activities:

- TRA continues to build international collaborations with institutes such as the [International Network of Twin Registries](#), [national twin registries](#), and [International Council of Multiple Birth Organisations](#)
- We offer [workshops](#) and [online training modules](#) for researchers to expand their skills into twin studies

Research capacity is also built through TRA-supported scholars and fellows supervising research students as well as providing workshop support for students. This year saw students - 14 PhD, five post-doctoral, and one Master of Philosophy – receive support.



# FUNDING AND SUSTAINABILITY

## Government support

Historically, Twins Research Australia was fortunate to receive continuous funding from the Federal Government's National Health and Medical Research Council (1981-2014). The most recent NHMRC Centre of Research Excellence (CRE) Grant commenced in 2015 and concludes at the end of this year, 2022.

TRA continues to seek new government funding, including applying for a new CRE Grant with the NHMRC, but we have been unsuccessful to date, mainly due to the changed funding parameters of the grant.

This has required us to seek alternate funding through other federal, state and philanthropic channels. We thank our team members and partner researchers for their considerable efforts in completing time-consuming grant applications in, what is, a very competitive environment.

In addition to NHMRC funding, TRA is reimbursed by researchers and research groups who use our services for study development, recruitment and analysis. We depend on grants to enable us to provide these services as cost-effectively as possible and to support studies into diverse medical conditions that impact millions of Australians.

The conclusion of our latest NHMRC grant has led to a review of our services and structure. To ensure our ongoing viability until new funding is found, we will be streamlining our structure in 2023, reducing costs where possible, and prioritising our core service of providing support to researchers in conducting twin studies. To continue our high level of service quality, however, it will be necessary to increase the cost to researchers of using TRA services.

TRA is a non-profit institute, and these changes will enable us to reach a break-even financial position.

## Community donations



The support of our community and the public has never been more important and appreciated.

We are very grateful to our members - twins, higher order multiples, and their families - who not only volunteer for studies, but also generously contribute the lion's share of public donations to our research. It is heartening to know that twins and their families are helping others in the multiple-birth community as well as all Australians.

Whether it is a one-off or regular donation, or planning a gift in your Will, all donations make a vital contribution to the sustainability of Twins Research Australia and to ensuring our research benefits many generations to come.

If you would like to know more about making a gift to our research, please visit [here](#).

## Business support

EasyDNA Australia has supported TRA and its members since 2018. We thank them most sincerely for their continued support in 2022. EasyDNA provides a discounted price for [zygosity testing](#) especially for TRA members. EasyDNA makes a small donation to TRA for each DNA test purchased by a member.