NEONATAL ALLOIMMUNE THROMBOCYTOPENIA (NAIT) REGISTRY WEB DATA ENTRY

Department of Epidemiology and Preventive Medicine
Monash University
Data Entry User Guide

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System Requirements

The NAIT Registry database requires only the recommended web browser, Microsoft Internet Explorer 7.0 (IE) to operate.

This software can be obtained from the Microsoft website at:


It is not necessary to install any software other than this web browser.

Below are the minimum requirements your computer needs to run Internet Explorer 7. Please note that it is possible that some components may require additional system resources not outlined below.

<table>
<thead>
<tr>
<th>Minimum Requirements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Computer/Processor</td>
</tr>
<tr>
<td>Operating System</td>
</tr>
<tr>
<td>Memory</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
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<tr>
<td></td>
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<tr>
<td>Display</td>
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<tr>
<td></td>
</tr>
<tr>
<td>Peripherals</td>
</tr>
</tbody>
</table>

**Note:** Internet Explorer 7 setup installs the majority of its files on the drive where the Windows operating system is installed, regardless of the installation location you choose. To free up space on your hard disk in order to meet disk-space installation requirements, do so on the drive where the Windows operating system is installed.
SYSTEM REQUIREMENTS

Web Browser

Like any web site a web browser is required to access the NAIT Registry database system.

Preferred Browsers

Microsoft Internet Explorer 7 (IE) (or newer version) is the web browser for which the NAIT database system has been developed. Alternatively, Mozilla Firefox 3.0 or newer version is also supported. However, some of the reporting features are not fully supported by Mozilla Firefox. A free copy of Mozilla Firefox can be downloaded from:

http://www.mozilla.org/

Users may experience some difficulty if using browsers other than those recommended.

Language of the browser

All dates in the application are in Australian format DD/MM/YYYY. Therefore it is very important that your browser is configured in Australian date format. Most browsers are set to default to American settings so this will need to be adjusted.

Date format is determined through the browser’s language set up. To set the language in Internet Explorer 7 (IE), click on Internet Options on the Tools menu. On the general tab, click Languages. Click Add and select English (Australia) [en-au] form the list. Make sure it is at the top of the list by clicking the Move Up button. The same screen can be found in Firefox through Tools menu, Options, Advanced tab and Edit Language.

If a TTP database page cannot be displayed because of a date error, or the current patient label displays the date differently from what is shown on the patient list, check the language settings for your browser.

Figure 1: Language preference window after setup
Auto-complete Password

Most web browsers provide an option for remembering the password used to log into a web site on that computer. Due to the sensitive nature of the NAIT Registry data, the auto-complete password option must be turned off to ensure privacy.

To do this in Internet Explorer, click on Internet Options on the Tools menu as shown in Figure 2. On the Content tab in the personal information section, click on AutoComplete. When the AutoComplete settings box appears uncheck Prompt me to save passwords and User names and passwords on forms boxes and click Clear passwords. Please note that this will clear any web-based addresses that have automatically saved passwords so be sure to record your passwords before completing this process.

Figure 2: How to stop auto-complete password in Internet Explorer
Web Access and Security

As with all web pages on the internet, the NAIT Registry web application can be accessed by specifying the URL address in the web browser. The URL Address for this application is:


On accessing the web site, you will need to click on Web Data Entry to be directed to the NAIT Registry login page below.

Figure 3: Login page viewed in IE 6.0

In order to access data in the application, a User Name and Password are required. If you already have a login, you can bypass the next section and go directly to Changing Login Details on page 5, otherwise a new login needs to be provided to you by NAIT Registry IT Staff.
New Login

To request a new login, click on **Need a Login?** as shown in Figure 3 above. This will open up your email and automatically address an email to the NAIT Registry IT staff. In the body of the email please provide your full name, the hospital or site you represent and the email address to which you wish to have your login information sent (if different from the account sending). A user name will be created from the first character of your given name and at least 6 characters from your surname. Your user name and temporary password will be emailed to you within 24 hours. On receipt of the new login and password it is imperative that the password is reset to something more secure and personal that is easily recalled. You will also need to provide a security question for further verification.

Changing Login Details

After logging in with your user name and password, you will be presented with 3 sub menus on the right of the menu panel.

Changing your Password

To change the password, click on the **Change Password** Link as indicated in Figure 4 above. You will be presented with the screen on the following page:
After entering your old password, create a new password of at least 7 characters, with at least one non-alpha-numeric character (eg! @ # $ % & * ( ) ?). It should be something more personal and able to be readily recalled, without being obvious. Visit the Monash University ITS web site for assistance in choosing a good password. [http://www.its.monash.edu.au/staff/security/passwords/goodpassword.html](http://www.its.monash.edu.au/staff/security/passwords/goodpassword.html).

You will need to enter the password again to confirm and prevent unauthorised use. Not only should the password be changed for a new login, but all existing logins should regularly change their password and security question.

Changing your Email Address

Your email address is used to communicate any login details with you as well as any outages that may occur. It is therefore important that your current email details are registered. To do this, click on the [Change Email Address](http://www.its.monash.edu.au/staff/security/passwords/goodpassword.html) Link as indicated in Figure 4 previously. You will be presented with the screen on the following page.

To verify your identity, enter your password and then overwrite your current email address. The new email address cannot be the same as the old one.
Changing your Security Question

Your security question is used to verify your login details in the event that you cannot recall your password. It is therefore important that you change this when you change your password and that it is not shared with anyone else. To do this, click on Change Security Question as shown in Figure 4. You will be presented with the screen in Figure 7 below to enter a question and answer:

![Change Security Question Screen]

Figure 7: Changing your security question
WEB ACCESS AND SECURITY

Password Recovery

If your password is misplaced, a new password can be requested by clicking **Forget your password?** on the login page as shown in Figure 8 below:

Figure 8: "Forget you password?" link on the login page

You must firstly supply your User Name:

Figure 9: Password Recovery page - submitting user name
The security question is then asked in order to identify the user.

If the answer is correct a new password is generated and sent to your registered email address with a confirmation message (as in Figure 11 below). It is very important to keep the answer to security question private.
Figure 11: Password recovery page - confirming password being recovered and email address to which the new password is sent. Also, an example email generated after the process.
Account Locked

The maximum number of attempts at supplying your password is three. If this number is exceeded, your account will be locked and you will be unable to access the database. You will be directed to the login page with the error message below.

The same restrictions apply to the number of login attempts and answering the security question. You will need to contact NAIT Registry IT staff to unlock your account.

Restricted Access

On establishing a new login, you will be granted access by NAIT Registry IT staff to data from the hospital specified in the Login request. This request is verified by NAIT Registry staff. You will not be able to access data from other project sites.

Logout and Timeout

You are advised to logout every time you finish working with the database by using the logout icon on the top right hand side of the main menu bar. This is to ensure unauthorised access does not occur. If you do leave your computer for any period of time it is strongly recommended that it is locked by pressing Control-ALT-Delete simultaneously and clicking on Lock Workstation. This should be standard organisation-wide practice. Users will need to re-enter the network and/or computer password to access the computer.

The TTP Registry is programmed to timeout after 30 minutes of inactivity. You will need to re-enter your login details at this point.
Navigation

Patient List

Figure 13: Home Page after logging in, displaying Patient List

Upon logging in a summary list of patients already on NAIT Registry (based on the restricted access discussed in the previous section) will appear. This list consists of their unique patient number, a hyphen, and the admission number – together these form the Registry number for a patient.

A patient record is selected by clicking on the Registry number.

Once the new case is created or an existing case selected, all subsequent data entry pages display information from the patient summary at the top of the page below the menu bar (shown in Figure 14).
Menu Bar

The menu bar is the primary means by which details of an existing or new patient are viewed or entered. After an existing patient is selected from the Patient List, you can access details relating to various aspects of that patient’s information by clicking on any of the menu bar options from Patient through to Complications and Outcome (Figure 14).

![Patient Details screen highlighting Patient Information](image)

The name of the page on view is displayed under the menu bar to the far right (Figure 15).

![Home page identifying the current page](image)

**Hint**

For both recommended browsers, users can press **F11** on their keyboard to switch to Full Screen display which reduces the need for scrolling.
Login information is also displayed on the menu bar at the far right. As shown below, your user name is displayed, following the text **Logged in as**; in this example ‘nschembri’.

![Home Page screen with Login information](image-url)
Data Entry Guidelines

General Principles
In order to maintain data integrity some data items are deactivated. This prevents data from being entered when it is unnecessary. When new data is being populated, some data items are activated only after a particular value has been entered.

Required Field Validation
All data items on each page must be completed, unless they are deactivated by the application. A red asterisk adjacent to a data item indicates that this field has been left un-entered (Figure 18). An explanation is given at the bottom of the screen when you attempt to save the data.

Range and Regular Expression Validation
To prevent invalid input into text boxes, Range and Regular Expression validators provide a way to examine the validity of data in each textbox. A Range validator allows a certain range of numbers for numeric or date input. Regular Expression validators only allow particular non-alphanumeric text input. Should you still not be able to decipher the offending character, refer to each form’s summary table in this guide for detailed validation rules.

A red asterisk will pop up after leaving the text box when invalid characters are identified. An error message will only be displayed after you attempt to save.
Page Validation

Page Validation is another means of controlling the consistency of data. It prevents invalid data from being entered in the database. A red-colored error message will appear on the screen notifying the reason of the validation failure. Page validation fires after the save button has been clicked. All validation must be satisfied before the data is saved by the database.
DATA ENTRY GUIDELINES

Page Warnings
A warning message is different from an error message and does not stop data from saving. This is often used for a reminder of an unknown date and time. It is shown in blue and remains in view when saved. This allows data to be saved even when they contain some unknown values. All date and time textboxes will generate an unknown date time warning message when they contain a value of unknown date: 09/09/9999 or unknown Time: 00:00.

Date and Time Fields
There are a number of factors to consider with date and time fields:

1. Dates are in the format: DD/MM/YYYY. You are not required to enter the forward slash character (/) in between days, month and years. If the date is unknown, enter 09/09/9999.

2. Times are in 24 hour format: hh:mm. You are not required to enter the colon (:) in between hours and minutes. If the time is unknown, enter 00:00. If the time is known and is 00:00 hours, please enter 00:01.

3. Some fields accept both date and time in the same field in the format: DD/MM/YYYY hh:mm. If a date and time are unknown, enter 09/09/9999 00:00. A ‘space’ is required between the date and time formats.

4. All dates and times are sequential. For example, the date of first identifiable symptom must be earlier than the date of diagnosis. An error will be raised if dates and times are not in the correct sequence.
Adding a New Case

To add a new case, click on New Case on the menu bar. Once the data entry process has started, patients are ideally entered as a complete dataset. It is therefore advisable to have all data readily available before starting. This process involves entering patient details, clinical presentation and context information, laboratory parameters, therapy, complications and outcome.

Hint: Clicking on the NAIT Registry banner (previously indicated in Figure 19) will take you out of new case mode, and reinstate the main menu and patient list.

Case Registration - New

When entering a new case on the Patient Page, the Main Menu and Patient List are hidden from view.

Figure 19: Hospital and patient information page for a new case with no main menu or patient list.

A summary of the patient page data items and the validation that takes place is provided on the next page, with specialised behaviour explained in the last column.

Hint: Clicking on Create A New Case will take you to the Patient Demographics Information page. Clicking on Cancel returns you to the home page (indicated in Figure 19).
## Case Registration Page Data Entry Summary

<table>
<thead>
<tr>
<th>Data item</th>
<th>Data Entry Required</th>
<th>Type of Data Entry</th>
<th>Permitted Characters and Values</th>
<th>Unknown Values</th>
<th>Special Behaviour</th>
</tr>
</thead>
<tbody>
<tr>
<td>Institution / Hospital / Site</td>
<td>Always</td>
<td>Drop down list</td>
<td>Select from list</td>
<td>-</td>
<td>N/A</td>
</tr>
<tr>
<td>Family Name</td>
<td>Always</td>
<td>Free Text</td>
<td>Alphanumeric</td>
<td>Not applicable</td>
<td>N/A</td>
</tr>
<tr>
<td>Given Name</td>
<td>Always</td>
<td>Free Text</td>
<td>Alphanumeric</td>
<td>Not applicable</td>
<td>N/A</td>
</tr>
<tr>
<td>Date of Birth</td>
<td>Always</td>
<td>Text Box, DD/MM/YYYY</td>
<td>Date (Range since 01/01/1901)</td>
<td>Not applicable (not allowed to be unknown on search screen)</td>
<td>N/A</td>
</tr>
</tbody>
</table>
Adding a New Case

Institution/ Hospital/ Site

Most Data Collectors will be able only to enter data for one hospital. Where data collectors are responsible for data collection at more than one hospital, multiple hospitals are displayed in a drop down list.

Figure 20: Case registration page with hospital field indicated.

Patient Family Name (Maternal)

The patient’s family name and given name are alphanumeric free text fields. The information that is entered as alphanumeric free text on the case registration page automatically populates throughout the subsequent case-related pages.

Figure 21: Case registration page with name and date of birth fields indicated.

Family name should be recorded in the format preferred by the person.

Punctuation

If special characters form part of the family name they should be included, e.g. hyphenated names should be entered with a hyphen. Examples:

*Hyphen:* e.g. Wilson-Phillips.
Do not leave a space before or after a hyphen, i.e. between the last letter of ‘Wilson’ and the hyphen, nor a space between the hyphen and the first letter of ‘Phillips’.

*Apostrophe:* e.g. O’Brien, D’Agostino.
Do not leave a space before or after the apostrophe, i.e. between the ‘O’ and the apostrophe, or a space between the apostrophe and ‘Brien’.

*Full stop:* e.g. St. John, St. George.
Do not leave a space before a full stop, i.e. between ‘St’ and the full stop. Do leave a space between the full stop and John.
Adding a New Case

Space: e.g. van der Humm, Le Brun, Mc Donald.
Record the family name leaving one space between each word.

Some people do not have a family name and a given name; they have only one name by which they are known. If the person has only one name, record it in the Family Name field and leave the Given Name field blank.

Patient Given Name (Maternal)

Given name(s) should be recorded in the format preferred by the person. If the person’s given name is not known, but the first letter (initial) of the given name is known, record the first letter in the preferred Given name field. Do not record a full stop following the initial. Some people do not have a family name and a given name; they have only one name by which they are known. If the person has only one name, record it in the Family name field and leave the Given name field blank.

Punctuation:

If special characters form part of the given name they should be included, e.g. hyphenated names should be entered with a hyphen.

Refer to examples under “Patient Family Name Maternal”, page 20.

Date of Birth (Maternal)

If date of birth is not known or cannot be obtained, an estimated age in years should be used for adults. When date of birth is an estimated value, use 0101, and, the estimated year.

When confident that all case registration details have been entered correctly select Create a New Case.

When Create a new case is selected the following warning will display:

![Case registration page warning](image)

It is very important to check with the mother on possible previous registration with their maiden name, or with any surname changes. If you are unable to locate a patient whom you believe has previously been registered, please contact Registry staff.
Adding a New Case

Once you have created a new case, information from the patient summary is displayed at the top of each page, below the menu bar on subsequent pages to identify the active record (see Figure 23).

Figure 23: Patient details screen highlighting patient information.
Adding a New Case

Parental Demographics Page

When entering a new case on the Parental Demographics Page, the Main Menu and Patient List are still hidden from view. The Patient Information is now visible because the patient exists on the database.

A summary of the Parental Demographics data items and validation is displayed on the following page.

It is important to note that this page contains multiple save points. Data for each section must be saved independently in order for the information to be retained on the system. Any data not saved will be lost and required to be re-entered.
## Parental Demographics Page Data Entry Summary

<table>
<thead>
<tr>
<th>Data Item</th>
<th>Data Entry Required</th>
<th>Type of Entry</th>
<th>Permitted Characters and Values</th>
<th>Unknown Values</th>
<th>Special Behaviour</th>
</tr>
</thead>
<tbody>
<tr>
<td>Registry Number</td>
<td>Automatic</td>
<td>Automatic</td>
<td>—</td>
<td>—</td>
<td>Assigned on creation of patient or addition of new pregnancy to existing patient (see below)</td>
</tr>
<tr>
<td>Maternal Details: Family Name</td>
<td>Display only on this screen</td>
<td>Automatic</td>
<td>—</td>
<td>—</td>
<td>Populated with data from Screen 1</td>
</tr>
<tr>
<td>Maternal Details: Given Name</td>
<td>Display only on this screen</td>
<td>Automatic</td>
<td>—</td>
<td>—</td>
<td>Populated with data from Screen 1</td>
</tr>
<tr>
<td>Maternal Details: Date of Birth</td>
<td>Display only on this screen</td>
<td>Automatic</td>
<td>—</td>
<td>—</td>
<td>Populated with data from Screen 1</td>
</tr>
<tr>
<td>Maternal Details: Age</td>
<td>Always</td>
<td>Text Box</td>
<td>Numeric: Decimal (2)</td>
<td>-1</td>
<td>N/A</td>
</tr>
<tr>
<td>Maternal Details: Genetic Ethnic Heritage 1-4</td>
<td>Always</td>
<td>Four Drop Down Menu</td>
<td>Select from List</td>
<td>Unknown</td>
<td>N/A</td>
</tr>
<tr>
<td>Maternal Details: Weight (kg)</td>
<td>Always</td>
<td>Text Box</td>
<td>Numeric (Range 10-300)</td>
<td>-1</td>
<td>N/A</td>
</tr>
<tr>
<td>Maternal Details: Height (cm)</td>
<td>Always</td>
<td>Text Box</td>
<td>Numeric (Range 50-250)</td>
<td>-1</td>
<td>N/A</td>
</tr>
<tr>
<td>Maternal Details: Gravidity</td>
<td>Always</td>
<td>Text Box</td>
<td>Numeric (1-20)</td>
<td>-1</td>
<td>N/A</td>
</tr>
<tr>
<td>Maternal Details: Parity</td>
<td>Always</td>
<td>Text Box</td>
<td>Numeric (0-20)</td>
<td>-1</td>
<td>N/A</td>
</tr>
<tr>
<td>Paternal Details: Family Name</td>
<td>Always</td>
<td>Free Text</td>
<td>Alphanumeric</td>
<td>Unknown</td>
<td>N/A</td>
</tr>
<tr>
<td>Paternal Details: Given Name</td>
<td>Always</td>
<td>Free Text</td>
<td>Alphanumeric</td>
<td>Unknown</td>
<td>N/A</td>
</tr>
<tr>
<td>Paternal Details: Date of Birth</td>
<td>Always</td>
<td>Text Box, DD/MM/YYYY</td>
<td>Date (Range since 01/01/1901)</td>
<td>09/09/9999</td>
<td>N/A</td>
</tr>
<tr>
<td>Paternal Details: Genetic Ethnic Heritage 1-4</td>
<td>Always</td>
<td>Four Drop Down Menu</td>
<td>Select from List</td>
<td>Unknown</td>
<td>N/A</td>
</tr>
</tbody>
</table>
Registry Number
The registry number is automatically generated on creation of a patient or addition of a new pregnancy to an existing patient. The registry number takes the form xxxx-y where xxxx is a unique patient number, assigned on registration, and y is the episode number, so for the patient’s first pregnancy y is 1, second pregnancy y is 2 and so on.

Maternal Details: Family Name and Given Name
These fields will be automatically populated from the information provided in Screen 1.

Maternal Details: Date of Birth
This will be automatically populated from the information provided in Screen 1.

Maternal Details: Age
Maternal age in years at the time of diagnosis of NAIT.

Maternal Details: Genetic Ethnic Heritage (Grandparents)
People from different parts of the world have slight differences in the types and proportions of genetic traits. We are interested in finding out if NAIT is related to different genetic populations and consequently need to know about the ethnic origin of the patient. Because Australia is a diverse multicultural community, many people are born from parents of different ethnic background. A patient’s parents themselves may be of mixed ethnic derivation. For this reason, we ask for ethnic heritage of each of the patient’s four grandparents.

Patient origin is answered from a choice of four drop down menus, one for each grandparent. Each drop down menu contains the following choices:

- African
- Native American (north or south)
- Asian (Indian subcontinent)
- Asian (Middle East)
- Asian (other)
- European
- Polynesian/Melanesian (including New Zealand Maori)
- Aboriginal or Torres Strait Islander
- Other

Selection of Other allows free text entry of details.

It is important that this question is answered in terms of genetic ethnic origin rather than cultural identification. For example, a person may identify as French because they grew up in France even though their ancestry is African. In this instance African should be chosen rather than European.

You will notice that there is no option to choose “Australian”, Australian citizens need to choose either Aboriginal or Torres Strait Islander or another relevant category, e.g. European.

Maternal Details: Weight
Maternal weight should be measured in kilograms (kg) and reported to the nearest 0.1kg.

Maternal Details: Height
Mother’s height measured in centimetres (cm).
Maternal Details: Gravidity
This is the number of times the mother has been pregnant. For her first pregnancy the maternal gravidity = 1, for her second pregnancy maternal gravidity = 2 and so on. Miscarriage or abortion should still be included in the gravidity count.

Maternal Details: Parity
The total number of previous pregnancies experienced by the woman that have resulted in a live birth or a stillbirth. For example, if she has had three pregnancies that resulted in one live birth and two miscarriages before 20 weeks, her parity would be 1.

Paternal Details: Family Name and Given Name
This information should be collected about the father of the child where available.

Family Name should be recorded in the format preferred by the person. Punctuation: If special characters form part of the family name they should be included, e.g. hyphenated names should be entered with a hyphen. Please see Maternal Details for examples.

Some people do not have a family name and a given name; they have only one name by which they are known. If the person has only one name, record it in the ‘Family Name’ field and leave the ‘Given Name’ field blank.

Given name(s) should be recorded in the format preferred by the person. Punctuation: If special characters form part of the given name they should be included, e.g. hyphenated names should be entered with a hyphen. Please see Maternal Details for examples.

If the person’s given name is not known, but the first letter (initial) of the given name is known, record the first letter in the preferred ‘Given name’ field. Do not record a full stop following the initial. Some people do not have a family name and a given name; they have only one name by which they are known. If the person has only one name, record it in the Family Name field and leave the Given Name blank.

Paternal Details: Date of Birth
If date of birth is not known or cannot be obtained, an estimated age in years should be used for adults. When date of birth is an estimated value use 0101 and the estimated year.

Paternal Details: Genetic Ethnic Heritage (Grandparents)
See explanation of Maternal Genetic Ethnic Heritage above.

Patient origin is answered from a choice of four drop down menus, one for each grandparent. Each drop down menu contains the following choices:

- African
- Native American (north or south)
- Asian (Indian subcontinent)
- Asian (Middle East)
- Asian (other)
- European
- Polynesian/Melanesian (including New Zealand Maori)
- Aboriginal or Torres Strait Islander
- Other

Selection of Other allows free text entry of details.
Clinical Background Page

When entering a new case on the Clinical Background Page, the Main Menu and Patient List are still hidden from view. The Patient Information is now visible because the patient exists on the database.

Figure 25 Clinical Background Screen with an example case.

The purpose of this page is to elucidate the context in which this case of NAIT was identified and to report on relevant clinical history.

Please note this page contains two save points. Each section must be saved separately for data to be retained on the system.

A summary of the Clinical Background data items and the validation that takes place is displayed on the next page.
## A D D I N G A N E W C A S E

### Clinical Background Page Data Entry Summary

<table>
<thead>
<tr>
<th>Data item</th>
<th>Data Entry Required</th>
<th>Type of Data Entry</th>
<th>Permitted Characters and Values</th>
<th>Unknown Values</th>
<th>Special Behaviour</th>
</tr>
</thead>
<tbody>
<tr>
<td>Case Description</td>
<td>Always</td>
<td>Free Text</td>
<td>Alphanumeric</td>
<td>Not applicable</td>
<td>N/A</td>
</tr>
<tr>
<td>Possible Alternative Cause of Clinical Presentation</td>
<td>Optional</td>
<td>Free Text</td>
<td>Alphanumeric</td>
<td>Not applicable</td>
<td>N/A</td>
</tr>
<tr>
<td>Stage at Which Case Identified</td>
<td>Always</td>
<td>Drop Down Menu</td>
<td>• Anticipated prior to pregnancy&lt;br&gt;• Not anticipated: Identified during pregnancy&lt;br&gt;• Not anticipated: Identified following delivery</td>
<td>Not applicable</td>
<td>If “Not anticipated: Identified following delivery” is selected</td>
</tr>
<tr>
<td>Reason for Case Identification</td>
<td>Always</td>
<td>Drop Down Menu</td>
<td>• Family History of NAIT&lt;br&gt;• Personal History of NAIT Affected Offspring&lt;br&gt;• Thrombocytopenia in Fetus or Newborn&lt;br&gt;• Bleeding in Fetus or Newborn&lt;br&gt;• Other fetal abnormality&lt;br&gt;• Other</td>
<td>Not applicable</td>
<td>If “Other Fetal Abnormality” is selected, a further field becomes available. Selection of “Other” allows free text entry of details</td>
</tr>
<tr>
<td>Other Fetal Abnormality Detail</td>
<td>If “Reason for Case Identification” = “Other fetal abnormality”</td>
<td>Drop Down Menu</td>
<td>• Hydrocephaly&lt;br&gt;• Proencephaly&lt;br&gt;• Ventriculomegaly&lt;br&gt;• Other</td>
<td>Not applicable</td>
<td>Selection of “Other” allows free text entry of details</td>
</tr>
</tbody>
</table>
## Adding a New Case

<table>
<thead>
<tr>
<th>Data item</th>
<th>Data Entry Required</th>
<th>Type of Data Entry</th>
<th>Permitted Characters and Values</th>
<th>Unknown Values</th>
<th>Special Behaviour</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any Previous NAIT Affected Offspring</td>
<td>Always</td>
<td>Drop Down Menu</td>
<td>• Yes</td>
<td>Unknown</td>
<td>If “Yes” is selected “Details of severity” field becomes available</td>
</tr>
<tr>
<td>Previous NAIT Affected Offspring: Details of Severity</td>
<td>If “Any Previous NAIT Affected Offspring” = “Yes”</td>
<td>Drop Down Menu</td>
<td>• Mildly affected</td>
<td>Not applicable</td>
<td>N/A</td>
</tr>
<tr>
<td>• Severely affected (live birth)</td>
<td></td>
<td></td>
<td>• Intrauterine fetal death</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comments On Any Previous Poor Pregnancy Outcomes</td>
<td>Optional</td>
<td>Free Text</td>
<td>Alphanumeric</td>
<td>Not applicable</td>
<td>N/A</td>
</tr>
<tr>
<td>Maternal Platelet Count at Diagnosis</td>
<td>Always (Clinician)</td>
<td>Text Box</td>
<td>Numeric (0-2000)</td>
<td>-1</td>
<td>N/A</td>
</tr>
<tr>
<td>Date of Maternal Platelet Count</td>
<td>Always (Clinician)</td>
<td>Text Box, DD/MM/YYYY</td>
<td>Date (Range since 01/01/1901)</td>
<td>09/09/9999</td>
<td>N/A</td>
</tr>
<tr>
<td>Maternal ABO Group</td>
<td>Always (Clinician)</td>
<td>Drop Down Menu</td>
<td>• A</td>
<td>Unknown</td>
<td>N/A</td>
</tr>
<tr>
<td>• B</td>
<td></td>
<td></td>
<td>• O</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• AB</td>
<td></td>
<td></td>
<td>• Unknown</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Case Description**

A description of the case is required. This should be comprehensive but it should be noted that the commentary entered here may later be visible to other health professionals caring for this patient. This field should include a description of the initial reason for looking into the case, any procedures or tests undertaken, and the course of treatment. Please also include specific information on why the treatment course taken was considered appropriate and when in the course of pregnancy this treatment was given. We are interested to gain some sort of understanding as to why certain treatments are given to treat NAIT, when during pregnancy, and the factors that may influence these treatment decisions.

For example, it is not sufficient to give the case description as “Pregnancy x 2”, instead here are some useful examples of a case description...

"First pregnancy was complicated by NAIT – sibling was born with severe thrombocytopenia diagnosed after delivery when they were found to have petechiae but no intracranial haemorrhage or other bleeding complication. This is the second pregnancy (G2P2). Mother was treated with IVIg 2g/kg/week from 14 weeks as this was considered a high risk pregnancy. FBS was performed at 22/40 and again prior to delivery. No IUT required, IVIg was continued throughout the pregnancy. Baby born by caesarean section at 36 weeks."

"First pregnancy (G1P1) with no known complications prior to delivery. Emergency caesarean section performed for fetal distress. Baby was small for gestation (2.4kg). Baby was noted to have petechiae and facial bruising. First FBE was done at 24 hours – baby was found to be thrombocytopenic (platelet count 13). No evidence of an intrauterine infection or congenital disorder. Other FBE indices (Hb, WCC) were normal. No evidence of intracranial haemorrhage on ultrasound. Mother had a normal platelet count and no history of autoimmune disease. Baby was treated with 2 platelet transfusions and a single dose of IVIg (because of the degree of thrombocytopenia) and did not have any haemorrhagic complications."

**Possible Alternative Cause of Clinical Presentation**

This field is optional. If there is a possible cause for the clinical presentation other than NAIT identified, then this should be entered here. For some patients it will be Not applicable as there will be no alternative cause of clinical presentation other than NAIT.

For example, if the clinical presentation was neonatal thrombocytopenia diagnosed after delivery and another cause of thrombocytopenia was identified, such as sepsis, then this should be entered in this field. If there was no other cause for the thrombocytopenia identified, then an entry in this field is not required.
Adding a New Case

Stage at Which Case was Identified

This is to document when during the course of the pregnancy or post-natal period NAIT was first suspected or diagnosed. The following options are available from the drop down menu:

Anticipated Prior to Pregnancy

It was identified prior to pregnancy that the baby was at risk of NAIT. This may be because of personal history (prior offspring affected by NAIT) or family history.

Not Anticipated: Identified During Pregnancy

There was no relevant past history to indicate the pregnancy was at risk of NAIT. NAIT was suspected or diagnosed during the pregnancy (for example if the fetus developed a complication due to thrombocytopenia such as an intracranial haemorrhage).

Not Anticipated: Identified Following Delivery

There was no relevant past history to indicate the pregnancy was at risk of NAIT. NAIT was suspected or diagnosed following delivery (for example, bruising or petechiae observed on baby after delivery).

If NAIT was Not Anticipated: Identified following delivery then later antenatal screens (refer page 41) are not available for data entry.

Reason for Case Identification

This is to report why or how the case was identified; only one option can be selected. The following options are available from the drop down menu:

Family History of NAIT

This option should be chosen if anyone in the patient’s (or their partner’s) immediate family (children, parents, siblings or grandparents) has ever been diagnosed with NAIT or produced NAIT affected offspring.

Personal History of NAIT Affected Offspring

This mother has given birth or miscarried offspring affected by NAIT.

Thrombocytopenia in Fetus or Newborn

This option should be selected if NAIT was identified after thrombocytopenia was detected in the fetus or newborn. Thrombocytopenia refers to a low platelet count and is diagnosed by laboratory tests. The most common symptoms of thrombocytopenia include bruising, petechiae (small red spots on the skin) and signs of bleeding in sites. This option should only be chosen if thrombocytopenia is confirmed by laboratory tests but other adverse consequences (such as bleeding) are not present.

Bleeding in Fetus or Newborn

This option should be selected if NAIT was identified as a result of bleeding either in the fetus or neonate. For example, if NAIT was diagnosed following the finding of thrombocytopenia and intracranial haemorrhage in a newborn.

Other Fetal Abnormality

Selection of this option will allow a further field to be accessed for details of the abnormalities.

Other

Selection of this option will allow a further field to be accessed for other details.
A D D I N G  A  N E W  C A S E
Other Fetal Abnormality

The following options are available from the drop down menu:

HYDROCEPHALY

Also known as hydrocephalus, this is an abnormal buildup of cerebrospinal fluid (CSF) in the ventricles of the brain.

PROSENECEPHALY

A very rare condition involving abnormal development of the forebrain.

VENTRICULOMEGALY

This is a brain condition that occurs when the lateral ventricles become dilated. The most common definition uses a width of the atrium of the lateral ventricle of greater than 10 mm.

OTHER

If none of the options above adequately describes the reasons for the case identification then this option should be selected. Selection of this option will allow a free field for data entry to explain the case identification.

Any Previous NAIT Affected Offspring

NAIT affected offspring include all pregnancies, whether resulting in live births or not, in which NAIT has been suspected or confirmed. Selection of Yes will allow details to be entered in the following fields. From the drop down menu the following options are available:

- Yes
- No
- Unknown

Previous NAIT Affected Offspring: Details of Severity

This field becomes available if Yes is selected in the Any Previous NAIT affected offspring field. If multiple offspring have been affected please choose the most severe relevant option and include details of all affected offspring in the following field Comments on Any Previous Poor Pregnancy Outcomes.

This field will bring up the following options from a drop down menu:

MILDLY AFFECTED

Includes neonates that have isolated mild or moderate thrombocytopenia with no haemorrhagic complications and no long-term morbidity.

SEVERELY AFFECTED (LIVE BIRTH)

Includes neonates with severe thrombocytopenia and / or major haemorrhagic complication due to NAIT (e.g. intracranial haemorrhage).

INTRAUTERINE FETAL DEATH

Fetal death in utero. This includes miscarriages and still births.
ADD A NEW CASE

Comments on Any Previous Poor Pregnancy Outcomes

This field is optional and will only apply to some cases. If the patient has had a previous poor pregnancy outcome then a comprehensive description of the case is required. Please refer to Case Description section on the previous page for examples of appropriate level of detail for case descriptions. If multiple offspring have been affected, please include details of all pregnancies and outcomes.

Maternal Platelet Count at Diagnosis

Maternal Platelet Count must be entered by the diagnosing clinician in the units x10^9.

Date of Maternal Platelet Count (DD/MM/YYYY)

This is the date the maternal platelet count was obtained. This date should not be earlier than the Date of Diagnosis.

Maternal ABO Group

Maternal ABO blood group is to be filled out by the treating clinician. The following options are available from the drop down menu:

- A
- B
- O
- AB
- Unknown
Parental Testing Page

When entering a new case on the Parental testing Page, the Main Menu and Patient List are still hidden from view. The Patient Label is able to be viewed as the patient exists on the database.

For every State except Western Australia (WA), details for this page will be entered onto the NAIT database directly by the Australian Red Cross Blood Service (ARCBS). When a new case is registered, the ARCBS laboratory will automatically be requested to enter the test results directly onto the Database. In Western Australia, testing for NAIT is undertaken by the Royal Perth Hospital laboratory. When a new case from WA is registered, the Royal Perth Hospital laboratory will be automatically requested to enter test results directly onto the Database.

Figure 26 Parental Testing Page in New Case Mode.

A summary of the Parental Testing data items and the validation that takes place is displayed on the next page, with more specialised behaviours referenced in the last column.
# Parental Testing Page Data Entry Summary

<table>
<thead>
<tr>
<th>Data item</th>
<th>Data Entry Required</th>
<th>Type of Data Entry</th>
<th>Permitted Characters and Values</th>
<th>Unknown Values</th>
<th>Special Behaviour</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maternal HPA Type</td>
<td>Always</td>
<td>Multiple Drop Down Menus (Row): HPA 1-15 (arrange in row)</td>
<td>(for each type)</td>
<td></td>
<td>Default “Not Tested”</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• AA</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• AB</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• BB</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Not Tested</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Paternal HPA Type</td>
<td>Always</td>
<td>Multiple Drop Down Menus (Row): HPA 1-15 (arrange in row)</td>
<td>(for each type)</td>
<td></td>
<td>Default “Not Tested”</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• AA</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• AB</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• BB</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Not Tested</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fetal/Neonatal HPA Type</td>
<td>Always</td>
<td>Multiple Drop Down Menus (Row) HPA 1-15 (arrange in row)</td>
<td>(for each type)</td>
<td></td>
<td>Default “Not Tested”</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• AA</td>
<td></td>
<td></td>
</tr>
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<td>• AB</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>• BB</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Not Tested</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HPA Crossmatch: Maternal/Random Donor</td>
<td>Always</td>
<td>Drop Down Menu</td>
<td>• Positive</td>
<td></td>
<td>Default “Not Tested”</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Negative</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Not tested</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date if “HPA Crossmatch: Maternal/Random Donor” = “Positive” or “Negative”</td>
<td>Always</td>
<td>Text Box, DD/MM/YYYY</td>
<td>Date (Range since 01/01/1901)</td>
<td>09/09/9999</td>
<td>N/A</td>
</tr>
<tr>
<td>HPA Antibody Specificity</td>
<td>Optional</td>
<td>Text Box</td>
<td>Alphanumeric</td>
<td></td>
<td>N/A</td>
</tr>
<tr>
<td>HPA Crossmatch: Maternal/Paternal</td>
<td>Always</td>
<td>Drop Down Menu</td>
<td>• Positive</td>
<td></td>
<td>Default “Not Tested”</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Negative</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Not tested</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Data item</td>
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<td>Type of Data Entry</td>
<td>Permitted Characters and Values</td>
<td>Unknown Values</td>
<td>Special Behaviour</td>
</tr>
<tr>
<td>-----------</td>
<td>---------------------</td>
<td>--------------------</td>
<td>---------------------------------</td>
<td>---------------</td>
<td>------------------</td>
</tr>
<tr>
<td>Date if “HPA Crossmatch: Maternal/Paternal” = “Positive” or “Negative”</td>
<td>Always</td>
<td>Text Box, DD/MM/YYYY</td>
<td>Date (Range since 01/01/1901)</td>
<td>09/09/9999</td>
<td>N/A</td>
</tr>
<tr>
<td>HPA Antibody Specificity</td>
<td>Optional</td>
<td>Text Box</td>
<td>Alphanumeric</td>
<td>Not applicable</td>
<td>N/A</td>
</tr>
<tr>
<td>HPA Crossmatch: Maternal/ Fetal-Neonatal</td>
<td>Always</td>
<td>Drop Down Menu</td>
<td>• Positive • Negative • Not tested</td>
<td>Not applicable</td>
<td>Default “Not Tested”</td>
</tr>
<tr>
<td>Date if “HPA Crossmatch: Maternal/ Fetal-Neonatal” = “Positive” or “Negative”</td>
<td>Always</td>
<td>Text Box, DD/MM/YYYY</td>
<td>Date (Range since 01/01/1901)</td>
<td>09/09/9999</td>
<td>N/A</td>
</tr>
<tr>
<td>HPA Antibody Specificity</td>
<td>Optional</td>
<td>Text Box</td>
<td>Alphanumeric</td>
<td>Not applicable</td>
<td>N/A</td>
</tr>
<tr>
<td>HPA Method</td>
<td>Optional</td>
<td>Text Box</td>
<td>Alphanumeric</td>
<td>Not applicable</td>
<td>N/A</td>
</tr>
<tr>
<td>HPA Antibody Titre</td>
<td>Optional</td>
<td>Multiple check and text boxes</td>
<td>Numeric (1-2048)</td>
<td>-1</td>
<td>If “check box” selected text must be entered and date field becomes available</td>
</tr>
<tr>
<td>HPA Antibody Titre Date Required if “HPA Antibody Titre” check boxes are selected</td>
<td>Always</td>
<td>Text Box, DD/MM/YYYY</td>
<td>Date (Range since 01/01/1901)</td>
<td>09/09/9999</td>
<td>N/A</td>
</tr>
<tr>
<td>Data item</td>
<td>Data Entry Required</td>
<td>Type of Data Entry</td>
<td>Permitted Characters and Values</td>
<td>Unknown Values</td>
<td>Special Behaviour</td>
</tr>
<tr>
<td>-----------------------</td>
<td>---------------------</td>
<td>-------------------------------------------------------------------------------------</td>
<td>--------------------------------</td>
<td>----------------</td>
<td>-------------------------------------------------------</td>
</tr>
<tr>
<td>Maternal HLA Typing</td>
<td>Always</td>
<td>Five text boxes: HLA-A, HLA-B, HLA-Cw, HLA-DRB1, HLA-DRB3/4/5 (Arrange in row)</td>
<td>Numeric (1-9999)</td>
<td>-1</td>
<td>N/A</td>
</tr>
<tr>
<td>Paternal HLA Type</td>
<td>Always</td>
<td>Five text boxes: HLA-A, HLA-B, HLA-Cw, HLA-DRB1, HLA-DRB3/4/5 (Arrange in row)</td>
<td>Numeric (1-9999)</td>
<td>-1</td>
<td>N/A</td>
</tr>
<tr>
<td>HLA Method</td>
<td>Always</td>
<td>Text Box</td>
<td>Alphanumeric</td>
<td>Not applicable</td>
<td>N/A</td>
</tr>
<tr>
<td>HLA Antibody Specificity</td>
<td>Optional</td>
<td>Text Box</td>
<td>Alphanumeric</td>
<td>Not applicable</td>
<td>N/A</td>
</tr>
<tr>
<td>HLA Antibody Titre</td>
<td>Optional</td>
<td>Multiple check and text boxes</td>
<td>Numeric (1-2048)</td>
<td>-1</td>
<td>If check box selected text must be entered and date field becomes available</td>
</tr>
<tr>
<td>HPA Antibody Titre Date Required if “HPA Antibody Titre” check boxes are selected</td>
<td>Always</td>
<td>Text Box, DD/MM/YYYY Date (Range since 01/01/1901)</td>
<td>09/09/9999</td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>Interpretive Testing Comments</td>
<td>Optional</td>
<td>Free Text</td>
<td>Alphanumerical</td>
<td>Not Applicable</td>
<td>N/A</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>----------</td>
<td>-----------</td>
<td>----------------</td>
<td>----------------</td>
<td>-----</td>
</tr>
<tr>
<td>Testing Site (HPA and HLA typing and antibody detection)</td>
<td>Always</td>
<td>Drop Down Menu</td>
<td>• ARCBS-New South Wales  • ARCBS-Queensland  • VTIS-Victoria  • Royal Perth Hospital  • Other  • Not Applicable</td>
<td>Not Applicable</td>
<td>Selection of “Other” allows free text entry of details</td>
</tr>
</tbody>
</table>
ADDING A NEW CASE

The following data items will automatically be filled out by ARCBS for all States except WA.

MATERNAL HPA TYPE

Human Platelet Antigens (HPA) are expressed on platelets. They are inherited as paired alleles – i.e. one from each parent. They are classified numerically (1 to 15) according to the date of discovery and in alphabetical pairs according to the allele frequency (‘a’ for high frequency, ‘b’ for low frequency). The maternal HPA type is the mothers’ allele type for HPA antigens 1 – 15 (for example, for HPA 1 the allele type options include aa, ab or bb). HPA typing is only performed at reference laboratories (including the Australian Red Cross Blood Service).

PATERNAL HPA TYPE

As per maternal HPA type.

FETAL/NEONATAL HPA TYPE

As per maternal HPA type.

HPA CROSSMATCH: MATERNAL/RANDOM DONOR

This is the result of testing performed at a reference laboratory. This test involves the use of maternal serum with random donor platelets to determine compatibility.

HPA CROSSMATCH: MATERNAL/PATERNAL

This is the result of testing performed at a reference laboratory. This test involves the use of maternal serum with paternal platelets to determine compatibility.

HPA CROSSMATCH: MATERNAL/FETAL-NEONATAL

This is the result of testing performed at a reference laboratory. This test involves the use of maternal serum with fetal/neonatal platelets to determine compatibility.

HPA ANTIBODY SPECIFICITY

If a HPA antibody was detected, the specificity of this antibody should be entered in this field. For example, if the antibody is specific for HPA 1a.

HPA METHOD

This refers to the method of testing used to determine the maternal and paternal HPA type.

HPA ANTIBODY TITRE

This is the result of the HPA antibody titre (a measure of the concentration of antibody present).

MATERNAL HLA TYPING

This is the result of testing for maternal Human Leukocyte Antigen (HLA) typing. HLA antigens include class I and class II antigens. Results of typing for HLA antigens –A, -B, -C and –DRB are to be entered in this field. HLA typing is only performed at reference laboratories.

PATERNAL HLA TYPING

This is the result of paternal Human Leukocyte Antigen (HLA) typing. Results of typing for HLA antigens -A, -B, -C and –DRB are to be entered in this field.

HLA METHOD

This refers to the method used to determine the maternal and paternal HLA typing.

HLA ANTIBODY SPECIFICITY
**ADDITION A NEW CASE**

If a HLA antibody was detected, the specificity of this antibody should be entered in this field.

**HLA ANTIBODY TITRE**

This is the result of the HLA antibody titre (a measure of the concentration of antibody present).

**INTERPRETIVE TESTING COMMENTS**

This refers to comments on the testing results provided by the reference laboratory.

**TESTING SITE (HPA AND HLA TYING AND ANTIBODY DETECTION)**

This is the reference laboratory which performed the HPA and HLA typing and antibody detection testing.
ADDING A NEW CASE

Antenatal Clinical Details Page

When entering a new case on the Antenatal Clinical Details Page, the Main Menu and Patient List are still hidden from view. The Patient Information is now visible because the patient now exists in the database.

Figure 27 Antenatal Clinical details Page with an example case.

This page is not available if it has been indicated that the case was identified post-natally.

A summary of the Antenatal Clinical Details data items and the validation that takes place is displayed on the next page.
## Adding a New Case

### Antenatal Clinical Details Page Data Entry Summary

<table>
<thead>
<tr>
<th>Data item</th>
<th>Data Entry Required</th>
<th>Type of Data Entry</th>
<th>Permitted Characters and Values</th>
<th>Unknown Values</th>
<th>Special Behaviour</th>
</tr>
</thead>
<tbody>
<tr>
<td>Estimated Date of Delivery</td>
<td>Always</td>
<td>Text Box, DD/MM/YYYY</td>
<td>Date (Range since 01/01/2001)</td>
<td>09/09/9999</td>
<td>When “estimated date of delivery” is saved it cannot be changed by the user. Please contact NAIT Registry staff to make changes.</td>
</tr>
<tr>
<td>Site of Antenatal Management</td>
<td>Always</td>
<td>Free text</td>
<td>Alphanumeric</td>
<td>Not applicable</td>
<td>N/A</td>
</tr>
<tr>
<td>Gestation at which Case Identified</td>
<td>Always</td>
<td>Text Box</td>
<td>Numeric (0-50)</td>
<td>-1</td>
<td>N/A</td>
</tr>
<tr>
<td>Cranial Imaging Performed?</td>
<td>Always</td>
<td>Drop down menu</td>
<td>• Ultrasound</td>
<td>Unknown</td>
<td>If “Ultrasound” or “Magnetic Resonance Imaging” or “MRI with CI and Ultrasound” are selected, the field “Cranial Imaging Findings” field becomes available</td>
</tr>
<tr>
<td>Cranial Imaging Findings</td>
<td>Required if “Cranial Imaging Performed” = “Ultrasound” or “Magnetic Resonance Imaging” or “MRI with CI and Ultrasound”</td>
<td>Free Text</td>
<td>Alphanumeric</td>
<td>Not applicable</td>
<td>N/A</td>
</tr>
</tbody>
</table>
## Adding a New Case

<table>
<thead>
<tr>
<th>Data Item</th>
<th>Data Entry Required</th>
<th>Type of Data Entry</th>
<th>Permitted Characters and Values</th>
<th>Unknown Values</th>
<th>Special Behaviour</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complications During Pregnancy</td>
<td>Always</td>
<td>Check box (one or many)</td>
<td>• None&lt;br&gt;• Intracranial haemorrhage&lt;br&gt;• Other bleeding&lt;br&gt;• Pre-eclampsia&lt;br&gt;• Fetal infection&lt;br&gt;• Placental abruption&lt;br&gt;• Other</td>
<td>Not applicable</td>
<td>Selection of “None” renders other options unavailable. If “Other Bleeding” is selected, the “Other Bleeding Site” field becomes available. If “Other” is selected the “Other: Please describe” field becomes available.</td>
</tr>
<tr>
<td>Other Bleeding Site</td>
<td>Required if “complications During Pregnancy” = “Other bleeding”</td>
<td>Free text</td>
<td>Alphanumeric</td>
<td>Not applicable</td>
<td>N/A</td>
</tr>
<tr>
<td>Outcome of Pregnancy</td>
<td>Always</td>
<td>Drop down menu</td>
<td>• Pregnancy Ongoing&lt;br&gt;• Fetal Death in Utero&lt;br&gt;• Live Birth&lt;br&gt;• Other&lt;br&gt;• Unknown</td>
<td>Unknown</td>
<td>If “Fetal Death in Utero” is selected, “Cause of Death” and related fields become available, Postnatal Clinical Details and Postnatal Therapy Screens become unavailable. If “Pregnancy Ongoing” is selected, Postnatal Clinical Details and Postnatal Therapy Screens are not available. If “Other” is selected “Other details” field becomes available.</td>
</tr>
<tr>
<td>Data item</td>
<td>Data Entry Required</td>
<td>Type of Data Entry</td>
<td>Permitted Characters and Values</td>
<td>Unknown Values</td>
<td>Special Behaviour</td>
</tr>
<tr>
<td>-----------------------------------</td>
<td>----------------------------------------------------------</td>
<td>--------------------</td>
<td>-----------------------------------------------------------------------------------------------</td>
<td>----------------</td>
<td>-------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Cause of Death</td>
<td>Required if “Outcome of Pregnancy” = “Fetal Death in Utero”</td>
<td>Drop down menu</td>
<td>• Intracranial Haemorrhage • Other Haemorrhagic • Other • Unknown</td>
<td>Not applicable</td>
<td>If “Other Haemorrhagic” is selected “Other Haemorrhage site” field becomes available.</td>
</tr>
<tr>
<td>Other haemorrhage site</td>
<td>Required if “Cause of Death” = “Other”</td>
<td>Free text</td>
<td>Alphanumeric</td>
<td>Unknown</td>
<td>N/A</td>
</tr>
<tr>
<td>Is Post-mortem to be performed?</td>
<td>If “Outcome of Pregnancy” = “Fetal Death in Utero”</td>
<td>Drop down menu</td>
<td>• Yes • No • Unknown</td>
<td>Unknown</td>
<td>If “Yes” is selected in the “Post-Mortem to be performed?” field “Comments on Findings at Post-Mortem” becomes available</td>
</tr>
<tr>
<td>Comments on Findings at Post-Mortem</td>
<td>Optional If “Is Post Mortem to Be Performed?” = Yes</td>
<td>Free text</td>
<td>Alphanumeric</td>
<td>Not applicable</td>
<td>N/A</td>
</tr>
</tbody>
</table>
**Estimated date of delivery**
This is the estimated date the mother will give birth if she is still pregnant with the child. This field cannot be altered by the user once it is saved. If changes are required please contact NAIT Registry staff.

**Site of antenatal management**
Some NAIT pregnancies will be managed at sites other than those where definitive management of the birth or neonate takes place, particularly in situations where the patient resides in a different location. This is a free text box for entry of location of antenatal management.

**Gestation at which case is identified**
The number of gestation weeks for this pregnancy, at which time the diagnosis of NAIT is made. This date should correspond to the date of diagnosis.

**Cranial imaging performed?**
Cranial Imaging of the fetus in utero may be used to assess whether intracranial haemorrhage has occurred. A drop down menu will include the following options:

**ULTRASOUND**
Ultrasound is a medical imaging technique that uses cyclic sound pressure with a frequency greater than the upper limit of human hearing.

**MAGNETIC RESONANCE IMAGING**
Magnetic Resonance Imaging (MRI), or nuclear magnetic resonance imaging (NMRI), is primarily a medical imaging technique most commonly used in radiology to visualize the internal structure and function of the body.

**NOT PERFORMED**
Select this option if no Cranial Imaging was performed.

**UNKNOWN**
Select this option if Cranial Imaging was performed is unknown.

**Cranial imaging findings**
This field will become available if either Ultrasound or Magnetic Resonance Imaging are selected above. A summary of the findings of these investigations should be included.

**Complications during pregnancy**
Complications arising up to the period immediately preceding delivery should be included. The complications may have significantly affected either care of the patient or fetus during the current pregnancy and/or pregnancy outcome.

One or more boxes must be checked in this field.
The following options are available:

NONE

If this option is selected, all other choices are rendered unavailable.

INTRACRANIAL HAEMORRHAGE

An intracranial haemorrhage is a haemorrhage, or bleeding, within the skull. Select this option if a diagnosis of intracranial haemorrhage in the fetus has been made including fetal death in utero from this cause.

OTHER BLEEDING

This option should be chosen if bleeding other than intracranial haemorrhage has been identified in the fetus including fetal death in utero from this cause. Selection of this option makes available the Other Bleeding Site field.

PRE-ECLAMPSIA

Pre-eclampsia (sometimes also referred to as Toxemia) is a complex disorder characterized by hypertension (elevated blood pressure) and proteinuria (urine in the protein) developing after 20 weeks gestation. Pre-eclampsia is present in about 5-10% of all pregnant women and approximately 10-15% of these develop thrombocytopenia. Pre-eclampsia is also implicated in the destruction of fetal platelets and may result in fetal thrombocytopenia.

FETAL INFECTION

This includes infections acquired in utero or during the birth process. These include the TORCH infections (toxoplasmosis, rubella, cytomegalovirus and herpes simplex virus) and other infections including both viral and bacterial (e.g. group B streptococcus). Fetal infection may result in both decreased production and increased destruction of fetal platelets causing thrombocytopenia.

PLACENTAL ABRUPTION

Placental abruption is a complication of pregnancy, wherein the placental lining separates either partially or completely from the uterus of the mother. It is the most common cause of late pregnancy bleeding. Placental abruption may be associated with maternal coagulopathy including thrombocytopenia and disseminated intravascular coagulopathy (DIC).

OTHER

Selection of this option makes available the Pregnancy Complications Other Details field.

Outcome of Pregnancy

This field records the outcome of the current pregnancy. A drop down menu will include the following options:

PREGNANCY ONGOING

When data entry for a case commences, the pregnancy may still be ongoing and this option should be selected. This field should be revised later to indicate final outcome. If the Pregnancy Ongoing field is selected then Postnatal Clinical Details and Postnatal Therapy Screens will not be made available.

FETAL DEATH IN UTERO

Fetal death in utero is defined as the death of a fetus at any time after the 20th week of pregnancy and/or weight of 500g or more. If Fetal Death in Utero box is selected then Cause of Death fields will become available. The Postnatal Clinical Details and Postnatal Therapy Screens will not be available.
LIVE BIRTH

A live birth occurs when a fetus, whatever its gestational age, exits the maternal body and subsequently shows any sign of life, such as voluntary movement, heartbeat, or pulsation of the umbilical cord, for however brief a time and regardless of whether the umbilical cord or placenta are intact.

OTHER

Selection of Other will produce a free text box for data entry.

UNKNOWN

Select this option if outcome of pregnancy is unknown.

Cause of Death

If Fetal Death in Utero is checked then Cause of Death and Is post-mortem to be performed? fields become available. A drop down menu will produce the following options:

INTRACRANIAL HAEMORRHAGE

Intracranial haemorrhage is haemorrhage or bleeding within the skull.

OTHER HAEMORRHAGIC

Selection of this option makes available the Other Haemorrhage site field for data entry.

OTHER

Selection of this option will produce a free text box for data entry.

UNKNOWN

Select this option if cause of fetal death in utero is unknown.

Is Post-mortem to be performed?

This field will only be available if the Fetal death in Utero is selected in Outcome of Pregnancy box. A drop down menu will provide the following options:

- Yes
- No
- Unknown

Comments on Findings at Post-Mortem

This field will become available if Yes is selected in the Post-Mortem to be Performed field. It allows free text entry of post-mortem details. When initial data entry is completed, findings from the post mortem may not yet be available, if so, leave this field blank. A red flag ### Post-mortem findings needs to be completed ### is shown. Once post-mortem findings are available, they should be entered. NAIT registry staff will receive an automatic notification if this field remains blank for three months and will follow up with users to remind them to complete this field.
Adding a new case

Antenatal Testing and Therapy Page

When entering a new case on the Antenatal Testing and Therapy Page, the Main Menu and Patient List are still hidden from view. The Patient Information is now visible because the patient exists on the database.

This page enables entry of multiple events of antenatal test or treatments.

Figure 28: Antenatal testing and therapy page with an example case.
**ADDING A NEW CASE**

When accessed for the first time, no therapy will have been entered under the heading Antenatal Testing and Therapy. The following will appear; “there is no therapy, record for the patient selected”. Details of testing or treatment procedures should be entered and saved. A summary of the details will then appear as shown in the figure above. Each new procedure is assigned a reference number which is shown on the left of the date the procedure was performed. Procedures may be deleted by clicking the red cross to the left of the procedure reference number, or edited by clicking on the reference number. The button **Add New Procedures** should be selected to add a subsequent procedure. Other therapies can also be included on this page.

Please note this page contains two save points. Each section must be saved separately for data to be retained on the system. A summary of the Antenatal Testing and Therapy data items and the validation that takes place is displayed on the next page.
## Antenatal Testing and Therapy Page Data Entry Summary

<table>
<thead>
<tr>
<th>Data item</th>
<th>Data Entry Required</th>
<th>Type of Entry</th>
<th>Permitted Characters and Values</th>
<th>Unknown Values</th>
<th>Special Behaviour</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of Procedure</td>
<td>Always</td>
<td>Text Box, DD/MM/YYYY</td>
<td>Date (Range since 01/01/2001)</td>
<td>09/09/9999</td>
<td>N/A</td>
</tr>
<tr>
<td>Procedure</td>
<td>Always</td>
<td>Drop Down Menu</td>
<td>• Fetal blood sampling only</td>
<td>Not applicable</td>
<td>If “Fetal blood sampling only” is selected “fetal blood sampling” field becomes available. If “Platelet transfusion” is selected “fetal platelet count post transfusion” and “Platelet type” fields become available</td>
</tr>
<tr>
<td>Fetal platelet count at fetal blood sampling</td>
<td>If “Procedure” = “Fetal blood sampling only”</td>
<td>Text Box</td>
<td>Numeric (0-1000)</td>
<td>-1</td>
<td>N/A</td>
</tr>
<tr>
<td>Fetal platelet count post transfusion</td>
<td>If “Procedure” = “Platelet transfusion”</td>
<td>Text Box</td>
<td>Numeric (0-1000)</td>
<td>-1</td>
<td>N/A</td>
</tr>
<tr>
<td>Platelet Type</td>
<td>If “Procedure” = “Platelet transfusion”</td>
<td>Drop Down Menu</td>
<td>• HPA Matched</td>
<td>Unknown</td>
<td>N/A</td>
</tr>
<tr>
<td>Complications of procedure</td>
<td>Always</td>
<td>Drop Down Menu</td>
<td>• None</td>
<td>Not applicable</td>
<td>If “Other” is selected the “Other details” field becomes available</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Umbilical Haemorrhage</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Bradycardia</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Cardiac Arrest</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Fetal Death</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Other</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Not applicable</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Data item</td>
<td>Data Entry Required</td>
<td>Type of Data Entry</td>
<td>Permitted Characters and Values</td>
<td>Unknown Values</td>
<td>Special Behaviour</td>
</tr>
<tr>
<td>-----------------------------------</td>
<td>---------------------</td>
<td>--------------------</td>
<td>--------------------------------</td>
<td>----------------</td>
<td>-------------------------------------------------------</td>
</tr>
<tr>
<td>Other therapies</td>
<td>Always</td>
<td>Drop down Menu</td>
<td>•Yes</td>
<td>Not Applicable</td>
<td>If selected related fields become available</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>•No</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>•Not Applicable</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intravenous Immunoglobulin</td>
<td>Optional if “Other Therapies?” = “Yes”</td>
<td>Check box</td>
<td>N/A</td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>Type of IVIg</td>
<td>If “Intravenous Immunoglobulin” is selected</td>
<td>Drop Down Menu</td>
<td>•Intragam®P</td>
<td>Chose “Other”</td>
<td>If “Other is selected “Other Details” field becomes available</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>•Octagam®</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>•Sandoglobulin®</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>•Other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date first dose</td>
<td>If “Intravenous Immunoglobulin” is selected</td>
<td>DD/MM/YYYY</td>
<td>Date (Range since 01/01/2001)</td>
<td>09/09/9999</td>
<td>N/A</td>
</tr>
<tr>
<td>Date last dose</td>
<td>If “Intravenous Immunoglobulin” is selected</td>
<td>DD/MM/YYYY</td>
<td>Date (Range since 01/01/2001)</td>
<td>09/09/9999</td>
<td>N/A</td>
</tr>
<tr>
<td>Dose (g)</td>
<td>If “Intravenous Immunoglobulin” is selected</td>
<td>Text Box</td>
<td>Numeric (0-2000)</td>
<td>-1</td>
<td>N/A</td>
</tr>
<tr>
<td>Data item</td>
<td>Data Entry Required</td>
<td>Type of Data Entry</td>
<td>Permitted Characters and Values</td>
<td>Unknown Values</td>
<td>Special Behaviour</td>
</tr>
<tr>
<td>--------------------------</td>
<td>-------------------------------------------------------------------------------------</td>
<td>--------------------</td>
<td>---------------------------------</td>
<td>----------------</td>
<td>-----------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Number of doses</td>
<td>If “Intravenous Immunoglobulin” is selected</td>
<td>Text Box</td>
<td>Numeric (0-100)</td>
<td>-1</td>
<td>N/A</td>
</tr>
<tr>
<td>Frequency</td>
<td>If “Intravenous Immunoglobulin” is selected</td>
<td>Drop Down Menu</td>
<td>• Twice Weekly</td>
<td>Not applicable</td>
<td>If “Other is selected “Other Details” field becomes available</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Weekly</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Alternate Weekly</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Monthly</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Corticosteroids</td>
<td>Optional if “Other Therapies?” = “Yes”</td>
<td>Check Box</td>
<td>N/A</td>
<td>Not applicable</td>
<td>If selected related fields become available</td>
</tr>
<tr>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Type</td>
<td>If “Corticosteroids” is selected</td>
<td>Drop Down Menu</td>
<td>• Prednisolone</td>
<td>Not applicable</td>
<td>If “Other” selected “Other details” field becomes available</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Hydrocortisone</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Dexamethasone</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date first dose</td>
<td>If “Corticosteroids” is selected</td>
<td>DD/MM/YYYY</td>
<td>Date (Range since 01/01/2001)</td>
<td>09/09/9999</td>
<td>N/A</td>
</tr>
<tr>
<td>Data item</td>
<td>Data Entry Required</td>
<td>Type of Data Entry</td>
<td>Permitted Characters and Values</td>
<td>Unknown Values</td>
<td>Special Behaviour</td>
</tr>
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<td>-----------------------</td>
<td>--------------------------------------------------</td>
<td>--------------------</td>
<td>-------------------------------------------------</td>
<td>------------------------</td>
<td>-------------------------------------------------------</td>
</tr>
<tr>
<td>Date last dose</td>
<td>If “Corticosteroids” is selected</td>
<td>DD/MM/YYYY</td>
<td>Date (Range since 01/01/2001)</td>
<td>09/09/9999</td>
<td>N/A</td>
</tr>
<tr>
<td>Dose (mg)</td>
<td>If “Corticosteroids” is selected</td>
<td>Text Box</td>
<td>Numeric (0-2000)</td>
<td>-1</td>
<td>N/A</td>
</tr>
<tr>
<td>Number of doses</td>
<td>If “Corticosteroids” is selected</td>
<td>Text Box</td>
<td>Numeric (0-100)</td>
<td>-1</td>
<td>N/A</td>
</tr>
<tr>
<td>Frequency</td>
<td>If “Corticosteroids” is selected</td>
<td>Drop Down Menu</td>
<td>•Daily</td>
<td>Not Applicable</td>
<td>If “Other” selected “Other details” field becomes available</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>•Alternate Daily</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>•Twice Weekly</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>•Weekly</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>•Other</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>•Not applicable</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Date of procedure**
This is the date of the specific antenatal procedure. Each procedure (i.e. antenatal test or therapy) should be entered separately.

**Procedure**
This refers to the antenatal procedure performed. Each antenatal procedure performed should be entered separately. From a drop down menu the following options are provided:

**FETAL BLOOD SAMPLING ONLY**
Fetal blood sampling, also known as percutaneous umbilical blood sampling (PUBS), is a procedure to remove a small amount of blood from the fetus during pregnancy. If Fetal blood sampling only is selected then Fetal platelet count under Fetal blood sampling field becomes available.

**PLATELET TRANSFUSION**
Platelet Transfusion here refers to the transfusion of platelets to the fetus while in Utero. If Platelet transfusion is selected then Platelet Type, and Fetal Platelet Count Post-Transfusion fields become available.

**AMNIOCENTESIS (FETAL GENOTYPING)**
Amniocentesis is a medical procedure, in which a small amount of amniotic fluid, which contains fetal tissues, is extracted from the amnion or amniotic sac surrounding a developing fetus. The fetal DNA is then examined for genetic abnormalities.

**Fetal platelet count at fetal blood sampling**
This field is required if Fetal blood sampling only is selected as the procedure. The fetal platelet count on the date that fetal blood sampling was undertaken should be reported. If a subsequent fetal blood sample is taken, it should be entered as a separate procedure.

**Fetal platelet count post transfusion**
This field is required if Platelet Transfusion is selected as the procedure. The fetal platelet count most closely following the platelet transfusion should be reported here. If subsequent platelet transfusions are given, they should be entered as separate procedures.

**Platelet type**
This field is required if Platelet Transfusion is selected as the procedure. From a drop down menu the following options are provided for platelet type:

**HPA MATCHED**
HPA matched or compatible platelets (usually collected by the Australian Red Cross Blood Service) are platelet concentrates collected from a donor who does not express the implicated platelet antigen. For example, for a case of NAIT due to maternal anti HPA 1a antibodies, matched platelets would be those from a donor who is HPA 1a negative. As the diagnosis of NAIT (and determination of the antibody specificity) may take some time, platelet concentrates that are negative for the platelet antigens most commonly implicated in NAIT cases (HPA 1a and HPA 5b) may be used. These should also be entered as HPA matched (even if the maternal platelet antigen type is not yet known).
A D D I N G  A  N E W  C A S E

NON-HPA MATCHED

This refers to platelet concentrates that have not been selected based on the HPA type of the donor. These include platelets collected by apheresis from a single donor and platelets pooled from multiple random donors (pooled platelet units).

MATERNAL

This refers to platelet concentrates that are collected from the mother (rather than from volunteer blood donors at ARCBS). These may be collected at the treating institution and require irradiation prior to transfusion.

UNKNOWN

This option can be selected if the type of platelet product (i.e. HPA matched, HPA unmatched or maternal) is not known.

Complications of Procedure

This refers to complications directly as a result of the antenatal procedure (antenatal test or therapy). From a drop down menu the following options are available:

NONE

Select this option if no complications are a direct result of antenatal procedures.

UMBILICAL HAEMORRHAGE

Bleeding from the umbilical cord due to the fetal blood sampling procedure or fetal platelet transfusion.

BRADYCARDIA

Fetal Bradycardia (slowed heartbeat, <100bmp) may occur in response to fetal blood sampling or transfusion.

CARDIAC ARREST

A cardiac arrest, also known as cardiopulmonary arrest or circulatory arrest, is the abrupt cessation of normal circulation of the blood due to failure of the heart to contract effectively during systole. In the context of fetal blood sampling or transfusion, cardiac arrest is an extreme form of fetal Bradycardia in which the fetal heart stops completely.

FETAL DEATH

This refers to fetal death as a result of the antenatal procedure.

OTHER

Other known complications of intrauterine procedures include intrauterine infection, premature rupture of membranes, emergency caesarean and others. Selection of this option will result in Other Details field becoming available.

Other Therapy

In some instances, as well as platelet transfusion, another therapy may also be prescribed. One or more of the following options can be selected and relevant details entered:
INTRAVENOUS IMMUNOGLOBULIN

Intravenous immunoglobulin (IVIg) is a blood product administered intravenously. It contains the pooled IgG immunoglobulin’s (antibodies) extracted from the plasma of over one thousand blood donors. The use of IVIg by the mother during pregnancy is thought to reduce the severity of fetal thrombocytopenia in some cases.

Once this option is selected, the following data fields become available:

TYPE OF IVIg

The majority of IVIg used in Australia is the domestically produced Intragam®P. To guarantee an adequate, safe and secure supply the National Blood Authority has established contracts for the supply of two imported IVIg products; Octagam® and Sandoglobulin®. The following options are available:

- Intragam®P
- Octagam®
- Sandoglobulin®
- Other

If the patient received a combination of products, please choose Other and specify products and quantities.

DATE OF FIRST DOSE

Date of first antenatal IVIg dose is entered in the format DD/MM/YYYY.

DATE OF LAST DOSE

Date of last antenatal IVIg dose is entered numerically in the format DD/MM/YYYY.

DOSE

Dose volume should be entered in grams for each dose.

NUMBER OF DOSES

Please record the total number of doses the patient received in the antenatal period. Postnatal therapy is recorded elsewhere.

FREQUENCY

Please select the frequency of doses from:

- Twice weekly
- Weekly
- Alternate weekly
- Monthly
- Other

Selection of Other makes available Other details free text field.

CORTICOSTEROIDS

Corticosteroids are a type of hormone and are either produced by the adrenal cortex or synthesized. Steroids may be used either on their own or in combination with intravenous immunoglobulin therapy. Once this option is selected the following data fields become available:
**ADD A NEW CASE**

**TYPE**

Commonly used corticosteroids are provided as the following options:

- Prednisolone
- Hydrocortisone
- Dexamethasone
- Other

Selection of **Other** makes available the **Other details** free text field.

**DATE OF FIRST DOSE**

Date of first antenatal corticosteroid dose is entered in the format DD/MM/YYYY.

**DATE OF LAST DOSE**

Date of last antenatal corticosteroid dose is entered in the format DD/MM/YYYY.

**DOSE**

Dose volume for each dose should be entered in mg.

**NUMBER OF DOSES**

Please record the total number of doses the patient received.

**FREQUENCY**

Will produce a drop down menu of the following options:

- Daily
- Alternate daily
- Twice weekly
- Weekly
- Other

Selection of **Other** makes available the **Other details** free text field.
Once the child has been born the **Postnatal Demographics** page should be completed.

![Postnatal Demographics Page with an example case.](image)

When accessed for the first time for a patient, this page will be completely blank and the only option available under the heading **Postnatal Demographics** at the drop down list **Select Postnatal** will be **Add new**. Once details have been entered and saved, summary details of the baby will appear in this list. For multiple pregnancies, **Add new** can be selected again and details of a second or subsequent child recorded. Please note this only applies to multiple infants from the same pregnancy. Separate pregnancies from the same mother should be recorded as separate NAIT cases.

A summary of the **Postnatal Demographics** page data items and the method of data entry are displayed on the next page.
## ADDING A NEW CASE

### Postnatal Demographics Page Data Entry Summary

<table>
<thead>
<tr>
<th>Data item</th>
<th>Data Entry Required</th>
<th>Type of Data Entry</th>
<th>Permitted Characters and Values</th>
<th>Unknown Values</th>
<th>Special Behaviour</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child Surname</td>
<td>Always</td>
<td>Free Text</td>
<td>Alphanumeric</td>
<td>Not applicable</td>
<td>N/A</td>
</tr>
<tr>
<td>Child Name</td>
<td>Always</td>
<td>Free Text</td>
<td>Alphanumeric</td>
<td>Not applicable</td>
<td>N/A</td>
</tr>
</tbody>
</table>
| Child Sex                  | Always              | Drop down menu     | • Male  
• Female  
• Unknown | Not applicable | N/A              |
| Child Birth Weight (g)     | Always              | Free Text          | • Numeric (500-5000)            | -1             | N/A              |
| Date of Delivery           | Always              | Text Box, DD/MM/YYYY | Date (Range since 01/01/1901) | Unknown values are not permitted for this field | N/A |
| Gestation at Delivery      | Always              | Free Text          | Numeric (20-50)                 | -1             | N/A              |
| Mode of Delivery           | Always              | Drop down menu     | • Spontaneous vaginal  
• Ventouse  
• Forceps  
• Caesarean (pre-labour)  
• Caesarean (after onset labour)  
• Unknown | Unknown | N/A |
| Timing of Delivery         | Always              | Drop down menu     | • Spontaneous  
• Induced  
• Emergent  
• Unknown | Unknown | N/A |
| Site of Antenatal Management | Always            | Free text          | Alphanumeric                   | Not applicable | N/A              |
| Transferred Patient        | Always              | Drop down menu     | • Yes  
• No  
• Not applicable | Not applicable | If "Yes" selected, "Transferred From" field becomes available |
| Transferred From           | Required if "Transferred Patient" = "Yes" | Free text          | Alphanumeric                   | Not applicable | N/A              |
**Adding A New Case**

**Child Family Name and Given Name**

If the newborn does not yet have a name, use the mother’s family name as the baby’s family name. The given name should be registered using the mother’s given name in conjunction with the prefix “Baby of”. For example, if the baby’s mother’s given name is Fiona, the baby’s name should be recorded as “Baby of Fiona”. If a name is subsequently given, this field should be changed. An unnamed baby from a multiple birth should use their mother’s given name plus a reference to the multiple births. For example “Twin 1 of Fiona” and “Twin 2 of Fiona”.

The following terms should be used for recording multiple births: Twin, Trip, Quad, Quin, Sext, and Sept.

**Child Sex**

From a drop down menu the following options are available:

- Male
- Female
- Unknown

Unknown should be used for babies for whom sex has not been determined for whatever reason.

**Child Birth Weight**

The first weight, in grams of the live-born or stillborn baby obtained after birth, or the weight of the neonate or infant on the date admitted if this is different from the date of birth and the former is not known.

**Date of Delivery**

Date on which the live-born or stillborn baby was born.

**Gestation at Delivery**

The estimated gestational age of the baby at the end of pregnancy in completed weeks, as determined by clinical assessment. The gestation at delivery may be determined using the date of the last menstrual period or based on an early fetal ultrasound. If accurate information on the date of the last menstrual period is not available and there was no early fetal ultrasound performed for this pregnancy, gestational age may be estimated by the clinician. For the purposes of calculation of gestational age from the date of the first day of the last normal menstrual period and the date of delivery, it should be kept in mind that the first day is day zero and not day one.

**Mode of Delivery**

From a drop down menu the following options are available:

**SPONTANEOUS VAGINAL**

Vaginal delivery with no assistance of instruments or surgical intervention.

**VENTOUSE**

Vacuum extraction device, or ventouse, may be used to assist the delivery of a baby when labour has not progressed adequately.

**FORCEPS**

Forceps are instruments designed to aid in the delivery of the fetus by applying traction to the fetal head. Many different types of forceps have been described and developed. Generally, forceps consist of 2 mirror image metal instruments that are manoeuvred to cradle the fetal head and are articulated, after which traction is applied to effect delivery. Where forceps are used to assist the extraction of the baby at caesarean section code as caesarean section.
A D D I N G  A  N E W  C A S E

CAESAREAN (PRE-LABOUR)

A caesarean delivery (also called a surgical birth) is a surgical procedure used to deliver an infant. It requires regional (or rarely general) anesthetic to prevent pain, and then a vertical or horizontal incision in the lower abdomen to expose the uterus (womb). Another incision is made in the uterus to allow removal of the baby and placenta.

Caesarean Section pre-labour may also be referred to as a planned or elective caesarean. There are a number of medical and obstetric indications for scheduling a caesarean delivery in advance, including the following examples: previous caesarean delivery, mechanical obstruction, unusually large infant, infection, multiple gestations, cervical cancer, infant has an increased risk of bleeding and placenta previa. In the setting of NAIT a caesarean delivery may be planned to avoid traumatic bleeding in a thrombocytopenic fetus.

CAESAREAN (AFTER ONSET LABOUR)

Some women who intend to deliver vaginally will eventually require caesarean delivery. Caesarean Section after the onset of labour may also be referred to as unplanned or emergency caesarean. Reasons for this include the following examples: labor is not progressing as planned, the baby’s heart rate is not normal, breech birth, placental abruption, other medical emergency.

UNKNOWN

Select this option if Mode of Delivery is unknown.

Timing of Delivery

This field records the manner in which labour started. Labour commences at the onset of regular uterine contractions that act to produce progressive cervical dilation, and is distinct from spurious labour or pre-labour rupture of membranes. From a drop down menu the following options are available:

SPONTANEOUS

Labor beginning and progressing without mechanical or pharmacologic stimulation.

INDUCED

That which has been brought on by mechanical or other extraneous means, usually by the intravenous infusion of oxytocin or prostaglandins. If prostaglandins were given to induce labour and there is no resulting labour until after 24 hours, then code the onset of labour as spontaneous.

EMERGENT

Early delivery performed because of maternal or fetal compromise or an immediate threat to the life of the mother or fetus. This option should only be chosen in association with caesarean section deliveries.

UNKNOWN

Select this option if Timing of Delivery is unknown.
Site of Antenatal Management

The hospital or healthcare service where the mother received antenatal care may be different from the hospital at which perinatal or postnatal care was delivered. The site of care should be specified even if it is the same as the peri or postnatal care.

A free text box is available to include these details.

Transferred Patient

From a drop down menu the following options are available: Yes or No. If Yes is selected then a free text box is made available to specify where the patient was transferred from.

If the patient has been transferred, details may be entered twice, or more detail may be available from the other hospital. These fields allow us to cross-check or to follow-up where appropriate to ensure sufficient detail of total care is included in the Registry.
Postnatal Clinical and Testing Details Page

Once the child has been born the **Postnatal clinical and testing details** page must be filled out.

Figure 30: Postnatal Clinical and Testing details page with an example case.

When opened for the first time, this page will show details under the heading **Postnatal Clinical and Testing**, of the last infant entered on the previous page. If more than one infant has been added from this pregnancy, separate postnatal clinical and testing details can be added from each child by selecting them, in turn, from the drop down menu.

A summary of the **Postnatal Clinical and Testing Details** page data items, and the method of data entry, are displayed on the next page.
## A D D I N G  A  N E W  C A S E

### Postnatal Clinical and Testing Details Page Data Entry Summary

<table>
<thead>
<tr>
<th>Data item</th>
<th>Data Entry Required</th>
<th>Type of Data Entry</th>
<th>Permitted Characters and Values</th>
<th>Unknown Values</th>
<th>Special Behaviour</th>
</tr>
</thead>
</table>
| Clinical Manifestations                         | Always              | Check Box (One or many)  | • Not applicable  
• Petechiae  
• Purpura  
• Pulmonary Haemorrhage  
• GI Haemorrhage  
• Intracranial Haemorrhage  
• Other | Not applicable     | Selection of “Not applicable” renders all other options unavailable  
Selection of “Other” makes available “Other details” field |
| Child’s First Platelet Count (x10^9)            | Always              | Text Box                 | Numeric (0-3000)                                 | -1             | N/A                                                                               |
| Child First Haemoglobin (g/L)                   | Always              | Text Box                 | Numeric (0-300)                                  | -1             | N/A                                                                               |
| Child’s First Total WCC (x10^6/L)               | Always              | Text Box                 | Numeric (0-100)                                  | -1             | N/A                                                                               |
| Child ABO Group                                 | Always              | Drop Down Menu           | • A  
• B  
• O  
• AB  
• Unknown | Unknown         | N/A                                                                               |
| Child Rhesus (D) Group                          | Always              | Drop Down Menu           | • Positive  
• Negative  
• Unknown | Unknown         | N/A                                                                               |
<p>| Date of First Blood Counts                      | Always              | Text Box, DD/MM/YYYY     | Date (Must be as least as recent as date of delivery) | 09/09/9999     | N/A                                                                               |
| Child’s Lowest Platelet Count (x10^6)           | Always              | Text Box                 | Numeric (0-3000)                                 | -1             | N/A                                                                               |</p>
<table>
<thead>
<tr>
<th>Data item</th>
<th>Data Entry Required</th>
<th>Type of Data Entry</th>
<th>Permitted Characters and Values</th>
<th>Unknown Values</th>
<th>Special Behaviour</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of Child’s Lowest Platelet Count</td>
<td>Always</td>
<td>Text Box, DD/MM/YYYY</td>
<td>Date (Must be as least as recent as date of delivery)</td>
<td>09/09/9999</td>
<td>N/A</td>
</tr>
</tbody>
</table>
| Cranial Imaging Performed?                    | Always              | Drop down menu      | • Computed Tomography  
• Ultrasound  
• Not Performed  
• Unknown                                              | Unknown        | If “computed Tomography” or “Ultrasound” are selected, “cranial Imaging Findings” becomes available |
| Cranial Imaging Findings                      | Required if “Cranial Imaging Performed?” = “Computed Tomography” or “Ultrasound” | Free Text          | Alphanumeric                                         | Not applicable | N/A                                                                               |
Clinical Manifestations

Frequently the thrombocytopenia in NAIT babies is mild and there may be none or few clinical symptoms. In cases with moderate to severe thrombocytopenia the infant may exhibit signs of bleeding such as petechiae or purpura. In up to 20% of NAIT affected infants there may be evidence of serious bleeding such as intracranial haemorrhage or pulmonary haemorrhage.

From a drop down menu the following options are available:

NOT APPLICABLE
This option should be selected if there are no clinical symptoms present.

PETECHIAE
A petechia is a small (1-2mm) red or purple spot on the body, caused by a minor haemorrhage (broken capillary blood vessels). Petechiae may be caused by physical trauma and are also seen in patients with thrombocytopenia.

PURPURA
Purpura is the appearance of red or purple discolorations on the skin that do not blanch on applying pressure. They are caused by bleeding underneath the skin. Purpura measure between 0.3 - 1 cm. They are an indication that greater bleeding has occurred and may be the result of spontaneous bleeding or mild birth trauma in an infant with thrombocytopenia.

PULMONARY HAEMORRHAGE
Pulmonary haemorrhage refers to bleeding from the lung.

GI HAEMORRHAGE
Gastrointestinal bleeding or gastrointestinal haemorrhage includes any haemorrhage (loss of blood) in the gastrointestinal tract, from the pharynx to the rectum.

INTRACRANIAL HAEMORRHAGE
An intracranial haemorrhage is a haemorrhage, or bleeding, within the skull. Neonates with NAIT are thought to be at greater risk of intracranial haemorrhage within the first 72 hours after birth.

OTHER
Section of Other makes available the Other Details free text field.

Child’s First Platelet Count
The first platelet count (x10^9) of the live-born infant obtained after the birth or the platelet count on admission, if the former is not known.

Child’s First Haemoglobin Count
The first haemoglobin level (g/L) of the live-born infant obtained after the birth or the haemoglobin level on admission, if the former is not known.

Child’s First Total WCC
The first total white cell count (WCC), (x10^6) of the live-born infant obtained after the birth or the total white cell count on admission, if the former is not known.
**Child ABO Blood Group**

The ABO blood group of the child. The ABO blood group system is the most important blood group system in blood transfusion. Blood types are inherited and represent contribution from both parents. Record here the child’s ABO group phenotype from the following options:

- A
- B
- AB
- O
- Unknown

**Child Rhesus (D) Group**

The rhesus system is the second most significant blood group system in human blood transfusion. The rhesus (D) antigen is the most immunogenic of the five main rhesus antigens. Record here the child’s Rhesus (D) group from the following options:

- Positive
- Negative
- Unknown

**Date of First Blood Counts**

The date refers to the platelet, haemoglobin and white cell counts above. If these tests were not all conducted on the same day please record the date of the platelet count. This date must be at least as recent as the child’s delivery date.

**Child’s Lowest Platelet Count**

The lowest recorded platelet count of the infant recorded during the hospital admission. In practice, this is likely to occur within the first 72-96 hours following birth and platelet count usually returns to normal ranges within two weeks.

**Date of Child’s Lowest Platelet Count**

This date refers to the platelet count above and must be at least as recent as the date of the child’s delivery date.

**Cranial Imaging Performed?**

Cranial Imaging is used to assess if intracranial haemorrhage has occurred. From a drop down menu the following options are available:

- **COMPUTED TOMOGRAPHY**
  
  Computed tomography (CT) is a medical imaging method.

- **ULTRASOUND**
  
  Ultrasound is a medical imaging method.

- **NOT PERFORMED**
  
  Select this option if Cranial Imaging is not performed.

- **UNKNOWN**
  
  Select this option if it is not known whether cranial imaging has been performed.
Cranial Imaging Findings

If **Computed Tomography** or **Ultrasound** are selected in the previous field then this free text field becomes available. Please provide a summary of the cranial image results.
Postnatal Therapy Page

Once the child has been born the Postnatal Therapy page must be filled out.

Figure 31: Postnatal Therapy page with an example case

When opened for the first time, this page will show details under the heading Postnatal Therapy, of the last infant entered on the previous page. If more than one infant has been added from this pregnancy, separate Postnatal Therapy details can be added from each child by selecting them in turn from the drop down menu.

Please note this page contains multiple save points. Each section must be saved separately for data to be retained on the system.

A summary of the Postnatal Therapy Page data items and the method of data entry are displayed on the next page.
## Adding a New Case

### Postnatal Therapy Page Data Entry Summary

<table>
<thead>
<tr>
<th>Data item</th>
<th>Data Entry Required</th>
<th>Type of Data Entry</th>
<th>Permitted Characters and Values</th>
<th>Unknown Values</th>
<th>Special Behaviour</th>
</tr>
</thead>
</table>
| Postnatal Therapy Details     | Always              | Check Boxes (One or many) | • Not applicable  
• Platelet Transfusion  
• Intravenous Immunoglobulin  
• Other                                                                  | Not Applicable | Selection of “Not applicable” renders remaining options unavailable. Selection of “Platelet Transfusion” or “Intravenous Immunoglobulin” makes available relevant fields for further details. Selection of “Other” makes available “Other Details” free text field. |
| Date of Transfusion           | Required if “Platelet Transfusion” is selected in “Postnatal Therapy Details” | Text Box DD/MM/YYYY    | Date must be equal to or later than date of birth                                                  | 09/09/9999     | Displayed in column, with ability to add column for additional transfusions.                                                                        |
| Platelet Type                 | Required if “Platelet Transfusion” is selected in “Postnatal Therapy Details” | Drop Down Menu          | • HPA Matched  
• Non-HPA Matched  
• Maternal  
• Unknown                                                                  | Unknown        |                                                                                                                                                   |
<p>| Child’s platelet count pre transfusion | Required if “Platelet Transfusion” is selected in “Postnatal Therapy Details” | Text Box               | Numeric (0-1000)                                                                                  | -1             |                                                                                                                                                   |</p>
<table>
<thead>
<tr>
<th>Data item</th>
<th>Data Entry Required</th>
<th>Type of Data Entry</th>
<th>Permitted Characters and Values</th>
<th>Unknown Values</th>
<th>Special Behaviour</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child’s platelet count post transfusion</td>
<td>Required if “Platelet Transfusion” is selected in “Postnatal Therapy Details”</td>
<td>Text Box</td>
<td>Numeric(0-1000)</td>
<td>-1</td>
<td></td>
</tr>
<tr>
<td>Type of IVIg</td>
<td>Required if “Intravenous Immunoglobulin” is selected in “Postnatal Therapy Details”</td>
<td>Drop Down Menu</td>
<td>• Intragam®P</td>
<td>N/A</td>
<td>Selection of “Other” makes available “Other Details” free text field.</td>
</tr>
<tr>
<td>Date first dose</td>
<td>Required if “Intravenous Immunoglobulin” is selected in “Postnatal Therapy Details”</td>
<td>DD/MM/YYYY</td>
<td>Date range must be equal to or later than date of birth</td>
<td>09/09/9999</td>
<td></td>
</tr>
<tr>
<td>Date last dose</td>
<td>Required if “Intravenous Immunoglobulin” is selected in “Postnatal Therapy Details”</td>
<td>DD/MM/YYYY</td>
<td>Date range must be equal to or later than date of birth</td>
<td>09/09/9999</td>
<td></td>
</tr>
<tr>
<td>Dose (g)</td>
<td>Required if “Intravenous Immunoglobulin” is selected in “Postnatal Therapy Details”</td>
<td>Text Box</td>
<td>Numeric (0-2000)</td>
<td>-1</td>
<td></td>
</tr>
<tr>
<td>Number of doses</td>
<td>Required if “Intravenous Immunoglobulin” is selected in “Postnatal Therapy Details”</td>
<td>Text Box</td>
<td>Numeric (0-100)</td>
<td>-1</td>
<td></td>
</tr>
</tbody>
</table>
**Adding a New Case**

### Postnatal Therapy Details

One or more of the following therapy options must be selected:

- **NOT APPLICABLE**
  
  If no therapy was given select this option. Selection of this option will render other options unavailable.

- **PLATELET TRANSFUSION**
  
  If this option is selected further fields relating to the transfusion become available.

- **INTRAVENOUS IMMUNOGLOBULIN**
  
  If this option is selected further fields relating to this therapy become available.

- **OTHER**
  
  Selection of Other enables a free text field to record therapy details.

### Platelet Transfusion

The following fields will only be made available once Platelet Transfusion check box is selected. When accessed for the first time for each infant, no transfusions will have been entered. Under the heading Platelet Transfusion the following will appear: **There is no transfusion record for the patient selected.** Details of platelet transfusion must be entered and saved. A summary of the transfusion will then appear.

The button **Add New Transfusion** should be selected to add a subsequent transfusion. Each new transfusion is assigned a reference number which is shown on the left of the date in the summary line. Transfusions may be deleted by selecting the Red Cross to the left of the reference number. Details of the transfusion may be edited by clicking on the reference number. This brings the details of this transfusion back into the Platelet transfusion details fields where changes can be made and saved.

#### Date of Transfusion

Date of transfusion refers to the date on which the Platelets entered the vein of the infant. Only post-natal transfusion should be included here.

#### Platelet Type

This field is required if Platelet Transfusion is selected as the procedure. From a drop down menu the following options are provided for platelet type.

#### HPA Matched

HPA matched or compatible platelets (usually collected by the Australian Red Cross Blood Service) are platelet concentrates collected from a donor who does not express the implicated platelet antigen. For example, for a case of NAIT due to maternal anti HPA1a antibodies, matched platelets would be those from a donor who is HPA 1a negative. As the diagnosis of NAIT (and determination of the antibody specificity) may take some time, platelet concentrates that are negative for the platelet antigens most commonly implicated in NAIT cases (HPA 1a and HPA 5b) may be used. These should also be entered as HPA matched (even if the maternal platelet antigen type is not yet known).
Adding a New Case

Child’s Platelet Count Pre-Transfusion

The infant’s platelet count (x109) most closely preceding the platelet transfusion should be reported here. This should be a postnatal sample if available.

Child’s Platelet Count Post-Transfusion

The infant’s platelet count (x109) most closely following the platelet transfusion should be reported here.

Non-HPA Matched

This refers to platelet concentrates that have not been selected based on the HPA type of the donor. These will include platelets collected by apheresis from a single donor and platelets pooled from multiple random donors (pooled platelet units).

Maternal

This refers to platelet concentrates that are collected from the mother (rather than from volunteer blood donors at ARCBS). These may be collected at the treating institution and require irradiation prior to transfusion.

Unknown

This option can be entered if the type of platelet product (i.e. HPA matched, HPA unmatched or maternal) is not known.

Therapy Details: Intravenous Immunoglobulin

The following fields will only be made available if the Intravenous Immunoglobulin check box is selected.

Type of IVIg

The majority of IVIg used in Australia is the domestically produced Intragam®P. To guarantee an adequate, safe and secure supply, the National Blood Authority has established contracts for the supply of two imported IVIg products; Octagam® and Sandoglobulin® P. The following data selection options are available:

- Intragam®P
- Octagam®
- Sandoglobulin®
- Other

If the patient received a combination of products, please choose Other and specify products and quantities.

Date of First Dose

Date of first postnatal IVIg dose is entered numerically in the format DD/MM/YYYY.

Date of Last Dose

Date of last postnatal IVIg dose is entered numerically in the format DD/MM/YYYY.

Dose (G)

Dose volume for each dose should be entered in grams.

Number of Doses

Please record the total number of doses the infant received in the postnatal period. Antenatal treatment of mother or infant should be recorded elsewhere.
Postnatal Outcomes Page

Once postnatal therapy has been initiated the **Postnatal Outcomes** page must be filled out.

Figure 32: Postnatal Outcomes page with an example case.

When opened for the first time, this page will show details under the heading **Postnatal Outcomes**, of the last infant entered on the previous page. If more than one infant has been added from this pregnancy, separate postnatal outcome details can be added from each child by selecting them in turn from the drop down menu.

A summary of the **Postnatal Outcomes** Page data items and the method of data entry are displayed on the next page.
## Postnatal Outcomes Page Data Entry Summary

<table>
<thead>
<tr>
<th>Data item</th>
<th>Data Entry Required</th>
<th>Type of Data Entry</th>
<th>Permitted Characters and Values</th>
<th>Unknown Values</th>
<th>Special Behaviour</th>
</tr>
</thead>
</table>
| Outcome of episode                     | Always                  | Drop down menu     | • Complete Recovery with no long term impairment  
• Recovery with persisting impairment  
  • Death  
  • Other  
  • Not applicable                      | Not applicable          | Selection of “Recovery with persisting impairment” makes “Nature of Persistent Impairment” available.  
Selection of “Death” makes “Cause of Death” and related fields available.  
Selection of “Other” makes “Other Details” field available. |
| Nature of Persistent Impairment        | Required if “Outcome of Episode” = “Recovery with persisting impairment” | Free Text          | Alphanumeric                                                                                       | Not applicable | N/A                                                                                                                                               |
| Cause of Death                         | Required if “Outcome of Episode” = “Death”  | Drop down menu     | • Intracranial Haemorrhage  
• Pulmonary Haemorrhage  
• Other Haemorrhagic  
  • Other  
  • Not applicable                      | Not applicable          | Selection of “Other Haemorrhage” makes “Other Haemorrhagic site” field available.  
Selection of “Other” makes “Other Details” field available. |
| Other Haemorrhagic site                 | Required if “Cause of Death” = “Other Haemorrhagic” | Free Text          | Alphanumeric                                                                                       | Not applicable | N/A                                                                                                                                               |
| Other Autopsy Findings                 | Required if “Outcome of Episode” = “Death” | Free Text          | Alphanumeric                                                                                       | Not applicable | N/A                                                                                                                                               |
## Adding a New Case

<table>
<thead>
<tr>
<th>Data item</th>
<th>Data Entry Required</th>
<th>Type of Data Entry</th>
<th>Permitted Characters and Values</th>
<th>Unknown Values</th>
<th>Special Behaviour</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comments</td>
<td>Optional</td>
<td>Free Text</td>
<td>Alphanumeric</td>
<td>Not applicable</td>
<td>N/A</td>
</tr>
</tbody>
</table>
Outcome of Episode

The outcome of the episode should be determined once all treatment for NAIT has been completed. Infants with other medical issues or long-term impairment may continue to require medical treatment but the NAIT episode may be considered resolved when NAIT-related treatments (e.g. Platelet transfusion or IVIg therapy) are concluded.

From the drop down menu the following options are available:

COMPLETE RECOVERY WITH NO LONG TERM IMPAIRMENT

Choose this option if the infant has no persisting sequelae from the NAIT episode.

RECOVERY WITH PERSISTING IMPAIRMENT

This should be selected if the child has recovered from NAIT but has a persisting impairment as a consequence of this episode. For example, if there is a persisting neurological deficit from an intracranial haemorrhage, this should be entered here.

Selection of Recovery with persisting impairment makes Nature of Persistent Impairment field available.

DEATH

This should be selected if the child dies as a result of the NAIT episode. If the child dies from non-NAIT related causes please make this clear in the Cause of death or Other findings fields.

Selection of Death makes Cause of Death and Other Autopsy findings fields available.

OTHER

This should be selected if the child has a persisting impairment from causes other than NAIT. Please indicate in this field the nature of the impairment if present and the cause of the impairment.

NOT APPLICABLE

Nature of Persistent Impairment

This data entry box is only available if Recovery with persistent impairment is selected in Outcomes of Episode.

A full explanation of the impairment as a direct result of NAIT should be supplied.

Cause of Death

This field will only be available if Death is selected in Outcome of Episode.

From the drop down menu the following options are available:

INTRACRANIAL HAEMORRHAGE

An intracranial haemorrhage is a haemorrhage, or bleeding, within the skull. Neonates with NAIT are believed to be at greater risk of intracranial haemorrhage within the first 72 hours after birth.
PULMONARY HAEMORRHAGE

Pulmonary haemorrhage refers to bleeding from the lung.

GI HAEMORRHAGE

Gastrointestinal bleeding or gastrointestinal haemorrhage includes any hemorrhage (loss of blood) in the gastrointestinal tract, from the pharynx to the rectum.

OTHER HAEMORRHAGIC

Selection of Other Haemorrhagic provides a free text box to enter site of haemorrhage.

OTHER

Selection of Other makes available the Other Details field. Death due to a cause other than NAIT should be entered here. Please provide details of the cause of death.

Other Autopsy Findings

This field is only available if Death is indicated in Outcome of Episode. A summary of autopsy findings should be entered here.

Comments

Any additional comments may be entered here.
Editing Data

Once a patient and related data items have been entered, existing data for any screen of any patient from your hospital can be modified by typing or selecting new information and clicking on the save command button located at the bottom of each screen. Data validation procedures are the same as when adding a new case and, if there is no error, data changes will be saved and the Last Updated field updated with your user name and the date and time.

Figure 33: Shows Postnatal Outcomes Page as an example of Last Updated Information and position of save and cancel buttons.
EDITING DATA

Record editing

1. Locate the record you wish to edit by using navigation controls on the ‘Home’ Screen.

2. Overwrite new data onto the appropriate existing data.

3. Select and press Save button located at the bottom of each record.

Hint: Use Cancel button to discard the change.
EDITING DATA

Editing or Deleting on the Antenatal Testing and Therapy or Postnatal Therapy pages

1. To edit any of the laboratory results already entered, locate the relevant results set in the list and click on the relevant line in the column Ref #. This will populate the Details fields below with the relevant results.

2. Make any changes as required and click Save at the bottom of the page to retain the corrections.

3. To delete any previously entered laboratory results, select the item and press Delete Image Button × to the left of the appropriate reference number.

4. Answer confirmation prompt to allow record to be deleted.

Figure 34: Antenatal testing and Therapy Page showing confirmation prompt when deleting procedure

Hint: Place mouse over the images to see the description of each button.
Printing a Case

Cases may be printed using the **Print Case** command located on the right hand side of the main menu.

![Main Menu showing Print Case Command](image)

The entire case information is supplied in a format that is able to be printed. A printout of a fictitious case is provided on the following pages.
Parental Demographic Information

Maternal Details
Poppy Mak - DOB: 16/06/1976 (34 years old)
Genetic Ethnic Heritage (Grandparents) 1: European
2: European
3: European
4: European
Weight (kg): 80 Height (cm): 170 Gravidity: 2 Parity: 2

Paternal Details
Harry Mak - DOB: 15/05/1974 (36 years old)
Genetic Ethnic Heritage (Grandparents) 1: European
2: European
3: European
4: European

Clinical Background
Case Description: Previous pregnancy confirmed NAIT. This pregnancy referred during first trimester for management.
Possible Alternative Cause of Clinical Presentation:

Stage at Which Case Identified: Anticipated prior to Pregnancy
Reason for Case Identification: Personal History of NAIT Affected Offspring

Any Previous NAIT Affected Offspring: Yes
Previous NAIT Affected Offspring: Details of Severity: Severely affected (live birth)
Comments on Any Previous Poor Pregnancy Outcomes: Previous NAIT affected offspring diagnosed post natal with severe thrombocytopenia and mild bleeding. No long term impairment. Serologically confirmed NAIT due to HPA-1a antibody
Maternal Testing (entered by clinician)

Maternal Platelet Count at Diagnosis: 185
Date of Maternal Platelet Count: 16/12/2009  
Maternal ABO Group: O

Parental Testing

Specialised Laboratory Testing (entered by laboratory)

Maternal HPA Type

<table>
<thead>
<tr>
<th>HPA-1: bb</th>
<th>HPA-2: ab</th>
<th>HPA-3: ab</th>
<th>HPA-4: ab</th>
</tr>
</thead>
<tbody>
<tr>
<td>HPA-5: ab</td>
<td>HPA-6: ab</td>
<td>HPA-7: ab</td>
<td>HPA-8: ab</td>
</tr>
<tr>
<td>HPA-9: ab</td>
<td>HPA-10: ab</td>
<td>HPA-11: ab</td>
<td>HPA-12: ab</td>
</tr>
<tr>
<td>HPA-13: ab</td>
<td>HPA-14: ab</td>
<td>HPA-15: ab</td>
<td></td>
</tr>
</tbody>
</table>

Paternal HPA Type

<table>
<thead>
<tr>
<th>HPA-1: aa</th>
<th>HPA-2: ab</th>
<th>HPA-3: ab</th>
<th>HPA-4: ab</th>
</tr>
</thead>
<tbody>
<tr>
<td>HPA-5: ab</td>
<td>HPA-6: ab</td>
<td>HPA-7: ab</td>
<td>HPA-8: ab</td>
</tr>
<tr>
<td>HPA-9: ab</td>
<td>HPA-10: ab</td>
<td>HPA-11: ab</td>
<td>HPA-12: ab</td>
</tr>
<tr>
<td>HPA-13: ab</td>
<td>HPA-14: ab</td>
<td>HPA-15: ab</td>
<td></td>
</tr>
</tbody>
</table>

Fetal/Neonatal HPA Type

<table>
<thead>
<tr>
<th>HPA-1: ab</th>
<th>HPA-2: ab</th>
<th>HPA-3: aa</th>
<th>HPA-4: bb</th>
</tr>
</thead>
<tbody>
<tr>
<td>HPA-5: ab</td>
<td>HPA-6: aa</td>
<td>HPA-7: bb</td>
<td>HPA-8: aa</td>
</tr>
<tr>
<td>HPA-9: bb</td>
<td>HPA-10: ab</td>
<td>HPA-11: aa</td>
<td>HPA-12: ab</td>
</tr>
<tr>
<td>HPA-13: bb</td>
<td>HPA-14: aa</td>
<td>HPA-15: ab</td>
<td></td>
</tr>
</tbody>
</table>

| HPA Crossmatch: Maternal/Random Donor: Positive | Date: 16/01/2010 |
| HPA Antibody Specificity: HPA-1a |
| HPA Crossmatch: Maternal/Paternal: Positive | Date: 16/01/2010 |
| HPA Antibody Specificity: HPA-1a |
| HPA Crossmatch: Maternal/Fetal-Neonatal: Not Tested | Date: |
| HPA Antibody Specificity: |

HPA Method: HPA Method
<table>
<thead>
<tr>
<th>Maternal HLA Typing</th>
<th>Paternal HLA Typing</th>
</tr>
</thead>
<tbody>
<tr>
<td>HLA-A: 1</td>
<td>HLA-A: 6</td>
</tr>
<tr>
<td>HLA-B: 37</td>
<td>HLA-B: 27</td>
</tr>
<tr>
<td>HLA-Cw: 7</td>
<td>HLA-Cw: 6</td>
</tr>
<tr>
<td>HLA-DRB1: 101</td>
<td>HLA-DRB1: -1</td>
</tr>
<tr>
<td>HLA-DRB3/4/5: 28</td>
<td>HLA-DRB3/4/5: -1</td>
</tr>
</tbody>
</table>

**Interpretive Testing Comments:** Maternal fetal incompatibility in HPA-1

**Testing Site:** VTIS-Victoria
**Antenatal Clinical Details**

- Estimated Date of Delivery: 01/06/2010
- Site of Antenatal Management: TEST1
- Gestation at which Case Identified: 10
- Cranial Imaging Performed?: Ultrasound - Cranial Imaging Findings: No evidence of haemorrhage

**Complications During Pregnancy**
- Intracranial haemorrhage: No
- Other bleeding: No
- Pre-eclampsia: No
- Fetal infection: No
- Placental abruption: No
- Other: No

Outcome of Pregnancy: Live Birth
<table>
<thead>
<tr>
<th>Ref# 39</th>
<th>Date of Procedure: 01/03/2010</th>
</tr>
</thead>
<tbody>
<tr>
<td>Procedure: Fetal blood sampling only</td>
<td></td>
</tr>
<tr>
<td>Fetal platelet count at fetal blood sampling: <strong>120</strong></td>
<td>Fetal platelet count post transfusion:</td>
</tr>
<tr>
<td>Complications of procedure: None</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ref# 40</th>
<th>Date of Procedure: 23/05/2010</th>
</tr>
</thead>
<tbody>
<tr>
<td>Procedure: Fetal blood sampling only</td>
<td></td>
</tr>
<tr>
<td>Fetal platelet count at fetal blood sampling: <strong>40</strong></td>
<td>Fetal platelet count post transfusion:</td>
</tr>
<tr>
<td>Complications of procedure: None</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ref# 41</th>
<th>Date of Procedure: 23/05/2001</th>
</tr>
</thead>
<tbody>
<tr>
<td>Procedure: Platelet transfusion</td>
<td></td>
</tr>
<tr>
<td>Fetal platelet count at fetal blood sampling:</td>
<td>Fetal platelet count post transfusion: <strong>150</strong></td>
</tr>
<tr>
<td>Platelet Type: HPA Matched</td>
<td></td>
</tr>
<tr>
<td>Complications of procedure: None</td>
<td></td>
</tr>
</tbody>
</table>
## Other Therapies

**Other therapies?**: Yes

<table>
<thead>
<tr>
<th>Therapy</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intravenous Immunoglobulin</td>
<td>Yes</td>
</tr>
<tr>
<td>Type of IVIg</td>
<td>Intragam P®</td>
</tr>
<tr>
<td>Date first dose</td>
<td>01/01/2010</td>
</tr>
<tr>
<td>Date last dose</td>
<td>29/05/2010</td>
</tr>
<tr>
<td>Dose (g)</td>
<td>2</td>
</tr>
<tr>
<td>Number of doses</td>
<td>20</td>
</tr>
<tr>
<td>Frequency</td>
<td>Weekly</td>
</tr>
</tbody>
</table>

| Corticosteroids                              | No                           |
| Date first dose                              |                              |
| Date last dose                               |                              |
| Dose (mg)                                    |                              |
| Number of doses                              |                              |
| Frequency                                    |                              |

| Other                                        | No                           |
| Date first dose                              |                              |
| Date last dose                               |                              |
| Dose (mg)                                    |                              |
| Number of doses                              |                              |
| Frequency                                    |                              |
## Postnatal Demographics

<table>
<thead>
<tr>
<th>Ref#</th>
<th>45</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child Family Name</td>
<td>Mak</td>
</tr>
<tr>
<td>Child Given Name</td>
<td>Ruby</td>
</tr>
<tr>
<td>Child Sex</td>
<td>Female</td>
</tr>
<tr>
<td>Child Birth Weight (g)</td>
<td>3000</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Date of Delivery</th>
<th>01/06/2010</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gestation at Delivery</td>
<td>37</td>
</tr>
<tr>
<td>Mode of Delivery</td>
<td>Caesarean (pre-labour)</td>
</tr>
<tr>
<td>Timing of Delivery</td>
<td>Induced</td>
</tr>
<tr>
<td>Site of Antenatal Management</td>
<td>TEST1</td>
</tr>
<tr>
<td>Transferred Patient</td>
<td>No</td>
</tr>
</tbody>
</table>
Postnatal Clinical and Testing

Postnatal# 45 - Ruby Mak (01/06/2010), Female

Clinical Manifestations

<table>
<thead>
<tr>
<th>Manifestation</th>
<th>Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Petechiae</td>
<td>No</td>
</tr>
<tr>
<td>Purpura</td>
<td>No</td>
</tr>
<tr>
<td>Pulmonary Haemorrhage</td>
<td>No</td>
</tr>
<tr>
<td>GI Haemorrhage</td>
<td>No</td>
</tr>
<tr>
<td>Intracranial Haemorrhage</td>
<td>No</td>
</tr>
<tr>
<td>Other</td>
<td>No</td>
</tr>
</tbody>
</table>

Child's First Platelet Count: 40 \(\times 10^9\)  
Child's First Haemoglobin: 210 \(g/L\)  
Child's First Total WCC: 20 \(x10^6/L\)  
Child ABO Group: O  
Child Rhesus(D) Group: Positive

Date of First Blood Counts (dd/mm/yyyy): 01/06/2010
Child's Lowest Platelet Count: 40 \(\times 10^9\)

Date of Child's Lowest Platelet Count (dd/mm/yyyy): 01/06/2010

Cranial Imaging Performed?: Ultrasound  
- Cranial Imaging Findings: Normal
## Postnatal Therapy

<table>
<thead>
<tr>
<th>Postnatal# 45 - Ruby Mak (01/06/2010), Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Platelet Transfusion: Yes</td>
</tr>
<tr>
<td>Intravenous Immunoglobulin: Yes</td>
</tr>
<tr>
<td>Other: No</td>
</tr>
</tbody>
</table>

### Platelet Transfusion

<table>
<thead>
<tr>
<th>Ref# 33</th>
<th>Date of Transfusion: 01/06/2010</th>
<th>Platelet Type: HPA Matched</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Child's platelet count pre transfusion: 40</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Child's platelet count post transfusion: 150</td>
<td></td>
</tr>
</tbody>
</table>

### Intravenous Immunoglobulin

<p>| Type of IVIg: Intragam P®                     |
| Date first dose: 01/06/2010                  |
| Date last dose: 06/06/2010                   |
| Dose (g): 2                                  |
| Number of doses: 2                           |</p>
<table>
<thead>
<tr>
<th>Postnatal Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Postnatal# 45 - Ruby Mak (01/06/2010), Female</td>
</tr>
<tr>
<td>Outcome of Episode: Complete Recovery with no long term impairment</td>
</tr>
<tr>
<td>Comments:</td>
</tr>
</tbody>
</table>