
The Australian Twin Registry

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The Australian Twin Registry (ATR), established in the late 1970s, is a volunteer registry of over 30,000 pairs of Australian twins of all zygosity types and ages unselected for their health or medical history. The ATR does not undertake research itself but acts as facilitator, providing an important national and international resource for medical and scientific researchers across a broad range of disciplines. Its core functions are the maintenance of an up-to-date database containing basic contact details and baseline information, and the management of access to the resource in ways that enhance research capacity within Australia while protecting the rights of twins. The ATR has facilitated more than 200 studies using a variety of designs, including classic biometrical twin and twin family studies, co-twin control studies, intervention studies, longitudinal studies, and studies of issues relevant specifically to twins. These have yielded more than 300 peer-reviewed publications to date. Areas of major research include studies of behavior, musculoskeletal conditions, teeth and face patterns, cardiovascular risk factors, substance abuse, and risk factors for melanoma and breast cancer. Extensive longitudinal data are available for around 10,000 pairs. DNA samples have been obtained from more than 6000 twins. Considerable efforts are devoted to maintaining the commitment of registry members and recruitment. The ATR hopes to secure funding to expand its activities, including the systematic collection of DNA samples, so that it can continue to play a major role in the development of twin research and contribute to the annotation of the human genome.

The Australian Twin Registry (ATR) was established in the late 1970s as a volunteer registry of twins of all zygosity types and ages. Australian-based twins are welcome to join regardless of their health or medical history. The ATR does not undertake research itself but acts as facilitator, providing an important national and international resource for medical and scientific researchers across a broad range of disciplines. Its core functions are the maintenance of an up-to-date database listing basic contact details and baseline information for twins willing to consider participating in research projects, and the management of access to that resource in ways that enhance research capacity within Australia while protecting the rights of twins. As an openly shared resource, the ATR provides researchers with access to an established infrastructure and a network of scientists and administrative staff who are experienced in running twin studies.

The ATR has been used for a wide variety of purposes, including:

1. *classic biometrical twin and twin family studies* attempting to quantify the roles of genetic and environmental causes of variation in traits, and in disease susceptibility;

2. *co-twin control studies*, using twins discordant for specific environmental factors or exposures, and twins discordant for disease outcomes or measures of morbidity;
3. *intervention studies*, in which twins within a pair are randomly allocated to treatment thereby matching naturally for age, sex and genetic susceptibility; and
4. *longitudinal studies*.

The above approaches use twins to make inferences about the general population, under important assumptions. In addition to the above, the ATR has been used for:

5. *studies of issues relevant specifically to twins*, such as learning difficulties, the inheritance of twinning, and bereavement.

Brief History

The seeds for a national twin registry were sown at a meeting held in Miami, Florida in 1973, attended by Richard Lovell of The University of Melbourne and Michael Hobbs of The University of Western Australia. The meeting was arranged by the Council for Tobacco Research in the USA, possibly inspired by an earlier Swedish report of no difference in the mortality of monozygous twins discordant for smoking. The Australian representatives returned convinced that, notwithstanding “deep reservations about the leading role apparently being played by a tobacco-related research organization”, establishment of an Australian twin registry as a research tool for medical science in general had a number of potential benefits. A letter seeking enthusiasts was published in the *Medical Journal of Australia* in 1974, but drew no response.

Nevertheless, in time several twin registries were established around the country. R. J. Walsh established a small Sydney-based registry at the University of New South Wales in the mid-1970s. The Victorian Twin Registry commenced in 1977 through a grant from The Anti-Cancer Council of Victoria to John Mathews at The University of Melbourne. In the course of his PhD in Birmingham, Nick Martin performed the first power calculations of the numbers of twins required to obtain meaningful answers to questions about the relative importance of nature and nurture. His calculations suggested that prior studies had

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been too small and that thousands of pairs were required. Martin returned to Australia in 1978 determined to establish a large registry and with John Gibson initiated an Australian Twin Registry at the Australian National University. In 1981, through a 5-year grant of \$25,000 per year from the National Health and Medical Research Council (NHMRC), the then ATR and VTR combined forces to establish the "Australian NHMRC Twin Registry" as a national resource for biomedical research.

The first major initiative was the development and mailing of the "Canberra Questionnaire" to the more than 4000 adult pairs then on the Registry. The questions addressed demographic and general health matters. The responses received have since formed the basis of a large number of Registry-based projects. In particular, the survey has served as the springboard for the extensive twin research activities led by Nick Martin at the Queensland Institute of Medical Research (QIMR); see below.

The ATR was reviewed by the NHMRC in 1983, leading to the establishment of a Scientific Advisory Committee chaired by Warren Ewens of Monash University, with John Mathews as Director. Christine Clifford succeeded Dr Mathews in 1985 and served until 1990, when the current Director was appointed and Graeme Griffin became the Chair. On Griffin's retirement at the beginning of 2001, Geoff Tregear was appointed Chair. During this period the ATR was reviewed regularly by NHMRC and awarded successive 5-year awards, the latest for 1998–2002 at an average of \$120,000 per year.

Over the two decades of its operations, the ATR's objectives, policies, and procedures have undergone a maturation process, and continue to be refined in line with developments in research methodologies. As an openly shared resource for twin researchers, the ATR has been able to play a leading role in fostering the development of synergistic research programs and has become a model for integrating public health and biomedical research. For example, its generally inclusive philosophy and many of the procedures that it has consequently developed for managing the needs of multiple research groups have been adopted by emerging cancer family registries such as the Kathleen Cuninghame Foundation for Research into Familial Breast Cancer (kConFab) funded by the National Breast Cancer Foundation of Australia and NHMRC, the Australian Breast Cancer Family Study (ABCFS), the Australasian Colorectal Cancer Family Study (ACCFS), the Australian Melanoma Family Study (AMFS) and the Victorian Paediatric Cancer Family Study (VPCFS). The ABCFS and ACCFS are funded by the National Institutes of Health (USA) as part of their international Breast and Colon Cancer Family Registries (CFRs) in which sites in the USA, Canada and Australia collect data according to common questionnaires and biospecimens storage protocols, and make their resources available to researchers world-wide. The NHMRC has remained consistently supportive of the ATR and has indicated a willingness to support an expansion of its activities under the umbrella of National Research Capacity funding.

Administration

The ATR is administered through The University of Melbourne under a director and an executive committee. The Executive meets once each year and consists of nationwide researchers with expertise in twin research, a gynaecologist specialising in multiple pregnancies, a representative of the Australian Multiple Births Association (AMBA), and a twin representative. Twin patrons are Sir James Balderstone AC and Robert Balderstone MC CMG, and long-term members of the national cricket team Stephen and Mark Waugh. The ATR's permanent staff consists of a part-time Administrative Officer who manages day-to-day operations, including the coordination of recruitment for studies, a full-time Research Assistant responsible for tracing twins and updating records, a part-time Research Assistant who works evenings in order to contact members who can not be reached during normal business hours, and a part-time Media Relations and Publications Coordinator to assist with the production of publicity, newsletters and recruitment drives. The ATR also contributes to the salary of a Database Manager.

Recruitment

The ATR is a volunteer registry. Recruitment occurs through a variety of means, including AMBA clubs, word of mouth, schools, medical centres, posters, and features in the electronic and print media. A concerted recruitment drive in 1990–91 resulted in 4000 new pairs, since which the rate of new registrations has been stable at just less than 1000 pairs per year. More than 75% of pairs recruited in the last decade have been under the age of 20 (cf. 30% of the population) and 5% aged 50 or older (cf. 24%).

Database

The ATR has a relational database that uses Microsoft Access as the interface. Individual records contain names, date of birth, contact details and other demographic information for each twin, as well as information on an alternate contact person who can assist with future address updates. At the time of registration both twins need to be alive and based in Australia (single or overseas twins are able to join a mailing list.) Once a pair has been registered, the ATR keeps track of the current status of each twin so as to identify "active" members who are willing and available to be approached for studies. Baseline data and records regarding approaches and participation in studies are kept in databases linked to this main registry.

Current State of the Registry

Table 1 (A & B) show that, as at the end of 2001, nearly 31,000 pairs had ever been registered with the ATR. For 9% of these, one or both were "inactive" — either deceased, no longer interested in participating, or unable to be traced — leaving 27,575 "active" pairs. The ATR also includes 168 sets of triplets and 7 sets of quadruplets.

The breakdown of active pairs by zygosity and sex is: 22% MZF, 16% MZM, 18% DZF, 15% DZM, 25% DZO and 5% same sex pairs of unknown zygosity, working out to 33% male, 42% female, and 25% mixed sex pairs.

Table 1A

State of the Australian Twin Registry as of 31 December, 2001:
Active and Lost Twins Pairs: Sex by Zygosity

	Active Pairs	% of group	% of total	Lost Pairs	% of group	% of total
Male / Male						
MZ	4348	48.3%	15.8%	136	50.0%	17.8%
DZ	4014	44.6%	14.6%	105	38.6%	13.7%
unknown	636	7.1%	2.3%	31	11.4%	4.1%
TOTAL:	8998	100.0%	32.6%	272	100.0%	35.6%
Male / Female						
DZ	6907	100.0%	25.0%	208	100.0%	27.2%
TOTAL:	6907	100.0%	25.0%	208	100.0%	27.2%
Female / Female						
MZ	6161	52.8%	22.3%	144	50.7%	18.8%
DZ	4865	41.7%	17.6%	107	37.7%	14.0%
unknown	644	5.5%	2.3%	33	11.6%	4.3%
Total:	11,670	100.0%	42.3%	284	100.0%	37.2%
Total Pairs:	27,575		100.0%	764	100.0%	

Table 1B

Active and Lost Twin Pairs by Age as of 31 December, 2001

Age	Active	% of all active	active as % of all registrations	Lost	% of all lost	lost as % of all registrations
0 to 9 years	3981	14.4%	14.0%	11	1.4%	0.0%
10 to 19 years	5809	21.1%	20.5%	97	12.7%	0.3%
20 to 29 years	5130	18.6%	18.1%	237	31.0%	0.8%
30 to 39 years	5742	20.8%	20.3%	266	34.8%	0.9%
40 to 49 years	3291	11.9%	11.6%	105	13.7%	0.4%
50 to 59 years	1966	7.1%	6.9%	36	4.7%	0.1%
60 to 69 years	914	3.3%	3.2%	8	1.0%	0.0%
70 to 79 years	564	2.0%	2.0%	2	0.3%	0.0%
80 to 89 years	164	0.6%	0.6%	2	0.3%	0.0%
90 to 99 years	14	0.1%	0.0%	0	0.0%	0.0%
Total Pairs	27,575		97.30%	764		2.70%

The breakdown by age is: 15% are 0–9 yrs, 21% are 10–19 yrs, 19% are 20–29 yrs, 21% are 30–39 yrs, 11% are 40–49 yrs, 7% are 50–59 yrs, 3% are 60–69 yrs, 2% are 70–79 yrs, and 1% are 80 yrs or older. The drop between the fourth and fifth decades is in part a reflection of the cohort of school-age twins recruited in the early 1980s. Twins reside in all states and territories in approximately the population frequencies, except for a higher proportion from Victoria (30% versus 25% in the population) and a lower proportion from New South Wales (25% versus 34%), reflecting the major contribution of the VTR at initiation of the ATR.

Operational Procedures

Use of the ATR is governed by established guidelines and procedures. The Application Kit For Researchers and application forms are available on the ATR web site (see below). Researchers are responsible for the design of the study, securing funding, and obtaining approval for the project from an appropriate Human Research Ethics

Committee (HREC). Consultation with the ATR Director and staff prior to making an application is generally encouraged. Members of the Executive Committee are informed of each new application and given the option of perusing it in full. In most instances, three reviews of each proposal are commissioned from a combination of members and external individuals with appropriate expertise. This process aims to provide prospective researchers with constructive feedback, and the ensuing dialogue often leads to improved studies and facilitates collaborative projects that build on previous research.

Recruitment is generally undertaken via postal invitations that include a letter from the ATR introducing the study and endorsing it as one that has been reviewed and approved. This is accompanied by a letter from the researcher which details the nature and purpose of the study, the procedures involved, any associated risks, any feedback that will be provided, the details of the person who should be contacted for further information, and directions for replying to the invitation. Importantly, twins

are assured that their participation is voluntary and any data or material they provide for the study will be kept confidential. Researchers are provided with personal or identifying information only if and when written consent of both twins (or a parent) has been obtained. Researchers are required to reimburse the ATR for any costs associated with recruitment. The need for, and magnitude of, follow-up of non-responders depends on the aims, size, and budget of each study, and is best done in collaboration with the ATR. The progress of ATR associated studies is monitored through annual reports.

Researchers wishing to amend their protocol, add sub-studies, or use the data or material they have for purposes other than those in the approved protocol must apply to the ATR and secure its approval for the changes. As a condition of using the Registry, researchers are expected to acknowledge the ATR in all publications. When a study is completed and the data checked and cleaned, the ATR requests a copy of the data for its archives, giving researchers the option of placing conditions on third party access.

Baseline Questionnaires

Several baseline questionnaires have been administered by the ATR in collaboration with researchers, and been entered onto the ATR database.

A. Canberra Questionnaire. This was mailed in 1980 to all adult pairs then registered and asked about basic demographics, lifestyle, and general health matters. Completed questionnaires from both members of 3808 pairs were returned.

B. Junior and Senior Baseline Questionnaires. Based on the Canberra Questionnaire, these shorter versions were mailed to pairs registering during the latter half of the 1980s and early 1990s. More than 15,000 questionnaires were returned.

C. Family Health Questionnaire. The Family Health Questionnaire was included in the *1997 Twins Newsletter* and sent to all newly registered pairs during 1998. It asked about the twins' personal and family history for 32 different diseases and conditions. More than 6000 questionnaires related to 5000 pairs were received. These data have been used by several studies to target or screen prospective participants with specific medical histories.

Scientific Research

Since its inception, more than 200 studies have been initiated using the ATR, with about 10 new studies commencing in each year of the last decade. Currently there are 40 active studies recruiting or collecting data, including several major long-term programs. Over the last four years the ATR has sent out over 100 mail-outs comprising more than 23,000 letters. There has been a range of major areas of interest addressed by Australian twin researchers using the ATR and some highlights are summarized below.

Behavior Genetics

Behavior Genetics has been the principal focus of work led by Nick Martin at the QIMR in Brisbane. The basis of this work was the Canberra Questionnaire mailed in 1980. The

cohort of 3808 adult twin pairs who replied to that survey was sent a follow-up questionnaire in 1988 and took part in a telephone interview. In 1993–95 they and their close relatives were invited to participate in twin family studies. In addition, twins who have become adults in the intervening years were mailed questionnaires in 1991 and interviewed by phone in 1996–2000. A number of papers on a variety of topics have appeared in journals such as *Behavior Genetics*.

A major area of interest has been alcohol consumption, stemming from a seminal project in which Martin and John Whitfield had twins consume alcoholic drinks before undergoing balance and other tests while their blood alcohol levels were monitored. The ability to follow these twins up in recent years has been of great value in investigating the natural history of alcohol use, especially now that DNA samples have been obtained from most twins. Key findings are that the influence of genetic factors on risk of alcoholism is substantial for both men and women (Heath et al., 1997), and that a polymorphism at the alcohol dehydrogenase gene cluster on chromosome 4 appears to account for at least part of this — one of the first examples of a quantitative trait locus for a complex behavioral trait (Whitfield et al., 1998).

Musculoskeletal Conditions

There have been a number of twin studies of bone mineral density (BMD), as measured by dual photon X-ray absorptiometry (DEXA) and other techniques, and of other musculoskeletal conditions including rheumatoid arthritis and disc degeneration (Bellamy et al., 1998; Sambrook et al., 1999). BMD studies started at the Garvan Institute under John Eisman and colleagues, and indicated that variation in female bone density may be under strong genetic control (Pocock et al., 1987). This led to a high-profile paper in *Nature* that implicated a non-functional variant in the vitamin D receptor (VDR) gene as being principally responsible for that genetic variation (Morrison et al., 1994). Subsequently it was found that the result may be incorrect due to genotyping errors (Morrison et al., 1997). It now appears that the variant in question explains little if any variation in bone mineral density, but nevertheless the original paper had instigated great interest in the genetics of osteoporosis.

Other researchers, in particular groups led by Ego Seeman and by John Wark in Melbourne and more recently by Phillip Sambrook in Sydney, have further investigated both the genetic and environmental determinants of variation in BMD, in both adults and adolescents of both sexes (Seeman & Hopper, 1996; Young et al., 1995). Although adult BMD may have a high heritability, there is evidence for strong effects of shared environment during adolescence that rapidly abate in early adulthood (Hopper et al., 1998). Another study used the Canberra Questionnaire to identify female twin pairs strongly discordant for smoking, including 21 pairs in which one twin had smoked more than 20 pack-years and the other had never smoked (Hopper & Seeman, 1994). The BMD of these pairs differed by up to 5%, indicating that tobacco smoking is a strong preventable risk factor for osteoporosis and fractures.

Attention Deficit Hyperactivity Disorder (ADHD)

David Hay, now at Curtin University in Western Australia, and Florence Levy of the University of New South Wales, conducted a longitudinal study of young twins and their families focusing on Attention Deficit Hyperactivity Disorder (ADHD). Questionnaires were mailed in three waves in 1992, 1994-95 and 2000. A seminal paper from this work demonstrated the existence of the entity ADHD as a continuum (Levy & Hay, 1997), and led to the first text book on genetics and ADHD (Levy & Hay, 2001) aimed at psychologists and psychiatrists. There are three subtypes of ADHD — young people can have inattentive symptoms, hyperactive-impulsive symptoms, or both types of symptom (called the combined type). The twin study showed that the subtypes breed true, as do the developmental progressions of ADHD — if one identical twin improved typically so did the other. That is, it appears that genetics may play a larger role in susceptibility to ADHD than in other childhood behavioral disorders.

Teeth and Face Patterns

Starting in the mid-1980s, Grant Townsend and colleagues in the School of Dentistry at the University of Adelaide have been studying the teeth and faces of 600 young twin pairs (including four sets of triplets) and their siblings, developing methods for acquiring, storing and displaying three dimensional images. New methods for analysing this data, such as those involving Fourier transformations, have been developed (see e.g., Tangchaitrong et al., 2000). Analyses have principally been focused on understanding the causes of variation in teeth size and shape (e.g., Townsend & Martin, 1992), but have also had wider implications for human biology (Townsend et al., 1998). Twin researchers may also be interested in the extent to which zygosity can be determined accurately from dental morphology (Townsend et al., 1988).

Cardiovascular Disease

Stephen Harrap at The University of Melbourne has conducted an adult twin family study of cardiovascular risk factors. This demonstrated that, as well as genetic factors, the causes of familial aggregation include environmental factors shared by children and their parents while they live together that are strong enough to persist into adulthood (Harrap et al., 2000). This study has also found evidence for specific genetic variants influencing baldness (Ellis et al., 1998, 1999).

Risk factors for Melanoma

The most important known risk factor for melanoma is a high density of melanocytic naevi, or common moles. Nick Martin and colleagues in Brisbane, which has the dubious honour of having the highest rate of melanoma in the world, have been counting moles on the skin of 12-year-old twins since 1992. They have shown that variation in moliness is strongly genetically influenced, perhaps surprising given the known role of sun exposure. A genome scan of 274 twin families suggested a locus influencing moliness exists on chromosome 9p that may account for 33% of variance in flat mole count (Zhu et al., 2000). Fine

mapping studies are underway to try to locate putative genes in other identified chromosomal regions.

Breast Density

Mammographic densities, as measured from breast scans, are one of the strongest risk factors for female breast cancer, with up to 5-fold difference in risk between women of the same age in the upper and lower quartiles. A twin study of more than 600 pairs conducted in Australia and North America (Boyd et al., 2002) has found that genetic factors could explain up to 60% of this variation, and the genes responsible for this could explain up to 10% of familial aggregation of female breast cancer (cf. mutations in BRCA1 and BRCA2, which explain less than 20% of familial aggregation).

Genetics of DZ Twinning

Nick Martin and Grant Montgomery at the QIMR have recruited sisters who have both had DZ twins for a linkage study of genes involved in DZ twinning. They also recruited mothers who had had two sets of spontaneous DZ twins for studies of reproductive hormones, and found evidence of atypical patterns in these twin-prone women.

Publications and Conference Proceedings

By the end of 2001, 307 peer reviewed papers had been published or were in press, and 322 conference proceedings, abstracts, and other publications had been reported, for a total of 629 publications from studies associated with the ATR. In recent years there have been about 30 peer-reviewed papers and 40 conference proceedings per year, and these rates have been increasing. A bibliography is available on the ATR web site.

Record Maintenance

On average the ATR updates the records of more than 7000 pairs each year (about one in every four members). In the process of responding to mail-outs, approximately 2300 ATR members verify or correct their contact details each year. Researchers with active twin studies also report back to the ATR changes for those pairs participating in their projects. Staff routinely check the records of long term members that have not been updated for 3 years, discovering hitherto unreported changes for about 50% of them. The ATR usually receives about 2500 return-to-senders following the distribution of the Newsletter. Prior to sending out the 2001 *Twins Newsletter*, the ATR did a crosscheck of all the Australian addresses against Australia Post's Change of Address Service. The high percentage (90.2%) of addresses matched shows that the database is in good order. Email addresses are on record for about 600 twins (2% of Active members), but we have found that, like mobile phone numbers, email addresses are subject to frequent changes which are difficult to track.

Promotion of the Australian Twin Registry

As a volunteer registry and nationally funded resource, the ATR needs to attract the interest and goodwill of both the general public and the medical and health research community in order to ensure that: (a) it has a ready pool of

volunteer twins willing to participate in studies, and (b) it continues to receive the quality research proposals from a wide range of disciplines that justify its continued existence in a competitive funding environment. Consequently, the promotion of the ATR has become an increasingly important activity and several initiatives have been undertaken to publicize the ATR's work within the general and scientific community.

Twin Research Workshop

From 1988–1992, the ATR hosted an annual twin research workshop titled *It Runs in the Family* (IRITF). Lack of funding brought about a discontinuation of the series, but in 2001 the concept was resurrected following a donation from Gemini Genomics Pty Ltd. The IRITF workshops are aimed at researchers, research staff, and students who are currently including twins in their projects or who may benefit from expanding into twin research. The main objectives of the workshops are: (a) to provide a showcase for Australian twin research and help the design, conduct and analysis of projects; (b) to draw the attention of researchers to the advantages of twin studies and how they could be used as a basis for a successful research career; and (c) to educate researchers about methodologies, genetics, and ethics. Key note speakers have included international leaders in genetic epidemiology and twin research, including Robert Elston, Lindon Eaves, David Fulker, Ken Lange, Lon Cardon and Dan Schaid.

New Look

In 1998 the ATR adopted a fresh new look with the redesigning of its logo, stationery, registration form and website. The new logo is popular and has proven effective in terms of establishing a recognizable identity for the Registry; see Figure 1.

Twins Newsletter

The *Twins Newsletter* is the ATR's pivotal means of maintaining contact with members and publicizing the work of twin researchers to the community. Currently, on a biannual basis, about 50,000 copies are produced and mailed to all adult Registry members and the parents of young twins, and used for promotional activities.

Twins' Picnic

In March of 2001, the ATR teamed up with AMBA to host the inaugural Twins' Picnic in the grounds of Government House in Melbourne. This was made possible by the donation from Gemini Genomics Pty Ltd. Given that 2001 was the "Year of the Volunteer", the Twins' Picnic was a "thank you" for the more than two decades of voluntary contributions Australian twins have made to medical and health research. The hundreds of twins and other multiples who attended were aged from a few months old to over 90 and came from all over the country. They were entertained by a variety of performers and participated in a range of activities. The Picnic included a number of marquees devoted to information about twin research, including one in which twins had their ears photographed for zygosity testing. Media coverage was excellent.

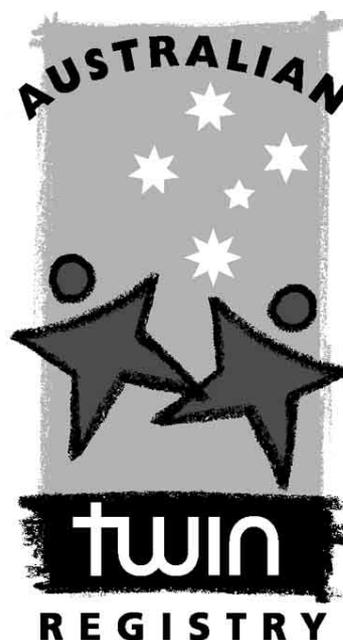


Figure 1

The new logo of the Australian Twin Registry, featuring elements recognizable to twins in Australia and overseas — the Southern Cross (five stars), the blue ocean surrounding the continent, the yellow sandy beaches and the red deserts of Central Australia, and of course the "stars" of the Registry, a pair of twins.

Web site

The ATR web address is www.twins.org.au. Researchers can access the Research Application Kit, including application form in PDF format, and information about the *It Runs in the Family* workshops. Twins can access information about studies, copies of the *Twins Newsletter*, information sheets, a registration form and photos from the Twins' Picnic.

Media

Each year the ATR receives numerous requests from the media for help with stories on twins. Every effort is made to assist on the proviso that information about the ATR is featured. Examples of successful collaborations are the "Two's Company" episode of *Couchman* televised by the ABC in March 1991 and the special "Secret Life of Twins" aired on Channel 7 in 1998, both of which led to numerous new registrations.

Other Initiatives

Other promotional initiatives have been undertaken whenever resources have allowed. These include the production of posters, postcards, refrigerator magnets and, more recently, bumper stickers, key rings, and coffee mugs. Fridge magnets, in particular, have proved to be an effective means of reminding members to inform the ATR of address changes. The ATR recently collaborated with distinguished author Tom Shapcott, a DZ twin and ATR member, on a book of Australian twin stories, *Twins In The Family: Interviews with*

Australian Twins, published by Lothian Books in 2001; see review by Sue and Carol Treloar in April 2002 issue of *Twin Research*. The ATR helped source twins and the Director contributed a Foreword. The book also contains chapters on twin research and the Twins' Picnic, and information about the ATR.

Future

The ATR is currently in the last year of a 5-year NHMRC Special Investigations Grant. In association with the expected review of the Registry's future funding, discussions are taking place that could see a substantial expansion of its activities so as to ensure that it continues to play a major role in Australia's National Research Capacity. Among the mooted possibilities are (a) establishment of a centralized repository for data from twin studies, and a bank of DNA samples from ATR members which would be made available to researchers under specific conditions; (b) provisions for the collection and up-dating of baseline data on a regular basis; and (c) development of a national cohort study of multiple birth families recruited antenatally. In addition, the ATR wishes to hold further events building upon the inaugural Twins' Picnic and conduct annual research workshops. It will continue to pursue initiatives that support the successful continuation of longitudinal studies of twins on the Registry.

Conclusion

The Australian Twin Registry has become an important national and international resource for medical and scientific research. It has evolved in concert with major developments in human health research since its inception in 1980, and promises to become even more relevant with the advances in the Human Genome Project. The ATR serves a broad range of disciplines by affording access to potential participants in twin studies while also working hard to safeguard the rights of its members and their willingness to act as voluntary research subjects. As an openly shared resource for twin researchers, the ATR has been able to play an integral role in fostering the development of synergistic research programs and has provided a valuable model for other registries, such as the emerging Cancer Family Registries.

The boundaries of human research in every field have been reconfigured by the dawning of the genome era. Twin research has long been recognized as an important contributor in the development of genetic research. Rapid advances in the field of biotechnology and accelerating interest in the human genome highlight the potential twin studies have to play an even stronger role due to:

- the ability of the twin design to tease apart the effects of genes from those of the environment;
- the longitudinal data that has been collected, over almost two decades in some instances, on large numbers of twins, and in many cases their relatives; and
- the availability of tens of thousands of Australian twins who have voluntarily enrolled because they understand their unique role in medical research and the importance of their on-going commitment to it.

With the unravelling of the genome, the twin design comes to the fore once again as it opens up the opportunity to identify variants associated with disease or medical conditions, understand their strengths of association, and investigate which environmental factors modify their effects (often referred to "gene-environment interactions"). Having been a major contributor to the development of twin research in Australia, the Australian Twin Registry is set to continue to play a vital role in the future.

Acknowledgments

I would like to acknowledge the help of Palma Ragno in preparing this paper and the Annual Reports of the last five years, and express my gratitude to my predecessors and the many members of the Executive without whom this resource would not exist. I dedicate this paper to Professor Graeme Griffin who, as a member of the Executive Committee for more than 15 years and Chair from 1990 to 2000, had a major impact on the operational procedures and code of conduct of the Australian Twin Registry and was of enormous assistance to me as Director.

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