

**The Barrett's
Oesophagus
Foundation**

Annual Report and Accounts

30 September 2003

BUZZACOTT

Charity Registration Number
1077633

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Legal and administrative information

Patron	His Grace the Duke of Devonshire KG PC MC
Vice-Presidents	Earl Attlee Professor A T R Axon MD FRCP Professor Carol Black CBE MD PRCP The Rt Hon David Blunkett MP Sir Barry Jackson MS FRCS FRCP Professor John Lennard Jones MD FRCP FRCS Martyn Lewis CBE Professor Sir Peter Morris PhD FRS PRCS Lord Turnberg of Cheadle MD FRCP FmedSci
Trustees	Professor A Watson MD FRCS Dr R C Fitzgerald MA MD MRCP R J Mayes BA FCA J F Mills LLB Dr P I Reed FRCP FRCPC
Principal office	UK National Barrett's Oesophagus Registry University Department of Surgery Royal Free Campus Royal Free and University College Medical School Rowland Hill Street London NW3 2PF
Telephone	020 7472 6223
Facsimile	020 7472 6224
Registrar	Dr C P J Caygill BSc PhD
Charity registration number	1077633

Legal and administrative information

Auditors PKF
New Garden House
78 Hatton Garden
London
EC1N 8JA

Accountants Buzzacott
12 New Fetter Lane
London
EC4A 1AG

Bankers Arbuthnot Latham
Royex House
Aldermanbury Square
London
EC2V 7NU

Solicitors B P Collins
Collins House
32-38 Station Road
Gerrards Cross
Bucks
SL9 8EL

The Barrett's Oesophagus Foundation

The Barrett's Oesophagus Foundation is the only charity whose main objective is related to prevention of oesophageal cancer.

'Barrett's oesophagus' is a pre-cancerous condition of the oesophagus (gullet) almost certainly related to prolonged regurgitation (reflux) of acid and bile from the stomach into the oesophagus, the lining of which in consequence alters its characteristics which in a proportion of sufferers can undergo malignant change and lead to the development of a special type of cancer of the oesophagus (adenocarcinoma) with a relatively poor outlook. The incidence of both Barrett's oesophagus and adenocarcinoma of the oesophagus and gastric cardia is increasing in many countries including the United Kingdom.

Because the natural history of Barrett's oesophagus and of its most important complication, adenocarcinoma of the oesophagus, is still not clearly understood, much more data are required to formulate the best ways of treating Barrett's oesophagus and preventing adenocarcinoma.

The United Kingdom National Barrett's Oesophagus Registry (UKBOR) was started in 1996 with a very generous donation from a non-medical charity, supplemented by other contributions from charities and patients with Barrett's oesophagus. UKBOR now has the largest database of Barrett's oesophagus patients in the world with over 10,000 patients from 43 UK hospitals. The results of its research have been published and presented nationally and internationally and several European countries plan to develop national registries based on the UK model.

The Barrett's Oesophagus Foundation exists to

- ◆ secure the long-term future of UKBOR;
- ◆ provide a support and education service for patients and relatives of patients with Barrett's oesophagus and associated adenocarcinoma of the oesophagus and gastric cardia;
- ◆ make research awards and project grants for research in the field of Barrett's oesophagus in the United Kingdom.

The trustees present their statutory report, together with the audited accounts, for The Barrett's Oesophagus Foundation for the financial year ended 30 September 2003.

Constitution

The Barrett's Oesophagus Foundation is a registered charity constituted under a Declaration of Trust dated 9 August 1999.

Preparation of report and accounts

The trustees have adopted the relevant provisions of the Statement of Recommended Practice (SORP) "Accounting and Reporting by Charities" issued in October 2000 in preparing their report and the audited accounts. The accounts comply with the charity's Declaration of Trust and applicable legislation and have been prepared in accordance with the accounting policies set out on pages 14 and 15.

Principal aims and objects

The principal aims and objects of the charity are to:

- ◆ expand and support long term the United Kingdom Barrett's Oesophagus Registry (UKBOR) which is contributed to by clinicians nationally to enable doctors and other scientists to obtain a more complete understanding of the condition known as 'Barrett's oesophagus'.
- ◆ provide a support and education service to sufferers from Barrett's Oesophagus and its complications and their relatives.
- ◆ support studies within the field of Barrett's Oesophagus relating principally to influencing the incidence of adenocarcinoma of the oesophagus and gastric cardia and their prevention.
- ◆ make publicly available the results of any specific and educational activity initiated or supported by the charity.

Trustees

The trustees of The Barrett's Oesophagus Foundation throughout the year are set out on page 1.

Trustees hold office, in accordance with the Declaration of Trust, for periods varying between one and three years, subject to re-appointment.

Ordinary meetings of trustees are held periodically – 4 such meetings were held during the year. The trustees also met formally on other occasions during the year.

Trustees (continued)

The scientific activities of UKBOR are overseen by a Scientific Advisory Committee which comprises some 10 members of the British Society of Gastroenterology, each with special expertise in specific aspects of Barrett's oesophagus. The committee is chaired by Dr. Robert Heading, a member of the British Society of Gastroenterology.

Review of activities

A review of the activities of the charity including UKBOR, during the financial year and an indication of likely future developments is contained in the report of the Chairman on pages 7 to 9.

There has been a great deal of interest in UKBOR nationally and internationally, stimulated by the exposure which the Registry has had through numerous presentations and publications.

A number of European countries have proposed the establishment of either national or regional Registries on the same lines as UKBOR and using the same, or similar, Registration Forms. Centres in USA and Canada are discussing regional Registries

The current numbers of registrants is more than 10,000 from 43 centres.

Reserves policy

Except for such funds as the trustees consider prudent to maintain for the purposes of management and administration of the charity for the foreseeable future, all unrestricted funds are for the purposes of the general charitable objects of the charity. Such free unrestricted funds at 30 September 2003 amounted to £16,720 (2002 - £13,828).

The Trustees regularly monitor and review the level of reserves in the light of available and projected funds and income and expenditure relating to planned activities.

Risk management

The trustees have considered, and continue to assess, the major risks to which the charity is exposed, in particular those relating to specific operational activities and to financial considerations. As the charity develops, the trustees monitor such risk factors and will establish appropriate systems to mitigate risk.

Trustees' responsibilities statement

Charity legislation requires the trustees to prepare accounts of the charity for each financial year. In so doing, the trustees are required to prepare accounts which show a true and fair view of the state of affairs of the charity and of the application of its resources for the financial period. In preparing those accounts, the trustees have regard to the Statement of Recommended Practice on 'Accounting and Reporting by Charities' issued by the Charity Commission; they are also required to:

- ◆ select suitable accounting policies and then apply them consistently;
- ◆ make judgements and estimates that are reasonable and prudent;
- ◆ state whether applicable accounting standards and statements of recommended practice have been followed, subject to any departures disclosed and explained in the accounts;
- ◆ prepare the accounts on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

In accordance with charity legislation, the trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and which enable them to ensure that the accounts comply with the Charities Act 1993. 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 ensuring that the Trustees' Report and the Chairman's Report are prepared in accordance with charity law in the United Kingdom.

Appreciation

The trustees wish to express their appreciation to those individuals, charities and companies who have generously supported the Foundation in its formative period.

Dr Christine Caygill, Registrar of the UK Barrett's Oesophagus Registry and Belinda Johnston BSc, who has voluntarily provided sterling administrative support, have made considerable efforts on behalf of the charity. The trustees also express thanks to John Cummins, David Jones, Richard Leslie and Steve Smith who have given freely their time and expertise as new members of the Planning Group.

The trustees are grateful for all these valued supporters.

Signed on behalf of the Trustees:

J F Mills
Trustee

Approved by the board on: 18 March 2004

The past year has again been a busy one for the Foundation and the UK National Barrett's Oesophagus Registry (UKBOR).

Patron and Vice Presidents

Two particular highlights of the past year have been the agreement of His Grace the Duke of Devonshire to be Patron of the Foundation and the Rt Hon David Blunkett to be a Vice President. Both have affirmed their strong support for the Foundation and their wish to be 'hands-on' in supporting the Foundation and particularly in fund-raising. They are both most welcome.

Fund-raising

There has been an increase in the number of small donations, principally from patients, but so far, the larger donations necessary to appoint a Campaign Director to launch the appeal proper have eluded us. In line with the recommendations of our Fundraising Feasibility Study, four individuals who provided external endorsement of the study joined with the Trustees to form the Planning Group. These were John Cummins, David Jones, Richard Leslie and Steve Smith and we are most grateful to them for their support and commitment. Planning Group meetings were held in London in February, May, and October at which various strategies for securing the funding to appoint a part-time Campaign Director and secretary have been discussed. These include the search for individual donations from personal contacts and arranging a dinner/presentation at a prestigious venue such as the House of Lords to which influential individuals will be invited. In addition, I visited the Duke of Devonshire in July, who has agreed to write to several of his contacts to seek donations. Also, David Blunkett has agreed to write on our behalf to one or more Pharmaceutical companies. We sincerely hope that during the coming year, we will achieve the necessary funding to appoint a Campaign Director and secretary for the first year, when the Appeal proper can be launched.

UK National Barrett's Oesophagus Registry

The Registry has had another productive year. New registrations have expanded the database to over 10,000 from 43 centres in the UK. Since the appointment of two Research Fellows, Piers Gatenby and James Ramus, detailed case note searches on almost 1,800 of the databased patients have been conducted by visiting individual hospitals. Preliminary analysis of some of the data obtained has resulted in presentations to the British Society of Gastroenterology, the American Gastroenterological Association, an international oesophageal society (OESO) and a further abstract has been accepted for presentation at the United European Gastroenterology Week in November. Details of these and publications during the year are appended.

UK National Barrett's Oesophagus Registry (continued)

In addition to the major studies being conducted under the auspices of UKBOR by the Research Fellows, the Registry has been fortunate in securing funding of £16,700 from one of its early benefactors to perform a 'flagging' study to determine cause of death in patients with Barrett's oesophagus. However, this cannot be commenced until we achieve exemption from Section 60 of the Health and Social Care Act, 2001, which requires patients' consent to maintain the database and conduct such studies. Our application for exemption is currently being considered by the Patient Information Advisory Group (PIAG).

With regard to funding of the Registry, we continue to be grateful to the Wexham Gastrointestinal Trust for its annual grant of £10,000, the last of which is due in February 2004. The Registry was fortunate to be awarded just over £43,000 following winding up of the European Cancer Prevention Trust, which followed the untimely death of its Founder, Professor Mike Hill. The Registry is, as a result, secure at its present level of expenditure for about 2½ years, but we are unable, until funds are raised, to appoint a much-needed assistant for the Registrar Dr. Caygill.

Publicity

The Foundation had another stand at the British Society of Gastroenterology meeting in March, which was well visited. All delegates to the Oesophageal Section Symposium were presented with the Annual UKBOR Newsletter, detailing the activities of the Registry and publicity about the Foundation. New leaflets were produced on the Foundation and the Registry, which are being distributed to patients and Healthcare professionals.

A great achievement of the Foundation this year was the launch of its website at www.barrettsfoundation.org.uk. Grateful thanks are due to Colin Harbour and Rebecca Fitzgerald for its production and to John Guest (a former mutual patient of Peter Reed and myself) for financial support. The website has been very well received and our leaflets are available on it for downloading. We have established a mechanism for on-line donations to the Foundation via the Charities Aid Foundation (CAF) e-fundraising facility but this has not, as yet, borne fruit. We are optimistic that the website will raise our profile, provide a much need information resource, and result in increased donations over the coming year.

Patient support

The number of requests for patient support continues to increase. In the absence of funding for patient support activities, enquires continue to be dealt with by the Registrar and Medical Directors in addition to their other activities. A request for donations is now being made at each enquiry so as to be able to offer a more formal, unhurried patient support service.

There are now 4 clinical leaflets on various aspects of Barrett's oesophagus written for a lay audience and all have been updated. These are distributed for a nominal charge to Gastroenterology units and are available for downloading free from the website.

Research

Although the Registry is busy conducting the epidemiological research to which it is suited, there is still no funding for laboratory studies or clinical trials in Barrett's oesophagus, which are becoming increasingly urgent. I was invited to give a presentation to an International Barrett's Research Group in the United States in May on the randomised clinical trial on treatment of Barrett's, which the Foundation hopes to be able to support. In addition to international experts in Barrett's, Directors of the National Institutes of Health (NIH) were present. The study was enthusiastically supported by all present and the NIH expressed interest in contributing to funding once we had secured enough to initiate the study. There is, therefore, an urgent need to raise monies to fund research.

Conclusion

We hope that more of our ambitions will be realised in the coming year, and in particular the appointment of a Campaign Director and launching of the appeal proper to raise much needed funds to secure the long-term future of the Registry and to be able to fund the urgently needed patient support service and research projects. In the meantime, I would like to thank my fellow Trustees, Rebecca Fitzgerald, Ray Mayes, Jeremy Mills and Peter Reed for all their hard work, together with our new Planning Group Members, John Cummins, David Jones, Richard Leslie and Steve Smith for their wisdom and hospitality in hosting meetings. Finally I would like to thank the UKBOR Registrar, Christine Caygill and our minutes secretary, Belinda Johnston, whose contributions vastly exceed their job descriptions.

Professor A Watson
Chairman of Trustees
October 2003

Independent auditors' report to the trustees of The Barrett's Oesophagus Foundation

We have audited the financial statements of The Barrett's Oesophagus Foundation for the year ended 30 September 2003 which comprise the Statement of Financial Activities, the Balance Sheet and the related notes. These financial statements have been prepared under the accounting policies set out therein.

This report is made solely to the trustees, as a body, in accordance with Regulation 6 of the Charities (Accounts and Reports) Regulations 1995. Our audit work has been undertaken so that we might state to the trustees those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the trustees as a body, for our audit work, for this report, or for the opinions we have formed.

Respective responsibilities of trustees and auditors

The trustees' responsibilities for preparing the Annual Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards are set out in the Statement of Trustees' Responsibilities.

Our responsibility is to audit the financial statements in accordance with relevant legal and regulatory requirements and United Kingdom Auditing Standards. We have been appointed as auditors under Section 43 of the Charities Act 1993 and report in accordance with regulations under Section 44 of that Act.

We report to you our opinion as to whether the financial statements give a true and fair view and are properly prepared in accordance with the Charities Act 1993. We also report to you if, in our opinion, the Trustees' Report is not consistent with the financial statements, if the charity has not kept proper accounting records, or if we have not received all the information and explanations we require for our audit.

We read the Trustees' Report and the Chairman's Report and consider the implications for our report if we become aware of any apparent misstatements within them.

Basis of audit opinion

We conducted our audit in accordance with United Kingdom Auditing Standards issued by the Auditing Practices Board. An audit includes examination, on a test basis, of evidence relevant to the amounts and disclosures in the financial statements. It also includes an assessment of the significant estimates and judgements made by the trustees in the preparation of the financial statements, and of whether the accounting policies are appropriate to the charity's circumstances, consistently applied and adequately disclosed.

Basis of audit opinion (continued)

We planned and performed our audit so as to obtain all the information and explanations which we considered necessary in order to provide us with sufficient evidence to give reasonable assurance as to whether the accounts are free from material misstatement, whether caused by fraud or other irregularity or error. In forming our opinion we also evaluated the overall adequacy of the presentation of information in the financial statements.

Opinion

In our opinion the financial statements give a true and fair view of the state of the charity's affairs as at 30 September 2003 and of its incoming resources and application of resources in the year then ended and have been properly prepared in accordance with the Charities Act 1993.

PKF
Registered Auditors

5 April 2004
London, UK

Statement of financial activities Financial year to 30 September 2003

	Notes	Unrestricted funds £	Restricted funds £	Total 2003 £	Total 2002 £
Income and expenditure					
Incoming resources					
Donations	1	4,087	74,058	78,145	14,733
Bank interest receivable		851	—	851	585
Total incoming resources		4,938	74,058	78,996	15,318
Resources expended					
Direct charitable expenditure					
Costs in furtherance of charity's objects					
. Registry		—	19,855	19,855	20,523
. Patient information and website		949	3,150	4,099	—
Management and administration of the charity		1,097	—	1,097	3,848
Total resources expended		2,046	23,005	25,051	24,371
Net incoming (outgoing) resources					
for the year	2	2,892	51,053	53,945	(9,053)
Fund balances					
Brought forward at 1 October 2002		13,828	7,109	20,937	29,990
Carried forward at 30 September 2003		16,720	58,162	74,882	20,937

All amounts relate to continuing activities of the Foundation.

The Foundation has no gains or losses other than the result for the period.

Balance sheet 30 September 2003

	Notes	2003 £	2002 £
Fixed assets			
Tangible assets	3	—	458
Current assets			
Other debtors		1,118	143
Cash at bank		80,690	24,261
		81,808	24,404
Creditors: amounts falling due within one year			
Other creditors		6,926	3,925
		74,882	20,479
Net current assets			
		74,882	20,479
Net assets			
		74,882	20,937
Represented by:			
Unrestricted funds			
. General		16,720	13,828
Restricted funds	4	58,162	7,109
Total funds		74,882	20,937

Approved by the Trustees
and signed on their behalf by:

A Watson

R J Mayes

Trustees

Approved on: 18 March 2004

Basis of accounting

The accounts have been prepared under the historical cost convention and in accordance with the requirements of the Charities Act 1993. Accounting standards and provisions of the Statement of Recommended Practice “Accounting and Reporting by Charities” (SORP 2000) applicable to small charities have been followed in these accounts.

Voluntary income

Donations represent voluntary amounts received during the period and arise within the United Kingdom. Covenant and Gift-aid income is included gross of attributable tax recoverable.

Investment income

Interest receivable is credited to income in the period in which it is earned and is included gross of attributable tax recoverable.

Expenditure

Expenditure is provided for on the accruals basis.

Direct charitable expenditure of the Registry (UKBOR) comprises principally staff costs and sundry running expenses.

Management and administration of the charity comprises costs directly attributable to the management of the charity including professional, regulatory and compliance costs.

Tangible fixed assets

Depreciation is provided at the following annual rates in order to write off the cost of each asset over its estimated useful life:

- ◆ Computer equipment - 3 years

Fund accounting

General funds comprise the accumulated surplus or deficit on the statement of financial activities. They are available for use at the discretion of the Trustees in furtherance of the general objectives of the charity. Restricted funds are funds subject to specific restricted conditions imposed by donors. The purpose and use of the restricted funds are set out in the notes to the accounts where appropriate. Designated funds are funds which have been set aside at the discretion of the trustees for specific purposes. The purpose and use of the designated unrestricted funds are set out, where appropriate, in the notes to the accounts.

Taxation

The charity is not liable to direct taxation (income tax) on its income as it falls within the various exemptions available to registered charities.

The charity is not registered for value added tax (VAT) and is therefore unable to reclaim the input tax, if any, it suffers on its purchases. Expenditure in the accounts is therefore shown inclusive of VAT where appropriate.

Notes to the accounts 30 September 2003

1 Donations

	Unrestricted funds £	Restricted funds £	Total 2003 £	Total 2002 £
Trusts	1,865	70,212	72,077	11,010
Individuals	2,222	3,846	6,068	693
Corporate	—	—	—	3,030
	4,087	74,058	78,145	14,733

The Royal Free Hospital Hampstead provides office accommodation on a rent free basis.

2 Net incoming (outgoing) resources

	2003	2002 £
Net incoming (outgoing) resources for the year is after charging:		
Staff costs	19,596	19,473
Auditors' remuneration (including VAT)	500	501

'Staff costs' represent the cost of reimbursements made for the provision of staff by a third party. The average weekly number of such staff (excluding Trustees) during the year was 1.

Trustees are not remunerated for their services as trustees. Trustees' expenses (5 trustees) reimbursed during the year amounted to £nil (2002 - £nil).

3 Tangible fixed assets

	Computer equipment £
Cost	
At 30 September 2003	1,382
Depreciation	
At 1 October 2002	924
Charge for year	458
At 30 September 2003	1,382
Net book values	
At 30 September 2003	—
At 30 September 2002	458

4 Restricted funds

	Balance b/f at 1 October 2002 £	Incoming resources £	Resources expended £	Balance c/f at 30 September 2003 £
UK Barrett's Oesophagus Registry (UKBOR)	7,109	70,212	19,855	57,466
Website development	—	3,846	3,150	696
	7,109	74,058	23,005	58,162

Restricted funds relating to UKBOR comprise those funds that are specifically provided for, and expended for the purposes of, the operation and management (including database management) of the Registry.

Unexpended UKBOR restricted funds at 30 September 2003 include £16,700 donated for the purposes of a 'flagging study'.

Website development relates to those funds specifically donated for and expended on development of the charity's website *www.barrettsfoundation.org.uk*.

5 Related party transactions

Donations during the period totalling £53,512 (2002 - £10,000) were received from the Wexham Gastrointestinal Trust (Charity registered 291586) (£10,000) and the European Cancer Prevention Trust (Charity registered 1002751) (£43,212), charities of which J F Mills and Dr P I Reed are trustees. The funds were donated towards the continuing running costs of UKBOR.

The Wexham Gastrointestinal Trust have also provided an interest free loan, repayable in February 2004, totalling £3,425 to enable the Foundation to fund a Fundraising Feasibility Study which was undertaken during 2002. At 30 September 2003, this loan is included in 'other creditors'.

The trustees received no reimbursement of expenses.

6 Research projects

Research projects conducted under the auspices of the UK National Barrett's Oesophagus Registry (UKBOR) but administered on its behalf and funded by third parties are not included in the accounts of the Barrett's Oesophagus Foundation.

During 2002, UKBOR was awarded a research grant of some £93,000 to conduct a study of the natural history of Barrett's oesophagus and the influence on that of medical, endoscopic and surgical treatment. The funding (provided by The Wexham Gastrointestinal Trust) enabled a research fellow to be appointed specifically for this study over three years. At 30 September 2003, funds amounting to £33,460 of the total grant had been expended. The project is administered through The Royal Free and University College Medical School.

Papers

- 1 Caygill CPJ, Watson A, Reed PI, Hill MJ (on behalf of the UK National Barrett's Oesophagus Registry (UKBOR) and the twenty seven participating centres)* (2003). Characteristics and Regional Variations of Patients with Barrett's oesophagus in the UK. *Eur J Gastroent and Hep* 15: 1217-1222.

Abstracts

- 1 Gatenby PAC, Caygill CPJ, Charlett A, Fitzgerald R, Watson A (2003) Length of Barrett's Oesophagus Segment: Demographic Associations and Cancer Risk. *Gut* **52**: (suppl. I) A41.
- 2 Gatenby PAC, Caygill CPJ, Watson A, Fitzgerald R, Charlett A (2003) Length of Barrett's Oesophagus Segment: Demographic Associations and Cancer Risk. *Gastroenterology* (in press).
- 3 Gatenby P, Caygill C, Ramus J, Bateson M, Johnston D, Fitzgerald R, Watson A (2003) Distribution of obesity by age and gender in Barrett's oesophagus patients at two culturally different centres registering with UK National Barrett's Oesophagus Registry. *J Clin Oncology* (in press).

Gatenby PAC, Ramus JR, Caygill CPJ, Watson A, Fitzgerald RC (2003). Association Between Lifestyle Factors and Histology in Barrett's Oesophagus. *Gut* (in press).