



Australian Twin Registry Newsletter

Twins 2008

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From the Director

Our 2014 Vision:

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

That is the 2014 Vision Statement of the Australian Twin Registry, endorsed by the Advisory Board in March, 2007. 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 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.

Fraternal twins play an equally important role

Much to our dismay, staff at the ATR often hear the comment “Oh, you would not be interested in registering my twins – they are fraternal”. On the contrary – we are just as interested in fraternal twins as we are in identical twins.

Studying identical twins is an important part of the role we play in medical research, but identical twins can only provide us with half of the answers to our research questions. The most powerful studies gather data from both identical and non-identical twins and compare the two groups to work out if there is a difference.

By comparing the similarities and differences between identical and non-identical twins, researchers can get a better understanding of how our genes and environment determine just who we are, what we do, and our future health and happiness. In addition, by studying boy/girl fraternal twins, researchers can also discover important information about gender differences in certain diseases and characteristics.



Fraternal twins Bailey and Jake – 6 years old

A showcase for ATR activities

The ATR has released a special Annual Report summarising its many activities during July 2005–07.

The report provides a detailed overview of the policies and procedures of the ATR in an accessible format. It describes the methods we use to recruit members, how we approach our members regarding studies, and how we maintain the accuracy of our records.

For the first time, the report is also being made freely available to all ATR members through the ATR’s website: www.twins.org.au. This is an important opportunity for ATR members to gain a greater understanding of the ATR and how it operates.

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www.twins.org.au

The Australian Twin Registry is supported by an Enabling Grant from the Australian National Health and Medical Research Council, administered by The University of Melbourne. Donations welcome.

The ATR enjoys a close relationship with the Australian Multiple Birth Association (AMBA)

Check out AMBA's shop

AMBA now has an online store providing an indispensable resource for all multiple birth families.

Not only are the products recommended by "those who know" and provided at discounted prices, a portion of every sale goes back to AMBA's clubs and national body to help provide services to multiple birth families.

The online store includes a Gift Registry, New Twin and Triplet Family checklists, monthly specials. There are further discounts when you purchase two or more of the same item.

See the store at www.store.amba.org.au



Web Wonders!

The Australian Multiple Birth Association's online Community Forum is going strong, with more than 2,000 members and 100 message boards to choose from.

Topics covered include "Being Twins, Triplets and More" and "Pregnancy and Parenting of Multiple Birth Children". Even if you prefer to "lurk" rather than chat online, there are more than 10,000 posts to read!

Visit today – it's free and has lots to offer: www.forum.amba.org.au



Magazine thrives

AMBA's Free Bi-Annual Magazine for members now has a celebrity multiple birth parent panel, including Kim Watkins, Chris Reason, Richard Clapton and Peter Beattie!

Andrew Greenfield, a child psychologist and identical twin, has also joined the editorial team answering the concerns of AMBA members and their children.

From the Director

(continued from page 1)

Ethically sound

The NHMRC has published a National Statement on Ethical Conduct in Human Research.

The statement emphasises each institutions' responsibilities for the quality, safety and ethical acceptability of research that they sponsor or permit to be carried out under their auspices". This statement includes those institutions whose "employees, resources and facilities are involved in research".

The ATR is invested with responsibility under these guidelines to monitor the ethical conduct of its own activities, and the activities of research projects that we approach our members to be involved in. This is a responsibility we take very seriously.

In 2007, the ATR was awarded University of Melbourne Human Research Ethics Committee (HREC) approval for the "Program of Work" that we supply to researchers. This covers all of our operational policy and procedures, from the discussion and approval of a project to the way we invite twin members to participate and the way we report to our key stakeholders and the NHMRC regarding our progress. The document outlining our Program of Work is available on the ATR website at: www.twins.org.au

Even a "NO" is important to us!

The ATR has had a busy year inviting more than 25,000 twins to participate in a range of studies.

Each invitation is accompanied by a Response Form and Reply Paid envelope so that our members can indicate whether or not they wish to participate.

It is always wonderful to receive positive responses, but did you know it's equally important you let us know when you are not interested in joining the study?

A "No" response confirms that you have received the information and have made a decision regarding your involvement.

The Response Form also allows us to keep up to date with your contact details.



Are you asking me if we had SEX to conceive our twins?

Most parents of twins will be familiar with this question. Now your responses to this sensitive subject are being studied.

Drs Ruth Morley and Supriya Raj, who run the ATR's Mothers and Twin Children, or **match** project, recently mailed a survey to find out if the parents of twins and multiples are prepared to tell researchers, health professionals, family, friends or their children how they conceived their babies.

In collaboration with the Australian Multiple Birth Association, 1,600 questionnaires were sent to Victorian families, who were encouraged to respond anonymously. Participants were asked how their twins were conceived and to whom they would disclose this information. Detailed comments were also invited. Altogether 975 (or 61%) of questionnaires were returned.



Of those couples who had used ART to conceive, almost all were willing to tell their twin children, close family members and medical practitioners.

Interestingly, friends were the group least likely to be told (15% of couples said they would not confide in friends).

Overall, those conceiving by GIFT were the least likely to divulge this information.

Comments returned with the questionnaire revealed the depth of feeling among parents of twins around questions regarding conception.

Respondents who had conceived their twins spontaneously, as well as those who

needed help, felt that this was offensive and an invasion of their privacy. Many felt that there was a general perception that multiples are a "side effect" of fertility treatment.

Some who had conceived their twins with assistance were reluctant to disclose this because it made them feel inadequate.

The majority of respondents were happy to discuss their twin babies' conception, but it is clear that the general public need to be made aware that some parents of twins or multiples will be offended by being asked how they conceived, or if they were "natural".

To find out more about the match project go to: <http://www.twins.org.au/match.html>

How many used Assisted Reproductive Technology (ART)?

Of the 975 respondents, 40% used some form of medical intervention to conceive their twins or multiples. These included IVF, Intracytoplasmic Sperm Injection (ICSI), ovarian stimulation, Gamete Intrafallopian Transfer (GIFT), donor eggs and donor sperm.

So how many parents would disclose their method of conception and to whom?

Pap test histories key to cervical cancer

Many more female twin pairs are needed to help the CECAGEEN study unlock the key to HPV and cervical cancer. Note: No additional Pap test is required!

As reported in the last *Twins Newsletter*, researchers at the Royal Women's Hospital in Melbourne are seeking the involvement of female twins over 30 who have had Pap screens within the past 10 years.

The study, researching the link between human papillomavirus, or HPV, and cervical cancer, began recruiting in 2007 and is now set to ramp up.

Participation is remarkably easy. Each time a woman has a Pap smear, her sample is put on a microscope slide and analysed by a scientist for signs of cell changes. The results of this analysis are provided to the woman's GP and are also recorded at the state-based Cervical Cytology Registry where the slide is stored. This allows each

woman's Pap smear history and previous Pap smear samples to be built up over time as valuable asset for researchers.

Researchers are initially asking women for permission to access the paper-based historical record from the Cervical Cytology Registry in their state. At this stage, the participant does not have to do anything beyond provide their permission for the Cervical Cytology Registry to release their file to the researchers.

No new tests required

Some women have reported being reluctant to join the study because they believed they would be asked to have additional Pap smears. This is not the case. The researchers only want to access

the existing Pap smear history and samples.

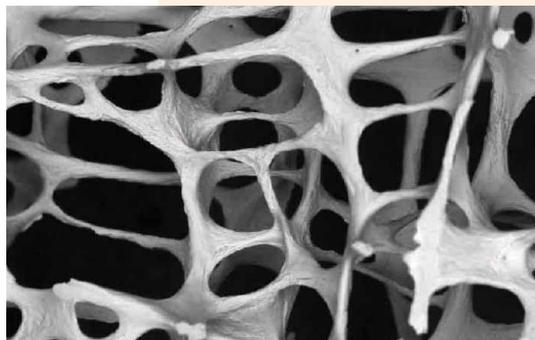
The scope of this study is huge – the researchers are looking for a very large pool of women to participate in order to gain a clear picture of the effects of lifestyle and genetic factors on a woman's risk of developing cervical cancer.

Here at the ATR we are inviting every female twin member to consider being part of the study. Unfortunately, not every twin pair has registered with us, and we need many more volunteers to make the study a success.

If you know of any twin pairs who are not on the Australian Twin Registry, but who may be interested in participating, please contact us on Freecall 1800 037 021.

You do not have to have another Pap smear in order to take part in this study!

Strong bones?



Structure of bone

Can calcium supplements help build better bones? Researchers at the Australian Catholic University School of Exercise Science are working with a group of young identical twin girls to find out.

The girls, aged between nine and 12 years, have recently completed Phase 2 of the study (six months after the initial data collection) which involved a repeat bone scan of their lower leg and wrist using the latest 3-D bone scanner – a Peripheral Quantitative Computerised Tomography (pQCT) device.

Throughout the study, one twin will take a calcium supplement tablet while the other twin will take a placebo (a fake tablet that looks

exactly the same as the calcium tablet). The twins take these tablets each day, being careful not to mix the tablets up!

After 12 months they will repeat the bone scan to see if there are any differences in their bones compared to their first scan and to each other.

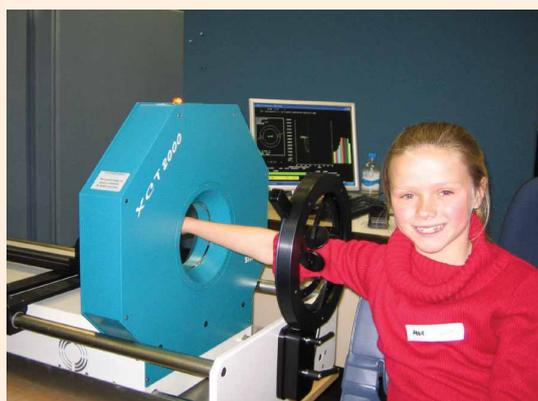
Results from the study are expected to reveal if calcium supplements increase bone health, leading to stronger bones.

This is an important study for parents and teenagers as it may provide insight into the best ways to help our daughters attain good bone health.

The study is undertaken in collaboration with USANA Health Sciences Inc.



ATR member Kelsey kicking back during a pQCT scan of her lower leg



ATR member Abbie lending a hand during a pQCT scan of her wrist

Twins teach us about seizures and epilepsy

For 20 years, researchers at the Epilepsy Research Centre, University of Melbourne at Austin Health, have been studying twin pairs in which one or both have had a seizure, epilepsy, or a history of convulsions with a fever when young. The research group now has more than 550 twin pairs enrolled in the study.

The researchers have found that twins do not have a greater chance of having epilepsy than the general population. The twin studies have also helped discover:

- which types of epilepsy have an inherited component,
- new forms of inherited epilepsy,
- the importance of non-inherited factors in some epilepsies, and
- using the insights provided by twin studies, new genes for epilepsies.

For epilepsies with a major inherited component, if an identical twin has epilepsy there is a 70% chance that their twin will too. An important question that

follows is: why is only one twin affected in 30% of the pairs? The answer is not yet known, but it is hoped that by carefully studying identical twin pairs in which one has epilepsy and the other does not, that answers will be found.

For example, by comparing the brain images of twins with seizures with those of their twin, the research team is investigating whether subtle differences in brain structure may explain why only one twin has had seizures.

Working in collaboration with the Brain Research Institute, the researchers have also analysed MRI brain scans of healthy identical twins. Findings have shown that the brains of identical twins are much more similar than the brains of non-twin individuals.

The Centre continues to seek the involvement of twin pairs in which one or both have had a seizure, epilepsy or a history of convulsions with a fever when young. Further information is available at www.epilepsyresearch.org.au

Twin experience pulls life into



Karen Thorpe, Professor in Early Childhood Development at the Queensland University of Technology, shares her insights into twins, the transition to school and her own early plans to be a princess!

After almost 20 years observing and interviewing twin children, their parents and teachers, Professor Karen Thorpe says it's the passion of the relationship between twins that is most memorable.

'Positive or negative, having a sibling the same age intensifies your experience of growing up,' she says.

It is this intensity that makes studying twins and their families so valuable to the Professor and her team. Interviewing and observing twin children and their families has given them a magnified view of human development.

Readers might relate to the tale of one little boy who quietly confided to Karen that he spent all his pocket money on sweets, while his brother ate them all!

Karen recalls with a laugh her own childhood ambitions. 'I wanted to be a mother, a teacher, and a princess!' She can tick the first two off her list but is not sure that her job quite cuts it in the princess-stakes.

Her career in research beckoned from her first year of undergraduate study. 'I loved the practical lessons,



QUT researcher Karen Thorpe

but found myself asking questions and wanting to find out more. I always knew I wanted to work with children and families, so I soon found my niche in research.'

Karen's first study drew on existing data on maternal depression and its connection to the age and spacing of children, but she soon was out talking to families and collecting her own data.

Karen credits Michael Rutter, a Children's and Adolescent Psychiatrist whom she worked with in England, for showing her how twin studies can be invaluable not just for

genetic research but also for developmental research.

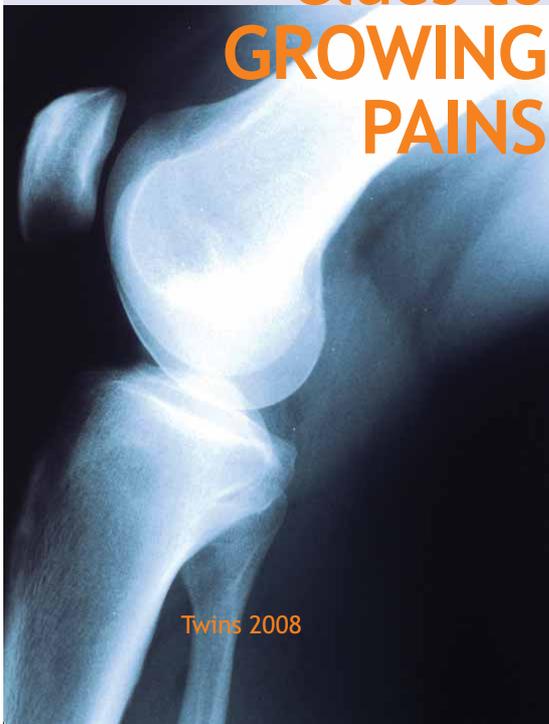
Her initial studies of maternal depression and children's language development led logically into studies of children's social development. Today she and her team focus on children's transition to school and the factors that affect their success.

While she has not finalised her latest research, she can say there are no hard and fast rules on the perennial question of whether or not to separate twins when they start school.

'It's the relationship between the twin pair that makes the difference,' she says. 'Some twins are better off separated; others use their twin as a resource and they can function extremely well together.'

She does stress that transition to school is about more than just the first weeks or year of school. As such, separating twins into different classrooms may be best achieved when it is staged over two or even three years.

Clues to GROWING PAINS



Twins 2008

Growing pains are a very real experience for many children. Some estimate that more than a third of children will experience growing pains in their legs, usually late in the day or at night and often after vigorous exercise.

Episodes of pain usually stop within an hour or two but may be severe enough to wake the child and cause crying, creating significant distress for the child and their family.

Even though it affects many children, it is not a long-term condition and little is known about the cause of growing pains. In fact, many believe that the name 'growing pains' is a misnomer as the condition does not appear to be directly related to growth.

One notable feature of growing pains is how it tends to run in

families. As many as 70% of children with growing pains have a family history of the condition. This raises the possibility that growing pains is a genetically influenced disorder.

Researchers at the Paediatric Pain Research Unit at Sydney Children's Hospital investigated this idea using a New South Wales wide-survey of twins aged three to 12 years.

Over 60 pairs of twins, in which at least one was affected by growing pains, participated in the study. The results of the research are yet to be finalised, but the evidence indicates that there is a genetic component to growing pains, at least partially addressing the question of what causes the disorder.

Watch for more details in future issues of the *Twins* newsletter.

Myth busted!

The team at the Centre for Eye Research Australia have busted a big myth about reading in the dark or reading "too much". It seems neither activity is going to make you short-sighted, as much as your mother might have warned you!

These and other findings have emerged from the ongoing Genes in Myopia (or GEM) twin study conducted at the Royal Victorian Eye and Ear Hospital, Centre for Eye Research Australia, over the past four years. So far more than 600 twin pairs have been recruited for the study through the ATR.

For the record, the GEM twin study has shown that our genes explain

up to 80% of myopia, or short-sightedness.

The GEM study investigated the links between personality, behaviour and myopia and found that the popularly held belief that short sightedness is mainly due to reading in the dark or excessive reading is not entirely true.

Their hunch is that a missing link in the relationship between behavioural factors and myopia may be explained through the study of intelligence.

They are hoping to explore the role of intelligence in myopia with collaborators at the Brain Sciences Institute at Swinburne University in Melbourne.

SUPER TOOTH S



Did someone say cheese?
Junior team members on the case.

Research results:

The ATR receives many calls from twins and their families who are naturally curious about the results of the research they have participated in. It is very reassuring for them to hear that their involvement has had some sort of tangible benefit.

Research can be a painstakingly slow process. Each study is like a single piece of a large jigsaw puzzle – the results from each study often adds only a small part to the overall picture. It can take years of work to find answers to the questions that researchers are asking about specific diseases and traits in the population.

So why does it take so long for us to see the full picture? Let's consider the life cycle of a typical research study.

The initial stage of a twin research project run in conjunction with the ATR begins with an Expression of Interest – this is where researchers have an idea for a scientific question, and start working out ways to get an answer. These scientific questions need to be very precise and defined so that the researchers know exactly what they are looking for.

The ATR works closely with researchers during this phase; sharing examples of other studies conducted in the same area, brainstorming options for recruitment and selection of twins and writing detailed research plans to make sure everyone's thinking on the same level. We also put researchers in touch with others in the field who work on similar issues.

The ATR reviews the final plan using independent experts in the area to make sure the research will be of benefit to the scientific community.

Once the research plan is formulated, the ATR and researchers develop a letter inviting twins to participate. This is an important step, as we need to make sure that our members fully understand what is being asked of them – we may only have one chance to introduce a new study to the twins and if they are confused by our letter, or the study seems too much trouble, they may choose not to participate.

The research documents and plans are then assessed by a Human Research Ethics Committee. These committees are set up in each hospital and university, and give the final and essential approval for studies to start. Often the Ethics Committee will require changes to the plans or documents. (It is the Committees' role to act on behalf of research participants to ensure that all studies are ethically sound and safe, and will not adversely affect the participant, and if this means that the research is delayed then so be it!) Research involving people cannot under any circumstances proceed until the relevant Ethics Committee has approved the study.

The next stage is when twins themselves get involved! The ATR sends out

letters describing the new study and twins decide if they want to be involved or not and send back a response form indicating their choice. Responses are received by the ATR and we record whether or not the twin/s (or the parents for studies where the twins are under 18) want to be involved. If both twins are interested in being involved in the study, we then send a copy of the response forms to the researchers. The researchers then organise interviews and/or appointments with the participants so that data collection can begin.

And you thought that was a lengthy process? Now comes the time consuming bit – data collection. Naturally the time it takes to complete data collection depends enormously on the number of participants involved and the type and amount of information to be collected. For example, some of our researchers want to talk with only a handful of twin pairs (maybe a few hundred or so) but others want to involve thousands of pairs – this is often because the question that the researchers are trying to answer is difficult and requires the input of many participants in order to get a clear picture of the answer.

The type of information collected also varies – some studies simply involve a single questionnaire, for example, the recent study we ran on *Folate During Twin Pregnancies* asked a set of

Slowly but surely the

I SLEUTHS AND THE MYSTERY OF TOOTH DECAY



Following a steady decline over the past 30 years, the number of Australian pre-schoolers with tooth decay is once again on the rise. It is now more important than ever to determine risk factors for tooth decay to enable the development of early prevention and intervention strategies.

The ongoing Australia-wide study, *Tooth Emergence and Oral Health in Twins and Their Families*, has produced some interesting discoveries about babies' and toddlers' oral health, in particular their susceptibility to tooth decay.

One important risk factor is the relationship between the emergence of the baby teeth and appearance of a bacteria called *Mutans streptococci*, or MS, in the mouth of the child. This is the main bacteria responsible for tooth decay in humans.

Multiple birth families are helping to improve our understanding of this link by charting when their babies' teeth emerge,

collecting regular oral swabs from all family members and completing questionnaires about their family's environment. This information is allowing the University of Adelaide research team, led by Professor Grant Townsend, to establish the contributions of a person's genes and their environment to the relationship between the timing of emergence of the baby teeth and appearance of the MS bacteria in the mouth.

Initial findings indicate that differences between individuals in the timing of tooth emergence and colonisation with MS are mostly due to differences in their genes. This finding may lead to early identification of young children who are more susceptible to tooth decay.

Professor Townsend expressed "A big thanks to all our families for their fabulous work as dental detectives helping us to answer the question: 'Why are Aussie kids still getting tooth decay?'"

jigsaw takes shape

questions over the phone. Other studies are much more detailed, for example the *Tooth Emergence Study*, which involves data collection over a number of months while the twins' teeth are coming through. The *Transition to School Study* asked a set of questions before the twins started school, some questions after they started school, and a few more questions a year later. The twins' teachers were also involved, and the twins themselves did sticker activity sheets, with some twins also taking part in a videotaped session while playing with their friends.

Other studies (usually involving adults) ask for blood tests or scans and measurements. Overall this data collection period can span months or even years.

After the data collection is completed, statisticians are brought in to check the data, analyse patterns and work out ways to interpret the huge amount of evidence collected. The researchers then collaborate with each other and with other scientists internationally to determine what story the information is telling them. This can confirm what the researchers were expecting the data to show, or present a totally different outcome to what they were expecting.

Once the data is understood, researchers write scientific articles ex-

plaining the data which are published in scientific journals – these journal publications are collections of articles in one particular field of work, such as cancer research, or diabetes. This is a vital part of the scientific process as it allows other researchers with expertise in that area to scrutinise and challenge the data and results.

Often different groups of researchers work on similar projects and each different project can yield alternative ideas regarding the answer to the scientific questions posed. This process can sometimes seem repetitive, but it is the fundamental basis of the development of the theory of science – that studies and results are repeatable and can be verified by other groups.

Journals also provide the ability for researchers to collate all the information on a particular area, to determine where the gaps in understanding are, and therefore determine the next research questions that need to be asked. And because each new result often adds only a small piece to the overall "jigsaw puzzle" of a disease, the research questions often build on each other to eventually form the big picture.

As you can see, in research at least – all good things take time!

Take, for example, one of our current projects: the *Genetics of Cannabis Use*

and *Mental Health in Australia Study*.

It is a telephone interview-based study conducted by the Queensland Institute for Medical Research in conjunction with Washington University and targets twins born between 1972 and 1979. Initial work with the ATR on developing this study began in early 2005 and letters inviting the first set of participants started being delivered in October 2006. The study is looking for over 8,000 participants, and recruitment will be ongoing until they reach this target – on current projections this will be sometime in 2009.

Understandably it will be years before the collection of data for this study is completed and results start to be interpreted and written up. Research into cannabis use is not new; recently results were posted from a similar study in the UK, emphasising the necessity of being able to reproduce studies to confirm results.

Scientific research is far from a straightforward process. It involves many twists and turns before it reaches conclusions that, hopefully, will have far reaching implications. By participating in this research, our members play an integral part in the development of many groundbreaking studies which contribute to the health and wellbeing of the whole population. Rest assured that one day the results of your contribution will be analysed, reported and maybe even save lives – it just might take a little longer than you expected!

Join our new Media Mailing List

The ATR is often contacted by casting agents looking for twins to appear in commercials and other productions.

While we are usually able to help them, it can be time consuming to contact potential participants by phone to gauge their interest, and our commitment to research must come first.

That's why we've started an email list for those twins (and twin families) who are interested in hearing about media opportunities. Now, when we are approached by the media, we simply circulate the details of their request via the email list, so that you and your twin can contact the agent directly if you are interested.

Usually agents are very specific about the age and gender of twins they are searching for, and often they will ask to see photos.

As always, all contact information provided to the ATR remains confidential – we will not pass on your email address to an agency.

If you and your twin are interested, please email us at dph-twins@unimelb.edu.au and ask to be placed on the Media Mailing List.

Arguably the biggest twin TV event of 2007 was the "Two of a Kind" episode of *Insight* which screened on SBS in mid-September. The ATR helped the show's producers recruit identical and fraternal twins of all ages from around the country to discuss the nature of twinship and the problems and advantages they experienced being one of a pair.

Twins also appeared in a special episode of *Ready, Steady, Cook!* which aired in mid-May. Sisters Kathy and Karen were pitted against each other with some help from two celebrity chefs in a fast and furious attempt to out-wit and out-cook each other. The delightful cook-off was organised by the Australian Multiple Birth Association as part of their Multiple Birth Week celebrations.



ATR members Kathy and Karen ham it up with their AMBA friends on the set of *Ready, Steady, Cook!* Photo courtesy Australian Multiple Birth Association.

Out and About

AMBA meetings

ATR staff enjoyed meeting local groups at the *New South Wales Australian Multiple Birth Association State Symposium* in Wollongong in May, 2007. The meeting was also a great opportunity for us to encourage participation.

The ATR was also invited to present a session on genetics at the *AMBA National Convention* in November 2007, in Newcastle. This was an important opportunity for us to educate families and boost our support across Australia.

GeneMappers 07

The ATR helped sponsor the *GeneMappers 2007* conference in Brisbane last August, led by Associate Professor Peter Visscher, father of twins (see *Twins 2005*).

Twinless Twins NEW GROUP FORMS

Australian Twinless Twins met for the first time in Sydney just before Christmas 2006, attracting participants from across the country, including Western Australia and Canberra.

Supporters from the Murraylands Twin Loss Group in South Australia also participated via conference call.

Invitations were circulated widely to anyone who had lost a twin, and the meeting was promoted through the Australian Twinless Twins e-list, NSW, and members of the former Lonesome Dove support group.

The new group met for dinner after a full-day workshop at the University of Sydney, where they explored twinless twinship issues in Australia.

"We found that while outreach to twins who have experienced twin loss can be difficult, it is often a relief when twinless twins contact and support each other," says the University's Chris Neff, a twinless twin who co-ordinated the event.

"As a result, the attendees agreed to work collectively as **Australian Twinless Twins**, with regional leadership and support. We hope to hold additional meetings across the country and have hosted several in New South Wales already."

For information, support or meeting opportunities, email australiantwinlessstwins@gmail.com or visit www.australiantwinlessstwins.com



Twins and Child Health Research

Child health researchers met in Melbourne in April 2007 to learn more about the possibilities available to them through research involving twins. Convened by Drs Ruth Morley and Supriya Raj from the ATR (**match**), the workshop also aimed to inform researchers of the age ranges of twins on the Register and included discussion on the collection of baseline data as the twins grow up.

Topics ranged from twin studies and research design issues to data analysis and generalisations from twin studies. Also discussed was the development of speech, language and behaviour in twins.

12th International Congress on Twin studies

Australian researchers made a strong showing at the *12th International Congress on Twin Studies* (ICTS) in Ghent, Belgium, in June 2007.

Dr Sue Treloar presented information about the number of times twins have been approached to participate in studies throughout their time as members of the Registry. She found that only about half of members under the age of nine had been approached for a study, but that twins were approached much more often as

they grew older. About 80% of twins aged between 19 and 60 years old had been approached to participate in one or more studies. Dr Treloar also found that participation dropped off after twins had been invited to participate in more than four or five studies.

Abstracts outlining scientific papers presented at the *12th International Congress on Twin Studies* can be found via the journal *Twin Research and Human Genetics* at <http://www.atypon-link.com/AAP/loi/twin> (see volume 10, supplemental edition)

ATR members hard at work!

Have the ATR and its members ever been busier? Last year we undertook active recruitment for **17** studies on a wide range of topics, including: Growing Pains; Brain Ageing; Calcium and Bones; Transition to School; Cervical Cancer; and Folate.

Our small team prepared **101** separate mail-outs, consisting of around **8,200** letters, and resulting in more than **4,900** responses by mail or phone.

This year, five new studies will be added to the 11 studies continuing from last year. The new studies examine: Autism; the Heritability of Reasoning Styles; Menopause and Bones; Diabetes and Dementia; and ADHD.

The *Older Australian Twin Study*, or *OATS*, has been recruiting in New South Wales, Queensland and Victoria throughout 2006 and 2007 and will be continuing this year. So far, 170 of 321 pairs aged 65 years or older, have agreed to participate and the researchers are hoping many more twins will put their hands

Sometimes twins think that, because they are no longer children, they are no longer useful to the ATR. Not so!

up to contribute to this important area of research.

Alternatively, those born between 1972 and 1979 are eligible to participate in the *Cannabis and Mental Health Study*. This study is hoping to capture the experiences of twins Australia-wide, including those who have had experiences with cannabis and those who have not.

So far we have approached 6,260 individuals (3,130 pairs) and almost 2,500 individuals have agreed to participate. We are slowly making our way through the list of eligible pairs and will be approaching another 1,668 twins over the coming year.

ATR studies vary greatly in terms of what they require of participants. Some need twins with very specific conditions, such as atrial fibrillation, diabetes or epilepsy, while others simply need as many participants as possible who fit an age or gender criteria.

It is always much harder for us to recruit eligible twins for studies with very specific selection criteria. For instance, we have been recruiting for the *Anti-Epileptic Medication and Bone Health Study* since 2006, looking for twin pairs in which at least one twin is currently taking anti-epileptic medication. Of more than 3,500 pairs we have approached, so far only 41 pairs have joined the study.

It is for this reason that we have included a flyer with this issue of *Twins* which calls for twins with these rare characteristics to contact us — this will greatly reduce the need to send multiple letters out to search for twins eligible for these important studies.

Adult twins and triplets are an essential part of the ATR community and provide an important contribution to twin research.

Despite continued high demand from researchers for adult twins, we find a smaller number of adult twins register every year compared to new registrations of junior twins.

If you know of any adult twins who are not registered with the ATR, please let them know about us — adult twins can join at any stage of life, regardless of any medical conditions they may have.



What a pair of toothiepegs!

Latest results just a click away

Are you interested in finding out more about a research topic in which you have played a part? While the ATR always welcomes questions from its members, the internet is a great resource for up-to-the-minute information.

One of the best ways to stay up-to-date with current thought in a given field is to read the scientific articles that are published by researchers throughout the year.

When a researcher comes up with data and results that are meaningful,

they write a paper to describe the study they have conducted and discuss the results. This is published in any one of a range of journals, often specific to the area of research.

The easiest way for anyone to access and absorb the latest papers published is to look at an electronic index of all articles written and use a search engine to help locate papers of interest.

The index widely used to search for papers written about medical science is *PubMed* which is



accessed through www.ncbi.nlm.nih.gov/sites/entrez. Access is free and available to anyone on the internet.

PubMed is basically an online database that lists information on millions of articles from all around the world. The most powerful way to use this index is to search for a particular subject – this will bring up a list of articles and their abstracts. An abstract is a detailed summary of the paper and its findings. The *PubMed* system is very easy to use and the website has self guided tutorials for new users. There is a search box at the top of the screen and you simply type in a set of keywords like “twins and diabetes” and click “Go”.

The list of articles returned by a search provides the name of the article, the authors and a clickable link to the abstract of the article. Sometimes a PDF copy of the full article can be accessed as well.

PubMed is a powerful way for the general public to find out about research going on all around them.

TwinsPlus Festival 2009

Venue: Sydney

Date: Sunday, March 15th 2009

Yes, you have read it right – the *TwinsPlus Festival* is on again! This time Sydney gets to host our internationally-recognised bi-annual festival. So circle the date on your calendar now – this event is not to be missed!

Interested in attending?

Register your interest by emailing twinsplusfestival@amba.org.au for the latest updates, announcements and travel and accommodation deals.

Note that the next *Twins* newsletter will not be mailed until after the 2009 Festival, so now is the time to register your email address so we can keep you in the loop.



PREGNANT WITH TWINS? Here's a match!



Melbourne mothers carrying twins are finding out about a new initiative by the ATR – the Mothers and Twin Children project, or **match**, headed up by Drs Ruth Morley and Supriya Raj.

match has now started at three major public hospitals in Melbourne; The Royal Women's Hospital, Mercy Hospital for Women and Monash Medical Centre. The project has also commenced at Cabrini Private Hospital with Geelong soon to commence as well.

All women who join **match** at these hospitals are given a folder containing useful information and resources on twin pregnancies.

Participants are asked to maintain a record book throughout their pregnancy, donate a sample from their standard 28-week blood test, and allow a cord blood sample to be taken from the part of the cord attached to the placenta after the twins are born. In the future, the data and blood samples may provide vital insights into the development of twins during pregnancy.

We are in the process of starting **match** at St Vincent's Private Hospital and waiting on ethics approval to start at Sunshine, Freemasons, Box Hill and Angliss Hospitals.

If you know of anybody at these hospitals expecting twins, or if you would just like more information about **match**, please contact us on **Freecall 1800 993 103**.

NEVER experienced PSYCHOSIS?

Then we need your HELP!

Our research group is trying to identify the causes of psychosis ... Okay, it's right about now that people who have never had psychosis will think "Ah, this isn't for me," and stop reading, but, please don't stop reading! It is vitally important that we also recruit people for this study who have never had psychosis!

While it's important for our study to research twins who have experienced psychosis, it is equally important for us to be able to compare these findings with twins who haven't.

This can be a difficult challenge. And it's all to do with how quickly people make up their minds when they open a letter.

When an approach letter inviting a twin to participate in a study is received in the mail, more often than not, the reader will quickly open the letter, look at the heading and then rapidly decide whether he or she is eligible to participate based on their familiarity with the topic.

Our experience is that many people see the word "psychosis" and automatically assume that they are not eligible because they have never experienced this complex disease.

Controls are vital

In fact the opposite is true! We also need pairs where neither has experienced psychosis – these pairs give us a baseline measurement of brain structure that we can use to compare with other twin pairs. These healthy pairs are called "control participants" and the technique is widely used in scientific research today.

We now know that psychosis arises from complex interactions between genetic and non-genetic risk factors. Understanding the nature of these interactions and how they affect brain function in people with psychosis is a difficult task and herein lies the importance of using "control participants" – the brain is such a complex organ that we need "normal" data to help us understand what is "not-normal".

Studying twin pairs who have and have not been affected by psychotic illness lets us identify key risk factors to target when developing treatments. Our findings to date have discovered new biological markers of risk for psychosis, in addition to identifying

new genetic pathways related to psychotic illness.

Participation as a "control" can be of real interest to twins who are keen to get involved in studies, but who continually find they are ruled out because they don't display a particular disease or characteristic.

Participants are given a clinical interview and are asked to provide a blood sample. They are also provided with the opportunity (if they choose) to have a brain scan using Magnetic

Resonance Imaging (MRI), and to complete a series of tasks measuring memory and attention abilities.

This study is conducted by the Melbourne Neuropsychiatry Centre together with the Queensland Centre for Mental Health Research.

If you would consider participating in this study (yes, even if you and your twin have never experienced psychosis) we would love to hear from you. Contact the ATR on **Freecall 1800 037 021** for details.

Should we re-use research data?

Scientists are increasingly turning to recycling techniques to conduct their research – using old data to extract new results. Contributions made by participants in one study can be of continued use to medical research and enable new questions to be answered without repeated collection of the same data.

With this trend in mind, the ATR is seeking the views of twins who have participated in past studies on how they would feel about the information they gave to one researcher being used for future studies by other researchers.

Over the past 25 years, many of you have provided individual research groups with invaluable details, measures, and indicators of your general health and wellbeing such as your age, height, weight, Body Mass Index (BMI), lifestyle, bone density, eye scans, Magnetic Resonance Images, mammograms, blood, and DNA samples.

With the use of new statistical methods and computer technologies it is now possible to pool all of these details into large databases or "databanks" that researchers can tap into to answer numerous different research questions.

In these cases, the use of identifying information such as the names, addresses and dates of birth of the individuals who contributed to the original study, is prohibited. This is known as "de-identified data". Researchers cannot and do not need to identify which person the information came from for the types of analyses they wish to conduct.

De-identified information maintains participants' privacy. It also has the potential to give researchers access to an amazing pool of data collected by more than 100 twin studies over the past three decades.

One potential problem with this exciting initiative is that, for most studies, the consent that participants gave for their original study did not foresee this potential re-use of the information.

To track down and write to every current and past ATR member who has ever been in a study to ask if they mind if their de-identified data is made available for re-use would be an expensive, time consuming and complicated exercise.

That is why the ATR is asking a representative sample of members for their views on the subject. In particular, do you have any objections or questions about your de-identified data being made available for re-use? What if you were in a study when you were a child and your parents gave their consent for the information to be collected? Would you object to this de-identified data and/or any samples you gave (such as blood or DNA) being re-used?

Please send your comments to Kim Dorrell, Senior Project Officer, Australian Twin Registry, Reply Paid 84241, University of Melbourne, VIC 3010 (no stamp required), or email: kdorrell@unimelb.edu.au

The ATR is currently investigating several possible models for encouraging the re-use of already collected research data and samples and we want to know what you think about the idea.

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Gift of Hope



USING OUR BRAINS

Every one of us is very special in many ways. We are unique in how we think and act, in our dreams and fears, in what makes us happy or upset or sick. Being a twin is even more amazing. We are looking for very special people, twins, who might be interested in helping to unravel answers to the questions that humanity has been asking for centuries:

- How the human brain works?
- Why we are unique? Where does talent come from?
- Why do we get sick? What causes schizophrenia, depression or bipolar disorder?
- Why do some of us become addicted to drugs, alcohol or tobacco?
- Why do some of us develop dementia or suffer from stroke or tumor?
- How can we help our children to avoid our mistakes and misfortunes?

The University of Sydney coordinates two brain donor programs designed to enable people to agree to donate their brain to research during life – this allows us to get to know you, carry out clinical and neuropsychological assessments and at the time of death facilitate donation.

If you would like to make an investment in the future – join the 'Using Our Brains' brain donor program (for all types of people) or the 'Gift of Hope' brain donor program, which is specifically designed for people with a major psychiatric illness.

Our contact details:
<http://www.braindonors.org> or phone: (02) 93512410

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The Australian Twin Registry is currently supported by an Enabling Grant (2004-2009) from the National Health and Medical Research Council which is administered by The University of Melbourne. This funding is allocated to staff salaries and core administration. To further its work facilitating health and scientific research projects, the Registry must seek alternative funding sources, in particular for targeted recruitment and public education projects.

As a member of the Registry you already contribute to the important work of Australian health and medical research. If you, or anyone you know, would also like to contribute financially please detach and complete the following slip and send (no stamp required) to:

Australian Twin Registry – University of Melbourne
Centre for MEGA Epidemiology
Reply Paid 84241
University of Melbourne VIC 3010



GIVING FORM

Personal Details: Mr / Mrs / Ms / Dr / Prof / Other _____
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Here is my gift of: \$50 \$100 \$250 \$500 Other \$ _____
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 Please charge my credit card: Visa MasterCard American Express
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Donations of \$2.00 or more to the Australian Twin Registry at the University of Melbourne are tax deductible within Australia. DGR No.90028197

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