

Charity Registration Number: 1144342 (England and Wales); SC043576 (Scotland)
Company Registration Number: 07790071 (England and Wales)

NARCOLEPSY UK

(A CHARITABLE COMPANY LIMITED BY GUARANTEE)

TRUSTEES' ANNUAL REPORT and STATEMENT OF FINANCIAL ACTIVITY

FOR THE YEAR ENDED 31ST DECEMBER 2018

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Trustees Report

The Trustees present their report and accounts for the year ended 31st December 2018, which are also prepared to meet the requirements for a Director's 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 2018 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 2019 are also described.

Conferences

The charity's main annual conference took place on 8-9 September 2018 in Central Manchester and was attended by around 200 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.

Feedback from delegates was excellent, with many commenting that the conference was the best yet. In 2019, we will seek to replicate that success, when our annual conference will return to Manchester, at the same venue

We also delivered a smaller conference - on 17 November 2018 - in Glasgow, kindly funded by Foundation Scotland. Again, a varied programme of speakers both professional and personal delivered presentations reported to be of great value to those in attendance.

Another smaller conference in Abergavenny, Wales – funded by the National Lottery – was held on 11 August 2018 with delegates by a whole new cohort of attendees. A superb and easily understood presentation from Dr Jose Thomas was the highlight of the day. Our thanks to Neville Hall Sleep Centre for use of their Lecture Theatre.

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 2019 which will also co-incide with the Inaugural World Narcolepsy Day.

Helpline

Our helpline service continued to provide support to many persons throughout the year. The most common requirement is for help with applications for financial benefits. During 2018 a new case worker was appointed to manage the Helpline and specifically work on Benefits Support from inception of Application through the almost inevitable Mandatory Reconsideration, and in some instances to Appeal Stage. When we say 'inevitable Mandatory Reconsideration' this is due to so many applications being mis-assessed initially for invisible illness. Our new member of staff has many years prior experience working within this framework and has proven 100% successful to date. She also has direct experience of narcolepsy which is especially useful. We have also appointed volunteer advisors to assist at peak times who also have great success rates.

The Helpline deals also with all manner of advice, guidance, signposting required – one other regular cry for help is from parents whose children are not receiving adequate, if any, assistance in school or further education. The Charity has supported a number of such cases throughout the year including liaison with Local Authorities in order to achieve the necessary support.

Campaigning

Throughout 2018, 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, something which we expect to be reviewed in the Courts in 2019.
- 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 at a Westminster Hall debate 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. We continue to lobby for this disparity to be rectified.

In 2019, 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 2018, 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.

It is clear people who have visited our site whilst reviewing symptoms of narcolepsy are now using this facility to show GPs who have not previously met this condition with the website being used as a 'teaching tool' to help potential sufferers gain referral to specialist centres for diagnosis.

In 2019, the charity will continue to augment the information available through the website and to up date it as new information becomes available.

The charity now uses Blog Posts to give alerts to new information being posted to the website – we also employ social media platforms to reach a greater audience.

External Engagement

Throughout 2018, 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.

This engagement culminated in a lecture at The Royal Society of Medicine on 27 October 2018 with persons with narcolepsy contributing their very personal experiences to the medical fraternity and other attendees. This was organised with Matt O'Neil Chair Narcolepsy UK to encourage more interest and understanding of the symptoms of the disability along with the need for better support and management.

During 2018 our Chair took part in the following pan European Events

8-11 February 2018	Nordic Narcolepsy Conference in Finland
9-10 March 2018	International Bed Race in Dublin
23-25 March 2018	Avadel EU Patient Advisory Group Paris
25-27 March 2018	IABS EU Meeting Brussels
22-25 April 2018	Attending and Speaking at Oslo Group Meeting in Norway
3 May 2018	Neurological Alliance Board Meeting
4-6 May 2018	Attending and Speaking at EU Narcolepsy Network Meeting Montpellier
13-15 May 2018	Royal Society of Medicine Sleep Conference

These meetings continued through 2018. This list just presents some of those events and will culminate in the Inaugural World Sleep Day in 2019 something still being planned but should see many Charities around the world presenting to Consultants and being champions for clients suffering sleep related disorders as Lay 'professionals'. Various Board Members, staff and volunteers also continued to represent the Charity at additional events and speaker commitments to schools and the like within the UK often using SKYPE as a cost reduction exercise.

The charity's Chair continues 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. The relationship with pharmaceutical companies allows the charity to seek information and alert those companies to concerns raised when supplies are not available in certain areas, this direct contact allows for patients to be updated more quickly than in the past.

The Narcolepsy Charter

As noted above, at our main conference in October 2017, we announced a major new project: the Narcolepsy Charter. During 2018 we have worked with a specialist agency to firstly create a Survey for both persons with narcolepsy and their supporters, from which a Charter document will be produced and launched in 2019

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 has been a major focus for the charity in 2018. The first stage was a process of consultation working 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, with the results of the survey being presented at Conference 2019.

In September 2018 a Development Grant of £50,000 was received from the National Lottery to review and improve the functionality of the charity as a whole, this continues to be worked on.

Data Protection

All requirements to conform to GDPR regulations were completed prior to coming into the force in May 2018.

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 the 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.

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 Malling 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 (resigned 28 July 2019) William Harris (resigned 25 October 2018) Stephen Jones (resigned 24 June 2019) Tim Kavanagh Henry Nicholls Matthew O'Neill Helen Strongman
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 (SCO43576).

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 Trustee Board tries to maintain a balance of skill sets whilst retaining the requirements of the constitution. This does make recruiting 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 the 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 in 2018.

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 of 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 of all staff who, by 31 December of that year, will have completed six months uninterrupted service should be adjusted for the forthcoming calendar year beginning 1 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.

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 where 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

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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 2018.

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

Statement of Financial Activities

Incoming and Outgoing Resources

	Note	Unrestricted Funds £	Restricted Funds £	Total 2018 £	Unrestricted Funds £	Restricted Funds £	Total 2017 £
INCOME AND ENDOWMENTS FROM:							
Donations and Legacies	3a	36665	43693	80358	38040	37183	75223
Charitable Activities	3b	17657	-	17657	34363	-	34363
Investments	3c	46	-	46	19	-	19
TOTAL INCOME AND ENDOWMENTS		54368	43693	98061	72422	37183	109605
EXPENDITURE ON:							
Raising Funds	4a	10993	-	10993	11223	-	11223
Charitable Activities	4b	57398	38905	96303	48750	28864	77614
TOTAL EXPENDITURE		68391	38905	107296	59973	28864	88837
NET INCOME/EXPENDITURE		(14023)	4788	(9235)	12449	8319	20768
Transfers Between Funds		-	-	-	-	-	-
Net Movement in Funds		(14023)	4788	(9235)	12449	8319	20768
Total Funds Brought Forward		35854	16211	52065	23405	7892	31297
Total Funds Carried Forward		21831	20999	42830	35854	16211	52065

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 2018 £	Total 2017 £
CURRENT ASSETS			
Debtors	6	1487	1505
Cash at Bank and in Hand		48757	63129
Total Current Assets		<u>50244</u>	<u>64634</u>
LIABILITIES			
Creditors Due within one Year	7	7414	12569
NET ASSETS		<u>42830</u>	<u>52065</u>
FUNDS OF THE CHARITY			
Unrestricted Funds			
General Funds		21831	35854
Restricted Income Funds		20999	16211
TOTAL FUNDS	8	<u>42830</u>	<u>52065</u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31st December 2018.

The members have not required the company to obtain an audit of its financial statements for the year ended 31st December 2018 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

and signed on their behalf by

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Statement of Cash Flows

	Note	Total 2018 £	Total 2017 £
Cash used in operating activities	10	(14418)	30452
Cash flows from investing activities			
Interest from investments		<u>46</u>	<u>19</u>
Increase/(decrease) in cash and cash equivalents in the year		<u>(14372)</u>	<u>30471</u>
Cash and cash equivalents at the beginning of the year		<u>63129</u>	<u>32658</u>
Total cash and cash equivalents at the end of the year		<u>48757</u>	<u>63129</u>

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 outflow of £9235 for the year after reporting a surplus in previous years. The medium to long term future of the charity is again 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	Unrestricted	Restricted	Total
3. Income and Endowments from:		Funds	Funds	2018	Funds	Funds	2017
		£	£	£	£	£	£
3a	Donations and Legacies						
	Donations	25565	-	25565	31990	-	31990
	Grants	2100	43693	45793	1050	37183	38233
	Sponsorship	9000	-	9000	5000	-	5000
		<u>36665</u>	<u>43693</u>	<u>80358</u>	<u>38040</u>	<u>37183</u>	<u>75223</u>
		Unrestricted	Restricted	Total	Unrestricted	Restricted	Total
		Funds	Funds	2018	Funds	Funds	2017
		£	£	£	£	£	£
3b	Charitable Activities						
	Conference	9442	-	9442	8112	-	8112
	Fundraising	8215	-	8215	26251	-	26251
		<u>17657</u>	<u>-</u>	<u>17657</u>	<u>34363</u>	<u>-</u>	<u>34363</u>
		Unrestricted	Restricted	Total	Unrestricted	Restricted	Total
		Funds	Funds	2018	Funds	Funds	2017
		£	£	£	£	£	£
3c	Investments						
	Bank Interest	46	-	46	19	-	19
		<u>46</u>	<u>-</u>	<u>46</u>	<u>19</u>	<u>-</u>	<u>19</u>

Notes to the Accounts (Continued)

4. Expenditure on:

	Unrestricted Funds £	Restricted Funds £	Total 2018 £	Unrestricted Funds £	Restricted Funds £	Total 2017 £
4a Raising funds						
Staff costs	10993	-	10933	10833	-	10833
Other costs	-	-	-	390	-	390
	<u>10993</u>	<u>-</u>	<u>10933</u>	<u>11223</u>	<u>-</u>	<u>11223</u>

	Charitable Activities £	Support and Governance Costs £	Total 2018 £	Charitable Activities £	Support and Governance Costs £	Total 2017 £
4b Charitable Activities						
Advocacy Services	12347	-	12347	20375	-	20375
Bookkeeping	-	1500	1500	-	1500	1500
Research grant	20240	-	20240	-	-	-
Conferences and meetings	18206	-	18206	20294	-	20294
Independent Examiner's fees	-	2364	2364	-	2376	2376
Local and regional support	5457	-	5457	5760	-	5760
Office and miscellaneous	-	5794	5794	-	4033	4033
Staff costs	-	21371	21371	-	17638	17638
Telephone and fax	-	1990	1990	-	1367	1367
Training	-	1569	1569	-	348	348
Travel costs - staff	-	563	563	-	262	262
Trustee expenses	-	3754	3754	-	1716	1716
Website development and maintenance	1148	-	1148	1945	-	1945
	<u>57398</u>	<u>38905</u>	<u>96303</u>	<u>48374</u>	<u>29240</u>	<u>77614</u>

Notes to the Accounts (Continued)

4c Staff Costs	Unrestricted Funds £	Restricted Funds £	Total 2018 £	Unrestricted Funds £	Restricted Funds £	Total 2017 £
Salaries and Employers NIC	49430	-	49430	53652	-	53652
Pension - Employers contributions	479	-	479	201	-	201
	<u>49909</u>	<u>-</u>	<u>49909</u>	<u>53853</u>	<u>-</u>	<u>53853</u>

The average number of employees during the year was 5 full time equivalent (2017: 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 from employment with the charity in the year (2017: £nil).

The Trustees had reimbursed expenses for the year of £3754 (2017: £1716).

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 £2364 (2017: £2376).

6. Debtors	Unrestricted Funds £	Restricted Funds £	Total 2018 £	Unrestricted Funds £	Restricted Funds £	Total 2017 £
Prepayments	1487	-	1487	1505	-	1505
	<u>1487</u>	<u>-</u>	<u>1487</u>	<u>1505</u>	<u>-</u>	<u>1505</u>

Notes to the Accounts (Continued)

	Unrestricted Funds £	Restricted Funds £	Total 2018 £	Unrestricted Funds £	Restricted Funds £	Total 2017 £
7. Creditors: Amounts falling due within one year						
Other creditors and accruals	7414	-	7414	12569	-	12569
8. Reconciliation of movement of funds by funds						
		Opening Balances £	Incoming Resources £	Resources Expended £	Transfers £	Closing Balances £
Unrestricted funds						
General fund		35854	54368	68391	-	21831
Restricted Funds						
Local and Regional Support		16211	43693	38905	-	20999
Total Funds		31297	109605	88837	-	52065

Notes to the Accounts (Continued)

8a 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.

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

9 Analysis of Net Assets Between Funds

The fund balances at 31 December 2018 are represented by:

	Unrestricted Funds £	Restricted Funds £	Total £
Current Assets			
Cash at bank	27758	20999	48757
Debtors	1487	-	1487
Creditors: Due within one year	(7414)	-	(7414)
	<u>21831</u>	<u>20999</u>	<u>42830</u>

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

	Total 2018 £	Total 2017 £
Net movement in funds	(9235)	20768
Deduct interest from investment activities	(46)	(19)
Decrease/(increase) in debtors	18	(218)
Increase/(decrease) in creditors	(5155)	9921
Net cash used in operating activities	<u>(14418)</u>	<u>30452</u>

2018 Supporters, Trusts and Foundation

Lincoln Medical
Worshipful Company of Actuaries
Awards for All England
James Neil Trust
Foundation Scotland
UCB
Corra
National Lottery Community Fund

The Charity would also like to thank all of those persons who have kindly made donations via small legacies or from collections at funerals/memorial services for loved ones which is very much appreciated.