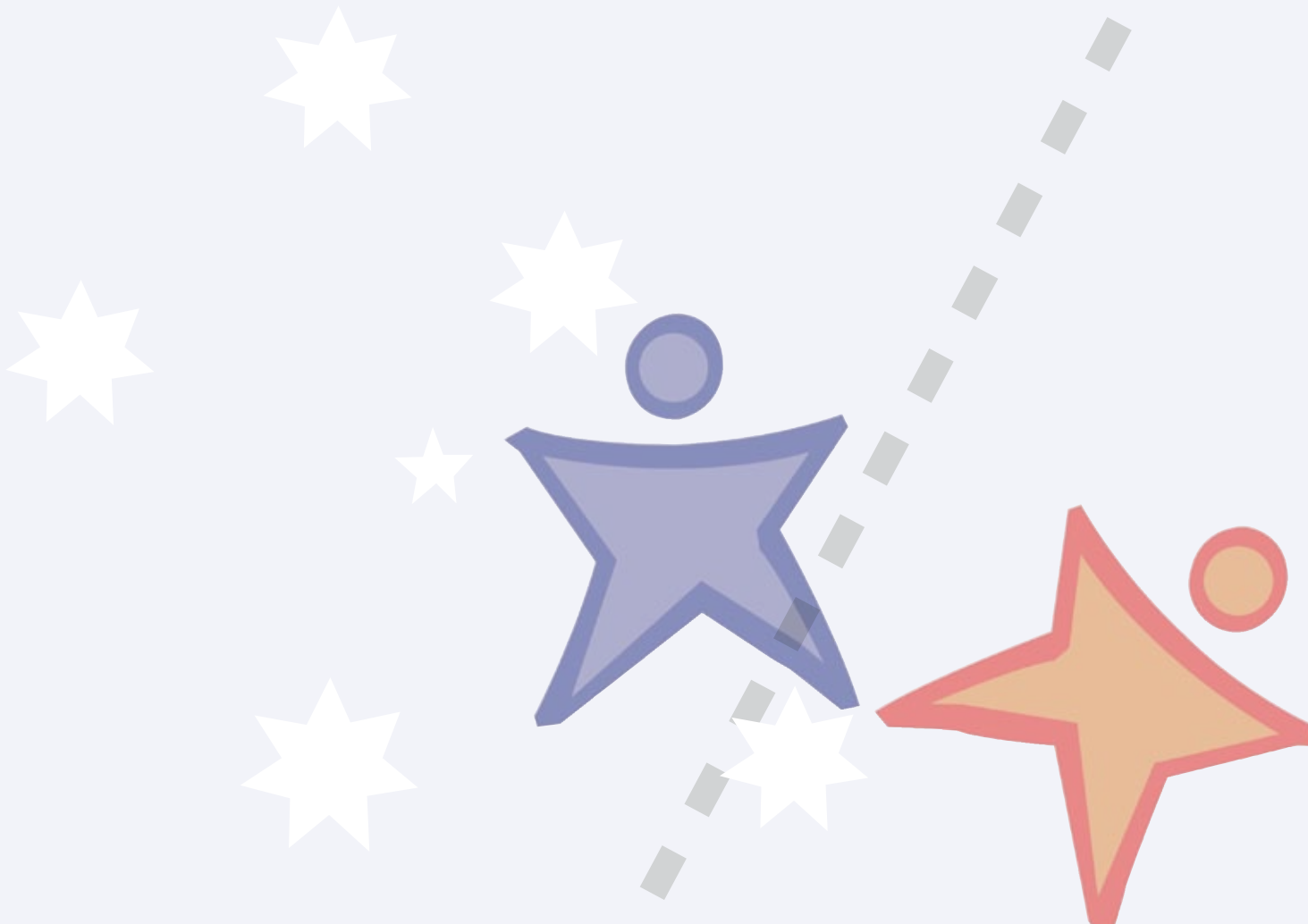


Australian Twin Registry

Annual Report

2008

A stylized graphic featuring two figures, one in blue and one in orange, holding hands. They are surrounded by several white stars of different sizes. A dashed grey line curves around the figures. The entire graphic is set against a light blue background with a decorative orange and red border at the top and bottom.

2008 Director's Report



Welcome to the 2008 Annual Report of the Australian Twin Registry (ATR).

Last year's publication of the 2005 - 2007 Annual Report was a major achievement and presented the objectives and new developments of the ATR in a format accessible to our two important stakeholder groups – twin members and researchers. This 2008 Annual Report provides a summary of the project management and activities of the ATR during Year 4 of the current grant (1 July 2007 to 30 June 2008).

2007-2008 has been the most productive year ever for the ATR

Over **30** research projects were actively supported by the ATR (compared to 21 in 2007), involving **133** mail-outs to **11,012** individuals, and over **1,500** hours in active telephone follow-up, which is a terrific achievement. 2007 also saw **87** peer reviewed publications produced by ATR-related studies, which is almost double the number of publications produced in the previous year (47 publications).

In addition, a substantial amount of the Registry's energy during the first 6 months of 2008 has been directed towards organising the *2008 Statistical Genetics Short Course featuring Mendel*, which will run 1-5 September 2008 in Coolangatta, Queensland. The ATR has invited 7 lecturers from the prestigious University of California (Los Angeles), headed by Professor Kenneth Lange, to conduct this intensive course, which covers state-of-the-art statistical genetics. This course has been planned by the ATR in response to requests from researchers for more hands-on tuition in this area. To date there has been great interest from the research community and the course is now full.

There have been many other major achievements in the last 12 months, perhaps the most significant being the successful launch of a unique component of the ATR – Mothers and Twin Children (**match**) in 13 hospitals across metropolitan Melbourne (see pp.9). **match** will expand the capacity of the ATR by collecting important data on the prenatal conditions of twin births, and the health of the mother during pregnancy.

"To realise the full potential of research involving twins to improve the health and wellbeing of all Australians."

The Australian Twin Registry is an Enabling Facility supported by a 5 year grant from the National Health and Medical Research Committee. The current grant was awarded in mid 2004 and is due to end in mid 2009. As such, the ATR is gearing up for submission of a new grant application. As part of this planning we have invested time and effort into developing a Vision Statement and Mission to lead the Registry into its next phase of growth and development.

The Vision of the ATR is to **realise the full potential of research involving twins to improve the health and wellbeing of all Australians**. The ATR sees itself as not just an "enabler" or "facilitator" of research, but as an active agent in making research happen. This includes all types of studies involving twins so as to harness the full potential of this national resource.

The Vision Statement acknowledges the importance of twin involvement, aiming for a true collaboration between ATR members and the researchers utilising the resource, recognising that both groups are committed to furthering medical and scientific research.

Research supported by ATR members has the potential to "make a contribution to the health and wellbeing of all Australians". This is the stated aim of the National Health and Medical Research Council (NHMRC), the Australian government agency that funds the core activities of the ATR. The NHMRC is Australia's peak body for supporting health and medical research; for developing health advice for the Australian community, health professionals and governments; and for providing advice on ethical behaviour in health care and in the conduct of health and medical research. Studies supported by the ATR will continue to include those that address issues of special relevance to twins themselves, as well as those that will provide new information of worldwide significance

Professor John Hopper, AM

Chairman's Report 2008

ATR Overview 2008



2007-2008 has been an extraordinary period of growth for the Australian Twin Registry (ATR), with an increase in the number and diversity of researchers wishing to include twins in their research projects. In addition the ATR has taken some major steps towards alignment with its satellite projects.

The ATR continually faces the hard task of providing excellent service and support to the research community on a limited budget and with finite resources. In 2008 I had the opportunity to lead the ATR Management Team through a series of business development workshops, as part of the McKinney Rogers Leadership Program. These workshops enabled the team to discuss and identify clear goals which will lead them into the future.

As a twin I have enjoyed being involved in the ATR at many levels. What I have learnt is that the Registry is very interested in the opinions of its members, as will be demonstrated via a member User Satisfaction Survey to be administered in early 2009. ATR staff work collaboratively with researchers to ensure that the scientific merit of proposed projects are balanced against the valuable time and contributions made by members and that these requirements are properly described to members at the outset of a new project. As an organisation, the ATR and its staff show a strong commitment to ongoing organisational improvement.

I congratulate Professor John Hopper on being inducted as a Member (AM) in the General Division for service to public health and biomedical sciences on Australia Day

in 2008. This honour recognises John's significant contribution to the field of genetic epidemiology through his research, and his dedication to the Australian Twin Registry over the past 20 years. More importantly however, it recognises the Registry itself and its significant role in Australian medical research.

And I would also like to thank my colleagues on the Advisory Board who give their time to discuss, encourage and provide invaluable advice to the Director, the new Deputy Director (Dr Debra Foley) and the rest of the ATR Management Team.

Vincent J. Pollaers

Chair, ATR Advisory Board

ABOUT THE AUSTRALIAN TWIN REGISTRY

Established in the 1970s, the Australian Twin Registry (ATR) is a national volunteer register of twins interested in contributing to research studies.

Funded by a National Health and Medical Research Council (NHMRC) Enabling Grant (2004-2009), the ATR's primary goal is to facilitate and support research studies involving twins.

In 2007/2008 the ATR maintained information from more than 30,000 sets of twins and higher order multiples, and was involved in the development and support of 30 research projects across a broad range of health related issues (refer Researcher Reports, pp 11)

POTENTIAL FOR TWIN RESEARCH

Studies involving twins play an important role in developing an understanding of epidemiological and clinical problems from a genetic and environmental perspective. They are a potential resource and research tool for all medical researchers. The special features that arise from twin designs enable questions about health and well-being to be answered in ways that they otherwise could not.

Twin research continues to utilise new technologies to establish the causes underlying the many health issues that affect all Australians. Most recently twin studies are playing a vital role in the emerging search for epigenetic effects. Epigenetics is the study of how proteins and other molecules that bind DNA and chromosomes can change gene expression without changing the DNA sequence. Faulty epigenetics have been linked to many diseases such as cancer and psychiatric disorders. Twins can significantly contribute to the investigation and identification of epigenetic factors that contribute to human disease, through their shared similar environments and often identical genetics.

The ATR provides twins with the opportunity to contribute to, and make a difference in, the development of knowledge around health and medical issues, which affect all Australians.

VALUES

The following values guide the ATR in achieving its core functions:

Respect: The ATR conducts its operations with the fullest respect for the volunteerism of the twins and their relatives in their registration and participation; for the ATR staff in monitoring and maintaining the use of this resource; and, for the researchers in their efforts to conduct timely and relevant studies in accordance with their commitments to their funding bodies, made with the agreement of the ATR.

Leadership: The ATR will maintain and expand its role as an independent facilitator of twin studies, in training and informing researchers about the potential, design, conduct and analysis of twin studies, and in providing information about issues of relevance to twins.

Equity of Access: The ATR undertakes its functions under the principles of equity of access by researchers irrespective of factors such as institution, discipline, and relationship to ATR, and equity of participation of twins eligible for particular studies and activities.

Privacy and Confidentiality: The ATR holds information on registered twins in strictest confidence and in accordance with Australian legislative requirements.

Consumer Participation: The ATR engages in and conducts activities with the twins and parents of twins whenever appropriate, whether or not they are members of the ATR.

Excellence in Research: The ATR strives to help researchers achieve excellence in their research.

The ATR does not undertake research itself but acts as facilitator. The ATR's core functions are:

Core Function 1:

Continue building and maintenance of an **up-to-date database** containing contact details and baseline information for twin members willing to participate in research.

Core Function 2:

Collaboration with researchers applying to the ATR to ensure that projects are of significant scientific merit and are appropriately described to ensure the ability of potential participants to provide informed consent.

Core Function 3:

Judicious management and administration of **approach to eligible twin members** to inform them of a new research project, determine their interest in participation, and seek their permission to release their contact details to the researcher.

Core Function 4:

Development of projects and programs to **value-add to research** in Australia.

Core Function 5:

Governance of the ATR in a fair, transparent and equitable manner.

The Registry

2008

Continue the building and maintenance of an up-to-date database containing contact details and baseline information for twin members willing to participate in research

THE REGISTRY AT A GLANCE – THE DATABASE

A foundation component of the Australian Twin Registry is the development and maintenance of an up-to-date register of twins willing to consider involvement in scientific studies. Underpinning this register is the database tool used to store, retrieve and update membership data to allow accurate record keeping and meaningful analysis of trends and results.

Building on the new Registry database launched in 2006, 2007-2008 saw the introduction of an enhanced Activity Logging module, enabling the ATR to more accurately collect reimbursement from researchers for work done on their behalf during studies. In addition, the ATR continued 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.

The ATR's Mothers and Twin Children (**match**) project was also incorporated with a custom built portal, specifically designed to capture **match** data. Due to the multiple trigger points for activity during the collection of data from pregnant mothers enrolled in the **match** program, the portal has been designed to manage critical time-sensitive tasks required of the **match** Coordinator. The result is a streamlined and efficient system, robust enough to support the future incremental roll out of **match** across Australia.

MEMBERSHIP

The Australian Twin Registry's (ATR) volunteer members are an integral part of the organisation, and management of the membership is a core component of its function.

Twins and higher order multiples (HOMS), including triplets, quadruplets and quintuplets of all ages, sex combinations, and zygosity are eligible to enrol with the ATR.

Members of the ATR are recorded under a specific status, depending on the currency of their contact details and individual preference for involvement in research activities. The majority of members (77.74%) are Active/Active, Active/Questionnaire and Questionnaire/Questionnaire, indicating they are willing to consider participating in research. An additional 6.89% of member's contact details require updating (recorded as Pending).

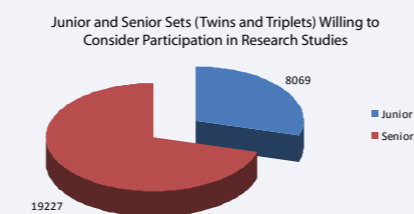
Of the 35,110 twin and triplet sets currently registered with the ATR, 27,296 sets are willing to consider involvement in research studies. The current status of members of the ATR is summarised in the following table as at 30 June 2008.

Table 1: Twin Pair Status Combination as at 30 June 2008

Please note: triplets are excluded from table

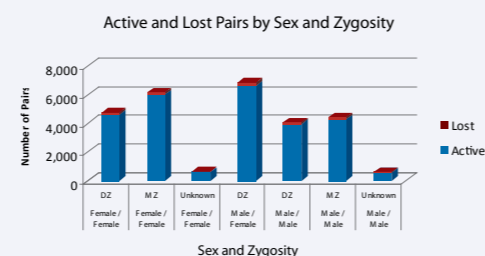
T1 Status	Active	Dec'd	Duplicate	Lost	Lost(OS)	No letter	Inactive	OS Temp	Q'aire	Pending	Total
Active	26683										26683
Deceased	620	472									1092
Duplicate	0	2	213								215
Lost	69	12	0	826							907
Lost (OS)	3	0	0	3	5						11
Newsletter	136	32	0	1	0	65					234
Inactive	593	335	0	13	1	21	1260				2223
OS Temp	413	2	0	1	0	1	8	104			529
Questionnaire	370	7	0	2	0	1	1	5	61		447
Pending	1339	61	0	23	1	11	49	24	19	1025	2552
Total	30226	923	213	869	7	99	1318	133	80	1025	34893

Graph 1: Junior and Senior Breakdown Where Status is Active/Active, Active/Questionnaire and Questionnaire/Questionnaire as at 30 June 08



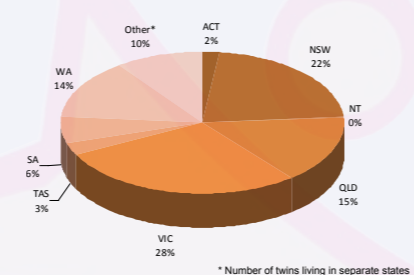
Graph 2: Active and Lost Twin Pairs by Sex and Zygosity

Please note: triplets are excluded from table



Graph 3: Active Twin Pairs Combination by Location

Please note: triplets are excluded from table



RECRUITMENT

Enabling Grant Goal: Increase Membership by 5000 over 5 years

Continual recruitment of new twin members is vital in ensuring the future significance of the ATR.

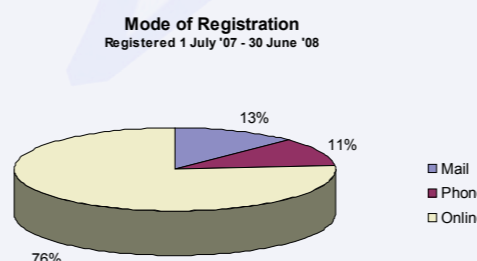
As of 30 June 2008 the ATR holds membership details on 35,110 twins and triplets. This represents an increase of 1,011 individuals between 30 June 2007 – 30 June 2008.

The majority (89%) of new members enrolling with the ATR during the reporting period were aged 0-9 years, a trend which has remained relatively consistent over a 20 year period. New registrants have come from all states and territories in Australia. However, the majority reside in Victoria (30%), New South Wales (32%), and Queensland (22%).

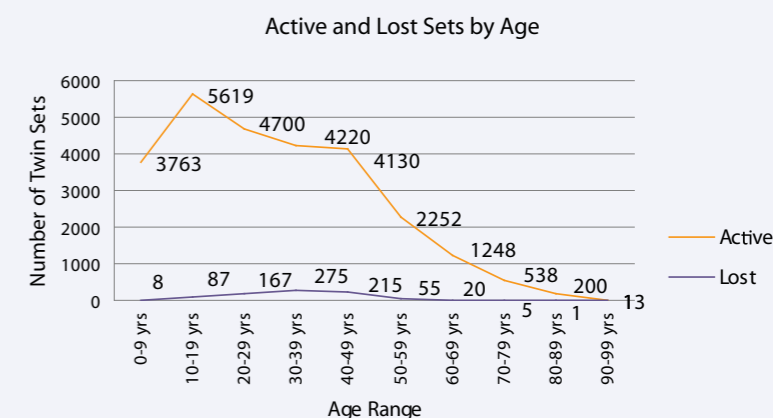
2007-2008 saw a significant increase in online registrations, with 76% of new members using the internet to register. The popularity of this mode of registration was demonstrated in the previous Annual Report and has continued to grow as an important channel for recruiting new members.

To date the Registry is on track in achieving its goal to increase membership by 5000 over 5 years. In the current grant period 4,922 new members (2,398 twin pairs and 42 triplet sets) have registered.

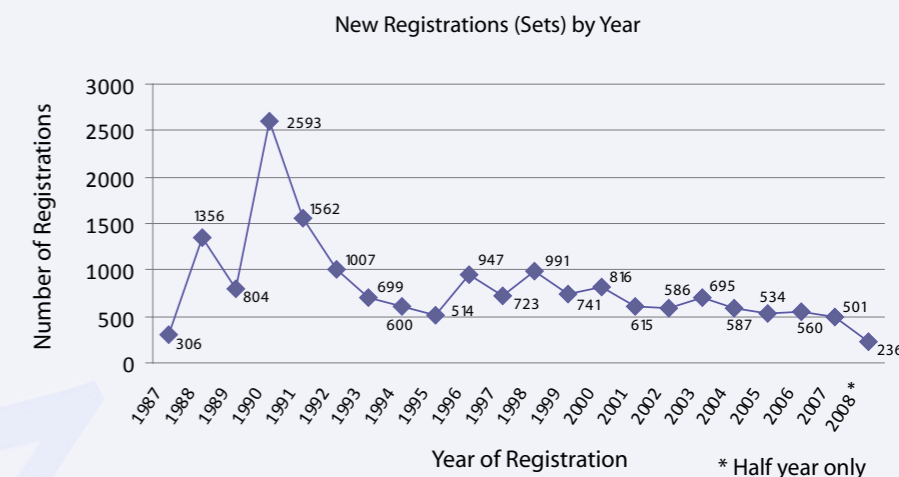
Graph 7: Mode of New Registrations (Sets) between 1 July 07 and 30 June 08



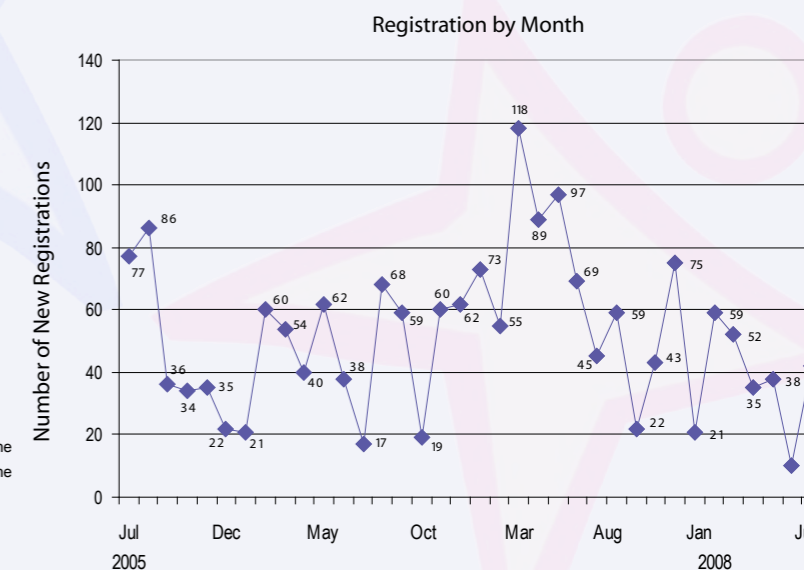
Graph 4: Active and Lost Twin Pairs by Age
Please note: triplets are excluded from table



Graph 5: New Registrations (Sets) by Year



Graph 6: New Registrations (Sets) per Month



The Registry

2008

AUSTRALIAN MULTIPLE BIRTH ASSOCIATION (AMBA)

The ATR was invited to submit articles for the November 07 and March 08 editions of the *AMBA* magazine. This was an opportunity to describe the process of twin studies and the twists and turns involved in generating research results. Contributing to this publication provides the ATR with an important tool for educating twin families in the significance of twin research.

- November 2007 *AMBA* Magazine Article
- March 2008 *AMBA* Magazine Article



AMBA NATIONAL CONVENTION

The ATR was invited to present at the AMBA National Convention in Newcastle, NSW in November, 2007. ATR Coordinator, Emily England, took the audience through an introduction to the genetics of twinning. This is an area where many parents of twins feel mystified and overwhelmed by the information presented via the scientific community. Emily's talk aimed to provide an overview of the topic, assisting parents in better understanding information presented in the news and online.

3RRR RADIO INTERVIEW WITH DEPUTY DIRECTOR

The ATR Deputy Director, Dr Debra Foley was a guest speaker on Radio 3RRR during *Medical Research Week 2008*. Debra spoke about the value of twins in research and the contribution the Australian Twin Registry and its members are making to research into health and medical issues, such as ADHD.

WEBSITE

2007-2008 saw additional material added to the ATR website, including information on **match**. For the first time, the ATR was proud to provide members with electronic access to the 2007 Annual Report, as well as important information regarding the ethical conduct of research.

See www.twins.org.au.

ADULT RECRUITMENT INITIATIVE

Recruiting of adult twins to the ATR has always proved challenging due to the lack of a clear means of contacting them as a "group". In June 2008, the ATR embarked on a recruitment drive in conjunction with two longitudinal research projects, the Tasmanian Asthma Study and the Cancer Families Studies, located at the University of Melbourne. Participants from these studies, who had identified themselves as twins, were contacted by the researchers via letter and invited to join the ATR. Results of this initiative are pending.

If this mode proves successful the ATR plans to explore further possible collaborations with similar large scale studies.

2009 TWINS PLUS FESTIVAL

Enabling Grant Goal: Convene two Twins Festivals



Following the success of the March 2006 Twins+ Festival held in Canberra, planning is now underway for the 2009 Twins+ Festival. The confirmed date and venue are: Saturday 14 March 2009 at Taronga Zoo, Sydney, NSW. Per capita, membership of twins residing in NSW is relatively low, so the ATR hopes this festival will assist in boosting NSW membership numbers, while sending a message of gratitude to current ATR members and their families for their participation in Registry activities.

CURRENCY AND ACCURACY OF MEMBERSHIP DATA

Enabling Grant Goal: Twins Newsletter to be published annually

ATR NEWSLETTER

Completed in June 2008, the recent edition of the *Twins* Newsletter was sent to **53,006** households. Due to funding constraints it was decided to roll together the 2007 and 2008 editions, resulting in significant savings on printing and postage. To offset the cost of postage, the ATR introduced a cover sheet to the newsletter which called for Expressions of Interest for studies requiring the participation of twins with rare characteristics, such as the heart condition atrial fibrillation.

Titled *Needle in a Haystack*, this cover sheet communicated this important information to all members in a cost effective manner. The *Needle in a Haystack* sheet also provided an efficient method for gathering information on Change of Address, reducing the subsequent number of telephone calls to the Registry.

While the Newsletter is first and foremost a tool for communication to members, it is also the largest opportunity available to assess the accuracy of member address data. Postage of *Twins* to **53,006** households in June 2008 resulted in 2,484 Return To Senders (4.7%). This response is vitally important to the ATR, alerting us to members who have moved locations, and triggers tracing of relocated members through a range of tools such as the White Pages and Electoral Roll.

Enabling Grant Goal: Accuracy of Database over 85%



Graph 8: Individual Records Updated Per Year



RECORD UPDATES

The ATR is aware that not all misdirected mail is in fact Returned to Sender (RTS), and as such, the Registry also undertakes proactive tracing of its members. This is an ongoing and important maintenance activity and ensures that the Registry remains viable. All prior addresses and any actions taken to trace individuals are recorded on the ATR database.

During 2007, **13,145** individual records were updated in the ATR database, with 5,532 in 2005 and 7,330 in 2006. These figures include those records followed up due to receipt of an RTS. This significant increase in the number of updates in 2007 is a result of an increase in telephone follow-up for studies in the last 12 months, plus modifications to the database, which have enabled the ATR to more accurately capture output.

CAPACITY BUILDING – MATCH, WATCH AND WATR

Enabling Grant Goal: Increase the capacity of the ATR to attract membership Australia-wide

The ATR financially supports 3 satellite projects: Mothers and Twin Children (**match**), the Western Australian Twin Children cohort (WATCH) and the Western Australian Twin Register (WATR), which act as embedded recruitment channels.

MATCH REPORT

As an integral part of the ATR, the Mothers and Twin Children (**match**) project is recruiting a large group of mothers and their newborn twins. This cohort will be a resource for future research addressing the role of factors around the time of conception and during gestation as determinants of maternal and foetal health and development.

match is collecting data and biological samples to measure periconceptional and intrauterine environment, including maternal pre-pregnant size, nutrition, lifestyle, hormonal status, and exposure to medication, alcohol or other substances, as well as recording infertility and its treatment, and chorionicity (placentation).

Stored maternal blood (taken at 28 weeks) and cord blood will be available to facilitate research in genetics, epigenetics and other rapidly evolving areas.

Recruitment is on a volunteer basis. Participating hospitals and private obstetricians provide women with a **match** twin pregnancy folder. Containing useful information about twin pregnancy, available sources of support, and an invitation to participate along with a **match** consent form, women who choose to join the project use the adjoining record book to provide data to **match** using the self-duplicating tear-out pages and pre-paid envelopes provided. Participants thereby retain the original record of their pregnancy.

The record book contains questionnaires relating to maternal and paternal factors, conception, obstetric history, pre-conception factors, ultrasound scans (and a request to collect data prints), pregnancy, and delivery. Additional pages include a notes section (including pages for mothers to record the twins' family tree), sample collection forms, forms to report loss of a baby or revocation of consent, and an envelope for collecting mementos of the pregnancy.

Developed in conjunction with a range of stakeholders such as the Australian Multiple Birth Association and members of the **match** Steering Committee, this publication has been approved by The University of Melbourne, The Royal Women's Hospital, Mercy Hospital for Women, and Monash Medical Centre.

Recruitment to **match** commenced in 2007 at four major sites in Melbourne: the Royal Women's, Mercy, Monash and Cabrini hospitals. During 2008, the project was successfully launched at a further

seven metropolitan and regional hospitals: Freemasons, St Vincent's Private, William Angliss, Sunshine, Box Hill, Frankston and Geelong. These sites include the Jessie McPherson and Frances Perry private maternity services.

The current pilot phase has been invaluable for testing **match** recruitment and sample collection protocols. Forty participants have registered to date and there have not been any withdrawals or complaints. After a suitable grace period, women who have subsequently given birth are contacted by ATR staff to complete the enrolment of their new twins onto the national Registry. Based on the success of this initial phase, additional funding will be sought in 2009 enabling **match** to expand to hospitals and states across Australia.

WATCH/WATR REPORT

WATCH (Western Australian Twin Child Health) is Australia's first population-based twins and family cohort. It consists of 5,459 families who had one or more multiple births in Western Australia between 1980 and 1997 inclusive, identified from the Maternal and Child Health Research database, which is housed at the Telethon Institute for Child Health Research in Perth. Records are linked to routine data sources, providing data on maternal and perinatal factors, some post-natal complications, deaths and all hospital admissions during childhood.

WATR (Western Australian Twin Registry) extends WATCH to include a population based sampling of adults born between 1974 and 1979, and children born from 1998 onwards. To date WATR has registered 507 adult multiples, of which there are 144 complete twin pairs and two complete triplet sets. As a satellite project, supported by the ATR, all twins and triplets

enrolled in WATR are informed they are automatically registered with the ATR.

In 2007-2008, active recruitment of new participants to the WATR cohort was put on hold whilst birth records back to 1950 are being digitised by the WA Registrar General. Once this digitisation has been completed WATR plans to extend its recruitment to identified multiple births born between 1950 – 1973.

Collaboration with researchers applying to the ATR to ensure that projects are of significant scientific merit and are appropriately described to ensure the ability of potential participants to provide informed consent

CURRENT RESEARCH STUDIES

Enabling Grant Goal: Increase number of studies supported by the ATR to 15 – 20 per year

Building on a previous average in 1999-2003 of 10 - 15 studies per year, the ATR aims to increase the number of studies supported per year to 15 - 20. This includes: studies that are in the initial stages of planning and development; studies which are involved in active recruitment; and those which have finalised recruitment but may require additional support for follow up and clarification with members.

For the current reporting period, the Registry has been involved in over **30** research studies, including active recruitment for 21 projects, a further 6 currently in development, plus additional studies requiring support after recruitment has concluded.

In addition to a slow rise in the rate of studies, the range, size and sophistication of these studies have increased markedly.

Table 2: Study status

Studies by Status 2008	
Study Status	Num
Discussion	4
EoI	6
Full Application	1
Ethics	1
APPROVED	3
ACTIVE - RECRUITING	16
ACTIVE - ONGOING PROGRAM	9
ACTIVE - DATA ANALYSIS	19
ACTIVE - WRITING UP	9
COMPLETED	52
ABANDONED	6
ON HOLD	2
UNKNOWN	1
Total	129

RESEARCHER REPORTS

The following Researcher Reports are provided by the researchers and associated staff and summarise major achievements. Please note, only studies that are currently active have been included. For detailed descriptions of all other studies, please see the 2007 Annual Report. Please also see Appendix 1 for a full listing of all studies by status.

98-001

GENETICS OF READING ABILITY

Principal Investigator: Professor Brian Byrne University Of New England, NSW



This study aims to identify genetic and environmental influences on children's early development in literacy, language and attention and to track these influences as they play out across development from age 4 to about 9.

This project is one of only a few that follows the twins longitudinally, starting prior to formal schooling. The extent of the data collected on each child, amounting to about 7 hours in total across four countries, is unique. The Researchers are

also collecting DNA with a view towards possible future genome-wide scanning in the search for genes impacting literacy growth.

In 2007-2008 the Researchers produced further publications, with emphases on genetic and environmental influences on growth in literacy and language, and how to reconcile evidence of strong genetic influences on literacy with other evidence of strong environmental influences, as documented in studies of how teaching practices can affect early literacy.

Future plans include the continuation of data collection in Australia and the US. In addition the researchers are in the planning stages of one final round of assessments when the twins are in high school, around Grade 8.

Funding		
ARC	1999-2009	\$827,000
NIH	2001-2005	\$580,000 US
ARC	2007-2009	\$583,000

Current Status: ACTIVE - ONGOING PROGRAM

2007-005

AN INVESTIGATION INTO THE NATURE OF GROWING PAINS

Principal Investigator: A/Prof David Champion St Vincent's Clinic, University of New South Wales, NSW

Growing pains is a prevalent condition of childhood characterised by a generalised disorder of somatosensory processing [central sensitisation of nociception].

Scientific Merit

2008

It has genetically influenced co-morbidities [migraine and recurrent abdominal pain] and familial link with genetically influenced restless legs syndrome and thus represents an opportunity to study genetic vulnerability to pain.

The aim of this study is to determine the heritability of the familial childhood idiopathic disorder growing pains.

In 2007-2008 data collection from 66 twin pairs and data analysis were completed and the student researcher, Shanthi Pathirana, achieved First Class Honours (B Med Sci) for her thesis.

The researchers will be presenting the study results at *The World Pain Congress*, in Glasgow, in August 2008 and hope to apply to conduct an Australia wide twin heritability study in the future.

Funding
Sydney Children's Hospital Foundation
2008 <\$1000
Current Status: ACTIVE - RECRUITING

2007-004

ROLE OF GENETIC AND ENVIRONMENTAL FACTORS IN ATRIAL FIBRILLATION

Principal Investigator:
Associate Professor Diane Fatkin
Sr Bernice Research Programme
Inherited Heart Diseases
Molecular Cardiology Unit Victor
Chang Cardiac Research Institute,
NSW

Atrial fibrillation (AF) is the most common sustained cardiac arrhythmia and a major cause of morbidity and mortality. Until recently, AF was regarded as a sporadic, non-genetic disorder. However, there is now accumulating evidence that familial aggregation of AF occurs in a substantial proportion of cases.

The current study aims to:

- Collect clinical details and blood samples from a population of monozygotic (MZ) and dizygotic (DZ) twin pairs in which one or both twins has AF.
- Determine the heritability of AF using a population of MZ and DZ twins.
- Identify and characterize disease-susceptibility polymorphisms.

In 2007-2008 twins were recruited for this study via a 'call for twins' in the *Twins 2007* newsletter and the *Twins 2008* newsletter cover sheet initiative, 'Needle in a Haystack'. Data collection has commenced and will continue through the second half of 2008.

In the next 12 months the researchers hope to expand recruitment and continue data collection, including clinical evaluation and blood sample collection.

Funding
National Heart Foundation 2008-2009
\$63,000/yr
Current Status: ACTIVE - RECRUITING

2006-004

GENETIC AND ENVIRONMENTAL FACTORS IN INVASIVE CERVICAL CANCER: A TWIN STUDY

Principal Investigator:
Professor Suzanne Garland
Royal Women's Hospital, VIC

This study has 3 aims:

- To assess whether genetic and environmental factors influence the development of persistent infection with high-risk (HR) HPV genotypes of the cervix

- To assess whether genetic and environmental factors influence further progression to cervical cancer (using HSIL abnormalities as a surrogate) among women infected with HR HPVs
- To assess the negative predictive value of HPV 16 and 18 serology for pre-existing infection by recruiting twins with no history of an abnormal Pap result, not HPV DNA positivity

In 2007-2008 a pilot study of 100 twin pairs was conducted, with 200 pap histories, 120 questionnaires and 44 blood samples collected. During this pilot phase, adopted lab methodologies were validated and collaborative relationships with Pathology providers and Cytology registries were established. In addition, the project employed a full-time Research Coordinator, and developed and implemented a database to track study participants.

During the next 12 months the researchers aim for recruitment and data collection to be rolled out Australia-wide. Laboratory analysis and manuscript preparation on the pilot study data will also commence.

Funding:
Cancer Council Victoria 1 year (pilot)
\$30,000
University of Melbourne 1 year (pilot)
\$70,000
NHMRC 2008-2010
\$737,763
Current Status: ACTIVE - RECRUITING

2007-001

CORTICAL AND TRABECULAR BONE MASS RESPONSE TO 12 MONTH CALCIUM AND VITAMIN D SUPPLEMENTATION IN MONOZYGOTIC PREADOLESCENT FEMALES

Principal Investigator:
Dr David Greene
Australian Catholic University,
NSW



Kelsey participating in the bone mass study



Abbie participating in the bone mass study

This study hypothesised that females randomised to receive calcium and vitamin D supplementation for a period of twelve months will display increased bone mineral properties at the tibia and distal radius compared to related individuals randomised to receive a placebo.

In early 2007 recruitment for this study concluded and baseline data was collected. During the period July 2007 to July 2008 follow-up data was collected at the 6 and 12 month stages. In addition, baseline to 6-month data comparison was completed. The Researchers are currently writing a manuscript for submission to a peer-reviewed journal (e.g. Osteoporosis International) by end 2008.

Future plans include the completion of bone scan analysis and feedback to all participants by November 2008. The Researchers will also undertake a baseline, 6-month and 12-month data comparison by December 2008. A second publication based on 12-month data will be submitted to the Journal of Bone and Mineral Research by February 2009.

Funding
ACU Dean Initiative Fund 2008 \$5000
Current Status: COMPLETED

2007-002

IMPACT OF FOLIC ACID (FA) ON PERINATAL OUTCOME OF TWINS

Principal Investigator:
Associate Professor Jane Halliday
Murdoch Children's Research
Institute, VIC

The aim of this study is to investigate if there is a difference between the perinatal outcome of twins whose mothers who took folic acid (FA) during the periconceptional period with twins whose mothers who did not take FA during this period. Perinatal outcomes include factors such as gestation of pregnancy, birth weight, health and well-being.

In 2007-2008 data collection and analysis was completed. The researchers found evidence of an increased likelihood of preterm delivery of less than 37 weeks gestation in women who had a total daily FA intake of more than 1mg per day. This finding is contrary to the original hypothesis that increased folic acid intake may lead to improved perinatal outcomes i.e. a lesser likelihood of preterm delivery. However, 1mg FA per day is more than double that of the recommended dose for pregnant women and given that a safe upper tolerable limit for FA has not been established, this may need to be taken into consideration in the future when making recommendation for women taking

supplements in pregnancy, particularly when they are expecting twins. The researchers are currently considering repeating this study in a larger sample of mothers to confirm these findings.

This study presents issues of interest in public health as well as of a methodological nature and a manuscript is currently being prepared to reflect this. Feedback to participants will also be prepared and distributed in the near future.

Funding
Murdoch Children's Research Institute
2007-2008 \$31,000.00
Current Status: Writing Up

2002-004-3

SOLVING THE JIGSAW! UNDERSTANDING BIOLOGICAL AND ENVIRONMENTAL EFFECTS ON ADHD THROUGH DISCORDANT MONOZYGOTIC TWINS.

Principal Investigator:
Professor David Hay
Curtin University of Technology,
WA

The recent Child and Adolescent component of the National Mental Health Survey identified Attention Deficit Hyperactivity Disorder (ADHD) as the most common behavioural problem among Australian children. Since 1991, the Australian Twin ADHD Project (ATAP) has developed as one of the world's largest programs on the genetics of ADHD, and in 2001 the researchers published their first text on this topic.

This current study focuses on the environmental influences of ADHD with the question: "Why can only one identical twin have ADHD, while the other twin has no difficulties?".

Scientific Merit

2008

The study aims to find over 100 identical twin pairs who are very different in regards to ADHD. To date, over 4000 sets of twins and their siblings have been screened in order to find the 100 required pairs. This resource is also being used in many other ways such as for developing new measures of ADHD and other behavioural problems which often co-occur, and developing new methods of genetic analyses to understand the overlap between behavioural disorders.

Achievements in the period 2007-2008 include the commencement of data collection and data entry for a new group of twins aged 6 to 17.9 years.

Goals for the coming year include the completion of data collection and entry from the new cohort and re-organisation of the research team in preparation for the retirement of the Principal Investigator.

Funding
NHMRC 2003-2005 \$595,862
NIH 2005-2009 \$2,400,000 US
Current Status: ACTIVE - RECRUITING

94-005-2

GENETIC AND ENVIRONMENTAL DETERMINANTS OF MAMMOGRAPHIC DENSITY: A TWINS AND SISTERS STUDY

Principal Investigator:
Professor John Hopper
The University of Melbourne, VIC



Prof John Hopper, Jill Wilson and Jan Leighton

Mammographic density, the area of bright white on a woman's mammogram, is increasingly recognised as a strong risk factor for breast cancer. Understanding why this is, may lead to major improvements in identifying other risk factors for breast cancer, and for developing interventions to prevent the disease.

This research project aims to study the genetic and environmental determinants of mammographic density.

In 2007-2008 the researchers completed recruitment of nearly 3,000 twins and sisters, and obtained blood samples for 2,800 participants. In addition, DNA was extracted and shipped to collaborators in Toronto, Canada for genome wide scanning, and work on digitising of mammograms and density measurements were completed. The researchers also submitted a paper on causal determinants of mammographic density based on new statistical methods.

In the future the researchers plan to analyse data from two genome wide scans.

Funding
NHMRC
Australia Fellowship til 2012
>\$1million
Current Status: ACTIVE – ONGOING PROGRAM

2006-001

CANNABIS AND OTHER ILLICIT DRUG USE: A TWIN STUDY

Principal Investigator:
Dr Michael Lynskey
Washington University, USA

This project aims to interview a sample of 6,600 young adult Australian twins using a structured interview assessing lifetime history of cannabis and other drug use and use disorders, and related aspects of substance use and mental health.

Achievements from 1 July 2007 – 30 June 2008 included the completion of 1,884 interviews and self report questionnaires. In addition, 2,057 interviews only and 1,904 self report questionnaires only were completed. To date, 2,533 interviews and self reported questionnaires, 2,725 interviews only, and 2,637 self report questionnaires only have been completed as part of this project.

In the next 12 months the researchers aim to continue recruitment and interviewing of this sample.

Funding
U.S National Institute of Drug Abuse
2005-2010 \$1,018,714 US
Current Status: ACTIVE - RECRUITING

2007-006

PRENATAL HORMONES AND THINKING STYLES: A TWIN STUDY

Dr Murray Maybery
University of Western Australia, WA

Recently Baron-Cohen (2002) proposed that prenatal exposure to high levels of testosterone is a causal factor in autism. He argued that high levels of testosterone favour development of the right hemisphere of the brain, which then affects two key psychological dimensions: systemising and empathising. Systemising refers to analysing the variables in a system in order to predict or control it. Empathising refers to identifying another person's thoughts and feelings, and responding appropriately. As well as contributing to autistic traits, it is argued that elevated levels of prenatal testosterone promote overdevelopment of systemising and underdevelopment of empathising. This is a fitting account of autism, because people affected by the disorder can show proficiency when working with predictable, concrete systems, yet have difficulty in social domains, for which empathising skills are essential.

This project aims to provide independent evidence addressed to the proposal that elevated levels of prenatal testosterone play a significant role in the etiology of autism. There is existing evidence that testosterone can pass between twins in-utero, resulting in a twins receiving an extra 'boost' of testosterone if the co-twin is male rather than female. This project plans to assess systemising, empathising, and mild autistic traits in dizygotic twin pairs.

If research is able to show that testosterone plays a critical role in the development of autism spectrum disorder, the implications for the early identification and treatment of the disorders would be substantial.

Over the last 12 months the researchers completed the first round of testing, involving a battery of web-based tests. Future plans include the analysis of the first stage data and the commencement of targeted recruitment for the final stage.

Funding
APEX Foundation – Trust for Autism
2007-2009 \$2944
Current Status: ACTIVE - RECRUITING

2002-002

A STUDY OF THE POTENTIAL CAUSES OF PSYCHOSIS IN A TWIN SAMPLE

Principal Investigator:
Professor Bryan Mowry
Queensland Centre for Mental Health Research, QLD

The goal of this study is to collect a large sample of twin pairs which have at least one member with a psychotic disorder and a sample of control twins where both members are unaffected, in order to investigate the role of genetic and non-genetic risk factors and behavioural markers reportedly associated with psychotic disorders.

To date 118 twin pairs have been recruited: 30 dizygotic (DZ) pairs where one (discordant) or both (concordant) twins have experienced psychosis; 31 monozygotic (MZ) twin pairs, discordant and concordant for psychosis; and 57 control twin pairs, where neither have experienced psychosis. Of these, 30 affected pairs and 47 control pairs have had an MRI scan, and 30 control pairs underwent MRI scanning tailored towards constructing detailed maps of structural and functional connectivity in the brain.

The researchers have found evidence of altered prefrontal-thalamic circuitry in schizophrenia using an optimised diffusion MRI study, which was published in *Neuroimage*, 2006. Using twin data, the researchers replicated effects of sex and genotype on gene expression in human lymphoblastoid cell lines. In addition, expression profiling in monozygotic twins discordant for bipolar disorder identified dysregulation of the WNT signalling pathways.

Future plans for the study include the further recruitment and assessment of affected twin pairs.

Funding
Stanley Foundation 2001-2003 \$100,000
NHMRC 2003-2006 \$457,500
Ian Potter Foundation 2007 \$50,000
Current Status: ACTIVE – RECRUITING

2005-003

THE TWIN STUDY OF BRAIN AGEING AND COGNITION (THE OLDER AUSTRALIAN TWIN STUDY)

Principal Investigator:
Prof Perminder Sachdev
Neuropsychiatric Institute, Prince of Wales Hospital, NSW

The overall aim of this study is to determine the relative contribution of

genetic and environmental factors, and their interaction, on markers of brain ageing and cognitive decline in elderly twins.



Aileen Radler and Martha Kastelyn

Specific aims include:

1. to measure the extent to which environmental factors, such as lifetime physical and mental activity, physical and psychological trauma, socioeconomic environment, alcohol and drug use, occupational exposure, and nutrition, influence DNA expression over time.

2. to determine how biological factors such as hypertension and antioxidant levels interact with genes to influence brain ageing.

Significant achievements for the last 12 months include the establishment of collaborative agreements between the primary research centre (NSW) and the secondary centres (Queensland and Victoria); plus the recruitment and training of staff and granting of ethics approval for those secondary study sites.

The research team was also awarded an NHMRC Dementia Research Grant to examine cardiovascular and metabolic indices. To date 194 twin pairs have been recruited and 130 pairs have been assessed across the three sites.

Future objectives include:

- The recruitment and retention of study participants
- Commencement of imaging analysis
- Commencement of a PhD neuroimaging scholarship and a second doctoral thesis

Scientific Merit

2008

- Organisation of an *Ageing Twins Symposium* as part of the annual meeting of the International College of Geriatric Psychoneuropharmacology (Sep, 2008), and
- The publication of 2-3 papers in 2008.

Funding
NHMRC/ARC
\$2,000,000
Current Status: ACTIVE – RECRUITING

2008-001 EFFECTS OF MENOPAUSE ON THE STRUCTURE OF BONE

Principal Investigator:
A/Prof Ego Seeman
Austin Health, Heidelberg
Repatriation Hospital, VIC

Fragility fractures are a common public health problem particularly in women. Although bone loss begins slowly in young adulthood, when women reach menopause bone loss accelerates. The structural basis underlying the menopausal bone loss and the hormonal factors that contribute to this bone loss are not clear.

This research project aims to prospectively study the heterogenous structural changes and biomechanical consequences of menopause, over a 3 year period, covering pre menopause, peri-menopause and post menopause. The researchers plan to measure:

- Bone macro and micro structure using new technique of HR pQCT
- Remodelling, and
- Bone strength

Recruitment of participants is scheduled to commence in July 2008.

Funding
Research Council of Norway
2007-2010 \$300 000
Current Status: ACTIVE – RECRUITING

2008-002

GENES, DIABETES MELLITUS AND DEMENTIA

Principal Investigator:
Dr Velandri Srikanth
Monash University, VIC

This study aims to establish if diabetes is associated with atrophy (neural loss and shrinkage) in the cerebral cortex, particularly the hippocampus, and thereby contributes to the risk of dementia. The researchers will test their hypothesis in the setting of twin research by comparing the brain volumes of twins who are discordant for diabetes.

By clarifying the effect of diabetes on the brain, such a study has the potential to open new avenues in dementia therapy. For example, drugs used in the control of diabetes or its complications may become useful either to prevent or delay onset of dementia. This research directly addresses the National Research Priorities of Ageing Well, Ageing Productively, and Preventative Healthcare.

Significant achievements in 2007-2008 include the finalisation of protocols and commencement of Victorian recruitment and data collection, and expansion of recruitment to the eastern seaboard states (NSW, QLD, TAS, ACT).

In the next 12 months the researchers plan to finalise recruitment and data collection, commence statistical analysis and publish results.

Funding
Diabetes Australian Research Trust
2008 \$49,000
**Current Status: ACTIVE
RECRUITING/DATA COLLECTION**

2006-005

COMPROMISED OR COMPETENT? A LONGITUDINAL STUDY OF TWIN CHILDREN'S SOCIAL COMPETENCIES, FRIENDSHIPS AND BEHAVIOURAL ADJUSTMENT

Principal Investigator:
Professor Karen Thorpe
**Queensland University of
Technology, QLD**

Twinning presents a unique situation in early childhood because twin children share a social and learning environment and are rarely apart. This study asks whether these circumstances compromise (Risk Hypothesis) or promote (Competency Hypothesis) the developmental progress and behavioural adjustment of twin children. This study examines the social relationships of twins across the preschool year through the key transition point of school entry.

The central aims of the study are to:

- Measure the social and behavioural competencies of twin children in early childhood and compare these with singleton age peers
- Examine the factors associated with peer relationship and friendship formation for twins, and a comparison group of singletons, in the preschool year and at school entry.
- Identify the mechanisms that link twinning, social competency, social interaction and behavioural adjustment across the preschool year through to school entry.
- Identify factors associated with risk and resilience in twin children's social and behavioural adjustment and adaptation, and
- Examine process and context in twin children's social interactions

In 2007-2008 data collection was completed in both the Queensland and West Australian sites. Twin children were visited in their school settings and data collected on their adjustment to school. Coding of all data, including a large body of video-taped observations of twin children with peers in the school setting, has been undertaken. In addition, data entry and cleaning are being finalised and analyses undertaken. The researchers have also presented their work at seven international conferences.

Future plans include the completion of data entry, and the continuation of analyses and manuscript writing. The researchers are also currently discussing a follow-up submission to the ARC to study twin children's social development across primary school.

Funding
ARC
2005-2008 \$290,000
**Current Status: ACTIVE – ONGOING
PROGRAM**

2004-007

RISK FACTORS FOR THE DEVELOPMENT OF EATING DISORDER PHENOTYPES AND ENDOPHENOTYPES IN ADOLESCENT TWINS

Principal Investigator:
Associate Professor Tracey Wade
Flinders University, SA

The overall aim of this study is to investigate the mechanisms by which different environments, temperaments, and genes work together to cause eating disorders. This study follows twins over 2 years, with a specific focus on the 12.5 to 15 years age range, because this is the greatest period for risk of emergence and growth in eating disordered behaviour.

Anorexia nervosa and bulimia nervosa are eating disorders that affect mainly young women. In both disorders, young women judge their self-worth in terms of their weight and shape, and thus acquiring an "acceptable" weight or shape becomes of supreme importance. Eating disorders are extremely difficult and costly conditions to treat, and are associated with high mortality, and a high level of disability. Around 10% of adolescent girls will be affected by eating disorders. Given the seriousness of the consequences of eating disorders, a better understanding of the causes of eating disorders that can recommend specific prevention approaches is urgently required.

In 2007-2008 the second wave of data was collected and two papers were submitted for publication. In addition, a newsletter updating participants on the study progress was produced, and an application for NHMRC funding to collect the third wave of data was successful.

In the coming 12 months the researchers plan to continue collection of the third wave of data and produce further publications.

Funding
NHMRC
2005-2007 263,500
NHMRC
2008-2010 487,860
**Current Status: ACTIVE- ONGOING
PROGRAM**

2006-006

GENETIC AND ENVIRONMENTAL CONTRIBUTIONS TO RETINAL MICROVASCULAR SIGNS IN AUSTRALIAN TWINS

Principal Investigator:
Professor Tien Wong
The University of Melbourne, VIC

This study is measuring and characterising retinal vascular caliber to determine the heritability of retinal vascular diameters. The study addresses an important question that will provide key insights into the early precursors of cardiovascular diseases in children: Are blood vessel changes in the eye seen in children inherited, and if so, do they indicate genetic susceptibility to cardiovascular disease later in life?

Data analysis has been completed and the researchers have found both birth length and current BMI (Body Mass Index) may significantly affect the variation of retinal arteriolar calibre in twins aged 7-11 years after taking into account factors including:

- BP (blood pressure)
- Maternal smoking
- Maternal alcohol consumption
- Current BMI
- Gestational age
- Birth weight, and
- Other birth parameters

The researchers are in the process of finalising the analysis and preparing the first draft of the manuscript.

Funding
Clifford Craig Medical Research
Trust Foundation for Children 2007-2008
\$50,537
Current Status: ACTIVE – DATA ANALYSIS

PUBLICATIONS

Enabling Grant Goal: Increase the number of peer reviewed articles to 50 per year

An important measure of the output of the ATR is the number of publications arising from studies supported by the facility. To date, 636 peer-reviewed publications and 474 conference proceedings have arisen from ATR supported projects, representing an increase of 60 publications in 2007-2008. Please see Appendix 2 for a listing of recent publications. For a listing of publications since 2003, please see the 2007 Annual Report

RESEARCHER HONOUR ROLL

The ATR would like to congratulate the following researchers on their significant achievements in 2007-2008.

Professor Sam Berkovic, The University of Melbourne

Professor Berkovic was awarded an NHMRC Australian Fellowship in 2007 and will use his Fellowship to work on the integration of high level clinical medicine, molecular genetics and cutting-edge neuro-imaging in the causes and treatment of epilepsy. This follows Professor Berkovic's 2006 *Zulch Prize for Basic Neurological Research* from the Max Planck Society in Germany, and recognises his world leadership in epilepsy research.

Professor John Hopper, The University of Melbourne

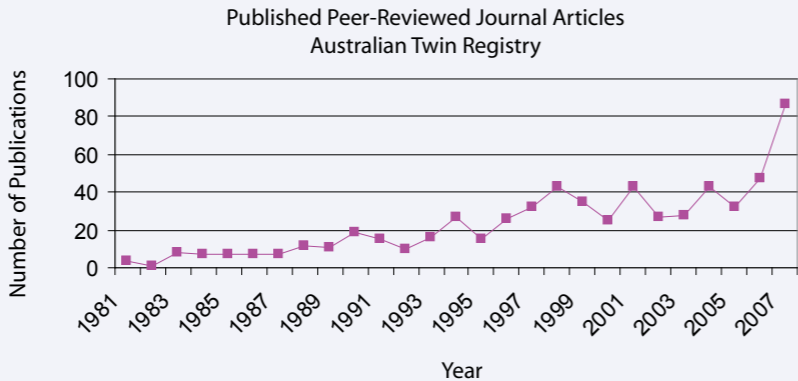
Professor Hopper, a world leader in genetic epidemiology, was awarded an NHMRC Australian Fellowship in 2007. This Fellowship will assist Professor Hopper in his research into the links between genes and the environment in breast, colorectal, and prostate cancers.

Professor Hopper was also recognised in the 2008 Australia Day Honours list. Inducted as a Member (AM) in the General Division for service to public health and the biomedical sciences, this award recognises Professor Hopper's sustained contribution as an academic

Table 3: Publications Arising from ATR Supported Projects Since 1981

Publications as of 30 June 2008				
	Completed In Press		Submitted In Preparation	
Book	3	1		
Book Section	55	4		
Published Abstracts	96			
Conference Proceedings	474			
Peer Reviewed Publications	636	17	2	11
Thesis	13			
Reports	7			
Newspaper Articles	20			
Magazine Articles	5			

Graph 9: Number of Articles Published per Year



and researcher, particularly in the field of genetic epidemiology, and his leadership of the Australian Twin Registry over the past 20 years, as Deputy Director and then Director.

Professor Nick Martin, Queensland Institute of Medical Research

Professor Martin was elected as a Fellow to the Australian Academy of Science in 2008 in recognition for his work in psychology, focusing on the genetics of human behaviour and complex diseases. Professor Martin's work has significantly advanced, and continues to advance, the world's scientific knowledge.

RESEARCHER TRAINING GENEMAPPERS 2007

Enabling Grant Goal: Hold Annual Twin Workshops

The ATR was a conference sponsor of *GeneMappers*, held at Royal on the Park in Brisbane, in August 2007. The ATR also staged an information booth at

the conference and made contact with researchers who are considering utilising the ATR in their studies. Registry Director, Professor John Hopper, chaired the 'Twins and Association Studies' session.

STATISTICAL GENETICS SHORT COURSE FEATURING MENDEL

In response to requests from researchers new to the field of research involving twins, the ATR will convene an intensive short course in September 2008, in the 'Twin Towns' of Coolangatta/Tweed Heads. This short course will cover state-of-the-art statistical genetics methods for detection of genetic loci for complex traits, either qualitative or quantitative, and will include hands-on computer exercises using statistical genetics computer programs, especially Mendel, SimWalk, and FBAT. Seven lecturers, headed by Professor Kenneth Lange, from the University of California (Los Angeles) have been invited to conduct the 5-day program.

RESEARCH TRAVEL GRANT SCHEME

As part of its commitment to promoting twin research, the ATR sponsors a Research Travel Grant Scheme. This scheme aims to foster the development of the Australian research community and spread the word regarding the value and power of twin studies. The scheme is geared toward early career researchers who have not yet gained substantial external funding supporting research related travel.

The Research Travel Grant Scheme awards partial funding, within the range of \$300 - \$2000, for relevant travel costs. Applications are competitive and open to all Australian-based researchers involving twins in their studies.

Successful applicants are required to submit a Travel Report, which is published on the ATR website: www.twins.org.au

The successful applicants for Rounds 4 and 5, offered between 1 July 2007 – 30 June 2008, are listed below.

RESEARCH TRAVEL GRANT SCHEME – SUCCESSFUL APPLICANTS ROUND 4 (LATE 2007)

Dr Sandra Petty, University of Melbourne
American Society for Bone and Mineral Research 29th Annual Meeting, 2007 in Honolulu, USA.

Dr Sandra Iuliano-Burns, University of Melbourne/ Endocrine Centre of Excellence
American Society of Bone Mineral Research 29th Annual Meeting in Honolulu, USA.

Dr Graham Byrnes, University of Melbourne
International Conference on Twin Studies (ICTS) in Belgium, in June 2007.

Dr Mohamed Dirani, Centre for Eye Research Australia
Genemappers Conference 2007 in Brisbane, Queensland, in August 2007.

Ms Cara Büsst, University of Melbourne
American Heart Association's Council for High Blood Pressure Research (CHBPR) Conference in Tucson, USA, in September 2007.
American Society for Human Genetics (ASHG) Conference in San Diego, USA, in October 2007.

Ms Andrea Lammél, University of New South Wales
21st International Workshop on Methodology of Twin & Family Studies: Introductory Course in Boulder, Colorado, in March 2008.

Mr Beben Benyamin, Queensland Institute of Medical Research
Joint 7th Human Genome Organization (HUGO)-Pacific Meeting and the 8th Asia-Pacific Conference on Human Genetics in Cebu, Philippines in April, 2008.

RESEARCH TRAVEL GRANT SCHEME - SUCCESSFUL APPLICANTS ROUND 5 (MID 2008)

Round 5 Travel Grants were awarded in June 2008. Following is a list of the recipients. Travel reports from the recipients will be posted on the ATR website, www.twins.org.au, in late 2008.

Ms Cong Sun, Centre for Eye Research Australia
2008 Statistical Genetics Short Course featuring Mendel, in Coolangatta, Queensland, in September 2008.

Dr Justine Gatt, Westmead Millennium Institute/University of Sydney
2008 Statistical Genetics Short Course featuring Mendel, in Coolangatta, Queensland, in September 2008.

Dr Laura Baglietto, The Cancer Council of Victoria
2008 Statistical Genetics Short Course featuring Mendel, in Coolangatta, Queensland, in September 2008.

Ms Emily Karahalios, The Cancer Council of Victoria
2008 Statistical Genetics Short Course featuring Mendel, in Coolangatta, Queensland, in September 2008.

Dr Penelope Lind, Queensland Institute of Medical Research
XVth World Congress on Psychiatric Genetics, in Osaka, Japan in October 2008.

Ms Karen Verweij, Queensland Institute of Medical Research
International Workshop on Methodology of Twin And Family Studies: The Advanced Course, in Boulder, Colorado, USA, in March 2009.

Ms Gabriella Blokland, Queensland Institute of Medical Research
International Workshop on Methodology of Twin And Family Studies: The Advanced Course, in Boulder, Colorado, USA, in March 2009.

Ms Cara Büüst, University of Melbourne
International Society of Hypertension/ European Society of Hypertension Conference in Berlin, Germany in June 2008.

Mr Abdullah Sheiki, Curtin University of Technology
38th Behavior Genetics Association (BGA) Conference, in Louisville, Kentucky USA, in June 2008.

Participation

2008

Judicious management and administration of approach to eligible twin members to inform them of a new research project, determine their interest in participation, and seek their permission to release their contact details to the researcher.

PARTICIPATION

The ATR acts as a recruitment and communication resource to facilitate research across Australia. To enable a successful research program, the ATR works closely with researchers to ensure that material sent to twin members inviting them to participate in a study is clear and concise. Providing clear and comprehensive information to ATR members is vital in ensuring that twins are adequately informed of the full burden of participating in a study, and are able to give their informed consent.

Initially, a new study is introduced to Registry members in the form of an "Approach Package", mailed by the ATR. This clearly details the aims, methods and requirements of the research. The contents of an approach package are developed collaboratively by the ATR and the researchers. All responses to the approach are returned to the ATR in the first instance. The contact details of twins who have indicated their willingness to be approached are then forwarded to the researchers. This way, member's rights to privacy and confidentiality are strictly observed.

Additionally, inbuilt processes within the ATR database ensure that twins selected to be approached regarding a study:

- Are eligible, based on criteria specified by the researcher
- Have not been previously approached for at least 6 months, and are
- Marked as willing to be approached for studies (status of 'Active' or 'Questionnaire')

Twin members are free to decline or withdraw from a study, and their participation is often dependent on their life situation at the time of invitation, the free time they have available, and the requirements of the study.

The ATR employs a range of methods to ensure that twin members are well informed regarding the study, including detailed mailed materials, follow up telephone calls and providing the opportunity for members to speak to a Research Assistant regarding the study. The ATR aims to obtain a response from the twin member regarding their participation, regardless of whether this is a 'Yes' or 'No' response.

MAIL OUTS

Mailouts to prospective participants for individual studies are a core component of the Registry's daily operations. Scheduling of mailouts and the total number of approaches sent is dependent on the requirements of the researcher. During the period 1 July 2007 – 30 June 2008, **113** mailouts were conducted, with **11,012** approaches made.

The table below summarises approaches for both Junior members (1 approach per family) and Senior members (1 approach per twin). The number quoted also includes reminder mailouts.

Table 4: Mailouts 1 July 2007 – 30 June 2008

Mailouts Summary (2007-2008)		
Study ID	No. of Mailouts	Total Approaches
94-005-2	9	356
2002-002	4	320
2002-004-3	9	1170
2003-001-2	2	14
2004-001	3	13
2005-002	4	235
2005-003	13	882
2005-003-1	1	66
2006-004	7	880
2006-005	3	41
2006-005-1	3	24
2006-001	32	3958
2007-004	1	37
2007-005	1	943
2007-006	4	1000
2007-002	4	199
2007-001	2	8
2008-002	3	142
2008-001	8	724
Total	113	11012

In addition to these mail-outs the ATR recruited twins for 2 further studies as part of the 2008 *Twins* newsletter initiative, *Needle in a Haystack*.

A steady increase in researchers requesting Telephone Follow Up and the Registry's adoption of a Verbal Response protocol, where a twin gives agreement over the telephone regarding their willingness to participate in a study, has reduced the number of follow up mailouts and approaches required.

TELEPHONE FOLLOW UP

As part of its services the ATR offers researchers the option of telephone follow-up, which can be used in conjunction with reminder letters or as a stand alone follow-up mechanism.

This form of follow-up is becoming increasingly popular, with the ATR conducting telephone follow-up for **15** out of **21** actively recruiting studies during the reported period.

Telephone follow-up for studies is a significant component of the day-to-day work of Registry staff. The number of hours and resulting phone calls for study phone follow-up are outlined below. Please note these figures do not include telephone calls and hours spent tracing twins who have moved address.

Table 5: Telephone Calls Made per Study

Study ID	Study Title	# Calls	# Hours
94-005-2	Mammographic Density: A twins and sisters study	297	84
97-001-3	Study of Monozygotic Twins Discordant for Epilepsy	9	2
2002-002	A Study of the Potential Causes of Psychosis in a Twin Sample	337	56.5
2002-004-3	Solving the Jigsaw! Understanding Biological and Environmental Effects on ADHD	809	98.75
2003-001-2	Genetic & Environmental Risk Factors in Myopia: Separated Twins	5	1.5
2005-002	Molecular Genetics of Inattention in Australia	274	67.5
2005-003	The Twin Study of Brain Ageing and Cognition	337	74.5
2006-001	Cannabis and Other Illicit Drug Use: A Twin Study	5266	975.15
2006-004	Genetic and Environmental Factors in Invasive Cervical Cancer: A Twin Study	866	105.25
2007-001	Calcium, Vitamin D & Bone Health in Pre-teen girls	14	1.5
2007-002	Impact of Folic Acid (FA) on Perinatal Outcome of Twins	121	33
2007-005	An Investigation into the Nature of Growing Pains	85	6
2008-002	Genes, Diabetes Mellitus and Dementia	93	14.25
Total		8513	1519.9

RESPONSE RATES

Table 6: Study Response Rates for a Selection of Active Studies

Study Response Statistics to Date							
Study Response Statistics to Date	Criteria	Total Pairs Approached	Positive Response Rate	Negative Response Rate	1 Twin Response Rate	No Response Rate	Total Response Rate
Juniors							
Genetics of Reading Ability	F/F, M/M, 3.75-5yrs - Syd	315	65%	12%	n/a	22%	78%
ADHD		1170	44%	8%	n/a	48%	52%
Tooth Emergence	F/F, M/M, M/F, 0-1yr - Aust wide	485	68%	14%	n/a	18%	82%
Calcium, Vitamin D & Bone Health in Pre-teen girls	Identical F/F, 9-12yrs - Syd	49	45%	55%	n/a	0%	100%
Folic Acid & Perinatal Outcome of Twins	M/M, F/F, M/F, 0-3yrs - Vic	199	78%	4%	n/a	18%	82%
The Nature of Growing Pains	M/M, F/F, M/F, 3-12yrs - NSW	944	12%	32%	n/a	57%	43%
Seniors							
Brain Ageing and Cognition	M/M, F/F, M/F, 65+yrs - Vic, NSW, Qld	512	42%	48%	5%	4%	96%
Cannabis and Mental Health*	F/F, M/M, M/F, 25-35yrs - Aust wide	3805	31%	32%	12%	25%	75%
Cervical Cancer	F/F, 30-60yrs, Vic	405	40%	37%	8%	15%	85%
Atrial Fibrillation (AF)	Targetted recruitment, AF sufferers	19	84%	11%	5%	0%	100%
Menopause & Bone Structure*	F/F, 40-60yrs, Melb	250	12%	23%	10%	55%	45%
Diabetes and Dementia*	50+yrs, diagnosed diabetes - Vic, NSW, Qld	71	31%	62%	4%	3%	97%

*Studies currently recruiting and undergoing follow-up to non-responders

The overall response rate for a study is defined as the number of Yes and No responses compared to the total number of twin members approached. The Response Rate is an important statistical element in the interpretation of research results and as such, the ATR aims to obtain a response from as many members approached as possible.

Response rates to Registry mailouts appear to be higher for those studies approaching either families with young

twins (under 18 years old) or older, adult twins (40 years and older).

Twins between the ages of 18-40 years old have the highest 'No Response' and 'Negative Response' rates and are the most difficult group to maintain current contact information for. Negative response rates also include twins who are ineligible to participate in a study based on the researchers' criteria, for example, if the member does not display a particular trait, or does/does not suffer from a particular disease.

ADVERSE EFFECTS AND COMPLAINTS

The ATR takes any complaint from members seriously and endeavors to promptly resolve the issue presented.

The ATR requires all adverse effects and complaints to be communicated to ATR Management.

There were no adverse effects or formal complaints communicated by members to the Registry in the period July 2007 – June 2008.

Development of projects and programs to value-add to twin research in Australia

ATR DATA ARCHIVE

As detailed in the 2007 Annual Report, the ATR is working toward establishing a consolidated electronic archive of data compiled from completed and ongoing ATR-facilitated studies. A feasibility study conducted in 2007-08 by the Registry's Senior Project Officer concluded the Registry lacks the funding and expertise to establish such an archive in-house, and recommended seeking an external specialist partner. Discussions were held with two potential service providers.

Like the ATR, WAGER (www.wager.org.au) is an NHMRC-funded national research enabling facility, established in 2004. WAGER has particular expertise in providing the necessary tools and computing infrastructure to simplify and reduce the workload associated with study conduct while improving the quality and accessibility of the collected data. As such, it is a logical home for the nascent ATR data archive. Some preliminary datasets will be archived with WAGER by June 2009 to test the system and provide estimates of the projected costs of establishing a full scale archive in the next Enabling Grant funding period.

The feasibility study also highlighted the need for consultation with ATR members regarding the re-use of previously collected, deidentified study data. At the time of writing, an article published in *Twins* 2008 has generated twenty-eight mailed, emailed and telephoned responses from members. All but one of the respondents indicated enthusiasm and support for the concept of re-using or 'recycling' deidentified study data.

ATR DATA INDEX

Pending the launch of a full scale archive, the Registry has engaged students from the University of Melbourne's Department of Information Systems to build and implement a web-based, searchable data index of all previous studies conducted via the ATR.

This system will be accessible via the ATR's current website (www.twins.org.au) and will enable users to search all previous ATR-facilitated studies based on keywords and specific criteria. The Data Index is due for completion on 31 October 2008 and will be launched to the wider Australian research community shortly thereafter.

Basic searches will yield details such as ATR study ID number, study title, investigator/s, host institution/s, year/s study conducted, and study status (completed, in progress, etc). Advanced searches will return details on the types of twins approached for each study (e.g. MZ/DZ, male/female, adult/junior combinations), any questionnaires or tests administered, and any other measures or samples taken.

Researchers interested in conducting new studies in collaboration with the investigators of these previous studies will be directed to contact the ATR who will then foster a link with the originating research group.

ATR BIOREPOSITORY

The ATR also plans to establish a backed-up biorepository of DNA samples and other biospecimens collected from previous twin studies, and a central inventory of existing biospecimens stored in other laboratories. Work on the set-up and development of the biorepository will follow the establishment of the data archive as core issues such as access, consent and coordination will be similar for both resources.

As with the data archive, an external specialist service provider will be engaged and small sets of samples will be used to pilot the chosen system and determine the likely costs of full implementation.

Data and biospecimen archiving will expand the ATR's core facilities keeping pace with recent and future developments in data-sharing technologies. Consequently, many additional research studies may be facilitated without increasing the burden of participation for ATR members.

Governance of the ATR in a fair, transparent and equitable manner

ATR MANAGEMENT

Dr Susan Treloar took up a position at the Centre for Military and Veterans Health, University of Queensland and as a result, reluctantly resigned her post as ATR Deputy Director on 13 July 2007. All staff at the ATR would like to express our gratitude for the efforts and dedication Sue gave to the role over her three year term.

Dr Debra Foley filled the vacant ATR Deputy Director position in November, 2007. Debra has extensive experience in twin related research both in Australia, with the Latrobe Twin Study, and in the USA at the Virginia Institute for Psychiatric and Behavioral Genetics. Debra is a trained psychiatric geneticist with an interest in youth mental health, psychiatric (genetic) epidemiology, and the application of genetic findings to real world clinical issues, and currently holds a position at the ORYGEN Research Centre, Parkville, VIC.

In March 2008 the ATR identified the need to expand its current management structure to include a second Deputy Director position. This position was filled by Dr Ruth Morley. Ruth is a Senior Research Fellow at the University of Melbourne, Department of Paediatrics, and the driving force behind the Mothers and Twin Children (**match**) project. Ruth's research focus is the role of factors during pregnancy as determinants of offspring health and neurodevelopment.

As at end June 2008 the ATR Management comprises:

- Prof John Hopper, Director, Australian Twin Registry; NHMRC Senior Principal Research Fellow; Director (Research), Centre for Molecular, Environmental, Genetic and Analytic (MEGA) Epidemiology, University of Melbourne

- Dr Debra Foley, Deputy Director, Australian Twin Registry; ORYGEN Research Centre
- Prof. Nick de Klerk, Director, Western Australia Twin Child Health (WATCH)
- Dr Ruth Morley, Deputy Director, Australian Twin Registry; Senior Research Fellow, Department of Paediatrics, University of Melbourne
- Prof. Lyle Palmer, Director, Western Australian Twin Registry (WATR)
- Mr Vincent Pollaers, Chair, Advisory Board
- Jenny Boadle, Project Support Officer (until May 2008); ATR Coordinator
- Emily England, ATR Coordinator (maternity leave from May 2008)
- Shaie O'Brien, ATR Project Support Officer (from May 2008)
- Kim Dorrell, ATR Senior Project Officer
- Supriya Raj, Coordinator, mothers and twin children (**match**)

Any member of ATR Management with a potential conflict of interest is required to declare this interest prior to any relevant discussions. Persons with a conflict of interest in any study are excluded from the review or application approval processes of that study.

ADVISORY BOARD

In late 2007, Prof Annette Dobson & Prof Peter Klinken, stepped down from their positions on the Board and 3 new members, Dr Keith Horsley, A/Prof David Whiteman and Prof David Ravine were welcomed.

The previously vacant AMBA representative position was filled by current AMBA National President, Ann-Marie Harli.

As at end June 2008 the current Advisory Board members are:

- Mrs Ann Marie Harli (AMBA Representative, Victoria)
- Dr. Paul Jelfs (Australian Bureau of Statistics, Australian Capital Territory)
- A/Professor Paul Lancaster (University of Sydney, Retired)
- Mr William Mackerras (Twin Representative, Australian Capital Territory)
- Dr. Keith Horsley (Australian Institute of Health and Welfare, Retired)
- Professor Margaret Otlowski (University of Tasmania)
- Mr Vincent Pollaers (Twin Representative, Chair, New South Wales)
- Professor David Ravine (Western Australian Institute of Medical Research)
- A/Professor David Whiteman (Queensland Institute of Medical Research)

EX-OFFICIO:

- Professor John Hopper (Director, ATR, University of Melbourne)
- Dr Debra Foley (Deputy Director, ATR, ORYGEN Research Centre)

EXPERT REFERENCE GROUP

The Expert Reference Group (ERG) is a resource available to the ATR to proactively and positively assist it in pursuing the ATR's primary objectives. Members of the ERG are:

- Professor Sam Berkovic, Epilepsy Research Centre, Austin Hospital, Melbourne, Victoria
- Professor Brian Byrne, School of Psychology and Language and Cognition Research Centre, The University of New England, New South Wales
- Professor Nick de Klerk, Department of Biostatistics & Genetic Epidemiology, Telethon Institute for Child Health Research, Western Australia
- Dr Ruth Morley, Department of Paediatrics, Royal Children's Hospital, University of Melbourne, Melbourne, Victoria
- Professor Lyle Palmer, Laboratory for Genetic Epidemiology, Western Australian Institute of Medical Research, Western Australia
- Dr Claire Roberts, Obstetrics and Gynaecology, The University of Adelaide, South Australia
- Dr Melissa Southey, Genetic Epidemiology Laboratory, Department of Pathology, University of Melbourne, Victoria
- Professor John Wark, Department of Medicine, Royal Melbourne Hospital, Victoria

ATR STAFF

The ATR is administered through The University of Melbourne, within the Centre for Molecular, Environmental, Genetic, and Analytic (MEGA) Epidemiology, in the School of Population Health. The

ATR currently employs two full time (Coordinator and Project Support Officer) and one part time (Senior Project Support Officer) administration staff; five casual staff (equivalent of 1.6 EFT), and a part time Database Manager. The ATR also provides an honorarium towards a part time Deputy Director.



Professor John Hopper, Director



Dr Ruth Morley, Deputy Director



Dr Debra Foley, Deputy Director



Jenny Boadle, Coordinator (from May '08); Emily England, Coordinator (maternity leave); Kim Dorrell, Senior Project Support Officer; Shaie O'Brien, Project Support Officer (from May '08)



Research Assistants (from top left): Jackie Arbuckle, Sallie Savi, Marian Fenwick, (from bottom left) Helen Rodais and Sharon Feher

Staff are employed via (and subject to terms and conditions of) The University of Melbourne. The part-time Deputy Director position is occupied by an external Researcher, employed as an external consultant. The ATR provides an honorarium via invoice from the Researcher.

ATR (match) STAFF

In 2008 **match** moved from being administered through the Department of Paediatrics, based at the Royal Children's Hospital to the Centre for MEGA Epidemiology, in the School of Population Health, within the University of Melbourne.



Dr Supriya Raj, **match** Coordinator

ATR (WATR) STAFF



Professor Lyle Palmer, WATR Director



Jessica Lee, WATR Coordinator

ATR (WATCH) STAFF



Professor Nick de Klerk



Jan Hansen, Coordinator



Phyllis Alessandri, WATCH Research Assistant

ATR BUDGET

The ATR welcomes donations towards the administration and management of the Registry. Donors are provided with a receipt for their donation. Donations may be earmarked for specific activity.

We are very grateful for all the support we receive from Registry members and the wider community and are pleased to be able to list below those who have donated from 1 July 2007 – 30 June 2008.

Ron Chambers
Geoff Cousins
Ailsa Cross
Wendy Garside
Kevin Hansen
Christine Hughes
Barbara Kearsley
Vivienne Kennedy
John Leece
Ian MacLeod
Maree Ovens
Jean Rees
David Thompson
Lynne Young

Thank you also to those donors who wish to remain anonymous.

The NHMRC Enabling Grant Special Facilities Scheme provides the ATR with a budget of \$350,000 per annum. The funding extends from 1 July 2004 to 30 June 2009 for a total of 5 years. In addition, the ATR recovers costs associated with approaching twins for studies from researchers.

The following Financial Statement outlines the Actual and Proposed budget for 2004 – 2009.

Governance

2008

AUSTRALIAN TWIN REGISTRY Financial Statement

	2004 Actual	2005 Actual	2006 Actual	2007 Actual	2008 Proposed	2009 Proposed
Income/Credits						(1 / 2 Year Only)
NHMRC	252,057	350,000	350,000	350,000	350,000	175,000
Costs Recouped from Researchers	41,633	13,727	43,213	66,167	79,984	30,000
Other Costs Recouped (Registration Fees etc)				67,384	18,045	
Total Income/Credits	293,690	363,727	393,213	483,552	448,029	205,000
Refunds						
Balance brought forward from previous year	68,992	103,010	21,503	1,795	14,214	13,261
Researcher debt write-off	-1,293					
Total funds	361,389	466,737	21,503	485,347	462,243	218,261
Expenditure						
Permanent Salaries (including on-costs)	111,291	112,888	144,111	139,661	155,000	77,500
Casual Salaries	24,679	34,577	68,331	132,076	115,000	60,000
		78,156				
Subtotal salaries	135,970	225,622	212,442	271,737	270,000	137,500
Other Expenditure						
Contracted Services Fees	26,788	32,573	35,964	43,289	14,336	5000
Consumable Supplies	595	121	80	1,221	1,250	250
Stationery	2,007	2,741	3,054	7,407	10,000	3750
Travel, Accommodation & Conference Registrations (including It Runs in the Family) & Travel Grants	9,782	19,878	26,432	35,022	6,000	15000
Entertainment	1,798	1,233	2,363	355	1,000	500
Postage	20,339	24,153	25,799	23,382	26,000	3127
Telephones - 1800 Freecall number, STD and Local	3,034	6,575	6,854		8,500	4250
Software Licensing	3,370	3,454	3,540	8,475	3,700	1500
Equipment Purchase & Maintenance	6,239	2,147	5,346	3,646	1,000	500
Internal Computing Charges (Website Hosting etc)	587	622	486	3,011	500	250
Photocopying (Internal)	1,157		11	451		
Copying (Design & Print Centre - Mailout Materials)	11,324	1,896	1,120	208		

	2004 Actual	2005 Actual	2006 Actual	2007 Actual	2008 Proposed	2009 Proposed
Printing (Design & Print Centre - Newsletter/Annual Report)	13,450	16,591	21,204		21,000	
Advertising	745		2,989	1,654	400	504
Journal Subscriptions	212	357	323		350	350
Freight/Couriers	105	225	535	41	100	100
Parking	32	18	8			
Staff Training and Development	370	235				
Subtotal Other Expenditure	101,934	112,819	136,108	128,162	94,136	35,081
WATCH						
Salaries						
Project Co-ordinator 0.4 FTE, ICHR SRO 2 - Jan Hansen	7,455	14,910	14,910	8,904		
Research Clerk 0.6 FTE, ICHR RSC 6 - Kerry Coleman	8,977	17,954	17,954	13,356		
Other Expenditure						
Postage (including reply paid)						
Initial letter: 315*\$4						
Follow up letters: 200*\$2						
Resending questionnaires 50*\$2						
Printing 500*\$10						
Stationery (envelopes etc.)						
Telephone calls 1500*\$1						
Data entry (questionnaire development, scanning etc)						
Computer maintenance etc						
Subtotal of Other Expenditure	5,516	11,032	11,032	8,023		
Subtotal WATCH	-	65,844	43,896	30,283	43,896	21,948
match						
Salaries - Cohort Co-ordinator 0.5 FTE		40,950		40,950		
Other Expenditure eg. recruitment kit, planning meetings	20,475		20,475			
Subtotal match	20,475	40,950	20,475	40,950	40,950	20,475
Total Expenditure	258,379	445,235	412,921	471,132	448,982	215,004
Balance as at 31st December (Total Funds - Total Expenditure)	103,010	21,502	1,795	14,214	13,261	3,257

Appendix 1

2008

Appendix 1

All Studies by Status

Study No.	Researchers and Study Title	Status Time Frame
00-001	Prof John Eisman (Garvan Institute Of Medical Research) Professor John Eisman (Garvan Institute, Sydney) OESTROGEN AND VITAMIN D INTERVENTION STUDY	COMPLETED
81-001	Prof Grant Townsend (The University Of Adelaide) Professor Brown, Dr Richards, Mr Travan (University of Adelaide) Teeth and Faces of Young Australian Twins	1981-2005 ACTIVE - ONGOING PROGRAM
84-001	Prof John Eisman (Garvan Institute Of Medical Research) Epilepsy in Twins	1984-COMPLETED
87-001	Prof Sam Berkovic (Epilepsy Research Centre) Epilepsy in Twins	1987-COMPLETED
88-001	Prof John Hopper (MEGA Epidemiology) Professor Margaret Hamilton (University of Melbourne), Dr David Hill, and Ms Vickie White (Anti-Cancer Council of Victoria) Longitudinal study of adolescent and young adult twins	1988-COMPLETED
88-001-2	Prof John Hopper (MEGA Epidemiology) Professor Margaret Hamilton (University of Melbourne), Dr David Hill, and Ms Vickie White (Anti-Cancer Council of Victoria) Longitudinal study of adolescent and young adult twins: Phase II	1988-2002-COMPLETED
88-001-3	Dr Vicki White (The Cancer Council Of Victoria) Why one twin smokes and the other doesn't: Understanding the reasons why children growing up in the same family develop different smoking behaviours (YATS Smoking Study)	2002-COMPLETED
88-001-4	Dr Vicki White (The Cancer Council Of Victoria) Genetic and environmental determinants of tobacco and alcohol use trajectories into adulthood: a prospective twin study (YATS Tobacco & Alcohol)	2003-ACTIVE - DATA ANALYSIS
88-002	Prof John Hopper (MEGA Epidemiology) Ego Seeman Co-twin Control Study of Tobacco Use and Bone Mass (Twins)	COMPLETED
89-001	Prof John Hopper (MEGA Epidemiology) Ego Seeman Twin-family study of lifestyle, genetic and environmental causes of variation in bone mass (A Study of Bone Mass in Twins and Their Families)	COMPLETED
90-001	Prof John Wark (The University Of Melbourne) Prof John Hopper (University of Melbourne), Prof Caryl Nowson (Deakin University), Prof Richard Larkins, Prof Doris Young (University of Melbourne) DIETARY INTERVENTIONS AND BONE MASS: PROSPECTIVE STUDIES IN FEMALE TWINS [Factors in gain and loss of bone in young, menopausal, and elderly twins] (Royal Melbourne Twin Bone Study, Royal Melbourne Twin Research Program, Twin and Sister Bone Research Program)	COMPLETED
90-001-2	Prof John Wark (The University Of Melbourne) Prof John Hopper (University of Melbourne), Prof Caryl Nowson (Deakin University), Prof Richard Larkins, Prof Doris Young (University of Melbourne) The effect of long-term calcium supplementation on bone densitometry in young female twins (an extension of the Twins Bone Program) (Royal Melbourne Twin Research Program)	COMPLETED
91-001	Prof Tony Cunningham (Westmead Hospital) Dr Hassan Naif (Westmead Hospital)Host cell genetic effect on HIV-1 replication in monocytes and macrophages using dential and non-identical twins	1991-2001 COMPLETED
91-002	Prof Stephen Harrap (The University Of Melbourne) Prevention of coronary disease – A genetic approach “The Victorian Family Heart Study” (VICTORIAN FAMILY HEART STUDY)	1991-2006 ACTIVE - DATA ANALYSIS
91-002-2	Prof Stephen Harrap (The University Of Melbourne) The Family Study of Heart Size	1997-2000 ACTIVE - DATA ANALYSIS
91-002-3	Prof Stephen Harrap (The University Of Melbourne) Dr Shannon Harrison, Dr Rodney Sinclair, Dr Justine Ellis, The Prevention of Coronary Disease - A Genetic Approach : The Androgen Receptor and Female Androgenetic Alopecia (Vic Family Heart Study - Female Baldness Control Study)	2002-ACTIVE - DATA ANALYSIS
92-001	Prof Patricia Noller (The University Of Queensland) Candida Peterson, Grania Sheehan (University of Queensland) SIBLING PERCEPTIONS OF DIFFERENTIAL PARENTAL TREATMENT	1992-COMPLETED
92-002	Mr Greg Murray (The University Of Melbourne) Survey Study of Seasonality	1992-COMPLETED
92-003	A/Prof Ego Seeman (Austin & Repatriation Medical Centre) Tobacco consumption, peak bone density and body composition in children: a co-twin control study (Smoking and Bone Mass, Adol. Smoking)	1992-COMPLETED

Study No.	Researchers and Study Title	Status Time Frame
92-008	Dr Sue Treloar (Queensland Institute Of Medical Research) Menopause, hysterectomy, and HRT: genetic and environmental influences (Menopause Study)	1991-COMPLETED
92-011	Dr Edward McMurchie (CSIRO) Dr Caryl Nowson (Deakin University) Genetic Factors associated with altered cheek cell sodium transport in human hypertension: a twin study (HUMAN CHEEK CELLS, SODIUM TRANSPORT AND ESSENTIAL HYPERTENSION)	1992-1997 COMPLETED
93-001	Prof Brian Morris (Institute For Biomedical Research) Molecular genetics of essential hypertension	1993-1999 COMPLETED
93-005	Prof Nick Martin (Queensland Institute Of Medical Research) OVER 50s TWIN STUDY: (Over 50's Twin Study)	1999-COMPLETED
93-007	Dr Judith Burstyner A study of dental anxiety and psychological variable in female twins (DENTAL ANXIETY IN FEMALE TWINS)	1993-1998 COMPLETED
93-011	Prof Nick Martin (Queensland Institute Of Medical Research) Dr Adele Green, Dr Joanne Aitken (QIMR) LONGITUDINAL STUDY OF MELANOCYTIC NAEVI IN TWINS (Mole Development in Pubescent Twins) (Twin Mole Study)	1993-2008 ACTIVE - ONGOING PROGRAM
93-014	Prof Patricia Noller (The University Of Queensland) Sibling perceptions of differential treatment by parents: Outcomes for personality, social competence and health	1993-COMPLETED
93-015	A/Prof Florence Levy (The Prince Of Wales Children's Hospital) Professor David Hay (Curtin University of Technology) Attention Deficit Hyperactivity Disorder in Twins and Siblings (Australian Twin ADHD Study)	1993-2002 COMPLETED
93-016	Prof Nancy Segal (California State University At Fullerton) Twin Study of Bereavement	1993-1997 COMPLETED
94-004	A/Prof Tracey Wade (Flinders University Of South Australia) Investigating the genetic epidemiology of disordered eating (TWIN STUDY OF EATING PATTERNS)	1994-1997 COMPLETED
94-005	Prof John Hopper (MEGA Epidemiology, The University of Melbourne) Prof Graham Giles (ACCV), Dr Margaret McCredie (NSW Cancer Council), Dr Dallas English (ACCV), Dr Norman Boyd (Ontario Cancer Institute), Dr Martin Yaffe (Sunnybrook Hospital, Toronto, Canada) A twin study of mammographic breast density and the risk of breast cancer (A TWIN STUDY OF MAMMOGRAPHIC PARENCHYMAL PATTERNS AND BREAST DENSITY)	1994-2003 ACTIVE - ONGOING PROGRAM
94-005-2	Prof John Hopper (MEGA Epidemiology, The University of Melbourne) Genetic and Environmental determinants of mammographic density: A twins and sisters study (The Australian Twins and Sisters Breast Density Study)	2003-2012 ACTIVE - ONGOING PROGRAM
94-007	Dr Leon Flicker (The University Of Melbourne) Prof John Wark, Prof John Hopper (University of Melbourne) Bone Density in Elderly Female Twins	1994-2002 COMPLETED
94-008	Ms Katie Wood (Swinburne University Of Technology) Professor David Hay (Curtin University of Technology) Attention deficit disorder with and without hyperactivity	1994-1999 COMPLETED
94-099	Dr Colin Robertson Prof Peter D Phelan (Royal Melbourne Children's Hospital) Asthma, atopy and bronchial reactivity in twins	1994-1995 COMPLETED
95-002	Prof Philip Sambrook (Royal North Shore Hospital) Genetics of cervical and lumbar spondylosis	1995-1996 COMPLETED
95-004	Prof Nick Martin (Queensland Institute Of Medical Research) Dr John Whitfield (RPA Hospital), Dr Andrew Heath (St Louis, USA) Persistence and change in drinking habits: A twin-family study (Twin Alcohol Study)	1995-2002 ACTIVE - DATA ANALYSIS
96-001	A/Prof Ego Seeman (Austin & Repatriation Medical Centre) Ms Georgina Pearce, Mr Yung Van Ho, Ms Sheila Matthews (Austin & Repatriation Hospital) BONE MASS IN ADOLESCENT MALE-MALE AND MALE-FEMALE TWIN PAIRS	1996- ACTIVE - ONGOING PROGRAM
96-002	Dr Raymond Kelly (St Vincent's Hospital/VCCRI) Dr Chris Hayward (St Vincent's Hospital) Non-invasive assessment of genetic influences on cardiovascular function	1996-1999 COMPLETED
96-003	Dr Michael Nicholls (The University Of Melbourne) The effect of uterine hormonal levels upon lateral preference	1996-1998 COMPLETED
96-005	Prof John Wark (The University Of Melbourne) Prof John Hopper (University of Melbourne), Dr Simon Foote (WEHI) Risk genes for osteoporosis and other common diseases: a twin approach to interval mapping of loci (an extension of the Royal Melbourne Twin Bone Research Program) (Royal Melbourne Twin Bone Study, Royal Melbourne Twin Research Program)	1996-ON HOLD
96-005-1	Prof John Wark (The University Of Melbourne) Prof John Hopper (University of Melbourne), Dr Simon Foote (WEHI) Protocol amendments: Fasting blood sample and Genetics of Common Human disease -a twin study (Gemini Genomics AUS002) (Twin Bone Study - Gemini Protocol AUS002)	1996-ON HOLD

Appendix 1

2008

Appendix 1

All Studies by Status

Study No.	Researchers and Study Title	Status Time Frame
96-006	Prof Nick Martin (Queensland Institute Of Medical Research) Dr Paul Burton, Prof John Hopper, Dr Mark Jenkins (University of Melbourne), Prof David Hay (Curtin University of Technology) An Australian multi-centre twin-based study of the genetic epidemiology of asthma and atopy	1996-1999 COMPLETED
96-007	Dr Sue Treloar (Queensland Institute Of Medical Research) Genetic epidemiology of endometriosis	1996-2010 ACTIVE - WRITING UP
96-007-2	Dr Sue Treloar (Queensland Institute Of Medical Research) Genes Behind Endometriosis	1999-2010 ACTIVE – WRITING UP
96-007-3	Dr Sue Treloar (Queensland Institute Of Medical Research) Dr D Purdie, Prof Adele Green, T Bell Antenatal, childhood and adolescent risk factors for endometriosis (Risk Factors for Endometriosis)	2001-2010 ACTIVE – WRITING UP
96-008	Dr Sue Treloar (Queensland Institute Of Medical Research) Twin studies of pre-eclampsia / eclampsia	1996-COMPLETED
96-009	Prof Philip Sambrook (Royal North Shore Hospital) Twin Studies of the genetics of osteoarthritis and osteoporosis	1996-2008 ACTIVE - ONGOING PROGRAM
96-009-1	Prof Philip Sambrook (Royal North Shore Hospital) Twin Study of the Genetics of Osteoarthritis and Osteoporosis (Protocol AUS001)	APPROVED
96-010	Dr Margie Wright (Queensland Institute Of Medical Research) Prof Nick Martin The genetic determinants of working memory, information processing and intelligence in twins (Quantitative & Molecular Genetic Analysis of Intelligence, Genes for cognition: The Brisbane Twin Memory, Attention, and Problem Solving (MAPS) Study)	1996-2008 ACTIVE - ONGOING PROGRAM
97-001	Prof Sam Berkovic (Epilepsy Research Centre) Epilepsy in Twins and Families: Analysis of Acquired Factors (CAUSES OF EPILEPSY)	1997-2002 COMPLETED
97-001-2	Prof Sam Berkovic (Epilepsy Research Centre) Prof Roger Short (Perinatal Research Centre, Royal Women's Hospital) Study of Twin Zygosity	1999-2001 COMPLETED
97-001-3	Prof Sam Berkovic (Epilepsy Research Centre) Dr Regula Briellman, A/Prof David Reutens, A/Prof Graeme Jackson Morphological and Spectroscopic Study of Monozygotic Twins Discordant for Epilepsy (Epilepsy and Twins Research Program; MRI Study)	2001-2010 ACTIVE - ONGOING PROGRAM
97-002	Prof Nick Martin (Queensland Institute Of Medical Research) Dr Kirsten Ohm Kyvik (Danish Twin Registry), Prof John Hopper (University of Melbourne) Diabetes in Australian Twins	1997-2002 COMPLETED
97-003	Prof David Handelsman (Concord Repatriation General Hospital) Epidemiology of Prostate Size in Healthy Australian Men	1997-2001 COMPLETED
97-004	Prof John Eisman (Garvan Institute Of Medical Research) Dr Chris White (Garvan Institute, Sydney) Genetic control of bone mineral density and ultrasound bone metabolism and body composition (an extension of Sambrook: "Genetics of cervical & lumbar spondylosis" (95-002) (Garvan Bone Study)	1997-1999 COMPLETED
97-006	Prof David Hay (Curtin University Of Technology) Prof Nick Martin (QIMR), Prof Florence Levy (Prince of Wales Hospital) Genetic relationship between adult behavioural traits and childhood behavioural disorders	1997-2002 COMPLETED
97-007	Dr Caryl Nowson (Deakin University) Predictors of blood pressure response to alterations in dietary salt	1997-2001 COMPLETED
98-001	Prof Brian Byrne (University Of New England) Genetics of Reading Ability	1998-2009 ACTIVE - ONGOING PROGRAM
98-001-1	Prof Brian Byrne (University Of New England) Genetics of Reading Ability: Extension	2008-2010 APPROVED
98-002	Prof Con Stough (Swinburne University Of Technology) Mr John Song Brain Electrical Activity and Intelligence	1998-2002 COMPLETED
98-003	Prof Nick Martin (Queensland Institute Of Medical Research) Prof Wendy Slutske Familial transmission of antisociality / conduct disorder and alcoholism	1998-2002 COMPLETED
98-006	A/Prof Florence Levy (The Prince Of Wales Children's Hospital) Prof David Hay (Curtin University of Technology) A developmental / genetic approach to the determination and expression of ADHD	1998-ACTIVE - ONGOING PROGRAM

Study No.	Researchers and Study Title	Status Time Frame
98-007	Prof John Wark (The University Of Melbourne) Dr Anne-Marie Cassano, Ms Natalie El Haber, Dr Kim Bennell A study of the heritability of balance in a cohort of twins (Gait and Balance Study)	1998-2006 ACTIVE – WRITING UP
98-008	Prof John Hopper (MEGA Epidemiology, The University of Melbourne) Australian Breast Cancer Twin Family Study	1998-2010 ACTIVE - DATA ANALYSIS
99-001	Prof Patricia Noller (The University Of Queensland) Prof SRH Beach (University of Georgia) Understanding Twins in Situations of Comparison and Competition (Competition)	1999-2002 COMPLETED
2000-001	Dr Mark Mclean (Westmead Hospital) Dr Wah Cheung The relationship between birth weight and the Metabolic Syndrome: A study in twins	2000-2003 COMPLETED
2000-002	Prof Gordon Parker (Prince Of Wales Hospital) Genetically Driven Constructs of Temperament: Assessing Variation in Self-report Scales	2000-2005 ACTIVE – WRITING UP
2001-002	A/Prof Tracey Wade (Flinders University Of South Australia) How do interactions between genes and specific environmental risk factors cause eating disorders in women? (Variations in Eating Behaviour Among Women)	2001-2007 ACTIVE - DATA ANALYSIS
2001-003	Dr Janet Fletcher (The University Of Melbourne) Ms Deborah Loakes A Forensic Phonetic Investigation of the Voices of Identical and Non-identical Twins	2001-2002 COMPLETED
2001-004	Prof Nick Martin (Queensland Institute Of Medical Research) The Genetics of Vulnerability to Nicotine Addiction	2001-2006 ACTIVE - DATA ANALYSIS
2001-005	A/Prof David Mackey (Royal Victorian Eye & Ear Hospital) Dr Jamie E Craig, Dr Johan Poulsen, Dr James Morgan Twin study of ophthalmic screening parameters	2001-2008 ACTIVE – DATA ANALYSIS
2001-005-1	A/Prof David Mackey (Royal Victorian Eye & Ear Hospital) Dr Jamie E Craig, Dr Johan Poulsen, Dr James Morgan Twin study of ophthalmic screening parameters	2005-2008 ACTIVE – DATA ANALYSIS
2002-000-1	Prof John Hopper (MEGA Epidemiology, The University of Melbourne) Andrew Thomson Test Australia - The National IQ Test 2002	2002-2002 COMPLETED
2002-002	A/Prof Bryan Mowry (Queensland Centre For Mental Health Research) Dr Dornique Hannah A Study of the Potential Causes of Psychosis in a Twin Sample	2002-2007 ACTIVE - RECRUITING
2002-003	Prof Andrew Butcher (Flinders University) The Genetics of Voice: A Comparison of Acoustic Parameters in MZ and DZ Twins (Genetics of Voice)	2002-COMPLETED
2002-004	Prof David Hay (Curtin University Of Technology) A/Professor Florence Levy Genetic Comparison of two measures of Attention Deficit Hyperactivity Disorder (ADHD) (A Study on the Behaviour of Children in Families with Twins)	2002-COMPLETED
2002-004-2	Ms Jillian Pearsall-Jones (Curtin University Of Technology) A/Prof Jan Piek; Dr Lyndall Steed; A/Prof Florence Levy; Prof F Xavier Castellanos Monozygotic Twins Discordant for Developmental Coordination Disorder and Attention Deficit Hyperactivity Disorder: An Integrated Approach to the Bio-Psycho-Social Correlates	2002-ACTIVE - DATA ANALYSIS
2002-004-3	Prof David Hay (Curtin University Of Technology) A/Professor Florence Levy, A/Professor Jan Piek Solving the Jigsaw! Understanding biological and environmental effects on ADHD through discordant monozygotic twins.	2004-2009 ACTIVE - RECRUITING
2002-004-4	Prof David Hay (Curtin University Of Technology) Main Principal Investigator: Abdullah R Sheikh (PhD Candidate) Co-Investigators: A/Professor Florence Levy, A/Professor Jan Piek Two Approaches to the Molecular Genetic Analysis of ADHD Subtypes in Australian Twins	2004-2009 ACTIVE – WRITING UP
2002-004-5	Prof David Hay (Curtin University Of Technology) Main Principal Investigator: Megan McDougall (PhD Candidate) Co-Investigators: A/Professor Florence Levy, A/Professor Jan Piek Family and Sibling Relationships When Twins Are Discordant for Attention Deficit Hyperactivity Disorder (ADHD)	2004-2008 ACTIVE - DATA ANALYSIS
2002-004-6	Prof David Hay (Curtin University Of Technology) Main Principal Investigator: James Dent (PhD Candidate) Co-Investigators: A/Professor Florence Levy, A/Professor Jan Piek Developmental correlates of reactive and proactive regression (RA/PA) (TBC)	2004-2007 ACTIVE – WRITING UP
2002-004-7	Prof David Hay (Curtin University Of Technology) A/Professor Florence Levy Genetic Comparison of two measures of Attention Deficit Hyperactivity Disorder (ADHD). Twin and Sibling Questionnaire: Supplement (A Study on the Behaviour of Children in Families with Twins)	2005-APPROVED

Appendix 1

2008

Appendix 1

All Studies by Status

Study No.	Researchers and Study Title	Status Time Frame
2002-005	Dr Rodney Sinclair (St Vincent's Hospital) Common Baldness, Dandruff and Greying of Hair in Twins	2002-2003 COMPLETED
2003-001	A/Prof Robyn Guymier (The University Of Melbourne) Dr Paul Baird, Dr Matthew Chamberlain Genetic & Environmental Risk Factors in Age-related Macular Degeneration - A Twin Study	2003-2008 ACTIVE - ONGOING PROGRAM
2003-001-1	Dr Paul Baird (The University Of Melbourne) Dr Robyn Guymier, Mohamed Dirani Genetic & Environmental Risk Factors in Myopia - A Twin Study (GEM)	2004-2007 ACTIVE – DATA ANALYSIS
2003-001-2	Dr Paul Baird (The University Of Melbourne) Mohamed Dirani Genetic & Environmental Risk Factors in Myopia - A Twin Study: Separated Twins	2007-ACTIVE – DATA ANALYSIS
2003-002	Prof Nick Martin (Queensland Institute Of Medical Research) The Genetics of Borderline Personality Disorder (Personality Features in Adulthood)	2003-2006 ABANDONED
2003-003-1	Prof Nick Martin (Queensland Institute Of Medical Research) Molecular Epidemiology of Alcoholism 1: Candidate Gene (IRPG 1)	2003-2006 ACTIVE - DATA ANALYSIS
2003-003-2	Prof Nick Martin (Queensland Institute Of Medical Research) Variations in the effects of alcohol on liver function (IRPG5)	2003-2008 ACTIVE - DATA ANALYSIS
2003-003-3	Prof Nick Martin (Queensland Institute Of Medical Research) Molecular Epidemiology of Alcoholism 3: EDAC Families (IRPG3)	2003-2006 ACTIVE - DATA ANALYSIS
2004-001	Prof Grant Townsend (The University Of Adelaide) A/Prof Kim Seow (UQ), A/Prof Theo Gotjamanos (UWA), Dr Toby Hughes (UA), Prof Lindsay Richards (UA). Tooth Emergence and Oral Health in Twins and Their Families	2004-2009 ACTIVE – RECRUITING
2004-002	Prof David Hay (Curtin University Of Technology) Associate Prof. Florence Levy, School of Psychiatry, University of NSW Associate Prof. Jan Piek, School of Psychology, Curtin University of Technology Investigations of ADHD: Magnetic Resonance Imaging	2004-2005 ACTIVE - DATA ANALYSIS
2004-003	Prof John Wark (The University Of Melbourne) A/Prof Terence O'Brien, Ms Lynda Paton, Prof Sam Berkovic, Prof Phillip Sambrook, A/Prof K Bennell, Dr Sandra Petty The Effect of Anti-Epileptic Medications on Bone Mineral Density, Balance and Fracture Risk - A Twin and Sibling Study (AED Twin Study)	2004-2009 ACTIVE - RECRUITING
2004-004	Prof John Wark (The University Of Melbourne) Ms Catherine Segan, Dr Richard Osborne, Assoc Prof Caryl Nowson, Assoc Prof Peter Ebeling (C l s) Prof Phillip Sambrook, Prof John Hopper, Dr Ronald Borland, Prof Nick Martin (A l s) 1. Cross-sectional, within-pair comparison of smoking discordant twins. 2. Smoking cessation and indices of bone health: a co-twin trial (Twin Smoking Study 1 (Discordant) and Twin Smoking Study 2	2004-2007 ACTIVE - RECRUITING
2004-006	Prof John Hopper (MEGA Epidemiology, The University Of Melbourne) Steve Gilbert - Supervising producer. Jeff Shenker - Production Manager Channel 9 - "Who Wants To Be A Millionaire" - Identical Twins Special (Who Wants To Be A Millionaire)	2004-2004 COMPLETED
2004-007	A/Prof Tracey Wade (Flinders University Of South Australia) Risk factors for the development of eating disorder phenotypes and endophenotypes in adolescent twins (Risk factors for the development of eating disorders in adolescent twins)	2004-2007 ACTIVE – DATA ANALYSIS
2005-001	Prof John Hopper (MEGA Epidemiology, The University Of Melbourne) Channel 7: Deal Or No Deal Twins Special	2005-2005 COMPLETED
2005-002	Prof David Hay (Curtin University Of Technology) Prof Nick Martin, Prof Richard Todd, Prof Florence Levy Molecular Genetics of Inattention in Australia	2005-2010 ACTIVE - RECRUITING
2005-003	Prof Perminder Sachdev (Prince Of Wales Hospital) Dr Julian Trollor The Twin Study of Brain Ageing and Cognition (The Twin Study of Brain Ageing and Cognition)	2005-2011 ACTIVE - RECRUITING

Study No.	Researchers and Study Title	Status Time Frame
2006-001	Dr Michael Lynskey (Washington University) Prof Nick Martin Cannabis and Other Illicit Drug Use: A Twin Study	2006-2010 ACTIVE - RECRUITING
2006-001-1	Dr Michael Lynskey (Washington University) Prof Nick Martin Cannabis and Other Illicit Drug Use: A Twin Study – Phase 2	2006-2010 FULL APPLICATION
2006-002	Prof John Hopper (MEGA Epidemiology, The University Of Melbourne) SBS Insight Twins Program	2006-COMPLETED
2006-003	Dr Paul Baird (The University Of Melbourne) Mr Robert van de Berg Myopia Sub-Study: Myopia and Personality (Myopia and Personality)	2006-2007 COMPLETED
2006-004	Prof Suzanne Garland (Royal Women's Hospital) A/Pr Dorota Gertig, Prof John Wark, A/Pr Sepehr Tabrizi, Prof Marian Pitts, Dr Bircan Erbas Genetic and environmental factors in invasive cervical cancer: a twin study (Cervical Cancer)	2006-2009 ACTIVE - RECRUITING
2006-005	Prof Karen Thorpe (Queensland University of Technology) Compromised or competent? A longitudinal study of twin children's social competencies, friendships and behavioural adjustment. (Primary School Transition)	2009-2008 ACTIVE - RECRUITING
2006-006	Prof Tien Wong (University Of Melbourne) Dr. Cong Sun (PhD student) Genetic and environmental contributions to retinal microvascular signs in Australian twins. (Retinal)	2006-ACTIVE - DATA ANALYSIS
2007-001	Dr David Greene (Australian Catholic University) Associate Professor Geraldine Naughton, Director – Centre of Physical Activity Across the Lifespan (CoPAAL) Australian Catholic University Ortical and trabecular bone mass response to 12 month calcium and vitamin D supplementation in monozygotic preadolescent females (Calcium and Bones in Pre-Teen Girls)	2006-2007 ACTIVE – WRITING UP
2007-002	A/Prof Jane Halliday (Murdoch Childrens Research Institute) Impact of Folic Acid (FA) on Perinatal Outcome of Twins (Perinatal Folate)	2006-2008 ACTIVE – WRITING UP
2007-003	Dr Anthony (Tony) Marks (University of New England) Dr Donald Hine, University of New England Professor Brian Byrne, University of New England The heritability of rational (analytical) versus experiential (intuitive) reasoning: A pilot study (Heritability of Reasoning: Pilot)	2006-ETHICS
2007-004	A/Prof Diane Fatkin (Victor Chang Cardiac Research Institute) A/Prof Jaime Vandenberg, Electrophysiology and Bioinformatics Program, VCCRI Statistical collaborator – TBC Dr Katrina Scurrah Role of genetic and environmental factors in atrial fibrillation (Atrial Fibrillation)	2006-2009 ACTIVE – RECRUITING
2007-005	A/Prof David Champion (University of NSW) Shanthi Pathirana An investigation into the nature of Growing Pains (Growing Pains)	2007-2008 ACTIVE – RECRUITING
2007-006	Dr Murray Maybery (University of Western Australia) Autism	2006- ACTIVE – RECRUITING
2008-001	A/Prof Ego Seeman (Austin & Repatriation Medical Centre) Jean Clare; Dr Roger Zebaze; Prof John Hopper Effects of Menopause on the Structure of Bone (Menopause and Bones)	2008-2010 ACTIVE- RECRUITING
2008-002	Dr Velandai Srikanth (Monash University) Prof David Reutens; Dr Thanh Phan; Prof John Hopper Genes, Diabetes Mellitus and Dementia (Diabetes and Dementia)	2006- ACTIVE – RECRUITING
2008-003	Dr Elizabeth Ellis (University of New England) Prof Brian Byrne; Mr Will Coventry; Dr Ines Anton-Mendez The genetic and environmental etiology of second language acquisition (Second language)	2007-2008 ACTIVE – RECRUITING
2008-004	A/Prof Leanne Williams (Westmead Millennium Institute) A/Prof Peter Schofield; Prof Richard Clarke; Dr Andrew Kemp Pathways to Affective Disorders: Interactions between Genes, Environment and Biological Mechanisms (Affective Disorders)	2007-2012 FULL APPLICATION

Appendix 2

2008

Appendix 2 Publications List

BOOK SECTION

Bennett, K. S., F. Levy, et al. (2007). Behaviour Genetic Approaches to the study of ADHD. Handbook of attention deficit hyperactivity disorder. M. Fitzgerald, M. Bellgrove and M. Gill. West Sussex, England, John Wiley and Sons: 111-128.

Byrne, B. (in press). Reading and reading acquisition. Encyclopedia of Library and Information Sciences, Taylor & Francis.

Byrne, B., D. Khlentzos, et al. (in press). Evolutionary and genetic perspectives on educational attainment. Handbook of educational psychology. K. Littleton, C. Wood and J. K. Staarman.

Byrne, B., R. K. Olson, et al. (in preparation). Tasking the learning in learning to read seriously: Evidence from intervention and twin studies (tentative title). Scientific Studies of Reading.

Byrne, B., D. Shankweiler, et al. (2008). Reading development in children at risk of dyslexia. Brain, Behavior, and Learning in Language and Reading Disorders. M. Mody and E. Silliman. New York, Guilford Press.

Hay, D. A. and A. Barton (in press). Attention-deficit/hyperactivity disorder and comorbid drug use. Responding to Co-occurring Mental Health and Drug Disorders. S. Allsop and W. Saunders. Perth, IP Communications.

Montgomery, G. W. and S. A. Treloar (in press). Genetic variation and endometriosis risk, Blackwell.

Noller, P., C. Conway, et al. (2008). Sibling relationships in adolescent and young adult twin and nontwin siblings: Managing competition and comparison. Social relationships: Cognitive, affective and motivational processes. J. Forgas and J. Fitness. New York, Psychology Press.

Olson, R. K., B. Byrne, et al. (2008). Reconciling strong genetic and strong environmental influences on individual differences and deficits in reading ability. How Children Learn To Read: Current Issues and New Directions in the Integration of Cognition, Neurobiology and Genetics of Reading and Dyslexia Research and Practice. K.Pugh and P. McCardle, Taylor & Francis.

Wright, M., N. A. Gillespie, et al. (2008). Genetics of personality and cognition in adolescents. Development Psychopathology and Wellness: Genetic and Environmental Influences. J. Hudziak. Washinton, American Psychiatric Publishing Inc.: 85-107.

PEER REVIEWED PUBLICATIONS

Anderson, C. A., D. L. Duffy, et al. (2007). "Estimation of variance components for age at menarche in twin families." *Behav Genet* 37(5): 668-77.

Anderson, C. A., G. Zhu, et al. (2008). "A genome-wide linkage scan for age-at-menarche in three populations of European descent." *J Clin Endocrinol Metab*.

Bates, T. C., M. Luciano, et al. (2007). "Replication of reported linkages for dyslexia and spelling and suggestive evidence for novel regions on chromosomes 4 and 17." *Eur J Hum Genet* 15(2): 194-203.

Bierut, L. J., P. A. Madden, et al. (2007). "Novel genes identified in a high-density genome wide association study for nicotine dependence." *Hum Mol Genet* 16(1): 24-35.

Bigault, O., S. N. Shekar, et al. (In prep). "High heritability of refractive error and axial length. The Twins Eye Study."

Busst, C. J., K. J. Scurrah, et al. (2007). "Selective genotyping reveals association between the epithelial sodium channel gamma-subunit and systolic blood pressure." *Hypertension* 50(4): 672-8.

Busst, C. J., K. J. Scurrah, et al. (2007). "Selective genotyping reveals association between the epithelial sodium channel y-subunit and systolic blood pressure." *Hypertension* (In press.)

Byrne, B., W. L. Coventry, et al. (2008). "A behavior-genetic analysis of orthographic learning, spelling and decoding." *Research in Reading* 31(1): 8-21.

Byrne, B., W. L. Coventry, et al. (under revision). "Genetic and environmental influences on aspects of literacy and language in early childhood: Continuity and change from preschool to Grade 2." *Journal of Neurolinguistics*.

Byrne, B., S. Samuelson, et al. (in preparation). "Title unknown:- update on preschool stage of longitudinal twin study of reading and language, with country comparison."

Byrne, B., S. Samuelsson, et al. (2007). "Longitudinal twin study of early literacy development: preschool through Grade 1." *Reading and Writing: An Interdisciplinary Journal* 20: 77-102.

Carbonaro, F., T. Andrew, et al. (2008). "The Heritability of Corneal Hysteresis and Ocular Pulse Amplitude A Twin Study." *Ophthalmology*.

Cobb, J., C. Busst, et al. (2008). "Searching for functional genetic variants in non-coding DNA." *Clin Exp Pharmacol Physiol* 35(4): 372-5.

Cornes, B. K., G. Zhu, et al. (2007). "Sex differences in genetic variation in weight: a longitudinal study of body mass index in adolescent twins." *Behav Genet* 37(5): 648-60.

Dirani, M., M. Chamberlain, et al. (2007). "Discordant Refraction in Monozygotic Twins." *Australian Orthoptic Journal* 47(11): 4756-4761.

Dirani, M., M. Chamberlain, et al. (2007). "Discordant unilateral myopia in adult female monozygotic twins." *Aust Orthoptic J*. 39(1): 17-18.

Dirani, M., M. Chamberlain, et al. (2008). "Testing protocol and recruitment in the genes in myopia twin study." *Ophthalmic Epidemiol* 15(3): 140-7.

Dirani, M., M. Chamberlain, et al. (in prep.). "Refraction - twin review."

Dirani, M., M. Chamberlain, et al. (in prep.). "Twin myopia study - methodology paper."

Dirani, M., T. Couper, et al. (In press 2007). "The role of genetic factors in lower and higher order aberrations? The Genes in Myopia (GEM) Twin Study." *Ophthalmic Epideiol*. 15(3): 140-147.

Dirani, M., A. Islam, et al. (in press). "The role of birth weight in Myopia? The Genes in Myopia (GEM) Twin Study." *Ophthalmic Res*.

Dirani, M., A. Islam, et al. (2008). "Body stature and myopia-The Genes in Myopia (GEM) twin study." *Ophthalmic Epidemiol* 15(3): 135-9.

Dirani, M., A. Islam, et al. (2008). "Dominant genetic effects on corneal astigmatism: the genes in myopia (GEM) twin study." *Invest Ophthalmol Vis Sci* 49(4): 1339-44.

Dirani, M., S. N. Shekar, et al. (2008). "Adult-onset myopia: the Genes in Myopia (GEM) twin study." *Invest Ophthalmol Vis Sci* 49(8): 3324-7.

Dirani, M., S. N. Shekar, et al. (2008). "Evidence of Shared Genes in Refraction and Axial Length - The Genes in Myopia (GEM) Twin Study." *Invest Ophthalmol Vis Sci*.

Dirani, M., S. N. Shekar, et al. (2008). "The role of educational attainment in refraction: the Genes in Myopia (GEM) twin study." *Invest Ophthalmol Vis Sci* 49(2): 534-8.

D'Onofrio, B. M., W. S. Slutske, et al. (2007). "Intergenerational transmission of childhood conduct problems: a Children of Twins Study." *Arch Gen Psychiatry* 64(7): 820-9.

Duffy, D. L., G. W. Montgomery, et al. (2007). "A three-single-nucleotide polymorphism haplotype in intron 1 of OCA2 explains most human eye-color variation." *Am J Hum Genet* 80(2): 241-52.

El Haber, N., B. Erbas, et al. (2008). "Relationship between age and measures of balance, strength and gait: linear and non-linear analyses." *Clin Sci (Lond)* 114(12): 719-27.

Ellis, J. A., K. J. Scurrah, et al. (2007). "Baldness and the androgen receptor: the AR polyglycine repeat polymorphism does not confer susceptibility to androgenetic alopecia." *Hum Genet* 121(3-4): 451-7.

Ellis, J. A., K. J. Scurrah, et al. (2007). "Comprehensive multi-stage linkage analyses identify a locus for adult height on chromosome 3p in a healthy Caucasian population." *Hum Genet* 121(2): 213-22.

Francks, C., S. Maegawa, et al. (2007). "LRRTM1 on chromosome 2p12 is a maternally suppressed gene that is associated paternally with handedness and schizophrenia." *Mol Psychiatry* 12(12): 1129-39, 1057.

Gosden, R. G., S. A. Treloar, et al. (2007). "Prevalence of premature ovarian failure in monozygotic and dizygotic twins." *Hum Reprod* 22(2): 610-5.

Grant, J. D., A. C. Heath, et al. (2007). "Spousal concordance for alcohol dependence: evidence for assortative mating or spousal interaction effects?" *Alcohol Clin Exp Res* 31(5): 717-28.

Hansell, N. K., M. R. James, et al. (2007). "Effect of the BDNF V166M polymorphism on working memory in healthy adolescents." *Genes Brain Behav* 6(3): 260-8.

Harden, K. P., S. K. Lynch, et al. (2007). "A behavior genetic investigation of adolescent motherhood and offspring mental health problems." *J Abnorm Psychol* 116(4): 667-83.

Harden, K. P., E. Turkheimer, et al. (2007). "Marital conflict and conduct problems in Children of Twins." *Child Dev* 78(1): 1-18.

Hatemi, P. K., S. E. Medland, et al. (2007). "The genetics of voting: an Australian twin study." *Behav Genet* 37(3): 435-48.

Hay, D. A., K. S. Bennett, et al. (2007). "A twin study of attention-deficit/hyperactivity disorder dimensions rated by the strengths and weaknesses of ADHD-symptoms and normal-behavior (SWAN) scale." *Biol Psychiatry* 61(5): 700-5.

He, M., J. Ge, et al. (2008). "Heritability of the iridotrabecular angle width measured by optical coherence tomography in Chinese children: the Guangzhou twin eye study." *Invest Ophthalmol Vis Sci* 49(4): 1356-61.

He, M., D. Wang, et al. (2008). "Heritability of anterior chamber depth as an intermediate phenotype of angle-closure in Chinese: the Guangzhou Twin Eye Study." *Invest Ophthalmol Vis Sci* 49(1): 81-6.

Helbig, I., N. A. Matigian, et al. (2008). "Gene expression analysis in absence epilepsy using a monozygotic twin design." *Epilepsia*.

Hewitt, A. W., J. P. Poulsen, et al. (2007). "Heritable features of the optic disc: a novel twin method for determining genetic significance." *Invest Ophthalmol Vis Sci* 48(6): 2469-75.

Hogg, R. and e. al. (in prep). "Heritability of Fundus Autofluorescence - A twin study."

Hogg, R., P. Dimitrov, et al. (in prep). "Heritability of visual function - a classical twin study."

Hogg, R., M. Dirani, et al. (In prep). "Heritability of AMD."

Hogg, R., M. Dirani, et al. (in prep). "Modification of the heritability of AMD accounting for common polymorphisms - A twin study."

Hottenga, J. J., J. B. Whitfield, et al. (2007). "Genome-wide scan for blood pressure in Australian and Dutch subjects suggests linkage at 5P, 14Q, and 17P." *Hypertension* 49(4): 832-8.

Hughes, T., M. Bockmann, et al. (in press). "Strong genetic control for timing of emergence of human primary incisors." *Journal of Dental Research*.

Hughes, T. E., M. R. Bockmann, et al. (2007). "Strong genetic control of emergence of human primary incisors." *J Dent Res* 86(12): 1160-5.

Kuo, P. H., P. Wood, et al. (2007). "Cohort trends in prevalence and spousal concordance for smoking." *Drug Alcohol Depend* 88(2-3): 122-9.

Law, V. and W. K. Seow (2007). "A longitudinal study of 0.2% chlorhexidine gel for removal of mutans streptococci infection in preschool children." *Aust Dent J* 52(1): 26-32.

Law, V., W. K. Seow, et al. (2007). "Factors influencing oral colonization of mutans streptococci in young children." *Aust Dent J* 52(2): 93-100; quiz 159.

Levy, F., D. A. Hay, et al. (in press). "Attention-Deficit/Hyperactivity Disorder in Twins: A developmental genetic analysis." *Australian Journal of Psychology*.

Levy, F., D. A. Todd, et al. (in press). "Should sluggish cognitive tempo symptoms be included in the diagnosis of Attention-Deficit/Hyperactivity Disorder?" *Journal of the American Academy of Child and Adolescent Psychiatry*.

Luciano, M., E. Hine, et al. (2007). "Effects of SCA1, MJD, and DPRLA triplet repeat polymorphisms on cognitive phenotypes in a normal population of adolescent twins." *Am J Med Genet B Neuropsychiatr Genet* 144(1): 95-100.

Luciano, M., P. A. Lind, et al. (2008). "Testing replication of a 5-SNP set for general cognitive ability in six population samples." *Eur J Hum Genet* 16(8): 1025.

Luciano, M., P. A. Lind, et al. (2007). "A haplotype spanning KIAA0319 and TTRAP is associated with normal variation in reading and spelling ability." *Biol Psychiatry*.

Luciano, M., G. Zhu, et al. (2007). "No thanks, it keeps me awake": the genetics of coffee-attributed sleep disturbance." *Sleep* 30(10): 1378-86.

Lynskey, M. T., J. D. Grant, et al. (2007). "Stimulant use and symptoms of abuse/dependence: epidemiology and associations with cannabis use-a twin study." *Drug Alcohol Depend* 86(2-3): 147-53.

Makovey, J., V. Naganathan, et al. (2007). "Gender differences in plasma ghrelin and its relations to body composition and bone - an opposite-sex twin study." *Clin Endocrinol (Oxf)* 66(4): 530-7.

Makovey, J., T. V. Nguyen, et al. (2007). "Genetic effects on bone loss in peri- and postmenopausal women: a longitudinal twin study." *J Bone Miner Res* 22(11): 1773-80.

Martin, N., K. S. Bennett, et al. (submitted). "Attention deficit hyperactivity disorder and reading ability: Results of latent class analyses."

Martin, N., D. Hay, et al. (In prep). "DARC: Deficits of attention, reading and coordination."

McLeod, K., V. White, et al. (submitted 2004). "She tried it and she hated it and I tried it and I loved it." Adult identical twins talk about becoming discordant for smoking status during adolescence." *Qualitative Health Research*.

McLeod, K., W. White, et al. (2008). "How might friends influence smoking uptake? Findings from qualitative interviews with identical twins." *Journal of Genetic Psychology* 169(2): 117-131.

McRae, A. F., N. A. Matigian, et al. (2007). "Replicated effects of sex and genotype on gene expression in human lymphoblastoid cell lines." *Hum Mol Genet* 16(4): 364-73.

Medland, S. E., D. Z. Loesch, et al. (2007). "Linkage analysis of a model quantitative trait in humans: finger ridge count shows significant multivariate linkage to 5q14.1." *PLoS Genet* 3(9): 1736-44.

Medland, S. E., D. A. Park, et al. (2007). "Ridgecounter: a program for obtaining semi-automated finger ridge counts." *Ann Hum Biol* 34(4): 504-17.

Mekel-Bobrov, N., D. Posthuma, et al. (2007). "The ongoing adaptive evolution of ASPM and Microcephalin is not explained by increased intelligence." *Hum Mol Genet* 16(6): 600-8.

Middelberg, R. P., N. G. Martin, et al. (2007). "A longitudinal genetic study of plasma lipids in adolescent twins." *Twin Res Hum Genet* 10(1): 127-35.

Middelberg, R. P., S. E. Medland, et al. (2007). "A longitudinal genetic study of uric acid and liver enzymes in adolescent twins." *Twin Res Hum Genet* 10(5): 757-64.

Montgomery, G. W., D. R. Nyholt, et al. (2008). "The search for genes contributing to endometriosis risk." *Hum Reprod Update* 14(5): 447-57.

Morley, K. I., M. T. Lynskey, et al. (2007). "Exploring the inter-relationship of smoking age-at-onset, cigarette consumption and smoking persistence: genes or environment?" *Psychol Med*: 1-11.

Nyholt, D. R., N. G. Gillespie, et al. (2008). "Common genetic influences underlie comorbidity of migraine and endometriosis." *Genet Epidemiol*.

Pearsall-Jones, J., J. Piek, et al. (in print). "A monozygotic twin design to investigate etiological factors for DCD and ADHD." *Journal of Pediatric Neurology* 6(3).

Appendix 2

2008

Appendix 2 Publications List

Perola, M., S. Sammalisto, et al. (2007). "Combined genome scans for body stature in 6,602 European twins: evidence for common Caucasian loci." *PLoS Genet* 3(6):97.

Petty, S., N. El Haber, et al. (2008). "Chronic antiepileptic drug treatment is associated with lower balance function scores - a twin and matched sibling AED discordant pair study." *The Journal of Clinical Neuroscience* 15(3): 360-361.

Petty, S., L. M. Paton, et al. (2007). "Chronic anti-epileptic drug treatment is associated with clinically significant impairment in balance function - a twin and sibling pair pilot study." *The Journal of Clinical Neuroscience* 14(10): 1034.

Petty, S. J., T. J. O'Brien, et al. (2007). "Anti-epileptic medication and bone health." *Osteoporos Int* 18(2): 129-42.

Piek, J., D. Rigoli, et al. (2007). "Depressive Symptomatology in Child and Adolescent Twins with Attention Deficit Hyperactivity Disorder and/or Developmental Coordination Disorder." *Twin Res Hum Genet* 10: 587-596.

Piek, J. P., D. Rigoli, et al. (2007). "Depressive symptomatology in child and adolescent twins with attention-deficit hyperactivity disorder and/or developmental coordination disorder." *Twin Res Hum Genet* 10(4): 587-96.

Pincombe, J. L., M. Luciano, et al. (2007). "Heritability of NEO PI-R extraversion facets and their relationship with IQ." *Twin Res Hum Genet* 10(3): 462-9.

Ponsonby, A., S. A. Brown, et al. (In press). "Environmental factors and childhood vision: The twins eye study in Tasmania." *Ophthalmic Epidemiol*.

Ponsonby, A. L., S. A. Brown, et al. (2007). "The association between maternal smoking in pregnancy, other early life characteristics and childhood vision: the Twins Eye Study in Tasmania." *Ophthalmic Epidemiol* 14(6): 351-9.

Ruddle, J., S. A. Brown, et al. (In prep). "Heritability of Inter pupillary disc: The Twins Eye Study."

Saccone, S. F., A. L. Hinrichs, et al. (2007). "Cholinergic nicotinic receptor genes implicated in a nicotine dependence association study targeting 348 candidate genes with 3713 SNPs." *Hum Mol Genet* 16(1): 36-49.

Saccone, S. F., M. L. Pergadia, et al. (2007). "Genetic linkage to chromosome 22q12 for a heavy-smoking quantitative trait in two independent samples." *Am J Hum Genet* 80(5): 856-66.

Samuelsson, S., B. Byrne, et al. (In press: 2008). "Response to early literacy instruction in the United States, Australia, and Scandinavia: A behavioral-genetic analysis." *Learning and Individual Differences*.

Samuelsson, S., B. Byrne, et al. (2007). "Genetic and environmental influences on prereading skills and early reading and spelling development in the United States, Australia & Scandinavia." *Reading and Writing: An Interdisciplinary Journal* 20: 51-75.

Scurrah, K. J., S. G. Zaloumis, et al. (2008 in press). "Contributions of genes and environmental variation in postural changes in mean arterial and pulse pressure."

Smith, R., H. Zaitoun, et al. (2008). "Defining new dental phenotypes using 3-D image analysis to enhance discrimination and insights into biological processes." *Arch Oral Biol*.

Stone, J., L. C. Gurrin, et al. (2007). "Mammographic density and candidate gene variants: a twins and sisters study." *Cancer Epidemiol Biomarkers Prev* 16(7): 1479-84.

Townsend, G. and L. Alvesalo (2008 in press). "Variation in the human dentition: some past advances and future opportunities." *J Dent Res*.

Townsend, G. and A. Brook (2008). "Genetic, epigenetic and environmental influences on the human dentition." *Ortho Tribune* 3(4): 3-6.

Townsend, G. and E. F. Harris (2008 in press). "Morphogenetic fields in the dentition: a new, clinically-relevant synthesis of an old concept." *Arch Oral Biol*.

Townsend, G. and T. Hughes (2008 in press). "Genetic and environmental influences on human dental variation: A critical evaluation of studies involving twins." *Arch Oral Biol*.

Treloar, S. A., K. I. Morley, et al. (2007). "Why do they do it? A pilot study towards understanding participant motivation and experience in a large genetic epidemiological study of endometriosis." *Community Genet* 10(2): 61-71.

Treloar, S. A., Z. Z. Zhao, et al. (2007). "Variants in EMX2 and PTEN do not contribute to risk of endometriosis." *Mol Hum Reprod* 13(8): 587-94.

van de Berg, R., M. Dirani, et al. (2008). "Myopia and personality: the genes in myopia (GEM) personality study." *Invest Ophthalmol Vis Sci* 49(3): 882-6.

Visscher, P. M., S. Macgregor, et al. (2007). "Genome partitioning of genetic variation for height from 11,214 sibling pairs." *Am J Hum Genet* 81(5): 1104-10.

Wade, T., S. Byrne, et al. (in press). "The Eating Disorder Examination: norms and construct validity with young and middle adolescent girls." *International Journal of Eating Disorders*.

Wade, T., N. A. Gillespie, et al. (2007). "A comparison of early family life events amongst monozygotic twin women with lifetime anorexia nervosa, bulimia nervosa or major depression." *International Journal of Eating Disorders* 40: 679-686.

Wade, T., M. Tiggemann, et al. (2008). "Shared temperament risk factors for anorexia nervosa: a twin study." *Psychosomatic Medicine* 70: 239-244.

Wade, T., S. A. Treloar, et al. (In press). "Shared and unique risk factors between lifetime purging and objective binge eating: a twin study." *Psychol Med*.

Wade, T. D. (2007). "A retrospective comparison of purging type disorders: eating disorder not otherwise specified and bulimia nervosa." *Int J Eat Disord* 40(1): 1-6.

Wade, T. D. and C. M. Bulik (2007). "Shared genetic and environmental risk factors between undue influence of body shape and weight on self-evaluation and dimensions of perfectionism." *Psychol Med* 37(5): 635-44.

Wainwright, M. A., M. J. Wright, et al. (2008). "Genetic covariation among facets of openness to experience and general cognitive ability." *Twin Res Hum Genet* 11(3): 275-86.

Waldron, M., A. C. Heath, et al. (2007). "Age at first sexual intercourse and teenage pregnancy in Australian female twins." *Twin Res Hum Genet* 10(3): 440-9.

White, V. M., G. B. Byrnes, et al. (2008). "Does smoking among friends explain apparent genetic effects on current smoking in adolescence and young adulthood?" *Br J Cancer* 98(8): 1475-81.

Whitfield, J. B., V. Dy, et al. (2007). "Evidence of genetic effects on blood lead concentration." *Environmental Health Perspectives Electronic Pub*. June.

Whitfield, J. B., V. Dy, et al. (2007). "Evidence of genetic effects on blood lead concentration." *Environ Health Perspect* 115(8): 1224-30.

Wilksch, S. and T. Wade (in press). "An investigation of temperament endophenotype candidates for early emergence of the core cognitive component of eating disorders." *Psychol Med*.

Willcutt, E., R. Betjemann, et al. (2007). "Preschool twin study of the relation between attention-deficit/hyperactivity disorder and prereading skills." *Reading and Writing: An Interdisciplinary Journal* 20: 103-125.

Williams, F. M., B. S. Kato, et al. (2008). "Lumbar disc disease shows linkage to chromosome 19 overlapping with a QTL for hand OA." *Ann Rheum Dis* 67(1): 117-9.

Williams, F. M., N. J. Manek, et al. (2007). "Schmorl's nodes: common, highly heritable, and related to lumbar disc disease." *Arthritis Rheum* 57(5): 855-60.

Wong, P. K., J. J. Christie, et al. (2007). "The effects of smoking on bone health." *Clin Sci (Lond)* 113(5): 233-41.

Wright, M. J., M. Luciano, et al. (2008). "QTLs identified for P3 amplitude in a non-clinical sample: importance of neurodevelopmental and neurotransmitter genes." *Biol Psychiatry* 63(9): 864-73.

Yewers, T., D. A. Hay, et al. (in press). "Attention-Deficit/Hyperactivity Disorder and severity of drug use in adult male drug users." *Australian Journal of Psychology*.

Zhao, Z., D. R. Nyholt, et al. (2008). "Common variation in the CYP17A1 and IFT1 genes on chromosome 10 do not contribute to risk of endometriosis." *The Open Reproduction Sciences Journal* 1(6): 35-40.

Zhao, Z. Z., D. R. Nyholt, et al. (2007). "Genetic variation in tumour necrosis factor and lymphotoxin is not associated with endometriosis in an Australian sample." *Hum Reprod*.

Zhao, Z. Z., D. R. Nyholt, et al. (2008). "Polymorphisms in the vascular endothelial growth factor gene and the risk of familial endometriosis." *Mol Hum Reprod*.

Zhao, Z. Z., P. M. Pollock, et al. (2008). "Common variation in the fibroblast growth factor receptor 2 gene is not associated with endometriosis risk." *Hum Reprod* 23(7): 1661-8.

Zhu, G., A. W. Hewitt, et al. (2008). "Genetic dissection of myopia: evidence for linkage of ocular axial length to chromosome 5q." *Ophthalmology* 115(6): 1053-1057 e2.

Zhu, G., G. W. Montgomery, et al. (2007). "A genome-wide scan for naevus count: linkage to CDKN2A and to other chromosome regions." *Eur J Hum Genet* 15(1): 94-102.

Zietsch, B. P., J. L. Hansen, et al. (2007). "Common and specific genetic influences on EEG power bands delta, theta, alpha, and beta." *Biol Psychol* 75(2): 154-64.

Zondervan, K. T., S. A. Treloar, et al. (2007). "Significant evidence of one or more susceptibility loci for endometriosis with near-Mendelian inheritance on chromosome 7p13-15." *Hum Reprod* 22(3): 717-28.

PUBLISHED ABSTRACTS

Chin, L. K., M. Sakellarides, et al. (2007). Is quantitative ultrasound a useful monitoring test for antiepileptic drug-associated bone disease? Australian and New Zealand Bone and Mineral Society (ANZBMS) 17th Annual Scientific Meeting. Queenstown, New Zealand: Abstract.

Dirani, M., M. Chamberlain, et al. (2007). Heritability for Known Risk Factors in Myopia - The Genes in Myopia (GEM) Twin Study. *Invest Ophthalmol Vis Sci*. 48: E-Abstract 3236.

Dirani, M., M. Chamberlain, et al. (2008). Heritability for known risk factors in myopia - the Genes in Myopia (GEM) Twin Study. *Ophthalmol Vis Sci*, 47 (4): ARVO E-abstract 3236.

Dirani, M., S. N. Shekar, et al. (2008). Shared genes influence both refraction and axial length - the Genes in Myopia (GEM) Twin Study. *Ophthalmol Vis Sci.*, 48(4): ARVO E-abstract 5424.

Helbig, I., N. A. Matigian, et al. (2007). Gene expression profiling in monozygotic twins with absence epilepsy. *Epilepsia*, 48.

Hogg, R., P. Dimitrov, et al. (2007). Identifying Genetic Components of Visual Function - A Classical Twin Study. *Invest Ophthalmol Vis Sci*. 48: E-Abstract 3237.

Hughes, T., G. Townsend, et al. (2007). Emergence of primary incisors in Australian twins. *Journal of Dental Research*. 83: Special Issue A: Abstract.

Hughes, T., G. Townsend, et al. (2007). Emergence of primary incisors in Australian twins. *Twin Res Hum Genet*: Abstract.

Kearns, L. S., C. Wilson, et al. (2008). Ocular Dominance, Refraction and Axial Length in Australian Twins. *World Ophthalmology Congress*. Hong Kong.

Mackey, D. A., S. A. Brown, et al. (2007). The association between maternal smoking in pregnancy, other early life characteristics and childhood vision: the Twin Eye Study in Tasmania. *RANZCO Tas Meeting*. Hobart.

Petty, S., N. El Haber, et al. (2007). Chronic antiepileptic drug treatment is associated with lower balance function scores - a twin and matched sibling AED discordant pair study. *Australia and New Zealand Bone and Mineral Society (ANZBMS) 17th Annual Scientific Meeting*. Alice Springs, Australia: Abstract.

Petty, S., N. El Haber, et al. (2007). Chronic anti-epileptic drug (AED) treatment is associated with inferior balance function in AED-discordant twin and matched sibling pairs. *12th International Congress of the International Society for Twin Studies*. Ghent, Belgium: Abstract.

Petty, S., N. El Haber, et al. (2007). Chronic anti-epileptic drug medication (AED) usage is associated with reduced balance: an AED-discordant twin and sibling pair study. *ESA 22nd Annual Scientific Meeting*. Adelaide, Australia: Abstract.

Petty, S., N. El Haber, et al. (2007). Chronic anti-epileptic drug treatment is associated with lower balance function test performance - an AED-discordant matched twin and sibling pair study. *Australia and New Zealand Bone and Mineral Society (ANZBMS) 17th Annual Scientific Meeting*. Queenstown, New Zealand: Abstract.

Petty, S., N. El Haber, et al. (2007). Chronic anti-epileptic drug treatment is associated with inferior balance function test results - a twin and matched sibling AED-discordant pair study. *American Epilepsy Society Annual Conference*. Philadelphia, USA: Abstract.

Petty, S., D. Hill, et al. (2008). Chronic anti-epileptic drug medication (AED) usage is associated with reduced bone disease? *Melbourne Health Research Week*. Melbourne, Australia: Abstract.

Petty, S., L. M. Paton, et al. (2007). Anti-epileptic drug usage and bone mineral density: a treatment discordant matched twin and sibling pair study. *Australia and New Zealand Bone and Mineral Society (ANZBMS) 17th Annual Scientific Meeting*. Queenstown, New Zealand: Abstract.

Petty, S., L. M. Paton, et al. (2007). The effect of anti-epileptic medications on bone mineral density - A twin and sibling study. *ASBMR 20th Annual Scientific Meeting*. Hawaii, USA: Abstract.

Sakellarides, M., L. K. Chin, et al. (2008). Is bone quantitative ultrasound (QUS) useful in assessing anti-epileptic drug induced bone disease? *Melbourne Health Research Week*. Melbourne, Australia: Abstract.

Townsend, G., L. Richards, et al. (2007). Explaining the causes of phenotypic variation in the teeth of twins. *Twin Res Hum Genet Suppl*: Abstract.

Treloar, S. A. (2007). Concordance in obstetric factors experienced by Australian MZ and DZ twins in their first deliveries. *Twin Research and Human Genetics*. 10: 55.

Treloar, S. A., E. England, et al. (2007). Research participation of twins enrolled with the national, volunteer Australian Twin Registry. *Twin Res Hum Genet*. 10: 55.

Treloar, S. A., N. Martin, et al. (2007). Prevalence of premature ovarian failure in Australian twins. *Twin Res Hum Genet*. 10: 56.

CONFERENCE PROCEEDINGS

Bell, T. A., D. Purdie, et al. (2008). Antenatal risk factors for endometriosis. *10th World Congress on Endometriosis*, Melbourne, VIC.

Bell, T. A., D. Purdie, et al. (2008). Menstrual risk factors for endometriosis. *10th World Congress on Endometriosis*, Melbourne, VIC.

Byrne, B. (2007). Genes and environment in early literacy development: Change and continuity from preschool to Grade 2. *Human Communication Science Network conference on Cognition Science and Text*, Leura.

Byrne, B. (2007). Genes, environment and education: Nature and nurture in literacy development. *15th Annual International Conference of the Lindamood-Bell Workshops*, London.

Byrne, B. (2008). Can there be a phonological (decoding) deficit without a phonological deficit? Insights from experimental and behavioral-genetic studies. *Symposium in Honor of Donald Shankweiler*, Asheville, North Carolina.

Byrne, B., W. L. Coventry, et al. (2008). Exploring "teacher effects" on early literacy in a twin study. *16th Annual Pacific Coast Research Conference*, San Diego.

Byrne, B., M. Gilliver, et al. (2007). Some sources of variation in vocabulary growth. *Words and Faces: International Workshop on Cognitive Neuroscience in Honour of Professor Ryoji Suzuki*, Macquarie University, Sydney.

Byrne, B., R. K. Olson, et al. (2007). Exploring environmental influences on literacy development within a genetically sensitive research design: The case of teacher effects. *14th Annual Conference of the Society for the Scientific Study of Reading*, Prague.

Appendix 2 Publications List

Danby, S. and K. Thorpe (2007). The social interactions of twin children in preschool: A case study of twin and peer relationships. Pacific Early Childhood Education Association Conference, Hong Kong.

Danby, S. and K. Thorpe (2007). Social isolation in a preschool classroom: A case study of one twin pair. International Congress of Twin Studies, Ghent, Belgium.

Dirani, M., M. Chamberlain, et al. (2007). Heritability for known risk factors in myopia - the Genes in Myopia (GEM) Twin study. The Association for Research in Vision and Ophthalmology, Fort Lauderdale, USA.

Dirani, M., S. N. Shekar, et al. (2007). The role of education in refraction - the Genes in Myopia (GEM) Twin Study. Australasian Ophthalmic and Visual Sciences Meeting, ANU, Canberra.

Dirani, M., S. N. Shekar, et al. (2008). Shared genes influence both refraction and axial length - the Genes in Myopia (GEM) Twin Study. The Association for Research in Vision and Ophthalmology, Fort Lauderdale, USA.

Hay, D., N. Martin, et al. (2007). Is there a genetic basis to DARC (Deficits of Attention, Reading and Co-ordination)? International Society for Child and Adolescent Psychopathology, London, England.

Hay, D., K. McDougall, et al. (2008). Family and Sibling Relationships when Twins are Discordant for Attention Deficit Hyperactivity Disorder. International Society for the Study of Behavioural Development (ISSBD) 20th Biennial Meeting, Wurzburg, Germany.

Helbig, I. (2008). Obstetric complications are not a major risk factor for epilepsies: a population based study in twins discordant for seizures. Epilepsy Society of Australia, Melbourne, Victoria

Hughes, T., M. Bockmann, et al. (2007). The relationship between primary incisor emergence and Mutans streptococci colonisation. Colgate Australian Clinical Dental Research Centre, Research Day, Adelaide, South Australia

Hughes, T., M. Bockmann, et al. (2007). The relationship between primary incisor emergence and Mutans streptococci colonisation. IADR (ANZ Division), Barossa Valley, SA.

Mackey, D. A. (2007). Dissecting glaucoma: understanding the molecular risk factors. Soroptimist International Melbourne Club, Melbourne, Victoria

Martin, N. and D. Hay (2007). Deficits of Attention, Reading and Coordination. 15th Biennial Conference of the Australasian Human Development Association.

Martin, N. and D. Hay (2008). The Overlaps of ADHD, DCD and RD and the use of Structural Equation Modeling and Latent Class Analysis. Invited Guest Talk, Durham University, UK

Martin, N., D. Hay, et al. (2007). DARC: Deficits of attention, reading and coordination. Australasian Human Development Association (AHDA) Conference, Sydney, Australia.

Martin, N., J. Piek, et al. (2007). DCD and ADHD: A genetic study of their shared etiology. 8th Motor Control and Human Skill Conference, Fremantle, Australia.

Martin, N. C., D. Hay, et al. (2007). Deficits of attention, reading and coordination. 7th International Conference on Children with DCD, Melbourne, Australia.

McDougall, M., D. Hay, et al. (2007). Twin relationships and attention deficit hyperactivity disorder. International Congress on Twin Studies, Ghent, Belgium.

McDougall, M., D. Hay, et al. (2007). Twin relationships and attention deficit hyperactivity disorder. International Society for Child and Adolescent Psychopathology, London, England.

Mihailidis, S. and S. Woodroffe (2008). Timing and sequence of emergence of primary incisors in twins. International Symposium on Dental Morphology, Greifswald, Germany.

Nagle, C., T. A. Bell, et al. (2008). Childhood weight and risk of endometriosis. 10th World Congress on Endometriosis, Melbourne, VIC.

Odefrey, F., M. C. Southey, et al. (2008). Molecular determinants of mammographic density. KConfab Meeting, Couran Cove, QLD.

Odefrey, F., M. C. Southey, et al. (2008). Molecular determinants of mammographic density. American Society of Human Genetics Annual Scientific Meeting, Philadelphia, USA

Pearsall-Jones, J. (2007). The relationship between motor difficulties and developmental disorders. Australasian Human Development Association Conference.

Pearsall-Jones, J., J. Piek, et al. (2007). Monozygotic twins discordant for attention deficit hyperactivity disorder and developmental coordination disorder: Genetics, epigenetics and environmental effects. Australasian Human Development Association (AHDA) Conference, Sydney, Australia.

Piek, J. (2007). The relationship between motor difficulties and developmental disorders. Australasian Human Development Association (AHDA) Conference, Sydney, Australia.

Rigoli, D., J. Piek, et al. (2007). Depression and anxiety in children with attention deficit hyperactivity disorder and/or developmental coordination disorder. Australasian Human Development Association (AHDA) Conference, Sydney, Australia.

Thorpe, K., S. Danby, et al. (2007). Do twin children have more behavioural difficulties? Twin - singleton and twin type comparison of SDQ scores in a sample of 4 year olds. International Congress of Twin Studies, Ghent, Belgium.

Thorpe, K., S. Danby, et al. (2007). Compromised or Competent: Twin children's social development. International Congress on Twin Studies, Ghent, Belgium.

Thorpe, K., N. Martin, et al. (2008). Twins or just good friends? Co-twin relationships and behavioural difficulties. International Society for the Study of Behavioural Development, Wurzburg, Germany.

Thorpe, K., R. Morgan, et al. (2008). Pre-school environment and friendship quality: evidence from a sociometric study. International Society for the Study of Behavioural Development, Wurzburg, Germany.

Thorpe, K., C. Tayler, et al. (2008). Self report from young children: presentation of a new method and its effectiveness in Norway and Australia. European Early Childhood Research Association Conference, Stavanger, Norway.

Townsend, G., T. Hughes, et al. (2008). How studies of twins can inform our understanding of dental morphology. 14th International Symposium on Dental Morphology, Greifswald, Germany.

Townsend, G., L. Richards, et al. (2007). Explaining the causes of phenotypic variation in the teeth of twins. 12th International Congress on Twin Studies, Ghent, Belgium.

Treloar, S. A. (2007). Concordance for obstetric factors in twin mothers. 12th International Congress on Twin Studies, Ghent, Belgium.

Treloar, S. A. (2007). Research update on endometriosis. Endometriosis Association (QLD) Inc. Information seminar, Brisbane Private Hospital, Queensland

Treloar, S. A., L. F. Cherkas, et al. (2007). Prevalence of premature ovarian failure in twins. 12th International Congress on Twin Studies, Ghent, Belgium.

Treloar, S. A., E. England, et al. (2007). Research participation of twins enrolled with the national, volunteer Australian Twin Registry. 12th International Congress on Twin Studies, Ghent, Belgium.

Treloar, S. A., N. G. Martin, et al. (2008). Pregnancies and pregnancy outcomes for diagnosed women in an Australasian cohort for genetic studies of endometriosis. 10th World Congress on Endometriosis, Melbourne, VIC.

Wade, T. (2008). Shared and unique risk factors between lifetime purging and objective binge eating: a twin study. International Conference on Eating Disorders, Seattle, USA.

Woodroffe, S., T. Hughes, et al. (2007). Timing and sequence of emergence of primary incisors in twins. Colgate Australian Clinical Dental Research Centre, Research Day, Adelaide, South Australia

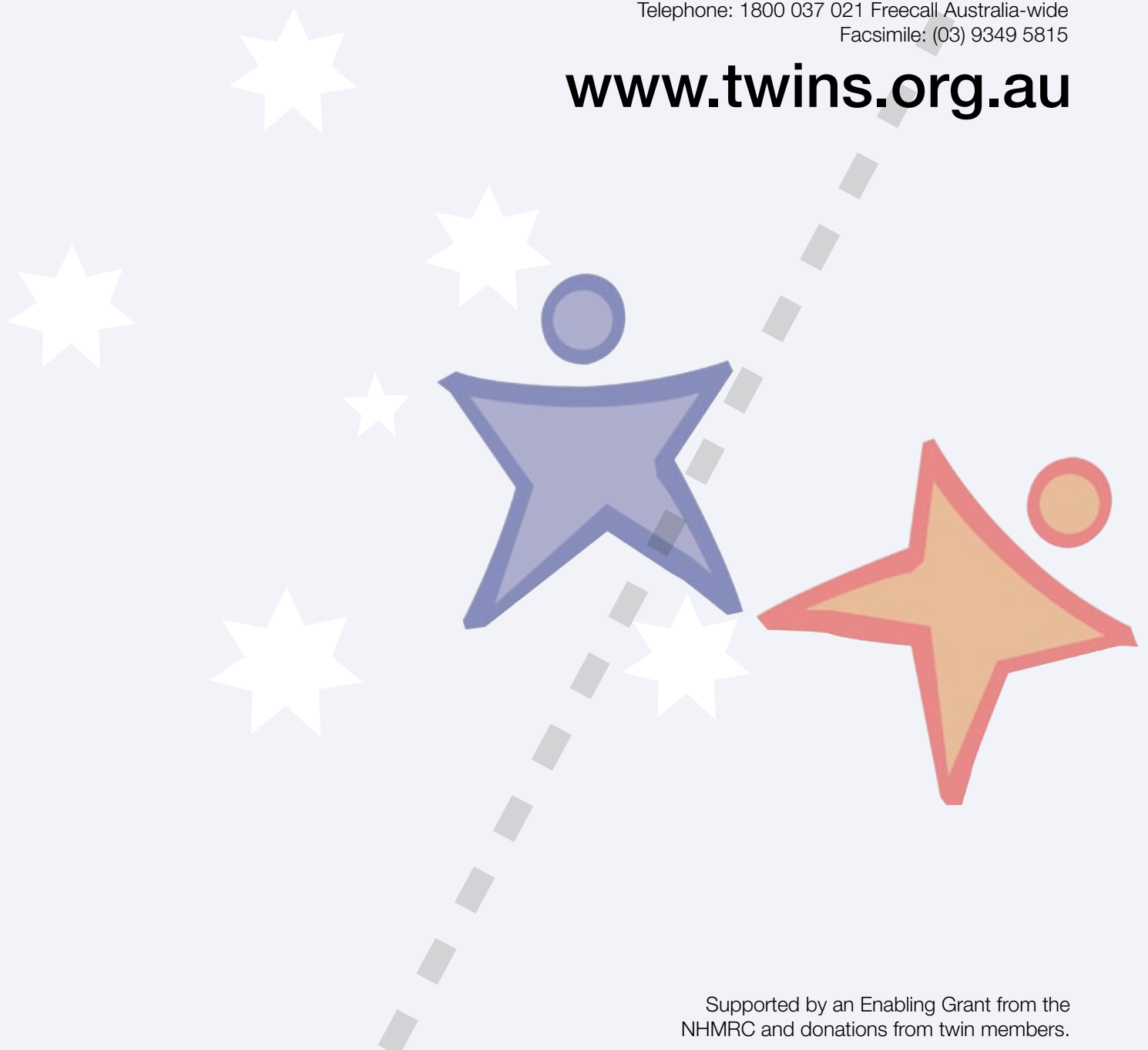
Woodroffe, S., T. Hughes, et al. (2007). Timing and sequence of emergence of primary incisors in twins. IADR (ANZ Division), Barossa Valley, SA.

Zhao, Z., S. A. Treloar, et al. (2008). Analysis of candidate genes from the endometriosis linkage region on chromosome 10q. 10th World Congress on Endometriosis, Melbourne, VIC.

Zondervan, K., S. A. Treloar, et al. (2008). Genome-wide association studies in endometriosis. 10th World Congress on Endometriosis, Melbourne, VIC

Australian Twin Registry
Level 1 /723 Swanston Street, Carlton, Victoria 3053
Telephone: 1800 037 021 Freecall Australia-wide
Facsimile: (03) 9349 5815

www.twins.org.au



Supported by an Enabling Grant from the
NHMRC and donations from twin members.