



NAITBABIES ANNUAL REPORT 2024



News and events from

1 June 2023 – 31 May 2024

Fetal and neonatal alloimmune thrombocytopenia - FNAIT

Reference and administrative details of the charity and its Trustees

Charity name:	Naitbabies
Other names we are known by:	NAIT babies
Charity number:	1161698
Principle address:	Naitbabies.org 13 Redinnick Terrace Penzance Cornwall, TR18 4HR, England

Members of the CIO are also the trustees who administer the charity.

Thea Palmer	Chair
Michelle Minshall	Treasurer
Stacy Corke	Secretary
Andrea Palmer	Trustee
Rachael Walker	Trustee

Treasurer:

Michelle Minshall
Minshall & Co
Bridge House
Nantwich
Cheshire, CW5 7JX

Independent examiner:

Mr Neill Hallam FCCA
Crane and Johnston
Chartered Certified Accountants
11 Alverton Terrace
Penzance
Cornwall, TR18 4JH

Bankers:

HSBC, 1 Green Market
Penzance
Cornwall, TR18 2SD

Type of governing document:	Constitution
How the charity is constituted:	Charitable Incorporated Organisation (CIO) Foundation
Date of governing document:	15 May 2015

Website:

<https://www.naitbabies.org/>

Naitbabies are members of:

[Genetic Alliance UK](#)

[Rare Disease UK](#)

Mission Statement

Our mission is to be a strong voice for parents, children and families who have been diagnosed with or suspect that they may have Fetal and neonatal alloimmune thrombocytopenia - FNAIT.

Objectives and Activities

The objects of the charity as set out in the CIO's constitution are:

The relief of sickness and the preservation and protection of good health of parents, children and their families and carers who have or are affected by the severe bleeding disorder neonatal alloimmune thrombocytopenia – FNAIT; in particular by the provision of support, advocacy and practical assistance as the trustees shall think fit;

To carry out, or to provide funds to support research into FNAIT, its causes, treatment and prevention and publish the useful results of such research; and

To advance the education of the public, in particular those involved in the diagnosis, treatment and care of those suffering from FNAIT.

Summary of the main activities undertaken for the public benefit in relation to these objects.

Naitbabies are a small Charitable Incorporated Organisation run by families whose children have been affected by the severe bleeding disorder FNAIT – Fetal and neonatal alloimmune thrombocytopenia.

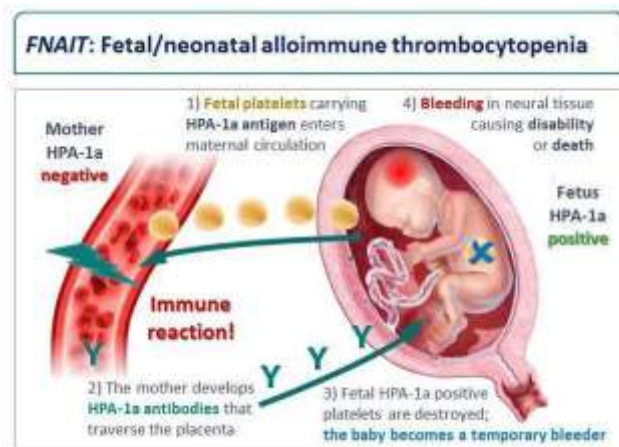
Registered in the UK we are the only organisation for this disorder. We provide information to the public in general.

We run an international FNAIT Parents Support Group and advocate for parents worldwide. To date we have over 1,600 members.

We support research into FNAIT and have contact with an expert medical panel of doctors who have a special interest in this devastating disease.

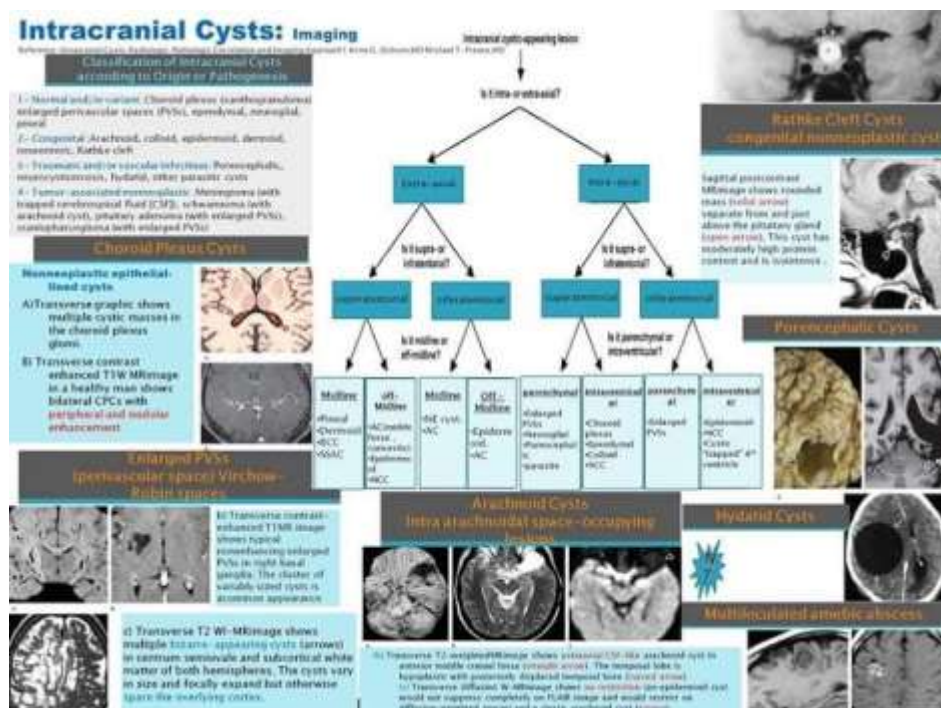
Watch our FNAIT video [here](#)

What is Fetal and alloimmune thrombocytopenia - FNAIT?



Fetal and neonatal alloimmune thrombocytopenia FNAIT (NAIT FMAIT) results from incompatibility between mother and baby for platelet-specific antigens that have been inherited from the father and are absent in mother.

The maternal immune response may make antibodies to destroy her baby's platelets which she sees as foreign. Platelet destruction can cause bleeding into all major organs including the stomach, spinal cord and lungs. The most feared is bleeding into the brain, known as intracranial haemorrhage - ICH. Babies are at serious risk of death or permanent neurological impairment such as epilepsy, cortical blindness, cerebral palsy, precocious puberty, motor and cognitive delays and sensory processing disorders.



NAIT is seen as analogous to the red blood cell disease Haemolytic Disease of the Foetus and Newborn - HDFN more commonly known as Rhesus disease.

Routine antenatal care has included screening of all expectant mothers for HDFN since the early 1970's. No country carries out antenatal screening for NAIT although it has been known about since the 1950's and is very well documented.

Treatment is available for mothers who have developed antibodies against their unborn baby's platelets and the success rate is high. If subsequent pregnancies are not treated they may also be at risk.

The UK National Screening Committee are committed to revisiting prenatal screening for FNAIT (FMAIT) in 2023 – 24.

See the 2020 UK NSC review below

<https://view-health-screening-recommendations.service.gov.uk/fmait/>

RARER DISEASES ARE SCREENED FOR!!!!



Highlights of our FNAIT journey through 2022 – 23.

June 2023



24 - 28 June

Rallybio presented the important results of their FNAIT Program 'RLYB212' at the "International Society of Thrombosis and Haemostasis Congress - ISTH2023" held at the Palais des Congrès de Montréal, Quebec, Canada. <https://www.isth2023.org/>

"Dose-Dependent Elimination of HPA-1a Platelets by Subcutaneous RLYB212, a Monoclonal Antibody to Prevent Fetal and Neonatal Alloimmune Thrombocytopenia"



Presenting Author: Christof Geisen

MD Institute of Transfusion Medicine and Immunohematology, German Red Cross Blood Transfusion Service Baden-Württemberg-Hessen GmbH, Frankfurt am Main, Germany.

July 2023



"Accessibility of Medical Products for Rare Diseases"

In July we received an invitation from Doctor Eva Hilberg from Sheffield University, to participate in a research project in the United Kingdom regarding access to Orphan Drugs.

Background information. In 2014 Thea Palmer, Chair of Naitbabies, was invited to speak on behalf of FNAIT families as part of the delegation who attended the FDA panel meeting in Maryland, USA when the prophylactic drug being developed to prevent FNAIT in HPA-1a negative women was awarded Orphan Drug Designation.



*FDA Orphan Drug Designation Team
Maryland USA - 19 August 2014*

August 2023

15 August. Genetic Alliance UK meeting. The agenda included presentations on RDCN's - Rare Disease Collaborative Networks" by NHS England and NHS Improvement.

Other subjects covered in the presentation included RDCC's - Rare Disease Collaborative Centres and RDAG – Rare Disease Advisory Group.

September 2023

Does anti-HPA-1a affect birthweight in Fetal and Neonatal Alloimmune Thrombocytopenia?

Naitbabies latest research will be published in the journal BJOG: an International Journal of Obstetrics & Gynecology early in 2024.

11 September. UK NSC

The UK National Screening Committee invited us to take part in their "Screening Inequalities Survey".

22 September. FNAIT REGISTRY

Further meetings with NHSBT regarding setting up an FNAIT Registry in England and Wales.

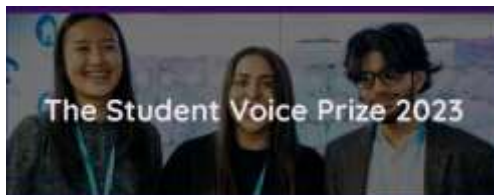
October 2023

'The Student Voice Prize'.

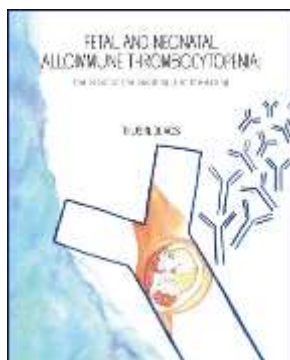


Naitbabies took part in the 2023 Student Voice Prize being run by M4RD – Medics for Rare Diseases and the Rare Beacon organisation.

The Student Voice Prize is an annual, international essay competition that raises the profile of rare diseases within the medical field, particularly with medical students, nurses and scientists who may have never come across rare diseases in their training.



Friday 20 October
Naitbabies AGM



26 October 2023



Thijs W de Vos, MD. Leiden University Medical Centre, Leiden, Netherlands.

“Natural history of human platelet antigen 1a-alloimmunised pregnancies: a prospective observational cohort study.”

[https://www.thelancet.com/journals/lanhae/article/PIIS2352-3026\(23\)00271-5/fulltext](https://www.thelancet.com/journals/lanhae/article/PIIS2352-3026(23)00271-5/fulltext)

Interpretation/ Summary – “our data suggest that, without intervention, the incidence of major clinically detectable bleeding in FNAIT is estimated as 11 (95% CI 0–32) per 10 000 HPA-1a-negative pregnancies. These findings imply that severe bleeding is a rare event that potentially could be prevented by a screening programme.”

November 2023

27 November - Naitbabies took part in an interview with CJAM radio, Toronto, Canada.

28 November.

Rallybio Announce **Preliminary Multiple Dose Data from the Completed Phase 1 Safety and Pharmacokinetics Study for RLYB212.**

The Rallybio program RLYB212 is an Anti-HPA-1a Monoclonal Antibody in development for the Prevention of Fetal and Neonatal Alloimmune Thrombocytopenia. “These data support our belief in the potential use of subcutaneous RLYB212 as a prophylactic therapeutic for the prevention of HPA-1a alloimmunization and FNAIT,” commented Róisín Armstrong, Ph.D., Rallybio’s RLYB212 Program Lead. Read more [here](#)

December 2023

9 December 2023.

Rallybio's natural history study on Fetal and Neonatal Alloimmune Thrombocytopenia featured at the 2023 [American Society of Hematology](#) (ASH) Annual Meeting held in San Diego, California.

Key insights in identifying pregnancies at higher risk of developing FNAIT can be read using this link in your browser: <https://bit.ly/3GCKgxA>

Previous FNAIT studies primarily conducted in Caucasian populations suggest that approximately 2% of expectant women are HPA-1a negative and, therefore, at risk for FNAIT. The FNAIT natural history study is the first prospective study that seeks to characterize risk for FNAIT in a racially and ethnically diverse population of pregnant women.

The study is presently being conducted in the United States and across multiple European countries including Germany, the Netherlands, Norway, Sweden, and the United Kingdom. Expectant mothers are screened at gestational weeks 10 to 14, enabling early identification and follow-up of women at higher risk of alloimmunisation. Rallybio expects to screen up to 30,000 expectant mothers in the natural history study, with an estimated 7,600 women screened by the end of 2023.

13 December 2023

Further meeting with NHSBT with regard to establishing an FNAIT registry in the UK.

January 2024

11 January.

Naitbabies most recent collaborative research has been published in the Paediatric Blood & Cancer Journal. We would like to thank all involved with special thanks to Professor J.B. Bussel, Weill Cornell Medical University, New York.

[Does anti-HPA-1a affect birthweight in fetal and neonatal alloimmune thrombocytopenia?](#)

Margaret McKelvy, Srishti Tyagi, Emilie Vander Haar, Madhavi Lakkaraja, Tim Tomy, Stacy Corke, Thea Palmer, Amihai Rottenstreich, Rick Kapur, Huiying Zhi, Debra Newman, Nina Scatz-Siemers, James Bussel.

January 2024 © Wiley Periodicals, LLC. Pediatric Blood & Cancer. doi.org/10.1002/pbc.30835

February 2024

29 February - RDD 2024 – rare disease day



March 2024



FNAIT Awareness Week 25 – 31 March 2024

This is the week our support group members from all over the world share their stories – how Fetal and neonatal alloimmune thrombocytopenia has affected their lives and their families.



Born in 2023, NAIT baby Lily Harrison suffered severe brain damage due to intra-cranial haemorrhages caused by fetal and neonatal alloimmune thrombocytopenia. She has recently had a shunt placed in her head to drain the cerebral spinal fluid, which will prevent her head from growing. #FNAIT – SCREENING for this devastating disease should be standard and routine!!!!



After their mum had several late term losses which, after investigation, were found to be due to FNAIT, Kiera Whitely and her sister from British Columbia, Canada, found they too had the rare platelet type HPA-1b1b. It's important for sisters to get their platelets typed (called platelet genotyping) if there is a maternal history of FNAIT or repeated pregnancy loss.

Read our latest stories [here](#)



April 2024



10 April

FNAIT Collaboration Agreement between Momenta Pharmaceuticals, Inc., a Johnson & Johnson Company, and Rallybio IPA, LLC

- Rallybio to Receive Funding for FNAIT Awareness Initiative and Equity Investment from Johnson & Johnson –

Read more [here](#)

May 2024

2nd review for GA UK

End of year 31 may 2024

Many thanks to everyone for reading our review and for your continued support!!!!

[DONATE: Just Giving/Naitbabies](#)



Charity registration number: 1161698

Naitbabies.org

Annual Report and Financial Statements

for the Year Ended 31 May 2024

Naitbabies.org

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Naitbabies.org

Reference and Administrative Details

Charity Registration Number

1161698

Trustees

Y D Palmer

A Palmer

S Corke

M Minshall

R Walker

Principal Office

13 Redinnick Terrace

Penzance

Cornwall

TR18 4HR

Independent Examiner

Mr Neil Hallam FCCA

Crane & Johnston

Chartered Certified Accountants

11 Alverton Terrace

Penzance

Cornwall

TR18 4JH

Bankers

HSBC

Penzance

1 Green Market

Penzance

Cornwall

TR18 2SD

Naitbabies.org

Trustees' Report

The trustees present the annual report together with the financial statements of the charity for the year ended 31 May 2024.

Objectives and activities

Objects and aims

The objects of the charity are as follows:

1. The relief of sickness and the preservation and protection of good health of parents, children and their families and carers who have or are affected by the genetic disorder 'Neonatal Alloimmune Thrombocytopenia' (also known as NAIT or FNAIT). In particular by the provision of support, advocacy and practical assistance as the trustees shall think fit;
2. To carry out, or to provide funds to support research into NAIT/FNAIT, its causes, treatment and prevention and publish the useful results of such research; and
3. To advance the education of the public, in particular those involved in the diagnosis, treatment and care of those suffering from NAIT/FNAIT.

Activities

Naitbabies.org is a non-profit making organisation that has been created to raise the knowledge and awareness of a severe bleeding disorder many have never heard of, neonatal alloimmune thrombocytopenia or NAIT.

On 15 May 2015 Naitbabies became a registered charity and is now a Charitable Incorporated Organisation (CIO). Its registered number with Charity Commission is '1161698'.

Mission statement

Our mission is to be a strong voice for parents, children and families who have been diagnosed with, or suspect that they might have the genetic disorder neonatal alloimmune thrombocytopenia. We support research into NAIT/FNAIT, its causes, treatment and prevention.

Trustees and officers

The trustees and officers serving during the year and since the year end were as follows:

Trustees:

Y D Palmer

A Palmer

S Corke

M Minshall

R Walker

Naitbabies.org

Trustees' Report (continued)

The annual report was approved by the trustees of the charity on 15 November 2024 and signed on its behalf by:

A handwritten signature in dark ink, appearing to read 'Y D Palmer', is written over a horizontal line.

Y D Palmer
Trustee

Naitbabies.org

Independent Examiner's Report to the trustees of Naitbabies.org

I report to the trustees on my examination of the accounts of Naitbabies.org for the year ended 31 May 2024.

Responsibilities and basis of report

As the charity trustees of Naitbabies.org you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the Naitbabies.org's accounts carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of Naitbabies.org as required by section 130 of the Act; or
2. the accounts do not accord with those records.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.



.....
Neil Hallam FCCA
Crane & Johnston
Chartered Certified Accountants
11 Alverton Terrace
Penzance
Cornwall
TR18 4JH

15 November 2024

Receipts & Payment Account for the Year Ended 31 May 2024

	Total 2024 £	Total 2023 £
Receipts:		
<i>Receipts from charitable activities</i>		
Donations	3,072	5,629
Fundraising	134	12
Interest receivable	819	173
Total Receipts	4,025	5,814
Payments:		
<i>Costs of charitable activities</i>		
Accountancy	(396)	(378)
Advertising and PR	(65)	166
Bank charges	(155)	(233)
Conferences and training	(1,664)	-
Equipment expensed	(342)	-
Insurance	(123)	(123)
PC consumables and software	(217)	-
Stationery and printing	(77)	(81)
Subscriptions	(421)	(427)
Sundry	(16)	(48)
Support	-	(1,150)
Telephone	(193)	(164)
Travel and subsistence	(492)	-
Total Payments	(4,161)	(2,438)
Net (payments)/receipts	(136)	3,376
Reconciliation of cash funds		
Total cash funds brought forward	48,987	45,611
Total cash funds carried forward	48,851	48,987

Naitbabies.org

(Registration number: 1161698)

Statement of Assets & Liabilities as at 31 May 2024

	2024 £	2023 £
Cash Funds		
Cash at bank and in hand	48,851	48,987
Unrestricted income funds		
Unrestricted funds	48,851	48,987
Total funds	48,851	48,987
Assets retained for the CIO's own use		
(estimated written down value)		

	Note	2024 £	2023 £
Computer equipment & other equipment - unrestricted funds		-	-
Computer equipment & other equipment purchased during the year - unrestricted funds		-	-
		-	-

Liabilities

Amounts relating to but not included in the accounts.

	Note	2024 £	2023 £
Grant payable - approved at year end		-	1,000
Accountancy fee		415	396
		415	1,396

The financial statements were approved by the trustees, and authorised for issue on 15 November 2024 and signed on their behalf by:



Y D Palmer
Trustee



A Palmer
Trustee

Notes to the Financial Statements for the Year Ended 31 May 2024

1 Accounting policies

Basis of preparation

The accounts have been prepared on the receipts and payments basis.

Naitbabies.org meets the definition of a public benefit entity under FRS 102. The accounts (financial statements) have been prepared under the historical cost convention with items recognised at cost or transaction value unless otherwise stated in the relevant note(s) to these accounts.

Receipts

Receipts are the total amounts received by the charity for goods and services provided to the public. Any donations have been included in the accounts when received.

Payments

Expenditure is included on a paid basis, including any VAT which cannot be recovered.

2 Trustees & Secretary remuneration and expenses

No trustees (or any persons connected with them) have received any remuneration from the charity during the year.

No trustees have received any reimbursed expenses from the charity during the year.

3 Guarantees

The trustees confirm, in accordance with the Charitable Incorporated Organisations (General) Regulations 2012, that at the year ending the CIO did not have any outstanding guarantees to third party nor any debts secured on assets of the CIO.