

# Annual Report

1 January - 31 December 2010



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## EXECUTIVE SUMMARY

### Welcome to the 2010 Annual Report of the Australian Twin Registry (ATR)

With every annual report, the ATR presents members and researchers with a summary of the major achievements, activities and research developments of the Registry. The 2010 Annual Report presents this summary and also inaugurates a new format, that of a calendar-year timetable. The 2010 reporting period covers the first year of the renewed Enabling Grant (2010 – 2014) from the National Health and Medical Research Council (NHMRC) that funds the ATR.

The ATR's Vision is to “**realise the full potential of research involving twins to improve the health and wellbeing of all Australians**” and 2010 saw the ATR taking significant strides towards achieving that vision.

#### Highlights and Achievements for 2010

- For the third consecutive year the number of research studies actively supported by the ATR increased to a record 78. This resulted in 17,677 mailed approaches to participants and required 1,659 hours of telephone follow-up.
- ATR Membership numbers grew, in line with the goal set in the Enabling Grant, as 1,178 twins and triplets were added to the Registry.
- The research benefits enabled by the ATR were significant, with 37 peer-reviewed articles based on ATR-related studies published, as well as 3 book chapters and 18 abstracts and posters.
- The ATR participated in the *13<sup>th</sup> Triennial International Congress on Twin Studies (ICTS)* held in Seoul, South Korea, which provided attendees with an international connection to researchers, multiple birth organizations around the world and international best practices.
- The ATR participated in the *38<sup>th</sup> Australian Multiple Birth Association (AMBA) National Convention* in Melbourne, a popular event that attracts many delegates from the multiple birth community across Australia and enables AMBA to gather the most current information on issues and products impacting the twin community. Participation of ATR in the AMBA National Convention strengthened the close relationship between the Registry and AMBA and also increases awareness of the ATR brand amongst the twin community.

Overall, 2010 has been filled with significant success in all areas of interest for the ATR, including research, funding and Registry growth. The outlook for 2011 is also busy and promises further progress.

#### Outlook for 2011

- The ATR will review and enhance the range and quality of services that it currently provides to the research community, optimising the ATR's ability to support research that has the potential to contribute to the health and wellbeing of Australians.
- The ATR will develop and implement a marketing initiative aimed at increasing the number of twins registered as members with the ATR, thus increasing the pool of members potentially available to participate in research studies.

## **ATR OVERVIEW**

### ***About the Australian Twin Registry***

Established in 1981, the ATR is a national volunteer register of twins interested in contributing to research studies.

The primary goal of the ATR is to facilitate and support research studies involving twins.

In 2010, the ATR maintained information on 36,462 sets of twins and triplets, and supported 78 active research projects covering a broad spectrum of health-related themes (see **Researcher Reports** in [Appendix 1](#)).

### ***Potential for Twin Research***

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

Studies involving twins play an important and unique role in developing an understanding of good health and clinical problems from a genetic and environmental perspective. Twins provide a potential resource and research tool for all medical and scientific researchers.

Twin research continues to utilise new technologies to establish the causes underlying the many health and medical issues that affect Australians. Twin studies have started to play a vital role in the emerging search for epigenetic effects produced by proteins and other molecules that bind to DNA, changing gene expression. Such epigenetic effects are a newly recognised phenomenon and have been linked to many diseases, including cancer and psychiatric disorders. Studies involving twins can significantly contribute to the investigation and identification of epigenetic factors that contribute to human disease, through their shared environments and genetics.

### ***Funding***

The ATR is supported by an Australian NHMRC Enabling Grant. The grant covers a 5-year period, *1 January 2010 - 31 December 2014*.

Enabling Grants fund Special Facilities, including biospecimen and data repositories, computational facilities and disease/attribute registries. This highlights the fact that ATR is not a private resource generated by a group of researchers for use in a particular study or program, but is a resource available for the wider use of all Australian researchers including those who have not previously conducted twin studies.

### ***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 and their relatives.

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 twins and parents of twins whenever appropriate, whether or not they are members of the ATR.

Excellence in Research: The ATR strives to enable researchers to 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 the 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

**Collaborate 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

Use 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 for the purpose of the project.

#### Core Function 4

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

#### Core Function 5

Apply **governance** of the ATR in a fair, transparent and equitable manner.

## **The Registry**

*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**

### ***Database***

The ATR maintains an up-to-date register of twins willing to consider involvement in scientific studies. This register is supported by a comprehensive database, which retrieves updated membership data to allow accurate record keeping and meaningful analysis of trends and results. The Registry database launched in 2006 enables the ATR to more accurately be reimbursed by researchers for work done on their behalf for studies.

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

### ***Membership***

The 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.

As at 31 December 2010, the database held data on 73,168 individuals representing 36,218 twin pairs and 244 triplets.

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 enrolled in the period covered by this report (99%) are categorised as Active/Active, Active/Questionnaire and Questionnaire/Questionnaire pairs, indicating that they are willing to consider participating in research. The current status of members of the ATR is summarized in **Table 1**. A total of 72.2% twin pairs have both members active, and an additional 7.2% of members' contact details require updating (recorded as Pending).

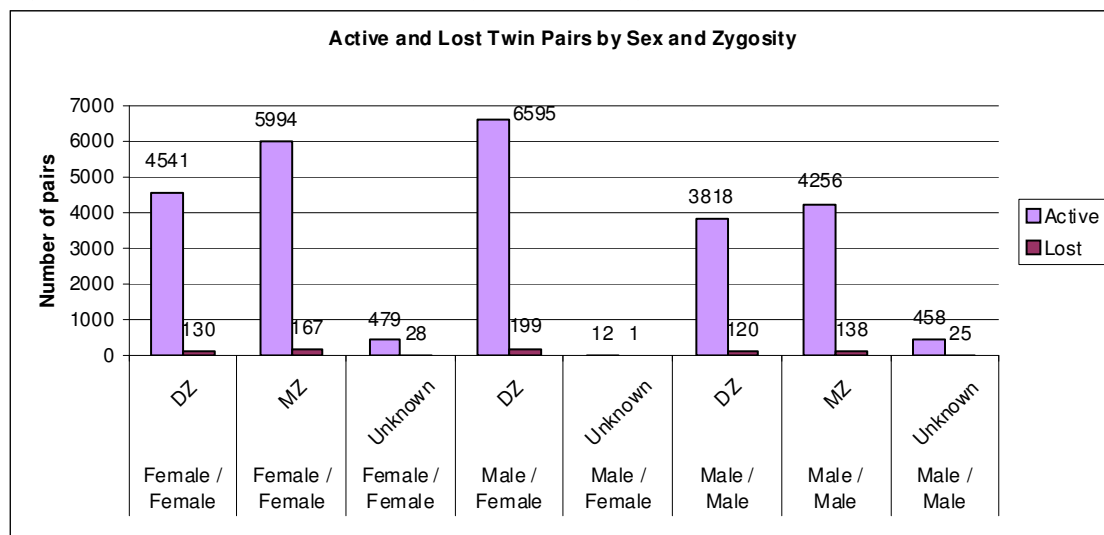
**Table 1:** Twin Pair Status Combination as of 31 December 2010. Top row details T1 (twin one) status, and left most column details T2 (twin two) status. **OS** identifies twin members who have moved overseas, but are still available for electronic surveys; **Lost OS** refers to members for whom the Registry has an unconfirmed overseas address, and it exhausted all avenues for obtaining up-to-date contact details.

T1/ T2 Status	Active	De- ceased	Dupli- cate	Lost	Lost OS <sup>1</sup>	News- letter	In- active	OS	Question- naire	Pen- ding	Total
Active	26,153										26,153
Deceased	331	887									1,218
Duplicate	0	1	261								262
Lost	64	5	0	870							939
Lost OS	2	0	0	2	12						16
Newsletter	86	26	0	4	0	194					310
Inactive	370	221	0	12	0	10	2,012				2,625
OS	152	1	0	0	0	0	5	247			405
Questionnaire	242	3	0	0	0	1	1	2	422		671
Pending	824	34	0	16	0	18	59	12	17	2,639	3,619
	28,224	1,178	261	904	12	223	2,077	261	439	2,639	36,218

<sup>1</sup>OS, overseas.

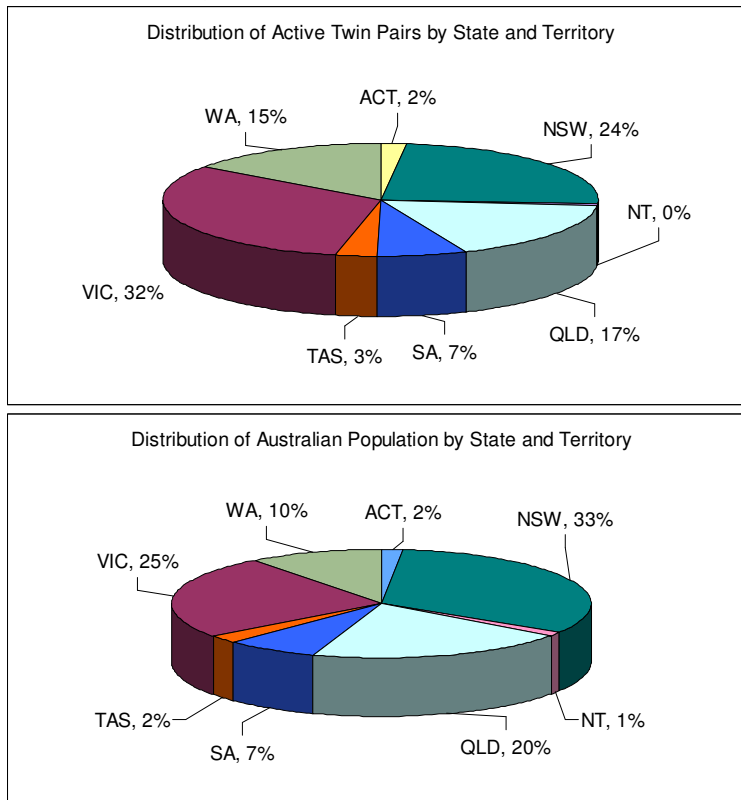
The current numbers of active and lost twin pairs by sex and zygosity are shown in **Figure 1**.

**Figure 1.** Active and Lost Twin Pairs by Sex and Zygosity as at 31 December 2010.



The distribution of active twin pairs by location is shown in **Figure 2**, together with the overall distribution of Australian population by State and Territory (as reported by the Australian Bureau of Statistics in 2010). Comparison of the two graphs shows that most populated states, New South Wales, Victoria and Queensland, are the same ones where most active ATR members reside.

**Figure 2.** Active Twin Pairs Combination by Location as at 31 December 2010 (**Top**) and overall distribution of Australians by State and Territory (**Bottom**). Note: because some twins live in separate states or one twin member in a pair lives overseas, this figure captures only 23,383 of the 26,153 shown as *Active/Active* in **Table 1**.

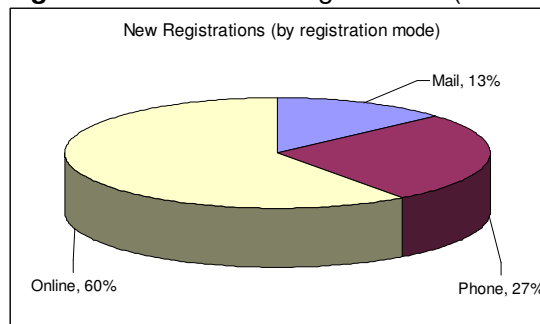


### Recruitment

Continuous recruitment of new twin members is vital to ensure the future viability of the ATR. The ATR's goal is to increase membership by more than 5,000 over 5 years.

In the reporting period, 1 January to 31 December 2010, the ATR added membership details on 1,178 twins and triplets; 571 sets of twins and 12 sets of triplets. This recruitment of more than 1000 new members in 2010 puts the Registry on track to achieve its 5 year goal. The majority of new members (60%) used the internet to register with the ATR (**Figure 3**).

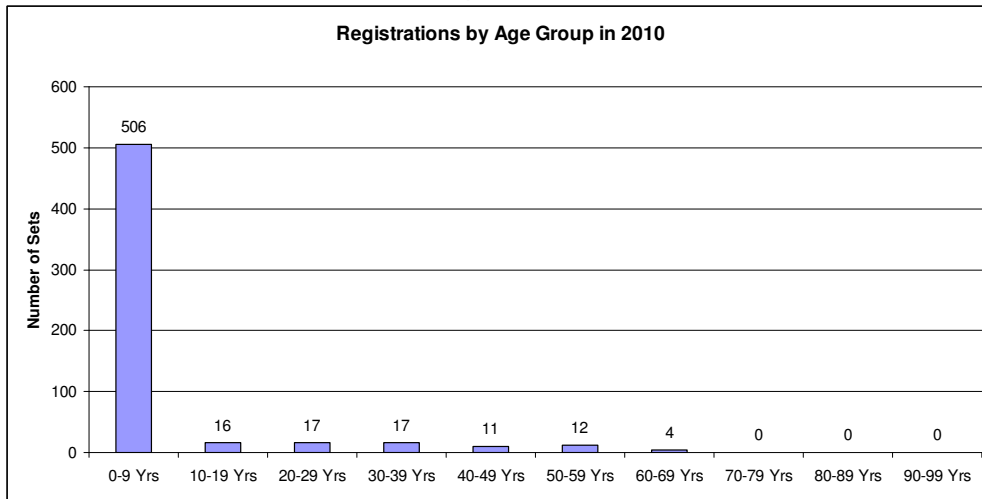
**Figure 3.** Mode of new registrations (twin and triplet sets) in 2010.



The majority of new members (85%; or 496 sets of twins and 10 sets of triplets out of 583 total) enrolling with the ATR during the reporting period were aged 0-9 years, a feature that has remained relatively consistent over the last 20 years (**Figure 4**).

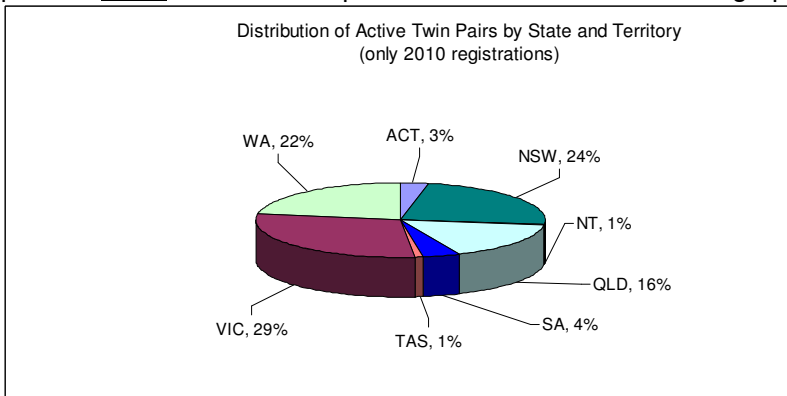


**Figure 4.** Number of new twins and triplet sets registered in 2010, shown by age range.

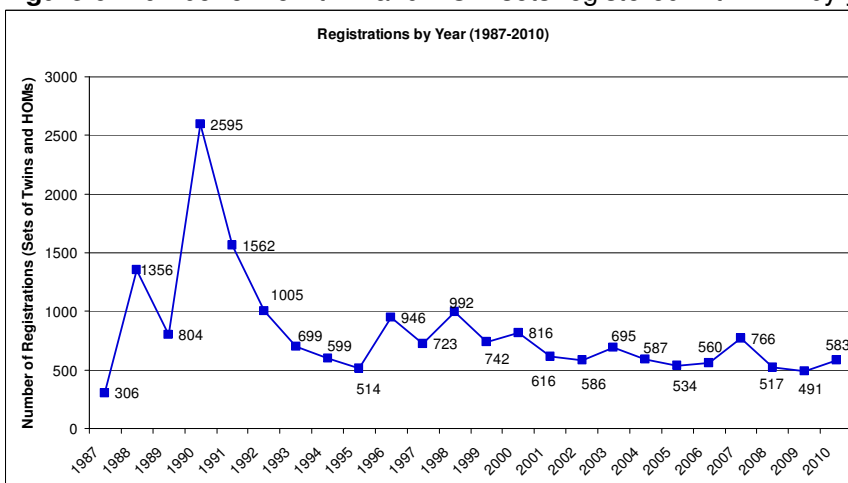


New registrants have come from all States and Territories in Australia, most from Victoria (29%), New South Wales (24%), and Western Australia (22%) (**Figure 5**). The numbers of new registrations by year since 1987 are represented in **Figure 6**.

**Figure 5.** Distribution of active twin pairs, by State or Territory, recruited during the reporting period. Note: numbers of triplet sets are not included in the graph.

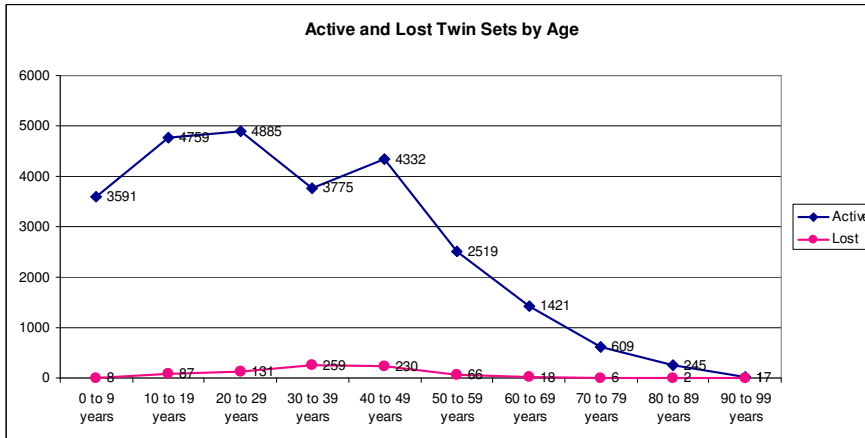


**Figure 6.** Number of new twin and HOM sets registered with ATR by year since 1987.



The distribution of active and lost pairs of twins, across the Registry, is shown relative to the age groups of members in **Figure 7**.

**Figure 7.** Active and lost twin pairs shown by age group, as at 31 December 2010. Note: data on triplets are not included in the graph.



### **Currency and Accuracy of Membership Data**

The goal of the ATR, as outlined in the NHMRC Enabling Grant, is to maintain current information for at least 85% of the membership. This acknowledges that a proportion of twin members who have moved and require tracing to update contact details.

Although the *Twins* Newsletter is first and foremost a tool for communication with members, it also presents an opportunity to assess the accuracy of member address data. Using the Newsletter and other communication methods, during 2010, the Registry received 2,742 Return to Sender (RTS) envelopes. This response is vitally important to the ATR, alerting us to members who have moved. Upon receiving the RTS, the ATR initiates the tracing of relocated members through a range of tools, such as the White Pages and Electoral Roll searches, as well as following up on the second or third contacts provided by the ATR members. At the end of 2010, the Registry maintained current information on 92.7% of the members (only 7.2% of members' contact details required updating and are listed as "pending" in **Table 1**).

### **ATR Newsletter**

During the 18 months since the previous *Twins* newsletter was mailed to members, the growth in requests from researchers to use web surveys, coupled with the proliferation of mobile phone technology providing email access more readily to people, has resulted in a great interest in the collection of email addresses. The ATR recognized a significant opportunity to capture member's email addresses using the 2010 *Twins* Newsletter, sent to 53,024 households.

The ATR undertook some market research and determined that an efficient mechanism to collect email addresses was to provide a secure, tailored website where members could visit and deposit their updated details – this information could then flow directly to the database, limiting double handling of the data. It was also an opportunity to ask members to update zygosity status and to let us know their preferred way of receiving the *Twins* Newsletter (electronically or via post). Bearing in mind that not all members would have the resources to use a website, we also included the traditional mechanisms to update their details: by emailing the ATR at [enquiries@twins.org.au](mailto:enquiries@twins.org.au); by writing any new details on a cover sheet form provided with the newsletter and sending it back to ATR in the Reply Paid envelope provided; or by calling the ATR's free line, 1 800 037 021.

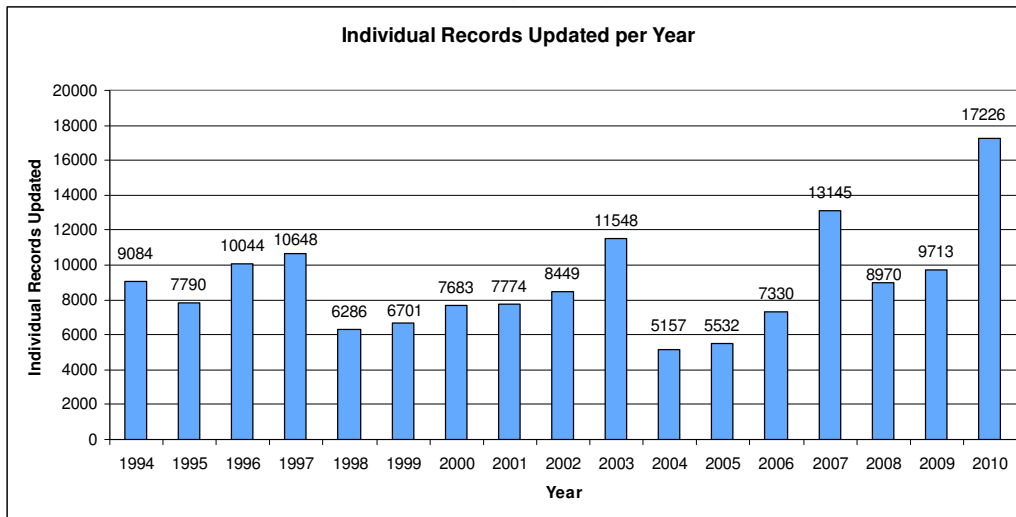
This was the first time the ATR requested email addresses from its members and much care was taken to ensure the security of the data provided online. The initiative proved to be successful, as the number of email addresses provided by the members increased from 12,950 to 21,000 (28% of all ATR members).

## Record Updates

The ATR is aware that not all misdirected mail is Returned to Sender, 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 members are recorded on the ATR database.

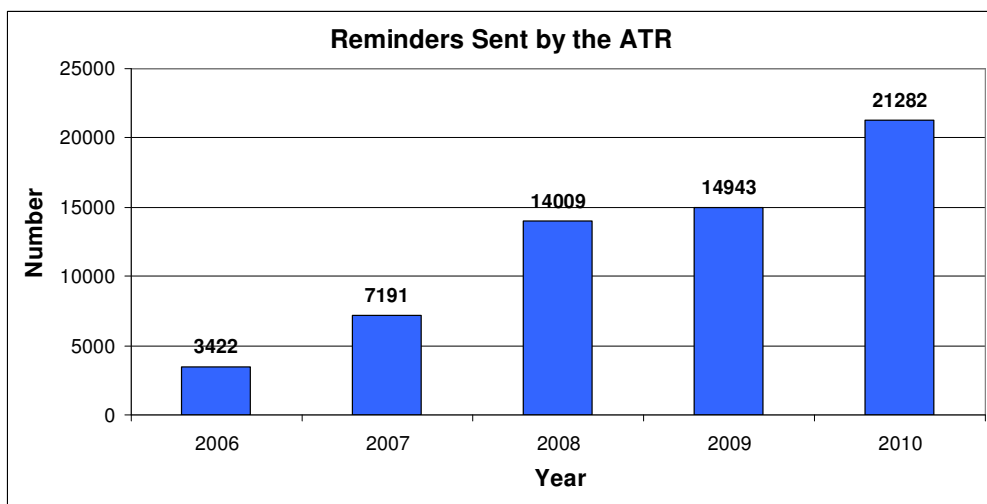
In 2010, a total of 17,226 member records were updated in the ATR database. This number includes those records followed-up due to receipt of an RTS, and those generated through routine tracing or contact after a study approach has been sent. A count of all individual records updated yearly since 1994 is shown in **Figure 8**.

**Figure 8.** Numbers of individual records updated per year (1994-2010).



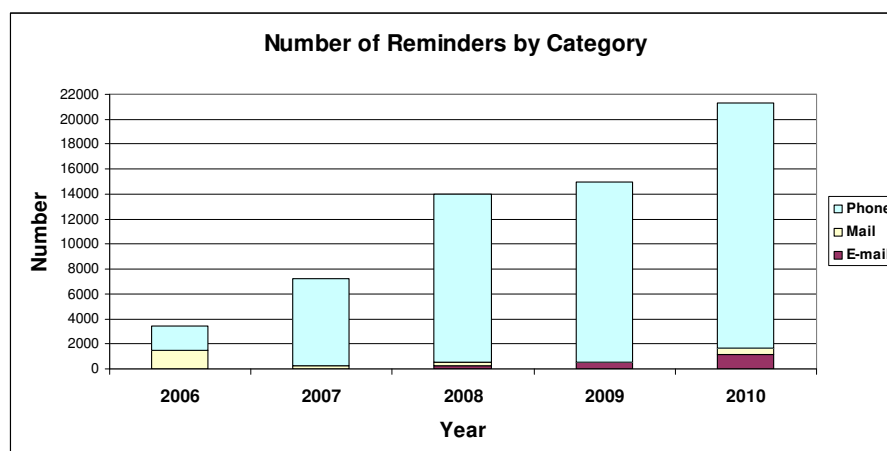
A significant increase in telephone follow-up for studies, modifications to the database, and submission of the *2010 Twins Newsletter* (sent to over 53,000 member households) enabled us to reach these high numbers of updated records in 2010. **Figure 9** illustrates the upward trend in the number of reminders and follow-ups being generated by ATR staff in the past five years.

**Figure 9.** Numbers of reminders sent by the ATR staff (2006 – 2010).



More than 90% of all reminders are undertaken by telephone (**Fig. 10**), which although is a labour-intensive and costly exercise, is of great benefit as it provides a personal touch with the ATR members and also increases response to studies facilitated by the ATR. Although email is potentially far more efficient and economical, it also has a reduced response and tends to select for members who respond more favourably to emails. Thus, ATR is working to use both communication methods and increase recorded email addresses, so that researchers and the ATR have this option of both communication tools. **Figure 10** highlights the increase in email use as a tool to send reminders to ATR members.

**Figure 10.** Number of reminders by category (phone, mail and email) since 2006.



### **Website**

During 2010, additional material was added to the ATR website:

- *2010 Twins Newsletter*
- *“Update your contact details here”* button on the home page of the ATR
- Results of Rounds 6 and 7 Travel Grant scheme

A significant change to the website was the addition of a form, opening with the *“Update your contact details here”* button, for updating of member contact information directly on the home page of twins.org.au.

As a result of direct member feedback, the ATR is currently updating the communication strategy with a view to introducing electronic newsletters and making its social networking debut on Facebook. The ATR’s goal is to give members more frequent news on the progress of ATR research and to let them know about upcoming events.

### **Media Activities**

Through the 2008 *Twins Newsletter*, the ATR instigated a Media Mailing List that enables the ATR to circulate media enquiries and opportunities to those members who have expressed an interest in receiving such information.

In 2010, the ATR used this mailing list to assist in circulating information for Channel Nine and Eyeworks Australia *“The National IQ Test”*, on November 9, 2010. This effort resulted in a twin pair being selected for the IQ test program.

## **Capacity Building - match, WATCH and WATR**

### **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 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. As a satellite project supported by the ATR, all twins and triplets enrolled in WATR are informed they are automatically registered with the ATR.

Activities for WATCH and WATR in the past two years were focused on securing the existing data with the Western Australia Genetic Epidemiology Resource (WAGER), an NHMRC Enabling Facility, which aims to support data management and storage for epidemiology projects across Australia.

Acquisition of new registrations was halted due to significant staffing changes in our Western Australian team. Jan Hansen, our WATCH Coordinator was diagnosed with ovarian cancer in 2009 and with much sorrow, passed away in late 2010. Jan was tireless in her dedication to WATCH to the end and will be sorely missed. WATR Director, Professor Lyle Palmer, accepted a position at the Ontario Institute for Cancer Research, and following Professor Palmer's move, Jessica Lee, WATR Coordinator, took up a new position in the Data Linkage Branch, Department of Health Western Australia.

Given the significant changes to the major drivers of the WATCH / WATR group, ATR management is now working on decisions regarding the long term maintenance of the data.

### **match report**

The Mothers and Twin Children (**match**) project recruits and collects data from mothers pregnant with 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.

Activities in 2009-2010 focused on actioning the findings of the critical review conducted in the previous year.

- Collection of maternal and cord blood has been temporarily suspended. Investigation of buccal cell collection is underway to provide biological samples for the project.
- Public enquiries regarding **match** are now channelled through the ATR free-call number to provide additional Research Assistant support, which also resulted in more streamlined communication regarding the relationship between the ATR and **match**.
- The information booklet developed as part of **match** is now offered to all women who are pregnant with twins regardless of their involvement with **match**; this has resulted in an increased enquiry and recruitment to the ATR, while still maintaining a channel to recruit participants to the **match** project.

During the review it was established that the role of the **match** Coordinator had come to a natural conclusion as the materials, protocols and processes had been developed. Responsibility for the management of the project moved to the ATR Coordinator.

Recruitment of **match** participants continued in 2009-2010 with 275 participants registered in total to date.

## SCIENTIFIC MERIT

*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*

## SCIENTIFIC MERIT

### **Current Research Studies**

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:

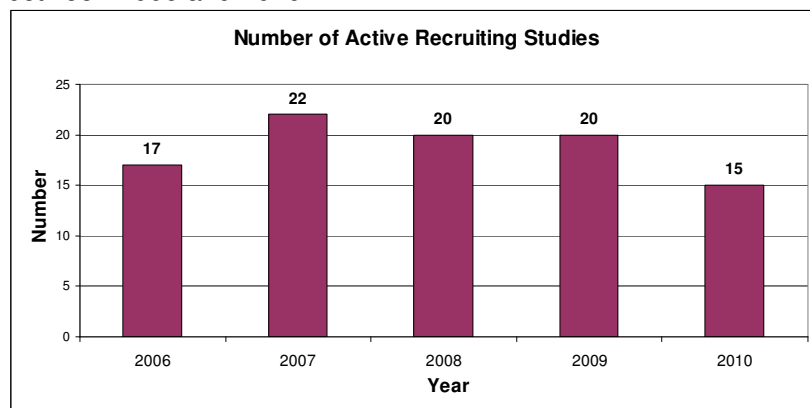
- are in the initial stages of planning and development;
- are involved in active recruitment;
- have completed or paused recruitment but may require additional support for follow-up and clarification with members.

The Registry has experienced a gradual rise in the rate, range, size and sophistication of studies. A complete count of all studies, by status, as of 31 December 2010, is shown in **Table 2** and a count of active recruiting studies in the past five years is shown in **Figure 11**.

**Table 2:** Studies by Status 2010.

Study Status	Number
Discussion	1
Expression of Interest	8
Full application	2
Approved	1
ACTIVE - RECRUITING	15
ACTIVE - PROTOCOL CHANGE/AMENDMENT	3
ACTIVE - DATA ANALYSIS	31
ACTIVE - ONGOING PROGRAM	13
ACTIVE - WRITING UP	4
COMPLETED	83
ABANDONED	36
ON HOLD	5
<b>TOTAL</b>	<b>202</b>

**Figure 11.** Number of active recruiting studies, reported as at Annual report publication, between 2006 and 2010.



## Researcher reports

The **Researcher Reports** provided by the researchers and associated staff summarise the current activities undertaken by each study active in the current reporting period (1 January to 31 December 2010), major achievements for this period and future plans. The reports for Active – Ongoing and Active – Recruiting studies are included in [Appendix 1](#) of this Annual Report.

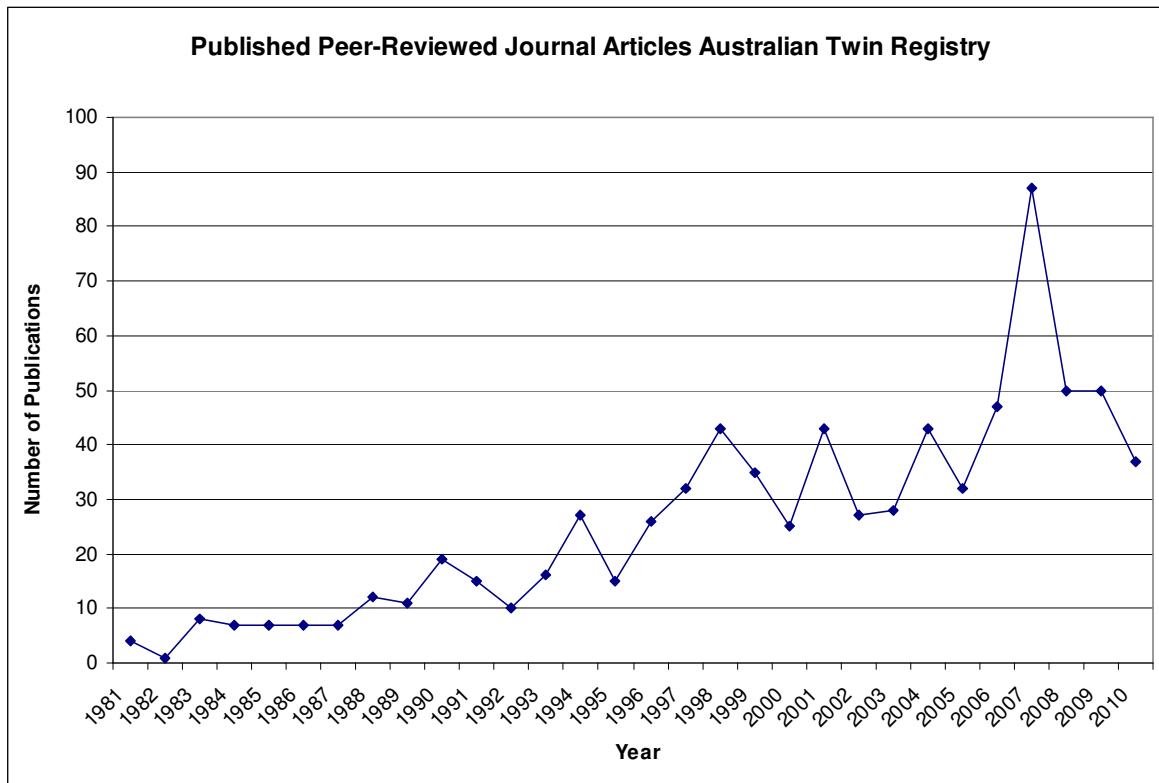
## Publications

An important measure of the output of the ATR is the number of publications arising from studies supported by the facility. An important goal set by the ATR in the Enabling Grant was to increase the number of peer-reviewed articles to 50 per year.

In 2010, the ATR has recorded 37 peer-reviewed articles (**Figure 12**), 3 book chapters, and 18 abstracts and posters, for a total of 58 publications. Although the goal of having 50 peer-reviewed articles yearly was not reached, a large number of publications were reported to be in press or in preparation.

The list of all 2010 publications can be found in [Appendix 2](#).

**Figure 12.** Number of articles arising from ATR studies that were published in peer-reviewed journals every year since 1981.



## Meetings and Conferences

- *The 13th triennial International Congress on Twin Studies (ICTS) held in Seoul, South Korea, June 4-7, 2010*

The Congress was organized by the International Society for Twin Studies (ISTS) – an international, non-political, non-profit, multidisciplinary scientific organization that aims to further research and public education in all fields related to twins and twin studies, for the mutual benefit of twins and their families and of scientific research in general.

The 13th triennial Congress provided attendees with an international connection to researchers and multiple birth organizations around the world, with a special emphasis on behaviour genetics, genetic epidemiology, obstetrics, paediatrics, endocrinology, ophthalmology, psychology, and psychiatry.

There was a strong contingency of Australians present at the congress and it was encouraging to see many first time researchers attend. The Director of the ATR gave a talk on the Australian Twin Registry. A poster of the **match** study was displayed and hard copies of the 2010 *Twins Newsletter* were handed out. Conferences of this scale are important to encourage more research and promotion of ATR in the field of twin studies and open up the Registry to more international collaborations.

- *38<sup>th</sup> AMBA National Convention (22<sup>nd</sup> – 25<sup>th</sup> October 2010) Bell City Event Centre, Preston, Victoria*

The Australian Multiple Birth Association (AMBA) was established in 1974 as a not-for-profit volunteer association that provides support, resources and education to families and/or carers with multiple birth children (twins, triplets, quads etc). They have multiple birth clubs in every state and territory of Australia with membership of around 5,000 families. The AMBA National Convention is a popular event that attracts more than 120 delegates from the multiple birth community across Australia. Delegates meet to gather the most current information on issues and products affecting our community and take it back to their local membership.

ATR acknowledges the benefit of maintaining a close relationship with AMBA, which enables the better support of each other's goals.

Debra Foley, Deputy Director (Research) of the ATR represented the Registry at this meeting. Dr Foley presented an overview of the ATR and its operations and the current research involving ATR twins and multiples.

### ***Research Travel Grant Scheme***

Round 6 of the ATR Research Travel Grant Scheme was awarded in April 2010. Congratulations to the following successful recipients:

- Jian Chen - Stroke and Ageing Research Group, Monash University
- Jemma Christie - University of Melbourne
- William Coventry - University of New England
- Paulo Ferreira - The George Institute for International Health
- Ali Ghasem-Zadeh - Austin Health, University of Melbourne
- Eric Joo - Murdoch Childrens Research Institute
- Teresa Lee - Euroa Centre, Prince of Wales Hospital
- Yi Lu - Queensland Institute of Medical Research
- Miriam Mosing - Queensland Institute of Medical Research
- Boris Novakovic - Murdoch Childrens Research Institute
- Jodie Painter - Queensland Institute of Medical Research
- Paul SanFilippo - Centre for Eye Research Australia
- Maria Schache - Centre for Eye Research Australia
- Jennifer Stone – Centre of Molecular, Environmental, Genetic and Analytical (MEGA) Epidemiology, University of Melbourne

Most of the study grants provided opportunities for new researchers to attend the ISTS congress in Seoul.



Round 7 of the ATR Research Travel Grant Scheme was awarded in September 2010.  
Congratulations to the following successful recipients:

- Sandra Saffieri – Centre for Eye Research Australia
- Lisa Kearns – Centre for Eye Research Australia
- Nicholas Martin – Genetic Epidemiology Laboratory, QIMR
- Ali Ghasem-Zadeh – Endocrinology Centre of Excellence

## PARTICIPATION

*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

### Mailouts

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 2010, **534** mailouts were conducted, with a total of **17,677** letters sent.

**Table 3** shows these numbers by study and summarizes approaches for both Junior members (1 approach per family) and Senior members (1 approach per twin). The number quoted for each study also includes reminder mailouts.

**Table 3:** Number of mailouts and total letters by study in 2010.

Study ID	Study Title	No. Mailouts	Total No. Letters	RTS Rcvd	RP Mail Rcvd
2005-003	The Twin Study of Brain Ageing and Cognition	12	142	0	71
2006-004	Genetic and Environmental Factors in Invasive Cervical Cancer: A Twin Study	116	5086	149	3153
2007-004	Role of Genetic and Environmental Factors in Atrial Fibrillation	1	54	1	40
2007-005-2	An investigation into the nature of Growing Pains in Australia	35	1400	31	548
2007-005-3	Growing Pains and Functional Pain Disorders	51	353	0	51
2007-006-2	Is foetal testosterone related to autism-like behaviours? A study of dizygotic twins	24	1720	45	650
2008-004	Pathways to Affective Disorders: Interactions Between Genes, Environment and Biological Mechanisms	150	3412	112	1128
2008-004-1	Pathways to Affective Disorders: Interactions Between Genes, Environment and Biological Mechanisms	7	96	0	0
2008-006	Genetics of Syncope and Breath Holding	87	2029	76	335
2009-003	Prevalence and risk factors of Lower Back Pain - A Pilot Study	10	984	1	65
2009-004	Gut Number Sense in Twins	24	1500	42	88
2010-001	Pilot study of adult socio-economic position and cardio-vascular risk in twins	12	600	14	195
2010-004	How Your Brain Recognises Who You Are - Finding the Neural Correlates of Autobiographical Visual Self Recognition	3	90	0	1
98-001-2	Genetics of Reading Ability Extension: Classroom placement of twins and triplets for kindergarten, year 1 and year 2	2	211	5	148
	<b>TOTAL</b>	<b>534</b>	<b>17,677</b>	<b>476</b>	<b>6473</b>

## 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 increasingly popular form of follow-up was used by most of the ATR 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 in **Table 4**. Please note these figures do not include telephone calls and hours spent tracing twins who have changed address.

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.

**Table 4:** Number of calls and hours spent on the calls by the ATR staff in 2010.

Study No.	Study Name	No. Phone Calls	Total Hrs	Total Hrs Chargeable
2010-001	Pilot study of adult socio-economic position and cardiovascular risk in twins	494	34	32.9
2010-004	How Your Brain Recognises Who You Are - Finding the Neural Correlates of Autobiographical Visual Self Recognition	115	11.5	11.3
98-001-2	Genetics of Reading Ability Extension: Classroom placement of twins and triplets for kindergarten, year 1 and year 2	160	13	11.8
2004-007	Risk factors for the development of eating disorder phenotypes and endophenotypes in adolescent twins		0.5	0.5
2005-003	The Twin Study of Brain Ageing and Cognition	93	17.4	16.9
2006-004	Genetic and environmental factors in invasive cervical cancer: a twin study	7127	626.9	580.6
2007-004	Role of genetic and environmental factors in atrial fibrillation	21	4	4
2007-005	An investigation into the nature of Growing Pains in Australia	1205	97.7	91.5
2007-006-2	Is foetal testosterone related to autism-like behaviours? A study of dizygotic twins	1329	109.5	102.3
2008-002	Genes, Diabetes Mellitus and Dementia		0.2	0.2
2008-004	Pathways to Affective Disorders: Interactions between Genes, Environment and Biological Mechanisms	4835	567.6	519.2
2008-004-1	The Emotional Well-being project phase 2	57	5.2	5.2
2008-006	Genetics of Syncope and Breath Holding	1510	145.7	136.9
2009-003	Prevalence and risk factors of Lower Back Pain - A Pilot Study	136	14.5	13.3
2009-004	Gut Number Sense in Twins	52	4.5	4.35
<b>Total</b>			<b>1658.6</b>	<b>1537.2</b>

## Response Rates

The overall response rate for a study is defined as the number of 'Positive ("Yes")' and 'Negative ("No")' responses over the total number of twin members approached. The 'Response Rate' (RR) 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.

**Table 5** shows response rates for most active studies.

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 and 40 years have the highest 'NR (*Nil Response obtained*)' and

'Negative' RR and are the most difficult group for which to maintain current contact information. 'Negative' RR also include twins who are ineligible to participate in a study based on the criteria set by researchers, for example, where the member does not display a particular trait or does/does not suffer from a particular disease.

**Table 5:** Study response statistics to date for most active studies (ongoing and recruiting).

Study ID	Study Name	Total RR	Positive RR	Negative RR	NR RR	Total Pairs Approached	Total Responses
81-001	Teeth and Faces of Young Australian Twins	100 %	100%	0%	0%	49	49
94-005-2	Genetic and Environmental determinants of mammographic density: A twins and sisters study	91%	46%	40%	9%	2656	2420
96-001	Bone mass in adolescent male-male and male-female twin pairs	49%	16%	31%	51%	1006	495
96-009	Twin Studies of the genetics of osteoarthritis and osteoporosis	69%	31%	30%	31%	1211	830
97-001-3	Morphological and Spectroscopic Study of Monozygotic Twins Discordant for Epilepsy	50%	15%	31%	50%	377	187
2004-001	Tooth Emergence and Oral Health in Twins and Their Families	82%	68%	14%	18%	485	398
2004-003	The Effect of Anti-Epileptic Medications on Bone Mineral Density, Balance and Fracture Risk - A Twin and Sibling Study	41%	1%	40%	59%	3543	1463
2004-004	1. Cross-sectional, within-pair comparison of smoking discordant twins. 2. Smoking cessation and indices of bone health: a co-twin trial	75%	4%	69%	25%	3036	2268
2008-002	Genes, Diabetes Mellitus and Dementia	96%	42%	51%	4%	177	170
2010-004	How Your Brain Recognises Who You Are - Finding the Neural Correlates of Autobiographical Visual Self Recognition	33%	12%	11%	67%	93	31
2005-002	Molecular Genetics of Inattention in Australia	77%	35%	39%	23%	1337	1030
2005-003	The Twin Study of Brain Ageing and Cognition	95%	45%	49%	5%	992	943
2005-003-1	The Twin Study of Brain Ageing and Cognition - Phase 2	100 %	76%	24%	0%	212	212
2006-004	Genetic and environmental factors in invasive cervical cancer: a twin study	82%	41%	30%	18%	4607	3797
2007-004	Role of genetic and environmental factors in atrial fibrillation	78%	36%	40%	22%	936	726
2007-005-2	An investigation into the nature of Growing Pains in Australia.	37%	22%	15%	63%	2906	1070
2007-005-3	Growing Pains and Functional Pain Disorders	48%	48%	0%	52%	483	232
2007-006-2	Is foetal testosterone related to autism-like behaviours? A study of dizygotic twins	45%	35%	9%	55%	1720	770
2008-004	Pathways to Affective Disorders: Interactions between Genes, Environment and Biological Mechanisms	77%	27%	44%	23%	3342	2570
2008-004-1	The Emotional Well-being project phase 2	83%	56%	14%	17%	81	67
2008-006	Genetics of Syncope and Breath Holding	73%	12%	60%	27%	2157	1567
2009-003	Prevalence and risk factors of Lower Back Pain - A Pilot Study	66%	36%	7%	34%	494	324
2009-004	Gut Number Sense in Twins	21%	6%	6%	79%	1997	429

### ***Adverse Effects and Complaints***

The ATR takes any complaint from members seriously and endeavours to promptly resolve the issue presented. The ATR requires all adverse effects and complaints to be communicated to ATR Management.

During the reporting period, one ATR member filed a complaint to the Registry about a study facilitated by ATR. ATR ensured the resolution of this complaint was carried out by the study in a timely manner.

## VALUE-ADD

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

## VALUE-ADD

### Quality Improvement Project

In response to the NHMRC's requirement for stakeholder feedback, the ATR implemented a Quality Assurance (QA) Program in 2006 that incorporates stakeholder satisfaction feedback, monitors the quality of service delivery to twin members and researchers, and identifies critical points during the implementation and roll out of a research project where reflection and forward planning are important to maintain quality. The ATR has two major stakeholders: twin members and researchers working with the ATR.

The 2010 Annual Researcher Satisfaction survey was administered as part of the Annual Progress Report submitted by researchers. It requested feedback relating to the previous 18 months on:

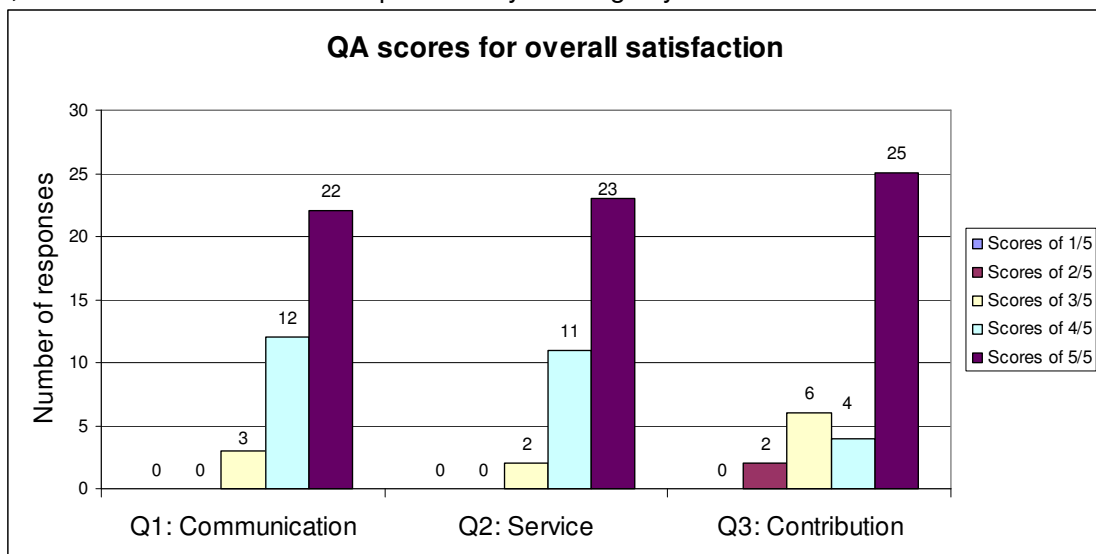
- (1) overall satisfaction with the researchers' communication with the ATR;
- (2) overall satisfaction with the services that the ATR provided; and
- (3) the value of the contribution that the ATR made to the overall research project

Responses were recorded as

*1 - Unsatisfactory / 2 - Satisfactory / 3 - Good / 4 - Very Good / 5 - Excellent*

We received feedback from 37 research groups. Overall, researchers were very satisfied with the communication and service provided by the ATR and the contribution the ATR has made to their project (**Figure 13**).

**Figure 13.** Overall satisfaction scores from researchers, evaluating communication with ATR, and service and contribution provided by the Registry.



## ***ATR Data Index Project***

To accomplish the ATR's goal of making previously collected data and biospecimens available for re-use by other groups and to fostering new collaborations, the Registry created a web-based, searchable index of questions and topics covered by all previous studies conducted via the ATR. The index was launched in 2009 and it is accessible at [http://www.twins.org.au/study\\_index/BasicSearch.php](http://www.twins.org.au/study_index/BasicSearch.php).

On this webpage, users can conduct searches based on keywords and specific criteria. A search generates a list of all previous studies matching the search items, including ATR study ID number, study title, Investigator/s, host institution/s, year/s study conducted, and study status (completed, in progress, etc). Advanced searches return 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. Records can be systematically reviewed and checked against existing hard copy files to ensure listings are complete.

Researchers interested in utilising these existing data contact the Registry initially, who then fosters a link with the originating research group.

## ***The Ark***

In 2010, the ATR became a collaborative development partner for The Ark, an international project based at the University of Western Australia. The Ark aims to build high-quality open source software information management system for the medical research community. The ATR assists in both the design and development of The Ark's registry and study management components. The Ark suite of informatics tools will be used by the ATR in the day-to-day operation and will also be made available to researchers conducting twin research. Software modules to support recruitment, subject management, electronic questionnaires, phenotypic and genotypic data management and biospecimen management will be made available along with a comprehensive set of reporting and data extraction tools.

Access to the ATR hosted instance of The Ark software will minimise the need for researchers to develop and host software to manage their studies. Researchers will be able to install separate local copies of The Ark software to support single studies or whole institutions, depending on their needs.

## **GOVERNANCE**

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

## **GOVERNANCE**

### ***ATR Management***

As of 31 December 2010, the ATR Management comprised:

- Prof John Hopper, Director, Australian Twin Registry; NHMRC Senior Principal Research Fellow; Director (Research), Centre for MEGA Epidemiology, University of Melbourne
- Dr Debra Foley, Deputy Director (Research), Australian Twin Registry; ORYGEN Research Centre
- Prof. Paul White, Deputy Director (Informatics), University of Western Australia
- Nick de Klerk, Director, Western Australia Twin Child Health (WATCH)
- Mr Vincent Pollaers, Chair, Advisory Board
- Kate Murphy, ATR Coordinator
- Emily England, ATR Senior Project Officer
- Shaie O'Brien, ATR Project Support Officer

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 review or application approval processes of that study.

Members of the Advisory Committee are available to help act as independent reviewers. In the event that the Director or Deputy Director is involved in a study as a researcher, they take no part in the approval process. If both are involved or unavailable, an independent person is brought in to oversee the processing of the application.

### ***Advisory Board and Charter***

In 2010, the Advisory Board members were:

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

Ex-officio:

- Professor John Hopper (Director, ATR, University of Melbourne)
- Dr Debra Foley (Deputy Director, ATR, ORYGEN Research Centre)
- Prof. Paul White, Deputy Director (Informatics), University of Western Australia



### **ATR Staff**

The ATR is administered by The University of Melbourne and is situated in the Centre for MEGA Epidemiology, School of Population Health. In 2010, the ATR employed two full time (Coordinator and Project Support Officer) and three part time (two Senior Project Officers and an Administration Assistant) administration staff; five casual staff (equivalent of 2.0 EFT), and a part time Database Manager.

The ATR provided an honorarium to the Director and both part-time Deputy Directors.

### **Dispute Resolution Process**

The Dispute Resolution Process approved by the Advisory Board enables impartial and transparent management of any dispute arising between the ATR and stakeholders. No action was necessary under this process in 2010.

### **ATR Budget**

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

We are very grateful for all the support we receive from Registry members and the wider community who have donated in 2010 towards a total of \$1,585.

The names of the ATR donors are listed below:

Angela Formato	Margaret Moody
Maree Klafas	Jean Murdoch
David Barnes	Laura Carniato
Debbie O'Connell	June Peters
Ailsa Cross-Johnston	Shirley Walton
Nancy Hansen	Ina Coventry
Betty Lovett	Vivienne Kennedy
Nina Johnson	Oriel Leighton
Margery Stevens	<i>Anonymous</i>
Patricia Ritchie	Kristy Busuttil
Jill Posener	June Petru
Margaret & Elsie Maddicks	Diane Routt
Elaine Simmons	Margaret Ross
Lorna Webber	Helene Kolozs
Dorothy Roberts	Neil Sayer
Bernard White	Margaret Mountford
Kerry Ballard	
Leon Friedman	

The NHMRC Enabling Grant Special Facilities Scheme provides the ATR with \$500,000 per annum between 2010 and 2014. The ATR also recovers costs associated with approaching twins for studies from researchers.