



# NAITBABIES ANNUAL REPORT 2022



News and events from

1 June 2021 – 31 May 2022

**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 Commission reg. 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	Trustee
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  
England

<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:**

<https://www.naitbabies.org>

**Naitbabies is a member of:**

[Genetic Alliance UK](#)

[Rare Disease UK](#)

[Genetic Disorders Charities & Patient Group Network](#)

[Cambridge Rare Disease Network](#)

### **Our 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 the severe bleeding disorder 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 Fetal and 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 is a small Charitable Incorporated Organisation run by families whose children have been affected by the severe bleeding disorder Foetal and neonatal alloimmune thrombocytopenia –FNAIT.

Registered in the UK Naitbabies is 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 medical panel of doctors who have a special interest in this devastating disease.

## What is FNAIT?

**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, FnaIt affected babies can have platelet counts as low as 1k



Fetal and neonatal alloimmune thrombocytopenia results from incompatibility between mother and baby for platelet-specific antigens that have been inherited paternally.

The maternal immune response may make antibodies to destroy her baby's platelets which she sees as foreign. Platelet destruction can cause bleeding into major organs such as 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 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. Much rarer diseases are 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.

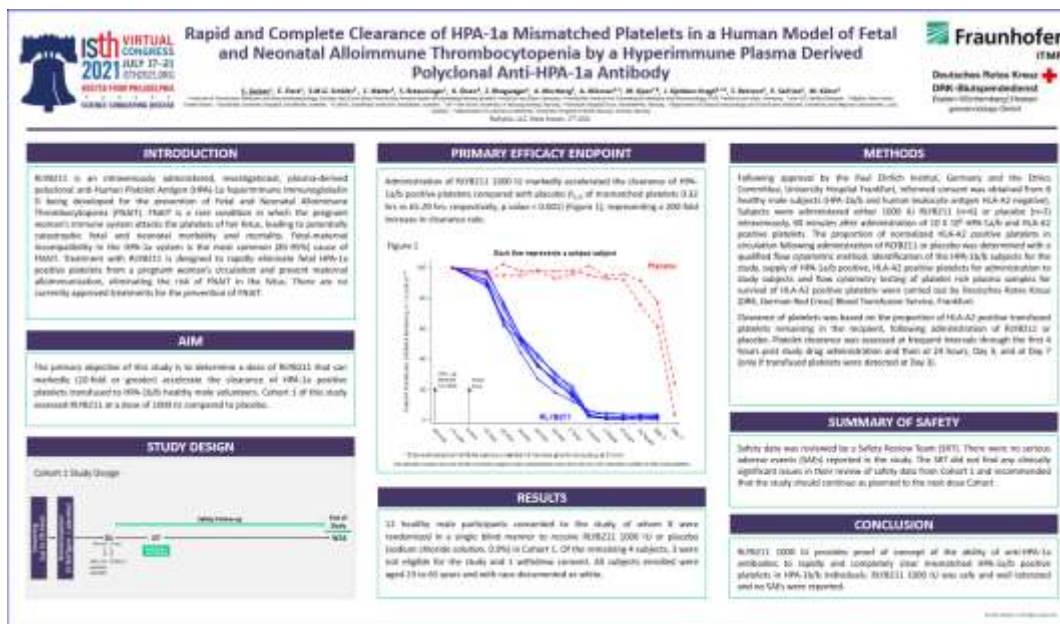
## June 2021



One of our lovely volunteers donating blood for Rallybio, the Connecticut based life science Company's FNAIT Study.

## July

Exciting milestone!! [Rallybio](#) Announces Clinical Proof of Concept for RLYB211, an Anti-HPA-1a Antibody for the Prevention of Fetal and Neonatal Alloimmune Thrombocytopenia (FNAIT) was presented on Monday 12 July, at the [ISTH2021](#) International Society on Thrombosis and Hemostasis 2021 Virtual Congress. See the Rallybio conference poster below.



## **August**

### **NHS Blood and Transplant**

August saw the start of the NHS Blood and Transplant plasma donation programme in England. Eleven plasma donation centers have been designated to date. Prior to this Plasma has been sourced from other countries.

## **September**

1-2 September 2021 saw the first ever ‘virtual’ European Platelet & Leucocyte Symposium. This year the conference was hosted by Israel and had been postponed from 2020 due to the covid-19 pandemic.

After cancelling all our 2020 fundraising events due to the pandemic, Saturday 4 September saw another intrepid Naitbabies team complete the annual army assault course ‘The Nuts Challenge’ held in London. Photos on this [link](#)

Sept 20. M4RD - Medics4RareDiseases hosted facts about FNAIT on their #RareDiseaseMonday Instagram portal. Only 28% of medics who took part had ever heard of this disease, which was quite shocking.

## **October**

FNAIT survey questionnaire near completion.

## **November**

AGM – 29 November

## **December**

Wednesday 1<sup>st</sup>

News release from Connecticut based life science Company Rallybio - “Reports Positive Data in Its Clinical Program for the Prevention of Fetal and Neonatal Alloimmune Thrombocytopenia (FNAIT).”

<https://investors.rallybio.com/news-releases/news-release-details/rallybio-reports-positive-data-its-clinical-program-prevention/>

## **January**

Friday 21. UK NSC meeting.

Tuesday Jan 25. Cambridge Rare Disease Network webinar. PLRH Patient led research hub

## **February**

### **28 Rare Disease Day**

Unfortunately due to the ongoing pandemic, this year we were still unable to attend any live events for Awareness week. However we had a great response online!!!





## MARCH

Thursday 3rd NHSBT Stakeholder meeting.

Monday 28th NHSBT New Strategy Launch meeting.

March 25 – 31 Awareness Week. Huge thanks to all who took part raising awareness around the world!



## April – Easter Break

## May

11/12 May PHC – Primary Health Care event at the NEC Birmingham UK.

## May 31 End of Year.

*Many thanks to everyone for reading our 2022 review  
and for your continued support!!!!*



Registered Charity no: 1161698

Naitbabies.org

Unaudited Report and Accounts

31 May 2022



**Naitbabies.org**  
**Report and accounts**  
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**Naitbabies.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.naitbabies.org](http://www.naitbabies.org)

**Charitable Incorporated Organisation**

Registration number - 1161698

**Naitbabies.org**  
**Trustees' Report**

The Trustees present their report and accounts for the period ended 31 May 2022.

**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:

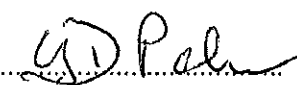
Y D Palmer  
S Corke  
M Minshall  
A Palmer

**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 18/11/22 and signed on its behalf.

  
Y D Palmer  
Trustee

**Naitbabies.org**

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

I report on the accounts of the charity for the year ended 31 May 2022, 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 Commissioner 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

24/11/22  
.....  
Dated


**Naitbabies.org**  
**Receipts & Payments Account**  
**for the year ended 31 May 2022**


	2022 £	2021 £
<b>Receipts</b>		
<b>Receipts from charitable activities:</b>		
Donations	8,647	4,146
Fund Raising	-	163
Interest receivable	5	8
<b>Total receipts</b>	<u>8,652</u>	<u>4,317</u>
<b>Less: Payments</b>		
<b>Costs of charitable activities:</b>		
Fundraising	-	323
Telephone and fax	163	(3)
Travel and subsistence	358	158
Stationery and printing	31	109
Subscriptions	330	323
Bank charges	152	173
Insurance	123	-
Sundry expenses	6	-
Accountancy fees	360	360
Advertising and PR	466	450
<b>Sub total</b>	<u>1,989</u>	<u>1,893</u>
<b>Asset purchases</b>		
Computer equipment & other equipment	<u>-</u>	<u>-</u>
<b>Sub total</b>	1,989	1,893
<b>Total payments</b>	<u>1,989</u>	<u>1,893</u>
<b>Net receipts for the year</b>	<u>6,663</u>	<u>2,424</u>
Cash at bank and in hand brought forward	38,948	36,524
<b>Cash at bank and in hand at 31 May 2022</b>	<u><u>45,611</u></u>	<u><u>38,948</u></u>

**Naitbables.org**  
**Statement of assets and liabilities**  
**as at 31 May 2022**

Notes	2022	2021
	£	£
<b>Monetary assets</b>		
Cash at bank and in hand	45,611	38,948
<b>Total</b>	<u>45,611</u>	<u>38,948</u>
<b>Unrestricted funds</b>	<u>45,611</u>	<u>38,948</u>
<b>Assets retained for the CIO's own use</b>		
(estimated written down value)	£	£
Computer equipment & other equipment - unrestricted funds	-	437
Computer equipment & other equipment purchased during the year - unrestricted funds	-	-
	<u>-</u>	<u>437</u>
<b>Liabilities</b>		
Accountancy fee - unrestricted fund	<u>378</u>	<u>360</u>

The accounts were approved by the Trustees on 18/11/22 and signed on their behalf by:

  
 YD Palmer  
 Trustee

  
 A R Palmer  
 Trustee

**Naitbabies.org**  
**Notes to the Accounts**  
**for the year ended 31 May 2022**

**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**

**2022**

**£**

At 1 June 2021

38,948

Net receipts for the period

6,663

At 31 May 2022

45,611

**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.