



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

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.

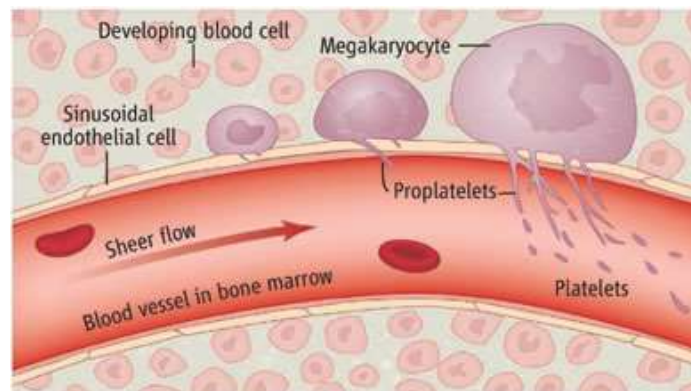
Watch our FNAIT video [here](#)

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 1st 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

	Page
General information	1
Trustees' report	2
Independent Examiner's Report	3
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

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 known as NAIT or FNAIT). In particular by the provision of support, advocacy and practical assistance as the trustees shall think fit;
2. To carry out, or to provide funds to support research into NAIT/FNAIT, its causes, treatment and prevention and publish the useful results of such research; and
3. To advance the education of the public, in particular those involved in the diagnosis, treatment and care of those suffering from NAIT/FNAIT.

This report was approved by the board on 18/11/2021 and signed on its behalf.


Y D Palmer
Trustee

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.

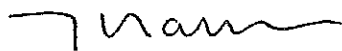
Basis of independent examiner's report

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

	2021	2020
	£	£
Receipts		
Receipts from charitable activities:		
Donations	4,146	11,994
Fund Raising	163	386
Interest receivable	8	64
Total receipts	<u>4,317</u>	<u>12,444</u>
Less: Payments		
Costs of charitable activities:		
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
Sub total	<u>1,893</u>	<u>15,056</u>
Asset purchases		
Computer equipment & other equipment	<u>-</u>	<u>1,310</u>
Sub total	1,893	16,366
Total payments	<u>1,893</u>	<u>16,366</u>
Net receipts for the year	<u>2,424</u>	<u>(3,922)</u>
Cash at bank and in hand brought forward	36,524	40,446
Cash at bank and in hand at 31 May 2021	<u><u>38,948</u></u>	<u><u>36,524</u></u>


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

	Notes	2021	2020
		£	£
Monetary assets			
Cash at bank and in hand		38,948	36,524
Total		<u>38,948</u>	<u>36,524</u>
Unrestricted funds		<u>38,948</u>	<u>36,524</u>
Assets retained for the CIO's own use			
(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>
Liabilities			
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.

2 Funds

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