

NET PATIENT FOUNDATION
TRUSTEES' REPORT AND UNAUDITED ACCOUNTS
FOR THE YEAR ENDED 30 SEPTEMBER 2014

NET PATIENT FOUNDATION

LEGAL AND ADMINISTRATIVE INFORMATION

Trustees

Mr P Gwilliam (Chairman)
Mr D Jones
Miss L Blackadder
Mrs M Phillips
Mrs R Littlejohn
Dr R Srirajaskanthan
Mr N Pearce

Charity number

1092386

Principal address

Enton Mill
Enton
Godalming
Surrey
GU8 5AH

Independent examiner

Chapman Worth Limited
6 Newbury Street
Wantage
Oxfordshire
OX12 8BS

Bankers

Bank of Scotland
33 Old Broad Street
London
EC2N 1HZ

NET PATIENT FOUNDATION

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NET PATIENT FOUNDATION

TRUSTEES' REPORT

FOR THE YEAR ENDED 30 SEPTEMBER 2014

The Trustees have pleasure in presenting the Trustees' Report and Accounts of the NET Patient Foundation for the year ended 30 September 2014. The Trustees are satisfied with the performance and progress of the charity during the year.

The accounts have been prepared in accordance with the accounting policies set out in note 1 to the accounts and comply with the charity's governing document, the Charities Act 2011 and the Statement of Recommended Practice, "Accounting and Reporting by Charities", issued in March 2005.

Structure, governance and management

The NET Patient Foundation was established on 21 February 2001. Its governing document is a Constitution which was adopted on that date and has been amended on a number of occasions subsequently. On 25 June 2013 the name of the charity was shortened to the NET Patient Foundation removing the words 'incorporating Living with Carcinoid'. The objects of the charity were amended on 5 December 2013 to more simply reflect the principle aims of the Foundation and details of these are set out later in this report.

The trustees who served during the year were:

Mr P Gwilliam (Chairman)

Mr R Craft (Resigned 14 May 2014)

Mr D Jones

Miss L Blackadder

Dr N Rushton MBBS MRCP (Resigned 9 July 2014)

Mrs M Phillips

Mrs R Littlejohn

Dr R Srirajaskanthan (Appointed 5 December 2013)

Mr N Pearce (Appointed 14 May 2014)

The Board of Trustees is responsible for the overall management and control of the charity and for the appointment of new Trustees. Two new trustees, Dr Rajaventhana Srirajaskanthan and Mr N Pearce were appointed during the year.

Objectives and activities

The Charity's Objects until 5 December 2013 were:-

- To provide support, education and information to anyone affected by neuroendocrine tumours
- To advocate for neuroendocrine cancer patients so that they may achieve the best possible outcomes
- To encourage standardised care for all NET cancer patients
- To provide community supportive care to patients and their carers or family members
- To raise awareness of NET cancers throughout the UK
- To raise funds for clinical and translational research projects

The Charity's Objects were amended on 5 December 2013 to the following:

- To advance the education of the general public (including relevant medical and scientific communities) in all areas relating to NETs.
- To promote the physical and mental health of those affected by NETs through the provision of support, advice and education to patients, their carers and family members.

The trustees confirm that they have followed the Charity Commission's general guidance on public benefit in undertaking their activities. All trustees are aware of the new Charity Commission Public Benefit Guidance (September 2013).

NET PATIENT FOUNDATION

TRUSTEES' REPORT (CONTINUED)

FOR THE YEAR ENDED 30 SEPTEMBER 2014

The Trustees and Cathy Bouvier have worked to raise the profile of the charity and to ensure that it has grown to provide the kind of information, education and support patients and their families affected by neuroendocrine tumours may require.

To date the support line is manned by Cathy Bouvier and is still active, although email queries are a larger growth area. The recruitment of another cancer nurse is a project for 2015 to support the supportive services provided by the NPF.

Support/educational group meetings have continued to grow including working with regional support groups - NET Natter groups. We currently have 24 'NET Natter' local groups currently active with 3 volunteer NET Natter Coordinators. This is a priority for the NPF and the new nurse will be working closely with all these groups.

Flyers, posters, NET Natter leader packs and pop up banners are available to all new groups.

Fundraising initiatives from the NET community have again been significant with a number of fundraising events.

A new fundraiser has been recruited for one year to look after our supporters and raise vital funds for the Foundation so we can continue to grow our support to all affected by neuroendocrine tumours. Some administrative support for the fundraisers is required and a project for 2015.

Education and information continues to be developed and work is nearly completed on updating all patient materials, adding in fact sheets that were not previously available. A new charity booklet and DVD for newly diagnosed patients is now available on line and on a memory stick. These are all available in a 'new patient information pack'. These have been distributed to 80 hospitals throughout the UK to date with the aim for patient information to be delivered to every hospital in the UK by the end of 2015. We have attended a number of major conferences and held education days for healthcare professionals lecturing on neuroendocrine tumours and the role of patient support. We have liaised with other charities notably with Ann Edgar Charitable Trust, Pancreatic Cancer UK and AMEND and Macmillan.

The NPF is an important part of the World NET Community Group using the global voice to raise awareness of NET cancers. We were responsible for the new website at www.netcancerday.org. This community facilitated a global NET day on 10th November. Recent developments are the publication of the Global survey of nearly 2000 patients run by INCA and supported by Novartis Global.

Plans for another political awareness event in Parliament in November are in full swing for this year. Our event in November 2014 was very successful.

We have been working closely with Wales and the NET Natter group there who have been pushing hard for a NET service in Wales. This has been a successful process and a bid for commissioning has been submitted. We are working with patients and staff in Northern Ireland at present to bring another patient education event there and have recently spoken at the launch of the new Scottish Guidelines for NET patients.

The online nursing course about neuroendocrine tumours is still live and Cathy Bouvier is currently involved in the new UK Nurse Research programme supporting the first event and encouraging affiliations with academic institutes such as Oxford Brookes. As a specialist nurse Cathy Bouvier is part of the steering committee for the European Nurse group. Collaboration between advocacy and specialist nurses is a very positive step and helps to improve the patient experience immeasurably alongside helping to raise awareness of this cancer, encourage best practice and support earlier diagnosis.

The website continues to be improved on a yearly basis.

NET PATIENT FOUNDATION

TRUSTEES' REPORT (CONTINUED)

FOR THE YEAR ENDED 30 SEPTEMBER 2014

The new clinical fund has raised just under £100,000. This money has been presented to the TransNET group who are doing work looking at the genetic and cellular aspects of neuroendocrine tumours to help improve accurate diagnosis, pre-empt new tumour growth, and optimise treatment options.

We have 6 places per year for the London 10k and are registered with Action Challenge. We have a charity skydive organised for 2015 and places in the London Triathlon.

We are currently working on 3 major projects:

- A patient experience survey that will be undertaken by Quality Health. The NHS Cancer Patient Experience Survey dataset showed that NET patients were not included. Patient experience and QOL are such vital aspects of patient care and we have had to produce our own survey to ensure that NET patients can have their say. This is nearing completion.
- A review of the current EORTC QOL-NET 21 questionnaire for patients throughout UK and Europe.
- To update the existing EORTC QLQ-GINET21 module to develop a specific module for use with patients with pancreatic neuroendocrine tumours and define and utilise a more effective patient and clinical user tool for QOL scoring for sub sets of NET patients

All three projects will be reported on and published.

Financial review

At 30 September 2014 the charity had funds of £196,584 (2013: £212,569), a decrease of £15,985.

The charity's policy on reserves is to hold sufficient funds to sustain the charity for a minimum of six months, in case of a fall in the level of donations. Currently funds equivalent to twelve months' costs are held but the charity plans to utilise some of these in supporting research activities and developing many aspects of its work in furtherance of the general objects of the charity.

The Trustees plan to continue to develop the work of the charity during the forthcoming year.

On behalf of the board of trustees

.....
Mr P Gwilliam (Chairman)

Trustee

Dated:

NET PATIENT FOUNDATION

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF NET PATIENT FOUNDATION

I report on the accounts of the charity for the year ended 30 September 2014, which are set out on pages 5 to 10.

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:

- (i) examine the accounts under section 145 of the 2011 Act;
- (ii) 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
- (iii) 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 130 of the 2011 Act; and
 - (ii) to prepare accounts which accord with the accounting records and comply with the accounting requirements of the 2011 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.

Anna Chapman FCA
Chapman Worth Limited

6 Newbury Street
Wantage
Oxfordshire
OX12 8BS

Dated:

NET PATIENT FOUNDATION

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 30 SEPTEMBER 2014

	Notes	2014 £	2013 £
<u>Incoming resources from generated funds</u>			
Donations and legacies	2	161,325	183,708
Investment income	3	140	46
		<hr/>	<hr/>
		161,465	183,754
Grants	4	42,890	35,955
Other incoming resources		1,671	634
		<hr/>	<hr/>
Total incoming resources		206,026	220,343
		<hr/>	<hr/>
<u>Resources expended</u>	5		
Costs of generating funds			
Costs of generating donations and legacies		5,894	16,643
		<hr/>	<hr/>
Net incoming resources available		200,132	203,700
		<hr/>	<hr/>
Charitable activities			
Direct charitable expenditure	6	213,383	157,304
Recruitment		729	-
		<hr/>	<hr/>
Total charitable expenditure		214,112	157,304
		<hr/>	<hr/>
Governance costs		2,005	2,131
		<hr/>	<hr/>
Total resources expended		222,011	176,078
		<hr/>	<hr/>
Net (expenditure)/income for the year/ Net movement in funds		(15,985)	44,265
		<hr/>	<hr/>
Fund balances at 1 October 2013		212,569	168,304
		<hr/>	<hr/>
Fund balances at 30 September 2014		196,584	212,569
		<hr/> <hr/>	<hr/> <hr/>

NET PATIENT FOUNDATION

BALANCE SHEET

AS AT 30 SEPTEMBER 2014

	Notes	2014 £	£	2013 £	£
Fixed assets					
Tangible assets	10		-		735
Current assets					
Debtors	11	5,007		4,258	
Cash at bank and in hand		193,506		209,460	
		<u>198,513</u>		<u>213,718</u>	
Creditors: amounts falling due within one year	12	<u>(1,929)</u>		<u>(1,884)</u>	
Net current assets			<u>196,584</u>		<u>211,834</u>
Total assets less current liabilities			<u>196,584</u>		<u>212,569</u>
Income funds					
Unrestricted funds			<u>196,584</u>		<u>212,569</u>
			<u>196,584</u>		<u>212,569</u>

The accounts were approved by the Trustees on

.....
Mr P Gwilliam (Chairman)
Trustee

NET PATIENT FOUNDATION

NOTES TO THE ACCOUNTS (CONTINUED)

FOR THE YEAR ENDED 30 SEPTEMBER 2014

5	Total resources expended		
		2014	2013
		£	£
	Costs of generating funds		
	Costs of generating donations and legacies	5,894	16,643
	Charitable activities		
	<u>Direct charitable expenditure</u>		
	Activities undertaken directly	213,383	157,304
	<u>Recruitment</u>		
	Activities undertaken directly	729	-
		214,112	157,304
	Governance costs	2,005	2,131
		222,011	176,078

Governance costs comprise payments to the Independent Examiner of £2,005 (2013: £2,131) for the Independent Examination.

6	Direct charitable expenditure			
		Unrestricted	Restricted	2014
		£	£	£
	Cost of charitable activities			2013
	Research	-	-	29,977
	Patient support	6,858	-	6,631
	New Patient Information	17,914	-	-
	Clinical Fund	29,063	-	-
	Audit and Survey	16,499	-	-
	Translation and editing services	140	-	3,221
	Conferences	8,555	-	2,595
	Staff costs	84,188	-	72,081
	Net nurse	2,127	-	3,017
	Travel, accommodation and subsistence	3,268	-	4,525
	Rent and rates	4,103	-	4,230
	Telephone	2,571	-	2,715
	Insurance	1,704	-	942
	Design and printing	22,751	-	13,050
	Postage and stationery	6,257	-	6,184
	Website	3,532	-	5,268
	Bookkeeping	1,387	-	1,313
	Depreciation	735	-	735
	Subscription	181	-	326
	Sundry	1,550	-	494
		213,383	-	157,304

NET PATIENT FOUNDATION

NOTES TO THE ACCOUNTS (CONTINUED)

FOR THE YEAR ENDED 30 SEPTEMBER 2014

7 Employees

Number of employees

The average monthly number of employees during the year was:

	2014	2013
	Number	Number
Full time employees	2	1
	<u> </u>	<u> </u>

There were no employees whose annual remuneration was £60,000 or more.

8 Trustees

None of the trustees (or any persons connected with them) received any remuneration or reimbursement for travelling expenses during the year.

9 Taxation

No taxation charge has been incurred and claimed during the year (2013: Nil).

10 Tangible fixed assets

	Office equipment £
Cost	
At 1 October 2013 and at 30 September 2014	3,103
	<u> </u>
Depreciation	
At 1 October 2013	2,368
Charge for the year	735
	<u> </u>
At 30 September 2014	3,103
	<u> </u>
Net book value	
At 30 September 2014	-
	<u> </u>
At 30 September 2013	735
	<u> </u>

NET PATIENT FOUNDATION

NOTES TO THE ACCOUNTS (CONTINUED)

FOR THE YEAR ENDED 30 SEPTEMBER 2014

11 Debtors	2014	2013
	£	£
Gift aid tax relief	5,007	4,258
	<u> </u>	<u> </u>
12 Creditors: amounts falling due within one year	2014	2013
	£	£
Independent examiner's fees	1,929	1,884
	<u> </u>	<u> </u>