

Charity Registration No. 1092386

**NET PATIENT FOUNDATION**  
**TRUSTEES' REPORT AND UNAUDITED ACCOUNTS**  
**FOR THE YEAR ENDED 30 SEPTEMBER 2015**

# NET PATIENT FOUNDATION

## LEGAL AND ADMINISTRATIVE INFORMATION

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<b>Trustees</b>	Mr P Gwilliam (Chairman) Mr D Jones Mrs M Phillips Mrs R Littlejohn Dr R Srirajaskanthan Mr N Pearce
<b>Charity number</b>	1092386
<b>Principal address</b>	Enton Mill Enton Godalming Surrey GU8 5AH
<b>Independent examiner</b>	Chapman Worth Limited 6 Newbury Street Wantage Oxfordshire OX12 8BS
<b>Bankers</b>	Bank of Scotland 33 Old Broad Street London EC2N 1HZ

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# NET PATIENT FOUNDATION

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# NET PATIENT FOUNDATION

## TRUSTEES' REPORT

### FOR THE YEAR ENDED 30 SEPTEMBER 2015

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The Trustees have pleasure in presenting the Trustees' Report and Accounts of the NET Patient Foundation for the year ended 30 September 2015. 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 D Jones

Miss L Blackadder (Resigned 23 June 2015)

Mrs M Phillips

Mrs R Littlejohn

Dr R Srirajakanthan

Mr N Pearce

The Board of Trustees is responsible for the overall management and control of the charity and for the appointment of new Trustees. Miss Lynn Blackadder resigned as a trustee 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 are now as follows:-

- 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 2015***

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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.

The recruitment of another full-time cancer nurse has been achieved with a start date of November 2015. We are fortunate to have had high interest in the position and the successful applicant is a neuroendocrine specialist nurse with 18 years experience. This will be a great asset to the NPF.

Support/educational group meetings have continued to grow including working with regional support 'NET Natter' groups. We currently have 20 'NET Natter' local groups currently active. A few group have disbanded but some new ones have started up and we hope to double the number of groups in the next 2 years. 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 once again been significant with a good number of successful events. Our fundraiser left in June 2015 and a new appointment is a priority in 2015/16 once some work has been completed on our fundraising strategy.

Additional administrative support will be recruited following the present administrator's retirement and to support the enhanced activities of the NPF.

We have received funding for a five year term to move to larger and more suitable premises in Leamington Spa, Warwickshire and moved into these in August 2015. These are leased from another charitable organisation.

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 2016. 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](http://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.

Our own patient experience survey has been completed with almost 1,000 English patients completing the questionnaire. This was run by Quality Health who are responsible for the NHS England patient experience surveys. Results will be published at various conferences and in a relevant journal.

# NET PATIENT FOUNDATION

## TRUSTEES' REPORT (CONTINUED)

### FOR THE YEAR ENDED 30 SEPTEMBER 2015

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We have been working closely with the NET Natter group in Wales which has 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 to hold another patient education event in early 2016. We have also recently spoken at the launch of the new Scottish Guidelines for NET patients.

The online nursing course about neuroendocrine tumours is now out of date and we are currently sourcing funds to support a new nurse course. We are working in conjunction with the Royal College of Nursing. 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. The first piece of research from this group is underway looking at the use of somatostatin analogues across the UK. 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 as well as helping to raise awareness of this cancer, encourage best practice and support earlier diagnosis.

The website continues to be improved on a yearly basis.

The new clinical fund has raised just under £30,000. This money has been used to support a nutritional study at the NET Centre of Excellence in Manchester and also for some in-house research for the patient experience survey.

We have 6 places per year for the London 10k and are registered with Action Challenge. We held a charity skydive event in April 2015 and the London 10K was run in July by 6 supporters. We also had 4 participants in the London Triathlon. All brought in good fundraising contributions.

We are currently working on 4 major projects:

- A patient experience survey is being undertaken by Quality Health. The NHS Cancer Patient Experience Survey dataset showed that NET patients were not specifically included. Given that patient experience and QOL are such vital aspects of patient care and we have decided to produce our own survey to ensure that NET patients have adequate data to enable them to have their say.
- A review of the current EORTC QOL-NET 21 questionnaire for patients throughout UK and Europe.
- An update of the existing EORTC QLQ-GINET21 module to develop one specifically for use with patients with pancreatic neuroendocrine tumours and to define and utilise a more effective patient and clinical user tool for QOL scoring for sub sets of NET patients
- A NET census and coding project working with Public Health England to define a list of codes relating to neuroendocrine cancers.

NHS data will be interrogated to provide statistics relating to neuroendocrine cancers in England 2015, and to compare this data with the equivalent data for Scotland, Wales and Northern Ireland to include:-

- Incidence of NET cancers (to include age, stage, ethnicity and morphology)
- Prevalence of NET cancers
- Mortality due to NET cancers
- 1 year / 5 year / 10 year survival rates
- Time to diagnosis (including number of referrals by GP)
- Referral pathways (e.g. referral to an ENETS Centre of Excellence)
- Access to appropriate scans (e.g. imaging, 5HiAA and Chromogranin A) and treatment (including GP prescriptions such as SSAs) and timing these
- Numbers of admissions and op visits of each patient, plus 30 day readmission
- Whether there are any pre-existing or concurrent second primary tumours making allowances to identify whether subsequent new malignancies are identified

These projects will be reported on and published.

# NET PATIENT FOUNDATION

## TRUSTEES' REPORT (CONTINUED)

**FOR THE YEAR ENDED 30 SEPTEMBER 2015**

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### **Financial review**

At 30 September 2015 the charity had funds of £313,249 (2014: £196,584), a increase of £116,665.

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 more than 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 objectives of the charity and in particular on the major projects set out above.

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: 6 July 2016

# NET PATIENT FOUNDATION

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

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I report on the accounts of the charity for the year ended 30 September 2015, which are set out on pages 6 to 11.

### **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. The charity's gross income exceeded £250,000 and I am qualified to undertake the examination being a qualified member of .

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: 14 July 2016

# NET PATIENT FOUNDATION

## STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 30 SEPTEMBER 2015

	Notes	Unrestricted funds £	Restricted funds £	Total 2015 £	Total 2014 £
<b><u>Incoming resources from generated funds</u></b>					
Donations and legacies	2	245,134	8,845	253,979	161,325
Investment income	3	220	-	220	140
		<u>245,354</u>	<u>8,845</u>	<u>254,199</u>	<u>161,465</u>
Grants	4	82,453	-	82,453	42,890
Other incoming resources		881	-	881	1,671
		<u>328,688</u>	<u>8,845</u>	<u>337,533</u>	<u>206,026</u>
<b><u>Resources expended</u></b>					
<b>Costs of generating funds</b>					
Costs of generating donations and legacies	5	13,208	-	13,208	5,894
		<u>13,208</u>	<u>-</u>	<u>13,208</u>	<u>5,894</u>
<b>Net incoming resources available</b>		<b>315,480</b>	<b>8,845</b>	<b>324,325</b>	<b>200,132</b>
<b>Charitable activities</b>					
Direct charitable expenditure	6	204,689	-	204,689	213,383
Recruitment		623	-	623	729
		<u>205,312</u>	<u>-</u>	<u>205,312</u>	<u>214,112</u>
<b>Total charitable expenditure</b>		<b>205,312</b>	<b>-</b>	<b>205,312</b>	<b>214,112</b>
Governance costs		2,348	-	2,348	2,005
		<u>220,868</u>	<u>-</u>	<u>220,868</u>	<u>222,011</u>
<b>Net income/(expenditure) for the year/ Net movement in funds</b>		<b>107,820</b>	<b>8,845</b>	<b>116,665</b>	<b>(15,985)</b>
Fund balances at 1 October 2014		196,584	-	196,584	212,569
		<u>196,584</u>	<u>-</u>	<u>196,584</u>	<u>212,569</u>
<b>Fund balances at 30 September 2015</b>		<b>304,404</b>	<b>8,845</b>	<b>313,249</b>	<b>196,584</b>
		<u><u>304,404</u></u>	<u><u>8,845</u></u>	<u><u>313,249</u></u>	<u><u>196,584</u></u>

# NET PATIENT FOUNDATION

## BALANCE SHEET

AS AT 30 SEPTEMBER 2015

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	Notes	2015 £	£	2014 £	£
<b>Current assets</b>					
Debtors	11	6,008		5,007	
Cash at bank and in hand		309,473		193,506	
		<u>315,481</u>		<u>198,513</u>	
<b>Creditors: amounts falling due within one year</b>	12	(2,232)		(1,929)	
<b>Total assets less current liabilities</b>			<b>313,249</b>		<b>196,584</b>
			<u><u>313,249</u></u>		<u><u>196,584</u></u>
<b>Income funds</b>					
Restricted funds			8,845		-
Unrestricted funds			304,404		196,584
			<u>313,249</u>		<u>196,584</u>
			<u><u>313,249</u></u>		<u><u>196,584</u></u>

The accounts were approved by the Trustees on 6 July 2016

Mr P Gwilliam (Chairman)  
**Trustee**



# NET PATIENT FOUNDATION

## NOTES TO THE ACCOUNTS (CONTINUED) FOR THE YEAR ENDED 30 SEPTEMBER 2015

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<b>5 Total resources expended</b>	<b>2015</b>	2014
	<b>£</b>	<b>£</b>
<b>Costs of generating funds</b>		
Costs of generating donations and legacies	<b>13,208</b>	5,894
	<hr/>	<hr/>
<b>Charitable activities</b>		
<u>Direct charitable expenditure</u>		
Activities undertaken directly	204,689	213,383
<u>Recruitment</u>		
Activities undertaken directly	623	729
	<hr/>	<hr/>
	<b>205,312</b>	214,112
	<hr/>	<hr/>
<b>Governance costs</b>	<b>2,348</b>	2,005
	<hr/>	<hr/>
	<b>220,868</b>	222,011
	<hr/> <hr/>	<hr/> <hr/>

Governance costs include payments to the Independent Examiner of £1,680 (2014: £1,620) for the Independent Examination.

# NET PATIENT FOUNDATION

## NOTES TO THE ACCOUNTS (CONTINUED)

FOR THE YEAR ENDED 30 SEPTEMBER 2015

### 6 Direct charitable expenditure

	Unrestricted £	Restricted £	2015 £	2014 £
<b>Cost of charitable activities</b>				
Net Natter	1,775	-	1,775	-
Net Cancer Day	3,090	-	3,090	-
Quality of Life Expenses	2,474	-	2,474	-
Legal and Professional Fees	3,544	-	3,544	-
Patient support	-	-	-	6,858
New Patient Information	186	-	186	17,914
Clinical Fund	30,000	-	30,000	29,063
Audit and Survey	-	-	-	16,499
Translation and editing services	-	-	-	140
Conferences	2,652	-	2,652	8,555
Staff costs	96,191	-	96,191	84,188
Net nurse	8,659	-	8,659	2,127
Travel, accommodation and subsistence	9,084	-	9,084	3,268
Rent and rates	3,850	-	3,850	4,103
Telephone	2,727	-	2,727	2,571
Insurance	2,568	-	2,568	1,704
Design and printing	19,932	-	19,932	22,751
Postage and stationery	4,109	-	4,109	6,257
Website	5,124	-	5,124	3,532
Computing Running Costs	2,170	-	2,170	-
Bookkeeping	2,125	-	2,125	1,387
Depreciation	-	-	-	735
Subscription	214	-	214	181
Sundry	4,215	-	4,215	1,550
	<u>204,689</u>	<u>-</u>	<u>204,689</u>	<u>213,383</u>

### 7 Trustees

None of the trustees (or any persons connected with them) received any remuneration during the year, but Mrs M Phillips was reimbursed a total of £445 travelling expenses (2014: No Trustees were reimbursed travel expenses during the year).

### 8 Employees

#### Number of employees

The average monthly number of employees during the year was:

	2015 Number	2014 Number
Full time employees	<u>2</u>	<u>2</u>

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

# NET PATIENT FOUNDATION

## NOTES TO THE ACCOUNTS (CONTINUED) FOR THE YEAR ENDED 30 SEPTEMBER 2015

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### 9 Taxation

No taxation charge has been incurred and claimed during the year (2014: Nil).

### 10 Tangible fixed assets

	Office equipment £
<b>Cost</b> At 1 October 2014 and at 30 September 2015	3,103
<b>Depreciation</b> At 1 October 2014 and at 30 September 2015	3,103
<b>Net book value</b> At 30 September 2015	-

11 Debtors	2015 £	2014 £
Gift aid tax relief	5,888	5,007
Other debtors	120	-
	<u>6,008</u>	<u>5,007</u>

12 Creditors: amounts falling due within one year	2015 £	2014 £
Accruals	2,232	1,929
	<u>2,232</u>	<u>1,929</u>