



National  
**Osteoporosis**  
Society



# Annual Review 2013

– **making a difference**

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Photographs on front cover, from left to right: Attendee, Birmingham Medicine and Me event; Dr. David Brookfield, National Osteoporosis Society Members and Volunteers Committee member; Sarah Newton, Member of Parliament for Truro & Falmouth; Emmie Morris, fundraiser; Debbie Stone MBE, Specialist Osteoporosis Nurse.

# Welcome

As the only UK-wide charity that supports the millions of people affected by osteoporosis and the Health Care Professionals that care for them, there continues to be a huge demand for our life-changing support and information services.

2013 was the first year of our 5 year strategic plan and the pages of this review reflect the five key areas of our work, along with some highlights showing how our work has continued to make a significant difference to people's lives.

This work includes raising awareness of the risk of broken bones through our high profile Stop At One campaign which highlights the steps people can take to improve their bone health.

2013 was the year when, thanks to the ICAP Charity Day, we were able to progress the development of Fracture Liaison Services.

Our research programme provided much-needed funding for a number of projects which will directly help those with osteoporosis and will help improve understanding of the condition.

Through our influencing work we continued to ensure the voices of those with osteoporosis were heard by politicians and policy makers across the UK.

All of the achievements outlined in this Annual Review have been made possible thanks to the passion and dedication of a huge number of people. Our President, Her Royal Highness The Duchess of Cornwall, has been of invaluable support and has raised the profile of osteoporosis and our work. We would also like to thank our members, our dedicated network of support groups, our volunteers, employees, trustees, supporters, donors, trusts and foundations, corporate partners, philanthropists, event participants and patrons, and the people who have chosen to remember us in their wills.

There is much work for us still to do to end the pain and suffering caused by osteoporosis and we have ambitious plans which depend on voluntary donations, grants and the generosity of others. We will continue to build on our strengths and take full advantage of our opportunities as we further advance our vision of a future without fragility fractures.

**Claire Severgnini**  
Chief Executive

**Kate Tompkins**  
Chairman



Claire Severgnini



Kate Tompkins

# Facts about osteoporosis

**Osteoporosis** is a fragile bone condition. It can lead to painful and debilitating broken bones, particularly of the wrist, hip and spine. Broken bones are also known as fractures. Often these occur from just a minor bump or fall, many of these could have been prevented with earlier diagnosis and treatment.

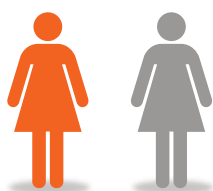
## The problem



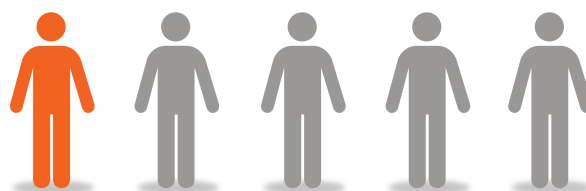
**3 million people**  
in the UK are estimated to have osteoporosis.

**Every year there are 300,000 fractures**  
That's almost 1 every 2 minutes

## Who it affects



**1 in 2 Women**



**1 in 5 Men**

People over the age of 50, **who will break a bone** mainly as a result of poor bone health.

## The personal cost

**80%**

of people who have broken a hip are unable to shop, garden or climb stairs, a year after their fracture.



## The financial cost



**£6 million per day**

The cost of hospital and social care for patients with a **hip fracture** alone.

## Where we are now

**Only 25%**

of adults are familiar with the term **osteoporosis**.



**Only 42%**

of Health Care Organisations in the UK provide a Fracture Liaison Service to **routinely assess** people, who have broken a bone, for osteoporosis.



**1 in 5 women who have broken a bone**



**break 3 or more bones before being diagnosed.**

## The future

If everyone over 50 who breaks a bone is identified and treated by a Fracture Liaison Service, 22,250 hip fractures a year could be prevented.



# Understanding

## Improving our knowledge of osteoporosis

Research into osteoporosis continues to be under-resourced across the UK, despite the fact that more and more people are living with the consequences of poor bone health as the population continues to age. We want to further our understanding of bone health to improve the prevention and diagnosis of osteoporosis as well as the day to day lives of those affected by the condition.

Our research grants programme allows us to develop new ways of helping people with osteoporosis. During 2013, it provided over £310,000 of funding for five new projects.

These exciting new projects cover a wide range of areas, including the safety of common osteoporosis drug treatments, how pain relief can be approached without the use of drugs and how combined vitamin D and resistance training could improve bone health in older men and women.

We also provided funding for a major study to generate the latest information on the prevalence of osteoporosis. This two year project will bring us up-to-date with our understanding on how common broken bones and osteoporosis are. It will give us more detailed information about how osteoporosis is affecting different groups of people in the UK.

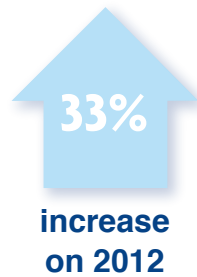
An example of where our past research has made a difference to those affected by osteoporosis was through our support of a project to investigate the effect of vitamin D injections on fractures. We were able to use the results in developing our Vitamin D Guideline which recommended tablets are used rather than injections.



Research is vital to our understanding of bone health.



In 2013 we received  
**40** research funding  
applications, **one third**  
more than in **2012**.  
We awarded **£310,000**.



By the end of 2013  
we had invested more  
than **£3 million** in over  
**130** research projects.



## Looking for new ways to help

“There is still an enormous amount we don’t know about osteoporosis and bone health and, while the research funding provided by the National Osteoporosis Society over the years has certainly furthered the scientific community’s understanding, there is still a great amount of research to be done. Anything we can do to help those with osteoporosis is a step forward.”

**Dr Emma Clark**  
**Osteoporosis Researcher at the University of Bristol**

# Awareness

## Raising awareness of osteoporosis and the National Osteoporosis Society

Recent research shows that awareness of osteoporosis continues to be very low, with only a quarter of adults saying they are familiar with the term. We recognise that greater awareness of the condition will empower people to seek help.

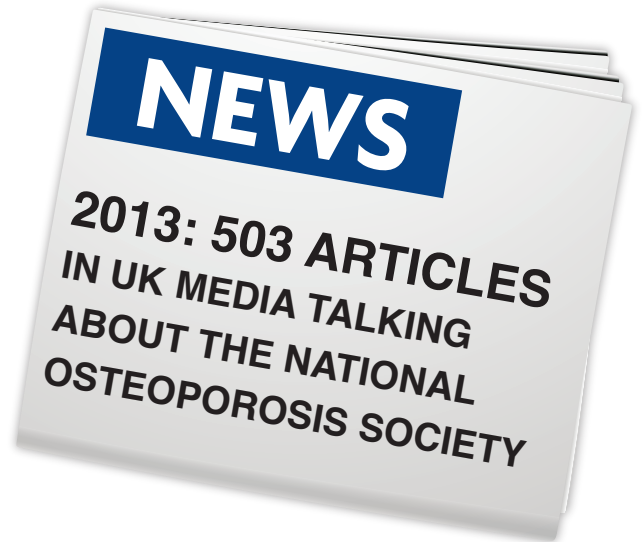
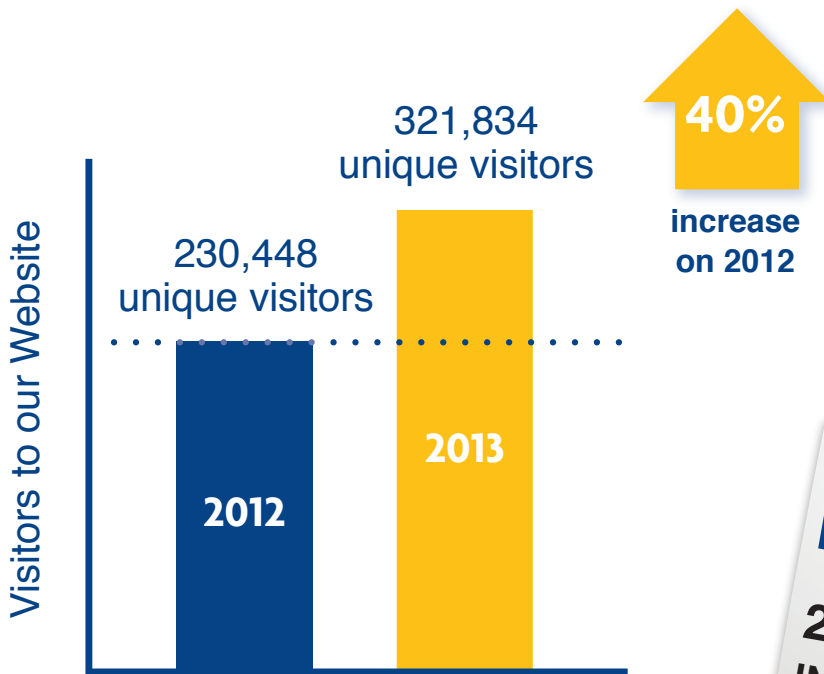
We tackled this problem head on through the launch of our ambitious public awareness campaign, Stop At One. This had a simple message encouraging those who have had a fracture and are therefore at high risk of having another to talk to their GP. The campaign attracted national media coverage and was widely shared across social media. It also prompted more visitors to our website where 2,015 people took our “Are you at risk?” quiz, helping more people who could have osteoporosis get treatment.

We also looked to raise awareness of the importance of vitamin D through our pioneering Sunlight Campaign, backed by beauty and well-being expert Liz Earle. The campaign focused on our new vitamin D guideline for Health Care Professionals. It also delivered a key message about safe sunlight exposure and the bone-health benefits of vitamin D.



(From left to right) Patrons Susan Hampshire OBE and Wendy Craig, broadcaster and journalist Sue MacGregor and Chief Executive Claire Severgnini at the launch of our Stop at One awareness campaign





2,015 people took our online “Are you at risk?” quiz, part of our **Stop at one Campaign** website, to find out if they were at risk.



## Delivering our awareness messages

“The Stop at One campaign has given the UK-wide network of National Osteoporosis Society Local Support Groups something new to talk about to the public and helped us raise awareness of the risk of fractures to people who just don’t understand what osteoporosis is. The posters are really eye-catching and it’s been really encouraging to hear people talk about the campaign.”

**Margo Berry**  
Chair, Portsmouth Support Group

# Influence

## Ensuring our voice is heard

Influencing government and NHS health policy was central to our work in 2013.

In partnership with Age UK, we continued to lead the Falls and Fractures Alliance driving forward principles of best practice and the ideal pathway for falls and fractures patients.

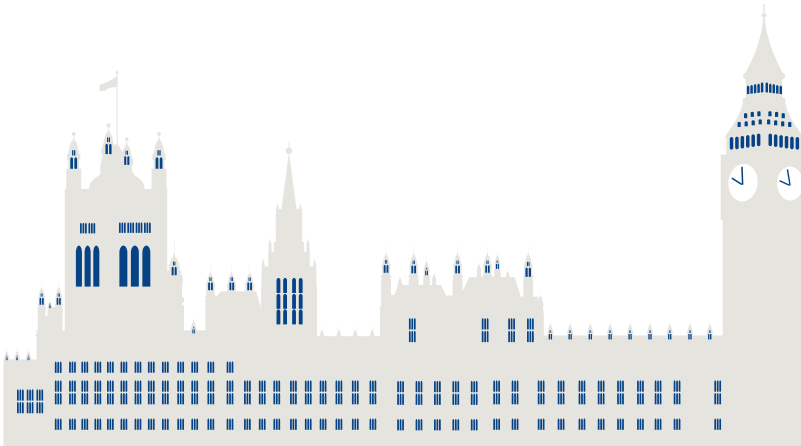
The All Party Parliamentary Osteoporosis Group (APPOG) has continued to ensure the condition is high on the agenda for politicians and amongst the wider health community. We have worked with policy makers across the devolved nations, responding to questions raised by politicians in Scotland, Wales and Northern Ireland. We have also spoken out at meetings to make sure our views were heard by decision makers.

We also strived to ensure that as many people as possible in positions of influence were aware of the importance of Fracture Liaison Services (FLS). These services ensure those who have fractured and might have osteoporosis are identified, assessed and treated. This approach to dealing with fractures has received support from Health Minister Norman Lamb MP and the Department of Health.

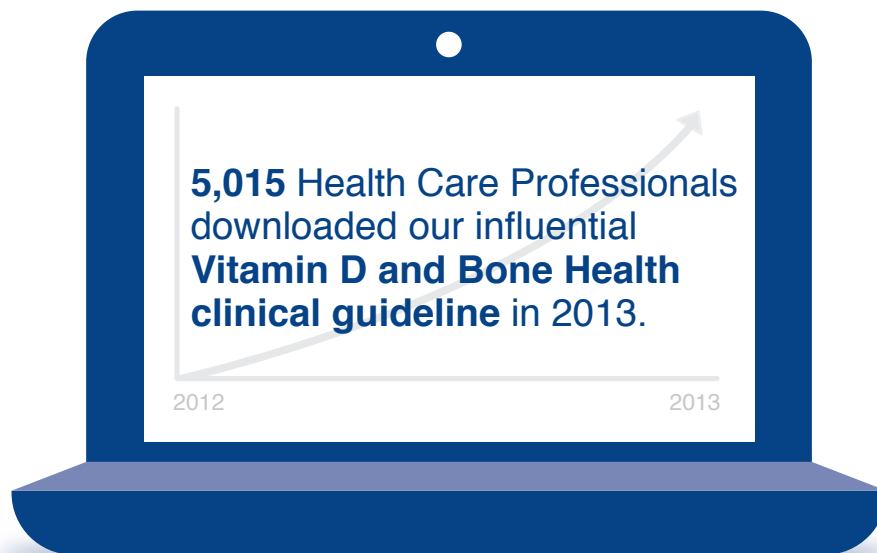


National Osteoporosis Society Chief Executive Claire Severgnini and Gordon Marsden MP raising awareness of the importance of Fracture Liaison Services.

**48** parliamentarians referred to osteoporosis or fractures in parliamentary debates or questions.



**37%** of Health Care Organisations across England, Wales and Northern Ireland now have a Fracture Liaison Service, compared with **29%** in **2009**. Scotland continues to lead the way with **66% coverage**.



## Working in Westminster

“Since I found out I had osteoporosis, I’m more aware of other people with the condition and I’m stunned that it is so widespread. My own experience of diagnosis and treatment was excellent, but I know that kind of treatment is not widespread. I think the key is to educate people about the importance of Fracture Liaison Services and preventing further fractures. The National Osteoporosis Society is doing all it can to raise awareness of the condition amongst politicians and policy makers.”

**Sarah Newton MP, Conservative Party Deputy Chairman**

# Information and Support

Empowering people to improve their bone health

We help people all over the UK to develop a better understanding and feel more confident about managing their condition and improving their bone health. We provide a range of information and support which people can access in different ways so that it best meets their needs and makes a real difference to their lives.

Our life-changing leaflets and factsheets are invaluable and are reaching more and more people. Clear and accurate, they are on our website, which was visited by a record number of people in 2013. We also supply our leaflets to clinics where they are greatly valued by Health Care Professionals for use with their patients.

Our nurse-led Helpline acts as a lifeline to people struggling to come to terms with the condition. It is staffed by nurses with specialist knowledge of osteoporosis who deal with enquiries via telephone, email, letter and our website. We have seen the nature of people's enquiries growing more complex and the nurses have ably responded by giving the time that is needed to each caller and keeping their knowledge up to date across a wide range of topics. An evaluation carried out in 2013 showed that 100% of callers were satisfied and 80% had taken positive action as a result of their call.

In 2013 we continued to develop our local information events and as a special initiative, we hosted a series of public 'Medicine and Me' events in partnership with the Royal Society of Medicine. Held in Aberdeen, Birmingham and Cardiff, over 300 people found out more, shared their experiences and questioned experts about the condition.

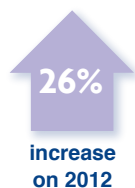


## Helping to understand osteoporosis

"An excellent day, I feel I have so much more information to be able to discuss future care with my doctor. I am awaiting an appointment to see a rheumatologist and I now feel I am much better equipped to see him."

**Birmingham Medicine and Me evaluation**

## Our information



**420,104**

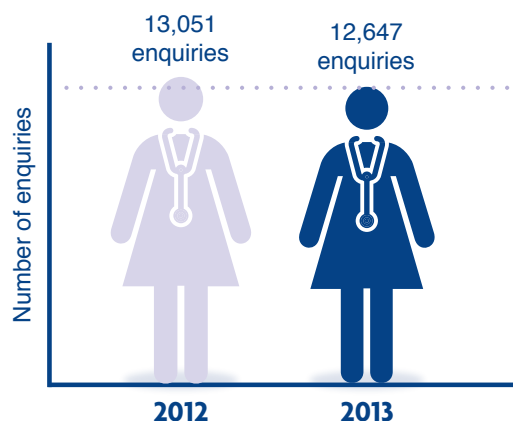
leaflets were  
distributed in 2013

Included were **12,997**  
copies of our free All About  
osteoporosis booklet.

We launched two new  
leaflets and distributed  
**47,000** copies.

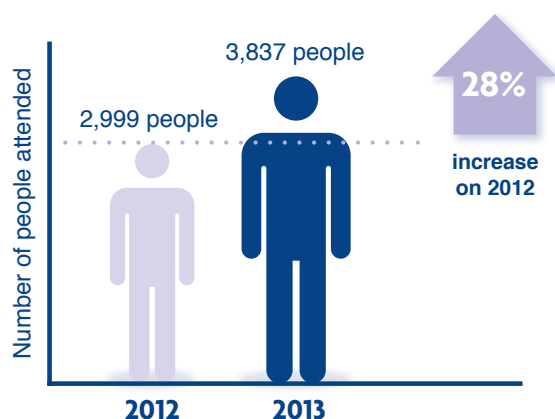
## Our helpline

**12,647** enquiries were handled by our helpline.



Our nurses spend an average of  
**11 minutes** talking to each  
enquirer on the phone.

## Our events



Our **78** osteoporosis  
information events were  
attended by **3,837** people.



# Information and Support - Health Care Professionals

## Educating and supporting Health Care Professionals

Understanding the needs of Health Care Professionals and supporting them in providing care for those affected by osteoporosis is enormously important to us.

Our UK Allied Health Professional Network provides invaluable peer support, a forum for sharing best practice and the opportunity to keep up to date with the latest developments. The Network went from strength to strength during 2013 with membership rising to 455 by the end of 2013, a 7% increase on 2012.

Our National Training Scheme for Bone Densitometry offers certification to Health Care Professionals who operate bone scanning equipment. The course is the only one in the UK of its kind and certified 8% more people in 2013 than in 2012 – that's more people on the ground helping to diagnose osteoporosis.

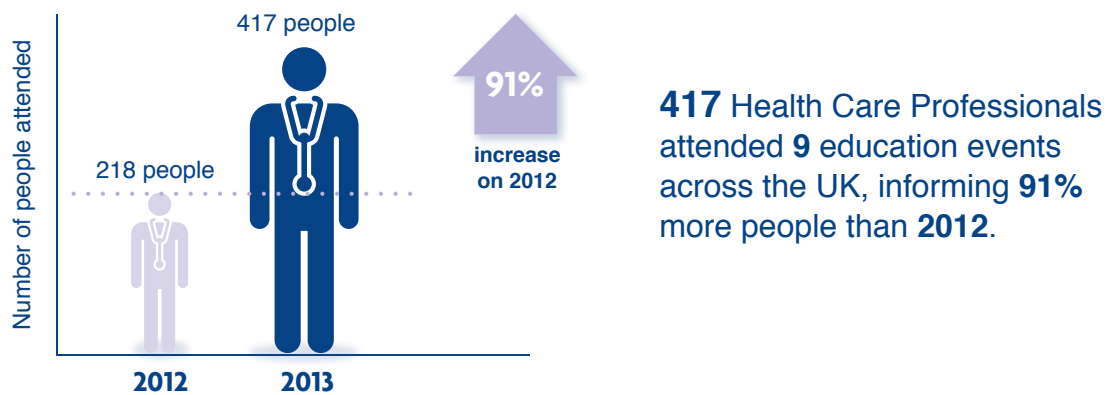
We also published Osteoporosis Review. The charity produces this respected scientific journal which keeps Health Care Professionals and Academics up to date with the latest developments in the field.



### Invaluable support

“We use these publications for many physiotherapy outpatients and community patients to emphasise the importance of a good diet and taking medications if prescribed in the correct manner. We also use them to compliment the Falls Prevention Training for staff working with individuals over 65. The publications use easy to understand language and are well received by patients and staff.”

**Steph Hay, Lead Physiotherapist, Rothesay Victoria Hospital**



Our UK Allied Health Professional Network was launched in 2012 and now has **455 members**. The network has been developed to provide support and professional development to Health Care Professionals, specialising in osteoporosis.



**12,000** Health Care Professionals visited our Osteoporosis Resources for Primary Care website, which gives GPs and Practice Nurses information on osteoporosis management.



By the end of **2013**, **385** Health Care Professionals were certified through our National Training Scheme for Bone Densitometry.

# You said, we did

The National Osteoporosis Society listens to the public, members and volunteers and Health Care Professionals to ensure that we continually improve the support, care and information that we provide. During 2013 we listened to feedback in a number of areas and, where possible, made improvements.



## Research priorities

Through engagement with our members, volunteers and the clinical community, we created a new list of priorities which will be used to assess research bids.



## Gold Membership

Our members told us they wanted an easy way to pay for their membership for a long-term period with one payment. We took this on board and in 2013 introduced our Gold Membership scheme which allows members to make a long term commitment to supporting the charity.



## Easy to download factsheets

During 2013 we converted 19 of our leaflets into a new download-friendly format following feedback from Health Care Professionals using our specialist leaflets. They told us they wanted to be able to download information from our website as easy to print PDFs to give to their patients.



## Osteoporosis Review

Our Professional Members told us that they highly value our scientific journal Osteoporosis Review, but found it difficult to read in its on-line only format. During 2013, we addressed this concern by returning the journal to its hard copy print format.

# Thank you

We would like to express our heartfelt thanks to all our volunteers and members of our committees for so generously giving of their time and expertise; to our supporters including our members, individual supporters, fundraising events committee members, corporate partners, trusts, foundations, event participants, runners, event organisers, local support groups and all those who chose to remember the charity in their will. It is not possible to mention every single person or organisation that has supported our work during 2013. However, we are very grateful to our patrons for their support and all that they do for the charity and to those who have made a special contribution to our work including David Brownlow, Duncan and Patricia Lindley, and Drue Heinz DBE.

## Companies

a2 Milk UK  
Amgen  
AO.com  
Blossoms Healthcare LLP  
Eli Lilly & Company Ltd  
ICAP Plc  
Internis Pharmaceuticals Limited  
Optasia Medical Ltd  
ProStrakan Group Ltd  
Rosemont Pharmaceuticals Ltd  
Rotork Controls Ltd  
Servier Laboratories Ltd  
Takeda UK Ltd  
Tropicana  
Yoplait UK Ltd  
Vitabiotics Ltd

## Trusts

Adint Charitable Trust  
The Alice Ellen Cooper Dean Charitable Foundation  
The Blagrave Trust  
The Cadogan Charity  
The Hugh Fraser Foundation  
The John Ellerman Foundation  
The Liz and Terry Bramall Foundation  
The Sylvia Aitken Charitable Trust



(From left to right) John Reynolds (third from right) helped us to raise vital funds to provide our services by running 192 miles in one go, including the London Marathon; Her Royal Highness The Duchess of Cornwall attending the 2013 ICAP Charity Day. The event saw the world's leading markets operator and provider of post trade risk and information generously donate all of the revenue and broker's commissions from its worldwide offices generated on December 3rd to over 200 charities, including the National Osteoporosis Society; Broadcaster and writer Sue MacGregor was the guest speaker at the National Osteoporosis Society's inaugural Annual Lecture in October. The event acted as a launch for our Stop at One campaign.



# Financial Report 2013

## Overview

In 2013, both the Charity's income and its expenditure decreased by 3%. However, in 2012, we held the Osteoporosis and Bone Conference, which takes place every two years. Without the impact of the conference, income increased by 7% and expenditure by 5%.

The Charity saw an overall surplus of £185k compared to a surplus in 2012 of £148k. This was achieved in the continuing uncertain economic climate amid some sector-wide declining trends in charitable giving. Despite this decline, we were able to continue to provide valuable support to people affected by osteoporosis as well as to strengthen our influencing work to further improve services across the UK.

## How we spent our money

The preceding pages of this Annual Review describe our activities in more detail, the following is a summary. Total expenditure in the year was £3.4m. This includes £2.6m spent on charitable activities, of which £325k was attributable to research.

Our Helpline responded to over 12,000 enquiries by phone, email, letter and the 'Ask the Nurse' forum.

We distributed over 420,000 free information leaflets and converted 19 of the more specialised leaflets into downloadable factsheets to make them more widely available.

Support Groups and volunteers continue to be an important channel for providing information and support. Our 75 Support Groups held 442 meetings to support people living with osteoporosis and 54 Newly Diagnosed sessions have been delivered by a partnership of NHS staff, volunteers and our regional team.

We invested in the Stop at One campaign to raise awareness of osteoporosis and specifically the need for improved levels of identification and assessment of people who have a fragility fracture. We appeared in 233 pieces of national and regional press coverage, 181 radio interviews and two pieces of television coverage.

We continued to lead the Falls and Fractures Alliance, driving forward principles of best practice and the ideal pathway for falls and fractures patients, and this will continue into 2014.

We contributed to the development of numerous pieces of clinical guidance with the aim to help influence the provision of services more widely.

We continue to support and monitor 14 research projects. In 2013, five new projects were approved.

One project, relating to the prevalence of osteoporosis, is particularly key to our goal of improving our understanding of the prevalence and impact of fragility fractures in the UK and will represent a significant step forward.

## How we generated our income

Income from fundraising increased by 5% year on year, thanks to legacy income.

Gifts in wills are vital to our success as a Charity and we are so very grateful to those supporters who chose to remember us in their will. In 2013 the Charity benefitted from £1.5m income from legacies compared with £1.1m in 2012.

As a charity dependent on voluntary donations and grants to fund all our work, it is vital that our fundraising is as effective as possible. In 2013, our fundraising return on investment (including legacies) was £4.32 for every £1 spent.

We continue to work hard at appealing to a broad range of supporters and stakeholders and developing a mixed, balanced and sustainable portfolio of fundraising activities. This is essential in what remains a challenging climate for fundraising.

We are very grateful to everyone who supported our work in 2013.

## Reserves

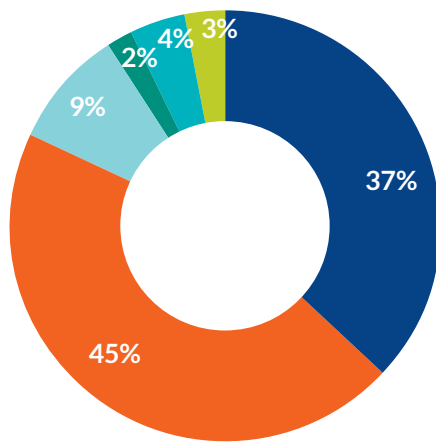
Thanks to effective and prudent financial management, we ended 2013 with reserves which were within the levels set by our Trustees.

## Summary

In 2013, thanks to the ongoing generosity of our donors combined with continual review of where our funds can best be spent, the finances of the National Osteoporosis Society remain sound. This is especially important to enable us to advance our impact for those people affected by osteoporosis and fragility fractures in line with our 5 year strategic plan. This is vital to enable us to continue to make a difference to those people affected by osteoporosis and fragility fractures.

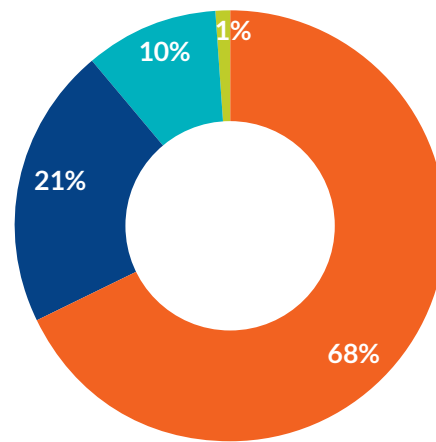


## In 2013 we raised £3.4m



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

## In 2013 we spent £3.4m



- 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 Resources before investment gains

Investment gains

### Net Incoming Resources

Total  
2013  
£000

Total  
2012  
£000

1,256  
1,516  
299  
70  
138  
90

1,476  
1,062  
383  
350  
112  
86

3,369

3,469

2,288  
710  
325  
44

2,498  
726  
192  
41

3,367

3,457

2

12

183

136

185

148

This financial summary is extracted from our full audited accounts for 2013 which are available from calling 0845 130 3076 or online at [www.nos.org.uk](http://www.nos.org.uk)

## Our vision

A future without fragility fractures.

## Our mission

Working together for a brighter future for people with or at risk of osteoporosis and fragility fractures across the UK, putting an end to preventable broken bones and helping people to live without pain and disability.

## Our values

We are caring, innovative, excellent, influential, ethical and passionate in all that we do.

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-  **Camerton, Bath BA2 0PJ**

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