

Charity Registration No: 1144342 (England & Wales); SC043576 (Scotland)
Company Registration No: 07790071 (England & Wales)



(A CHARITABLE COMPANY LIMITED BY GUARANTEE)

**TRUSTEES' ANNUAL REPORT and STATEMENT
OF FINANCIAL ACTIVITY**

FOR THE YEAR ENDED 31 DECEMBER 2017

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Trustees' Report

The Trustees present their report and accounts for the year ended 31 December 2017, which are also prepared to meet the requirements for Directors' report and accounts for Companies House purposes.

The financial statements comply with the Charities Act 2011, the Companies Act 2006, the Memorandum and Articles of Association, and *Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015)*.

Objectives and Activities

As set out in its Articles of Association, the objectives of Narcolepsy UK are to provide relief and aid to those suffering from narcolepsy. To that end, we support people with narcolepsy, their families, carers and others interested in improving their quality of life.

Our principal activities to achieve these objectives are:

- The promotion and organisation of conferences relating to narcolepsy and its effects.
- The promotion and/or assistance in promoting and carrying out research, surveys and investigations into narcolepsy and its effects.
- Creating the funding strategies that make this work possible.
- Arranging and providing exhibitions, meetings, lectures, classes and training courses.
- Collecting and distributing information, primarily through the Narcolepsy UK media portfolio comprising website, Facebook, Twitter and social media generally.

Narcolepsy UK's achievements in relation to these objectives are summarised below under the heading Achievements and Performance.

Our vision is to help provide a world where narcolepsy is understood and people with narcolepsy have the support they need to ensure that their rights are upheld and that they have the same opportunities as others in society.

We will deliver our objectives by:

- Raising professional, political and public awareness and understanding of the needs of people with narcolepsy, their families and carers.
- Campaigning to influence the policies of legislators and funding bodies.
- Delivering relevant sustainable services that satisfy the needs of people with narcolepsy, their families and carers.
- Providing information and practical support to people with narcolepsy, their families and carers, either directly, in partnership with others or through facilitating and supporting the work of other organisations.
- Supporting research into the effects and management of narcolepsy.

We seek to work in partnership with those who share our vision and mission.

Our strategic aim is to achieve all this through a combination of fundraising, continuing dialogue with politicians, medical professionals, other patient groups across the European Union in particular and a variety of projects.

Achievements and Performance

The principal activities of the charity during 2017 are described below, with an indication of the extent to which these activities met the objectives of the charity. The ways in which the charity will build on these achievements during 2018 are also described.

Conferences

The charity's main annual conference took place on 7-8 October 2017 at Newbury Racecourse, and was attended by around 150 delegates.

The conference included the announcement of our major initiative for the coming year: the development and implementation of "The Narcolepsy Charter". This is discussed further below.

As usual, conference included an excellent and informative programme of talks by medical practitioners and others, and we are once again grateful to all those who give up their time to present at conference.

The main presentations from conference were video-recorded, and subsequently were uploaded to our YouTube channel, where they can still be viewed. The presentations were also streamed live on Facebook so that they could be followed by anyone unable to be present in person.

A new aspect of conference in 2017 was the presence of representatives of three pharmaceutical companies with interests in the treatment of narcolepsy: Lincoln Medical/Bioprojet Pharma, UCB and Flamel/Avadel. We believe all three were pleased to have attended the conference, and we were certainly pleased to welcome them.

Feedback from delegates was excellent, with many commenting that the conference was the best yet. In 2018, we will seek to replicate that success, when our annual conference will return to Manchester, the same venue as in 2016.

We also delivered a smaller conference – on 9 September 2017 - in Glasgow, kindly funded by Foundation Scotland. Again, a varied programme of speakers delivered presentations of great value to those in attendance.

Provided resources permit, we will again seek to organise one or more regional conferences of this nature.

Networking meetings

In addition to our formal conferences, we facilitated the organisation of numerous networking meetings around the country. These provided small groups of attendees to share experiences and to support each other in informal and friendly surroundings. We will seek to continue to provide such meetings during 2018.

Helpline

Our helpline service continued to provide support to many callers. The most common requirement is for help with applications for financial benefits. Demand on the service became so high towards the end of 2017 that we were forced to temporarily close the helpline to new enquiries for a short period. An objective for 2018 is to recruit and train additional benefits advisors in order to cope with the volume of enquiries.

Campaigning

Throughout 2017, the charity continued to campaign for the rights of people with narcolepsy. Particular areas of focus were:

- Raising awareness of the condition amongst the medical profession and the public generally.
- Seeking proper compensation for those who contracted narcolepsy as a result of having the Pandemrix flu vaccine.
- Fair treatment for those who have to apply for benefits as a result of their narcolepsy.
- Support for people facing difficulties at work or in education as a result of their narcolepsy.
- Ensuring people with narcolepsy have access to the best medications.

Support has been provided in many forms, including direct assistance on an individual basis, representations made to official bodies, and submissions of evidence to tribunals and in legal proceedings.

In March 2017, the charity attended Parliament attend a Westminster Hall debate and to support the family of a young person with narcolepsy who was the subject of a question put by their MP to the Right Honourable Theresa May MP in Prime Minister's Questions. In the debate, we raised the disparity between adult and paediatric treatment and also the role of the Ex Gratia Xyrem Scheme for Pandemrix victims.

In relation to access to medication, an important landmark in 2017 was the adoption by the NHS of a clinical commissioning policy for children in relation to sodium oxybate (Xyrem®). We will continue to campaign for a similar policy for adult patients.

In 2018, the charity will continue to campaign in relation to all these matters.

Website

The Narcolepsy UK website www.narcolepsy.org.uk continues to be the main vehicle for the dissemination of information to our community. Throughout 2017, we continued to populate the website with resources of use to people with narcolepsy, and their families and carers. In addition, we use the website to promote fundraising, and to advertise events of interest to our community, both organised by the charity and external events.

An important development of the website during 2017 was "search" functionality, which has made it much easier for users to locate relevant information.

In 2018, we will continue to augment the information available through the website and to keep it up to date.

No edition of Catnap, the charity's paper newsletter, was published during 2017. The Board of Trustees will consider whether publication of a newsletter in that form is an appropriate use of the charity's resources or whether in future we should rely only on the website and other forms of electronic communication.

External Engagement

Throughout 2017, the charity engaged actively with a variety of external organisations. These included medical bodies such as the Royal Society of Medicine, and patient groups in other countries, principally elsewhere within the European Union. Contact was also maintained with other overseas patient groups, for instance in the USA, via social media and direct correspondence.

The charity's Chair continued to serve on the board of the Neurological Alliance.

The charity also engaged with pharmaceutical companies with an interest in narcolepsy. Opportunities to collaborate with such companies for the benefit of people with narcolepsy were explored. Where donations were accepted from such companies, this was done strictly in accordance with the charity's policy statement "Working with Pharmaceutical Companies", which was originally adopted in 2015, and was reviewed and approved again by the Board in December 2017. In 2017, donations were received from Avadel and UCB

The charity was also represented at a meeting of the Charities Forum of the Driver and Vehicle Licensing Agency.

The Narcolepsy Charter

As noted above, at our main conference in October 2017, we announced a major new project: the Narcolepsy Charter.

Aimed at tackling the challenges and discrimination faced by the narcolepsy community across the UK, the Charter will be a written statement of the rights of people with narcolepsy and their carers. It will set out the basic rights that people with narcolepsy and their carers deserve and should expect.

Once it has been finalised, the Charter will first be presented to the narcolepsy community. This will be followed by a major launch event at which the Charter will be introduced to the public. A series of smaller presentations and workshops will follow at regional and local level. We will encourage as many individuals and organisations as possible to sign up to the Charter. These will include GPs and other medical practitioners such as health visitors and nurses, teachers, occupational therapists, local government service providers (eg education welfare officers, social workers), and employers, as well as professional bodies and trade organisations.

There are a number of issues that we expect the Charter to address:

- **Diagnosis** – The shortage of UK Sleep Consultants and specialist sleep centres creating unacceptable delays in formal diagnosis of narcolepsy.
- **Treatment** - We deserve specific and measurable criteria for best practice treatment. Currently, many medications are deemed too expensive for us. This is unjust.
- **Mental and Physical Health** - The impact of sleep deprivation on the body along with the prevalence of loneliness and depression needs to be recognised and appropriate support put in place.
- **Social Care** - The support network that many of us rely on for Disability Living Allowance/Personal Independence Payments or Employee Support Allowance and other benefits is broken and we cannot sustain the withdrawal of benefits and all that entails.
- **Employment** - Poor understanding means many employers fail to accommodate people with narcolepsy through "reasonable adjustments". This means many people lose or leave their jobs – lack of awareness among employers must be addressed.
- **Children and young people** – Students with narcolepsy struggle in the education system because teaching staff do not fully understand the needs of their pupil with narcolepsy, leaving many children failing to achieve their academic potential.
- **Co-morbid disorders** - Need to be recognised and medical practitioners need to give appropriate support and advice to people so they can manage these.

Progress on this project will be a major focus for the charity in 2018. The first stage will be a process of consultation in which we will work with a market research agency to obtain evidence of what issues really affect people with narcolepsy in the UK. This project will hopefully lead to significant benefits for the whole of the narcolepsy community.

Data Protection

Towards the end of 2017, the charity began the process of ensuring that it will be compliant with the requirements of the General Data Protection Regulation (GDPR) that was due to come into force in May 2018. Steps will be taken in early 2018 to put in place all necessary measures before the deadline.

Financial Review

Financial Review and Results for the year:

The Statement of Financial Activity reflects all incoming resources receivable in the period irrespective of when the income is spent. The Trustees are satisfied with the results for the period.

Reserves policy and going concern

Free reserves available for use by Narcolepsy UK are deemed to be those that are readily realisable, less funds whose uses are restricted or designated for particular purposes.

Narcolepsy UK introduced a policy relating to reserves. Unrestricted assets should be apportioned between an operating reserve" held to cover six months' cash flow, and then a "capital reserve" to be held against future liability to expenditure.

The operational reserve should hold liquid assets (cash or near cash), the total of which should equate to a least six months' cash flow. However this is not always possible requiring careful management of available funds during critical periods and sourcing new income streams. In the medium term the Trustees believe that all activities should be self-funding and any additional income should be placed in a free reserve whose policy should be to maximise income.

With income, the major risk is of a decline in Trust-related income particularly due to economic or other factors leading to both declining legacy values and reduced donations. This is something which has been and will continue to be addressed on a daily basis. Alongside this more project related funding will be sourced.

The present range for operating reserves remains at £50,000. The actual sum has diminished significantly this year however careful budgets for 2018 along with plans to source new income streams are intended to put the charity back on a more even footing next year. As with many charities the economy has impacted upon income rather more than expenditure yet is anticipated that additional Community Fundraising will come online over the next 12 months to bolster day to day overheads. The Trustees believe that most prudent course remains building charitable activities in the first instance before building up a free reserve.

The Trustees have reviewed the circumstances of Narcolepsy UK and consider that adequate resources continue to be available to fund the activities of the charity in the medium term. The trustees are of the view the charity is a going concern.

Plans for the Future

Future plans are outlined as part of the summary of Achievements and Performance above.

Reference and Administrative Details

Company Number: 07790071

Charity Number: 1144342

Scottish Charity Number: SCO43576

Registered Office: c/o Prentis & Co LLP
115c Milton Road
Cambridge CB4 1XE

Independent Examiner: Nigel A Prentis FCA
Prentis & Co LLP
115c Milton Road
Cambridge CB4 1XE

Bankers: Royal Bank of Scotland
747 Attercliffe Road
Sheffield S9 3RF

CAF Bank Ltd
25 Kings Hill Avenue
West Mailing
Kent ME19 4JQ

Directors and Trustees: The Directors of the charitable company (the charity) are its Trustees for the purpose of charity law. The Trustees and officers serving during the year and since the year-end were as follows:

Trustees: Edmund Coates
Hugh Davies-Webb
William Harris (appointed 3 May 2018)
Stephen Jones
Tim Kavanagh
Jenny Taylor (resigned 11 April 2017)
Henry Nicholls
Matthew O'Neill
Helen Strongman (appointed 3 May 2018)

Chair: Matthew O'Neill

Company Secretary: Nicola Rule

Structure, Governance and Management

Brief History

Narcolepsy UK originated in 1983 as UKAN, an unincorporated association governed by a constitution. On 13 December 2009 the name of the charity was changed to Narcolepsy UK. The Board continues to acknowledge Dorothy Hand as Founder of the charity.

Narcolepsy UK was incorporated as a Company Limited by Guarantee (07790071) on 28 September 2011 and registered as a charity in England and Wales (1144342) on 19 October 2011. The charitable company commenced charitable activities on 9 January 2012 when it took over the assets of the unincorporated association Narcolepsy UK (326361).

On 17 October 2012 the unincorporated charity (326361) was amalgamated with the charitable company (1144342), thus creating one legal entity.

On 20 November 2012 Narcolepsy UK received Scottish Charitable Status (SC043576).

Appointment of Trustees

The Board of Trustees is responsible for the overall governance of the charity. Trustees are either elected or co-opted and the total number of Trustees may not exceed 12. The majority of Trustees and the Chair of the charity are required by the constitution to be diagnosed narcoleptics. The Board tries to maintain a balance of skill sets whilst retaining the requirements of the constitution. This does make recruitment of active Trustees difficult, yet has the positive result that a considerable number of Trustees have first-hand knowledge of this chronic neurological condition.

Trustees' Induction and Training

New Trustees receive an induction pack containing detailed information about the charity, its organisation and its work. They are then invited to spend time liaising with current Trustees and employees to familiarise themselves with the activities of the charity in order to prepare themselves for effective and informed decision-making. As part of the induction process, all prospective Trustees are invited to attend at least one Trustee meeting as an observer. Under its Articles of Association Narcolepsy UK appoints Trustees for fixed terms not exceeding three years, at the end of which they must retire but are then eligible for reappointment. The Trustees collectively have a portfolio of interests, experiences and skills, which contribute to the overall operations of Narcolepsy UK.

Organisation

Trustees are required to meet at least four times per year. These meetings include the AGM and three other Board meetings where Trustees review strategy and performance and set operating plans and budgets. In addition, regular Skype calls are also made to allow for low-cost administration and decision-making.

Related parties and co-operation with other organisations

None of our Trustees receive remuneration or other benefit from their work with the charity. Any connection between a Trustee or senior manager of the charity must be disclosed to the full board of Trustees in the same way as any other contractual relationship with a related party. No such related party transactions were reported during 2017.

Pay policy for staff

The Directors consider the board of Directors, who are the charity's Trustees, and the Operations Manager to comprise the key management personnel of the charity, in charge of directing and controlling, running and operating the charity on a day-to-day basis. All Directors give their time freely and no Director received remuneration in the year. Details of Directors' expenses and related party transactions are disclosed in note 4c to the accounts.

The pay of the Operations Manager is reviewed annually – as is the pay of other staff – in accordance with the charity's Remuneration Policy. In particular, in December each year the Trustees determine whether the salaries for all staff who, by 31st December of that year, will have completed six months uninterrupted service should be adjusted for the forthcoming calendar year beginning 1st January, to reflect changes in the cost of living.

The Trustees determine whether this is appropriate in the context of:

- (i) the charity's financial situation;
- (ii) the charity's performance;
- (iii) cost of living adjustments made in recent years;
- (iv) pay reviews elsewhere.

Employees

Narcolepsy UK aims to be an organisation where employees enjoy a sense of fulfilment and where they feel supported and developed. Employees are kept fully informed about our strategy and objectives as well as day-to-day news and events. Regular information is available through briefings and meetings. All employees are encouraged to give their suggestions and views on performance and strategy.

Narcolepsy UK supports equal opportunities with a policy of recruitment and promotion on the basis of aptitude and ability. The charity pursues both the employment of disabled people whenever a suitable vacancy arises and the continued employment and retraining of employees who become disabled whilst employed. We are committed to the training, career development and promotion of all employees.

Pensions

A defined contribution pension scheme has been set up by the charity and became operational in May 2017.

Corporate Governance

Processes are in place to ensure that expenditure, performance and progress are monitored and that appropriate management information is prepared and reviewed regularly by the Board of Trustees. The systems of internal control are designed to provide reasonable assurances against material misstatement or loss. They include:

- A strategic planned annual budget approved by the Trustees
- Regular consideration by the Trustees of financial results, variances from budgets and non-financial performance indicators
- Delegation of day-to-day management authority
- Identification and management of risks

Risk Management

The Trustees recognise that, like other organisations and charities, Narcolepsy UK is exposed to risk.

The risk could be financial, strategic or regulatory but in some way could affect the running of the charity and needs constant monitoring and managing. The Trustees formally assess these risk areas and apportion them amongst the individual Trustees to review specific areas.

The Trustees are satisfied that they have systems in place or are putting systems in place that mitigate exposure to risk.

Business-as-usual operations and policy implementation are delegated to the employees of the charity, supported by the Board of Trustees. Employees of the charity have clearly defined reporting lines and are also able to escalate risks and issues to the relevant Trustee when appropriate.

Trustees' Responsibilities in relation to the financial statements

The charity's Trustees (who are also directors of Narcolepsy UK for the purposes of company law) are responsible for preparing the Trustees' report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

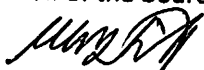
Company law requires the charity Trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charitable company and of the incoming resources and application of resources, including the income and expenditure, of the charity for that period. In preparing these financial statements the Trustees are required to:

- Select suitable accounting policies and then apply them consistently.
- Observe the methods and principles in the Charities SORP.
- Make judgements and estimates that are reasonable and prudent.
- State whether applicable UK accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements.
- Prepare the financial statements on the going-concern basis unless it is inappropriate to presume that the charity will continue in operation.

The Trustees are responsible for keeping adequate accounting records that disclose with reasonable accuracy at any time the financial position of the charitable company and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities. The Trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charity's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

This report has been prepared in accordance with the special provisions relating to small companies within Part 15 of the Companies Act 2006.

On behalf of the Board of Trustees



Matthew O'Neill, Chair

28/9/18

INDEPENDENT EXAMINER'S REPORT

To the Trustees of Narcolepsy UK

I report to the charity Trustees on my examination of the accounts of the company for the year ended 31st December 2017.

Responsibilities and Basis of Report

As the Trustees of the company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Charities and Trustee Investment (Scotland) Act 2005 ('the 2005 Act'), the Charities Accounts (Scotland) Regulations 2006 (as amended) and the Companies Act 2006 ('the 2006 Act'). You are satisfied that the accounts of the company are not required by charity or company law to be audited and have chosen instead to have an independent examination.

Having satisfied myself that the accounts of the company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of the company's accounts carried out under section 44 (1) (c) of the 2005 Act and section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the requirements of Regulation 11 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and the Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

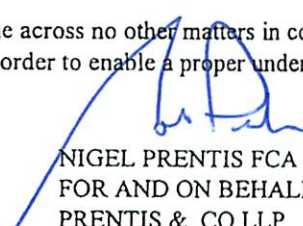
Independent Examiner's Statement

Since the company is required by company law to prepare its accounts on an accruals basis and is registered as a charity in Scotland your examiner must be a member of a body listed in Regulation 11(2) of the Charities Accounts (Scotland) Regulations 2006 (as amended). I can confirm that I am qualified to undertake the examination because I am a registered member of The Institute of Chartered Accountants in England and Wales.

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

1. accounting records were not kept as required by section 386 of the 2006 Act and Regulation 4 of the 2006 Accounts Regulations; or
2. the accounts do not accord with those records with the accounting requirements of Regulation 8 of the Charities Accounts (Scotland) Regulations 2006; or
3. the accounts do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a 'true and fair view' which is not a matter considered as part of an independent examination; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statements of Recommended Practice for accounting and reporting by charities [applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)].

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.


NIGEL PRENTIS FCA
FOR AND ON BEHALF OF
PRENTIS & CO LLP
CHARTERED ACCOUNTANTS
& INDEPENDENT EXAMINERS

115c Milton Road
Cambridge
CB4 1XE

Statement of Financial Activities

Incoming and Outgoing Resources

	Note	Unrestricted Funds £	Restricted Funds £	Total 2017 £	Total 2016 £
INCOME AND ENDOWMENTS FROM:					
Donations and Legacies	3a	38040	37183	75223	32014
Charitable Activities	3b	34363	-	34363	17768
Investments	3c	19	-	19	72
TOTAL INCOME AND ENDOWMENTS		72422	37183	109605	49854
EXPENDITURE ON:					
Raising Funds	4a	11223	-	11223	10923
Charitable Activities	4b	48750	28864	77614	85976
TOTAL EXPENDITURE		59973	28864	88837	96899
NET INCOME/EXPENDITURE		12449	8319	20768	(47045)
Transfers Between Funds	8	-	-	-	-
Net Movement in Funds		12449	8319	20768	(47045)
Total Funds Brought Forward		23405	7892	31297	78342
Total Funds Carried Forward		35854	16211	52065	31297

The Statement of Financial Activities includes all gains and losses recognised in the year.
All income and expenditure derive from continuing activities.

Balance Sheet

	Note	Total 2017 £	Total 2016 £
CURRENT ASSETS			
Debtors	6	1505	1287
Cash at Bank and in Hand		63129	32658
Total Current Assets		<u>64634</u>	<u>33945</u>
LIABILITIES			
Creditors Due within one Year	7	12569	2648
NET ASSETS		<u>52065</u>	<u>31297</u>
FUNDS OF THE CHARITY			
Unrestricted Funds			
General Funds		(16261)	(28710)
Designated Funds		52115	52115
Restricted Income Funds		<u>16211</u>	<u>7892</u>
TOTAL FUNDS	8	<u>52065</u>	<u>31297</u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31st December 2017.

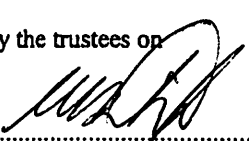
The members have not required the company to obtain an audit of its financial statements for the year ended 31st December 2017 in accordance with Section 476 of the Companies Act 2006.

The directors acknowledge their responsibilities for:

- (a) ensuring that the charitable company keeps accounting records which comply with Sections 386 and 387 of the Companies Act 2006 and
- (b) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of each financial year and of its income or expenditure for each financial year in accordance with the requirements of Sections 394 and 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the company.

The financial statements have been prepared in accordance with the provisions of Part 15 of the Companies Act 2006 relating to small companies.

Approved by the trustees on



28/9/18

and signed on their behalf by

.....
MATTHEW O'NEILL
DIRECTOR AND CHAIR

Statement of Cash Flows

	Note	Total 2017 £	Total 2016 £
Cash used in operating activities	10	30452	(49990)
Cash flows from investing activities			
Interest from investments		19	72
Increase/(decrease) in cash and cash equivalents in the year		30471	(49918)
Cash and cash equivalents at the beginning of the year		32658	82576
Total cash and cash equivalents at the end of the year		63129	32658

Notes to the Accounts

1. Accounting Policies

The principal accounting policies adopted, judgements and key sources of estimation uncertainty in the preparation of the financial statements are as follows:

a) **Basis of preparation**

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102), Companies Act 2006, The Charities Accounts (Scotland) Regulations 2006 and the Charities and Trustee Investment (Scotland) Act 2005.

Narcolepsy UK meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

b) **Preparation of the accounts on a going concern basis**

The charity reported a cash inflow of £20768 for the year after recurring deficits in previous years. The medium to long term future of the charity was of concern. The Trustees feel that this has been addressed but continue to monitor the situation.

The current reserves held are adequate to cover any deficits made over the next 24 months and on this basis the Trustees feel that the charity is a going concern.

c) **Income**

Income is recognised when the charity has entitlement to the funds, any performance conditions attached to the item(s) of income have been met, it is probable that the income will be received and the amount can be measured reliably.

Income from government and other grants, whether 'capital' grants or 'revenue' grants, is recognised when the charity has entitlement to the funds, any performance conditions attached to the grants have been met, it is probable that the income will be received and the amount can be measured reliably and is not deferred.

For legacies, entitlement is taken as the earlier of the date on which either: the charity is aware that probate has been granted, the estate has been finalised and notification has been made by the executor(s) to the Trust that a distribution will be made, or when a distribution is received from the estate. Receipt of a legacy, in whole or in part, is only considered probable when the amount can be measured reliably and the charity has been notified of the executor's intention to make a distribution.

d) **Interest receivable**

Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the charity; this is normally upon notification of the interest paid or payable by the bank.

e) **Fund accounting**

Unrestricted funds are available to spend on activities that further any of the purposes of charity. Designated funds are unrestricted funds of the charity which the trustees have decided at their discretion to set aside to use for a specific purpose. Restricted funds are donations which the donor has specified are to be solely used for particular areas of the charity's work or for specific projects being undertaken by the charity.

Notes to the Accounts continued

f) Expenditure and Irrecoverable VAT

Expenditure is recognised once there is a legal or constructive obligation to make a payment to a third party, it is probable that settlement will be required and the amount of the obligation can be measured reliably. Expenditure is classified under the following activity headings:

- Costs of raising funds comprise the costs of their associated support costs.
- Expenditure on charitable activities includes the costs of conferences and fundraising and their associated support costs.

Irrecoverable VAT is charged as a cost against the activity for which the expenditure was incurred.

g) Allocation of support costs

Support costs are those functions that assist the work of the charity but do not directly undertake charitable activities. Support costs include back office costs, finance, personnel, payroll and governance costs which support the charity's activities.

h) Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

i) Cash at bank and in hand

Cash at bank and cash in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

j) Creditors and provisions

Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

k) Financial instruments

The trust only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value with the exception of bank loans which are subsequently measured at amortised cost using the effective interest method.

2 Legal status of the Trust

The Trust is a company limited by guarantee and has no share capital. In the event of the charity being wound up, the liability in respect of the guarantee is limited to £1 per member of the charity.

Notes to the Accounts (Continued)		Unrestricted	Restricted	Total	Total
3. Income and Endowments from:		Funds	Funds	2017	2016
		£	£	£	£
3a	Donations and Legacies				
	Donations	31990	-	31990	22686
	Grants	1050	37183	38233	9328
	Sponsorship	5000	-	5000	-
		<u>38040</u>	<u>37183</u>	<u>75223</u>	<u>32014</u>
		Unrestricted	Restricted	Total	Total
		Funds	Funds	2017	2016
		£	£	£	£
3b	Charitable Activities				
	Conference	8112	-	8112	5028
	Fundraising	26251	-	26251	12740
		<u>34363</u>	<u>-</u>	<u>34363</u>	<u>17768</u>
		Unrestricted	Restricted	Total	Total
		Funds	Funds	2017	2016
		£	£	£	£
3c	Investments				
	Bank Interest	19	-	19	72
		<u>19</u>	<u>-</u>	<u>19</u>	<u>72</u>
		Unrestricted	Restricted	Total	Total
		Funds	Funds	2017	2016
		£	£	£	£
4	Expenditure on:				
4a	Raising funds				
	Staff costs	10833	-	10833	10893
	Other costs	390	-	390	30
		<u>11223</u>	<u>-</u>	<u>11223</u>	<u>10923</u>
		Unrestricted	Restricted	Total	Total
		Funds	Funds	2017	2016
		£	£	£	£
4b	Charitable Activities		Support and	Total	Total
	Advocacy Services	20375	Governance	2017	2016
	Bookkeeping	-	Costs	£	£
	Research grant	-			
	Conferences and meetings	20294			
	Independent Examiner's fees	-	2376	2376	2232
	Local and regional support	5760	-	5760	7648
	Office and miscellaneous	-	4033	4033	5230
	Printing and stationary	-	-	-	3095
	Staff costs	-	17638	17638	17730
	Telephone and fax	-	1367	1367	835
	Training	-	348	348	1059
	Travel costs - staff	-	262	262	-
	Trustee expenses	-	1716	1716	3630
	Website development and maintenance	1945	-	1945	5087
		<u>48374</u>	<u>29240</u>	<u>77614</u>	<u>85976</u>

Notes to the Accounts (Continued)

4c	Staff Costs	Unrestricted Funds £	Restricted Funds £	Total 2017 £	Total 2016 £
	Salaries and Employers NIC	53652	-	53652	54147
	Pension - Employers contributions	201	-	201	-
		<u>53853</u>	<u>-</u>	<u>53853</u>	<u>54147</u>

The average number of employees during the year was 4 full time equivalent (2016: 4 full time equivalent) with all employee time involved in providing either support services to charitable activities or support to the governance of the charity.

The charity Trustees were not paid or received any other benefits form employment with the charity in the year (2016: £nil).

The Trustees had reimbursed expenses for the year of £1716 (2016: £3630).

No employee received more than £60000 in the year or previous year.

5 Independent Examiner's Remuneration

The independent examiner's remuneration constituted an independent examiner fee of £2376 (2016: £2232).

6	Debtors	Unrestricted Funds £	Restricted Funds £	Total 2017 £	Total 2016 £
	Prepayments	1505	-	1505	1287
		<u>1505</u>	<u>-</u>	<u>1505</u>	<u>1287</u>

7	Creditors: Amounts falling due within one year	Unrestricted Funds £	Restricted Funds £	Total 2017 £	Total 2016 £
	Other creditors and accruals	12569	-	12569	2648
		<u>12569</u>	<u>-</u>	<u>12569</u>	<u>2648</u>

8 Reconciliation of movement of funds by funds

	Opening Balances £	Incoming Resources £	Resources Expended £	Transfers £	Closing Balances £
Unrestricted funds					
General fund	(28710)	72422	59973	-	(16261)
Designated Funds					
Large legacies and donations	52115	-	-	-	52115
Restricted Funds					
Local and Regional Support	7892	37183	28864	-	16211
Total Funds	<u>31297</u>	<u>109605</u>	<u>88837</u>	<u>-</u>	<u>52065</u>

Notes to the Accounts (Continued)

8a Designated Funds

Names and Purposes of Designated Funds

Large Legacies and Donations Fund (LLandD Fund)

The purpose of this Designated Fund is to allow the charity to avoid situations in which the occasional receipt of a large legacy or donation significantly inflates the charity's reserves. Such situations can distort the charity's priorities for meeting its charitable objects and lead to the charity taking on commitments which are not sustainable once those legacy/donations funds have been exhausted.

By holding such monies in a Designated Fund from which they can be released back into the charity's reserves in a controlled manner over a period of time the charity is better able to ensure that it generates the maximum sustainable public benefit from its resources.

8b Narcolepsy UK has no Permanent or Expendable Income Restricted Funds.

8c Names and Purposes of Restricted Funds

Local and Regional Support

These funds have been donated specifically to allow the charity to provide support and information services within a particular region, both through enabling the creation and development of local volunteer/supporter sub-groups which are better able to focus on local needs and through the provision of a local and regional support infrastructure to ensure that such groups operate efficiently and effectively in a co-ordinated manner to the highest standards.

9 Analysis of Net Assets Between Funds

The fund balances at 31st December 2017 are represented by:

	Unrestricted Funds £	Designated Funds £	Restricted Funds £	Total £
Current Assets				
Cash at bank	(5197)	52115	16211	63129
Debtors	1505	-	-	1505
Creditors: Due within one year	(12569)	-	-	(12569)
	<u>(16261)</u>	<u>52115</u>	<u>16211</u>	<u>52065</u>

10 Reconciliation of Net Movement in Funds to Net Cash Flow from Operating Activities

	Total 2017 £	Total 2016 £
Net movement in funds	20768	(47045)
Deduct interest from investment activities	(19)	(72)
(Decrease)/increase in debtors	(218)	(237)
Increase/(decrease) in creditors	9921	(2636)
Net cash used in operating activities	<u>30452</u>	<u>(49990)</u>

2017 Supporters, Trusts and Foundation

AWA England
AWA Scotland
AWA Wales
Clarke Charitable Settlement
Company of Actuaries Charitable Trust
The Corra Foundation
Flamel Ireland
Foundation Scotland
Haberdashers CT
James Tudor
Lloyds Bank Foundation/Corra/Alec
The Fulmer Trust
UCB Pharma
Woodward Trust