

Families with school-age twins and higher multiples are needed

Please join the Australian Twin Registry

to help researchers learn more about multiple birth children

The Australian Twin Registry (ATR) helps researchers contact multiples who might be willing to consider taking part in approved studies. A major new initiative aimed at learning more about school-age multiples aged 6-17 years is underway. The study is looking at why some multiples are doing well while others have problems. It is also examining a range of related health issues. Professor David Hay and Associate Professor Florence Levy began a large scale study of twins aged 4-12 years in 1991-92 and followed the twins' progress over the next ten years. Their study made a substantial contribution to our understanding of the genetics of behaviour and behavioural problems, the long term effects of early difficulties, and how many children actually "grow out" of them. They are now investigating how things may be different for a newer generation of multiples.

Does the participation of my family really matter?

Yes, absolutely. The more families that join the ATR and participate in the Twin Behaviour Study, the more accurate the information collected about Australian multiples will be.

Our children don't have any problems, will studying them be helpful?

It is as important to study healthy multiples and those without problems as it is to study the sets with medical or behavioural difficulties. Looking at the entire spectrum of multiples is necessary to get a complete picture and put all of the issues into perspective.

What do we have to do?

First, become a member of the ATR. This will indicate that you are willing to consider requests to participate in various medical and health related studies. All of the studies are voluntary and you are always free to decline an invitation. The ATR is currently approaching families with multiples aged 6 to 17 to take part in the Twin Behaviour Study. When you receive the information about the study, you will be asked to return a form stating whether or not you are willing to participate. If you are willing, the research team will be provided with your contact details and you will be sent the questionnaire.

Is that all?

Yes and no. As members of the ATR, you may be approached from time to time regarding participating in other studies. All of the studies are carefully reviewed. Approved projects must satisfy ethical guidelines and be of significant value to the area of proposed research.

The nature of the studies and the frequency of the invitations depend upon the type of research that is being undertaken in Australia and your multiples' suitability for the project. You may never be asked to be involved in another study, or you may receive several invitations over the years or even in a short period of time. Some studies, like the Twin Behaviour Study mainly involve completing a questionnaire, while others involve more extensive interviews and clinical assessments.

You are not obligated to participate in any of the studies. You are always free to refuse or withdraw from a study. Your personal information will be kept strictly confidential and will never be given out without your prior consent. Regardless of whether or not you participate in particular studies, you will receive the ATR's regular newsletters about twin research in Australia.

Why should we take part in this or other studies – how does it benefit my family?

Twin research has wide-ranging and long terms benefits. For example, many families kindly participated in the studies that ultimately allowed Professors Hay, Levy, and their colleagues to develop resources for multiple birth families, such as the Twins in School website - www.twinsandmultiples.org. These resources offer vital support to parents as they tackle the complex issues associated with raising multiple birth children. This new study will ensure that this important information remains up-to-date.

To register with the Australian Twin Registry

Ring 1800 037 021 (free call within Australia)

or visit www.twins.org.au

