

**NARCOLEPSY UK FORMERLY NARCOLEPSY ASSOCIATION (UK)**  
**TRUSTEES' REPORT AND UNAUDITED ACCOUNTS**  
**FOR THE YEAR ENDED 31 MARCH 2010**

# NARCOLEPSY UK FORMERLY NARCOLEPSY ASSOCIATION (UK)

## LEGAL AND ADMINISTRATIVE INFORMATION

---

<b>Trustees</b>	Zoe Shardlow Ann Williams Jenny Taylor Graeme Moir Mike Armstrong William Harris Ed Coates
<b>Chair</b>	William Harris
<b>Executive officer-Director</b>	John Cherry
<b>Treasurer</b>	Mike Armstrong
<b>Secretary</b>	Ann Williams
<b>Charity number</b>	326361
<b>Principal address</b>	PO Box 13842 Penicuik Midlothian EH26 8WX
<b>Independent examiner</b>	J O Matthews Ensors Cardinal House 46 St Nicholas Street Ipswich IP1 1TT
<b>Bankers</b>	Royal Bank of Scotland 747 Attercliffe Road Sheffield S9 3RF

---

# NARCOLEPSY UK FORMERLY NARCOLEPSY ASSOCIATION (UK)

## CONTENTS

---

	<b>Page</b>
Trustees' report	1 - 6
Statement of trustees' responsibilities	7
Independent examiner's report	8
Statement of financial activities	9
Balance sheet	10
Notes to the accounts	11 - 13

---

# **NARCOLEPSY UK FORMERLY NARCOLEPSY ASSOCIATION (UK)**

## **TRUSTEES' REPORT**

### ***FOR THE YEAR ENDED 31 MARCH 2010***

---

The trustees (UKAN) present their report and accounts for the year ended 31 March 2010.

#### **Structure, governance and management**

Narcolepsy UK is an unincorporated association governed by a constitution adopted in 1983 and revised on November 17th 1990, September 25th 1999 and October 17th 2008. A further revision to change the name of the association from The Narcolepsy Association (UK) to Narcolepsy UK was proposed and accepted at an EGM called on 13th December 2009. For the purposes of this report the charity will be referred to as UKAN. For further information please see the section on significant post annual report information.

Narcolepsy UK is a registered charity, charity number 326361.

The trustees who served during the year were:

Zoe Shardlow

Ann Williams

Jenny Taylor

Graeme Moir

Mike Armstrong

William Harris

Emma Forsberg

(Resigned 28 February 2010)

Ed Coates

Kay Underwood

(Resigned 30 September 2009)

Under its Constitution UKAN activity is directed by a Management Committee. All of the above trustees serve on that committee and Ms Emma Forsberg who resigned as a trustee continues to serve on the Management Committee.

#### **Executive Officers**

Director - John Cherry (appointed 1 February 2010).

# **NARCOLEPSY UK FORMERLY NARCOLEPSY ASSOCIATION (UK)**

## **TRUSTEES' REPORT (CONTINUED)**

### ***FOR THE YEAR ENDED 31 MARCH 2010***

---

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 15. The majority of trustees and the Chair of the charity are required by the constitution to be diagnosed narcoleptics. In addition, the charity appointed an Honorary Solicitor who may attend Board meetings as required.

The Trustee Board tries to maintain a balance between clerical, clinical and others with specific skills whilst retaining the requirements of the constitution. This does make trustee recruitment difficult as to a large extent the trustees must rely on members to fill posts. 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, a number of Trustees meet on a more regular basis to monitor those actions.

In 2010 the Trustees decided to appoint a number of standing sub committees which operated from February 2010, they were:

- " Finance, Audit and Risk Committee
- " Marketing Committee
- " General Purpose Committee

New Trustees receive an induction pack containing detailed information about the charity, its organisation and its work. They are then invited to spend time with the Director and 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, the charity appoint 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 the charity works.

#### **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 Director and the Board of Trustees. The systems of internal control are designed to provide reasonable assurances against material misstatement or loss. They include:

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

#### **Risk Management**

The Trustees recognise that, like other organisations and charities, UKAN 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 areas of risk amongst the individual trustees to review specific areas. The newly appointed Finance, Audit and Risk Committee will review these areas in a specific meeting held for this purpose.

Reporting lines are constantly monitored to enable regular checking of the Charity's short and long-term profile and make all key parties aware of the impact of risk. The Trustees are satisfied that they have systems in place or are putting systems in place that mitigate the Charity's exposure to risk.

#### **The Director**

The Director is responsible for the day-to-day management of UKANs affairs and for implementing policies agreed by the Board of Trustees.

---

# **NARCOLEPSY UK FORMERLY NARCOLEPSY ASSOCIATION (UK)**

## **TRUSTEES' REPORT (CONTINUED)**

### ***FOR THE YEAR ENDED 31 MARCH 2010***

---

#### **Objectives for the 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 fulfilling this objective.

#### **Objectives, Vision and Principal Activities of the Narcolepsy Association (UK)**

UKANs objects remain to provide relief and aid to those persons suffering from Narcolepsy. Our principal activities to achieve these objects 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.  
Create the funding strategies that make this work possible.  
Arrange and provide exhibitions, meetings, lectures, classes and training courses.  
To collect and publish information via our publication "Catnap" and the Narcolepsy UK website.

The objectives of those activities for the year and UKAN's achievements against them are discussed 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 aim to achieve this vision by:

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

# NARCOLEPSY UK FORMERLY NARCOLEPSY ASSOCIATION (UK)

## TRUSTEES' REPORT (CONTINUED)

### FOR THE YEAR ENDED 31 MARCH 2010

---

#### Review Of Developments, Activities and Achievements

This year's objectives and achievements are summarised as follows:

##### Core Activities

o Our aim was to produce four editions of catnap in 2009/2010

This was achieved. Catnap continues to receive good responses from the members and generates many positive comments in the regular questionnaires we ask UKAN members to complete. All members still receive a paper version of the newsletter and a significant number of members remain without access to the internet.

o The Charity wanted to refresh its identity

This was not achieved. The trustees had hoped to have new design formats ready for review in December 2009. This was not possible and the trustees felt it was important to have input from the Director. A marketing brief was issued in February 2010 and responses are being reviewed.

o The Charity aimed to change its name

The trustees agreed at a board meeting in September 2009 on the name change and at an EGM held on December 13th 2009 members agreed to change the name to Narcolepsy UK. The Charity Commission approved this after the year end.

o We aimed to employ a full time Director to the charity.

This was achieved and in December 2009 appointed a Director to take over the day-to-day control of the charity and maintain the momentum put in place by the interim manager.

o We had a target to appoint a fund raising executive.

This was not achieved. Discussions are taking place with the Director as to how he would like to move fund raising forward. It is possible that an agency will be employed to assist with raising funds and awareness of the charity rather than employ an individual.

For this year we aim to:

- o Hold a major conference and at least one local conference;
- o Update the information packs and leaflets available to our members;
- o Increase the awareness of the charity and the condition;
- o Update the charity website.
- o Refresh the charity identity.
- o Re-invigorate the UKAN branch network.

##### Fundraising

o We aimed to increase the number of individuals donating to UKAN by 10%.

This was not achieved and while the numbers of supporters did increase, we were disappointed by the final result. Whilst UKAN did receive sizable legacy income in 2008 this did cause a level of uncertainty among the core supporters. It is an accepted fact that money is in shorter supply than ever and this is likely to become worse in the years ahead. It is assumed that it will become increasingly difficult to increase funds from this important constituency for the charity.

For this year we aim to:

- o Increase the number of individuals supporting the charity;
- o Apply to grant giving trusts for donations;
- o Promote legacy giving to UKAN;
- o Introduce the charity to potential corporate donors.

We continue to rely heavily on the generous donations and legacies we receive from our supporters.

# **NARCOLEPSY UK FORMERLY NARCOLEPSY ASSOCIATION (UK)**

## **TRUSTEES' REPORT (CONTINUED)**

### ***FOR THE YEAR ENDED 31 MARCH 2010***

---

#### **Financial review**

##### Financial Review and Results for the Year

The Statement of Financial Activities, set out on page 8, reflects all incoming resources receivable in the year irrespective of when income is spent. This has been another unusual year for the Charity. Income has decreased while general expenditure has increased. This was expected as revenue in 2009 was increased by two legacies that totaled £231,600. Expenditure has increased as the trustees achieved the requirements of their strategic plan and started to employ skilled people and increase the reach of their activities. During the year, our gross income fell to £17,892 and charitable expenditure increased by £2,459 to £2,863 against the previous years figures. A further £51,154 was expended on generating funds and governance costs. The trustees expected this to happen as 2009 and a significant part of 2010 were considered a transitional period as new employees came to the charity and new systems were put in place.

#### **Management Policies**

##### **Reserve policy**

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

UKAN 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. This reserve is now in place. The capital reserve should hold liquid assets (cash) in a number of bank accounts and be ready for use over the next eighteen months as the charity increases its reach and awareness campaigns. 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 voluntary 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.

##### **Investment Policy and Performance**

The Trustees believe that the investment policy will be to maximise the long-term total return of its investment funds subject to the obligations of UKAN and the risks associated with any portfolio. With the current turbulence in world stock markets the trustees believe that security is more important than asset growth and have therefore decided to stay in cash or near cash investments. The trustees accept these investments may underperform stocks but feel this is the prudent approach. When reserves are invested in stocks the trustees will expect and encourage the fund managers to invest only in companies that have appropriate governance and social responsibility policies.

##### **Employees and Pensions**

###### **Employees**

# **NARCOLEPSY UK FORMERLY NARCOLEPSY ASSOCIATION (UK)**

## **TRUSTEES' REPORT (CONTINUED)**

### ***FOR THE YEAR ENDED 31 MARCH 2010***

---

UKAN aims to be an organisation where employees enjoy a sense of fulfillment 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.

UKAN 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. The Charity is committed to the training, career development and promotion of all employees.

#### **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.

#### **Plans for the future**

The Trustees believe that UKAN 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 sufferers of narcolepsy. New key objectives for this area are set out above under the heading of Achievement and Performance.

The charity also aims to assist other charitable bodies financially.

#### **Significant post annual report information.**

On the 19th of April 2010 the Charity Commission approved the new name of the charity. It is now operating as Narcolepsy UK, though the charity registration number remains the same.

On behalf of the board of trustees

**Ann Williams**

Secretary

Dated: .....

# **NARCOLEPSY UK FORMERLY NARCOLEPSY ASSOCIATION (UK)**

## **STATEMENT OF TRUSTEES' RESPONSIBILITIES**

---

The trustees are responsible for preparing the Trustees' Report and the accounts 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 accounts for each financial year which give a true and fair view of the state of affairs of the Association and of the incoming resources and application of resources of the Association for that year.

In preparing these accounts, 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 accounting standards have been followed, subject to any material departures disclosed and explained in the accounts; and
- prepare the accounts 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 Association and enable them to ensure that the accounts comply with the Charities Act 1993, the Charity (Accounts and Reports) Regulations and the provisions of the 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.

# NARCOLEPSY UK FORMERLY NARCOLEPSY ASSOCIATION (UK)

## INDEPENDENT EXAMINER'S REPORT

### TO THE TRUSTEES OF NARCOLEPSY UK FORMERLY NARCOLEPSY ASSOCIATION (UK)

---

I report on the accounts of the Association for the year ended 31 March 2010, which are set out on pages 9 to 13.

#### **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 43(2) of the Charities Act 1993 (the 1993 Act) and that an independent examination is needed.

It is my responsibility to:

- examine the the accounts under section 43 of the 1993 Act;
- to follow the procedures laid down in the general Directions given by the Charity Commission under section 43(7)(b) of the 1993 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:

- (a) which gives me reasonable cause to believe that in any material respect the requirements:
  - (i) to keep accounting records in accordance with section 41 of the 1993 Act; and
  - (ii) to prepare accounts which accord with the accounting records and comply with the accounting requirements of the 1993 Act;have not been met; or
- (b) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

**J O Matthews**

Ensors  
Cardinal House  
46 St Nicholas Street  
Ipswich  
IP1 1TT

Dated: .....

# NARCOLEPSY UK FORMERLY NARCOLEPSY ASSOCIATION (UK)

## STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 MARCH 2010

	Notes	2010 £	2009 £
<b><u>Incoming resources from generated funds</u></b>			
Donations and legacies	2	10,260	238,348
Investment income	3	1,720	469
		<u>11,980</u>	<u>238,817</u>
Incoming resources from charitable activities	4	2,400	2,839
Other incoming resources	5	3,512	3,810
		<u>17,892</u>	<u>245,466</u>
<b>Total incoming resources</b>			
<b><u>Resources expended</u></b>			
<b>Costs of generating funds</b>			
Costs of generating donations and legacies	6	35,097	7,876
		<u>35,097</u>	<u>7,876</u>
<b>Net incoming resources available</b>			
		<u>(17,205)</u>	<u>237,590</u>
<b>Charitable activities</b>			
Catnap		2,863	404
		<u>2,863</u>	<u>404</u>
Governance costs		16,057	7,470
		<u>16,057</u>	<u>7,470</u>
<b>Total resources expended</b>			
		<u>54,017</u>	<u>15,750</u>
<b>Net (expenditure)/income for the year/ Net movement in funds</b>			
		<u>(36,125)</u>	<u>229,716</u>
Fund balances at 1 April 2009		259,030	29,313
		<u>259,030</u>	<u>29,313</u>
<b>Fund balances at 31 March 2010</b>			
		<u>222,905</u>	<u>259,029</u>

# NARCOLEPSY UK FORMERLY NARCOLEPSY ASSOCIATION (UK)

## BALANCE SHEET

AS AT 31 MARCH 2010

---

	Notes	2010 £	2009 £
<b>Current assets</b>			
Debtors	9	37	126
Cash at bank and in hand		<b>228,668</b>	260,017
		<hr/>	<hr/>
		<b>228,705</b>	260,143
<b>Creditors: amounts falling due within one year</b>			
	10	<b>(5,800)</b>	(1,114)
		<hr/>	<hr/>
<b>Total assets less current liabilities</b>		<b>222,905</b>	259,029
		<hr/> <hr/>	<hr/> <hr/>
<b>Income funds</b>			
Unrestricted funds		<b>222,905</b>	259,029
		<hr/>	<hr/>
		<b>222,905</b>	259,029
		<hr/> <hr/>	<hr/> <hr/>

The accounts were approved by the Trustees on .....

.....  
William Harris  
Chair

# NARCOLEPSY UK FORMERLY NARCOLEPSY ASSOCIATION (UK)

## NOTES TO THE ACCOUNTS

FOR THE YEAR ENDED 31 MARCH 2010

---

### 1 Accounting policies

#### 1.1 Basis of preparation

The accounts have been prepared under the historical cost convention.

The accounts have been prepared in accordance with applicable accounting standards, the Statement of Recommended Practice, "Accounting and Reporting by Charities", issued in March 2005 and the Charities Act 1993.

### 2 Donations and legacies

	2010 £	2009 £
Donations	10,260	238,348

### 3 Investment income

	2010 £	2009 £
Interest receivable	1,720	469

### 4 Incoming resources from charitable activities

	2010 £	2009 £
Conference and AGM	2,374	2,698
Publications	26	141
	<u>2,400</u>	<u>2,839</u>

### 5 Other incoming resources

	2010 £	2009 £
Subscriptions	3,512	3,810

# NARCOLEPSY UK FORMERLY NARCOLEPSY ASSOCIATION (UK)

## NOTES TO THE ACCOUNTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2010

6 Total resources expended	Staff costs £	Other costs £	Total 2010 £	Total 2009 £
<b>Costs of generating funds</b>				
Costs of generating donations and legacies	30,876	4,221	35,097	7,876
<b>Charitable activities</b>				
<u>Catnap</u>				
Activities undertaken directly	-	2,863	2,863	404
<b>Governance costs</b>	-	16,057	16,057	7,470
	<u>30,876</u>	<u>23,141</u>	<u>54,017</u>	<u>15,750</u>

Other costs totalling £2,037 have been allocated evenly between costs of generating funds and governance costs. All other expenses are apportioned on an actual basis.

7 Governance costs	2010 £	2009 £
Other governance costs comprise:		
Room hire	245	25
Printing postage and stationery	414	295
Conference and AGM expenses	7,363	4,224
Office costs	3,065	415
Telephone and fax	159	121
Trustees expenses	3,487	1,236
Subsistence	338	165
Independent examiners fees	986	989
	<u>16,057</u>	<u>7,470</u>

# NARCOLEPSY UK FORMERLY NARCOLEPSY ASSOCIATION (UK)

## NOTES TO THE ACCOUNTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2010

---

### 8 Employees

#### Number of employees

The average monthly number of employees during the year was:

	<b>2010</b>	2009
	<b>Number</b>	Number
Administrative staff	<u>1</u>	<u>1</u>

#### Employment costs

	<b>2010</b>	2009
	£	£
Wages and salaries	<u>30,876</u>	<u>6,857</u>

### 9 Debtors

	<b>2010</b>	2009
	£	£
Trade debtors	<u>37</u>	<u>126</u>

### 10 Creditors: amounts falling due within one year

	<b>2010</b>	2009
	£	£
Bank overdrafts	<b>4,351</b>	-
Trade creditors	<u>1,449</u>	<u>1,114</u>
	<u><b>5,800</b></u>	<u>1,114</u>

### 11 Related parties

7 Trustees were paid a total of £3,070 for mileage claims in the year. (2009: 7 Trustees were paid £1,236).

In addition a further £690 was paid by way of reimbursed expenses to 7 trustees (2009: 5 Trustees were paid £480).

**NARCOLEPSY UK FORMERLY NARCOLEPSY ASSOCIATION (UK)**

**MANAGEMENT INFORMATION**

**FOR THE YEAR ENDED 31 MARCH 2010**

**The following pages do not form part of the statutory financial statements.**

# NARCOLEPSY UK FORMERLY NARCOLEPSY ASSOCIATION (UK)

## DETAILED STATEMENT OF FINANCIAL ACTIVITIES

*FOR THE YEAR ENDED 31 MARCH 2010*

---

	2010	2009
	£	£
<b>INCOME</b>		
Donations	10,260	238,348
Bank interest receivable	1,720	469
Conference and AGM	2,374	2,698
Publications	26	141
Subscriptions	3,512	3,810
	<hr/>	<hr/>
<b>TOTAL INCOME</b>	17,892	245,466
	<hr/>	<hr/>
<b>MANAGEMENT AND ADMINISTRATION</b>		
<b>Costs of generating funds</b>		
Wages and salaries	30,876	6,857
Other costs	4,221	1,019
<b>Charitable activities</b>		
Catnap	2,863	404
<b>Governance costs</b>		
Room hire	245	25
Printing postage and stationery	414	295
Conference and AGM expenses	7,363	4,224
Office costs	3,065	415
Telephone and fax	159	121
Trustees expenses	3,487	1,236
Subsistence	338	165
Independent examiners fees	986	989
	<hr/>	<hr/>
<b>Total resources expended</b>	54,017	15,750
	<hr/>	<hr/>
<b>Net (expenditure)/income for the year</b>	(36,125)	229,716
	<hr/> <hr/>	<hr/> <hr/>

---