



2017 ANNUAL REPORT

1 January - 31 December 2017



Twin discoveries to benefit everyone's health

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About Twins
Research
Australia

Twins Research Australia (TRA) is Australia's only national twin research centre of excellence and maintains one of the largest volunteer twin research registries in the world. It both undertakes and supports twin research in institutes and hospitals across Australia and globally. Twins and their families make research possible by volunteering to be part of studies.

Based at the Melbourne School of Population and Global Health, University of Melbourne, the two main goals of TRA are: (1) to bring twins and researchers together to undertake health research to benefit everyone and (2) to advocate for and engage with twins and multiples.

Our vision

Our vision is for a vibrant and unified global twin research community to improve health and medical knowledge for the benefit of all humankind.

Our mission

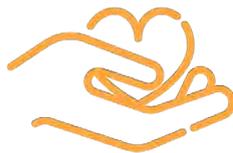
Our mission is to generate twin research that demonstrates how new knowledge can improve health and prevent disease.

Our values



Accountability

To be accountable to our members, our researchers, our supporters and each other.



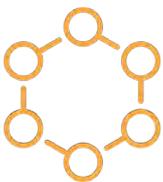
Integrity

To act honestly and ethically in the way that we conduct ourselves.



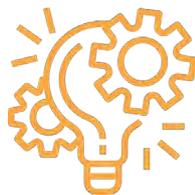
Excellence

To use our expertise, energy and resources to deliver best-practice, sustainable results.



Collaboration

To build and facilitate domestic and international connections within the twin, research and wider community to more effectively advance health and wellbeing.



Innovation

To find resourceful and inventive solutions to advance people's health and wellbeing.

Key activity areas

Twins Research Australia activities fall across three key objective areas: research, knowledge exchange and building research capacity.

1.

Research

- a. Conduct research:**
lead innovative twin research to accelerate research advances.
- b. Cost effectiveness:**
leverage cost efficiencies available through the application of the twin design and twin registry access.
- c. Enable research:**
provide access to participants, de-identified data, expert advice on research methods (twin model design) and twin data analytic services.
- d. Registry management:**
maintain and build a people bank of over 70,000 twin and family members willing to participate in research.

2.

Knowledge exchange

- a. Research community:**
translate knowledge in twin research and registry management to the research community through education programs and materials, publications and mentoring. Communicate study findings back to key stakeholders to influence policy and practice.
- b. Twin community:**
provide evidence-based resources and stimulate discourse on the experiences and needs of the twin and multiple-birth community.
- c. Wider community:**
contribute to the public discourse of the issues and challenges faced by twin and multiple-birth families.

3.

Building research capacity

- a. Education:**
teach, train, mentor and support researchers and students in research methods that harness the unique contribution of twins.
- b. Collaborative partnerships:**
build strong collaborations to increase research infrastructure and resources available to researchers internationally.



2017 highlights

Raising national awareness of twin research

National broadcast of twin research special on ABC-TV science program, *Catalyst*

Presentation of a community forum to encourage engagement between the multiple-birth community, researchers and health professionals

Launch of Melbourne and Sydney workshops for researchers in statistical analysis of twin data

35
Publications

Fast tracking research

10 studies conducted in 2017, including an innovative men's health project

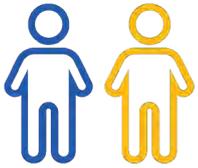
17 travel grants supporting researchers translating their work

Growing our membership

1,055 twin pairs & **9** triplet sets joined us this year

1,399 twin pairs approached in studies

Our lifetime impact



40,000

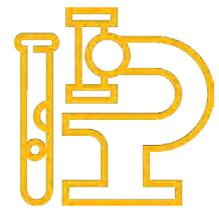
TWIN PAIRS ON OUR DATABASE

Nearly 17% of Australia's twin population volunteer for studies and help to fast track research.

Twin research has contributed to break-through knowledge into major health issues including diabetes, epilepsy, breast cancer, brain ageing, bone health, autism, children's education and learning.

240

STUDIES



120

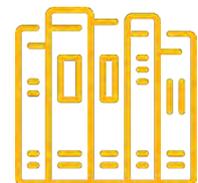
RESEARCHERS

Our researchers collaborate in universities, hospitals and institutes Australia-wide (and globally) to generate new knowledge in priority health issues.

We translate study findings into practice, policy and evidence-based resources for our communities.

1,180

PUBLICATIONS





Director's message

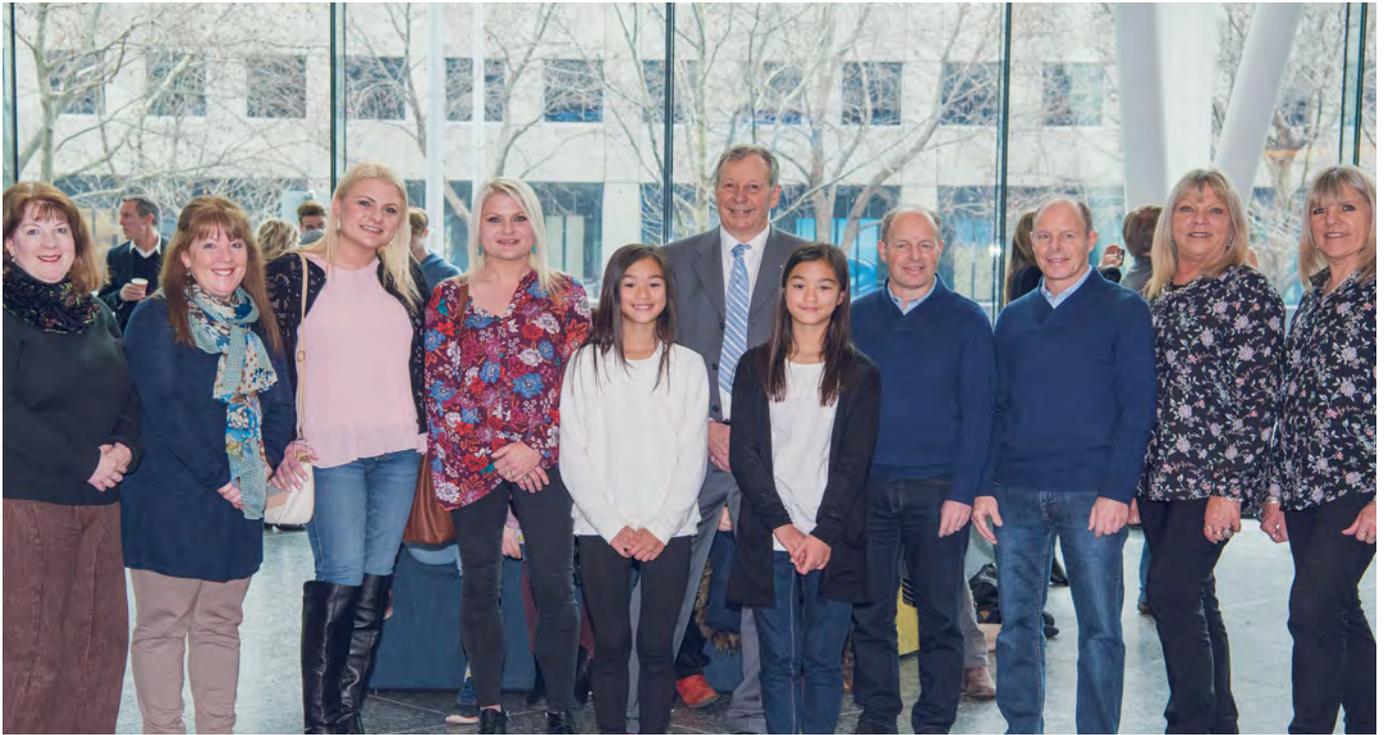
In 2017 we launched our new organisational name, Twins Research Australia, to encompass the Australian Twin Registry and to reflect our broader range of services.

This important step in the evolution of our organisation was taken to better represent the increasing diversity and depth of our work. Over the preceding years we have grown to become much more than a twin research register. We are now a driving force in conducting our own innovative studies and educating medical researchers Australia-wide about the power of twin research.

We are also taking an increasing role in advocating for the twin community through the seeding of research that studies the unique health concerns of twins and their families, and the development of evidence-based educational resources.

During 2017 we focused on strengthening our knowledge translation and research capacity. This saw the development of a knowledge translation plan, and involvement in the ABC-TV Catalyst program *It's a twin thing*. We also ran the successful public forum *Better health for twins and multiples: from conception to school and beyond*, where we were very pleased to have Keith Reed, CEO of Twins and Multiple Birth Association UK present the keynote speech.

This event was key to the development of new collaborations with clinicians, researchers and the multiple-birth community. It has resulted in the development of two white papers looking at the gaps in research knowledge in relation to the health and wellbeing of twins and their families.



Our focus on building research capacity saw the roll-out of successful workshops, in Melbourne and Sydney, called *Introduction to statistical analysis of data from twins*. We also conducted a series of presentations and meetings both nationally and internationally aimed at building stronger collaborative networks. At an international level this included Brazil, New Zealand, England and mainland Europe.

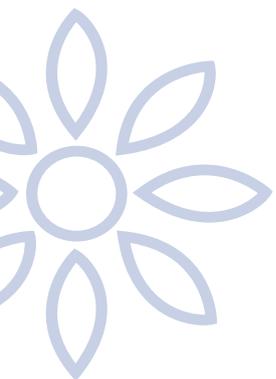
On the research front, 2017 saw TRA seed new studies in the areas of men's health, and educational outcomes of twins compared with singletons. TRA supported further research in the areas of exercise, speech and language, temperament, NAPLAN, ageing, bone health and autism. We also commenced our expansion towards becoming a twin and family registry.

The involvement of both twins and their families in studies has the potential to provide even greater insights in health and medical research, and is an exciting development which will provide us with enormous potential for future research.

2017 has been a year of enormous growth and change and I would like to thank our twins and their families, our research collaborators and our wonderful team of dedicated professional staff. The support and commitment of all our stakeholders have ensured the continuing success of Twins Research Australia.

Warm regards,

John Hopper
Director, Twins Research Australia



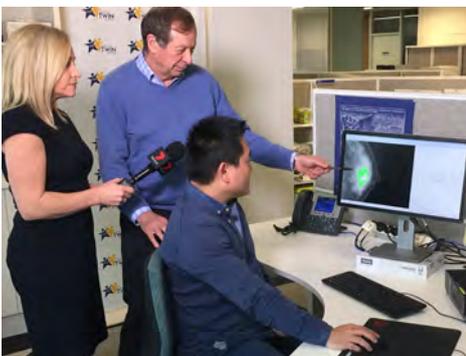


Research



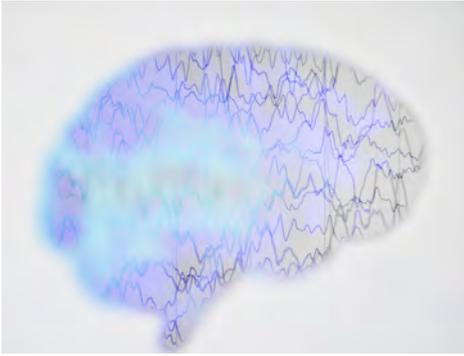
Research impact

To mark our 35th anniversary, University of Melbourne magazine *Pursuit* asked Twins Research Australia to nominate five of the most significant discoveries to come from its more than 230 twin studies.



Identifying the genetic and epigenetic risk of breast cancer

Through studying twin pairs, Professor John Hopper and his team identified the first gene that influences both mammographic density and risk of breast cancer (LSP1). This study also found a new epigenetic risk factor for breast cancer that is determined in the uterus.



Epilepsy can be inherited

Professors Sam Berkovic and Ingrid Scheffer from the University of Melbourne found a genetic basis to specific forms of epilepsy, transforming how epilepsy is defined and treated.



The environment in the womb impacts our future health

By comparing the level of epigenetic differences in identical and non-identical twins, Associate Professor Jeff Craig and his team showed that experiences in the womb help determine the epigenetic profile we are born with.



Healthy brain ageing

The longitudinal *Older Australian Twins Study*, led by neuro-psychiatrist Professor Perminder Sachdev, is following twins over the age of 65 to investigate healthy brain ageing. The researchers are uncovering novel findings about what causes brains to age faster, or slower, by comparing twins' lifetime of experiences in exercise, diet, smoking and so on.



Maths and reading skills are largely genetic

Professor Brian Byrne analysed the NAPLAN scores of about 3000 sets of twins in Years 3, 5, 7 and 9. His team discovered that up to 75 per cent of differences in children's abilities in maths, reading and spelling, and up to 50 per cent of their differences in writing skills, could be due to genetic differences.

For more on these studies, please read the [full Pursuit article](#).

TRA collaborative projects

CHeReL data analysis – are educational outcomes for twins different to those of singletons?

Katrina Scurrah, Natasha Nassar, Patrick Kelly, Justine Zeltzer and John Hopper

Twins are known to be at higher risk of poor developmental outcomes at birth in comparison with singletons, partly due to lower gestational age. However, less is known about the extent to which this higher risk persists into childhood, and whether this risk is due to twin-specific factors or to risk factors such as low gestational age and small size for gestational age (SGA), which are more common both in twins and in individuals with poor educational outcomes.

To investigate this, a Sydney-Melbourne collaboration involving TRA looked at educational outcomes using data from the NSW Perinatal Data Collection linked to school performance indicators from the National Assessment Program for Literacy and Numeracy (NAPLAN). This linkage was facilitated by the Centre for Health Record Linkage (CHeReL), which links multiple sources of data while maintaining a record linkage system that protects privacy.

Men's health project

Australian males experience poorer health compared with Australian females. They have a shorter life expectancy and are at greater risk of developing health problems such as lung cancer, heart diseases, respiratory diseases and stroke. These outcomes not only affect males, but also have a significant impact on their partners, children, families and society. Twins Research Australia has two projects planned to address factors contributing to poor health outcomes for males.

First, the *Men's Health* questionnaire will ask about a range of health and lifestyle topics including: life events, mental health, fertility, alcohol use, social supports, family and work life. Members of Twins Research Australia will be approached to participate in the survey. The data will be available in a de-identified format for ethically and TRA approved research projects.

Secondly, a collaborative project aims to look at how environments encountered by men of reproductive age modify their sperm, thereby affecting the next generation.

Children of twins: the effects of parental mental health on child mental health outcomes

Intergenerational transmission of mental health problems is an important area of research, with growing evidence of the increased risk of mental and behavioural problems in children of parents with a mental illness. While numerous studies have documented persistence between parents' and children's mental health, these often provide little insight into causal mechanisms underlying this relationship due to the difficulty of disentangling the genetic and shared family environmental components.

This project aims to address three questions:

- If parents experience poor mental health, how does this impact on their children's mental health?
- To what extent is any impact due to genes or environmental factors?
- If the impact is at least partially through environmental mechanisms, how much of it is mediated by parenting style?

Enabling
research



Enabling research

Twins Research Australia enables research through provision of expertise in study recruitment, access to twin and multiple participants, the maintenance of a registry, and access to de-identified research data.

There were 41 active and ongoing studies utilising TRA services and/or involving TRA members in 2017. This includes the active processing of eight expressions of interests (EOIs) for new research and two new research applications (as a result of approved EOIs) throughout the year. In total, there were 10 active recruiting studies with participants in 2017. TRA also provided ad hoc support to a further 17 studies in varying stages of study development, data collection, data analysis and writing up.

Please see next page for a list of actively supported studies.

Recruitment

Table 1. Number of studies supported by TRA in 2017 by status

Study Status	Number
Application (EOIs, Full Application, Protocol Change)	14
Recruiting	10
Data Collection/Data Analysis	7
De-identified Data Analysis	3
Writing Up/Publishing	7
Total	41

Actively supported studies

The below studies were actively supported by Twins Research Australia in 2017

Genetics of speech and language disorders

Professor Angela Morgan,
Murdoch Children's
Research Institute



Twins and exercise training study

Professor Daniel Green,
The University of Western
Australia

Older Australian Twin Study

Scientia Professor
Perminder Sachdev,
University of New
South Wales

Characterising differences between twins with or without Autism Spectrum Disorder (ASD)

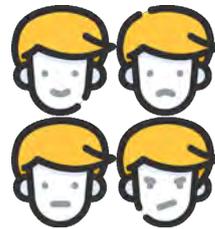
Emmanuel Pua, PhD candidate
Murdoch Children's Research Institute

Effect of menopause on bone structure in twins

Professor Ego Seeman,
The University of
Melbourne

Investigating the genetic and environmental factors contributing towards temperament in children

Eloise Cameron, PhD candidate
Murdoch Children's Research Institute



A twin study of the NAPLAN

Professor Brian Byrne,
Doctor William Coventry
University of New
England

Efficacy of a sleep quality intervention in people with chronic low back pain controlling for genetics: a preliminary randomised co-twin controlled trial

Associate Professor Paulo Ferreira,
The University of Sydney

Is caesarean delivery related to obesity and back pain in children and adolescents? A population-based study of Australian twins

Hercules Leite, The University of Sydney

Western Australia twin eye study

Professor David Mackay,
Lions Eye Institute

Study invitations

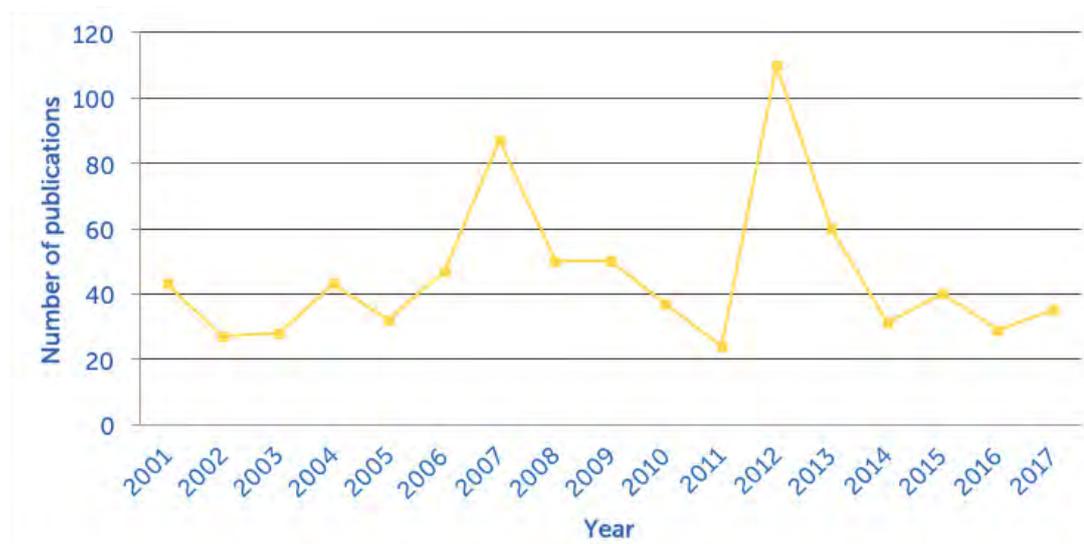
Mail-outs to prospective participants for individual studies are a core component of Twins Research Australia's daily operations. The scheduling of mail-outs, and total number of sent approaches, is dependent on the requirements of each research project.

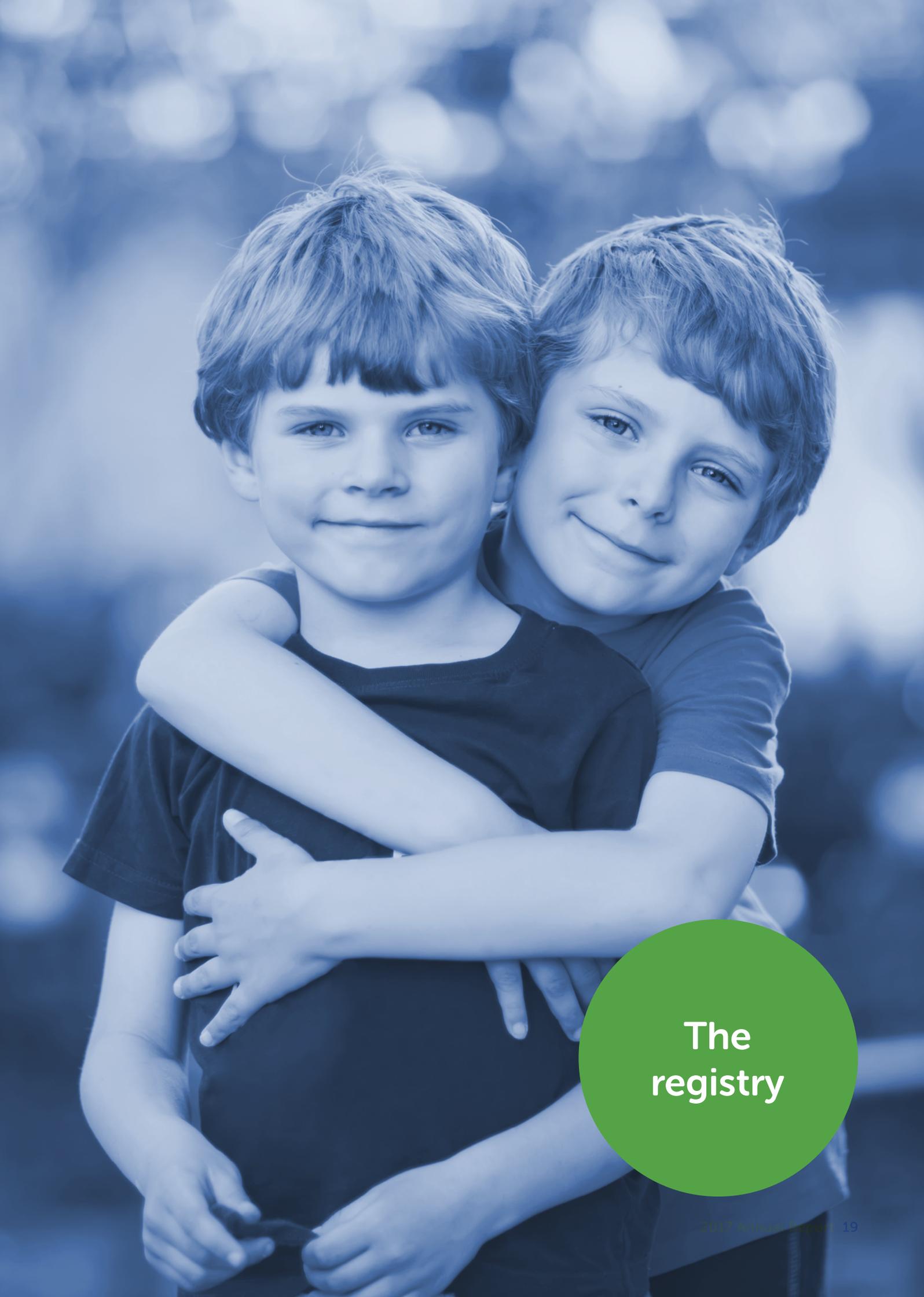
During 2017, 14 mail-outs were conducted and a total of 1,399 study invitations were sent.

Publications

An important measure of TRA's contribution to research is the number of publications arising from studies supported by the facility. In 2017, TRA recorded a total of 35 peer-reviewed journal articles. These arose from both collaborative and internal projects (Figure 2). There have been more than 700 publications in the last 15 years. TRA's CRE goal is to increase annual twin publications by 20 percent. The list of all 2017 publications can be found in the appendix.

Figure 1. Published Peer-Reviewed Journal Articles Twins Research Australia





**The
registry**



Twins and families' cohort

Twin families provide an excellent means to help unravel different causes of disease. Identical twins share 100 percent of their genetics while non-identical twins share on average 50 percent of their genetics.

They can act as controls for each other as they are matched for a lot of environmental factors as well. Including information from more family members will mean a greater range of genetic similarities as well as environmental differences and similarities. For example, a parent will share on average 50 percent of their child's genetics, as would a full sibling. The parent would have been raised in a different time and likely a different place while the sibling would likely have been raised within a few years of the twins and maybe in the same house.



In 2017, Twins Research Australia commenced its planned expansion of its twin registry to a Twins and Family Registry through the creation of the Twins and Families Cohort Study (TFCS) and the development and piloting of the TRA Family Questionnaire to families of twins under 18 years of age. The Family Questionnaire will be used to help twin and family research by learning about the relationships between twins and their family members.

This online questionnaire asks for basic information about biological and non-biological parents, guardians, siblings and children of twins. The questionnaire also asks for some contact information for any adult family members who may wish to join Twins Research Australia and for permission to add any children in the family to their membership.

Parents of twins have always been included in registrations. Parents, siblings and children of twins have been able to participate in several twin studies. The TFCS formalises the inclusion of family members as TRA members and will involve basic health and lifestyle data collection for these family members. Information on family factors, including genetics and shared environment, play a crucial role in the study of health and disease, therefore it is important for us to know as much as possible about our members' biological and non-biological family members.

Membership

Twins Research Australia's volunteer members are an integral part of the organisation, and management of the membership is a core component of its function.

Twins Research Australia undertakes a wide range of activities to keep its membership active and engaged. These include providing opportunities to update details on the website, eNews, printed newsletter, and via phone calls to the twins or their second and third contacts; and following up 'return to sender' mail from study approaches.

Two notable areas of engagement in 2017 were in the areas of social media and collaboration with ABC-TV's Catalyst program. These are detailed in the 'Knowledge Exchange' section on page 27.

Our members

Twins Research Australia maintains an up-to-date register of twins and higher order multiples (HOMs) - or in the case of twins and HOMs under the age of 18, their parents - willing to consider involvement in scientific studies.

Twins Research Australia continues to update and improve internal database processes and mechanisms to better assist staff in providing a cost effective and efficient service to twins and researchers.

Twins and HOMs - including triplets, quadruplets and quintuplets of all ages, sex combinations and zygosity - are eligible to enrol with TRA. In 2017, the database held data on 93,502 individuals representing 47,460 twin pairs and 458 HOM sets. Of these, 26 percent were juniors (<18years) and 74 percent adults (>=18 years); 41 percent were same sex female pairs, 33 percent same sex male pairs and 25 percent opposite sex pairs. In addition, 39 percent were identical (MZ), 57 percent non-identical (DZ) and four percent unsure of their zygosity. Members reside in all states and territories of Australia. In addition, 154 twin pairs identify as Aboriginal and/or Torres Strait Islander. This includes 107 junior pairs and 47 adult pairs; 67 identical pairs, 81 non-identical pairs and six of unknown zygosity.

Members of TRA are recorded under a specific status, depending on their current contact details and individual preference for involvement in research activities. The current status of members of TRA is summarised in [Table 2](#).

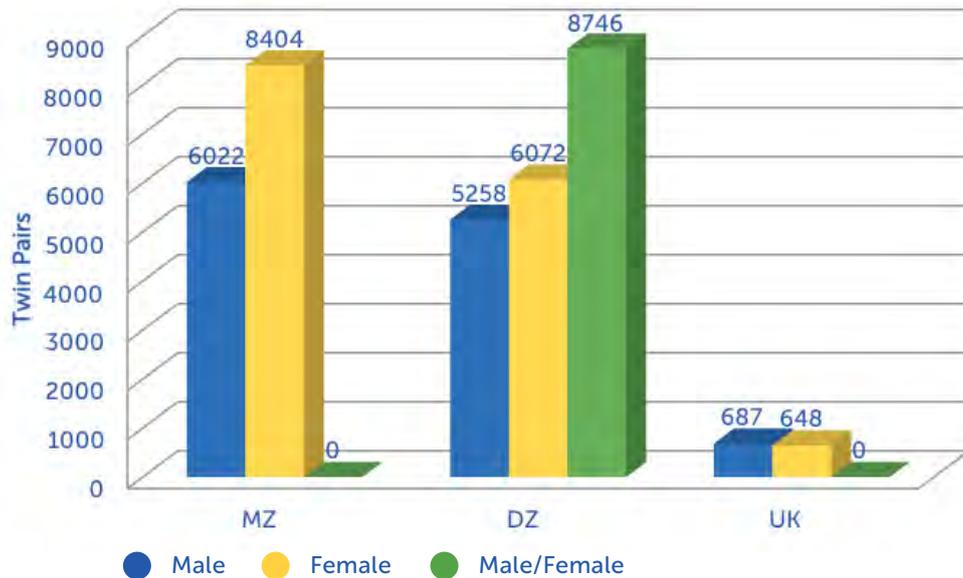
Table 2. Twin pair registration status

T1/T2 Status		Active	Inactive	Deceased	Lost	Total
Twin 2	Active	35,836	507	472	1614	38,429
	Inactive	534	1602	290	177	2603
	Deceased	431	247	601	70	1,349
	Lost	1563	110	73	3331	5,077
	Total	38,364	2,466	1,436	5,192	47,458
		Twin 1				

Active twin pairs by sex and zygosity

The current numbers of active twin pairs by sex and zygosity are shown in **Figure 2**. It includes individuals in a pair who have a registration status of: Active, Newsletter or Questionnaire.

Figure 2. Active twin pairs by sex and zygosity 2017



Distribution of active twin pairs

The distribution of active twin pairs by location is shown in **Figure 4** together with the overall distribution of the Australian population by state and territory (as reported by the Australian Bureau of Statistics in 2017) in **Figure 3**. Comparison of the two graphs shows that most populated states are also the states where most active TRA members reside.

Figure 3. Australian population by state and territory 2017

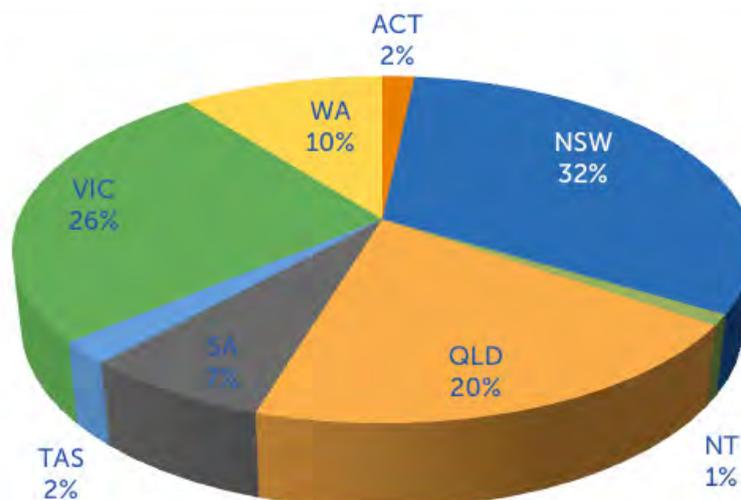
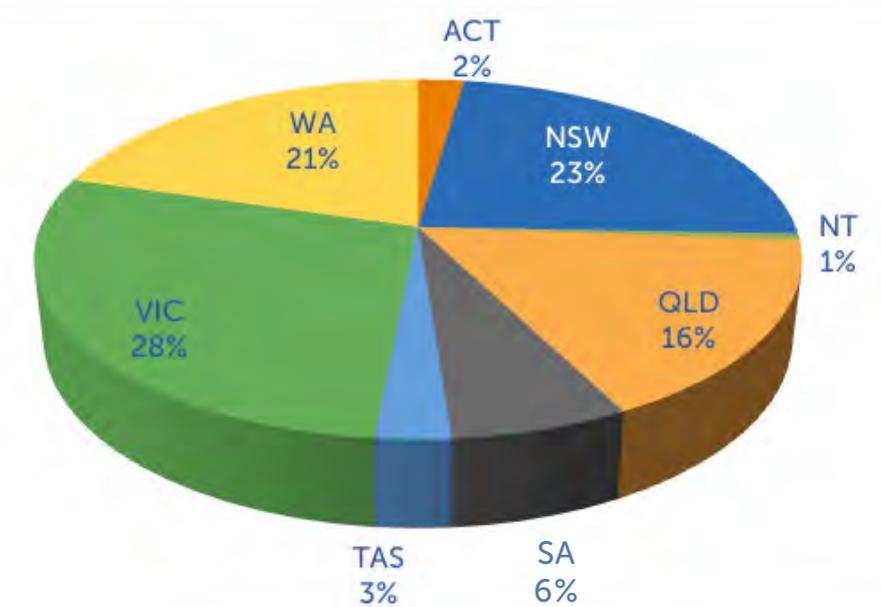


Figure 4. Distribution of active twin pairs by state and territory 2017



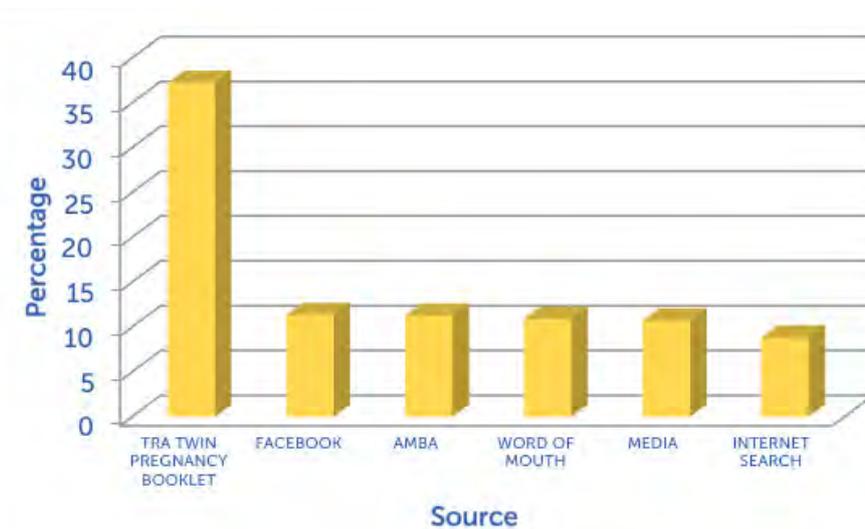
Recruitment

Continuous recruitment of new members is vital to ensure the future viability of TRA. In the reporting period 1 January 2017 to 31 December 2017 TRA recruited a total of 1,064 twin and HOM sets, a decrease from 2016 (1,385 twin and HOM sets recruited).

Sources

The internet continues to be the dominant means of registration (73 percent), as it was for 2016, with 26 percent recruited by phone (similar to 2016) and less than one percent via mail. Figure 5 shows the top six recruitment sources in 2017.

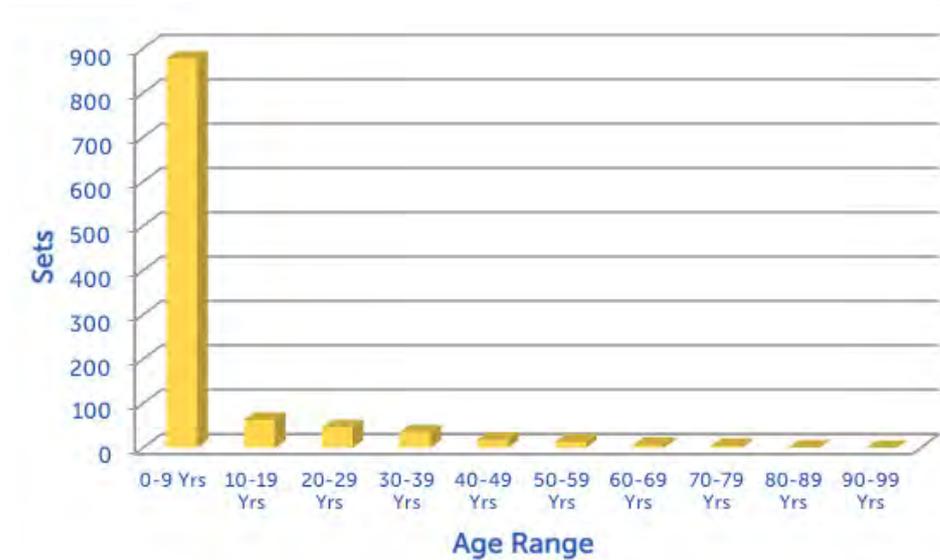
Figure 5. Registration ascertainment 2017: Major sources



Age range

As shown by Figure 6 the majority of new members (79 percent) enrolled with TRA during the reporting period were aged 0-9 years. This is consistent with the previous 20 years.

Figure 6. Number of active twin and triplet sets registered in 2017 shown by age range*

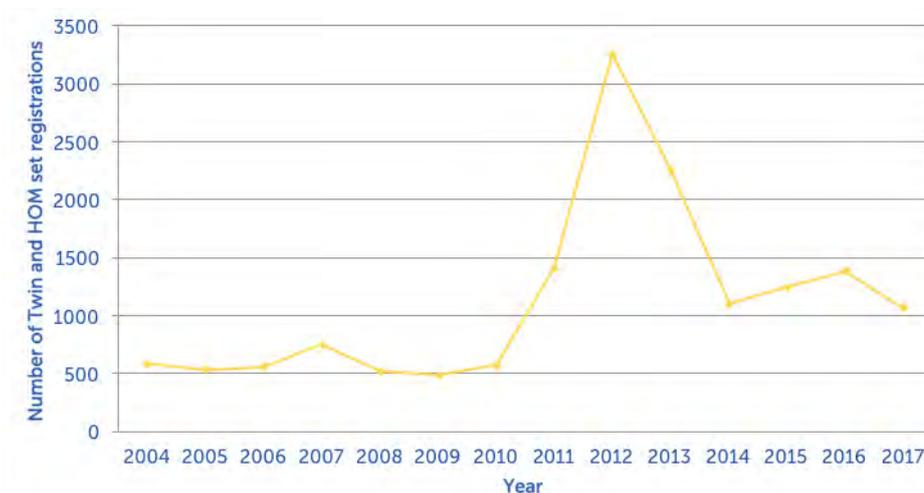


* Includes individuals who are alive and all individuals in the pair have a registration status of: Active, Newsletter, Questionnaire

New registrations by year

The numbers of new registrations by year since 2004 are represented in Figure 7.

Figure 7. Number of new twin and HOM sets registered with TRA by year since 2004

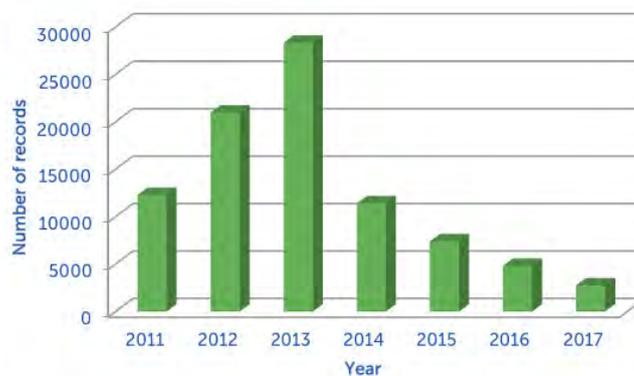


Updating records

The registry also undertakes proactive tracing of its members, this is an ongoing and important maintenance activity and ensures that the registry remains viable. In 2017 TRA maintained accurate information on 78 percent of its members. All prior addresses and any actions taken to trace members are recorded on the TRA database.

In 2017, a total of 2,759 individual twin and other contacts (i.e. parent or secondary carer) member records were updated in the TRA database. This includes instances where an individual record, address information or phone number/email address was edited; and those records followed-up due to receipt of a Return to Sender (RTS); and routine tracing or contact after a study approach has been sent. A count of all individual records updated yearly since 2010 is shown in **Figure 8**.

Figure 8. Individual records updated per year (2010-2017)

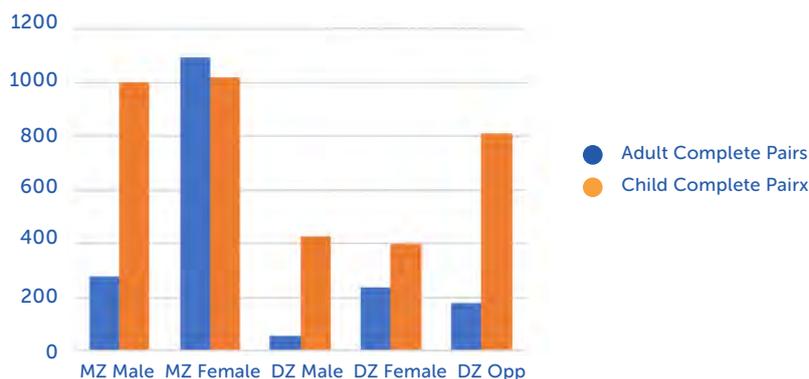


The health and lifestyle questionnaire

The Health and Lifestyle Questionnaire (HLQ) was launched in 2014, in part, to better describe TRA’s membership through the publication of summary statistics to both the twin and researcher communities. These statistics include zygosity, age, gestation term and medical conditions. The HLQ enables identification of potential participants for specific research studies to reduce costs to researchers and unnecessary approaches to ineligible TRA members. It also enhances fast-track research by providing de-identified data to researchers for ethically approved research analyses.

Invitations for the adult HLQ were sent to 386 individuals in 2017 and 155 of them participated. Invitations for the child HLQ were sent to 818 parents of twin child pairs and 144 of them participated. In 2017, more than five studies utilised information from the questionnaire to conduct targeted recruitment and formulate project plans.

Figure 9. Sex zygosity of members 2017





Knowledge
exchange



Our new name, logo and website

In 2017, Twins Research Australia became the new voice of the Australian Twin Registry. The name change reflects the growth of the organisation from a twin research register to a driving force in innovative studies as well as an education provider and knowledge broker for researchers.



TRA is also taking an increasing role in advocating for twins and addressing health research of specific relevance to them. A major aim is to empower twins to live happy and healthy lives by providing evidence-based educational resources.

The new logo reflects the organisation's proud heritage – the blue and yellow 'signature' colours of over 35 years. The 'entwined' twins form a heart, representing health; the twin bond that makes TRA research possible; and the diversity of TRA twin members.

These changes were accompanied by an updated website, providing improved and expanded content, easier navigation and other features for greater user engagement.

TRA's knowledge translation plan

Since 2015, Twins Research Australia has operated as an NHMRC Centre of Research Excellence, a funding program leaning heavily towards knowledge translation (KT) and implementation science. In response, TRA has developed a plan in collaboration with Public Health Insight as part of its efforts to drive knowledge translation in a more systematic way. This plan has aims, objectives, strategies and proposed activities in three main areas: stakeholder engagement, research capacity and knowledge translation capacity.

The knowledge translation plan is aligned with TRA's overall strategic plan and its positioning on future financial sustainability, including traditional funding programs and alternative pathways. It will create a common language around knowledge translation for TRA's internal and external purposes, while clearly documenting KT-related actions. It is anticipated the development of the KT Plan will help TRA strengthen its relationship with several stakeholders, especially researchers, clinicians and the twin community. As a result, it is also expected that TRA will be better positioned to support relevant changes in practice and policy to improve the health and wellbeing of twins and their families.



Community engagement

Twin community forum: Better health for twins and multiples from conception to school and beyond

Twins Research Australia joined with the UK's Twins and Multiple Births Association and the Australian Multiple Birth Association to present a half-day public forum on 13 October 2017. The forum aimed to provide pathways for engagement between the twin and multiple-birth community, researchers and health professionals. The event was part of TRA's overall objective to shape public conversations and policy-making to address the social and health inequalities of twin and multiple-birth families. It also provided a space for collective learning and sharing of knowledge specific to the Australian context.

Over 100 guests attended the forum at the University of Melbourne and, in a new initiative, the keynote address was live-streamed on Facebook, and watched by a further 2000 viewers. Presentations from the forum were recorded on video and will be released progressively via TRA's website and social media channels to ensure widespread sharing of the forum's outcomes.

Presenters at the forum included:

Keynote speaker, Keith Reed, CEO Twins and Multiple Births Association (TAMBA UK), *How can we best work together to benefit the lives of twins, multiples and their families?*

Professor Mark Umstad, Director of Maternity Services, Royal Women's Hospital Melbourne, *Current issues in managing multiple pregnancies and birth*

Dr Katie Wood, Clinical Psychologist, Swinburne University of Technology, *The psychology of rearing twin children*

Professor Karen Thorpe, Institute for Social Science Research, *Twin children's language, social development and transition to school*

Ashlee Tenberge, Chair of Australian Multiple Birth Association, *What support multiple-birth families need from Australian health services, researchers and government*

A highlight was an audience and expert panel discussion about the gaps, challenges and next steps in addressing the needs of twins and the multiple-birth community.

The development of a discussion paper is planned for 2018 to progress the ideas and issues discussed at the forum.

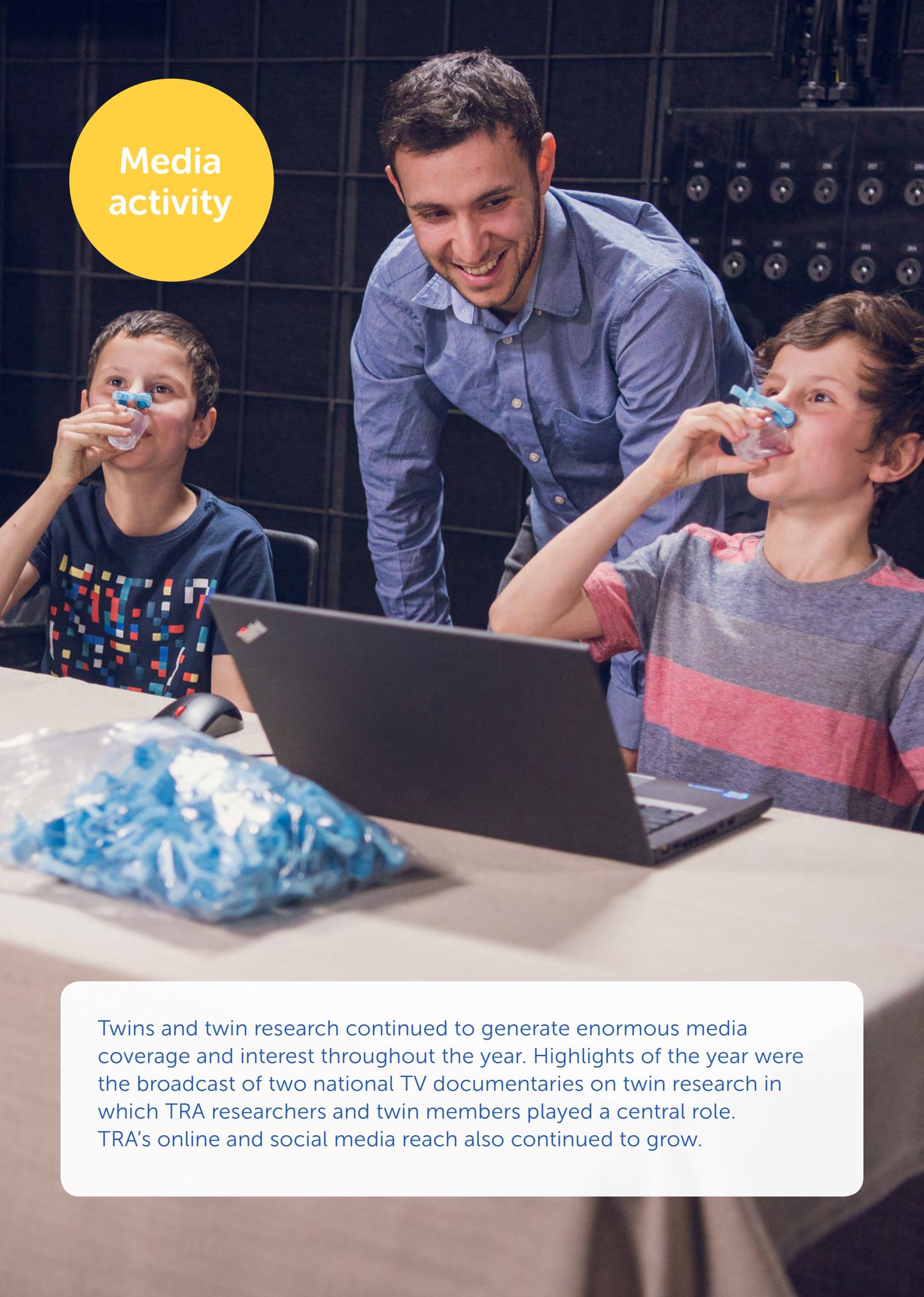


Twin pregnancy resources

TRA makes available a wide range of health resources to ensure findings from research are shared widely with relevant stakeholders.

One such popular resource is TRA's *Twin Pregnancy Booklet*. This free printed educational guide is distributed to around 1,000 expectant and new parents of twins Australia-wide, annually. This year a review of the booklet was coordinated by Deborah Osborne, a Master of Public Health student. She worked with experts in the fields of prenatal and neonatal care to ensure the guide reflected the latest evidence-based information and practices. The revised guide will be printed and available later in 2018.

Since the printed guide was first launched in 2011, there has been growing popularity in the use of digital resources, particularly mobile applications, to access twin pregnancy information. This has led to a review by TRA into other ways (in addition to its printed guide) that its twin pregnancy information could be delivered to potential users. Mobile applications and interactive websites are two such formats being investigated by TRA. Findings from the review will be available in 2018.



Media activity

Twins and twin research continued to generate enormous media coverage and interest throughout the year. Highlights of the year were the broadcast of two national TV documentaries on twin research in which TRA researchers and twin members played a central role. TRA's online and social media reach also continued to grow.



TV documentaries

SBS-TV's *Insight* program first broadcast a two-part series on twin research in March 2016. So popular was the series, called *Twins*, that SBS-TV chose to repeat it. It was broadcast for a second time on 18 and 25 July this year. The series looked at the valuable role twins play in helping us understand more about the health of everyone. Nine TRA researchers were guest panellists on the two episodes and discussed how twins 'open up new doors' to teach us more about what it is to be human. Public interest spread far beyond the actual TV show with further online stories about the series on SBS-TV and TRA reaching thousands of more viewers. Two posts about the series on TRA's Facebook alone reached nearly 100,000 followers. The series led to increased numbers of member registrations and expressions of interest in studies.

ABC-TV's premier science program, *Catalyst*, also broadcast a new documentary Australia-wide on twin research, *It's a Twin Thing*, on 31 October 2017. The documentary looked at why twins are so important to health research and was described by ABC-TV Online as follows:

"Twins for the past 35 years have been some of the most carefully studied people in Australia.

Over 70,000 twins have been revealing the secrets of how much we inherit from our parents and in what ways our experience shapes who we become.

Researchers are trying to understand what determines their personalities, makes them succeed at school or even live longer. It turns out that twins research is contributing to knowledge about what makes us who we are. We are a complex interplay of genes and environment. In fact, revealing the secrets of this extraordinary group of people may just help all of us live a longer, healthier life."

TRA researchers and members played a central role in the documentary. TRA recruited nearly 100 members to appear in an ABC-TV studio audience, and TRA researchers featured in the episode including Associate Professor Jeff Craig (epigenetics), Professor Mark Umstad (antenatal and neonatal care), Professor Bryan Byrne (education and learning), Professor Sarah Wilson (singing ability) and Professor Sam Berkovic (epilepsy).

Both the SBS and ABC documentaries remain on the websites of the respective broadcasters and continue to be viewed by more members of the public each week. They will also remain a valuable resource for TRA for public education well into the future.

Social media engagement

Digital and online media

TRA’s digital and social media activities continued to increase awareness of TRA and its research work throughout 2017.

A particular highlight was the release of the article on the University of Melbourne’s digital channel, *Pursuit*, about the “Five Discoveries We Can Thank Twins for”. The article achieved nearly 20,000 online views globally via the Pursuit channel. Interestingly, the article was not only well received by Australian audiences (57 percent of reader numbers) but also in the USA (24.5 percent) and other countries including the UK, Canada, Spain, India, Greece and Saudi Arabia. The article also received a reach of 58,161 followers on TRA’s own Facebook page.

TRA’s social media channels continued to gather follower numbers with Instagram (891 followers), Twitter (1,386 followers), Facebook (11,610 followers) and a LinkedIn profile. Of these, Facebook is TRA’s strongest social media channel in terms of followers, reach and engagement. TRA Facebook follower numbers increased by 26 percent in 2017 compared to 2016, and reach and engagement more than doubled – see diagram below.

Favourite Facebook posts included: promoting repeat of SBS-TV’s *Insight* episode on twins (reach 78,500); five discoveries we can thank twins for (58,700); fraternal twins can run in the family (64,200); triplets who are all obstetricians (54,600); treating twins as unique individuals (41,800); why one twin may be born smaller than the other (47,400); making twin births safer (33,100); why even identical twins can look different (36,100).

Facebook metrics 2017 January to December

Reach of 1,703,500	The number of people who were served any activity from our page including our posts, posts to our page by other people, mentions and check-ins.
Facebook followers increased from 9,162 (2016) to 11,610 (2017)	<p>90% of followers are women</p> <p>Overall</p> <p>26% aged 25-34</p> <p>38% aged 35-44</p> <p>15% aged 45-54</p>

Engagement – 151,136 post clicks; 36,526 reactions, comments and shares

Building
research
capacity





Key research capacity building activities

Twins Research Australia aims to develop and support projects and programs to build research capacity.

Scoping a trans-Tasman collaboration for a New Zealand Twins and Family Registry

In September, Kate Murphy, TRA's Deputy Director, began preliminary conversations with potential collaborators to establish a New Zealand (NZ) Twins and Family Registry. This initiative builds on opportunities to translate the twin registry model to countries without an existing registry.

NZ is well positioned to create a national research resource due to;

- A strong track record in conducting longitudinal population studies (Dunedin Study, and A Better Start)
- Access to the Integrated Data Infrastructure with the potential to link to registry members
- A population that actively supports research
- A national not-for-profit organisation supporting families of multiples, Multiples NZ, to assist with recruitment
- The percentage of multiple births in NZ being similar to Australia and accounting for 1.4 percent of all births in 2015

The establishment of a NZ Twin and Family Registry has great potential to address health issues relevant to the NZ and global population and we look forward to the opportunity to take this concept further in 2018.

European collaborations: twin registries and cohorts

In November 2017, TRA's PhD candidate Lucas Ferreira visited twin registries and cohorts in Europe to explore new ideas and collaborative projects. He met with staff members, researchers and leaders of the Danish Twin Register, Finnish Twin Cohort and TwinsUK. International initiatives involving aspects of sharing and linking data for future twin studies through the International Network of Twin Registries were discussed. Lucas has also visited the UK's Twin and Multiple Births Association, setting the background for the development of a white paper to identify issues faced by twins, multiples and their families in Australia, from pregnancy through to early life.

New initiatives in Brazil



Twins Research Australia continues to expand its collaboration with Brazilian researchers and institutions. In June 2017, Paulo Ferreira, Associate Professor, University of Sydney and Lucas Ferreira arranged meetings and presentations at large universities including UFMG (Belo Horizonte), UFMG (Diamantina) and UNICID (Sao Paulo). These researchers are now initiating a collaborative project with researchers in Australia, Brazil and the USA to look at lifestyle interventions to treat low back pain and lumbar disc degeneration disease. Future funding opportunities between Brazil and Australia were also discussed with local and national funding agencies such as FAPEMIG and CAPES.

Paulo and Lucas are also coordinators of the Brazilian Twin Registry, which was established in 2013 in partnership with Twins Research Australia. The collaboration is funded by an IRRTF grant from the University of Melbourne. For further details, please contact Lucas Ferreira at lucas.cf@unimelb.edu.au.

TRA's presence at the International Society for Twin Studies (ISTS) Conference 2017

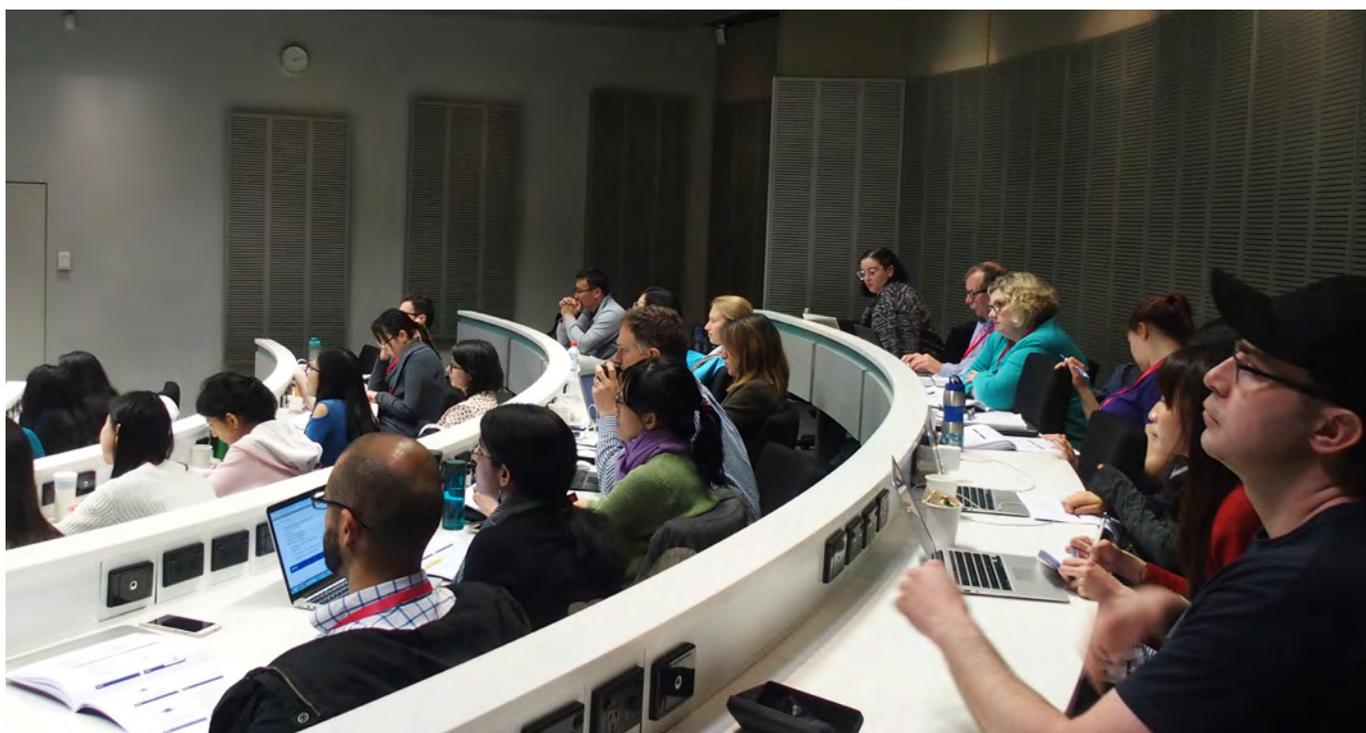
Jeff Craig (TRA's Deputy Director), Tess Cutler (TRA's Research Assistant), Lucas Ferreira and Shuai Li (TRA's PhD students) delivered a variety of oral and poster presentations in the most prestigious international conference in twin studies in November 2017. Their presentations in Madrid, Spain, included topics such as TRA's Knowledge Translation Strategy, the Health and Lifestyle Questionnaire and the collaboration between TRA and the Brazilian Twin Registry. Scientific talks from TRA's group included twin research topics such as epigenetics and DNA methylation as predictors of human traits and conditions. Jeff Craig was elected President of the International Society for Twin Studies (ISTS) at the meeting.

TRA Charles Perkins Centre (CPC) research project twin node/ University of Sydney

In August, Professor John Hopper and Dr Katrina Scurrah visited the CPC at the University of Sydney. The aim of the trip was to increase awareness of, and interest in, twin research from the statistical community and among medical researchers more generally.

The Sydney School of Public Health hosted Professor John Hopper and Dr Katrina Scurrah's presentation "Statistical methods for studies involving twins: recent applications and new approaches". This was attended by 30 people, with public health biostatisticians well represented.

The visit was very successful in terms of introducing and promoting versatility and utility of twin designs in epidemiology in general, and TRA specifically, to a wider audience. In particular it enabled Professor Hopper and Dr Scurrah to meet with leading statisticians and epidemiologists to further strengthen ties and to form the basis of future collaborations. It also provided an opportunity for current TRA collaborators to network with each other, statisticians and members of the TRA team. The new CHeReL data analysis project (see page 14) was one successful outcome of this visit.



Research education and early career researchers

Statistical analysis workshops: introduction to statistical analysis of data from twins

In 2017, Twins Research Australia officially launched its education program with the *Introduction to statistical analysis of data from twins* workshop. Designed and led by Dr Katrina Scurrah and Dr Gillian Dite, with contributions from Dr Enes Makalic, the workshop program aimed to build analytic skills in twin research within the wider research community.

The program covered exploration, analysis and interpretation of data from twin studies. The focus was on determining when and why particular statistical models and tests are appropriate; the assumptions underlying these; how these can be tested; and what the results of the models mean in the context of specific research questions.

The program was run twice in 2017, in Melbourne and Sydney, and was open to researchers of all backgrounds including students, though places were capped. These events were very popular, with 28 attending in Melbourne and 20 attending in Sydney, reflecting the demand for further training on twin analysis.

A workshop is planned for 2018 in Perth, WA.

Early-career researchers step up engagement with the new TRA ECR Group

During 2017, with the support of Twins Research Australia, a group of early-career twin researchers established the TRA Early Career Research Group, aimed at facilitating collective learning in various aspects of conducting twin studies. Members of the group work in a diverse range of health science domains and are using the twin methodology to improve the health and wellbeing of the population.

The group's second meeting was held in July 2017. Attendees included Masters, PhD and post-doctoral students from Australian universities and institutions including University of Melbourne, Murdoch Children's Research Institute, University of Sydney, University of Western Australia and Monash University.

To join the group or to know more about the initiative, please email the group's chair Namitha Mohandas at namitha.mohandas@mcri.edu.au.

Supervision of students by TRA Chief Investigators

MD

- Taylor Day, Murdoch Children's Research Institute (supervised by A/Prof Jeff Craig; supported by Dr Katrina Scurrah, Shuai Li)
- Alice Morgan, Murdoch Children's Research Institute (supervised by A/Prof Jeff Craig; supported by Dr Gillian Dite, Dr Katrina Scurrah)

PhD

- Anita Amorim, University of Sydney (supervised by A/Prof Paulo Ferreira, Dr Milena Simic, A/Prof Evangelos Pappas)
- Eduardo Caputo, University of Sydney (supervised by A/Prof Paulo Ferreira)
- Henri Dohnt, University of New England (supervised by Dr William Coventry, Prof Brian Byrne)
- Lucas Ferreira, University of Melbourne (supervised by Prof John Hopper, Dr Louisa Flanders)
- Kevin Ho, University of Sydney (supervised by Dr Milena Simic, A/Prof Paulo Ferreira, Ms Marina Pinheiro)
- Shuai Li, University of Melbourne (supervised by Prof John Hopper, Prof Melissa Southey, and Prof Richard Saffery)
- Gareth Lingham, University of Western Australia (Prof David Mackey, Dr Seyhan Yazar, Prof Robyn Lucas)
- Channa Marsh, University of Western Australia (supervised by Prof Danny Green; supported by Dr Katrina Scurrah)
- Namitha Mohandas, Murdoch Children's Research Institute (supervised by A/Prof Jeff Craig)
- Eloise Cameron, Murdoch Children's Research Institute (supervised by Dr Marc Seal; supported by Dr Katrina Scurrah)
- Ana Paula, University of Sydney (supervised by A/Prof Paulo Ferreira, Dr. Alison Harmer, Ms Marina Pinheiro)
- Emmanuel Pua, University of Melbourne (supervised by Dr Marc Seal; supported by Dr Katrina Scurrah)
- Mihiri Silva, Murdoch Children's Research Institute (supervised by A/Prof Nicky Kilpatrick, A/Prof Jeff Craig, Prof David Manton; supported by Dr Katrina Scurrah)

- Josh Zadro, University of Sydney (supervised by A/Prof Paulo Ferreira, Deborah Ashley); University of Melbourne (supervised Dr Katrina Scurrah, A/Prof Jeff Craig)

MSc

- Munkh-Erdene Bayartai, University of Sydney (supervised by Dr Justin Sullivan, A/Prof Paulo Ferreira)

MEpi

- Deborah Ashley, Murdoch Children's Research Institute (supervised by A/Prof Jeff Craig; supported by Dr Katrina Scurrah)

MPH

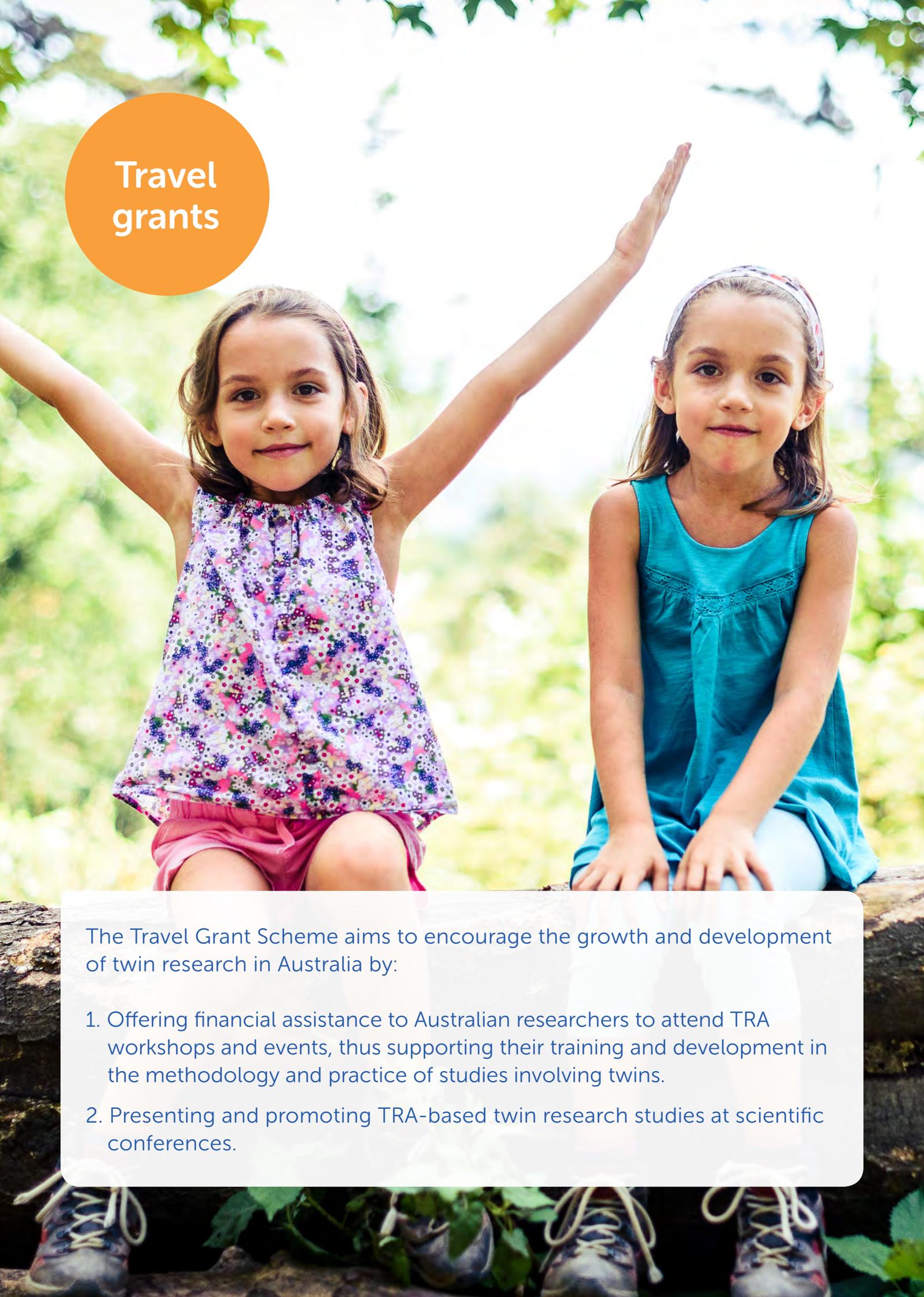
- Deborah Osborne, University of Melbourne (supervised by Lynette Walker, Jenny Boadle)

Honours

- Dayyan Gil, University of Sydney (supervised by A/Prof Paulo Ferreira)
- Emma Ho, University of Sydney (supervised by A/Prof Paulo Ferreira)

Postdoc projects

- Morgan Han, Murdoch Children's Research Institute (in collaboration with Prof Richard Saffery, supported by Dr Katrina Scurrah and Shuai Li)
- Pamela Leong (in collaboration with A/Prof Jeff Craig)
- Hercules Leite (in collaboration with A/Prof Paulo Ferreira)
- Callie Little, University of New England (in collaboration with Dr William Coventry, Prof Brian Byrne)
- Jane Loke, Murdoch Children's Research Institute (in collaboration with A/Prof Jeff Craig)

A photograph of two young girls sitting on a large log in a lush, green forest. The girl on the left is wearing a colorful floral top and pink shorts, with her arms raised in the air. The girl on the right is wearing a teal top and light blue pants, sitting with her hands on her lap. The background is filled with vibrant green foliage and sunlight filtering through the trees.

Travel grants

The Travel Grant Scheme aims to encourage the growth and development of twin research in Australia by:

1. Offering financial assistance to Australian researchers to attend TRA workshops and events, thus supporting their training and development in the methodology and practice of studies involving twins.
2. Presenting and promoting TRA-based twin research studies at scientific conferences.

Two rounds were held in 2017. Grants were awarded to support travel to general research conferences in June and to Twins Research Australia's workshop in October. Each received an overwhelming number of applications for travel to national and international research conferences.

Congratulations to the following recipients:

Round 1: General round

- Dr Ali Ghasem-Zadeh, Department of Medicine and Endocrinology, Austin Health, The University of Melbourne
- Dr Daniela Cisoto Ribeiro, Orthodontic Unit, The University of Adelaide
- Dr Katrina Grasby, Psychiatric Genetics, QIMR Berghofer Medical Research Institute
- Mr Kevin Ho, Faculty of Health Sciences, The University of Sydney
- Namitha Mohandas, Early Life Epigenetics, Murdoch Children's Research Institute (MCRI); Department of Paediatrics, The University of Melbourne
- Mr Reece Lavender, Psychology Department, School of Behaviour, Cognitive and Social Sciences, University of New England
- Dr Rico Sze Chun Lee, Brain and Mental Health Laboratory, Monash University
- Ms Ruby Tsang, Centre for Healthy Brain Ageing, The University of New South Wales

Round 2: TRA workshop and Madrid ISTS

- Munkh-Erdene Bayartai, Faculty of Health Sciences, The University of Sydney
- Dr Vibeke Sørensen Catts, Centre for Healthy Brain Ageing, School of Psychiatry, The University of New South Wales
- Shuai Li, Centre for Epidemiology and Biostatistics, Melbourne School of Population and Global Health, The University of Melbourne
- Dongli Liu, Centre of Advanced Sensory Science, School of Exercise and Nutrition Sciences, Deakin University
- Namitha Mohandas, Early Life Epigenetics, Murdoch Children's Research Institute/ Department of Paediatrics, The University of Melbourne
- Emmanuel Pua Peng Kiat, Melbourne School of Psychological Sciences, The University of Melbourne
- Sara Sarraf, Department of Pain & Palliative Care, Sydney Children's Hospital
- Dr Yi Ting Tan, Melbourne School of Psychological Sciences, Redmond Barry Building, The University of Melbourne
- Liza van Eijk, School of Psychology, The University of Queensland

Personal story

Shuai Li, Centre for Biostatistics and Epidemiology, The University of Melbourne



"I am grateful that the Twins Research Australia Travel Grant could support my attendance to the International Society for Twin Studies Conference between 16-18 November 2017 at Madrid, Spain.

With their support, I attended the conference and gave an oral presentation about my PhD research, titled "A Twin Model for Making Causal Inference: Applications to Observational Epigenetic Associations". In this presentation, I introduced a novel analytic method using data for twins to make causal inference about observational associations, "Inference on Causation through Examination of FAMiliaL CONfounding (ICE FALCON)", and its applications in my PhD to epigenetic data, using the observational association between DNA methylation and body mass index as an example.

This conference provided me a platform to introduce my PhD work to international academia and an opportunity to catch up with fellow researchers in twin research on epigenetics. By attending the conference, my presentation received several comments, which in turn improved my PhD project involving twins to research DNA methylation. The most direct benefit was perhaps being motivated by the recognition I received for my PhD work. I have published a research article on using ICE FALCON to investigate the potential causation between smoking and DNA methylation. Another article on body mass index and DNA methylation is currently under review. Through this conference, I also established an international collaborative project with researchers from Korea, which will be helpful to my transition from a PhD student to an early career researcher. Without the support from the TRA Travel Grant, these benefits were unlikely to be expected."

Liza van Eijk, School of Psychology, The University of Queensland

"Receiving the Twins Research Australia award gave me the opportunity to take part in the Twins Research Australia workshop 'Twin Statistical Methodology and Analysis' at the University of Melbourne on 26 September 2017.

In short, this workshop has provided me with the knowledge and skills for successful twin analyses. The course was outstanding. It was well-organized, and focused on the knowledge and skills I needed to get started with twin analyses. I also much appreciated the practical component of this course."



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people

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es


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**EXPECTING
TWINS?**



Our people

Twin Research Australia's system of governance ensures accountability, fairness and transparency with all its stakeholders. TRA comprises a leadership team of a director, deputy directors, chief investigators and associate directors from institutes around Australia, and is overseen by an advisory board.

We are supported by a team of passionate staff and administered by The University of Melbourne.





Advisory board members

Mr Vincent Pollaers, Chair, Advisory Board

Dr Paul Jelfs, Australian Bureau of Statistics, Australian Capital Territory

A/Professor Paul Lancaster, The University of Sydney, Honorary Associate Professor

Prof Margaret Otlowski, University of Tasmania

Mrs Karen Willetts, AMBA Representative, New South Wales

Ms Sue Carrick, Twin Representative, New South Wales

The TRA governance structure was reviewed in 2017. As a result of this review, the Advisory Board will be replaced in 2018 by a Stakeholder Advisory Group.

Chief investigators of the Centre for Research Excellence grant from the National Health and Medical Research Council

Professor John Hopper, ATR Director, The University of Melbourne

Associate Professor Jeffrey Craig, ATR Deputy Director,
Murdoch Children's Research Institute

Professor David Mackey, The University of Western Australia

Professor Stephen Simpson, The University of Sydney

Professor Brian Byrne, University of New England

Associate Professor Paulo Ferreira, The University of Sydney

Ms Susan Carrick, Charles Perkins Centre, The University of Sydney

The Chief Investigators are supported by Associate Investigators who bring additional skills and expertise, such as being a twin or parent of twins, corporate management, expertise in legal and ethical matters, policy and research translation, molecular epidemiology, obstetrics and perinatal data.

Associate Investigators

Professor Grant Townsend, dental health
Professor Elizabeth Sullivan, perinatal/maternal health
Professor Richard Saffery, molecular & cellular biology
Professor Brian Oldenburg, health policy
Professor Margaret Otlowski, health law
Karen Willetts, parent of twins
Professor Mark Umstad, obstetrics & perinatal data
Vince Pollaers, corporate management

Staff

John Hopper, Director
Jeff Craig, Deputy director
Kate Murphy, TRA Manager (Jan-Mar); Deputy director (March – Dec)
Jenny Boadle, TRA Study coordinator (Jan-Mar); TRA Manager (Mar-Dec)
Katrina Scurrah, Statistician
Lynette Walker, Marketing communications coordinator
Shaie O'Brien, Project support officer (Jan-Jun)
Sarah Stevenson, Research liaison and coordinator (Jun-Dec)
Angela Shi, Graphic designer
Janine Lam, Project support & administration
Tessa Cutler, Research assistant
Sally Savi, Member support
Jodie Lipman, Member support and administration
Lucas Ferreira, Research assistant
Sue Carrick, Charles Perkins Centre twin node
Ada Castle, Communication and project support (Apr-Oct)

Stakeholder satisfaction

The Annual Researcher Satisfaction survey is administered each year as part of the Annual Progress Report submitted by researchers. This questionnaire provides feedback to Twins Research Australia on their services to twin researchers, and an opportunity to improve on these services where possible.

The survey requests feedback relating to the previous 12 months on:

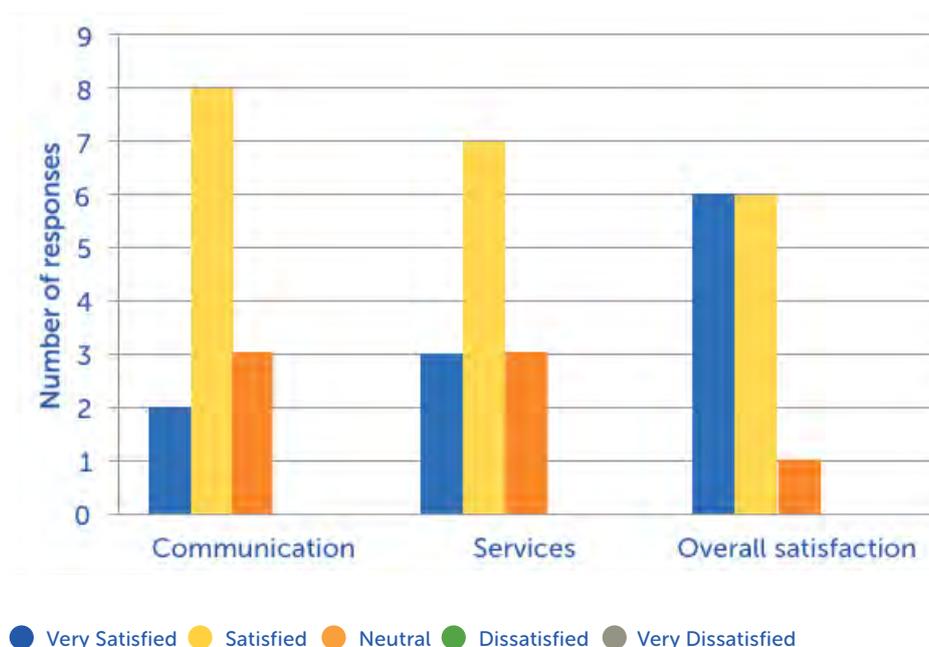
- The researcher's overall satisfaction with communication with the TRA;
- The researcher's overall satisfaction with the services that the TRA provided; and
- The value of the contribution that the TRA made to the overall research project

Responses are recorded as:

- 1 - Very Dissatisfied
- 2 - Dissatisfied
- 3 - Neutral
- 4 - Satisfied
- 5 - Very Satisfied

Twins Research Australia received feedback from 19 research groups for 2017. Overall, researchers were highly satisfied with the contribution provided by TRA and also the communication and service that TRA provided.

Figure 10. Overall Satisfaction Scores from Researchers:
Evaluating communication, services and overall contribution provided by the registry





Funding



Funding

Twins Research Australia is funded by a Centre of Research Excellence Grant (2015-2019) from the National Health and Medical Research Council. In addition TRA is reimbursed by external research groups for the costs involved in study development, recruitment and analysis.

Generosity of the twin community 2017 annual appeal

Twins Research Australia, like most medical research initiatives, relies on funding sources other than government to continue our vital services and to support the next generation of researchers. TRA's 2017 Annual Appeal resulted in 97 donations from our generous twin community. Money raised was directed towards the development of the research project, *Children of twins: the effects of parental mental health on child mental health outcomes*.

Gifts and bequests

Gifts and bequests in a person's Will are ways that TRA supporters can make a real difference to the future health of Australians. If you have any questions or comments, please call **1800 037 021** or email jboadle@unimelb.edu.au.





Appendix

Ageing

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