



AUSTRALIAN TWIN REGISTRY

Research for a healthier community

Welcome to our new patron, HRH Crown Princess Mary of Denmark

HRH Crown Princess Mary of Denmark is the new patron of the Australian Twin Registry as well as the Danish Twin Registry. In a message of support to the two registries, she said she was proud of her new role:

“As a parent of twins, Vincent and Josephine, I look forward to contributing to awareness of the unique role that twins and their families can play in health research, and to encouraging other families with twins to support this important work.”

The announcement generated news around the world – we share some of the highlights with you (see page 2).

See her full message of support, plus photos and video of her meeting twins, at www.twins.org.au.



Photo: The Crown Princess meets some twins at her first official engagement as patron of the Australian and Danish twin registries.

URGENT email – you can win an iPad!

Why is your email address so important to the Australian Twin Registry?

Well, having your correct email address can save thousands of dollars of precious research funding and enables the ATR to better achieve our number one priority - more twin research to improve the health of everyone.

One area where the ATR can save money - with your help - is member communications. We are committed to regularly informing members about vital twin health research and findings.

But we would like to move away from this printed newsletter to an online one.

If we have correct member email addresses, we can deliver our news electronically and reduce our considerable print and mail costs, and impact on the environment.

As an added incentive, members who provide or update their contact details, go automatically into a competition with a prize of an Apple iPad. Visit our website www.twins.org.au and follow the competition link to enter.

Please donate to twin research

Help us in the fight against disease.

Donate at:

- Freecall 1800-037-021
- Online at www.twins.org.au
- Or mail

Australian Twin Registry
Level 3, 207 Bouverie Street
Carlton, VIC 3010

Twin union for ACTU President

ACTU president Ged Kearney is used to the spotlight but was happy for attention to be focused on another high-profile mother of twins when she visited the ATR for the first time recently.

Ged attended the Melbourne media event to announce the ATR's new international patron, Princess Mary. Like the Crown Princess, Ged is a mother of twins and is providing her support to twin research. She has become one of the ATR's Australian ambassadors.

According to Ged, she is excited about her new role as an ATR ambassador as it combines her greatest passions with supporting a cause close to her heart.

As a former health care professional and the mother of twins, she hopes to combine these experiences with her national profile to give back to the multiple-birth community and twin research.

Long-time ATR supporters, Ged and her twins joined their first twin study looking into genetic factors in epilepsy in 1997. More studies were to follow, investigating such diverse subjects as twin social behaviour, diet and bone mass, and Attention Deficit Hyperactivity Disorder.

"As a mother of twins, I know that twins are special and it has been very rewarding to give back something that is unique to our family to improve the lives of others," says Ged.



Photo: ACTU president, Ged Kearney, with her twins Bridget and Alexandra.



Photo: Junior ATR members in Melbourne wave the flags of Denmark and Australia to show the twin allegiances of their new patron.

New ATR patron generates world news

ATR members shared in the excitement when Her Royal Highness Crown Princess Mary of Denmark was recently announced as the new patron of the Australian Twin Registry and of the Danish Twin Registry.

The ATR's Facebook lit up with hundreds of messages of support from excited ATR members and the registry's website was inundated as people viewed photos and video of the princess enjoying her first official outing in her new role and meeting twins in Denmark.

ATR twins also appeared centre-stage at a huge media event held at the registry's head office in Melbourne to announce the princess's patronage and to highlight twin research.

"Everyone was thrilled about the princess's involvement," said Daniela

Ahimastos, a twin and ATR member who spoke to the large media contingent. "She has raised awareness of twin research to a whole new level."



The Crown Princess hopes to combine her interests in health and scientific research, with her experience as a mother of twins, to contribute to raising awareness of twin research globally."

- ATR Chair, Vince Pollaers.



Photo: ATR director, Professor John Hopper, presented toy twin platypuses to the Crown Princess as gifts for her twins.

According to ATR Chair, Vince Pollaers, the Crown Princess is a fantastic ambassador for twin research.

"The Crown Princess's patronage is also a vote of thanks to all of our twin volunteers, and acknowledgement of the important contribution they make," he said.

Find out more about the princess's patronage at www.twins.org.au.



Photo: ATR twins participate in the NAPLAN study – see story on right.

Twin research of the future

The ATR is launching one of the biggest national initiatives in its 30-year history to streamline services to its key supporters – twin members and researchers.

Every active ATR member, or over 70,000 twins, will be invited to participate in the *Australian Twins Health and Lifestyle Questionnaire*.

According to ATR director, Professor John Hopper, the questionnaire is designed to increase understanding of our members' health and lifestyle plus enable more and broader twin research.

"With more information, we can streamline our services to members, enhance their study experiences, keep our costs down, and support even more vital health research," he explains.

The roll-out of invitations begins mid 2013 and Professor Hopper encourages all members to complete the questionnaire.

"This is one of the most important initiatives in our history and the outcome will shape the ATR for future generations.

"With this information we can stimulate new research into areas of importance to our members and to the wider Australian community," he says.

Here are some answers to possible member questions:

When does it begin?

Invites will begin being mailed and emailed to members from mid 2013. But it may take up to 18 months for every member to receive an invite. The ATR is staggering the project over time to enable it to process the incoming new information while ensuring regular services are maintained.

What does it involve?

You will be invited to answer an online questionnaire that takes about 30 minutes. Questions will relate to your health, lifestyle and family e.g. education, ethnicity, and medical conditions such as cancer, back pain and heart disease.

What will be the benefits for members?

Researchers can conduct more vital research with flow-on benefits for members. For example, we can reduce the burden of time on members by ensuring repeated questions are not asked by different researchers (e.g. place of birth, ethnicity, zygosity). We can also reduce unnecessary study approaches to ineligible members (e.g. researchers interested in a particular disease can approach already-known twins with this condition).

Learn more at www.twins.org.au or join us on Facebook and Twitter for regular updates.

Twins urgently needed for new studies

Identical and non-identical twins are urgently needed to join new health studies commencing around Australia. Please join in and help in research that benefits everyone at www.twins.org.au or freecall 1800-037-021.

NAPLAN

A nationwide study of the genetic and environmental factors that influence how well a child performs in the National Assessment Program: Literacy and Numeracy (NAPLAN). Open to: any twin who has sat a NAPLAN test in the past, or will be completing the test in 2013 or 2014.

Impulsive/compulsive behaviours

This study aims to gain a greater understanding of the extent to which genetics, shared environment and unique environmental factors explain why people differ in these types of behaviours. Open to: all adult twin pairs, aged 18–55 years and able to complete an online questionnaire.

Causes of autism

This study aims to provide new knowledge about the causes of Autism Spectrum Disorders, in particular the influence of early life environment, genes and epigenetic gene switches. Open to: twin pairs aged 2-14 years, in which one or both twins have had a diagnosis of an Autism Spectrum Disorder.

Why do some people consume excess fat?

This study aims to identify why some people consume excess fat by asking twin pairs to take part in a 12 week program where one twin has a high fat diet and the other a low fat diet. Open to identical and non-identical twins, aged 16 years and over, who can attend Deakin University Sensory Laboratory in Melbourne.

Bone health and anti-epileptic drugs

This study is examining if the use of anti-epileptic medication affects the bone health of young people. Open to: twin pairs (and triplets) aged 5-18 years of the same gender, able to attend Royal Children's Hospital Melbourne, where one twin (or same sex sibling within a 2-year age range) is taking anti-epileptic medicine and the other isn't.



Join us at www.facebook.com/AustralianTwinRegistry or <https://twitter.com/TwinsATR>

Connect on Facebook

Where in the world might you meet over 3000 other twins, their families and friends in the one place at the one time? That would be the ATR's Facebook page!

Join us for stories about twin health research around Australia and the world, interesting twin profiles, twin festivals and special events, twin parenting issues, and much more.



Australia's biggest twins festival ever!



It is an experience like no other – seeing thousands of identical and fraternal twins join together for one big celebration. We share the highlights of Australia's biggest ever festival for twins and reveal the date for an even bigger event in 2015.

People can be forgiven for seeing double – or even triple – vision when attending the 2012 Twins Plus Festival.

The festival held in Melbourne in March brought together a record 3000 twins, families and friends as well as higher-number multiples with many sets of triplets attending.

It was a day to celebrate all-things-twins and they came in all shapes and sizes – identical twins posing in matching outfits, fraternal twins celebrating their similarities and differences, and twins of all ages from newborn babies to the oldest set of twins aged 83.

Highlights included appearances by celebrity fraternal twins, Isabella and Sofia Bliss, from Channel 10's *Junior Masterchef* and identical twins, Laura and Emily Sayers, from Channel 9's *The Block*. It seems twins love to be photographed with the all-in group photo drawing a big crowd.

As you would expect at a twins festival,

there were many unique sights: identical twin policemen on patrol; identical twin clown unicyclists entertaining the crowds; twin singers, dancers and musicians performing in the *Multiples Got Talent Show*.

As a co-organiser of the event, the Australian Twin Registry attended in force with displays and twin researchers on hand to talk about their studies, and zygosity testing for twins who were unsure if they were identical or not.

"It was an amazing day with twins relishing the chance to meet other twins, and immersing themselves for the day in the special experience of being a twin," ATR director, Professor John Hopper said.



The festival just keeps getting bigger and better. There is nothing like it anywhere else in Australia."

- ATR Director, John Hopper.

Thanks to our 2012 festival partner, the Australian Multiple Birth Association, and the following festival gold sponsors:



See more festival photos and an entertaining video of the day at www.twinsfestival.com.au



Unmissable 2015 Twins Plus Festival

Not about to rest on their laurels after the last record breaking twins festival, organisers have already launched the date of the next Twins Plus Festival and are promising an “unmissable” experience.

Note the date down for your ‘bucket list’ for 2015: **Sunday 22 March 2015** at Melbourne’s Caulfield Racecourse. See the fresh new-look website www.twinsfestival.com.au and find out about the big plans for the 2015 festival.

“This is going to be our best festival yet,” said co-chair of the festival planning committee, Ann Marie Harli. “2015 will see many new additions to the program to surprise and delight patrons.

“We would especially like to see more twins and their families from interstate. Plan to visit Melbourne in 2015 for this one-of-a-kind festival and spend a couple more days exploring this wonderful city and surrounds.”

Twins from around Australia are already making their plans. ATR members and NSW twins, Phillip and Stuart Daniel, travel from Port Stephens and wouldn’t miss the twins festival for the world.

They have attended every Australian festival as well as twins festivals around the world.

“We have met life-long friends at festivals. They are like nothing else we’ve been to, and we’ve travelled extensively. We all have so much in common as twins and it is great to share stories about our twin lives.

“Once you go to one, you go back again and again as they are so interesting and fun,” they say.

Mother of twin toddler boys and ATR member, Melissa Kirkwood, brought the whole family from Brisbane to Melbourne for the last festival.

“It’s such a unique opportunity and we didn’t want to miss out,” she says. “Fantastic entertainment and the competitions were the favourite part of our day. Our little boys were DNA-tested and found out they were identical!”



Photos: Celebrity twins, Isabella and Sofia Bliss, from Channel 10’s Junior Masterchef meet some fans at the festival.



Volunteer for an experience of a lifetime!

Planning is already underway to present the best ever Twins Plus Festival in 2015. Volunteers are needed to contribute their ideas, experience and skills to creating an unforgettable event.

You can help from anywhere in Australia. Prior relevant experience or skills may be helpful but are not necessary. All you need is enthusiasm and we’ll help you with the rest! You’ll join a fun and friendly multi-skilled team who pitch-in together to get the various jobs done. Find out more at www.twinsfestival.com.au.

Twins power brain research

Do you bounce back easily from adversity or do you struggle emotionally? It seems how you respond to life's difficulties may be partly explained by your genes.

With the help of ATR twins, researchers at the Brain Dynamics Centre at the University of Sydney's Westmead Millennium Institute of Medical Research are analysing the part of nature versus nurture in emotional wellbeing.

Is it your genes that determine how resilient you are, or is it something in your upbringing or life experiences, perhaps a particular event as a child or during adulthood?

Initial findings show genetics contribute more to how some brain regions work over others. It seems genetics play a bigger role in the cortical brain functions, such as the frontal cortex, which are associated with more controlled emotional processing and coping behaviours.

In contrast, our environment or life experiences influence the sub cortical regions of the brain, responsible for the automatic, non-conscious processing of innate danger cues. This is often called the 'fight versus flight' response.

Significantly, results from this early research indicate that we can change our automatic responses with help and training, and this can benefit our ability to cope with stress.

The study is next conducting brain training exercises with twins to assess if this can improve their emotional resilience and wellbeing.

Ultimately, it is hoped to better understand which factors protect someone from becoming mentally ill.



Double incidence of fainting

Research has found that identical twins are nearly twice as likely to both faint compared to non-identical twins.

A recent twins study by the University of Melbourne and Austin Health has revealed that a complex interplay of genetics and environmental factors can trigger this condition.

Fainting, also called vasovagal syncope, is a brief loss of consciousness when your body reacts to certain triggers, such as experiencing heat, pain, distress, anxiety, hyperventilating or the sight of blood.

Around 25 percent of the population faint at some time in their life. While fainting is normally a very mild condition, it can cause blackouts and dizziness and can be confused with epilepsy.

According to the study author, Professor Sam Berkovic, the mechanisms of fainting are poorly understood.

"This study is helping us to better understand the genetic and

environmental mechanisms behind fainting, and will contribute to improved treatments for those who suffer frequent fainting attacks as well as improving diagnosis," he said.

In his study involving 51 ATR twin pairs, identical twins reported more episodes of fainting and environmental triggers to fainting than fraternal or non-identical twins. Identical twins were more likely to both experience fainting associated with typical triggers than fraternal twins.

The frequency of fainting in non-twin relatives was low, suggesting that the way fainting is inherited is usually not by a single gene.

"Our results suggest that, while fainting appears to have a strong genetic component, there may be multiple genes and multiple environmental factors that influence the phenomenon," he said.

Twins give food for thought

Twins are helping researchers to unlock why some people crave fatty food more than others, and the link to weight gain and obesity.

We know a high intake of fatty food can lead to weight gain and obesity, a condition with serious health consequences including cardiovascular disease, cancer and type 2 diabetes.

Researchers at Deakin University's Centre for Physical Activity and Nutrition Research in Melbourne have already found that some people are less sensitive to the taste of fat i.e. they are less able to detect fat in foods. They consume more fatty

foods and weigh more than those who are more sensitive to the taste of fat.

With the help of twins, researchers are now seeking to better understand whether it is genetics, or the environment in which a person lives, that influence dietary fat intake.

The first stage of this study saw 50 ATR twin pairs visit Deakin University's sensory laboratory to taste a range of different foods and to answer questions about their eating habits and food preferences.

Initial findings indicate that the complex interplay of a person's taste receptors, hormonal factors, sense of fullness, and preference for high fat foods may lead to consuming excess fat.

Researchers wish to examine these ideas further through a new twin study, and are asking twin pairs to take part in a 12 week program where one twin has a high fat diet and the other a low fat diet. It is hoped these findings will contribute to improved treatments for weight gain and obesity.

Learn more about this study and register your interest at our homepage or freecall 1800-037-021.



Photo: ATR ambassadors, Emily and Laura Sayers, taste different foods with researcher, Professor Russell Keast.



Photo: Identical and non-identical twins are helping in research to solve the puzzle of growing pains.

Solving the puzzle of growing pains

Growing pains have long been the subject of speculation and research, and this childhood condition continues to puzzle. The Pain Research Unit at Sydney Children's Hospital is unravelling some of the mystery of this condition with the help of nearly 3000 ATR families.

The condition is characterized by periodic and irregular pains in both legs, and often the arms, usually occurring during the night. Interestingly, it doesn't lead to significant limitation in activity or limping during the day.

"Growing pains are common in childhood, especially in the age range from three to 12 years, peaking at four to six years," says the study's chief investigator, Professor David Champion. "Up to 30 percent or more children experience this disorder for at least three months.

"Growing pains are also associated with headaches and recurrent abdominal pain, the most common pain disorders of young childhood," he says.

The researchers found there is also a connection between growing pains and restless legs syndrome – and that there appears to be a genetic component to them.

Restless legs syndrome is a disorder of the nervous system affecting sleep with symptoms including unpleasant sensations, even pain, in the legs when at rest and accompanied by an urge to move them. The disorder is more common in adults with 10 to 15 percent affected, compared with two percent of children and adolescents.

The link between the two disorders has prompted researchers to extend their studies to investigate common pain conditions during childhood which occur without an obvious reason, known as *functional pain disorders* e.g. migraine, headaches, recurrent abdominal pain, growing pains and some types of back-pain.

It seems that functional pain disorders may run in families, and they can occur in association with each other. There is evidence that these disorders, particularly in combination, predict risk of chronic pain in adolescence.

Thanks to the ATR families who have contributed to this ground-breaking study.

Learn more about this study and register your interest at our homepage or freecall 1800-037-021.

Get by with the help of your friends

The ATR could not get by without the wonderful support of its many friends!

ATR twin members, Craig and Brenton Gurney, are two such friends. They told their moving story about Craig's cancer battle to the media as a way of encouraging twins to join in health research.

When the ATR invited twins to attend the celebration of Crown Princess Mary becoming its patron, ATR members Daniela Ahimastos and Silvana Kelly stepped forward.

Of course, there are the thousands of members who have participated in more than 400 research projects over the ATR's 30-year history.

Every day in little ways, and in big ways, our members support our services. In recognition of our members' dedication and enthusiasm, the ATR is launching a new volunteer group – *Friends of the ATR*.

The ATR recognises there is a wealth of talent amongst our members, and many have expressed their interest in using these talents to support the registry and its work.

Friends of the ATR will provide a forum for these skills, passions and interests - wherever they might be. It will also provide a way for us to seek member feedback, and for twins to connect with each other.

Here are some of the ways that *Friends of the ATR* may become involved:

- Helping to organise a fundraising event;
- Volunteering for special events such as the Twins Plus Festival;
- Joining an ATR consumer group to provide us with early feedback on proposed new member and research initiatives;
- Joining our 'media darling' group comprised of twins who are happy to undertake media appearances/interviews for the ATR.

To learn more about *Friends of the ATR*, please visit our homepage (or freecall 1800-037-021) where you can register your areas of interest and any relevant skills. We look forward to connecting with our many friends!

Things you should know about your membership

Have you ever wondered how the ATR uses your membership information and results from your study participation?

The confidentiality of our member information is of paramount importance to us and we have strict protocols in place to ensure member privacy.

The ATR collects information about its members both at the time of registration and during the life of your membership. Personal details are not given out without the prior consent of the individual concerned.

As an ATR member, your personal information is held for the purposes of:

- Inviting you to participate in new twin studies.
- Updating you with findings and/or progress related to a study.
- Research which may be presented in publications, conferences and general media. This information is of a general nature and individuals are not identified.
- Seeking feedback from you about our services.



- Informing you about general registry news, such as twins festivals and fundraising events, general twin research.
- Checking your details against the Australian and state electoral rolls.

As a member, your involvement with the registry and any associated study is always voluntary and you can withdraw at any stage.

For other queries, contact us at twins-atr@unimelb.edu.au.

Helpful contacts

Our members often ask us for twin-specific resources. We hope you find these useful.*

Psychologists

Andrew Greenfield: A twin himself and a Child and Education Psychologist, NSW
M: 0412 341 201
E: andrew@child-psychologist.com.au

Dr Katie Wood: Clinical Psychologist, Victoria
M: 0447 574 274
E: CWood@groupwise.swin.edu.au

Yael Clark: Perinatal and Paediatric Psychologist (and also a parent of twins and ATR member)
M: 0438 559 601
W: www.supportingparents.com.au

* *This information is for general use only. Please consult your GP or health care professional for specific medical or health advice.*

Grief Support

www.twinlesstwins.org
www.bereavementcare.com.au

Family support

www.twinsrealm.com
www.raisingchildren.net.au
www.mytime.net.au
www.twinsandmultiples.org

Australian Multiple Birth Association

www.amba.org.au

Zygosity Testing

DNA Solutions
Ph: 1800 000 362
W: www.dnasolutions.com.au
Cost: Special price of \$139 exclusive to ATR members.



The ATR connects twins and researchers for vital health research that benefits everyone

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Contact us at:

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