NAIT REGISTRY – Offline Data Collection Form

DATA COLLECTOR DETAILS

First Name & Surname:	
Your contact phone number:	
Your contact email address:	
Date of data collection:	
Has patient been given/sent the 'Brochure for Patients and Families?' Available on request from Monash or print from registry homepage https://trauma.med.monash.edu.au/NAIT	☐ Yes - proceed

Section A: PARENTAL DETAILS

A1	**Mother's Surname**		
A2	**Mother's First Name**		
A3	**Mother's Date of Birth (DD/MM/YYYY)**		
A4	**Mother's Ethnic Heritage**	**Mother's grandparent 1** ☐ Unknown ☐ African ☐ Native American (North or South) ☐ Asian (Indian Subcontinent) ☐ Asian (Middle East) ☐ Asian (Other) ☐ European ☐ Polynesian/Melanesian (inc Maori) ☐ Aboriginal or Torres Strait Islander ☐ Other ……	**Mother's grandparent 2** ☐ Unknown ☐ African ☐ Native American (North or South) ☐ Asian (Indian Subcontinent) ☐ Asian (Middle East) ☐ Asian (Other) ☐ European ☐ Polynesian/Melanesian (inc Maori) ☐ Aboriginal or Torres Strait Islander Other ……
		Mother's grandparent 3 ☐ Unknown ☐ African ☐ Native American (North or South) ☐ Asian (Indian Subcontinent) ☐ Asian (Middle East) ☐ Asian (Other) ☐ European ☐ Polynesian/Melanesian (inc Maori) ☐ Aboriginal or Torres Strait Islander Other ……	**Mother's grandparent 4** ☐ Unknown ☐ African ☐ Native American (North or South) ☐ Asian (Indian Subcontinent) ☐ Asian (Middle East) ☐ Asian (Other) ☐ European ☐ Polynesian/Melanesian (inc Maori) ☐ Aboriginal or Torres Strait Islander Other ……

Section A: PARENTAL DETAILS (continued)

A5	**Mother's "booking weight" or estimated pre-pregnancy weight (kg)**		
A6	**Mother's Height (cm)**		
A7	**Mother's Gravidity** (exclude this pregnancy)		
A8	**Mother's Parity** (exclude this baby)		
A9	**Father's Surname**		
A10	**Father's First Name**		
A11	**Father's Date of Birth (DD/MM/YYYY)**		
A12	**Father's Ethnic Heritage**	**Father's grandparent 1** ☐ Unknown ☐ African ☐ Native American (North or South) ☐ Asian (Indian Subcontinent) ☐ Asian (Middle East) ☐ Asian (Other) ☐ European ☐ Polynesian/Melanesian (inc Maori) ☐ Aboriginal or Torres Strait Islander ☐ Other ……	**Father's grandparent 2** ☐ Unknown ☐ African ☐ Native American (North or South) ☐ Asian (Indian Subcontinent) ☐ Asian (Middle East) ☐ Asian (Other) ☐ European ☐ Polynesian/Melanesian (inc Maori) ☐ Aboriginal or Torres Strait Islander Other ……
		Father's grandparent 3 ☐ Unknown ☐ African ☐ Native American (North or South) ☐ Asian (Indian Subcontinent) ☐ Asian (Middle East) ☐ Asian (Other) ☐ European ☐ Polynesian/Melanesian (inc Maori) ☐ Aboriginal or Torres Strait Islander Other ……	**Father's grandparent 4** ☐ Unknown ☐ African ☐ Native American (North or South) ☐ Asian (Indian Subcontinent) ☐ Asian (Middle East) ☐ Asian (Other) ☐ European ☐ Polynesian/Melanesian (inc Maori) ☐ Aboriginal or Torres Strait Islander Other ……

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Section B: CLINICAL BACKGROUND

B1	**Case Description**	
B2	**Possible Alternative Cause of Clinical Presentation**	
B3	**Stage at which case identified as NAIT**	☐ Anticipated prior to pregnancy ☐ Not anticipated: Identified during pregnancy ☐ Not anticipated: Identified following delivery - *Skip to Section E*
B4	**Reason for Case Identification**	
B5	**Any previous NAIT-affected offspring?**	☐ Yes ☐ No - *Skip to B7* ☐ Unknown - *Skip to B7*
B6a	**Previous NAIT-affected offspring #1: Details of severity**	
B6b	**Previous NAIT-affected offspring #2: Details of severity**	
B6c	**Previous NAIT-affected offspring #3: Details of severity**	
B7	**Comments On Any Previous Poor Pregnancy Outcomes**	
B8	**Maternal platelet count at diagnosis (x10^9)**	
B9	**Date of Maternal platelet count**	
B10	**Maternal ABO group**	☐ A ☐ B ☐ O ☐ AB ☐ Unknown

Section C: ANTENATAL CLINICAL DETAILS

C1	**Estimated Date of Delivery**	
C2	**Site of Antenatal Management**	
C3	**Gestation at which Case Identified (weeks)**	
C4	**Antenatal cranial imaging performed?**	☐ Ultrasound ☐ Magnetic Resonance Imaging ☐ Not Performed -*Skip to C6* ☐ Unknown - *Skip to C6*
C5	**Antenatal cranial imaging findings**	
C6	**Complications During Pregnancy**	☐ None ☐ Intracranial haemorrhage ☐ Other bleeding; Site of bleeding:…… ☐ Pre-eclampsia ☐ Fetal infection ☐ Placental abruption ☐ Other; Details:……
C7	**Outcome of Pregnancy**	☐ Fetal Death in Utero ☐ Live Birth - *Skip to Section D* ☐ Pregnancy Ongoing - *Skip to Section D* ☐ Other; Details: …….. ☐ Unknown - *Skip to Section D*
C8	**Cause of Death**	☐ Intracranial Haemorrhage ☐ Other Haemorrhage; Details: …… ☐ Other; Details: …….. ☐ Unknown
C9	**Is Post-mortem to be performed?**	☐ Yes ☐ No - *Skip to Section D* ☐ Unknown - *Skip to Section D*
C10	**Comments on Findings at Post-Mortem**	☐ Tick here if PM findings not available now, and we will contact you in 3 months

Section D: ANTENATAL TESTING & THERAPY

D1	**Foetal Blood Sampling performed?**	☐ Yes, number of times performed …… ☐ No - *Skip to D3*
D2a	**Foetal Blood Sampling** **Episode #1**	Date: …… Fetal platelet count from foetal blood sampling (x10^9) …….. Complications of foetal blood sampling ☐ None ☐ Umbilical haemorrhage ☐ Bradycardia ☐ Cardiac Arrest ☐ Foetal death ☐ Other; Details: ……
D2b	**Foetal Blood Sampling** **Episode #2**	Date: …… Fetal platelet count from foetal blood sampling (x10^9) …….. Complications of foetal blood sampling ☐ None ☐ Umbilical haemorrhage ☐ Bradycardia ☐ Cardiac Arrest ☐ Foetal death ☐ Other; Details: ……
D2c	**Foetal Blood Sampling** **Episode #3**	Date: …… Fetal platelet count from foetal blood sampling (x10^9) …….. Complications of foetal blood sampling ☐ None ☐ Umbilical haemorrhage ☐ Bradycardia ☐ Cardiac Arrest ☐ Foetal death ☐ Other; Details: ……
D2d	**Foetal Blood Sampling** **Episode #4** *(attach additional copy of this page for more episodes, if required)*	Date: …… Fetal platelet count from foetal blood sampling (x10^9) …….. Complications of foetal blood sampling ☐ None ☐ Umbilical haemorrhage ☐ Bradycardia ☐ Cardiac Arrest ☐ Foetal death ☐ Other; Details: ……

D3	**Antenatal platelet transfusion performed?**	☐ Yes, number of times performed ……. ☐ No - *Skip to D5*
D4a	**Antenatal platelet transfusion Episode #1**	Date: …… Fetal platelet count post-transfusion (x10^9) …….. Platelet type: ☐ HPA Matched ☐ Non-HPA Matched ☐ Maternal ☐ Unknown Complications of foetal platelet transfusion ☐ None ☐ Umbilical haemorrhage ☐ Bradycardia ☐ Cardiac Arrest ☐ Foetal death ☐ Other; Details: ……
D4b	**Antenatal platelet transfusion Episode #2** *(attach additional copy of this page for more episodes, if required)*	Date: …… Fetal platelet count post-transfusion (x10^9) …….. Platelet type: ☐ HPA Matched ☐ Non-HPA Matched ☐ Maternal ☐ Unknown Complications of foetal platelet transfusion ☐ None ☐ Umbilical haemorrhage ☐ Bradycardia ☐ Cardiac Arrest ☐ Foetal death ☐ Other; Details: ……
D4c	**Antenatal platelet transfusion Episode #3** *(attach additional copy of this page for more episodes, if required)*	Date: …… Fetal platelet count post-transfusion (x10^9) …….. Platelet type: ☐ HPA Matched ☐ Non-HPA Matched ☐ Maternal ☐ Unknown Complications of foetal platelet transfusion ☐ None ☐ Umbilical haemorrhage ☐ Bradycardia ☐ Cardiac Arrest ☐ Foetal death ☐ Other; Details: ……

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Section D: ANTENATAL TESTING & THERAPY (continued)

D5	**Amniocentesis (Foetal genotyping)**	Date: …… Complications of amniocentesis ☐ None ☐ Umbilical haemorrhage ☐ Bradycardia ☐ Cardiac Arrest ☐ Foetal death ☐ Other; Details: ……
D6	**IVIg given to mother?**	☐ None - *Skip to D6* ☐ Intragam P® ☐ Octagam® ☐ Sandoglobulin® ☐ Other; Details: …… Date of first dose: …… Date of last dose: …… Grams per dose: …… Total number of doses: …… Frequency: ☐ Twice weekly ☐ Weekly ☐ Fortnightly ☐ Monthly ☐ Other: ……
D7	**Corticosteroids given to mother?**	☐ None - *Skip to Section E* ☐ Prednisolone ☐ Hydrocortisone ☐ Dexamethasone ☐ Other; Details: …… Date of first dose: …… Date of last dose: …… Milligrams per dose: …… Total number of doses: …… Frequency: ☐ Daily ☐ Alternate daily ☐ Twice weekly ☐ Weekly ☐ Other: ……
D8	**Other antenatal therapy**	Give details:

Section E: POSTNATAL DEMOGRAPHICS

E1	**Child Surname**	
E2	**Child First Name**	
E3	**Child sex**	☐ Male ☐ Female ☐ Unknown
E4	**Child birth weight (g)**	
E5	**Date of delivery (DD/MM/YYYY)**	
E6	**Gestation at delivery (weeks)**	
E7	**Mode of delivery**	☐ Spontaneous vaginal ☐ Ventouse ☐ Forceps ☐ Caesarean (pre-labour) ☐ Caesarean (after onset labour) ☐ Unknown
E8	**Timing of delivery**	☐ Spontaneous ☐ Induced ☐ Emergent ☐ Unknown
E9	**Site of antenatal management**	
E10	**Transferred Patient**	☐ Yes ☐ No -*Skip to Section F*
E11	**Patient transferred from:**	

Section F: POSTNATAL CLINICAL & TESTING DETAILS

F1	**Clinical Manifestations**	☐ Petechiae ☐ Purpura ☐ Pulmonary Haemorrhage ☐ GI Haemorrahge ☐ Intracranial Haemorrhage ☐ Other; Details: ……..
F2	**Child's first platelet count (x10^9)**	
F3	**Child first haemoglobin (g/L)**	
F4	**Child's first total WCC (x10^6/L)**	
F5	**Child ABO Group**	☐ A ☐ B ☐ O ☐ AB ☐ Unknown
F6	**Child Rhesus (D) Group**	☐ Positive ☐ Negative ☐ Unknown
F7	**Date of child's first blood counts (DD/MM/YYYY)**	
F8	**Child's lowest platelet count (x10^9)**	
F9	**Date of child's lowest platelet count**	
F10	**Postnatal cranial imaging performed?**	☐ Computed Tomography ☐ Ultrasound ☐ Not Performed - *Skip to Section G* ☐ Unknown- *Skip to Section G*
F11	**Postnatal cranial imaging findings**	

Section G: POSTNATAL THERAPY

G1	**Postnatal therapy given?**	☐ Yes ☐ No - *Skip to Section H*
G2	**Postnatal therapy type:**	☐ Platelet transfusion/s, number of times performed …….. ☐ IVIg ☐ Other; Details: ……
G3a	**Platelet transfusion to newborn Episode #1**	Date of Transfusion: …….. Child's platelet count pre transfusion (x10^9)…… Post-transfusion…… Platelet Type: ☐ HPA-matched ☐ Non HPA-matched ☐ Maternal ☐ Unknown
G3b	**Platelet transfusion to newborn Episode #2**	Date of Transfusion: …….. Child's platelet count pre transfusion (x10^9)…… Post-transfusion…… Platelet Type: ☐ HPA-matched ☐ Non HPA-matched ☐ Maternal ☐ Unknown
G3c	**Platelet transfusion to newborn Episode #3**	Date of Transfusion: …….. Child's platelet count pre transfusion (x10^9)…… Post-transfusion…… Platelet Type: ☐ HPA-matched ☐ Non HPA-matched ☐ Maternal ☐ Unknown
G3d	**Platelet transfusion to newborn Episode #4**	Date of Transfusion: …….. Child's platelet count pre transfusion (x10^9)…… Post-transfusion…… Platelet Type: ☐ HPA-matched ☐ Non HPA-matched ☐ Maternal ☐ Unknown
G3e	**Platelet transfusion to newborn Episode #5** *(attach additional copy of this page for more episodes, if required)*	Date of Transfusion: …….. Child's platelet count pre transfusion (x10^9)…… Post-transfusion…… Platelet Type: ☐ HPA-matched ☐ Non HPA-matched ☐ Maternal ☐ Unknown

Section G: POSTNATAL THERAPY (continued)

G4	**IVIg given to newborn?**	☐ None – *Skip to Section H* ☐ Intragam P® ☐ Octagam® ☐ Sandoglobulin® ☐ Other; Details: …… Date of first dose: …… Date of last dose: …….. Grams per dose: …… Total number of doses: ……..

Section H: POSTNATAL OUTCOME

H1	Outcome of episode	☐ Complete Recovery with no long term impairment - *Skip to Section I* ☐ Recovery with persisting impairment - *Skip to H4* ☐ Death
H2	Cause of death	☐ Intracranial haemorrhage ☐ Pulmonary haemorrhage ☐ Other haemorrhage; Details: …… ☐ Other; Details: ……..
H3	Other Autopsy findings	
H4	Nature of Persistent Impairment	
H5	Comments on postnatal outcome	

Section I: GENERAL COMMENTS ON CASE

I	

Thank you for helping us with this important study. The clinical details above will be merged with platelet testing details from ARCBS/PathWest laboratories.

Please submit your form to:
NAIT Registry Project Officer
Transfusion Research Unit
Department of Epidemiology & Preventive Medicine
Level 6, The Alfred Centre
99 Commercial Rd
Melbourne 3004

Or email: **torc.sphpm@monash.edu**