NARCOLEPSY UK
(A CHARITABLE COMPANY LIMITED BY GUARANTEE)

TRUSTEES’ ANNUAL REPORT and
STATEMENT OF FINANCIAL ACTIVITY

FOR THE YEAR ENDED 31st December 2013
Legal and Administrative Information

Trustees
William Harris
Edmund Coates
Graeme Moir
Jenny Taylor
Tim Kavanagh
Hugh Davies-Webb
Matt O'Neill

Chair
Matt O'Neill

Company Secretary
Nicola Rule (appointed 21 June 2013)

Company Number
07790071

Charity Number
1144342
Scottish Charity Number
SC043576

Principal Address
PO Box 26865
Kirkaldy, KY2 9BX

Registered Office
Cardinal House, 46 St. Nicholas Street, Ipswich, IP1 1TT

Independent Examiner
J A Francis
Ensors, Warwick House, Ermine Business Park,
Huntingdon, Cambridgeshire, PE29 6XY

Bankers
Royal Bank of Scotland
747 Attercliffe Road, Sheffield, S9 3RF
CAF Bank Ltd,
25 Kings Hill Avenue, Kings Hill, West Malling
Kent, ME19 4JQ
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Trustees Annual Report and Statement of Financial Activity
NARCOLEPSY UK
Year Ended 31 December 2013

Trustees Report

The Trustees present their report and accounts for the year ended 31 December 2013.

Structure, Governance and Management

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 9th 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 20th November 2012 Narcolepsy UK received Scottish Charitable Status (SC043576).

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.

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 between clerical, clinical and other specific 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 are required to meet at least four times per year. Regular Skype calls are also made to allow for low-cost administration and decision-making. These meetings include the AGM and three other Board meetings where Trustees review strategy and performance and set operating plans and budgets. In addition, a number of Trustees meet on a more regular basis to monitor those actions.

The Trustees have a number of standing sub-committees which continue to operate, they are: Finance, Audit and Risk Committee; Marketing Committee (including Fundraising); General Purpose Committee. The number of sub committees is projected to increase, in line with our three-year strategic plan and the increasingly successful support Narcolepsy UK is able to offer.

The Trustees who served during the period were:

<table>
<thead>
<tr>
<th>Name</th>
<th>Appointed Date</th>
<th>Resigned Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Matt O’Neill</td>
<td>8 December 2012</td>
<td></td>
</tr>
<tr>
<td>William Harris</td>
<td>28 September 2011</td>
<td>15 December 2013</td>
</tr>
<tr>
<td>Edmund Coates</td>
<td>28 September 2011</td>
<td>13 June 2013</td>
</tr>
<tr>
<td>Tim Kavanagh</td>
<td>28 September 2011</td>
<td>24 October 2013</td>
</tr>
<tr>
<td>Graeme Moir</td>
<td>28 September 2011</td>
<td></td>
</tr>
<tr>
<td>Jenny Taylor</td>
<td>28 September 2011</td>
<td></td>
</tr>
<tr>
<td>Hugh Davies-Webb</td>
<td>28 September 2011</td>
<td></td>
</tr>
<tr>
<td>Nicola Rule</td>
<td>28 September 2011</td>
<td></td>
</tr>
<tr>
<td>Thomas Bamford</td>
<td>28 September 2011</td>
<td></td>
</tr>
<tr>
<td>Zoe Shardlow</td>
<td>28 September 2011</td>
<td></td>
</tr>
<tr>
<td>Brian Seaton</td>
<td>24 February 2013</td>
<td></td>
</tr>
</tbody>
</table>
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 governing document 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. Each Trustee will have a portfolio of interests, which contribute to an understanding of specific aspects of how Narcolepsy UK operates.

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

A revised Strategic Plan for the next 3 years has been adopted. This new Strategic Plan will build on the work already delivered and reflect a vision which acknowledges the UK’s current financial profile and how this may impact upon small charities, thus ensuring Narcolepsy UK recognises its continued need to maximise value for money.

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 Finance, Audit and Risk Committee will review these areas specifically throughout the year.

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.
Objectives and Activities

Narcolepsy UK’s objectives continue to be to provide relief and aid to those persons suffering from narcolepsy.

Our principal activities to achieve these objectives are:

- The promotion and organisation of conferences and exhibitions relating to narcolepsy and its effects.
- The promotion and/or assistance in promoting and carrying out research, surveys and investigation 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 via our publication "Catnap" and the Narcolepsy UK media portfolio comprising website, Facebook and Twitter.

The objectives of those activities for the year and Narcolepsy UK’s achievements against them are summarised under the heading of Achievement 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.

Public Benefit

In reviewing the objectives of the charity, the Trustees are aware of the guidance issued by the charity Commission on public benefit and consider that they are complying with that guidance.

To aid supporters and those who take an interest in The charity to understand what is planned for 2014 a section detailing activity for the coming year is laid out at the end of this report.
Achievements and Performance

Core Activities

The aims of the charity as set out in the last report are stated below, with information on whether these core activities were met.

Hold a major Conference in 2013

Achieved with a Regional Conference in Watford specifically targeted towards children with narcolepsy but equally as involving for adults.

Feedback confirmed this was a well-received meeting and that delegates found the informal chats with fellow People with Narcolepsy (PWN) to be very worthwhile.

Delegates came from as far afield as Iceland and Nigeria.

Throughout 2013, a major area requiring charity support has been the very considerable impact of the H1N1 Swine Flu “Pandemrix” vaccine with many children, and some adults, being diagnosed with ‘Pandemrix Narcolepsy’. The end of 2013 saw the booking of a meeting on this specific topic for mid-January.

Based on current information, there could be up to 400 children and adults impacted by this vaccination programme, requiring additional, often pan-European co-operation with patient organisations across the E.U.

Our conferences provide a valuable opportunity for attendees, existing and new, to compare experiences and treatments and now for parents of newly diagnosed youngsters to ask questions of mature people with narcolepsy who have been diagnosed with ‘Organic Narcolepsy’ since their youth.

Coping strategies people share with each other really have a profound effect on the people and families we support.

- Update the information packs and leaflets available to our supporters

More new literature was purchased from NHS Scotland during 2013 which has been distributed for provision to schools and family members of young children. This was made available at conference and is available by request from the Narcolepsy UK website. Further initiatives follow for 2014.

- Increase the awareness and profile of Narcolepsy UK

Trustees are keen to continue raising awareness, in particular at events where there are a mixture of people, displaying their banner and T-shirts promoting the charity at various events run by supporters of the charity. These events have been fun, whilst raising awareness and fundraising, thus extending awareness of the condition to all sectors.

At least one Trustee has been proactive in encouraging his MP to understand the inequalities across medical care, schooling and employment, with the intention of raising open questions in the House of Commons. Others have also contacted their MP.

Narcolepsy UK has made increasing use of social media to outline its activities and those of supporters - in all instances the remit is to educate more people about the condition and potentially offer their personal or financial support. In 2013 the charity has worked with a number of Facebook groups already created and with large numbers of followers to draw attention directly to Narcolepsy UK and its services, advocacy, website and advice helpline.
• Update The charity website

Narcolepsy UK remains on page one of all the leading search engines without the use of optimisation and is usually in the top three for all the main narcolepsy "header" searches. The site is updated with news and information as regularly as possible within current funding and resource levels, the current operators of the website being people with narcolepsy. The Forum provides a regular, private-to-supporters, facility to ask questions, discuss personal circumstances and receive advice from the administrators of the site. In 2013 the website infrastructure was refreshed to make use of more modern "open-source" software. This work was undertaken largely by volunteers and Trustees and the Board is grateful for their commitment.

In 2014 further work is planned to provide a more accessible site for people with narcolepsy and their families and carers in addition to medical and educational practitioners seeking detailed information on the condition.

• Re-invigorate the Narcolepsy UK branch network

2013 has seen an increasing number of volunteers and networking groups being set up from Newcastle to the West Country – there are still gaps, however these are slowly filling.

This will provide volunteer supporters in localised areas to form smaller contact groups, building a network on a countywide basis. Prior to securing persons to operate these groups there is the necessity for referencing and VBS checking to ensure probity.

It is clear that younger members’ means of regular contact are via social media and mobile hardware such as smartphones, tablets and laptops which is something Narcolepsy UK is reviewing to ensure both accessibility and safe and secure environments for minors and young adults.

• Fundraising

The aims of The charity as set out in the last report are stated below, with information on whether these core activities were met.

• We aimed to make giving easier

The creation of the incorporated charitable company and the change in bankers to Charities Aid Foundation meant that during 2013 it was possible to attract funding from more varied sources, utilising CAF’s Not-For-Profit sector experience and on-line functionality.

The 2013 leaflet on 50 ways to raise money has been amended as we have listened to the voice of supporters and their requirements for fundraising events.

We have also become far more proactive in supporting and encouraging people to raise funds on behalf of the charity utilising ideas which interest and enthuse them.

We continue to rely heavily on the generous donations and legacies we receive from our supporters. The charity was proactive in focusing on increasing income, with its first (part-time) fundraiser producing 405 funding applications to trusts and foundations in 2013.

Growth since 2012:

28% more trusts have supported us
Application success rate up 48% (from 4.6% of applications made to 6.8%)

As with other charities, we continue to look for opportunities to maintain and grow our income stream within our existing risk appetite. Personal sponsorships are hugely important to Narcolepsy UK as we see funding from Trusts and other organisations become increasingly challenging to secure, despite our best endeavours.

**Electronic Giving and Payment Functionality**

Give As You Earn (GAYE) schemes promoted.

Options to download “Give As You Live” internet links that generate a % income from supporters’ transactions with many on-line retailers.

A direct link to an outsourced greeting card company where income is generated for the charity on a per-card basis, removing costs associated with internal production/administration of charity cards.

Additional direct-payment functionality is planned for 2014.

**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 income is spent. The Trustees are satisfied with the results for the period, but would point out that they are influenced by the one-off transfer of assets from the unincorporated charity Narcolepsy UK (326361)

**Management Policies**

**Reserve policy**

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 at least six months’ cash flow. 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.

The present range for operating reserves remains at £50,000. The Trustees believe that the most prudent course remains building charitable activities in the first instance before building up a free reserve.
Employees and Pensions

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 its 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.

In 2013 an award from Volunteer Action Fund (Scotland) was received for a Volunteer Co-ordinator. The role was advertised through the network of supporters and two persons short-listed. The role was awarded to Liam Sloan, himself a narcoleptic who has now undergone initial training and is sourcing and signing up new volunteers to work on specific roles within the charity.

In December 2013 Margaret Roxburgh, the long-standing Benefits Advisor and Helpline Operator, gave notice and Rebecca Malone was interviewed and appointed to this role commencing 04-01-14. Rebecca is a nurse and also has a daughter with Pandemrix narcolepsy so has a deep insight into this chronic neurological disorder.

In December 2013 the Trustees saw the need to have an employed person undertake the regular administrative and secretarial tasks required of the charity. Nicola Rule had been the Trustee undertaking such tasks in recent times and made the transition from Trustee to employee to save any lapse in continuity and protect the best interests of Narcolepsy UK.

Pensions

As Narcolepsy UK employs less than 5 staff the charity is not obliged to offer a pension. Should the charity grow to the size where pensions become appropriate the Trustees confirm they would offer a defined contribution pension scheme and will certainly broker the Government scheme.

Plans for the Future

The Trustees believe that Narcolepsy UK has a sound basis upon which to build for the future. We continue to strengthen and develop existing services yet further to reach even more people with narcolepsy, their families and carers.

During 2014 Narcolepsy UK expects to hold a Regional Conference, possibly in the North of England, as well as mini-conferences in other areas facilitated by regional Trustees supporting such events. This will give greater scope for supporters to meet together without the overheads of a main Conference for either the charity or the delegates.

The website, now one of the leading portals for information on narcolepsy in the world, has had a major structural overhaul but the presentation and content still require a massive effort in terms of time and funding to ensure they are fit for their target audience.

Narcolepsy UK will also increase its commitment to social media, having already done so by working with existing groups and signposting to Narcolepsy UK.
The charity has introduced extra hours for its helpline, reflecting changes in benefits as a result of the Welfare Reform Act 2012 and its impact on individuals which led to a significant uplift in calls in the third quarter of 2013. We expect 2014 to bring yet more questions about the Pandemrix situation.

The website has had new information uploaded and this is regularly reviewed to take account of change.

The on-going Pandemrix situation and the fight for adequate support and compensation will continue to energise Narcolepsy UK until results are achieved. While Pandemrix is within the Vaccine Damage Compensation Scheme the burden of proof does seem to remain firmly in favour of the Government. With seasonal flu vaccination for children planned, what is given to vulnerable children will take up much charity time. Narcolepsy UK has facilitated joining together families who have been affected and has taken on a far more European stance than previously to ensure we are in-step with similarly affected countries across the E.U.

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

Matt O’Neill, Chair

23rd April 2014
Statement of Trustees' Responsibilities

The Trustees 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). The law applicable to charities in England and Wales requires the Trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources 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 judgments and estimates that are reasonable and prudent.
- State whether applicable 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 proper accounting records that disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the financial statements comply with the Charities Act 1993, the charity (Accounts Reports) Regulations 2008, and trust deed. 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 charity 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.
Independent Examiner's Report

To the Trustees of Narcolepsy UK

I report on the accounts of the Trust for the year ended 31 December 2013, which are set out on pages Statement of Financial Activities 14 to 21.

Respective Responsibilities of Trustees and Examiner

The charity's trustees are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year under section 144(2) of the Charities Act 2011 (the 2011 Act) and that an independent examination is needed.

It is my responsibility to:

• examine the accounts under section 145 of the 2011 Act;
• to follow the procedures laid down in the general Directions given by the charity Commission under section 145(5)(b) of the 2011 Act; and
• to state whether particular matters have come to my attention.

Basis of Independent Examiner's Report

My examination was carried out in accordance with the general Directions given by the charity Commission. 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 seeking 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:

(1) which gives me reasonable cause to believe that in any material respect the requirements:

• to keep accounting records in accordance with section 130 of the 2011 Act; and
• to prepare accounts which accord with the accounting records and comply with the accounting requirements of the 2011 Act

have not been met; or

(2) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

James Francis
Ensors,
Warwick House, Ermine Business Park, Huntingdon, Cambridgeshire PE29 6XY
Date 16th May 2014
## Statement of Financial Activities

### Incoming and Outgoing Resources

**Note:**
Narcolepsy UK has no Endowment Funds.
Narcolepsy UK has no recognised gains or losses, *eg:* revaluations of fixed assets or investment assets.

<table>
<thead>
<tr>
<th>Note</th>
<th>Unrestricted Funds</th>
<th>Restricted Funds</th>
<th>Total 2013</th>
<th>Total 2012</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>£</td>
<td>£</td>
<td>£</td>
<td>£</td>
</tr>
</tbody>
</table>

### INCOMING RESOURCES

**From Generated Funds**

- **Voluntary Income**
  - 3a: £63,855
  - **Total Voluntary Income:** £63,855

- **Income Generation**
  - 3b: £11,185
  - **Total Income Generation:** £29,123

- **Investment Income**
  - 3c: £86
  - **Total Investment Income:** £86

- **Charitable Activities**
  - 4: £1,976
  - **Total Charitable Activities:** £1,976

**Total Incoming Resources**

- **Total:** £95,040
- **Previous Year:** £74,355

### RESOURCES EXPENDED

**Generating Funds**

- **Total Generating Funds:** £51,204
- **Previous Year:** £98,269

**Charitable Activities**

- **Total Charitable Activities:** £27,837
- **Previous Year:** £60,795

**Governance**

- **Total Governance:** £17,932
- **Previous Year:** £17,932

**Total Resources Expended**

- **Total:** £56,179
- **Previous Year:** £98,269

### Net Incoming/-Outgoing Resources

**Net Movement in Funds**

- **Total:** £38,861
- **Previous Year:** (£23,914)

**Brought Forward from Previous Year**

- £62,115
- **Total Brought Forward:** £63,815

**Assets Transferred from Old Charity**

- £87,729

**Total Funds Carried Forward to 2014**

- £102,676
- **Previous Year:** £63,815
Trustees Annual Report and Statement of Financial Activity
NARCOLEPSY UK
Year Ended 31 December 2013

Balance Sheet

Note:
Narcolepsy UK has no Tangible, Investment or Stock and Current Work in Progress Assets.

<table>
<thead>
<tr>
<th>Note</th>
<th>Unrestricted Funds</th>
<th>Restricted Funds</th>
<th>Total 2013</th>
<th>Total 2012</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>£</td>
<td>£</td>
<td>£</td>
<td>£</td>
</tr>
<tr>
<td>CURRENT ASSETS</td>
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<td></td>
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<tr>
<td>Debtors</td>
<td>10</td>
<td>626</td>
<td>-</td>
<td>626</td>
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<tr>
<td>Cash at Bank and in Hand</td>
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<td>90,737</td>
<td>14,663</td>
<td>105,400</td>
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<tr>
<td>Total Current Assets</td>
<td></td>
<td>91,363</td>
<td>14,663</td>
<td>106,026</td>
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<tr>
<td>LIABILITIES</td>
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<tr>
<td>Creditors Due Within One Year</td>
<td>11</td>
<td>3,350</td>
<td>-</td>
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<tr>
<td>NET ASSETS</td>
<td></td>
<td>88,013</td>
<td>14,663</td>
<td>102,676</td>
</tr>
<tr>
<td>FUNDS OF THE CHARITY</td>
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<tr>
<td>Unrestricted Funds</td>
<td>12</td>
<td>35,898</td>
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<td>General Funds</td>
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<td>Designated Funds</td>
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<tr>
<td>Large Legacies and Donations</td>
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<td>Restricted Income Funds</td>
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<td>700</td>
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<td>Advocacy Services</td>
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<td>Website Development</td>
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<td>Conferences and Meetings</td>
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<td>2,530</td>
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<tr>
<td>Local and Regional Support</td>
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<td>-</td>
<td>2,530</td>
<td>2,530</td>
</tr>
<tr>
<td>TOTAL FUNDS</td>
<td></td>
<td>88,013</td>
<td>14,663</td>
<td>102,676</td>
</tr>
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</table>

For the year ending 31 December 2013 the company was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies.

- The members have not required the company to obtain an audit of its accounts for the year in question in accordance with section 476,
- The directors acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and the preparation of accounts.

These accounts have been prepared in accordance with the provisions applicable to companies subject to the small companies' regime.'

The accounts were approved by the Board on 23.01.2014

Matt O'Neill,
Chair

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1 Accounting policies

Basis of preparation
The financial statements have been prepared under the historical cost convention and in accordance with the Financial Reporting Standard for Smaller Entities (effective April 2008). The financial statements have been prepared in accordance with the Statement of Recommended Practice (SORP), "Accounting and Reporting by Charities" published in March 2005, applicable accounting standards and the Companies Act 2006.

The trustees believe that the charity has adequate resources to continue in operational existence for the foreseeable future. Therefore they have continued to adopt the going concern basis in preparing these financial statements.

Company Status
Narcolepsy UK is a charitable company limited by guarantee and has no share capital. The members of the company are the Trustees named on page 2. In the event of the charitable company being wound up, the liability of each member in respect of the guarantee is limited to £1.

Fund accounting
General funds are unrestricted funds which are available for use at the discretion of the Trustees in furtherance of the general objectives of the charitable company and which have not been designated for other purposes.

Designated funds form part of the general funds set aside by the Trustees for specific purposes. Restricted funds are funds which are to be used in accordance with specific restrictions imposed by donors which have been raised by the charitable company for particular purposes. The cost of raising and administering such funds are charged against the specific fund. The aim and use of each restricted fund is set out in the notes to the financial statements.

Investment income, gains and losses are allocated to the appropriate fund.

Incoming resources
All incoming resources are included in the Statement of Financial Activities when the charitable company is legally entitled to the income and the amount can be quantified with reasonable accuracy.

Resources expended
All expenditure is accounted for on an accruals basis and has been included under expense categories that aggregate all costs for allocation to activities. Where costs cannot be directly attributed to particular activities they have been allocated on a basis consistent with the use of the resources. All expenses incurred with the intention of raising funds for the charity are allocated to costs of generating voluntary income.
Trustees Annual Report and Statement of Financial Activity
NARCOLEPSY UK
Year Ended 31 December 2013

NOTES TO THE ACCOUNTS (Continued)

<table>
<thead>
<tr>
<th>3a Voluntary Income</th>
<th>Unrestricted Funds</th>
<th>Restricted Funds</th>
<th>Total 2013</th>
<th>Total 2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Donations</td>
<td>£22,492</td>
<td>-</td>
<td>£22,492</td>
<td>£36,413</td>
</tr>
<tr>
<td>Legacies</td>
<td>£41,363</td>
<td>-</td>
<td>£41,363</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>£63,855</td>
<td>-</td>
<td>63,855</td>
<td>36,413</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3b Income Generation</th>
<th>Unrestricted Funds</th>
<th>Restricted Funds</th>
<th>Total 2013</th>
<th>Total 2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fundraising/Grants - Trusts</td>
<td>£11,185</td>
<td>£17,938</td>
<td>£29,123</td>
<td>£36,359</td>
</tr>
<tr>
<td></td>
<td>11,185</td>
<td>17,938</td>
<td>29,123</td>
<td>36,359</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3c Investment Income</th>
<th>Unrestricted Funds</th>
<th>Restricted Funds</th>
<th>Total 2013</th>
<th>Total 2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bank Interest</td>
<td>£86</td>
<td>-</td>
<td>£86</td>
<td>£393</td>
</tr>
<tr>
<td></td>
<td>86</td>
<td>-</td>
<td>86</td>
<td>393</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4 Income from Charitable Activities</th>
<th>Unrestricted Funds</th>
<th>Restricted Funds</th>
<th>Total 2013</th>
<th>Total 2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conference</td>
<td>£1,976</td>
<td>-</td>
<td>£1,976</td>
<td>£1,190</td>
</tr>
<tr>
<td></td>
<td>1,976</td>
<td>-</td>
<td>1,976</td>
<td>1,190</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>5 Costs of Generating Funds</th>
<th>Unrestricted Funds</th>
<th>Restricted Funds</th>
<th>Total 2013</th>
<th>Total 2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff Costs</td>
<td>£13,137</td>
<td>-</td>
<td>£13,137</td>
<td>£14,915</td>
</tr>
<tr>
<td>Other Costs</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>£4,627</td>
</tr>
<tr>
<td></td>
<td>13,137</td>
<td>-</td>
<td>13,137</td>
<td>19,542</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>6 Costs of Charitable Activities</th>
<th>Unrestricted Funds</th>
<th>Restricted Funds</th>
<th>Total 2013</th>
<th>Total 2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advocacy Services*</td>
<td>£18,816</td>
<td>-</td>
<td>£18,816</td>
<td>£38,902</td>
</tr>
<tr>
<td>Local and Regional Support</td>
<td>-</td>
<td>£470</td>
<td>£470</td>
<td>£600</td>
</tr>
<tr>
<td>Conferences and Meetings</td>
<td>-</td>
<td>£4,505</td>
<td>£4,505</td>
<td>£7,927</td>
</tr>
<tr>
<td>Website development and maintenance**</td>
<td>£738</td>
<td>-</td>
<td>738</td>
<td>9,258</td>
</tr>
<tr>
<td>Catnap</td>
<td>£3,308</td>
<td>-</td>
<td>£3,308</td>
<td>£4,108</td>
</tr>
<tr>
<td></td>
<td>22,862</td>
<td>4,975</td>
<td>27,837</td>
<td>60,795</td>
</tr>
</tbody>
</table>

* Support and advice (excluding medical advice) services for beneficiaries with state benefits problems and/or were attempting to change their medication.

* There is a considerable drop in overheads as the CEO has not been replaced.

**There is a reduction in cost as upgrading of the site to a new platform during 2013 was undertaken by a Trustee and a ‘pro bono’ team of professionals.
NOTES TO THE ACCOUNTS (Continued)

<table>
<thead>
<tr>
<th>Unrestricted Funds</th>
<th>Restricted Funds</th>
<th>Total 2013</th>
<th>Total 2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>£</td>
<td>£</td>
<td>£</td>
<td>£</td>
</tr>
</tbody>
</table>

7 Costs of Governance

7a Independent Examiner’s Fees 3,850 - 3,850 5,167
Room hire 694 - 694 1,082
Printing and stationary 2,191 - 2,191 563

7b Trustee expenses
(Travel and accommodation to attend meetings) 2,720 - 2,720 3,182
Phone and Fax 823 - 823 562
Office and Miscellaneous 1,904 - 1,904 1,151

Sub-total 12,182 - 12,182 11,707

Staff costs 3,023 - 3,023 6,225

Total 15,205 - 15,205 17,932

8 Employees

8a Number of Employees

The average monthly number of employees during the period was:
Administrative staff, part time 3

8b Employment Costs (Wages and salaries)

| Cost of generating funds 13,137 | - | 13,137 | 14,915 |
| Advocacy services 18,489 | - | 18,489 | 46,484 |
| Website development and maintenance * - - - 7,728 |
| Governance costs 3,023 | - | 3,023 | 6,225 |
| 34,649 | - | 34,649 | 65,324 |

Total INCLUDES Social Security costs of: 1,837 4,759

* Governance costs have reduced as all incorporation matters are now cleared, there are no CEO overheads, and Trustees spent more time working in this sector.

9 Trustees

9a No remuneration was paid to Trustees during the period.

9b Total expenses for the period reimbursed to 6 Trustees 2,720 5,721
### Debtors

<table>
<thead>
<tr>
<th></th>
<th>Unrestricted Funds</th>
<th>Restricted Funds</th>
<th>Total 2013</th>
<th>Total 2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trade debtors</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>14,351</td>
</tr>
<tr>
<td>Prepayments</td>
<td>626</td>
<td>-</td>
<td>626</td>
<td>-</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>626</strong></td>
<td><strong>-</strong></td>
<td><strong>626</strong></td>
<td><strong>14,351</strong></td>
</tr>
</tbody>
</table>

### Creditors: Amounts falling due within one year

<table>
<thead>
<tr>
<th></th>
<th>Unrestricted Funds</th>
<th>Restricted Funds</th>
<th>Total 2013</th>
<th>Total 2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other creditors</td>
<td>3,350</td>
<td>-</td>
<td>3,350</td>
<td>4,800</td>
</tr>
</tbody>
</table>
12 Income Restricted Funds

12a Narcolepsy UK has no Permanent or Expendable Income Restricted Funds.

12b Names and Purposes of Other Restricted Funds

Advocacy Services Restricted Fund
These funds have been donated to cover the cost, mostly staff salaries, of providing one-to-one support to people with narcolepsy (and related conditions), their families and carers who, due to lack of knowledge about the causes and consequences of narcolepsy (and related conditions) in their local health and social services, are finding it difficult to get adequate access to skilled professional clinical care and to appropriate social benefits and services.

Website Development and Maintenance Restricted Fund
These funds have been donated specifically to allow the charity to develop and maintain up-to-date a credible and respected website which will be universally recognised as a primary source of information for everyone who has an interest in narcolepsy and related conditions. As well as contributing to the technical costs of hosting the website, ensuring that its content is relevant, accurate and up-to-date, and ensuring that it remains compatible with evolving trends in internet communications and social media, the fund will from time to time also be used to sponsor original contributions to the website.

Conferences and Meetings Restricted Fund
These funds have been donated specifically to allow the charity to run conferences and meetings, both nationally and regionally, for the dissemination of information on narcolepsy and related conditions both formally through presentations, displays and publications and informally through networking and break-out discussion groups. The funding will be used to keep the costs of attending and participating in conferences and meetings as low as possible, particularly for people with narcolepsy (and related conditions), their families and carers.

Local and Regional Support Restricted Fund
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.

12c Movements in Income Restricted Funds

<table>
<thead>
<tr>
<th>Name of Fund</th>
<th>Balance B/Fwd</th>
<th>Incoming Resources</th>
<th>Outgoing Resources</th>
<th>Transfers</th>
<th>Balance C/Fwd</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advocacy Services</td>
<td>700</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>700</td>
</tr>
<tr>
<td>Website Development</td>
<td>-</td>
<td>2,500</td>
<td>-</td>
<td>-</td>
<td>2,500</td>
</tr>
<tr>
<td>Conferences and Meetings</td>
<td>-</td>
<td>13,438</td>
<td>(4,505)</td>
<td>-</td>
<td>8,933</td>
</tr>
<tr>
<td>Local and Regional Support</td>
<td>1,000</td>
<td>2,000</td>
<td>(470)</td>
<td>-</td>
<td>2,530</td>
</tr>
<tr>
<td>TOTAL FUNDS</td>
<td>1,700</td>
<td>17,938</td>
<td>(4,975)</td>
<td>-</td>
<td>14,663</td>
</tr>
</tbody>
</table>
13 **Designated Funds**

13a **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/donation 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.

13b **Movements in Designated Funds**

<table>
<thead>
<tr>
<th>Name of Fund</th>
<th>Balance B/Fwd</th>
<th>Incoming Resources</th>
<th>Outgoing Resources</th>
<th>Transfers</th>
<th>Balance C/Fwd</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>£</td>
<td>£</td>
<td>£</td>
<td>£</td>
<td>£</td>
</tr>
<tr>
<td>Large Legacies and Donations</td>
<td>52,115</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>52,115</td>
</tr>
<tr>
<td>TOTAL FUNDS</td>
<td>52,115</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>52,115</td>
</tr>
</tbody>
</table>

14 **Analysis of Net Assets Between Funds**

The fund balances at 31 December 2013 are represented by:

<table>
<thead>
<tr>
<th></th>
<th>Unrestricted Funds</th>
<th>Designated Funds</th>
<th>Restricted Funds</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>£</td>
<td>£</td>
<td>£</td>
<td>£</td>
</tr>
<tr>
<td><strong>Current Assets</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cash at Bank and in Hand</td>
<td>38,622</td>
<td>-</td>
<td>-</td>
<td>38,622</td>
</tr>
<tr>
<td>General Fund</td>
<td></td>
<td>-</td>
<td>-</td>
<td>38,622</td>
</tr>
<tr>
<td>Large Legacies and Donations {D}</td>
<td>-</td>
<td>52,115</td>
<td>-</td>
<td>52,115</td>
</tr>
<tr>
<td>Advocacy Services {R}</td>
<td>-</td>
<td>-</td>
<td>700</td>
<td>700</td>
</tr>
<tr>
<td>Local and Regional Support {R}</td>
<td>-</td>
<td>-</td>
<td>2,530</td>
<td>2,530</td>
</tr>
<tr>
<td>Conferences and Meetings {R}</td>
<td>-</td>
<td>-</td>
<td>8,933</td>
<td>8,933</td>
</tr>
<tr>
<td>Website Development {R}</td>
<td>-</td>
<td>-</td>
<td>2,500</td>
<td>2,500</td>
</tr>
<tr>
<td>Debtors</td>
<td>626</td>
<td>-</td>
<td>-</td>
<td>626</td>
</tr>
<tr>
<td>Creditors: Due within one year</td>
<td>(3,350)</td>
<td>-</td>
<td>-</td>
<td>(3,350)</td>
</tr>
<tr>
<td></td>
<td>35,898</td>
<td>52,115</td>
<td>14,663</td>
<td>102,676</td>
</tr>
</tbody>
</table>
2013 Supporters – Trusts and Foundations

The Aylesford Family Charitable Trust
Company of Actuaries Charitable Trust
The David Gibbons Foundation
The Dennis Alan Yardy Charitable Trust
Duchy of Lancaster Benevolent Fund
The Eveson Charitable Trust
The Foresters Charity Stewards UK Trust
The Fulmer Charitable Trust
The GC Gibson Charitable Trust
The Joicey Trust
JTH Charitable Trust
Haberdasher's Company Charitable Foundation
The Hull and East Riding Charitable Trust
The Lynn Foundation
The Mickel Fund
The Paul Bassham Charitable Trust
The Pharsalia Charitable Trust
Pilkington Charitable Trust
The Russell Trust
Schuster Charitable Trust
The Sir Jules Thorn Charitable Trust
Souter Charitable Trust
The Sovereign Health Care Charitable Trust
The W. M. Mann Foundation