



National
Osteoporosis
Society



*Working together for a break**free** future*

Annual Review | **2012**



Claire Severgnini and Kate Tompkins

Welcome

Working together for a breakfree future

The last twelve months have been another busy period for the National Osteoporosis Society as we continue to pursue our vision of a future without fragility fractures. We are pleased to say that we have strived to achieve this vision through all of our areas of work: caring support, understanding, influencing and research.

The charity did this in a number of ways. We launched new services targeting health professionals and hosted our successful Osteoporosis and Bone Conference 2012. We worked hard to inform and influence politician in all four UK countries to ensure that osteoporosis is prioritised in health and social care policy. Our Helpline continues to be an unsurpassable source of information and caring support and our research programme had another busy year with over £150,000 invested in ground-breaking projects. We also took time during the last twelve months to think about the future through the publication of our new strategic plan which will guide the work of the charity over the next five years.

The fact that the charity achieved all of this during very difficult economic conditions and ended the financial year with a surplus is a real testament to the support and dedication of many people. Our President, Her Royal Highness The Duchess of Cornwall, worked tirelessly on our behalf to support the charity and raise the profile of osteoporosis. We would like to pass on our heartfelt thanks to her for everything she has done. We would also like to thank our volunteers, members, support groups, friends, employees, patrons and trustees who have worked so hard during 2012.

Through the continued passion and dedication of all of these people, and the generosity of our many supporters, we are confident we will continue to transform the lives of people affected by osteoporosis and fragility fractures.

Claire Severgnini
Chief Executive

Kate Tompkins
Chairman

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Caring support

Giving people with osteoporosis the information and support they need

“The information and support provided by the National Osteoporosis Society really has been a lifeline.”

“When I was first told that I had osteoporosis around eight years ago, it came as a real shock because I had no family history of the condition. I didn’t know where to turn. However, thanks to the information I’ve received from the National Osteoporosis Society, I’ve been able to change my lifestyle, exercise more and build up my general strength.

I looked at the charity’s website and found it so useful. It is full of the information I needed to learn about eating the right foods to build strong bones, how vitamin D can help me and lots of other things I can do to help myself.

I download information on everything from drug treatments to exercise and nutrition. All of the information the charity provides is up to date and absolutely invaluable and it’s great to know it has all been put together by experts.

The charity’s Helpline nurses provide an excellent service and are able to offer real expert help and support. It’s so comforting to know that they are just a phone call away.

I’m a member of the North West London support group and the exercise classes and talks from medical professionals organised by the group are another huge help.

The information and support provided by the National Osteoporosis Society really has been a lifeline.”

Anne Hunt, Member, National Osteoporosis Society North West London support group

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Caring support

Finding out you have osteoporosis can be devastating and it can be difficult for people to understand how the condition will affect their lives. During 2012 the National Osteoporosis Society worked hard to help people come to terms with osteoporosis and fragility fractures by providing life-changing information and support through our Helpline, free publications and patient-focused education events.



Local Medical Updates and Newly Diagnosed Sessions were held all over the UK.

Local Medical Updates and Newly Diagnosed Sessions

Throughout 2012 the National Osteoporosis Society's network of support groups and volunteers worked hard to support the needs of the charity's members and all those affected by osteoporosis and fragility fractures by holding Medical Update meetings.

Seventy three meetings were organised all over the UK throughout 2012 and we helped just under 3,000 people affected by osteoporosis to have a better understanding of their condition.

We also worked with the NHS to hold 69 sessions for those who have been newly diagnosed with osteoporosis and reached over 2,000 people.



Our Helpline celebrated its 20th anniversary during 2012.

Celebrating 20 years of providing information and support through our Helpline

Our Helpline was established in 1992 in response to the increasing numbers of calls and letters asking for help. The Helpline started with two part-time nurses but now has 10 full and part-time nurses who take calls and answer emails, letters and website discussion forum posts.

The Helpline is staffed by fully qualified nurses, each of whom has very specialist knowledge of osteoporosis, and offers a lifeline for the thousands of people each year who contact the nurses to ask about a range of issues.

During 2012 our nurses responded to 13,051 enquiries via telephone, email and post.

Invaluable publications

We provide a wide range of publications covering information which is essential to anyone affected by osteoporosis and fragility fractures and those who are interested in how to improve their bone health.

During 2012 we produced two new leaflets: *Healthy Living for Strong Bones* and *Exercise and Osteoporosis*.

Altogether we distributed 434,567 leaflets including almost 13,000 copies of our essential 68-page book *All about osteoporosis*.



Our leaflets provide essential information for anyone affected by osteoporosis and fragility fractures.

Understanding

Increasing awareness and understanding of osteoporosis and fragility fractures

“I see first-hand the pain and distress fragility fractures can cause. Thankfully, the National Osteoporosis Society is able to provide invaluable resources that help me and the people I see.”

“My job as a Falls and Fracture Prevention Nurse Specialist means I see first-hand the pain and distress fragility fractures can cause. Thankfully, the National Osteoporosis Society is able to provide invaluable resources that help me and the people I see.

During 2012 I joined the charity’s newly established UK Allied Health Professional Network which has helped me enormously. It means I can keep up to date with developments in the field, feel part of a supportive community of UK health professionals, share information and ask for opinions. I was also able to update my knowledge of osteoporosis by attending the Osteoporosis and Bone Conference 2012.

I pass this knowledge on through my day-to-day job and also through giving awareness talks to staff at GP practices.

I give out a significant number of the charity’s leaflets to the people I see in my clinic, which are always well received. I also always tell them about the charity’s website, which is such an invaluable resource and talk about the Helpline and how there are nurses who can answer any further questions.”

**Alison Doyle, Falls and Fracture Prevention Nurse Specialist,
University Hospitals, Birmingham**

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Understanding

The National Osteoporosis Society works hard to improve the understanding of osteoporosis and fragility fractures. During 2012 we did this by raising awareness among the general public and driving improvements in the education and training of health professionals. By doing so, we helped to improve the day-to-day lives of those affected by osteoporosis and fragility fractures.



The UK Allied Health Professional Network provides support to those working in the field of osteoporosis and bone health.

UK Allied Health Professional Network established

The National Osteoporosis Society is passionate about supporting health professionals working in the field of osteoporosis and bone health. One of the many ways we do this is through our newly established UK Allied Health Professional Network.

By the end of 2012, 422 Allied Health Professionals had joined the network.

Conference showcases latest research

Over 640 health professionals travelled to Manchester in July to attend the National Osteoporosis Society's Osteoporosis and Bone Conference 2012. Delegates represented a wide range of disciplines, all coming to learn about the latest research and recommendations in the fields of osteoporosis and bone health. In 2012, the conference was staged in conjunction with the Bone Research Society and the Paget's Association, offering a wider focus on bone health.

Our three day conference covered a great deal of ground and, when followed-up after the conference, 86 per cent of delegates told us that attendance had improved their clinical practice.



Professor Dame Nancy Rothwell speaking at the Osteoporosis and Bone Conference 2012.



(From left to right) Hugh MacPherson, Beverley Collins, Her Royal Highness The Duchess of Cornwall, Shona Mills and Joanna Hawkes pose for an "Unbreakable Embrace" photograph.

Bone densitometry training course

Our National Training Scheme for Bone Densitometry went from strength to strength during 2012, offering certification to healthcare professionals and clinical scientists who operate bone densitometry equipment in the UK.

In 2012, 78 delegates attended our National Training Scheme for Bone Densitometry training course.

Online resource encourages bone health awareness

We marked World Osteoporosis Day with the launch of an online risk assessment tool called How Strong Are Your Bones? - a downloadable "app" which encourages younger people to be more aware of the importance of good bone health.

Over 1,000 people downloaded and completed the app following its launch on October 20th and are now more aware of their risk of fractures. Try the app for yourself at www.nos.org.uk/risk.

Unbreakable Embrace

To highlight the plight of the millions of people all over the world affected by osteoporosis, groups in a number of different countries posed for a series of "Unbreakable Embrace" photographs to symbolise solidarity in the fight against fragility fractures.

Our President, Her Royal Highness The Duchess of Cornwall showed her own support by taking part in a photoshoot with Hugh MacPherson, Beverley Collins, Shona Mills and Joanna Hawkes, all of whom are affected by fragility fractures.

Our "Unbreakable Embrace" photo appeared on websites throughout the world.

Influencing

Influencing change in policy and healthcare

“Decision-makers need to know that there are things that can be done to improve quality of life and restore independence.”

“My late mother suffered from severe osteoporosis for over 30 years and I regard it as a privilege to do what I can to help advance the causes for funding, research and support for people affected by osteoporosis and fragility fractures and their families and carers. I know at first-hand how painful, debilitating and inhibiting this cruel condition can be, so it is fantastic to be able to help.

Osteoporosis is something we cannot cure, but we can reduce its impact. It is therefore vital that we make sure people suffering from the condition are given the best possible treatment and care.

As Co-Chair of the All Party Parliamentary Osteoporosis Group (APPOG) along with Baroness Cumberlege, I know how important it is to raise awareness of the condition among Parliamentarians, as well as to influence legislation and policy making.

We need to make sure – especially during a time of austerity – that decision-makers are aware that there are things that can be done to improve quality of life and restore independence; not just new drugs but exercise and diet initiatives – whose net effect can help save thousands of lives each year as well as tens of millions of pounds in treatment costs.”

Gordon Marsden MP, Co-Chair of the All Party Parliamentary Osteoporosis Group

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Influencing

With an aging population and the ever-rising cost to the NHS of looking after those affected by fractures, it is more important than ever before that public policy and health and social care provision meet the needs of people with osteoporosis and fragility fractures. That is why our work in this area during 2012 sought to make sure osteoporosis remained firmly on the agendas of politicians and policy makers throughout the UK.



(From left to right) National Osteoporosis Society Policy Officer Liza Williams demonstrates an osteoporosis simulation suit to James Arbuthnot MP at a Falls and Fractures Alliance event.

Falls and Fractures Declaration

Falls and fragility fractures are a growing burden on health and social care. To address this problem we are chairing a new Falls and Fractures Alliance, a wide and varied group of organisations involved in caring for people who suffer fragility fractures, all of whom have pledged to work together to ensure that every person affected by them will receive timely and appropriate treatment.

Twenty one organisations including Age UK, The British Geriatrics Society and the Royal College of Nursing joined the Alliance and have signed a declaration pledging their commitment to a series of statements and contributing to a five year action plan.



Our Osteoporosis Resources for Primary Care website provides information for GPs and health professionals.

Capitalising on the inclusion of osteoporosis in the UK-wide GP contract

In April 2012, osteoporosis was included in the Quality and Outcomes Framework (QOF) of the UK-wide GP contract for 2012 - the mechanism that provides financial incentives to GPs for identifying osteoporosis among their patients.

The charity supported GPs by launching a new website jointly developed with the Royal College of General Practitioners, called Osteoporosis Resources for Primary Care (www.osteoporosis-resources.org.uk).

Our members and supporters helped us to capitalise on this by throwing their weight behind a letter writing campaign.

Hundreds of supporters downloaded a template letter from our website and sent it to their GP, helping us to pass on crucial information about our invaluable resources. The resources site received over 13,000 visits during 2012.

Influencing change across the UK

Scotland

We provided background information and briefings to Members of the Scottish Parliaments in advance of an audit report published by the Scottish government on falls and fragility fracture services for older people. The report showed that 66 per cent of local communities had access to a Fracture Liaison Service and three quarters of the population of Scotland have access to these services.

We also provided crucial information for the Scottish government's consultation on the Integration of Health and Social Care and to the Demographic Change and Ageing Population Inquiry carried out by the Scottish Parliament Finance Committee.

Wales

We met with Welsh Assembly Members, health professionals and patients to discuss Fracture Liaison Service provision in Wales.

We encouraged Assembly Members to help us press for new services in Wales and also supported and promoted the implementation of the National Service Framework for Older People falls standard.

Northern Ireland

We continued to take an active role in the implementation group driving forward the recommendations of the Northern Ireland Fragility Fracture Working Group report (2009). We updated Members of the Legislative Assembly on progress at a roundtable meeting and those present showed a commitment to raising the issue with the Assembly's Health, Social Services and Public Safety Committee and with local health commissioners.

Following our roundtable meeting, media coverage highlighted the need for Fracture Liaison Services to be universally available across Northern Ireland.

Research

Supporting vital research

“By funding research, the National Osteoporosis Society has certainly helped to advance our knowledge.”

“I have been involved in research with the National Osteoporosis Society for a number of years and have worked on two projects that have received funding from the charity.

The first looked at the role of whole body vibration and vibration platforms in the rehabilitation of older people. The second study, which is still on-going, examined whether certain exercise programmes would help to reduce falls and build bones.

Finding funding for research projects is generally becoming quite difficult. As a researcher, you are competing with other disease areas such as cardiology and cancer, so there is a real need for an organisation such as the National Osteoporosis Society to provide targeted funding for research into osteoporosis and bone health.

By funding research, the National Osteoporosis Society has certainly helped to advance our knowledge of osteoporosis. However, there are still many areas of osteoporosis that we desperately need to understand and there is a great deal of research still to be done.

The National Osteoporosis Society supports the clinicians and young scientists of tomorrow specialising in osteoporosis and bone health research. By doing so, the charity will ensure that the highest quality of research continues to be performed in the UK.”

Professor Tahir Masud, Consultant Gerontologist, Nottingham University Hospitals

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Research

Despite the fact that more people than ever are living with the potentially devastating effects of osteoporosis and fragility fractures, research into this crucial area is significantly under resourced in the UK. During 2012, the National Osteoporosis Society's research grants programme provided funding totalling over £157,000 for ground-breaking research including the two projects outlined below, to help improve the lives of people affected by osteoporosis and fragility fractures.

Can targeted exercise therapy reduce fracture risk?

We know that exercise is an effective way of building stronger bones, but a research team from the University of Cambridge want to find out more about how exercise can really help.

We have awarded the team at Cambridge a grant of £13,672 to find out whether exercise can help to build up an important outer shell of bone.

The research team at Cambridge, in collaboration with scientists at Loughborough University, have worked with a group of 36 older men who have exercised on just one leg for 12 months, allowing changes in that leg to be compared to the leg that has had no exercise. The men all had scans of the hip as well as bone-density measurements before and after the exercise. The scans showed bone density increased in the exercised leg and declined in the non-exercised leg.



Researchers at the University of Cambridge have received over £13,000 in funding from the National Osteoporosis Society to investigate how exercise can help to build bone strength.

This new research project will now use innovative scanning technology to find out whether the increase in bone density is due to thickening of the outer bone shell.

This study may lead to future research in developing exercise programmes to increase bone thickness at regions that are important for maintaining bone strength.



Research into the extent of osteoporosis and fragility fractures among ethnic minority groups is underway at the University of Manchester thanks, in part, to National Osteoporosis Society funding totalling £18,800.

How widespread are osteoporosis and fragility fractures among ethnic minority groups in the UK?

The UK's ethnic mix has been steadily changing, with the proportion of people from an ethnic-minority background projected to rise to 20 per cent by 2050. At the moment, we don't know how widespread the problems of osteoporosis and fragility fractures are among these groups.

The National Osteoporosis Society has provided funding totalling £18,831 for a research team at the University of Manchester to analyse a database containing the medical records of over 10 million people from different ethnic backgrounds living in the UK. The research will look at records from 2006 to 2011 to determine whether the number of fractures during that time were different for specific ethnic-minority groups compared to Caucasians.

This information should help to inform future health policies aiming to give health service providers a better understanding in order to plan and budget for future health care. Also, if there are found to be differences in fracture risk between ethnic groups, this would point the way to future studies to try and understand the causes of any observed differences.

Our research priorities

In 2012 we undertook a consultation with key audiences involved in osteoporosis and bone health to identify our research priorities. The current priorities are:

- **Burden of disease:** the impact fragility fractures are having on individuals and the community
- **Current/novel treatment and patient care:** pain management, long-term effects of bisphosphonates, vitamin D
- **Diagnosis and risk assessment:** ensuring new and existing techniques are used effectively
- **Mechanisms of disease:** understanding the mechanisms of pain from fragility fractures, especially vertebral fractures

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Thank you

The National Osteoporosis Society receives no government funding and relies upon voluntary donations in order to provide our life-changing services. We would like to express our heartfelt thanks to all of our supporters, members, patrons, individual supporters, corporate partners, trusts, foundations, event participants, runners, event organisers, local support groups and those who chose to generously leave the charity a gift in their will. It is not possible to mention every single person or organisation that has supported our work during 2012. However we are very grateful to those who have made a special contribution to our work:

All those who remembered the National Osteoporosis Society in their will.

Companies

Amgen Ltd
Infused Calcium Technologies
Optasia Medical
Principle Healthcare
Servier Laboratories
Tropicana
Vitabiotics Ltd
Whey Forward Health Industries Ltd
Yoplait UK Ltd

Individuals

Mohamed Amersi
Ivor Braka
David Brownlow
Kevin Burke
Philip and Linda Harley
Drue Heinz DBE
Sir Ralph Kohn
Duncan and Patricia Lindley
Nicholas and Heather Porter
Claude Wiles

Trusts

The Alice Ellen Cooper Dean Charitable Foundation
The BAND Trust
The Bryan Guinness Charitable Trust Ltd
The Charles Wolfson Charitable Trust
The Childwick Trust
The David Saunders Family Charitable Trust
Donald Forrester Trust
The Dunhill Medical Trust
Esmee Fairbairn Foundation
The Evan Cornish Foundation
The Forte Charitable Trust
Garfield Weston Foundation
The Headley Trust
The Herbert and Peter Blagrove Charitable Trust
The John Ellerman Foundation
John James Bristol Foundation
The Rothermere Foundation
The Rumi Foundation
The Trusthouse Charitable Foundation

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2012 in pictures

Christmas concert

Choirmaster Grenville Jones, children from Widcombe Infant School and the Bath Chorus at our festive Sing concert held at Bath Abbey in November. The concert raised more than £4500.



London 25

On the 25th of May 2012, 25 people, led by Consultant Gynaecologist Michael Dooley and travel writer and conservationist Mark Shand, walked around London for 25 hours to celebrate the conclusion of the 25th year of the National Osteoporosis Society, aiming to raise £25,000. With 50 miles of London covered on foot. The group covered 1,250 miles in aid of the National Osteoporosis Society and a hospice based locally to many of the walkers. More astonishing than the miles covered, though, was the money raised. Between both charities, the total fundraising exceeded £60,000.



Chance to Shine

(From left to right) Chairman of the English Cricket Board Giles Clarke, National Osteoporosis Society Chief Executive Claire Severgnini, BBC Sports presenter Manish Basu and Chief Executive of the Cricket Foundation Wasim Khan at the launch of the strategic partnership between the National Osteoporosis Society and the Cricket Foundation's "Chance to Shine" programme. The partnership will reach thousands of children and young people throughout the UK with evidence-based advice on exercise, diet and safe sun exposure.



Orange Appeal 10K run

(From left to right) Spencer Medcalf, National Osteoporosis Society Patron Barbara Windsor and race organisers Evelyn Medcalf and Andrea Magold at the Orange Appeal 10k run held in Hyde Park in September. The run raised an amazing £2,000.



Your personal best

(From left to right) Choreographer Arlene Phillips, National Osteoporosis Society Chief Executive Claire Severgnini, National Osteoporosis Society Communications and Public Affairs Director Juliette Morgan and dance judge Len Goodman at the launch of the Your Personal Best campaign at the Olympic stadium in London. The campaign was created to inspire the 7.78 million people over 55 with long-term conditions to lead a more active lifestyle.



MSP raises money for support group

(From left to right) Outgoing National Osteoporosis Society Chairman Professor David Reid and Berwickshire Member of the Scottish Parliament and Patron of the Borders National Osteoporosis Society support group John Lamont. John ran in the New York Marathon in 2012 raising over £3,000 for the Borders support group.

Working together for a *breakfree* future

Financial Report 2012

Overview

In 2012, the charity's income increased by 7 per cent and its expenditure by 1 per cent. These increases were due to the Osteoporosis and Bone Conference 2012 which takes place every 18 months and without which there was a small overall reduction in income and expenditure for the year. This was achieved in an economic environment of continuing hardship for the charitable sector, despite which, we were able to consolidate and improve our reach and effectiveness in the influencing and education of healthcare professionals, policy makers and the general public and in the provision of caring support to those affected by osteoporosis and fragility fractures.

How we spent our money

In 2012, charitable activities constituted 72 per cent of our expenditure and with savings on staffing and administration, fundraising costs fell by 5 per cent. Utilising digital media, 2012 saw improved accessibility through websites, webinars, email newsletters, the bone health smartphone app and our growing social media following. We reached over a million TV viewers through the BBC Lifeline Appeal. We launched the UK Allied Health Professional Network and worked in partnership with Age UK, the Royal Society of Medicine, the Cricket Foundation and our partners in the new Falls and Fractures Alliance. Our Helpline responded to over 13,000 enquiries, 83 support groups held 546 meetings, and 434,000 free information leaflets were distributed. We held numerous Newly Diagnosed Sessions and Medical Updates countrywide, continued to give financial support to research projects and contributed to professional training and understanding with the Osteoporosis and Bone Conference 2012 and the National Training Scheme for Bone Densitometry.

How we raised our money

Despite a difficult year, the charity's income decreased by only 2 per cent in 2012 (excluding conference income). Trust income showed a 54 per cent increase and resulted in our first £100,000 trust grant. We have worked hard to spread risk and improve our range of sustainable income sources, attracting new donors with a series of specific events. We are developing ways to understand supporter needs and enable donors to more fully appreciate the charity's effectiveness through quantitative and qualitative impact reporting. Legacy income is vital to our success and we were able to sustain year-on-year levels at £1.1m. With our organisation of and participation in fundraising events as varied as the Virgin London Marathon, tea parties, World Osteoporosis Day and the festive Sing Concert held at Bath Abbey, and our popular range of membership schemes, we continued to appeal to a wide variety of donors. The Osteoporosis and Bone Conference 2012 made a £71,000 profit, while our investment policy resulted in a valuation gain of £136,000. We increased our fundraising return on investment to £4.09 for every £1 spent.

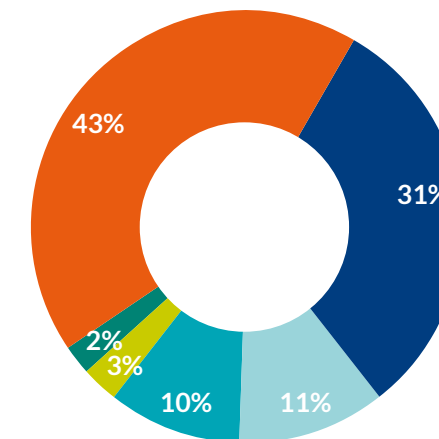
Reserves

Thanks to effective and prudent financial management, we ended 2012 with a £148,000 surplus and free reserves of £2.2m, well within reserves levels set by our trustees.

Summary

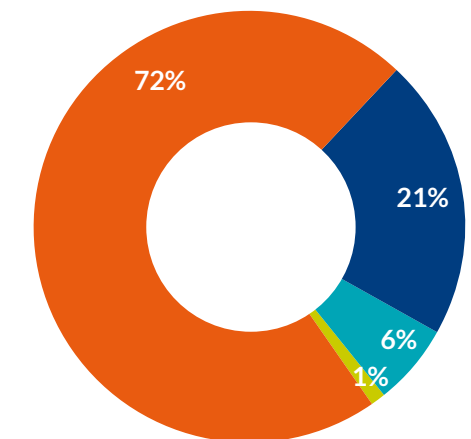
In 2012 we considered our activities and directed resources into areas where we can make the biggest difference. Thanks to our expert and committed employees and the invaluable contribution of effort, time and money by volunteers and supporters, we are in a strong position to positively work on behalf of those affected by osteoporosis and fragility fractures.

In 2012 we **raised £3.5m**



- Voluntary income
- Legacies
- Fundraising events
- Education
- Trading activities
- Investment income

In 2012 we **spent £3.5m**



- Charitable activities
- Cost of generating income
- Research
- Governance costs

Income

Voluntary income
Legacies
Fundraising events
Education
Trading activities
Investment income

Total income

Expenditure

Charitable activities
Cost of generating income
Research
Governance costs

Total expenditure

Net incoming /(outgoing) Resources before investment gains/(losses)

Investment gains/(losses)

Net incoming /(outgoing) Resources

	Total 2012 £000	Total 2011 £000
Income		
Voluntary income	1,476	1,494
Legacies	1,062	1,085
Fundraising events	383	393
Education	350	24
Trading activities	112	132
Investment income	86	109
Total income	3,469	3,237
Expenditure		
Charitable activities	2,498	2,438
Cost of generating income	726	761
Research	192	175
Governance costs	41	36
Total expenditure	3,457	3,410
Net incoming /(outgoing) Resources before investment gains/(losses)	12	(173)
Investment gains/(losses)	136	(67)
Net incoming /(outgoing) Resources	148	(240)

This financial summary is extracted from our full audited accounts for 2012 which are available by calling 0845 130 3076 or online at www.nos.org.uk

Working together *for a breakfree future*

Our organisation

Board of Trustees:

Chairman: Professor David Reid (retired July 2012)
Kate Tompkins (appointed July 2012)

Vice Chair: Mary Regnier-Leigh

Treasurer: Philip Newborough

Janine Chandler
Dr Alun Cooper
Professor Roger Francis
Jeremy Stern
Professor Terry O'Neill
Carole Walker
Carlyn Chisholm

President: HRH The Duchess of Cornwall

for a breakfree future

People with fragile bones should be able
to hope for a future without fractures.





National
Osteoporosis
Society

Working together for a breakfree future



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0845 130 3076 (General Enquiries)



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National Osteoporosis Society is a registered charity No. 1102712 in England and Wales and no. SC039755 in Scotland.

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