NEONATAL ALLOIMMUNE THROMBOCYTOPENIA (NAIT) IS AN UNCOMMON DISEASE, AND WE ARE STILL DISCOVERING HOW BEST TO PREVENT AND TREAT IT.

From July 2008, some key information about all women, unborn and newborn babies nationally who are being treated for NAIT is being collected by the NAIT Registry at the Monash University–Australian Red Cross Blood Service Transfusion Outcomes Research Collaborative.

The purpose of the NAIT Registry is to help doctors and nurses provide the best possible care to women and children with NAIT, and assist researchers in improving the treatment of this disease.

ABOUT THE TRANSFUSION OUTCOMES RESEARCH COLLABORATIVE

The Transfusion Outcomes Research Collaborative is a partnership between the Australian Red Cross Blood Service and Monash University. The aim of this partnership is to explore blood component usage and patient outcomes following transfusion, and so enhance the quality of transfusion practice and help improve clinical care.

www.torc.org.au

Version 4, dated January 2013

transfusionoutcomes research collaborative
NAIT REGISTRY

MONASH University
Medicine, Nursing and Health Sciences

Australian Red Cross
BLOOD SERVICE

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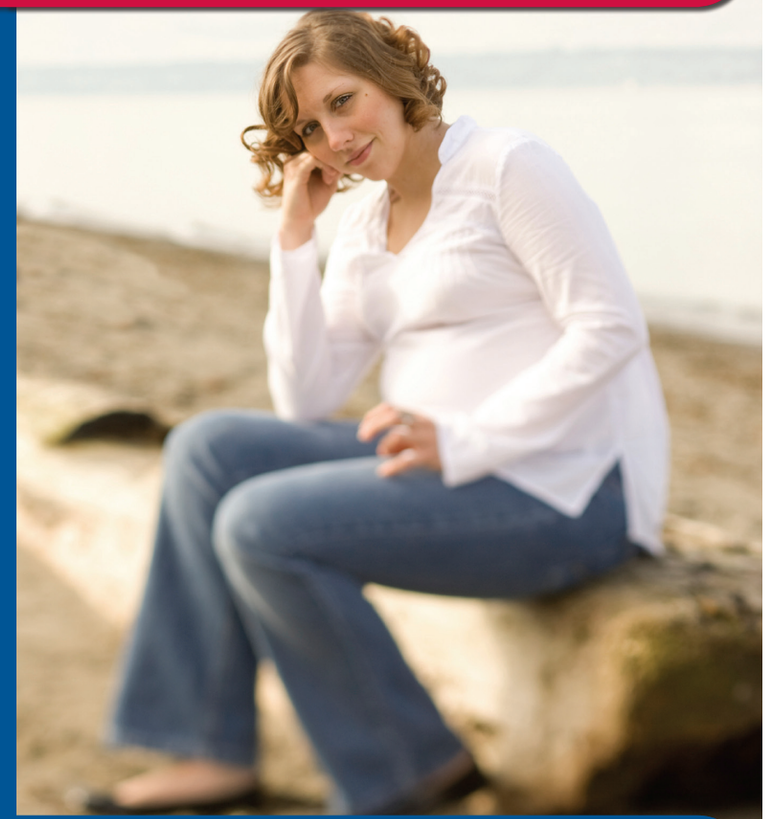
Information for Patients and Families



Neonatal Alloimmune Thrombocytopenia (NAIT) Registry

WHY IS THIS INFORMATION NEEDED?

The information for the NAIT Registry will provide an important resource for women and children with NAIT, clinicians who treat NAIT, and our community.

The NAIT Registry will tell us about:

- the frequency of NAIT in our community;
- ways of preventing NAIT, especially in women who have previously had babies affected by NAIT;
- the usefulness of different treatments for NAIT, including treatment for unborn babies with NAIT; **and**
- the variety of care provided for people with NAIT in our community, and how it compares to best practice internationally.

With this information we will be able to ensure women and children with NAIT in our community continue to receive the best possible care, including the specialised testing and blood products necessary for the treatment of NAIT.

We will also be able to assist researchers as they look for new tests and therapies to help prevent and treat NAIT in the future.

WHAT INFORMATION IS COLLECTED?

Women and their babies being treated for NAIT nationally will be referred by their treating clinician.

The information collected will be limited to:

- names of the parents and child, and of your doctor, so we can identify progress of your treatment over time;
- the type of treatment you and your child receive, the response of the illness to those treatments and any complications of the illness or treatment; and
- any relevant medical history you may have, including any previous history of NAIT.

SAFEGUARDING YOUR PRIVACY

The NAIT Registry has been designed in accordance with the strictest privacy principles, including State and Commonwealth privacy laws, and has been reviewed by independent ethics committees including the committee at your hospital.

The information collected will:

- comply with all privacy legislation;
- remain confidential and never be released in a way which could potentially identify a specific individual - the information provided will only ever be used by bona fide researchers with ethical approval to compile tabulations and statistics; **and**
- be stored securely, with access restricted only to Registry officers, each of whom is committed to maintaining confidentiality.

QUESTIONS OR CONCERNS?

If you would like more information, or have any concerns about the privacy of your personal information, or wish to withdraw from the Registry, please complete and return the accompanying "Decline to Participate" form or contact the Registry Project Manager below, or the secretary of your hospital ethics committee.

NAIT Registry Project Manager
Transfusion Outcomes Research Collaborative
Department of Epidemiology and Preventive Medicine,
Monash University, Australia

Toll Free - Phone 1800 811 326

Email - torc.sphpm@monash.edu

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