



Annual Report 2010



About Myeloma UK

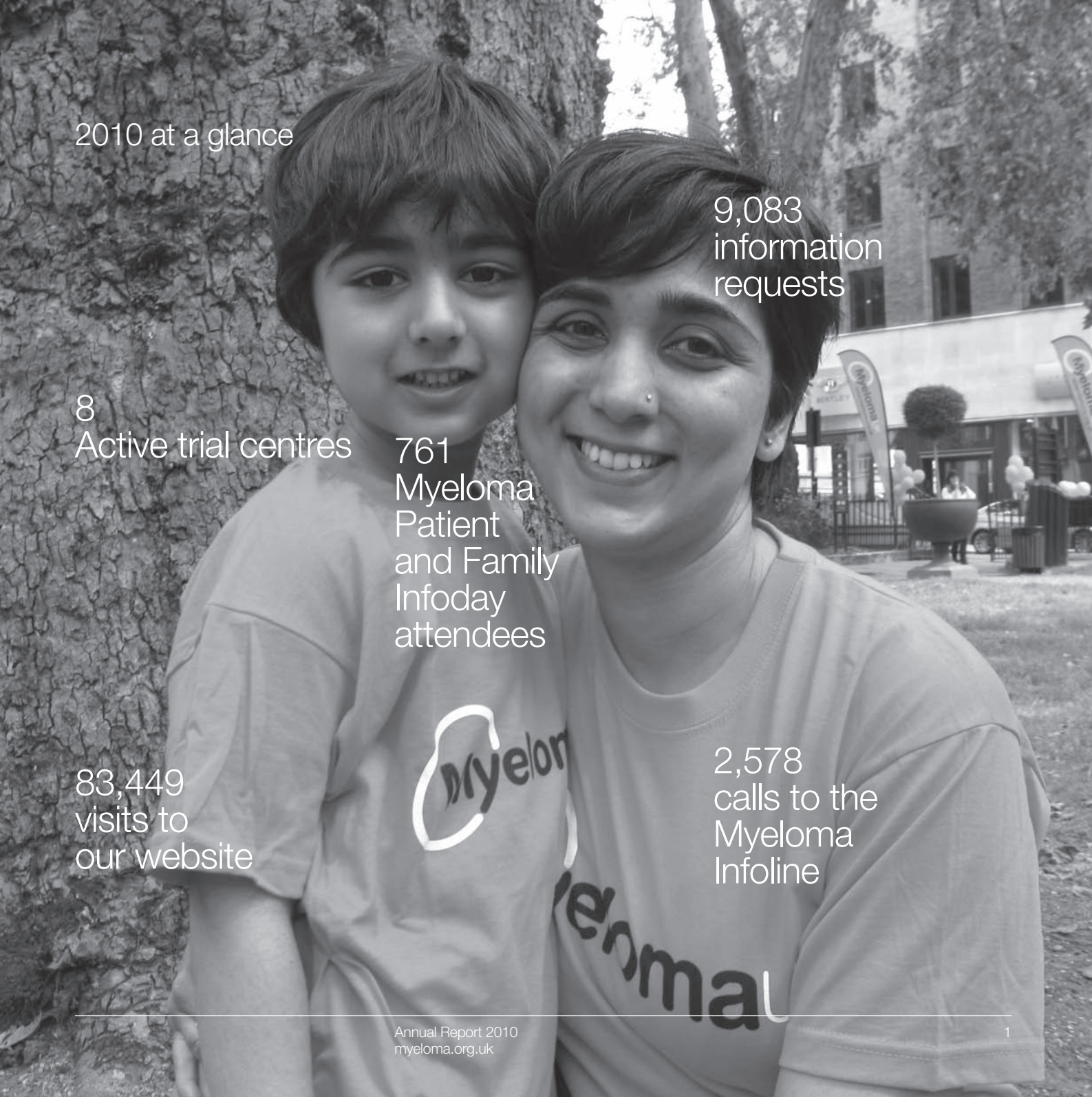
Myeloma UK is the only organisation in the UK dealing exclusively with myeloma.

Our broad and innovative range of services cover every aspect of myeloma from providing information and support, to improving standards of treatment and care through research, education, campaigning and raising awareness.

Our strategy is to take an integrated approach to systematically address the barriers and challenges that are slowing down myeloma research and the development of, and access to, new treatments. In addition, we are committed to making sure that people affected by myeloma have access to optimal care, information and support.

At Myeloma UK we are passionate and dedicated about what we do and have a relentless commitment to achieving our goals. We are staffed by a small but effective team, managed by an expert Board and guided by professional advisory boards.

We receive no government funding and rely almost entirely on voluntary donations and fundraising activities; our administration and running costs are kept to an absolute minimum.



2010 at a glance

9,083
information
requests

8
Active trial centres

761
Myeloma
Patient
and Family
Infoday
attendees

83,449
visits to
our website

2,578
calls to the
Myeloma
Infoline

About Myeloma

Myeloma is an increasingly common cancer of plasma cells. Plasma cells are found in the bone marrow and are responsible for protecting the body against infection.

There is currently no cure, but treatment can halt its progress and improve patients' quality of life.

Complications of myeloma include severe bone pain, bone fractures, kidney impairment, fatigue and frequent infection.

The causes of myeloma are uncertain, but there are thought to be multiple potential trigger factors, including exposure to petroleum-based products and some pesticides. Myeloma is the second most common type of blood cancer but represents only 1% of all cancers.

Every year in the UK, nearly 4,000 people are diagnosed with myeloma and at any given time it is estimated that there are between 12-14,000 people living with myeloma in the UK.

Approximately 80% of patients are over the age of 65. The number of cases of myeloma has more than doubled in the last 30 years and evidence suggests that better awareness and diagnosis levels have contributed to increased detection rates.

A report published by the Office of National Statistics in April 2010 has shown that overall survival in myeloma has improved at a faster rate than any other cancer in the UK in the last 10 years.

A black and white microscopic image showing a dense field of myeloma cells. The cells are large and irregularly shaped, with prominent, dark, hyperchromatic nuclei and a high nucleus-to-cytoplasm ratio. Some cells show binucleation or multinucleation. The cytoplasm is relatively scant and pale. The overall appearance is that of a malignant plasma cell neoplasm.

Every year in the UK,
nearly 4,000 people are
diagnosed with myeloma.

A message from
our Chairman and
Chief Executive

Your ongoing support and generosity is much appreciated and means a huge deal to us. With your support, Myeloma UK is continuing to punch above its weight and we are steadfastly implementing our strategy.



We are extremely proud of the progress we have made over the past 12 months and the significant impact this is making to the lives of myeloma patients.

Over the next few years, and with your continued support, we will achieve even more. Critically, the next phase of our Strategic Plan will ensure patients will soon benefit from the research we have been funding in the form of personalised medicine strategies.

This means that by using the information we have about the genetics of myeloma along with a platform of diagnostic tests we are developing, treatment decisions will soon be much more tailored to each individual patient based on their genetic make-up rather than the current one-size-fits-all approach.

With a strong track record in delivery and innovation, we are confident our Plan will continue to go from strength to strength. We will continue to fund the best research, set up studies of new effective treatments, influence policy and ensure access to the best treatments, optimal care, information and support.

Once again, thank you very much for your generous support.

A handwritten signature in black ink, appearing to read 'Judy Dewinter'.

Judy Dewinter
Chairman

A handwritten signature in black ink, appearing to read 'Eric Low'.

Eric Low
Chief Executive

Our organisational structural model

Our innovative model has been developed to rapidly and systematically address the critical challenges that are slowing down research, the development of and access to new treatments, optimal care, information and support.

We have a focused and targeted model set up within existing infrastructures, to direct into critical areas new investment as well as leveraging existing investments.

In doing so, we are able to fast-track treatments out of the laboratory, through the clinical development process and into the clinic where patients will benefit.

In addition, we work tirelessly and relentlessly to raise awareness of myeloma and educate GPs, nurses and hospital doctors to ensure that patients and their families have access to the best possible treatment, care, information and support.

Through our advocacy and campaigning work, we ensure that the policy environment acts to benefit our model rather than to stifle it.

Finally, our comprehensive range of information and support programmes and services ensures that outside of the NHS and hospital setting, myeloma patients and their families can access the emotional support they need, a listening ear and information to help them come to terms with a diagnosis of myeloma and to make informed decisions about their treatment and care.

We continue to make significant steps in understanding the biological and genetic characteristics thought to be implicated in the onset and progression of myeloma.

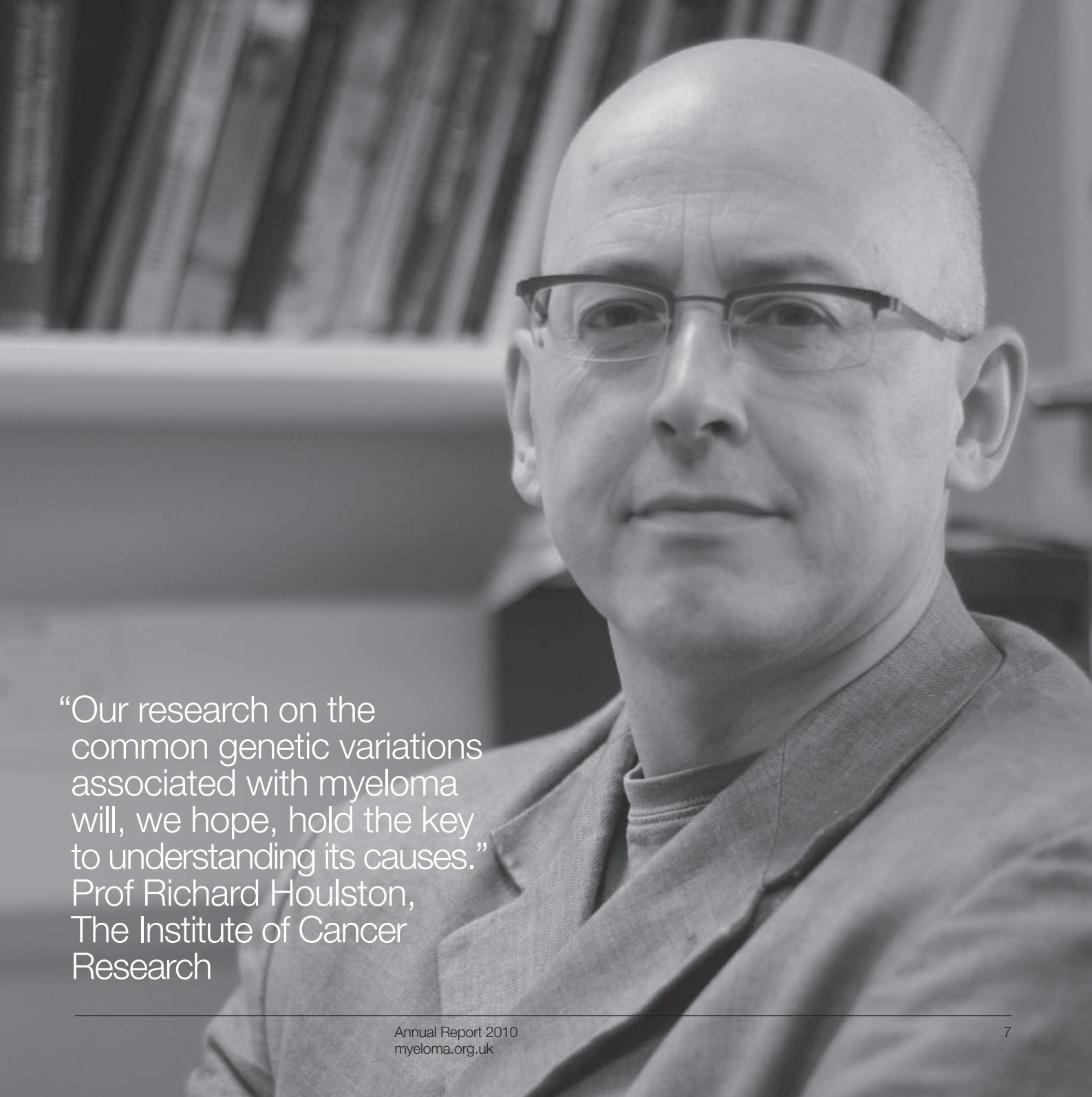
Our investment in this area of research will help to define specific subgroups of myeloma based on certain genetic characteristics, enabling doctors to put in place personalised treatment strategies for individual myeloma patients in the near future.

This work has already provided important information about which patients will respond to certain treatments and which patients are at a higher risk of getting specific treatment-related side-effects.

This year, we funded the world's first Genome-Wide Association Study (GWAS) at The Institute of Cancer Research. A GWAS is an examination of all or most of the genes of different myeloma patients to see how much their genes vary. These different variations are then associated with particular traits and characteristics, helping to define myeloma in terms of risk, performance and treatment response.

What next?

- The GWAS study is expected to complete in 2011. Should results show a region or regions of the myeloma genome to be implicated in the onset or progression of myeloma we will continue to investigate these specific areas.
- We will continue to define myeloma sub-groups to design and validate diagnostic tests for each. Our hope is that one day every patient in the UK will have access to a diagnostic test that will define their specific genetic sub-type of myeloma.
- Efforts to develop a national bio-bank will be expanded, in particular to collect tissue from patients in certain genetic sub-groups, to investigate in greater numbers and depth.



“Our research on the common genetic variations associated with myeloma will, we hope, hold the key to understanding its causes.”
Prof Richard Houlston,
The Institute of Cancer
Research

Testing new treatments

In 2009 we launched a national Early Phase Clinical Trial Network designed to bring prioritisation, strategy, speed and efficiency to the testing of and access to new myeloma treatments.

The Network brings together researchers, the pharmaceutical industry, the NHS and patients to conceive, design and manage a portfolio of clinical studies of new myeloma treatments.

MUK one, the first Network study, opened for recruitment in December 2010, less than a year on from the first discussion about the study. This was approximately twice as fast as it would normally take. MUK one is examining the effects of the chemotherapy drug bendamustine in combination with thalidomide and dexamethasone in relapsed and/or refractory patients.

The need for a prioritised approach to the new drug development will become increasingly important as the finances available to develop and pay for new treatments come under increased pressure. We need to ensure that this does not affect the potential of the treatment pipeline for myeloma.

What next?

- Begin recruitment for forthcoming studies, which include a novel combination therapy of tosedostat (an aminopeptidase inhibitor) and CHR 3996 (and HDAC inhibitor).
- Hold a series of ‘busting red tape’ meetings in each of our Active Trial Centres to improve the efficiency and speed of starting clinical studies in each local site.
- Continue to populate and implement Network studies to ensure that myeloma patients may access novel experimental treatments, and equip UK regulators with high-quality evidence on which to base their decisions.



“The Myeloma UK Clinical Trial Network is an impressive and innovative approach to conducting clinical studies of new myeloma treatments and is unique in the UK.”
Dr Jim Cavet, Christie Hospital, Manchester

Policy and campaigning

In 2010, Myeloma UK continued to campaign and consult on a broad range of policy issues to influence them for the maximum benefit of myeloma patients.

We have focused particularly on how treatments are priced and approved. Ensuring that future drugs are priced according to their value will be a major step towards ensuring that patients are not denied or delayed access to effective new treatments.

We submitted a detailed response to the Academy of Medical Sciences' review of the research environment in the UK. In doing so, we are helping to shape plans to reduce unnecessary bureaucracy, to cut the time it takes to initiate studies so that patients benefit sooner and to make the NHS a more attractive environment to undertake important clinical studies.


During the 2010 Myeloma Awareness Week we launched the TAKE 2 Campaign to improve early diagnosis of myeloma. We raised awareness with GPs on signs and symptoms, and the tests to request if myeloma is then suspected. The Campaign reached over 5,000 GPs and has been showcased, via the National

Awareness and Early Diagnosis Initiative as an example of effective GP awareness-raising on rare cancers.

We also helped shape the Department of Health for England's new Cancer Strategy, ensuring that issues affecting rare cancers, such as myeloma, receive a greater focus.

What next?

- Continue to influence the UK Government's review of how new drugs are priced and approved for use.
- Campaign for changes to the UK Government's planned reforms to the benefits system so that the reforms do not disadvantage myeloma patients of any age.
- Work closely with Government, the pharmaceutical industry and the drug approval bodies across the UK to ensure that all patients have fair and equal access to important new myeloma drugs.



“The level of knowledge that Myeloma UK has about complex policy issues is impressive. They are one of the leading voices in the debate around pricing and approval of medicines and are driving the agenda forward to ensure the very best outcomes for the myeloma community.”
John Baron MP, Chair, All Party Parliamentary Group on Cancer

Informing and supporting patients and their families

Myeloma UK continues to place a huge priority on support and information to people affected by myeloma when they need it most.

To do this effectively, this needs to be available in the right format and be provided by the right person. This is our passion and is an area of our work that we develop and grow year on year. In 2010, we responded to more than 9,000 queries and requests from myeloma patients and their families for information and support.

We launched a Patient Diary, a compact notebook style diary that enables patients to manage their treatment schedules and to chart side-effects. Over 1,000 copies were requested within the first three weeks of it being available.

We also expanded our PEER Network Programme; bringing dozens of people together seeking information and support from others who have been in a similar situation to share experiences and provide practical advice.

What next?

- Expand patient information materials to keep patients and their families abreast of clinical studies and latest developments in novel treatments and research.
- Provide information and support programmes to more myeloma patients and their families by working with Government health information initiatives and healthcare professionals across the UK.
- Continue to develop online resources and communities to connect patients, families and caregivers more quickly and directly.
- Build a comprehensive caregiver information and support programme.

“The support and information Myeloma UK has given us has been critical in helping us deal with myeloma. Knowing that they are there is a huge comfort.”
Lesley Roberts, carer



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How you
have helped
and supported
us during the year

2010 was our best ever year, as Myeloma UK raised £3 million: a remarkable achievement given the extremely challenging economic conditions affecting almost all of us in some way.

Put your best foot forward

More than 200 Myeloma UK supporters joined our Retail Therapy Walk for Research, raising more than £40,000 for the Myeloma UK Early Phase Clinical Trial Network.

Dizzying heights

25 brave fundraisers took part in the first Myeloma UK Skydive jumping out of a plane at 13,000 feet. The event raised more than £30,000 to support our information and education programmes.

Time for a cuppa

Hundreds participated in the Myeloma UK Coffee Morning Month in over 70 family homes, local community centres, schools and church halls across the UK. Mugs were flowing with coffee, generously donated by Lavazza, and £25,000 was raised.

Cricket capers

Our fundraising event at Lord's Cricket Ground was an outstanding

success, raising £170,000. A host of celebrities and more than 300 guests teamed up with Bunbury Cricket Club to stage a Twenty20 cricket match between The Bunburys and Joe Kinnear's team of footballers.

Myeloma on stage

2010 was the year myeloma met Hollywood. "A Night at the Oscars" raised £20,000 at the 4th annual Angelo's Angels Ball, with an auction followed by more than 300 attendees dancing into the night. This successful year brings Angelo and Helen Clark's total to over £80,000.

Pirates and Princesses...

"Life is a Cabaret", an evening of Christmas carols, mulled wine, mince pies and a sprinkling of snow raised an incredible £4,500. "It was such a lovely atmosphere and such a great way to start celebrating Christmas," said Sophie Tickle, who has so far raised more than £15,000 for Myeloma UK.



Financials 2010

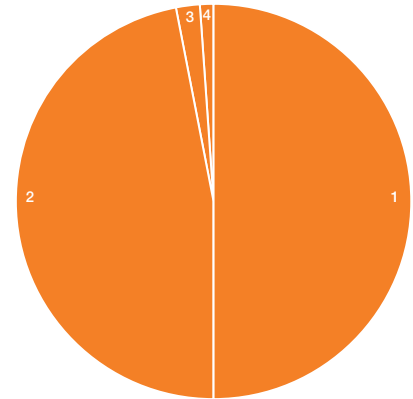
Despite the continued uncertain economic climate, the total income for the year ending 31 December 2010 was £3m, an increase of 52% on 2009 income.

£3m
in 2010
52%
growth on 2009

Income

We thank the many people who worked tirelessly throughout 2010 to fundraise in their communities. We are indebted to our supporters and grateful that you have stood by us and maintained your generosity and loyalty.

Myeloma UK invests in research, services and programmes aligned to our strategic business model, delivering measurable outcomes for myeloma patients. Without this income, we could not achieve these results.

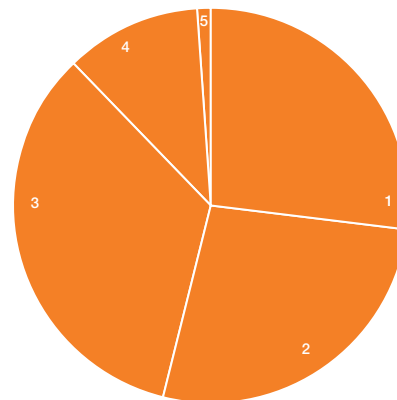


- 1 50% Voluntary Giving
- 2 47% Fundraising Income
- 3 2% Investment Income
- 4 1% Programmes and Services

£1.7m
in 2010
27%
growth on 2009

Expenditure

Total expenditure for the year ended 31 December 2010 was £1.7m which we invested in research, clinical trials, campaigning and health promotion and community initiatives. We were able to designate £2.7m of reserves for future research programmes. We work hard and are fully committed to using our resources effectively and efficiently to ensure their maximum use to the benefit of myeloma patients and their families.



- 1 27% Patient & Family
- 2 27% Fundraising
- 3 34% Healthcare & Professional
- 4 11% Communications
- 5 1% Governance

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Charity No. SC 026116

Myeloma Awareness Week
21 – 28 June

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Judy Dewinter

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Eric Low

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