

# NAITBABIES

England & Wales · Charity number 1161698

## Details

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Other names	NAIT BABIES
Status	Registered
Legal form	CIO
Registered	2015-05-15
Register	<a href="#">View on the Charity Commission register</a>

## Contact

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Address	13 Redinnick Terrace Penzance TR18 4HR
Phone	01736447163
Email	<a href="mailto:info@naitbabies.org">info@naitbabies.org</a>
Website	<a href="http://www.naitbabies.org">www.naitbabies.org</a>

## Activities

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**Objects:** 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:** Activities for the public good Naitbabies support research into the causes, treatment and prevention of the severe bleeding disorder FNAIT which may cause unborn/newborn babies to bleed into their brain or other major organs. We provide support, advocacy and practical assistance and a worldwide family support communication network. Promote public awareness and advocate for prenatal screening.

## Classification

- **How:** Makes Grants To Individuals, Provides Advocacy/advice/information, Sponsors Or Undertakes Research, Other Charitable Activities
- **What:** Education/training, The Advancement Of Health Or Saving Of Lives, Other Charitable Purposes
- **Who:** People With Disabilities, Other Defined Groups, The General Public/mankind

## Geography

- Throughout England And Wales

## Finances

Period end	Income	Expenditure	Assets	Employees
2025-05-31	£3,007	£4,065	-	-
2024-05-31	£4,025	£4,161	-	-
2023-05-31	£5,814	£2,438	-	-
2022-05-31	£8,652	£1,989	-	-
2021-05-31	£4,317	£1,893	-	-

## Trustees

Name	Role	Appointed
YVONNE DOROTHEA PALMER	Chair	2011-04-27
ANDREA PALMER		2015-03-02
Michelle Minshall		2017-10-10
Rachael Walker		2024-04-09
STACY CORKE		2015-03-02

**NAITBABIES**

England & Wales - Charity number 1161698

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# Accounts

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# NAITBABIES ANNUAL REPORT 2025



**News and events from**

**1 June 2024– 31 May 2025**

## **Fetal and neonatal alloimmune thrombocytopenia - FNAIT**

Charitable Incorporated Organisation (Foundation).  
Registered in England and Wales No.1161698.

## **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	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

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

### **Website:**

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

## **Naitbabies are members of:**

[Genetic Alliance UK](#)

[Rare Disease UK](#)

[NORD USA National Organization for Rare Disorders](#)

## **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 medical panel of doctors who have a special interest in this devastating disease.

Watch our FNAIT video [here](#)

## What is FNAIT?

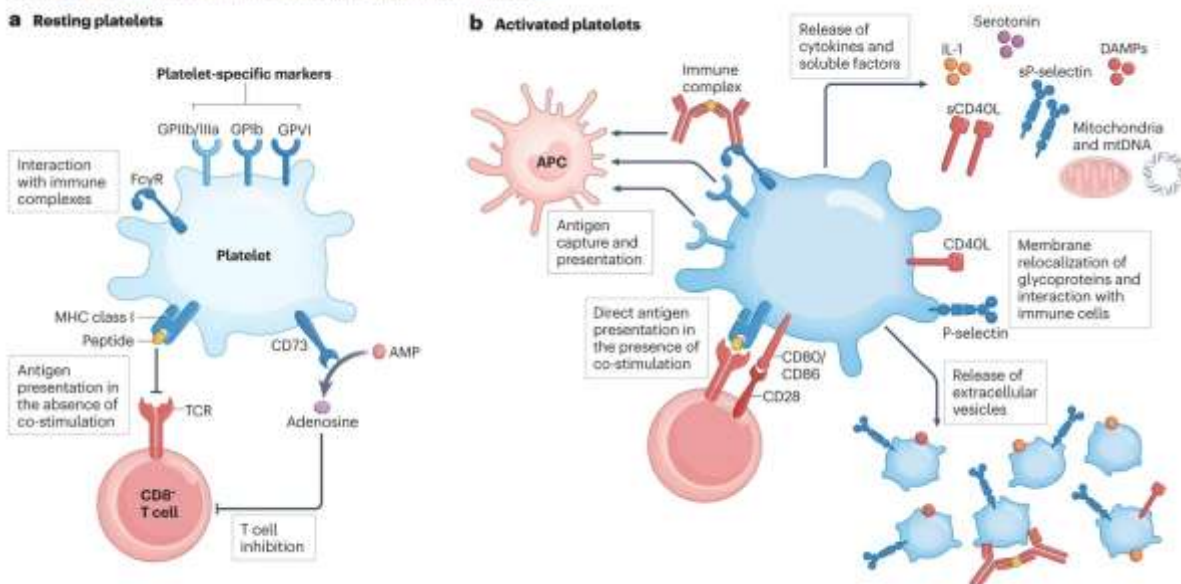


Fetal and neonatal alloimmune thrombocytopenia FNAIT (NAIT FMAIT) results from incompatibility between mother and baby for platelet-specific antigens that have been inherited from the father and are absent in mother.

The maternal immune response may make antibodies to destroy her baby's 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.

## What are platelets?

From: [The role of platelets in immune-mediated inflammatory diseases](#)





Petechial rash result from areas of haemorrhage into the dermis.

NAIT is analogous to the red blood cell disease Haemolytic 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.

## ***Highlights of our journey through 2024-25***

### **JUNE 2024**

#### **FNAIT – Mental health**

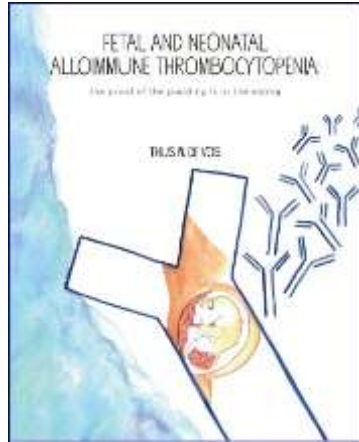
Naitbabies began an important FNAIT mental health research project in collaboration with Professor J B Bussel, Weill Cornell Medical University, New York, USA.

6 June - Pharmaceutical Company Janssen Research & Development, LLC, have registered the clinical trial study FREESIA-1. Nipocalimab is an investigational, monoclonal antibody that aims to selectively block the FcRn receptor to reduce levels of circulating immunoglobulin G (IgG) antibodies, including autoantibodies and alloantibodies. Nipocalimab is also known as M281 *FREESIA-1 represents the first placebo-controlled, randomized, multicentre clinical trial investigating the efficacy and safety of Nipocalimab, a non-invasive antenatal therapy, for the treatment of alloimmunized pregnant individuals at standard risk for FNAIT.*

*ClinicalTrials.gov ID NCT06449651*

[Study Details | A Study of Nipocalimab in Reducing the Risk of Fetal and Neonatal Alloimmune Thrombocytopenia \(FNAIT\) | ClinicalTrials.gov](#)

11 June - Professor Thijs W de Vos, Leiden Medical University, Netherlands has received the H.C.J.M. van Dijk prize at the 2024 NVB-TRIP Symposium for "the best dissertation of 2023-2024 within the field" Entitled "Fetal and Neonatal Alloimmune Thrombocytopenia: The proof of the pudding is in the eating" his dissertation can be read on this link <https://books.gildeprint.nl/thesis/586840-deVos/17/>



## JULY 2024

OUR NEW TRUSTEE Rachel Walker celebrated the run up to her 50<sup>th</sup> birthday by taking part in 50 park runs for NAIT babies!! Raising a magnificent £724!!!!



Rachel has three children, two of whom have been affected by FNAIT. Her first born, a son Otto, suffers from cerebral palsy and epilepsy. As there is no screening yet for FNAIT his intracranial haemorrhages were not picked up before his birth.

Rachel and husband Jamie have a 50% chance of every pregnancy being affected, due to Jamie's platelet type being 'HPA-1a/1b', which makes him heterozygous for HPA-1.

Out of two further pregnancies, both girls, one was not affected and one was. Rachel was treated for FNAIT with weekly infusions of IVIG and her affected daughter had a normal platelet count at birth.

## **AUGUST 2024**

8 August - Latest news from Rallybio, Connecticut, USA, Clinical Stage pharmaceutical company developing an FNAIT prophylaxis RLYB212:

*' – On Track to Initiate RLYB212 Phase 2 Dose Confirmation Trial in Pregnant Women at Higher Risk of FNAIT in 4Q 2024 – '*

[PDF Version](#)

## **SEPTEMBER 2024**

27 – 29 September. ESPGIXVII

Three trustees attended the Seventeenth European Symposium on Platelet and Granulocyte Immunobiology held in Ede, The Netherlands.

<https://sanquinacademy.nl/17th-european-symposium-on-platelet-and-granulocyte-immunobiology-espigi/>



## **OCTOBER/NOVEMBER 2024**

RALLYBIO's Amanda Hayward, Head of Global Business Development presented their research, in partnership with Health Lumen, on quantifying the proportion of women at risk of an FNAIT pregnancy in diverse populations in the United States at NORD24. Using genetic data, researchers found that nearly 20,000 pregnancies in the U.S. are at higher risk for FNAIT each year—far more than previously estimated.

The study highlights that non-white populations also carry significant FNAIT risk, challenging past assumptions. These findings make a compelling case for universal screening of pregnant women for FNAIT risk, regardless of race or ethnicity.

# Quantifying the proportion of women at risk of an FNAIT pregnancy in diverse populations in the United States

Amelia Hayward (a), James Cook (b), Joshua Card-Gowers (b), Tim Coker (b), Róisín Armstrong (a)

## Introduction

- Fetal and neonatal alloimmune thrombocytopenia (FNAIT) is a rare immune disorder that can occur during pregnancy and can lead to potentially catastrophic consequences in the fetus and newborn, including lifelong neurological disability and loss of the baby.
- FNAIT can arise due to an immune incompatibility between a pregnant woman and her fetus in a specific platelet antigen called HPA-1. HPA-1a negative women carrying an HPA-1a positive fetus are at risk of alloimmunizing and developing FNAIT. Women who also carry the HLA-DRB3\*01:01 allele are 25x more likely to alloimmunize and are therefore considered at higher risk.
- To date, the risk of FNAIT has only been well characterized in White Caucasian populations.

## Objective

- The aim of this study was to quantify:
  - The number of women across racial and ethnic groups in the US likely to be at-risk and at higher-risk of maternal alloimmunization and FNAIT based on their HPA-1 and HLA-DRB3\*01:01 genotypes.
  - The expected number of affected pregnancies, based on the genotype counts and the US birth rate.

## Assumptions and Limitations

- Hardy-Weinberg equilibrium (HWE) was considered applicable in calculating the carrier frequencies of both HPA-1 and HLA-DRB3\*01:01 from the allele frequencies.
- All women in the US were considered equally likely to become pregnant; this study did not account for differences in the ancestral composition of the population of women overall vs. the population of women of child-bearing age.
- The 2023 US birth rate was calculated using the reported number of births in the US and the number of women in the US population, and assumed to be the same in all ancestry groups in the US.
- Only maternal genotypes were considered.

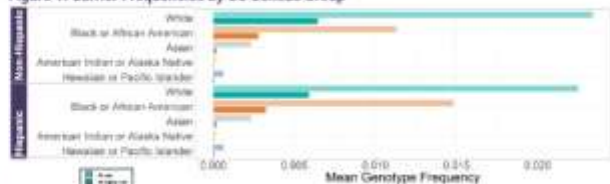
## Methods

- Allele frequencies were obtained from gnomAD v4 for HPA-1 with an additional article<sup>1</sup> (denoted as \* in Table 1) used to provide more granular HPA-1 frequencies in East Asian populations, and from the US National Marrow Donor Registry (NMDR) for HLA-DRB3\*01:01. HPA-1a negative rates and HLA-DRB3\*01:01 carrier frequency were both calculated from the population specific allele frequencies assuming HWE.
- The proportion of women 'at-risk' of FNAIT in each ancestry was taken as the HPA-1a negative proportion, and the proportion of women at higher-risk of FNAIT was obtained by multiplying the HPA-1a negative proportion by the population-specific HLA-DRB3\*01:01 carrier frequency after mapping the gnomAD v4 ancestry groups to the NMDR populations.
- The number of women 'at-risk' and at 'higher-risk' of FNAIT was calculated by multiplying the genotype frequency by the number of women in the US in 2023 after mapping population groups to US Census Groups.

Table 1. Carrier Frequencies by Ancestry Group

US Census Population	gnomAD Ancestry Group	HLA-DRB3*01:01	HPA1b	Birth
North American American	Admixed American - Amerindigenous	0.3150	1.72E-04	5.53E-03
European/Caucasian	European (non-Finnish)	0.2756	2.34E-02	6.44E-03
	Ashkenazi Jewish	0.2756	2.35E-02	6.51E-03
	Middle Eastern	0.2756	2.25E-02	6.21E-03
	European (Finnish)	0.2756	2.03E-02	5.60E-03
	Ariah	0.2756	2.22E-02	6.13E-03
Mexican or Chicano	Admixed American - European	0.2619	2.25E-02	5.89E-03
Caribbean Black	African / African American	0.2497	1.13E-02	2.83E-03
African American pop 2	African / African American	0.2492	1.13E-02	2.82E-03
African	African / African American	0.2363	1.13E-02	2.68E-03
Caribbean Hispanic	Admixed American - African	0.2189	1.48E-02	3.25E-03
Middle East / North Africa	Middle Eastern	0.1741	2.25E-02	3.52E-03
South Asian Indian	South Asian	0.0971	9.28E-03	9.01E-04
Korean	East Asian - Korean*	0.1410	1.44E-04	2.03E-03
Japanese	East Asian - Japanese*	0.1213	4.00E-06	4.85E-07
Southeast Asian	East Asian - Malay*	0.0861	6.25E-04	5.38E-05
Chinese	East Asian - Han Chinese*	0.0750	3.60E-05	2.73E-06
Filipino	East Asian - Indonesian*	0.0585	8.10E-05	4.77E-06

Figure 1. Carrier Frequencies by US Census Group



## Results

- Genotype carrier frequencies for HLA-DRB3\*01:01, HPA1b and both are displayed in table 1 for the US NMDR population and gnomAD v4 ancestry groups, and in figure 1 for US Census groups.
- Risk of alloimmunization and FNAIT was highest in White Caucasian populations, with the highest proportions in the Ashkenazi Jewish population (2.34% and 0.62% of women at-risk and at higher-risk, respectively), followed by non-Finnish Europeans (2.34% and 0.64%), Middle Eastern (2.25% and 0.62%), Ariah (2.25% and 0.62%), White Hispanic (2.25% and 0.58%) and Finnish (2.03% and 0.56%).
- Women in non-White population groups were also found to carry higher FNAIT risk, with the highest proportions in the Caribbean Hispanic population (1.46% and 0.23%), followed by African / African American (1.13% and 0.28%) and women of South Asian, East Asian, and Amerindigenous ancestries (0.1% and 0.1%).
- A total of 905,602 women are estimated to carry both risk alleles (HPA-1a negative, HLA-DRB3\*01:01 positive). A further 2,475,187 (or 2,583,750 in total) women carry the HPA-1a negative risk genotype.
- Multiplying these figures by the 2023 US birth rate gives estimated totals of 70,095 at-risk of FNAIT and 19,822 pregnancies at higher risk of FNAIT in the US in 2023.

## Conclusions

- This study is the first to report FNAIT risk across diverse ancestries using data from genetic databases to calculate the expected number of women carrying the underlying causal genetic variants.
- Estimations of the FNAIT at-risk and at higher-risk populations in White Caucasian groups were broadly in line with previously reported estimates of allele frequencies.
- With the identification of non-White populations also carrying higher FNAIT risk, this study suggests that nearly 20,000 pregnancies in the US are at higher FNAIT risk each year, a significantly greater number than previously estimated.
- These data support the case for screening all pregnant women for potential FNAIT risk, regardless of race and ethnicity.

Presented at the 2024 American Society of Human Genetics Meeting, November 5-9 (Orlando, FL); Blood 2024; 117(11):2177-2181; Blood Transfus; 2024; 20(2):248-274. Contact: For additional information, please contact: Amelia Hayward, ahayward@ucl.ac.uk

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5 November – NAIT babies research with Professor J B Bussel and his team at Weill Cornell Medical University, New York, USA.  
 "Analysis of Screening for Autism Spectrum Disorders in Children Affected By FNAIT with and without Intra-Cranial Hemorrhage"  
 Katherine A. Knightly, Margaret H. McKelvy, James B. Bussel, Emilie Vander Haar, Eleanore A. McFarland, Thea D. Palmer, Stephanie V. Volpe, Stacy Corke.  
 Published in the American Society of Hematology 'Blood' Journal.  
<https://doi.org/10.1182/blood-2024-205475>

DECEMBER 2024

3 December – NAIT babies AGM

7 – 10 December – ASH, the 66th American Society of Hematology Annual Meeting and Exposition took place on December 7-10, 2024, in San Diego, California. An oral and abstract poster was presented of the research paper in the ASH Blood journal.

[Analysis of Screening for Autism Spectrum Disorders in Children Affected By Fnaait with and without Intra-Cranial Hemorrhage | Blood | American Society of Hematology](#)

NAIT babies published research “*Medical Problems of Mothers of Children with Fetal-Neonatal Alloimmune Thrombocytopenia (FNAIT): Autoimmunity and Psychological Symptoms*” can be found on this link <https://ash.confex.com/ash/2024/webprogram/Paper203685.html>

9 December - Johnson & Johnson announce FREESIA-3 Clinical Trial “Nipocalimab v IVIG”, being held in the United Kingdom and other European countries.

Scientific name: “Multicenter, open-label, randomised study of Nipocalimab or IVIG in pregnancies at risk of fetal and neonatal alloimmune thrombocytopenia (FREESIA-3)”.

Principal investigator: Dr Katie Morris, Birmingham Women’s Hospital.

UK Study participating centres:

*Birmingham Women's Hospital, Mindelsohn Way, Edgbaston, Birmingham, B15 2TG*

*Liverpool Women's Hospital, Crown Street, Liverpool, L8 7SS*

*Queen Charlotte's and Chelsea Hospital, Du Cane Road, London, W12 0HS*

United Kingdom link: <https://www.isrctn.com/ISRCTN17841362>

ClinicalTrials.gov number NCT06533098



Secondary identifying numbers: 80202135FNAIT3003, CPMS 62590

## JANUARY 2025

10 January - Naitbabies were invited to the first NHSBT “Plasma for Medicines” meeting.


The UK are now producing their own plasma for medicines, which had previously been purchased from the USA and the EU.

Plasma contains antibodies that can be used to treat many illnesses and injuries including:



Rare diseases    Immune disorders    Heart conditions    Genetic conditions    Blood disorders    Infectious disease

Nervous system disorders    Liver disease    Kidney failure    Sepsis    Major burns    Major traumas



Save lives  
Give plasma

## February 2025

11 February - The clinical-stage biotechnology company [rallybio.com](https://rallybio.com) have dosed the first participant in the Phase 2 clinical trial program RLYB212. The company expect pharmacokinetic and safety data from the second trimester in the second quarter of 2025, with pharmacokinetic and safety data at the time of delivery expected in the third quarter of 2025.

Read the full news release - <https://investors.rallybio.com/news-releases/news-release-details/rallybio-announces-initiation-dosing-rlyb212-phase-2-clinical>

28 February – Rare Disease Day 2025



## March/April

### 25 – 31 March - FNAIT Annual Awareness week

2 April – At the invitation of Doctor Mike Desborough, Honorary Consultant Haematologist, NHS Blood and Transplant, Thea and Andrea Palmer, Trustees at Naitbabies presented at the first **NHSBT UK National FNAIT Meeting** held at Pembroke College, Oxford University.



8 April - **Rallybio LLC** announced they are to discontinue development of their RLYB212 Program. This was based on pharmacokinetic (PK) data from the Phase 2 clinical trial' demonstrating the inability of the RLYB212 dose regimen to achieve predicted target concentrations, as well as the minimum target concentration required for efficacy.

[\*\*Rallybio to Discontinue Development of RLYB212 for Prevention of FNAIT | Rallybio\*\*](#)

11 April – Naitbabies research article has been published in the British Journal of Haematology. "Fetal-neonatal alloimmune thrombocytopenia: Mothers are affected too"

<http://doi.org/10.1111/bjh.20112>

April 2025 - Rising to the challenge: an international Delphi consensus study on fetal and neonatal alloimmune thrombocytopenia.

[https://doi.org/10.1016/S2352-3026\(25\)00029-8](https://doi.org/10.1016/S2352-3026(25)00029-8)

## May

14 May – NHSBT National Blood Week – media partners.

31 May – Naitbabies End of Year.

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

***SAVING BABIES ONE TREATMENT AT A TIME!!!!***



**Naitbabies.org**

Charity registration number: 1161698

# Naitbabies.org

Annual Report and Financial Statements

for the Year Ended 31 May 2025

# **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 2025.

### **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 20 August 2025 and signed on its behalf by:



.....  
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 2025.

### 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

21 August 2025

## Naitbabies.org

### Receipts & Payment Account for the Year Ended 31 May 2025

	<b>Total 2025 £</b>	<b>Total 2024 £</b>
<b>Receipts:</b>		
<b><i>Receipts from charitable activities</i></b>		
Donations	2,094	3,072
Fundraising	28	134
Interest receivable	885	819
Total Receipts	<u>3,007</u>	<u>4,025</u>
<b>Payments:</b>		
<b><i>Costs of charitable activities</i></b>		
Accountancy	(414)	(396)
Advertising and PR	-	(65)
Bank charges	(150)	(155)
Conferences and training	(641)	(1,664)
Equipment expensed	-	(342)
Insurance	(149)	(123)
PC consumables and software	-	(217)
Stationery and printing	(29)	(77)
Subscriptions	(496)	(421)
Sundry	(6)	(16)
Telephone	(193)	(193)
Travel and subsistence	<u>(1,987)</u>	<u>(492)</u>
Total Payments	<u>(4,065)</u>	<u>(4,161)</u>
Net (payments)/receipts	(1,058)	(136)
<b>Reconciliation of cash funds</b>		
Total cash funds brought forward	<u>48,851</u>	<u>48,987</u>
Total cash funds carried forward	<u>47,793</u>	<u>48,851</u>

# Naitbabies.org

## (Registration number: 1161698) Statement of Assets & Liabilities as at 31 May 2025

	2025 £	2024 £
<b>Cash Funds</b>		
Cash at bank and in hand	47,793	48,851
<b>Unrestricted income funds</b>		
Unrestricted funds	47,793	48,851
<b>Total funds</b>	47,793	48,851
<b>Assets retained for the CIO's own use</b> (estimated written down value)		


	2025 £	2024 £
<b>Note</b>		
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.

	2025 £	2024 £
<b>Note</b>		
Accountancy fee	438	415

The financial statements were approved by the trustees, and authorised for issue on 20 August 2025 and signed on their behalf by:

.....  .....

Y D Palmer  
Trustee

.....  .....

A Palmer  
Trustee

# Naitbabies.org

## Notes to the Financial Statements for the Year Ended 31 May 2025

### 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.

Two trustees (2024: no trustees) were reimbursed expenses from the charity during the year totalling £334 (2024: £Nil).

### 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.

**NAITBABIES**

England & Wales - Charity number 1161698

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# Accounts

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# 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.

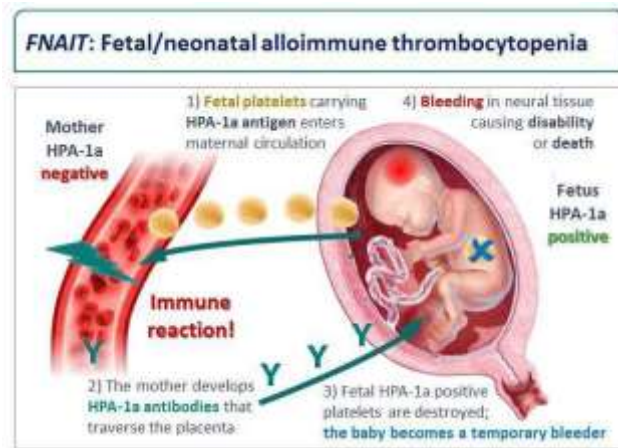
Registered in the UK we are the only organisation for this disorder. We provide information to the public in general.

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 is 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.

### Intracranial Cysts: Imaging

Classification of Intracranial Cysts according to Origin or Pathogenesis

- Normal and/or variant: Choroid plexus (subependymal), enlarged perivascular spaces (PVS), meningeal, meningoepithelial, germinal.
- Congenital: Arachnoid, colloid, epidermoid, dermoid, neurocysticercosis, Rathke cleft.
- Traumatic and/or vascular infarction: Porencephalic, aneurysmal, hydatid, other parasitic cysts.
- Tumor-associated meningoepithelial: Meningeoma (with trapped embryonic fluid [EMF]), schwannoma (with walled-off cyst), primary adenoma (with enlarged PVS), meningioangioma (with enlarged PVS).

**Choroid Plexus Cysts**

**Non-neoplastic epithelial-lined cysts**

A) Transverse graphic shows multiple cystic masses in the choroid plexus.

B) Transverse contrast-enhanced T1W MRI image in a healthy man shows bilateral CPCs with peripheral and nodular enhancement.

**Enlarged PVS, perivascular space, Virchow-Robin spaces**

B) Transverse contrast-enhanced T1W image shows typical ring-enhancing enlarged PVS in right basal ganglia. The cluster of variable sized cysts in asymmetric appearance.

C) Transverse T2 W-MRI image shows multiple tubular-appearing cysts (arrows) in centrum semiovale and subcortical white matter of both hemispheres. The cysts vary in size and focally expand but otherwise spare the overlying cortex.

**Arachnoid Cysts**  
Intra- or extra-axial space-occupying (benign)

**Rathke Cleft Cyst**  
Congenital meningoepithelial cysts

Sagittal post-contrast MRI image shows rounded mass (red arrow) separate from and just above the pituitary gland (green arrow). This cyst has moderately high protein content and is incompressible.

**Porencephalic Cysts**

**Hydatid Cysts**

**Multiloculated amebic abscess**

Intracranial cysts appearing lesion

Is extra-axial?

- Extra-axial
  - Is large or lobulated?
    - Supratentorial: Meningeal (Meningeal Cyst, MCA, MCA), dural (Meningeal Cyst, MCA, MCA)
    - Infratentorial: Arachnoid (Arachnoid Cyst, MCA, MCA)
  - Is large or lobulated?
    - Supratentorial: Epidermoid (Epidermoid Cyst, MCA, MCA), Dermoid (Dermoid Cyst, MCA, MCA)
    - Infratentorial: Epidermoid (Epidermoid Cyst, MCA, MCA), Dermoid (Dermoid Cyst, MCA, MCA)
- Intra-axial
  - Is large or lobulated?
    - Supratentorial: Meningeal (Meningeal Cyst, MCA, MCA), dural (Meningeal Cyst, MCA, MCA)
    - Infratentorial: Epidermoid (Epidermoid Cyst, MCA, MCA), Dermoid (Dermoid Cyst, MCA, MCA)
  - Is large or lobulated?
    - Supratentorial: Epidermoid (Epidermoid Cyst, MCA, MCA), Dermoid (Dermoid Cyst, MCA, MCA)
    - Infratentorial: Epidermoid (Epidermoid Cyst, MCA, MCA), Dermoid (Dermoid Cyst, MCA, MCA)

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.

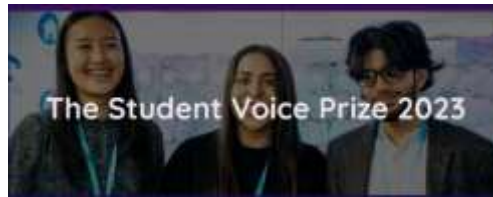
### **October 2023**

#### **'The Student Voice Prize'.**

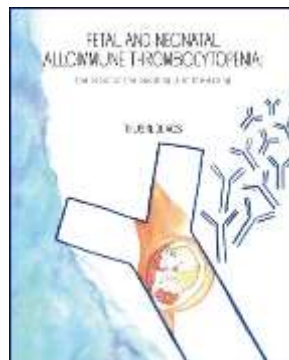


Naitbabies took part in the 2023 Student Voice Prize being run by M4RD – Medics for Rare Diseases and the Rare Beacon organisation.

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 loses 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**

2<sup>nd</sup> 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**

## **Contents**

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Independent Examiner's Report	4
Receipts & Payment Account	5
Statement of Assets & Liabilities	6
Notes to the Financial Statements	7

# 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

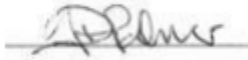
M Minshall

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 black ink, appearing to read 'Y D Palmer', 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

## Naitbabies.org

### Receipts & Payment Account for the Year Ended 31 May 2024

	<b>Total 2024 £</b>	<b>Total 2023 £</b>
<b>Receipts:</b>		
<b><i>Receipts from charitable activities</i></b>		
Donations	3,072	5,629
Fundraising	134	12
Interest receivable	819	173
Total Receipts	<u>4,025</u>	<u>5,814</u>
<b>Payments:</b>		
<b><i>Costs of charitable activities</i></b>		
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	<u>(4,161)</u>	<u>(2,438)</u>
Net (payments)/receipts	(136)	3,376
<b>Reconciliation of cash funds</b>		
Total cash funds brought forward	<u>48,987</u>	<u>45,611</u>
Total cash funds carried forward	<u>48,851</u>	<u>48,987</u>

# Naitbabies.org

## (Registration number: 1161698) Statement of Assets & Liabilities as at 31 May 2024

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

	2024 £	2023 £
<b>Note</b>		
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.

	2024 £	2023 £
<b>Note</b>		
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

# Naitbabies.org

## 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.

**NAITBABIES**

England & Wales - Charity number 1161698

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# Accounts

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# 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

**Type of governing document:** Constitution  
**How the charity is constituted:** Charitable Incorporated Organisation (CIO) Foundation  
**Date of governing document:** 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.

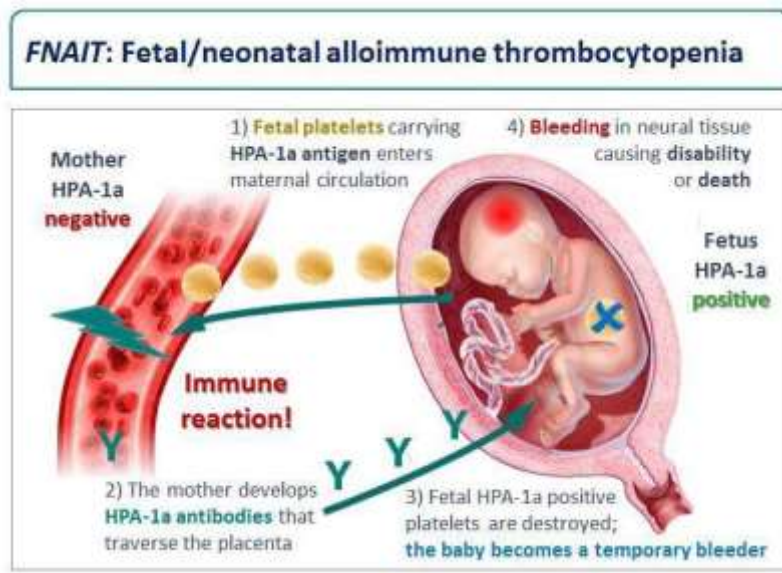
Registered in the UK we are the only organisation for this disorder. We provide information to the public in general.

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.

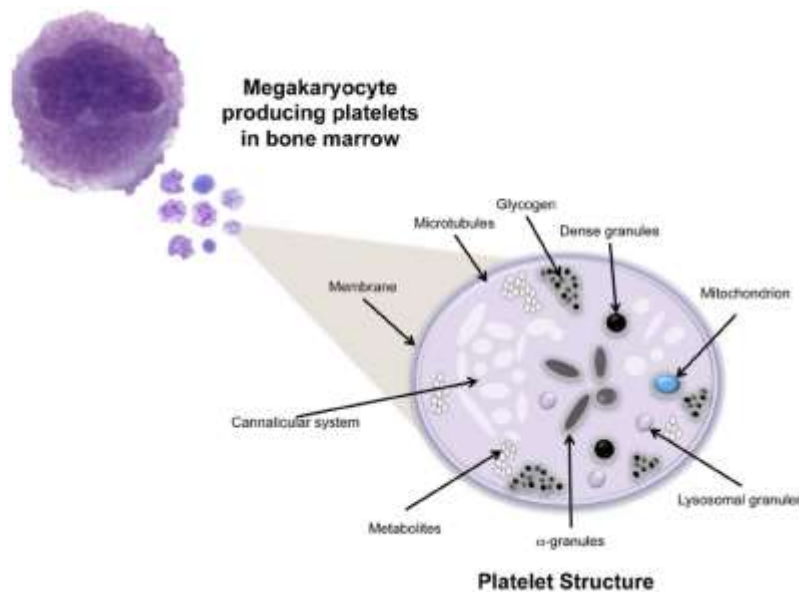
A healthy platelet count should be over 200k, FnaIt affected babies can have platelet counts as low as 1k



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.

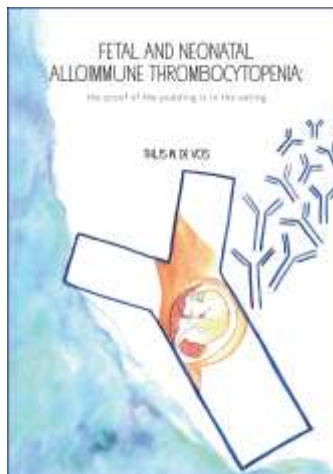
Naitbabies have been collaborating with Dr J B Bussel, Weill Cornell Medical University on a questionnaire for women who have fetal and neonatal alloimmune thrombocytopenia. This research project was started in 2020 and delayed for 2 years due to the Covid pandemic.

## **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-rlyb212-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](http://Naitbabies.org)

Registered Charity no: 1161698

Naitbabies.org

Unaudited Report and Accounts

31 May 2023

**Naibables.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

**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 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
	<u>6,814</u>	<u>8,652</u>
<b>Total receipts</b>		
<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
	<u>2,438</u>	<u>1,989</u>
<b>Sub total</b>		
<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>48,987</u>	<u>45,611</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 GIO'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>
	<u>-</u>	<u>-</u>
<b>Liabilities</b>		
Grant payable - approved at year end	1,000	-
Accountancy fee - unrestricted fund	<u>396</u>	<u>378</u>
	<u>1,396</u>	<u>378</u>

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

  
 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.

**NAITBABIES**

England & Wales - Charity number 1161698

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# Accounts

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# 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

**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 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.**

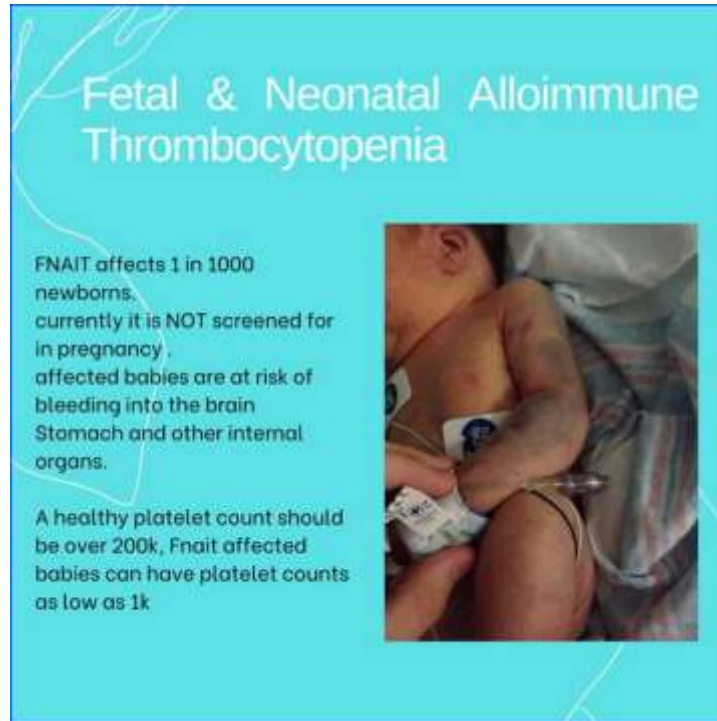
Naitbabies is a small Charitable Incorporated Organisation run by families whose children have been affected by the severe bleeding disorder Foetal and neonatal alloimmune thrombocytopenia –FNAIT.

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, Fnaït 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.

# Highlights from our FNAIT journey through the last year:

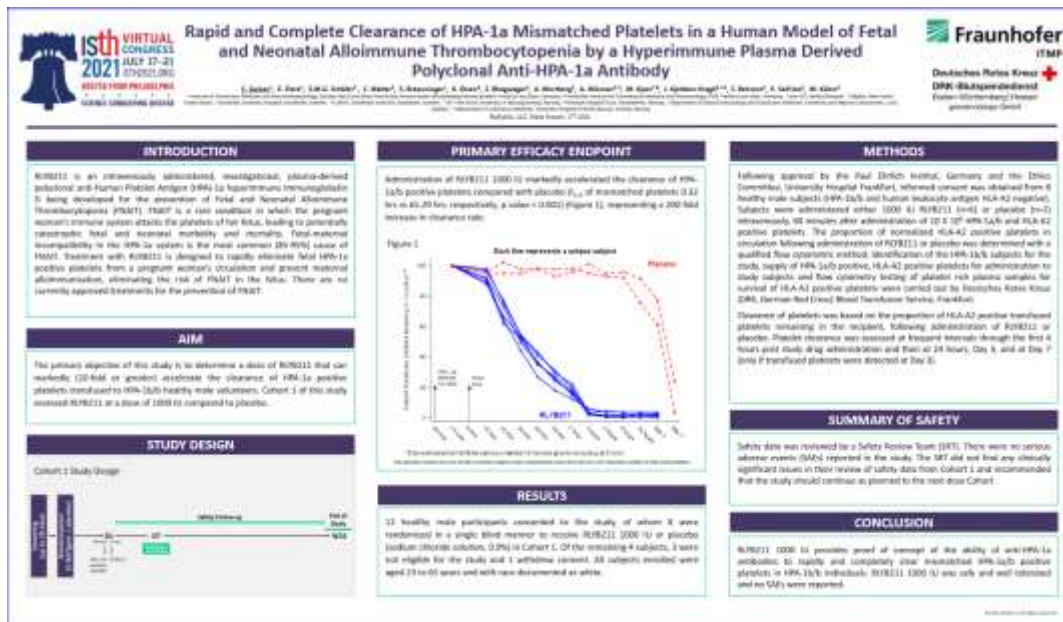
## June 2021



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  
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**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 Charly Commisssion 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:

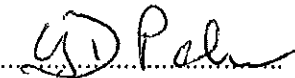
Y D Palmer  
S Corke  
M Minshall  
A Palmer

**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 know 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**


	<b>2022</b>	<b>2021</b>
	<b>£</b>	<b>£</b>
<b>Receipts</b>		
<b>Receipts from charitable activities:</b>		
Donations	8,647	4,146
Fund Raising	-	163
Interest receivable	5	8
	<u>8,652</u>	<u>4,317</u>
<b>Total receipts</b>		
<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
	<u>1,989</u>	<u>1,893</u>
<b>Sub total</b>		
<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>

**Natbabies.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>-</u>
	<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.

<b>2 Funds</b>	<b>2022</b>
	<b>£</b>
At 1 June 2021	38,948
Net receipts for the period	6,663
At 31 May 2022	<u>45,611</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.

**NAITBABIES**

England & Wales - Charity number 1161698

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# Accounts

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# NAITBABIES ANNUAL REPORT 2021



News and events

1 June 2020 - 31 May 2021

**Fetal and neonatal alloimmune thrombocytopenia – FNAIT  
(NAIT/FMAIT)**

## **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

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

**Website:** [www.naitbabies.org](http://www.naitbabies.org)

### **Naitbabies are members of:**

[Genetic Alliance UK](#)  
[Rare Disease UK](#)

## **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 NAIT 'neonatal alloimmune thrombocytopenia' also known as FNAIT or FMAIT.

## **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 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;

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

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 medical panel of doctors who have a special interest in this devastating disease.

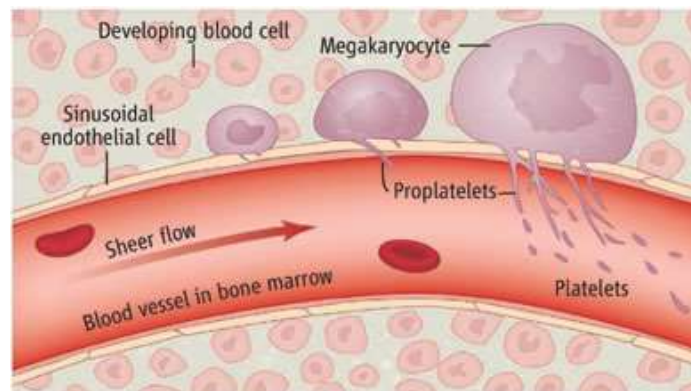
Watch our FNAIT video [here](#)

## 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 her baby's 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.



Platelets forming in bone marrow

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.

## Our journey through the past year:

June 2020.

The Covid-19 pandemic and restrictions that began in March are still in effect at the start of our fiscal year beginning 1<sup>st</sup> June 2020.

Like many we have been getting used to working entirely from home at this time, scheduling and attending 'virtual' meetings and conferences. Our normal FNAIT stands/exhibitions for the year have been cancelled or postponed, as have our fundraising events.

FNAIT Progress update, 1 June, by James B Bussel, MD. [Pediatric Hematology & Oncology, New York, NY](#) Read more [here](#)

08 – 10 June. We were due to exhibit at the BMFMS British Maternal and Fetal Medicine Society, the Neonatal Society and BAPM - British Association of Perinatal Medicine - Perinatal Conference being held in London, sadly this was our first conference to be postponed due to Covid-19.

During June/July we embarked on some exciting new projects with FNAIT medical professionals and hope to bring more news at a later date.

September:

The European Symposium on Platelet & Granulocyte Immunobiology to have been held in Israel has been postponed until next year.

August.



Our online Parents Support Group membership continues to rise. We have also welcomed many new babies throughout the past year.

September/November

Rallybio are a biopharmaceutical company committed to identifying and accelerating the development of life-transforming therapies for patients with severe and rare disorders and who we have been collaborating with, released their brilliant FNAIT Animation, which can be seen on

this link - <https://rallybio.com/>

November 2020 Rallybio announced the following news [First-in-Human Dosing in RLYB211 Phase 1/2 Study. RLYB211 is in Clinical Development for the Prevention of FNAIT.](#)

Read more about the FNAIT programs. <https://rallybio.com/pipeline/rlyb211-rlyb212/>

December

Meetings and Christmas!

January/February 2021

9 February. UK NSC Stakeholders Focus Group Meeting

24 February. We connected with Monique Kinney from the US charity 'Allo Hope Foundation, which support people with the alloimmune disease HDFN – haemolytic disease of the fetus and newborn.

28 Feb - Rare Disease Day.

March

25 – 31 March FNAIT Awareness Week – Naitbabies 10 year anniversary. Thanks to all who told their stories and to all who generously **donated!** As our Board members are volunteers, all money raised goes to into our organisations work!

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

April

On Thursday 18 April we attended the on-line Conference –'Innovations in Fetal Therapy', hosted by Dr D Oepkes, Leiden University Medical Center, Netherlands.

May 31 End of Year.

***Many thanks to everyone for reading our 2021 review  
and for your continued support!!!!***



**Naitbabies.org**

Registered Charity no: 1161698

**Naitbabies.org**  
**Unaudited Report and Accounts**  
**31 May 2021**

**Naitbabies.org**  
**Report and accounts**  
**Contents**

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Trustees' report	2
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Receipts and payments account	4
Statement of assets and liabilities	5
Notes to the accounts	6

**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 2021.

**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 know 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 18/11/2021 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 2021, 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.

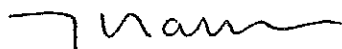
**Basis of independent examiner's report**

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

23rd November 2021

Dated


**Naitbabies.org**  
**Receipts & Payments Account**  
**for the year ended 31 May 2021**


	<b>2021</b>	<b>2020</b>
	<b>£</b>	<b>£</b>
<b>Receipts</b>		
<b>Receipts from charitable activities:</b>		
Donations	4,146	11,994
Fund Raising	163	386
Interest receivable	8	64
	<hr/>	<hr/>
<b>Total receipts</b>	<b>4,317</b>	<b>12,444</b>
<b>Less: Payments</b>		
<b>Costs of charitable activities:</b>		
Fundraising	323	1,679
Telephone and fax	(3)	178
Travel and subsistence	158	2,742
Stationery and printing	109	1,181
Subscriptions	323	328
Bank charges	173	206
Insurance	-	35
Support	-	500
Sundry expenses	-	1
Accountancy fees	360	360
Advertising and PR	450	7,846
	<hr/>	<hr/>
<b>Sub total</b>	<b>1,893</b>	<b>15,056</b>
<b>Asset purchases</b>		
Computer equipment & other equipment	-	1,310
	<hr/>	<hr/>
<b>Sub total</b>	<b>1,893</b>	<b>16,366</b>
<b>Total payments</b>	<b>1,893</b>	<b>16,366</b>
	<hr/>	<hr/>
<b>Net receipts for the year</b>	<b>2,424</b>	<b>(3,922)</b>
Cash at bank and in hand brought forward	36,524	40,446
	<hr/>	<hr/>
<b>Cash at bank and in hand at 31 May 2021</b>	<b>38,948</b>	<b>36,524</b>

**Naitbabies.org**  
**Statement of assets and liabilities**  
**as at 31 May 2021**

Notes	2021	2020
	£	£
<b>Monetary assets</b>		
Cash at bank and in hand	38,948	36,524
<b>Total</b>	<u>38,948</u>	<u>36,524</u>
<b>Unrestricted funds</b>	<u>38,948</u>	<u>36,524</u>
<b>Assets retained for the CIO's own use</b>		
(estimated written down value)	£	£
Computer equipment & other equipment - unrestricted funds	437	649
Computer equipment & other equipment purchased during the year - unrestricted funds	-	873
	<u>437</u>	<u>1,522</u>
<b>Liabilities</b>		
Accountancy fee - unrestricted fund	<u>360</u>	<u>360</u>

The accounts were approved by the Trustees on 18/11/2021 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 2021**

**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.

<b>2 Funds</b>	<b>2021</b>
	<b>£</b>
At 1 June 2020	36,524
Net receipts for the period	2,424
At 31 May 2021	<u><u>38,948</u></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.

One of the trustees was reimbursed expenses of £5 during the period.