



# 2018 ANNUAL REPORT

1 January - 31 December 2018



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 wellbeing through new knowledge for the benefit of all humankind.

# 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 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 80,000 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 resources, publications and mentoring.
- b. Twin community:**  
provide evidence-based resources; advocate for their needs to influence policy and practice; and stimulate discussion on the experiences and needs of the twin and multiple-birth community.
- c. Wider community:**  
Communicate study findings back to key stakeholders to influence policy and practice. Raise awareness of the value of research to the wider community.

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 interdisciplinary collaborations to optimise new knowledge and availability to expertise and research resources nationally and internationally.



# 2018 highlights

## Research impact

25 publications

Reporting on findings into medical conditions such as addiction and drug behaviour, autism and ADHD, genetics and epigenetics, glaucoma, musculoskeletal, neuroscience and mental health, nutrition, and pain disorders – see appendix.

## Fast tracking research

9 studies conducted in 2018 including an innovative twin study into the genetic basis of singing ability

31 Australian and international institutes involved in our research

Over 18,000 invitations sent to twins to participate in our studies

## Supporting multiple-birth family health

Launch of national discussion paper, *Multiple Perspectives: What Support Do Multiple-birth Families Need to Live Happy and Healthy Lives*

Collaborating internationally through *The Global Twins and Multiples Research Priority Setting Partnership Project*

Expanding reach of our twin pregnancy resources

## Expanding twin research capability & capacity

Launch of revamped database and geocoding of all registry members

More workshops and resources for researchers including an online *Tool Kit for Twin Research*

13 travel grants supporting researchers in translating their work

# Our lifetime impact



**37,000**

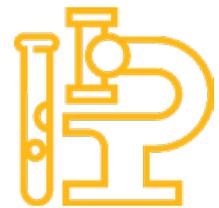
TWIN PAIRS ON OUR DATABASE

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.

**245**

STUDIES



**271**

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.

**1,205**

PUBLICATIONS



A portrait of a middle-aged man with grey hair, smiling, wearing a dark blue suit jacket over a light blue shirt. A yellow circle in the top left corner contains the text 'Director's message'.

## Director's message

In 2018, we strengthened the diversity and depth of our work with a special focus on community engagement and education programs for the research community. These initiatives enabled us to maximise our research impact for the benefit of the wider community.

Her Royal Highness, Crown Princess Mary of Denmark, herself a parent of twins, has been International Patron of Twins Research Australia since 2013 and we appreciate her support in raising awareness of our work. This year, she confirmed her ongoing patronage for another five years, much to the delight of TRA and our members.

On the research front, TRA led and enabled research from a wide range of disciplines including men's health, sleep, temperament, speech disorders, ageing and dental health. We are also currently gathering more information on the environment of potential participants for our research through the integration of geospatial data. This can inform us about a person's location relative to environmental factors and how this may impact health outcomes. This rich source of information provides another level of environmental

measurements to study. To date we have linked socioeconomic data to all members on our twin registry at a postcode level across Australia.

This year we have continued to move towards the expansion of TRA to encompass not only a twin registry but a *Twins and Family Registry* to provide greater research opportunities for family design studies.

A key to the increasing success of TRA is the open access of our national *Twins and Family Registry* to all researchers. We are also strengthening our training and educational programs for researchers and students from many disciplines and of varying skillsets across the country and internationally. In 2018 we began development of a series of online training modules in statistical analysis of data from twins to be released in 2019.



HRH Crown Princess Mary of Denmark, herself a parent of twins, has been International Patron of Twins Research Australia since 2013. In 2018, HRH confirmed her continuing support in this role.

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. We have led collaborations to identify priority research and gaps in health knowledge as determined by families of multiples, and to develop evidence-based educational resources to meet their needs.

During 2018 we worked on the creation of two new initiatives: firstly, a national discussion paper, *Multiple Perspectives: What Support Do Multiple-birth Families Need to Live Happy and Healthy Lives*; and secondly, *The Global Twins and Multiples Priority Setting Partnership Project*. TRA is demonstrating global leadership in the area of advancing the needs of twins and multiple-birth families.

2018 has been a year of enormous growth and change. Awareness of our research continues to grow through substantial media coverage and increasing engagement through our communication channels. 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  
 Director (Research),  
 Centre for Epidemiology and Biostatistics  
 Melbourne School of Population and Global Health  
 The University of Melbourne



A scientist with blonde hair in a ponytail, wearing glasses and a white lab coat, is focused on her work in a laboratory. She is using a pipette to transfer liquid into a multi-well plate. The background is a blurred laboratory environment with various pieces of equipment. An orange circle in the upper right corner contains the text "Our research".

Our  
research



## Overview

Twins Research Australia facilitates, conducts and enables research involving twins through our expertise in study design, twin and family recruitment, data analysis and maintaining membership and study data.

There were 62 active and ongoing studies utilising TRA services and/or involving TRA members in 2018. These studies were undertaken in 26 institutes around Australia as well as five international institutes.

Diagram 1. Location of TRA's active and ongoing studies



TRA's research work included the active processing of 13 expressions of interests (EOIs) for new research and 10 new research applications (as a result of approved EOIs) throughout the year. There were also nine studies actively recruiting participants and eight studies which had de-identified data transferred to them in 2018. TRA also provided ad hoc support to studies in varying stages of study development, data collection, data analysis and writing up.

Table 1. Total number of studies supported by TRA/involving TRA members in 2018 by status

Study Status	Number
Application (EOIs, Full Application, Protocol Change)	13
Recruiting	9
Data Collection/Data Analysis	12
De-identified Data Analysis	12
Writing Up/Publishing	16
<b>Total</b>	<b>62</b>

## Actively recruiting studies

The studies highlighted below were actively recruiting participants through TRA in 2018.



### Heart, Brain and Artery Health: Effects of Exercise Training

**Collaborators:** Professor Daniel Green at the University of Western Australia in collaboration with Ms Hannah Thomas, Ms Channa Marsh, Dr Louise Naylor, Dr Angela Spence, Mr Howard Carter, Ms Ceri Atkinson and Mr Andrew Haynes.

Exercise is known to improve health and wellbeing and to help prevent chronic illness such as heart disease, cancers, stroke and dementia. Recent evidence suggests some people respond to exercise more than others and that different people respond better to certain types of exercise. This project is looking at the genetic influence of exercise on the health of blood and whether different types of exercise can alter the level of health benefits.

An additional phase of recruitment and data collection was conducted for this study in 2018 with more than 10 new twin pairs getting involved.



## The AUstralian Twin BACK Pain (AUTBACK) Study

**Collaborators:** Associate Professor Paulo Ferreira at the University of Sydney in collaboration with Ms Ana Paula Silva, Dr Marina De Barros Pinheiro, Professor Kathryn Refshauge and Dr Manuela Ferreira.

This study aimed to investigate the effects of domestic, recreational, and work-related physical activity on the risk of low back pain in Australian twins using an innovative twin design approach that controls for genetic effects.

More than 170 twins joined the study in 2018, bring the total number since the study started to more than 300. During 2018, questionnaires and actigraphs (which measure activity) were sent to all new participants.



## Children of Twins Study

**Collaborators:** Dr Katrina Scurrah at the University of Melbourne in collaboration with Associate Professor Nicola Reavley, Dr Jinhua Li, Ms Janine Lam and Twins Research Australia.

This study is a pilot to test the feasibility of using a design, *Children of Twins*, to examine intergenerational transmission of mental health problems in Australia. It addresses three questions: a. Is parental anxiety and depression transmitted to offspring? b. To what extent is this transmission due to genes or environmental factors? c. If the transmission is at least partially through environmental mechanisms, how much of this transmission is mediated by parenting style?

Recruitment and data collection were completed for the pilot study in 2018 with nine twin pairs and their families involved.



## Face Perception: Who May Judge a Book by its Cover?

**Collaborators:** Professor Gillian Rhodes at the University of Western Australia in collaboration with Dr Clare Sutherland, Dr Nichola Burton, Dr Jeremy Wilmer and Dr Laura Germine.

By looking at someone's face, we make decisions about their character, including how trustworthy we think they are. The impressions we get from people's faces can influence important decisions in everyday life and this study aims to better understand the role played by genetics.

In 2018, 757 twin pairs were recruited to participate in the online questionnaire for this project. The researchers collected all data and have begun the analysis.



## TRA Men's Health Study

**Collaborators:** TRA's Professor John Hopper in collaboration with Ms Janine Lam, Dr Katrina Scurrah, Associate Professor Jeffrey Craig, Professor Tony Hannan, Professor Robert McLachlan and the TRA team.

The Men's Health Study aims to help research address factors contributing to poor health outcomes for males. It is a questionnaire developed for adult male TRA members and asks about a range of health and lifestyle topics including: life events, mental health, fertility, alcohol use, social supports, family and work life.

In 2018, TRA finalised the research plan and questionnaire, then conducted pilot recruitment and quality assurance with 25 twin pairs.



## TRA Health and Lifestyle Questionnaire (Adults and Juniors)

**Collaborators:** TRA's Professor John Hopper in collaboration with Ms Tessa Cutler and the TRA team.

The Health and Lifestyle Questionnaire is used to help research. It is a questionnaire developed for TRA members and asks about a range of topics including members' background, health conditions and lifestyle information. Recruitment, data collection and data use continued through 2018. This work is further highlighted below.

## The health and lifestyle questionnaire

The Health and Lifestyle Questionnaire 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.

In 2018, invitations for the adult HLQ were sent to 1,246 individuals, 230 of whom participated. Invitations for the child HLQ were sent to 1,130 parents of twin child pairs, 439 of whom participated.

At the end of 2018, a total of 19,689 adult individuals (including 7,574 pairs and 4,541 singles) and 11,725 parents of child twin pairs had been invited to participate in the HLQ. Of everyone invited, 7,117 adult individuals (including 1,928 pairs and 3,261 singles), and 4,826 parents of child pairs had completed the questionnaire.

Over the course of 2018, eight studies utilised data collected from the questionnaire to conduct their research projects. Each study used between 700 and 4,474 data records. HLQ data was also used to target study recruitment to appropriate people; to develop education materials for genetic epidemiology post-graduate level classes and twin statistical methodology workshops; and to provide examples for twin statistical methodology concept papers.

## Research impact

### Geospatial coding

In 2018, Twins Research Australia was able to team up with a geospatial research specialist from the University of New England to expand our data resource with geocoding. Dr Callie Little worked with TRA staff to geocode more than 50,000 addresses and match these to a range of area-based measures. Going forward, this will allow TRA to better describe our membership with data such as the *Health and Lifestyle Questionnaire* as well as making the resource available to researchers in a way that preserves the privacy of members.

### Tooth decay

A team of researchers, including Dr Mihiri Silva from the Murdoch Children's Research Institute and Dr Katrina Scurrah from Twins Research Australia, conducted a study on dental health. It looked at the teeth of 173 sets of twins from pregnancy through to six years of age. They found that tooth decay and cavities were just as different between identical twins as they were between other siblings which means that environmental factors determine cavities, not genetics. Evidence was found of a link between the mother's health and lifestyle during pregnancy and the child's future dental health, with obesity in pregnancy a marker for increased risk of child tooth decay, though the mechanisms behind this are believed to be complex and requiring further investigation.

## Studies of DNA methylation

PhD student Shuai Li, supervised by TRA director John Hopper, studied DNA methylation from seven studies previously conducted with twins and their families, including four studies facilitated by TRA. The combined data from these studies provided evidence that the variation in genome-wide average DNA methylation is mainly determined by environmental factors, including those shared by twins in the womb. Shuai's work also found that a twin birth makes lasting changes to the mother's intrauterine environment which means siblings born after a twin birth are correlated in their average DNA methylation. Another important insight from within- and between-pair analyses of twin and sibling data was that an apparent association between DNA methylation at the SOCS3 gene and body mass index is due to familial confounding.

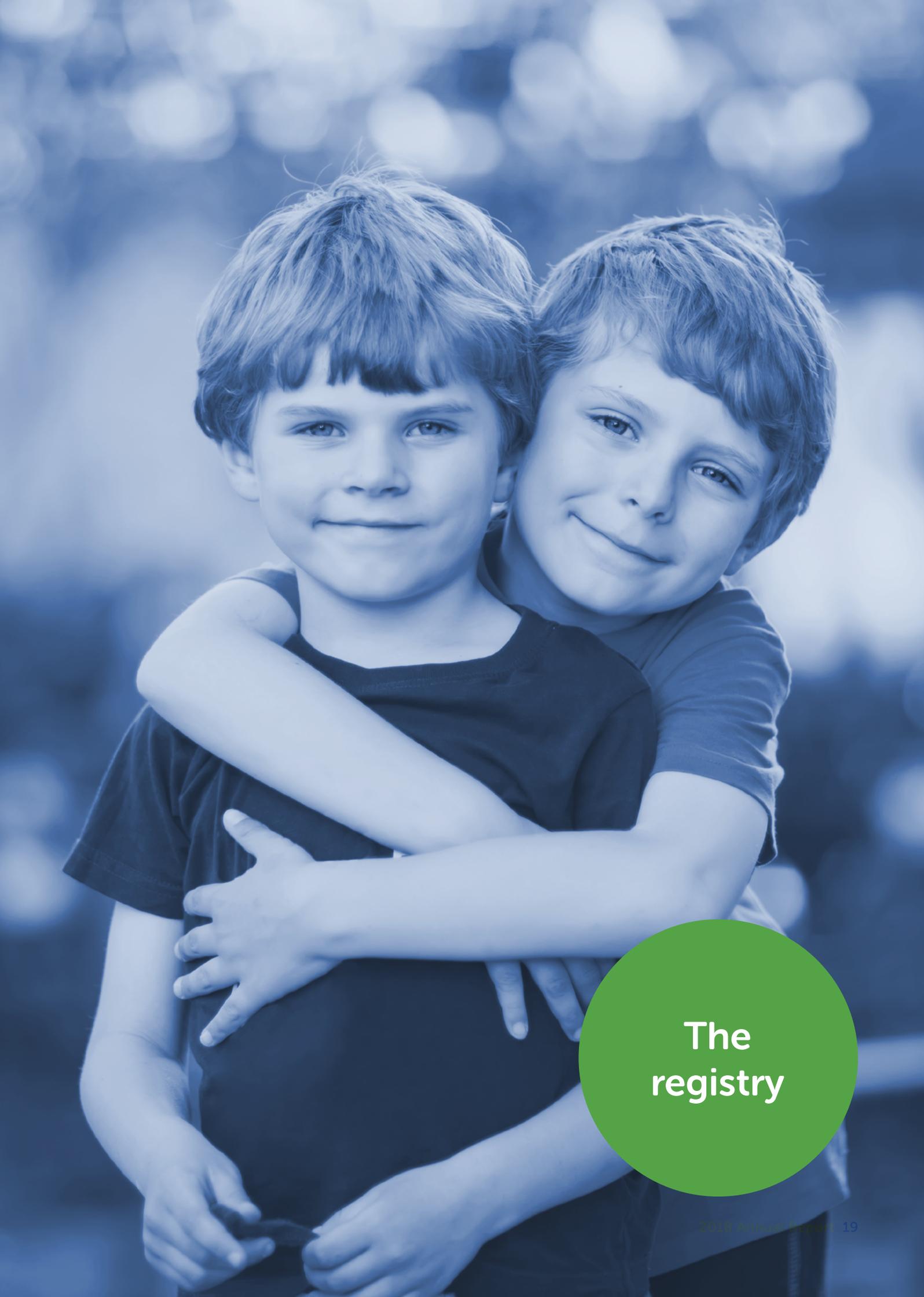
## Study invitations

Mail-outs to prospective participants for individual studies are a core component of TRA's daily operations. The scheduling of mail-outs, and the total number of sent approaches, is dependent on the requirements of each research project. During 2018, a total of 18,045 study invitations were sent for nine different studies.

## Database upgrade

Over the course of 2018, Twins Research Australia's membership database underwent a major revamp. The membership database had been in place for over 12 years, built on outdated software and had limited functionality and support. Developers at Kiandra IT worked with TRA staff and technical specialists at the University of Melbourne to create a new front-end that was released in October of 2018. This now allows TRA to more efficiently manage member, researcher and other stakeholder information and processes.





**The  
registry**



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.

TRA 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.

TRA undertakes a wide range of activities to keep its membership active and engaged. These include opportunities to update member details on the TRA website; receiving communications via eNews, printed newsletter or social media; phone calls to twins (or their second and third contacts); and following up 'return to sender' mail from study approaches.

TRA 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.

## Membership overview

Twins and HOMs – including triplets, quadruplets and quintuplets of all ages, sex combinations and zygosity – are eligible to enrol with TRA. In 2018, the database held data on 97,951 individuals of twin pairs and HOM sets, representing 48,273 twin pairs and 468 HOM sets. Of these, 74 percent are adult (18 years of age or older) twins/HOMs, and 26 percent are children (under 18 years of age) twins/HOMs.

Members of TRA are recorded under a specific status, depending on the currency of their contact details and individual preference for involvement in research activities. The current status of individual members of TRA is summarised in [Table 2](#) while the current status of twin pairs of TRA is summarised in [Table 3](#).

Of the active adult twin individuals, 20,067 have up-to-date email addresses listed with TRA. Of the active junior twin pairs, 10,395 have an up-to-date email address of at least one parent listed with TRA.

**Table 2. Registration status of individual twin/HOM members**

	Adults	Juniors	Total	Percent
Active	53,877	24,123	78,009	79.64
Questionnaire	975	91	1,066	1.09
Newsletter	508	12	520	0.53
Non-active/current	17,333	1,023	18,356	18.74
Total	72,693	25,258	97,951	100

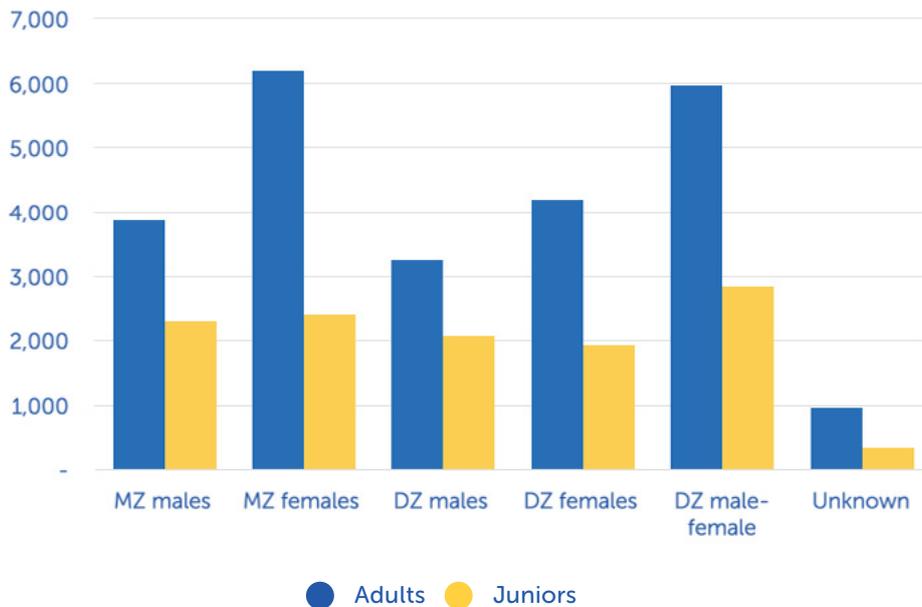
**Table 3. Registration status of twin pairs**

	Adults	Juniors	Total	Percent
Both active/ questionnaire	24,457	11,882	36,339	75.28
One active/ questionnaire	2,595	0	2,595	5.38
Neither active/ questionnaire	8,838	501	9,339	19.35
Total	35,890	12,383	48,273	100

## Active twin pairs by sex and zygosity

The current numbers of active twin pairs by sex and zygosity are shown in **Figure 1**. It includes both adult and junior twin pairs where both twins have a registration status of Active or Questionnaire. Of these twin pairs, 41 percent are identical twins, 56 percent are fraternal twins and three percent are of unknown zygosity. Thirty-four percent of these pairs consist of two males, 42 percent of two females and 24 percent of one male and one female.

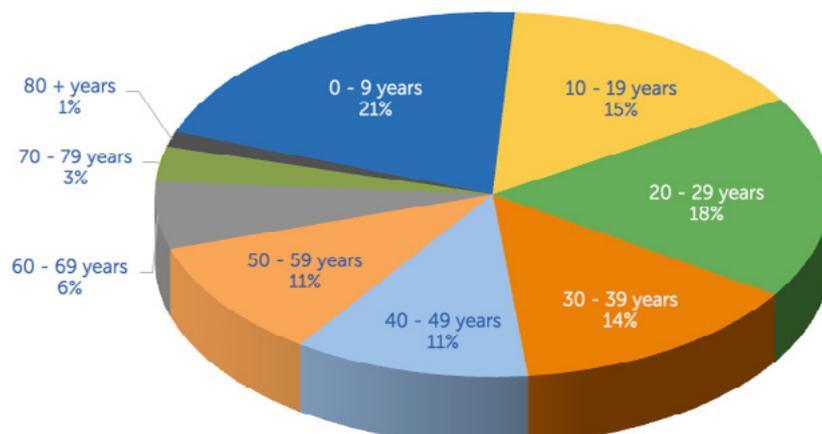
**Figure 1. Active twin pairs by sex and zygosity**



## Ages of active twin pairs

Parents of twins register themselves and their twin children from birth and members often stay active until the late stages of their lives. The distribution of active twin pairs by age groups is shown in **Figure 2**. Thirty-six percent of active TRA twin pairs are less than 20 years of age and 54 percent are aged 20 to 59 years of age.

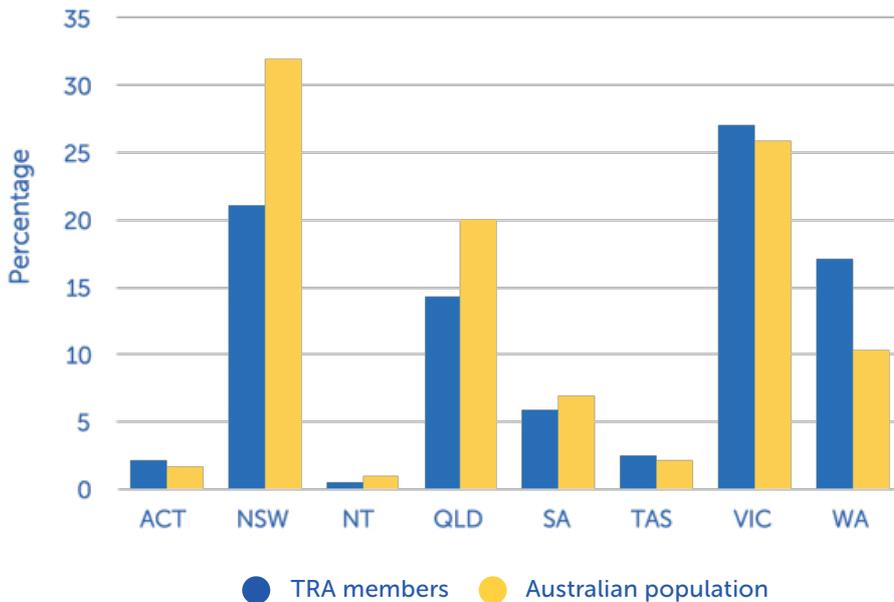
**Figure 2. Percentage of active twin pairs by age groups**



## Distribution of active twin pairs

Members reside in all states and territories of Australia. The distribution of active twin pairs by location is shown in **Figure 3** together with the overall distribution of the Australian population by state and territory (as reported by the Australian Bureau of Statistics in 2018). Comparison of the two groups shows that most populated states are also the states where most active TRA members reside.

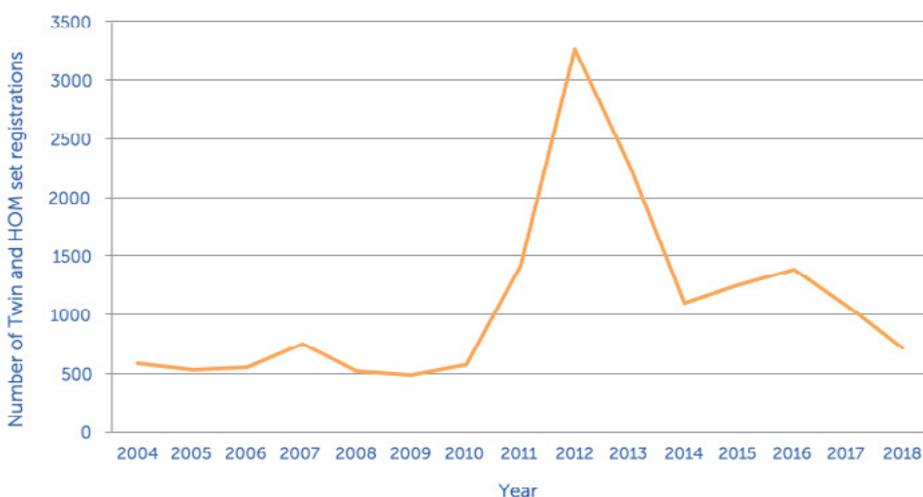
**Figure 3. Percentage of active twin pairs by states and territories compared with the Australian population (Australian Bureau of Statistics, 2018)**



## New member recruitment

Continuous recruitment of new members is vital to ensure the future viability of TRA. In the reporting period 1 January 2018 to 31 December 2018 TRA recruited a total of 717 twin and HOM sets, 701 of which were twin pairs. The numbers of new registrations by year since 2004 are represented in **Figure 4**.

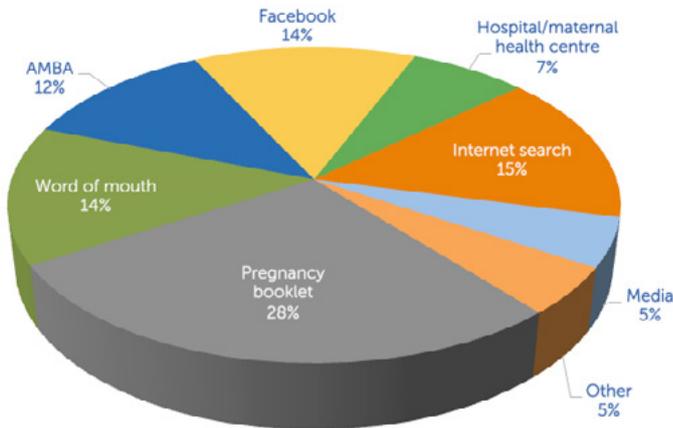
**Figure 4. Number of new twin and HOM sets registered with TRA by year since 2004**



## Sources of recruitment

The TRA *Twin Pregnancy Booklet* is the dominant means of registration (28 percent), followed by internet searches (15 percent), word of mouth and Facebook (both 14 percent), and the Australian Multiple Birth Association (12 percent). **Figure 5** shows each of the main recruitment sources in 2018.

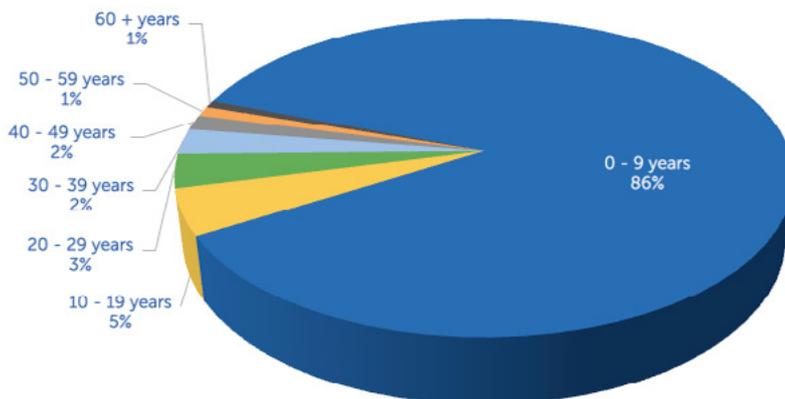
**Figure 5. Registration ascertainment 2018: major sources**



## New member ages

The majority of new members are enrolled by their parents with TRA in the first couple of years after birth. As **Figure 6** shows, 86 percent of new enrolments in 2018 were aged 0-9 years, with 81 percent of these aged 0-4 years. This is consistent with the previous 20 years.

**Figure 6. Age break-down of 2018 new member registrations**



## Updating records

TRA also undertakes proactive tracing of its members. This is an ongoing and important maintenance activity and ensures that the registry remains viable. In 2018 a new initiative was rolled out which saw more than 1,300 members update their email addresses. These are members who had a mobile number linked to their TRA record and they were sent an SMS asking them to update their email.



Knowledge  
exchange &  
engagement



## Overview

Twins Research Australia prioritises knowledge exchange and translation in its work to enable twin research to have impact in society. It has implemented a knowledge translation plan to ensure it engages with stakeholders in a structured and systematic way. This plan focuses on the twin community and aims to maximise the transfer of research outcomes to health policy and practice. It aligns TRA with community and funding organisations that expect knowledge translation to be at the forefront of all TRA's work .

# Stakeholder engagement

TRA has identified the following key stakeholder groups: twins and their families, researchers, educators, non-government organisations, end users and beneficiaries of research outcomes, governments and funders. TRA has developed a matrix to describe the depth of stakeholder engagement with TRA, and how to engage with the most relevant groups, to strengthen relationships and to ensure translational efforts are as effective as possible - see [Diagram 2](#). This process has allowed us to identify stakeholders with high power and high interest, high power and low interest or low power and low interest.

Diagram 2. TRA stakeholder matrix: depth of engagement or participation

Depth of engagement or participation <span style="float: right;">→</span>			
Inform	Consult	Involve	Collaborate
Provide balanced and objective information to assist understanding of the problem, opportunities and solutions.	Obtain feedback on analysis, alternatives and/or decisions.	Work directly with stakeholders throughout the process to ensure concerns and aspirations are consistently understood and considered.	Work together in all decision-making.
<ul style="list-style-type: none"> <li>• Broad mass media</li> <li>• Social media</li> <li>• Website</li> <li>• Newsletter to peak bodies</li> <li>• Webinar</li> <li>• Tailored communication products</li> <li>• Teaching</li> </ul>	<ul style="list-style-type: none"> <li>• Consultation on survey questions</li> <li>• Conference or forum</li> <li>• Knowledge broker</li> </ul>	<ul style="list-style-type: none"> <li>• Face-to-face meeting</li> <li>• Roundtable</li> <li>• Deliberative dialogue</li> <li>• Priority setting</li> <li>• Communities of practice</li> <li>• Thought leader support</li> </ul>	<ul style="list-style-type: none"> <li>• Strategic leadership group</li> <li>• Stakeholder advisory group</li> </ul>

- High power and high interest – *Look for opportunities for engagement at all levels*
- High power and low interest – *Strengthen awareness so that depth of engagement increases in later years*
- Low power and low interest – *Keep informed and look for opportunities to empower*

# TRA's knowledge translation programs

## Discussion paper: multiple perspectives

In November 2017, TRA conducted a one-day forum with researchers, clinicians and peak-body associations to discuss the needs of twins, higher-order multiples and their families. This event was a community-driven initiative designed to highlight potential ways to address social and health inequities of multiple-birth families. Key stakeholders came together to share and listen to each other's knowledge and experience.

Encouraged by the success of this initiative, it was decided to develop a discussion paper entitled [Multiple Perspectives: What Support Do Multiple Birth Families Need To Live Happy And Healthy Lives?](#) in collaboration with the Australian Multiple Birth Association, the Twin and Multiple Births Association UK, and the International Council of Multiple Birth Organisations. This paper aims to stimulate discussion, identify recommendations, and influence practice and policy-making in Australia. It also brings the twin and multiple-birth community closer by providing them with an opportunity to voice their concerns.

## Global twins and multiple-birth priority setting partnership

Launched in 2018, the Global Twins and Multiple Birth Priority Setting Partnership brings together parents, carers, clinicians and scientists to identify the top 5-10 priorities for research in twin and multiple-birth health. This initiative is being led collaboratively by Twins Research Australia, Twins and Multiple Births Association UK, and St George's University of London.

The partnership aims to reduce twin and multiple-birth mortality and morbidity, and to improve long-term health outcomes of multiple-birth babies and their families. Priority-setting initiatives are potentially powerful and useful, as they guide national and international research funding policies. They also give more validity to research questions by considering the views of parents, carers, clinicians and scientists.



In 2018, the first of two surveys asked for stakeholders' opinions on the unanswered research questions, or "research uncertainties", they thought were most important. In 2019, a second survey will then ask stakeholders to rank the research uncertainties they deem most important. The top 5-10 priorities will be determined at a final workshop.

There has been much research and development around the health of single-birth babies, but this does not necessarily reflect the unique needs of multiple-birth babies and their families. This partnership aims to ensure the voices of twins, HOMs, parents, carers and professionals are at the forefront of future research and practices that benefit the multiple-birth community.

## Conversations in twin research: highlighting twin research to external stakeholders

*Conversations in Twin Research* is an ongoing [series](#) of papers highlighting twin-related issues of public importance. TRA's aim is to produce a freely available series of short papers written by experts, using accessible language. To date, TRA has published six papers covering topics such as the importance of zygosity knowledge, understanding early-life origins of chronic disease, twin research design methodologies and conducting clinical trials in twin populations.



## Twin pregnancy guide

An ongoing popular resource is TRA's *Twin Pregnancy Booklet*. This free printed educational guide (also available as an eBook) is distributed to around 1000 expectant and new parents of twins Australia-wide each year. Following a review in 2018, a revised version of the booklet has been developed and will be printed in late 2019. This updated guide will reflect the latest evidence-based information and practices from experts in the field. As well as its popularity with expectant parents, the booklet is being increasingly used in as a resource for hospital prenatal classes and tertiary teaching institutes in nursing.

TRA also undertook a review into other delivery channels (in addition to its printed guide) to increase the reach and use of its twin pregnancy resources. The review recommended the development of a microsite embedded within the TRA website to deliver online resources. This will enable TRA to provide added information and features in a cost-effective way, and a more flexible, accessible and sustainable delivery channel. A framework for the microsite will be developed in 2019 – with content initially based on the booklet content - with its launch expected towards the beginning of 2020.

## General resources

TRA's comprehensive [website](#) is central to its communication/translational efforts for members and the broader twin community. Website updates were undertaken during the year to improve navigation to TRA's most popular resources and to provide a better mobile-friendly interface.

Other main communication/translational platforms are TRA's social media channels, quarterly eNews, study invites and feedback, and phone-assist service. All twins and parents of twins who participate in studies receive study-specific feedback. Facebook is TRA's strongest social media channel in terms of followers, reach and engagement – growing by 12.2 percent in 2018 to over 13,000 followers.

A new initiative in 2018 was the launch of a blog page, [Twins Impact](#), on TRA's website covering issues of interest to members and the broader twin community. The page features stories, opinions and news from researchers, experts, partners, members and staff. Blogs covered issues such as: the benefits of multiples in research; whether to keep twins together or separate at school; twin children's language and social development; the psychology of raising twins and multiples; and different types of twinning.

A further highlight was the launch of a special series called *We are: Twins Research Australia* across TRA's social media channels. In a series of short stories, twins and their parents shared insights into their unique lives. Developed by a team of volunteer science communication students from the University of Melbourne, the series aimed to increase awareness of the special challenges faced by twins; to provide an opportunity for twins to connect with each other; and to inspire other twins to join TRA. Its popularity had led to TRA continuing it as a regular feature on its social media.

## Media activity

Twins and twin research continued to generate substantial media coverage and interest throughout the year. This coverage is important to increasing awareness in the broader community about the value of twin research to population health. Highlights of the year included media interest into the findings of TRA-supported research at Deakin University into people's [fat taste sensitivity](#) and how this might impact on weight gain; a world first study investigating the relative [roles of genetic and environmental influences on singing ability](#); and [why twins live longer](#).

Building  
research  
capacity &  
capability





## Overview

TRA's aim is to make twin research a standard part of the repertoire of population health researchers by building their capacity and capability, and facilitating collaborative research.

While playing an active research role itself, TRA openly promotes the registry and its data resources to all researchers. Across all disciplines, TRA offers researchers an established infrastructure and access to an increasing 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 its website.

## Research supervision, training and education programs

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. TRA aims to build capacity and capability in twin research through traditional and non-traditional educational training, professional development, and mentoring activities that are integrated with other TRA activities.



TRA conducts a highly successful workshop for researchers, *Introduction to Statistical Analysis of Data from Twins*. It focuses on teaching the basics of statistical analysis of data from twins in a straightforward and statistically rigorous way that is accessible to researchers from all disciplines. The program covers exploration, analysis and interpretation of data from twin studies. The focus is 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.

To date we have presented three successful workshops in Melbourne and Sydney (2018) following the first workshop in Perth (2017). By holding the workshops around Australia, research teams can access hands-on help they wouldn't otherwise receive plus strengthen their relationships within research teams, domains and institutes.

We also build capacity through TRA-supported scholars and fellows supervising research students as well as providing workshop support for students. The research students are also given training and opportunities in statistical consulting and collaboration (as appropriate depending on skills). In 2018 TRA supervised six Masters, four Honours and 16 PhD students (see list below).

As a means of providing a national reach and peer-to-peer support, TRA has formed a Twin Researcher and Statistics Group using a social media platform to enable further teaching and learning from more experienced twin researchers. This group is aimed not only at early career researchers but all researchers new to, or interested in increasing their knowledge of, twin studies. Researchers and students can also subscribe to TRA's free Researcher eNews to stay informed of major global and Australian studies; training and events; and new published papers and other resources.

We have also begun the creation of a comprehensive online education and resource portal providing access to an online toolkit for researchers. This Tool Kit for Twin Research will include code for analysis of data in multiple standard software packages including R, SAS and Stata; and written and video materials such as tutorials based on existing workshops.

## Collaborations and networks

Collaboration is essential to the way TRA conducts all its activities. TRA seeks to generate and foster enduring relationships with collaborators across all of its networks. By doing this, it is ensuring twin research has maximum impact on the wellbeing of society. Key partnerships include the establishment of the *Twin Node at the Charles Perkins Centre* at the University of Sydney.

TRA also actively participates in international collaborative twin research. It has played a key role in establishing and supporting the International Network of Twin Registries, and provided data to large international consortia.

TRA continues to support the development of the Brazilian Twin Registry, the first national twin registry in South America

# 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)

## 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, A/Prof Jeff Craig, Dr Louisa Flander)
- 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 (supervised by 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)
- Hannah Thomas, 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)
- Deborah Ashley, Murdoch Children's Research Institute (supervised by Dr Katrina Scurrah and A/Prof Jeff Craig)
- Josh Zadro, University of Sydney (supervised by A/Prof Paulo Ferreira)

## MBiostats

- Carl Higgs, University of Melbourne (supervised by Dr Katrina Scurrah, Dr Enes Makalic)
- Xi Su, University of Melbourne (supervised by Dr Gillian Dite and Dr Katrina Scurrah)

## MEpi

- Nancy Tran, University of Melbourne (supervised by Dr Katrina Scurrah and Dr Enes Makalic)

## MPH

- Janine Lam, University of Melbourne (supervised by Dr Katrina Scurrah and A/Prof Nicola Reavley)
- Jess Tyler, University of Melbourne (supervised by Dr Gillian Dite and Dr Katrina Scurrah)

## Postdoc projects

- 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 patterned top and pink shorts, with her arms raised in the air. The girl on the right is wearing a teal sleeveless top and light blue pants, looking directly at the camera. 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.

## TRA grants 2018

One travel grant round was held in 2018. TRA received an overwhelming number of applications both for travel to national and international research conferences. Grants were awarded to support travel to general research conferences in Boston, Boulder, Dublin, Sydney, and to the *Twins Research Australia Workshop in Statistical Methodology and Analysis in Perth*.

Travel grants were awarded to a total of 13 recipients, representing eight institutes throughout Australia and one in the USA.

Congratulations to the following recipients.

### Round 18: general round

- Ana Paula de Moura Campos Carvalho Silva, Faculty of Health Sciences, University of Sydney
- Brittany Leigh Mitchell, Genetic Epidemiology Department, QIMR Berghofer Medical Research Institute and Queensland University of Technology
- Channa Marsh, Sport Science, Exercise and Health, University of Western Australia
- Hannah Thomas, School of Human Sciences, University of Western Australia
- Islay Davies, Queensland Brain Institute, University of Queensland
- Javad Jamshidi, Neuroscience Research Australia, University of New South Wales
- Kate Fairweather-Schmidt, Human Behaviour and Health Research Unit, Flinders University
- Miranda Chilver, Gatt Resilience Group, Neuroscience Research Australia, University of New South Wales
- Namitha Mohandas, Murdoch Children's Research Institute, Department of Paediatrics, University of Melbourne
- StellaMay Gwini, Barwon Health, Research Directorate
- Toyin Olumolade, College of Health Professions, Central Michigan University
- Victoria O'Callaghan, Queensland Brain Institute, University of Queensland

## Personal stories



Lucas Ferreira, Centre for Epidemiology and Biostatistics,  
Melbourne School of Population and Global Health, University of Melbourne



“Since arriving in Melbourne from Brazil to conduct my PhD project under supervision from Prof John Hopper, A/Prof Jeff Craig and Dr Louisa Flander, TRA has been very supportive of my candidature while also providing financial support for travel costs to present my work in Australia and overseas.

Due to the nature of my thesis titled, *The Challenges of International Collaboration in Twin Research*, it made sense to work closely with TRA to gather valuable understanding of how collaborative research occurs in international twin research. My project also investigated the many aspects of establishing and running a successful twin registry, and my engagement with TRA provided me with additional insights that will be hopefully valuable to other researchers and research groups wanting to create twin registries and studies across the globe. Finally, TRA has supplied me with hands-on knowledge that has been tremendously useful in working with colleagues on the challenging task of maintaining a volunteer twin registry in Brazil.

It has been an amazing experience to follow closely TRA's work in enabling and supporting a variety of twin studies in Australia. It gave me substantial understanding of the depth and breadth of twin studies and how they can be such an important tool in any health researcher's repertoire. I would recommend any health researcher to know more about twin research and how TRA can potentially help in how to address research questions more efficiently with twin studies.”



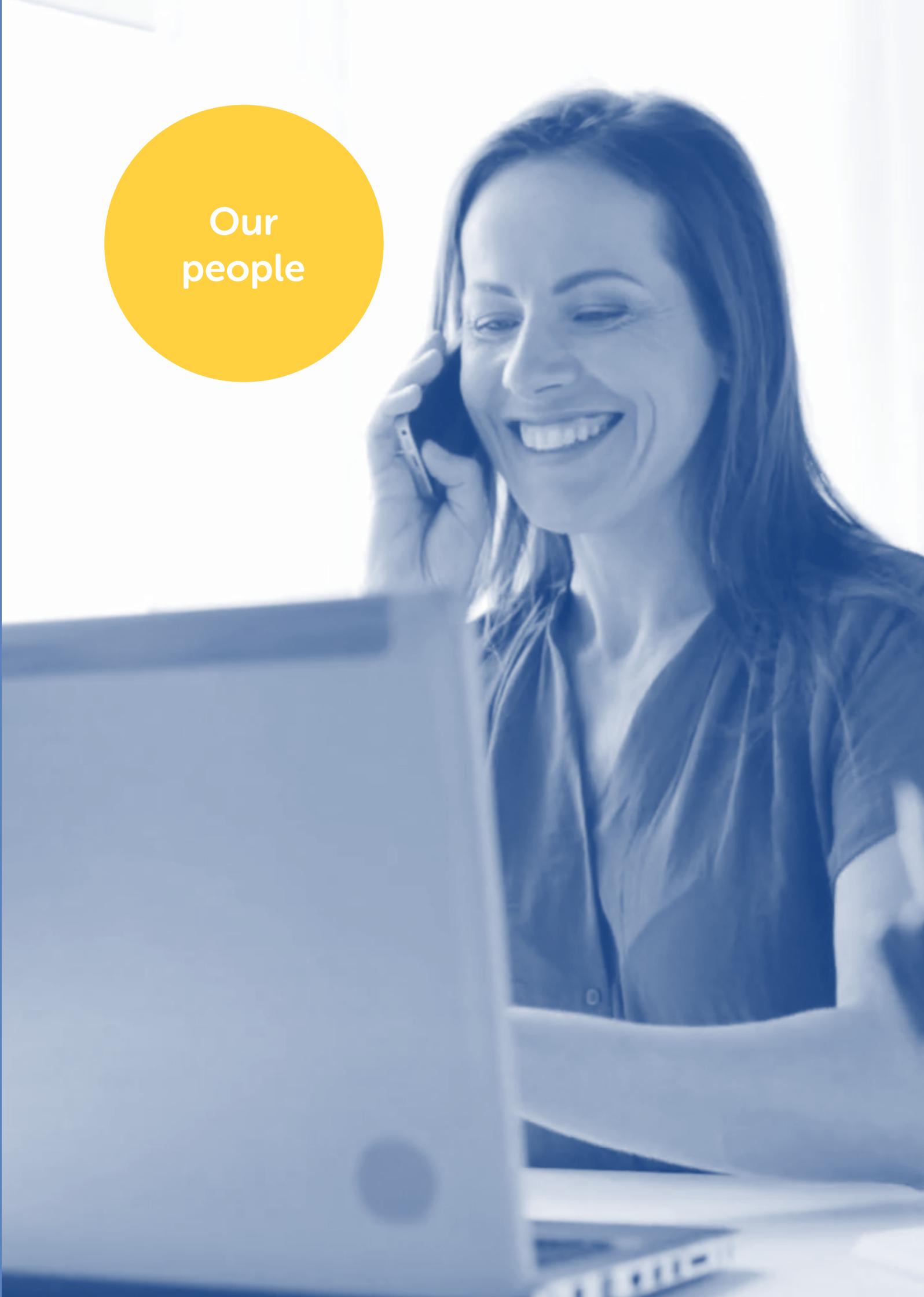
"I attended the *International Workshop on Statistical Genetic Methods for Human Complex Traits* in Boulder, Colorado, as a premier workshop covering twin study analysis methods. The workshop was scheduled for March 2018, which was perfect timing as it meant I could learn everything I would need for my PhD at the very start of my degree.

My favourite lecture was when all the faculty members took turns telling us about their research. To me, this was the most interesting as you could see how all the techniques we had been learning over the week could be put into practice and used to answer fascinating research questions. The skills I learnt at the workshop now allow me to do the same. For my PhD I am planning to investigate the genetic and environmental influences on the relationship between sleep disorders and depression. I will utilise a twin design and conduct a multivariate ACE or ADE model which will tell me the heritability of both disorders, as well as the relationship between them.

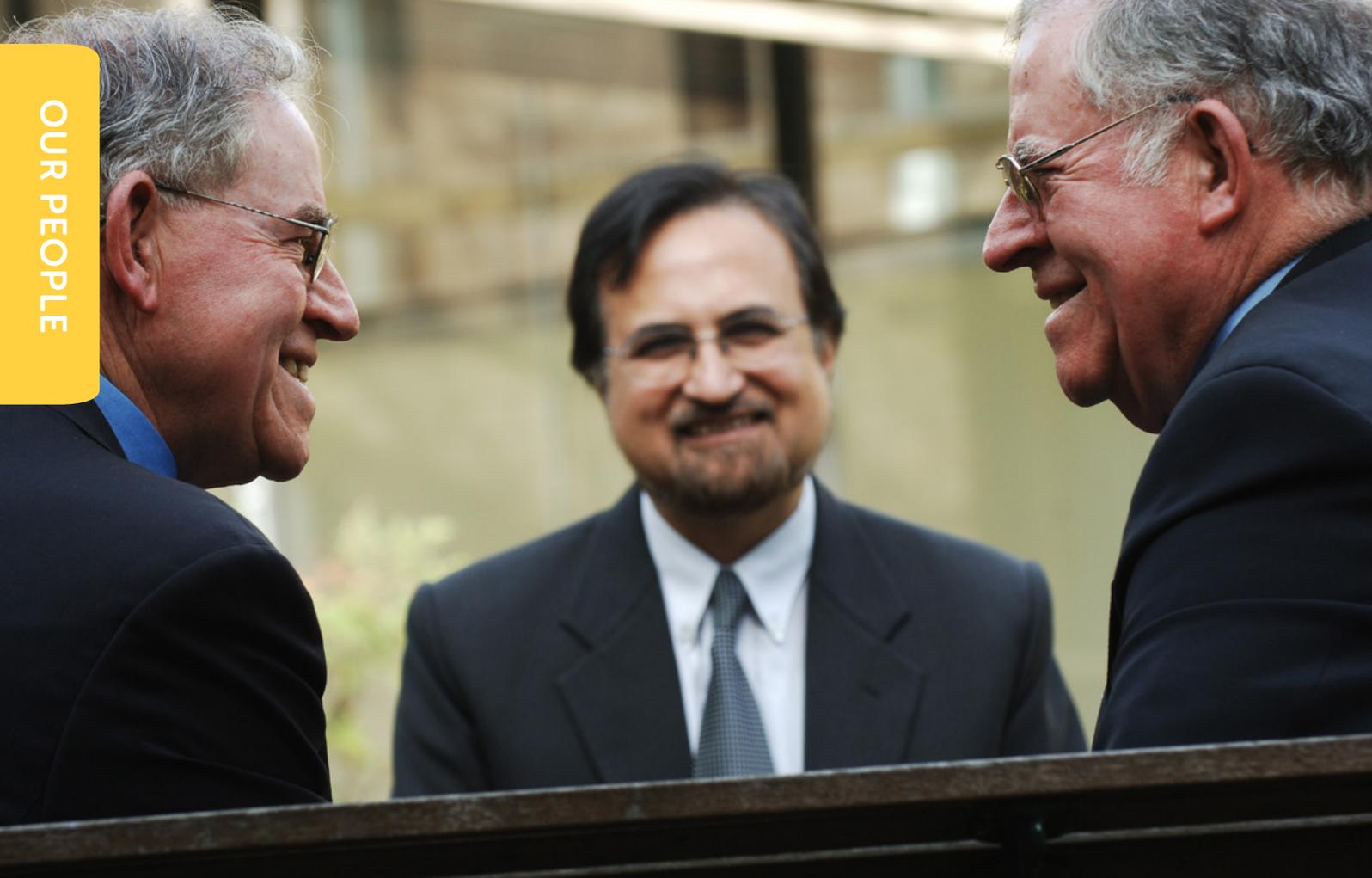
The other great thing about the workshop was that there were many receptions after the workshop lessons, during which we were encouraged to speak one-on-one with both faculty members and other students. This was a truly rich experience which has given me much insight into the world of twin research. The faculty members were quick to offer friendly advice, as well as much needed encouragement! I was told this huge networking event may even lead to future positions as apparently a lot of current faculty members met their post-doc supervisors at the workshop.

On a more personal note, I also made great friendships during the week, particularly with students from other institutes including some at overseas universities. I expect this will be highly beneficial for future collaborations. As well as this, I have now built a strong support network with like-minded students who will be going through similar situations at similar stages in our careers.

I thoroughly enjoyed my time at the *International Workshop on Statistical Genetic Methods for Human Complex Traits* and definitely recommend it to anyone starting out in the field of twin research. I would like to strongly thank Twins Research Australia for its financial contribution, which enabled me to attend this highly valuable and career-boosting workshop."



Our  
people



## Our people

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

TRA is also committed to developing long-term, mutually beneficial partnerships with research, community and corporate organisations that share its goals and values. Our partnerships reflect our local, state and national spheres of influence. Of particular note during 2018 was TRA's collaborations with TAMBA, AMBA and ICOMBO in a global multiple-birth priority setting project; linking with EasyDNA to provide affordable zygosity testing for our members; and involvement in the Population Health Research Network, a national collaboration to bring together existing research data for potential sharing for future research.

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

Professor John Hopper, TRA Director, University of Melbourne  
Associate Professor Jeffrey Craig, TRA Deputy Director, Deakin University  
Professor David Mackey, University of Western Australia  
Professor Stephen Simpson, University of Sydney  
Professor Brian Byrne, University of New England  
Associate Professor Paulo Ferreira, University of Sydney  
Ms Susan Carrick, Charles Perkins Centre, 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 of Research  
Kate Murphy, Deputy Director of Operations and Strategy  
Jenny Boadle, TRA Manager  
Katrina Scurrah, Statistician  
Lynette Walker, Marketing Communications Coordinator  
Sarah Stevenson, Research Liaison & Coordinator (Jan-July)  
Tessa Cutler, Research Assistant (Jan-July); Research Liaison & Coordinator (Aug-Dec)  
Janine Lam, Project Support & Administration  
Jodie Lipman, Member Support and Administration  
Jess Tyler, Project and Communication Support  
Lucas Ferreira, Research Assistant  
Deborah Osborne, Research Assistant (March-August)  
Angela Shi, Graphic Designer  
Sue Carrick, Charles Perkins Centre Twin Node

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

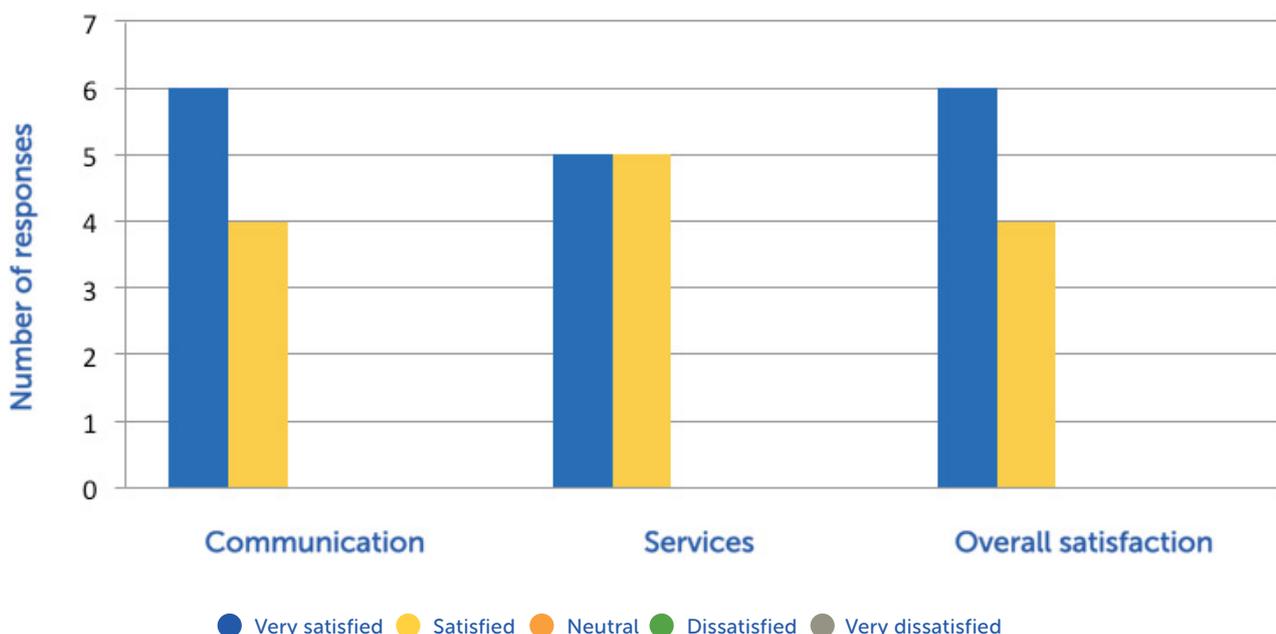
Responses are recorded as:

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

Twins Research Australia received feedback from 27 research groups for 2018. Overall, researchers were highly satisfied with the contribution provided by TRA and also the communication and service provided.

Positive feedback was given about interactions with TRA, with one researcher commenting TRA staff were "helpful, responsive, and cheerful". Another researcher commented that "I have enjoyed the communication and support received from TRA in the last 18 months. It is such a wonderful resource."

Figure 7. Overall satisfaction scores from researchers:  
Evaluating communication, services and overall contribution provided by the registry



## Researcher quality assurance survey

In 2018 TRA undertook a *Researcher Quality Assurance Survey* by contacting current and past researchers that have conducted a twin project with it in the last 10 years.

The purpose of the survey was to understand how effective TRA services and support have been compared to expectations, and what future improvements could be made.

The survey was broken into four themes, covering TRA's effectiveness at enabling research, building the workforce, supporting knowledge exchange, and establishing collaborations and networks.

Overall TRA achieved very positive feedback. The main areas for improvement were: to publicly display and promote the availability of twin data; and for past twin studies to demonstrate the opportunities for future studies. There was large support for the continuation of the training programs; assistance in statistical methods and analyses by TRA; and for building local expertise at an institutional level.



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

Twins Research Australia, like most medical research initiatives, relies on funding sources other than government to continue its vital services and to support the next generation of researchers. TRA's 2018 Annual Appeal resulted in 55 donations from a 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 Kate Murphy at [murphyks@unimelb.edu.au](mailto:murphyks@unimelb.edu.au).





Appendix

## Addiction and drug behaviour

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