

NET PATIENT FOUNDATION
TRUSTEES' REPORT AND UNAUDITED ACCOUNTS
FOR THE YEAR ENDED 30 SEPTEMBER 2016

CHARITY COMMISSION
FIRST CONTACT
- 5 JUN 2017
RECORDED
ACCOUNTS
RECEIVED

NET PATIENT FOUNDATION

LEGAL AND ADMINISTRATIVE INFORMATION

Trustees	Mr P Gwilliam (Chairman) Mr D Jones Mrs M Phillips Mrs R Littlejohn Dr R Srirajaskanthan Mr N Pearce
Charity number	1092386
Principal address	Second Floor Holly House 74 Upper Holly Walk Leamington Spa Warwickshire CV32 4JL
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 2016

The Trustees have pleasure in presenting the Trustees' Report and Accounts of the NET Patient Foundation for the year ended 30 September 2016. 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 January 2015.

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

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.

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 2016

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 that patients and their families affected by neuroendocrine tumours may require.

The recruitment of another cancer nurse (Patient Support Manager) has been achieved and has provided outstanding benefit to the NET Community with very positive feedback an example of which is:

"I just wanted to say how lucky we are to have you visit us each month, giving us support and advice. It is so reassuring to listen to you going into depth about the different problems that we have. These are often areas which we wouldn't think of highlighting, but when you explain coping strategies, for me personally it is a huge relief to sit and listen to you. We are all very grateful for the travelling you do to be with us once a month. See you soon"

The role has highlighted even more the need for community support for our patients and the demand for our Patient Support Manager's time has exceeded all expectations and we are now seeking another more junior nurse to support these activities further. This role will be full time and titled Patient Support Nurse. Funding has been secured for the first year's costs of this position.

Support and educational group meetings have continued to grow including working with our regional Net Natter support groups. We currently have 24 such groups active and plan to double this number in the next 2 years. This is a key priority for the NPF and the new nurse will be working closely with these groups. Flyers, posters, NET Natter leader packs and pop up banners are available to all new groups together with support for meeting costs.

Fundraising initiatives from the NET community have once again been very successful with some major events raising significant funds for the charity. Information on these events can be found in the fundraising section of our website.

Educational information continues to be developed and work is nearly complete on updating all patient materials, adding in fact sheets that were not previously available. A new charity handbook (156 Guide to Living with a NET) is nearly complete and 3 videos for newly diagnosed patients are now available on line and on a memory stick. Once complete the new Patient Handbook will be disseminated to 300 hospitals throughout the UK that support NET patients. The plan is to ensure that all patients and their families and carers and appropriate medical centres get access to the most accurate and up to date information to enable the best outcomes for those with NET cancers.

The NPF has attended a number of major conferences and held education days for healthcare professionals (including the largest GP conference in the UK) lecturing on neuroendocrine tumours and the key role that patient support has to play. We have also 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. The NPF now sits on the Advisory Board of this organisation which is planning the first patient/medical meeting in Europe in March 2016. The NPF will be speaking at this event.

Working within the European Community is also part of the NPF remit and notably working with the ENETs nursing group on education for nurses across Europe and also with the European Parliament raising awareness of NETs within the European Commission.

Our own patient experience survey has been completed with nearly 1,000 English patients completing the questionnaire which was managed by Quality Health who are responsible for NHS England patient experience surveys. Results have been published and used by many organisations as a reference to highlight the need for improvements in NET patient care.

NET PATIENT FOUNDATION

TRUSTEES' REPORT (CONTINUED)

FOR THE YEAR ENDED 30 SEPTEMBER 2016

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 agreed. A new service lead is in place and recruitment for specialist nurses is underway to support the Welsh NET community. We have worked with patients and staff in Northern Ireland to provide another patient educational event there in February 2016 and this was oversubscribed. A video of the event was prepared and sent to all patients who were unable to attend.

The website continues to be improved on a yearly basis.

The clinical fund has raised around £30,000 again this year. This money has been used to support a project looking at the relevance of adding rectal and colonic NETs to the national bowel screening programme.

We are currently working on 4 major projects:

1 - The Chapter 10 Report providing a helpful and accurate report on the cancer strategy and recommendations on ways in which it could be most relevant and impactful for NET patients. It's not about trying to fit all cancers into one pathway but looking at ways to support those cancers that do not fit, that do not follow a common pathway. The report will highlight the fact that NET patients are quite a small group but we do ask that our proportional input is recognized, not simply left out.

2 - Updating 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.

3 - Developing GP Awareness Tools to help encourage earlier diagnosis of a NET or referral for further investigation. A 'Hints and Tips' booklet and banner pens have been produced and patients are working their way around the country sharing these with primary health care teams. We also attended the RCGP conference where we handed out this information.

4 - NET Census and Coding Project working with Public Health England to define a list of codes relating to neuroendocrine cancers and to interrogate NHS data to provide statistics relating to neuroendocrine cancers in England in 2015, and to compare this data to equivalent data sets in 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, also 5HiAA, Chromogranin A) and treatment (including GP prescriptions e.g. SSAs) and timing
- numbers of admissions and op visits of each patient, plus 30 day readmission
- whether there are any pre-existing or concurrent second primary tumours and making allowances to identify if subsequent new malignancies are identified.

All of these projects will be reported on and published.

NET PATIENT FOUNDATION

TRUSTEES' REPORT (CONTINUED)

FOR THE YEAR ENDED 30 SEPTEMBER 2016

The online nursing course about neuroendocrine tumours is now out of date and we are currently sourcing funds to support a new such course 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 has been presented at the national NET meeting 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 together with helping to raise awareness of this cancer, encourage best practice and support earlier diagnosis.

Finally the recruitment of an Operations Manager was achieved in January 2016. This has been a vital addition to the small team ensuring presence in the office at all time, caring for our fundraisers, providing administrative support for all team members, arranging patient events, staff and trustee meetings and database management.

Financial review

At 30 September 2016 the charity had funds of £429,719 (2015: £313,249), an increase of £116,470.

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: 13/4/17

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 2016, which are set out on pages 6 to 12.

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 the Institute of Chartered Accountants in England and Wales.

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: 26 May 2017

NET PATIENT FOUNDATION

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 30 SEPTEMBER 2016

	Notes	Unrestricted funds £	Restricted funds £	Total 2016 £	Restated Total 2015 £
<u>Incoming resources from generated funds</u>					
Donations and legacies	2	238,055	-	238,055	246,259
Investment income	3	181	-	181	220
		<u>238,236</u>	<u>-</u>	<u>238,236</u>	<u>246,479</u>
Grants	4	44,060	130,000	174,060	90,173
Other incoming resources		570	-	570	881
		<u>282,866</u>	<u>130,000</u>	<u>412,866</u>	<u>337,533</u>
<u>Resources expended</u>					
5					
Costs of generating funds					
Costs of generating donations and legacies		24,295	-	24,295	13,208
		<u>258,571</u>	<u>130,000</u>	<u>388,571</u>	<u>324,325</u>
Net incoming resources available					
Charitable activities					
Direct charitable expenditure	6	242,902	25,555	268,457	204,689
Recruitment		-	-	-	623
		<u>242,902</u>	<u>25,555</u>	<u>268,457</u>	<u>205,312</u>
Total charitable expenditure		<u>242,902</u>	<u>25,555</u>	<u>268,457</u>	<u>205,312</u>
Governance costs		3,644	-	3,644	2,348
		<u>270,841</u>	<u>25,555</u>	<u>296,396</u>	<u>220,868</u>
Total resources expended		<u>270,841</u>	<u>25,555</u>	<u>296,396</u>	<u>220,868</u>
Net income for the year/ Net movement in funds		<u>12,025</u>	<u>104,445</u>	<u>116,470</u>	<u>116,665</u>
Fund balances at 1 October 2015		<u>304,404</u>	<u>8,845</u>	<u>313,249</u>	<u>196,584</u>
Fund balances at 30 September 2016		<u><u>316,429</u></u>	<u><u>113,290</u></u>	<u><u>429,719</u></u>	<u><u>313,249</u></u>


NET PATIENT FOUNDATION

BALANCE SHEET

AS AT 30 SEPTEMBER 2016

	Notes	2016 £	£	2015 £	£
Current assets					
Debtors	11	5,577		6,008	
Cash at bank and in hand		426,026		309,473	
		<u>431,603</u>		<u>315,481</u>	
Creditors: amounts falling due within one year	12	(1,884)		(2,232)	
Total assets less current liabilities			429,719		313,249
			<u><u>429,719</u></u>		<u><u>313,249</u></u>
Income funds					
Restricted funds	13		113,290		8,845
Unrestricted funds			316,429		304,404
			<u>429,719</u>		<u>313,249</u>
			<u><u>429,719</u></u>		<u><u>313,249</u></u>

The accounts were approved by the Trustees on 13/4/17


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

NET PATIENT FOUNDATION

NOTES TO THE ACCOUNTS (CONTINUED) FOR THE YEAR ENDED 30 SEPTEMBER 2016

4 Grants (Continued)

The 2015 figures have been restated to include an Ipsen grant of £7,720.

5 Total resources expended	2016	2015
	£	£
Costs of generating funds		
Costs of generating donations and legacies	24,295	13,208
	<hr/>	<hr/>
Charitable activities		
<u>Direct charitable expenditure</u>		
Activities undertaken directly	268,457	204,689
	<hr/>	<hr/>
<u>Recruitment</u>		
Activities undertaken directly	-	623
	<hr/>	<hr/>
	268,457	205,312
	<hr/>	<hr/>
Governance costs	3,644	2,348
	<hr/>	<hr/>
	296,396	220,868
	<hr/> <hr/>	<hr/> <hr/>

Governance costs include payments to the Independent Examiner of £1,680 (2015: £1,680) for the Independent Examination.

NET PATIENT FOUNDATION

NOTES TO THE ACCOUNTS (CONTINUED)

FOR THE YEAR ENDED 30 SEPTEMBER 2016

6 Direct charitable expenditure

	Unrestricted £	Restricted £	2016 £	2015 £
Cost of charitable activities				
Net Natter	6,556	-	6,556	1,775
Net Cancer Day	2,999	-	2,999	3,090
Quality of Life Expenses	25,833	-	25,833	2,474
Legal and Professional Fees	-	-	-	3,544
PR Projects	-	16,710	16,710	-
Clinical fund	-	8,845	8,845	-
Events	6,593	-	6,593	-
New Patient Information	4,268	-	4,268	186
Clinical Fund	-	-	-	30,000
Translation and editing services	225	-	225	-
Conferences	15,536	-	15,536	2,652
Staff costs	118,553	-	118,553	96,191
Net nurse	46	-	46	8,659
Travel, accommodation and subsistence	7,921	-	7,921	9,084
Rent and rates	15,313	-	15,313	3,850
Telephone	4,382	-	4,382	2,727
Training	1,445	-	1,445	-
Insurance	1,831	-	1,831	2,568
Design and printing	18,742	-	18,742	19,932
Postage and stationery	2,738	-	2,738	4,109
Website	-	-	-	5,124
Computing Running Costs	2,551	-	2,551	2,170
Bookkeeping	2,628	-	2,628	2,125
Subscription	226	-	226	214
Sundry	4,516	-	4,516	4,215
	<u>242,902</u>	<u>25,555</u>	<u>268,457</u>	<u>204,689</u>

7 Trustees

None of the Trustees (or any persons connected with them) received any remuneration during the year, but trustees were reimbursed a total of £487 travelling expenses (2015: Trustees were reimbursed travel expenses of £445 during the year).

NET PATIENT FOUNDATION

NOTES TO THE ACCOUNTS (CONTINUED)

FOR THE YEAR ENDED 30 SEPTEMBER 2016

8 Employees

Number of employees

The average monthly number of employees during the year was:

	2016 Number	2015 Number
Full time employees	4	2

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

9 Taxation

No taxation charge has been incurred and claimed during the year (2015: Nil).

10 Tangible fixed assets

	Office equipment £
Cost At 1 October 2015 and at 30 September 2016	3,103
Depreciation At 1 October 2015 and at 30 September 2016	3,103
Net book value At 30 September 2016	-

11 Debtors

	2016 £	2015 £
Gift aid tax relief	5,577	5,888
Other debtors	-	120
	5,577	6,008

12 Creditors: amounts falling due within one year

	2016 £	2015 £
Accruals	1,884	2,232

NET PATIENT FOUNDATION

NOTES TO THE ACCOUNTS (CONTINUED) FOR THE YEAR ENDED 30 SEPTEMBER 2016

13 Restricted funds

The income funds of the charity include restricted funds comprising the following unexpended balances of donations and grants held on trust for specific purposes:

	Balance at 1 October 2015 £	Movement in funds		Balance at 30 September 2016 £
		£	£	
Donation	8,845	-	(8,845)	-
Imaging Equipment Ltd	-	75,000	-	75,000
Imaging Equipment Ltd	-	30,000	(16,710)	13,290
Victory Net	-	25,000	-	25,000
	<u>8,845</u>	<u>130,000</u>	<u>(25,555)</u>	<u>113,290</u>