



# NAITBABIES ANNUAL REPORT 2023



News and events from

1 June 2022 – 31 May 2023

## 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:	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	Company Secretary
Andrea Palmer	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

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

### **Website:**

[www.naitbabies.org](http://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.

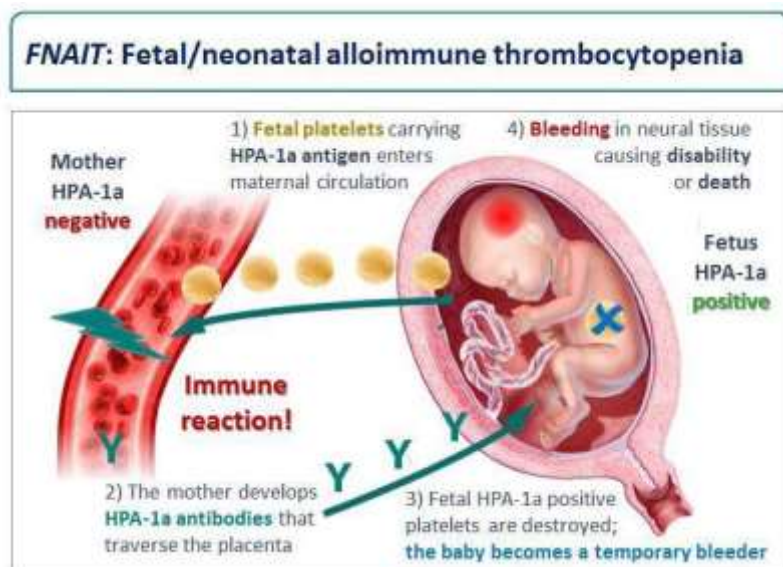
Registered in the UK we are the only organisation for this disorder. We provide information to the public in general.

We run an international FNAIT Parents Support Group and advocate for parents worldwide. To date we have over 1,200 members.

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

Watch our FNAIT video [here](#)

## What is 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 fetal platelets which she sees as foreign. Platelet destruction may cause bleeding into all major organs e.g. 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.

**Fetal & Neonatal Alloimmune Thrombocytopenia**

FNAIT affects 1 in 1000 newborns, currently it is NOT screened for in pregnancy. affected babies are at risk of bleeding into the brain. Stomach and other internal organs.

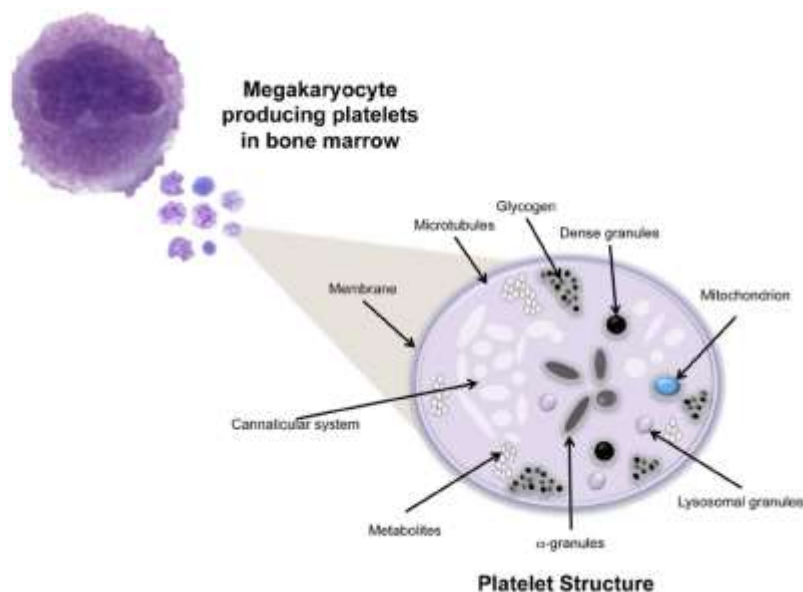
A healthy platelet count should be over 200k, Fnaït affected babies can have platelet counts as low as 1k



NAIT is seen as the platelet equivalent of the red blood cell disease Hemolytic Disease of the Fetus 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. Rarer diseases are also screened for.

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.



Platelets forming in bone marrow

## Highlights of our journey through the last year.

### June 2022

NORD. On the 21 June 2022 Naitbabies were invited to register as a patient organisation on the North American Rare Disease Organization Database.

<https://rarediseases.org/non-member-patient/naitbabies/>

### July

On July 2 Alan Halliday and his team mates Gareth Rees, Garry Bowman, Andy Donald, James Phillips, Andy Hogg, James Turner, Jeff Biggs and Nathan Turner took part in the UK [Yorkshire Three Peaks Challenge](#) a circular trek which encompasses three major peaks in the Yorkshire

Dales, Pen-Y-Ghent, Whernside, and Ingleborough in under 12 hours raising a magnificent £1,473.16.



Alan's 8 year old son Theo was affected by FNAIT after being born with a platelet count of only 11k. He received blood, IVIG and platelet transfusions all within the first 18 hours of his birth.



On July 9-13 The International Society on Thrombosis and Haemostasis (ISTH) reconvened for the ISTH 2022 Congress held in London, England. <https://www.isth2022.org/> Professor Ulrich Sachs Germany, presented the manuscript PB1110 - *Buffy-coat-derived megakaryocytes for monoclonal antibody immobilization of platelet antigens (MAIMA) assay.*

## August



*'He's never alone'*

One of our FNAIT Parents Support Group members, Carlos Marquez from New Jersey, USA, has a tattoo for each of his 5 children. This one, which depicts a shunt and the words “*His fight is my fight*” is EXTRA special as his son Luke has already been through five brain surgeries due to intracranial haemorrhages caused by FNAIT and has a shunt fitted into his brain.



A shunt is a hollow tube surgically placed in the brain to help drain cerebrospinal fluid and redirect it to another location in the body where it can be reabsorbed.

## **September**

September 28, 2022

Preliminary data from the ongoing Phase 1b study shows RLYB212 rapidly and completely eliminates transfused HPA-1a positive platelets. More news is expected in the first quarter of 2023.

[Rallybio Announces Positive Preliminary Results for RLYB212, an anti-HPA-1a Monoclonal Antibody for the Prevention of Fetal and Neonatal Alloimmune Thrombocytopenia](#)

## **October**

FNAIT SURVEY.

Naitbabies have been collaborating with Dr J B Bussel, Weill Cornell Medical University on a questionnaire for women who have fetal and neonatal alloimmune thrombocytopenia. This research project was started in 2020 and delayed for 2 years due to the Covid pandemic.

## **November**

AGM – 28 November 2022

## **December**

Grant. In December we were delighted to be able to support Dr T W de Vos, Leiden Medical University by providing a grant of £1000 towards his important FNAIT doctorate thesis publication.



## **January 2023**

31 Jan – FNAIT Survey completed. The results will be published in 2023.

## **February**



28 February Rare Disease Day

## **March**

Latest news on the development of a prophylactic treatment for FNAIT.

6 March 2023, Rallybio Announced Clinical Proof-of-Concept Achieved for its Lead Product Candidate, RLYB212, a Monoclonal Anti-HPA-1a Antibody, in the First Quarter of 2023.

<https://investors.rallybio.com/news-releases/news-release-details/rallybio-announces-proof-concept-achieved-rylb212-novel>

The Company also announced today that RLYB211, a plasma-derived polyclonal anti-HPA-1a antibody, will not be advanced further in clinical development.

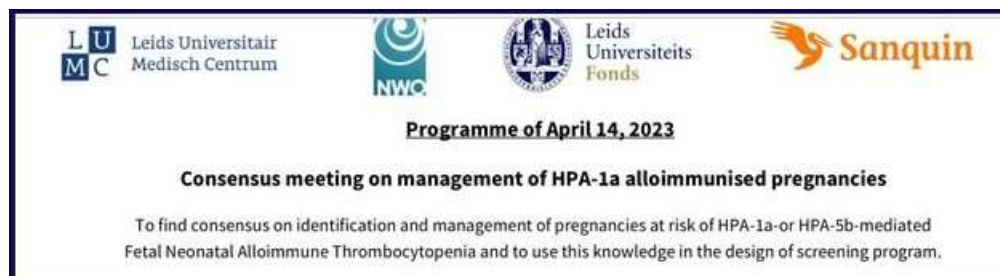
## **25 – 31 March – FNAIT Awareness Week.**

Our awareness week competition was won this year by one of our FNAIT families living in Northern Ireland.

## **April**

On April 13th and 14th, [Leiden University Medical Center](#) together with [Sanquin](#) (Sanquin Research and Diagnostic) Services, Holland, organized the **International Consensus Meeting on Fetal and Neonatal Alloimmune Thrombocytopenia: FNAIT**.

After the conference a spokesman for LUMC posted “We were pleased to welcome so many colleagues from various countries with expertise in fetal maternal medicine, in neonatology, in laboratory testing, in basic science and representatives from NAITbabies, who have direct personal experience in how FNAIT itself can impact the life of children and their families”.



## **May**

Support group Membership = 1,611 as of May 29 2023.

Naitbabies CIO run a private support group for FNAIT parents with members from all over the world.

## **May 31 2023 - End of Year**

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

**Naitbabies.org**



Registered Charity no: 1161698

Naitbabies.org

Unaudited Report and Accounts

31 May 2023

**Naitbables.org**  
**Report and accounts**  
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**Naltbables.org**

**General information**

**Trustees**

Y D Palmer

S Corke

M Minshall

A Palmer

**Independent Examiner**

Mr Neil Hallam FCCA

Crane & Johnston

Chartered Certified Accountants

11 Alverton Terrace

Penzance

Cornwall

TR18 4JH

**Bankers**

HSBC

1 Green Market

Penzance

Cornwall

TR18 2SD

**Contact address**

13 Redinnick Terrace

Penzance

Cornwall

TR18 4HR

**Website**

[www.naltbables.org](http://www.naltbables.org)

**Charitable Incorporated Organisation**

Registration number - 1161698

## **Naitbabies.org**

### **Trustees' Report**

The Trustees present their report and accounts for the period ended 31 May 2023.

#### **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. 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.

#### **Committee**

The following persons served as committee members during the period:

Y D Palmer  
S Corke  
M Minshall  
A Palmer

#### **Charitable objects**

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.

This report was approved by the board on 5/10/23 and signed on its behalf.



Y-D Palmer  
Trustee

**Independent examiner's report to the Trustees of Naitbables.org**

I report on the accounts of the charity for the year ended 31 May 2023, which are set out on pages 4 to 6.

**Respective responsibilities of trustees and examiner**

The charity's trustees are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year under section 144(2) of the Charities Act 2011 (the 2011 Act) and that an Independent examination is needed.

It is my responsibility to:

- examine the accounts under section 145 of the 2011 Act;
- to follow the procedures laid down in the General Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act; and
- to state whether particular matters have come to my attention.

**Basis of independent examiner's report**

My examination was carried out in accordance with the General Directions given by the Charity Commissioner. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts and the seeking of explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and, consequently no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the statement below.

**Independent examiner's statement**

In connection with my examination, no matter has come to my attention:

- which gives me reasonable cause to believe that, in any material respect, the requirements:
  - (a) to keep accounting records in accordance with section 130 of the 2011 Act; and
  - (b) to prepare accounts which accord with the accounting records and to comply with the accounting requirements of the 2011 Act have not been met; or
- to which, in my opinion, attention should be drawn 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

6/10/23  
Dated

**Naithables.org**  
**Receipts & Payments Account**  
**for the year ended 31 May 2023**

	2023 £	2022 £
<b>Receipts</b>		
<b>Receipts from charitable activities:</b>		
Donations	6,629	8,647
Fund Raising	12	-
Interest receivable	173	5
<b>Total receipts</b>	<u>6,814</u>	<u>8,652</u>
<b>Less: Payments</b>		
<b>Costs of charitable activities:</b>		
Telephone and fax	164	163
Travel and subsistence	"	358
Stationery and printing	81	31
Subscriptions	427	330
Bank charges	233	152
Insurance	123	123
Support	1,150	-
Sundry expenses	48	6
Accountancy fees	378	360
Advertising and PR	(166)	466
<b>Sub total</b>	<u>2,438</u>	<u>1,989</u>
<b>Asset purchases</b>		
Computer equipment & other equipment	<u>-</u>	<u>-</u>
<b>Sub total</b>	2,438	1,989
<b>Total payments</b>	<u>2,438</u>	<u>1,989</u>
<b>Net receipts for the year</b>	<u>3,376</u>	<u>6,663</u>
Cash at bank and in hand brought forward	45,611	38,948
<b>Cash at bank and in hand at 31 May 2023</b>	<u><u>48,987</u></u>	<u><u>45,611</u></u>




Naitbables.org  
Statement of assets and liabilities  
as at 31 May 2023

Notes	2023	2022
	£	£
<b>Monetary assets</b>		
Cash at bank and in hand	48,987	45,611
<b>Total</b>	<u>48,987</u>	<u>45,611</u>
<b>Unrestricted funds</b>	<u>48,987</u>	<u>45,611</u>
<b>Assets retained for the CIO's own use</b>		
(estimated written down value)	£	£
Computer equipment & other equipment - unrestricted funds	-	-
Computer equipment & other equipment purchased during the year - unrestricted funds	-	-
	<u>-</u>	<u>-</u>
<b>Liabilities</b>		
Grant payable - approved at year end	1,000	-
Accountancy fee - unrestricted fund	396	378
	<u>1,396</u>	<u>378</u>

The accounts were approved by the Trustees on 5/10/23 and signed on their behalf  
by:

  
Y D Palmer  
Trustee

  
A R Palmer  
Trustee

**Naitbabies.org**  
**Notes to the Accounts**  
**for the year ended 31 May 2023**

**1 Accounting policies**

***Accounting Convention***

The accounts have been prepared on the receipts and payments basis. The accounts are in accordance with applicable accounting standards and comply with the Charities (Accounts and Reports) Regulations issued under the Charities Act 2011.

***Receipts***

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

***Payments***

Expenditure is included on a payments basis, inclusive of any VAT which cannot be recovered.

**2 Funds**

	<b>2023</b>
	<b>£</b>
At 1 June 2022	45,611
Net receipts for the period	3,376
At 31 May 2023	<u>48,987</u>

**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 parties nor any debts secured on assets of the CIO.

**4 Trustees**

None of the trustees (or any persons connected with them) received any remuneration during the period.

None of the trustees were reimbursed for any expenses during the period.