

cancer52

the common voice  
for less common cancers

# Annual Review 2012



# Honorary President introduction

I remain honoured to be Honorary President of Cancer52, especially now the organisation is forging ahead with increasing membership levels, presence and profile. I firmly believe that no national cancer initiative should exist without rare and less common cancers having a view. That is a really great goal, I'm delighted to support it, and I am also absolutely committed to Cancer52 being the route for those cancers to have that view.

I encourage one and all to support the work of the organisation, which has made substantial progress in recent years and which will need to make further significant steps to ensure that the one voice of rare and less common cancers does not go unheard in the rapidly changing face of today's NHS.

**Baroness Delyth Morgan of Drefelin**  
*Honorary President, Cancer52*



*Honorary President Baroness Delyth Morgan*



# Chair introduction

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I am proud to be Chair of Cancer52 as it grows steadily in scope and size. Membership increased from 45 to 61 during the course of 2012, which I believe demonstrates that those representing rare and less common cancers are increasingly coming together to make its voices heard.

Engaging with members and stakeholders is essential in achieving the organisation's key aims. For those that are involved in policy, or the development of services or treatments, there are really rich rewards for communicating with this community of people that represent rare and less common cancers. It is a voice that previously hasn't been heard significantly and is becoming increasingly important.

I would like to thank those companies that have provided funding so far and encourage others to follow, as securing further finance was crucial to achieving the organisation's goal of creating a "go-to organisation" for anyone that has anything to do with rare and less common cancers.

Finally my thanks to the extremely talented and hard working team within the Cancer52 Strategy Group, our Development and support team and of course to all members who contribute resource and ideas to us.



*Simon Davies*

**Simon Davies**  
*Chair, Cancer52*



# Key people and infrastructure

Cancer52's key strength lies within the expertise and skills of those individuals who give their time to help drive forward the agenda for rare and less common cancers.

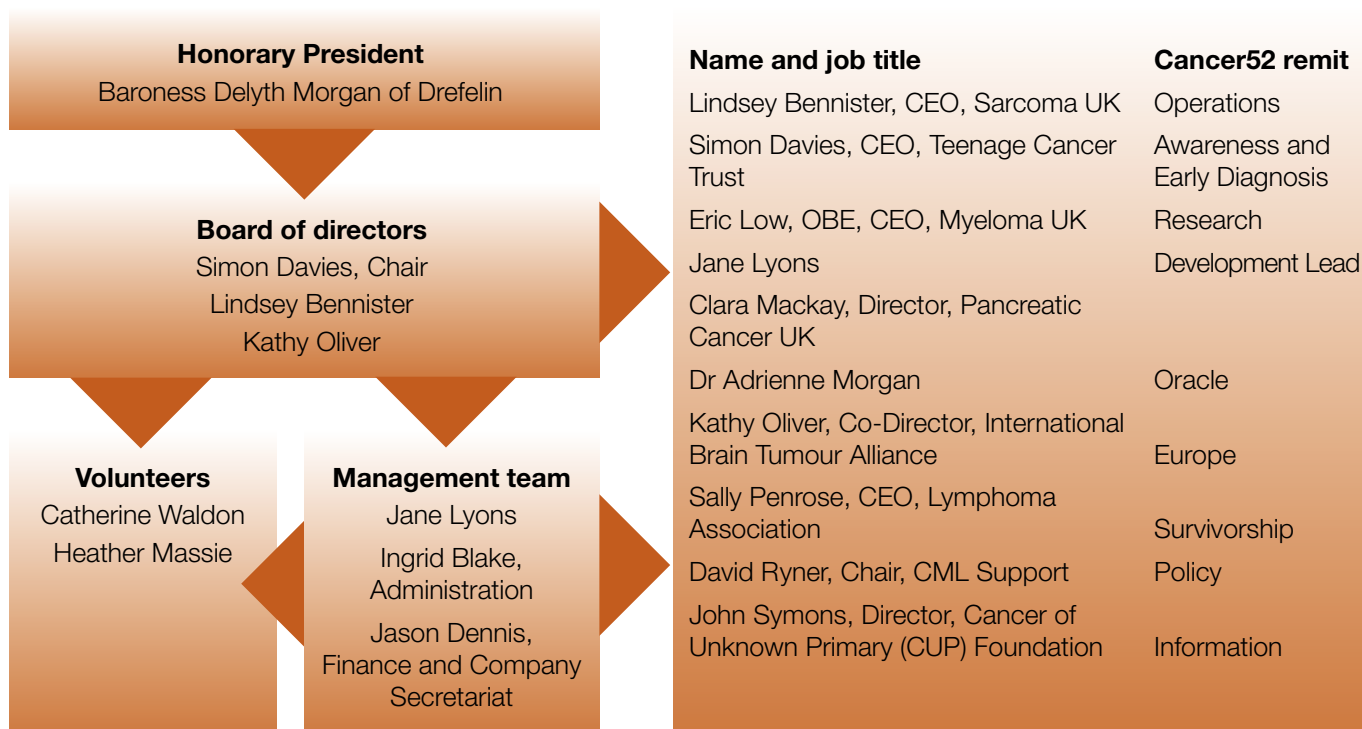
All are experienced individuals at board and strategy level, established within their own organisations and acknowledged within their field.

The board of directors was established in early 2012 alongside the creation of the organisation's new status as a not for profit company limited by guarantee.

This formalisation of status has given Cancer52 a new lease of life in its ability to work in partnership with its members, whilst not placing it in 'competition' with any of those organisations, all of which are charities.

The wider strategy group, on which the board also sits, is responsible for shaping the direction of Cancer52, supporting its Chair and guiding the work of contractors.

At the helm of the organisation sits our honorary president, Baroness Delyth Morgan of Drefelin, giving Cancer52 both a route through to the seat of government as well as a good understanding of the broader context.



Our 61 members are all organisations concerned with rare and less common cancers. Many of our members are small: over half have an annual income below £200,000 and many exist on incomes of only hundreds of pounds a year.

The African Caribbean Leukaemia Trust (ACLT)	<a href="http://www.aclt.org">www.aclt.org</a>
Adam's Hats (now part of CCLG)	<a href="http://www.adamshats.org">www.adamshats.org</a>
AMEND	<a href="http://www.amend.org.uk">www.amend.org.uk</a>
AMMF – The Cholangiocarcinoma Charity	<a href="http://www.ammf.org.uk">www.ammf.org.uk</a>
Barrett's Oesophagus Foundation	<a href="http://www.barrettsfoundation.org.uk">www.barrettsfoundation.org.uk</a>
Bone Cancer Awareness Trust	<a href="http://www.bonecancerawarenesstrust.org">www.bonecancerawarenesstrust.org</a>
Bone Cancer Research Trust (BCRT)	<a href="http://www.bcrt.org.uk">www.bcrt.org.uk</a>
Brainstrust	<a href="http://www.brainstrust.org.uk">www.brainstrust.org.uk</a>
Brain Tumour Research	<a href="http://www.braintumourresearch.org">www.braintumourresearch.org</a>
Brain Tumour UK	<a href="http://www.braintumouruk.org.uk">www.braintumouruk.org.uk</a>
British Lymphology Society	<a href="http://www.thebls.com">www.thebls.com</a>
British Thyroid Foundation	<a href="http://www.btf-thyroid.org">www.btf-thyroid.org</a>
Butterfly Thyroid Cancer Trust	<a href="http://www.butterfly.org.uk">www.butterfly.org.uk</a>
Cancer Laryngectomy Trust	<a href="http://www.cancerlt.org">www.cancerlt.org</a>
Cancer of Unknown Primary (CUP) Foundation – Jo's friends	<a href="http://www.cupfoundjo.org">www.cupfoundjo.org</a>
The Children's Cancer and Leukaemia Group (CCLG)	<a href="http://www.cclg.org.uk">www.cclg.org.uk</a>
Childhood Eye Cancer Trust	<a href="http://www.chect.org.uk">www.chect.org.uk</a>
CHILDREN with CANCER UK	<a href="http://www.childrenwithcancer.org.uk">www.childrenwithcancer.org.uk</a>
CLIC Sargent	<a href="http://www.clicsargent.org.uk">www.clicsargent.org.uk</a>
Chronic Myeloid Leukaemia Support Group	<a href="http://www.cmlsupport.org.uk">www.cmlsupport.org.uk</a>
CORE	<a href="http://www.corecharity.org.uk">www.corecharity.org.uk</a>
GIST Support UK	<a href="http://www.gistsupportuk.com">www.gistsupportuk.com</a>
Guy Francis Bone Cancer Research Fund	<a href="http://www.gfbonecancer.org.uk">www.gfbonecancer.org.uk</a>
Heartburn Cancer Awareness & Support (HCAS)	<a href="http://www.h-cas.org">http://www.h-cas.org</a>
International Brain Tumour Alliance	<a href="http://www.theibta.org">http://www.theibta.org</a>
It's in the Bag – Supporting Men with Testicular Cancer	<a href="http://www.uhbristol.nhs.uk/itsinthebag">http://www.uhbristol.nhs.uk/itsinthebag</a>
Jo's Cervical Cancer Trust	<a href="http://www.jostrust.org.uk">www.jostrust.org.uk</a>
Kidney Cancer Support Network	<a href="http://www.kidneycancersupportnetwork.co.uk">www.kidneycancersupportnetwork.co.uk</a>
Leukaemia CARE	<a href="http://www.leukaemiacare.org.uk">www.leukaemiacare.org.uk</a>
Lymphoedema Support Network	<a href="http://www.lymphoedema.org">www.lymphoedema.org</a>

Lymphoma Association	<a href="http://www.lymphomas.org.uk">www.lymphomas.org.uk</a>
Maggie's Cancer Caring Centres (Maggie's Centres)	<a href="http://www.maggiescentres.org">www.maggiescentres.org</a>
Melonoma Focus	<a href="http://www.melanomafocus.com">www.melanomafocus.com</a>
Meningioma UK	<a href="http://www.meningiomauk.org">www.meningiomauk.org</a>
MDS UK Patient Support Group	<a href="http://www.mdspatientsupport.org.uk">www.mdspatientsupport.org.uk</a>
Mouth Cancer Foundation	<a href="http://www.mouthcancerfoundation.org">www.mouthcancerfoundation.org</a>
Myeloma UK	<a href="http://www.myelomaonline.org.uk">www.myelomaonline.org.uk</a>
Myrovlytis Trust	<a href="http://www.myrovlytistrust.org">www.myrovlytistrust.org</a>
NET Patient Foundation	<a href="http://www.netpatientfoundation.com">www.netpatientfoundation.com</a>
Neuroblastoma Society	<a href="http://www.nsoc.co.uk">www.nsoc.co.uk</a>
Oesophageal Patients Association	<a href="http://www.opa.org.uk">www.opa.org.uk</a>
Orchid Cancer Appeal	<a href="http://www.orchid-cancer.org.uk">www.orchid-cancer.org.uk</a>
Ovacome	<a href="http://www.ovacome.org.uk">www.ovacome.org.uk</a>
Ovarian Cancer Action	<a href="http://www.ovarian.org.uk">www.ovarian.org.uk</a>
Oxfordshire Oesophageal and Stomach Organisation (OOSO)	<a href="http://www.ooso.org.uk">www.ooso.org.uk</a>
Pancreatic Cancer UK	<a href="http://www.pancreaticcancer.org.uk">www.pancreaticcancer.org.uk</a>
Pancreatic Cancer Action	<a href="http://www.pancreaticcanceraction.org">www.pancreaticcanceraction.org</a>
Pelvic Radiation Disease Association	<a href="http://www.prda.org.uk">www.prda.org.uk</a>
Pseudomyxoma Survivor	<a href="http://www.pseudomyxomasurvivor.co.uk">www.pseudomyxomasurvivor.co.uk</a>
Rare Disease UK	<a href="http://www.raredisease.org.uk">www.raredisease.org.uk</a>
Rarer Cancers Foundation	<a href="http://www.rarercancers.org.uk">www.rarercancers.org.uk</a>
Samantha Dickson Brain Tumour Trust	<a href="http://www.braintumourtrust.co.uk">www.braintumourtrust.co.uk</a>
Sarcoma UK	<a href="http://www.sarcoma.org.uk">www.sarcoma.org.uk</a>
Tanya's Courage Trust	<a href="http://www.tanyascourage.org.uk">www.tanyascourage.org.uk</a>
Target Ovarian Cancer	<a href="http://www.targetovarian.org.uk">www.targetovarian.org.uk</a>
Teenage Cancer Trust	<a href="http://www.teenagecancertrust.org">www.teenagecancertrust.org</a>
The Eve Appeal	<a href="http://www.eveappeal.org.uk">www.eveappeal.org.uk</a>
The Ipswich Head & Neck Cancer Support Group	<a href="http://www.theipswichheadandneckcsg.org.uk">www.theipswichheadandneckcsg.org.uk</a>
Thyroid Cancer Support Group Wales	<a href="http://www.thyroidsupportwales.co.uk">www.thyroidsupportwales.co.uk</a>
Wellbeing of Women	<a href="http://www.wellbeingofwomen.org.uk">www.wellbeingofwomen.org.uk</a>
Wessex Urology Support Group	<a href="http://www.wusg.co.uk">www.wusg.co.uk</a>



During the course of 2012 Cancer52's strategy group reviewed the organisation's progress to date and revisited and redefined key aspects of the organisation's vision, aims and objectives.

At the heart of everything we do is the belief that rare and less common cancers must have a presence and a voice within every national cancer initiative; an overarching vision of Cancer52 is to become the 'go to' organisation of choice for rare and less common cancers for all stakeholders.

## Who we are

- Cancer52 represents numerous organisations united in improving the future for everyone affected by rare and less common cancers, which account for more than half of all cancer deaths in the UK.

## What we do

- Over half of all cancer deaths are from rare and less common cancers
- Everyone affected by these cancers are represented by a plethora of separate, discrete, tumour-specific organisations
- The majority of these organisations are insufficiently resourced and are not represented at a national level
- Cancer52 unites these organisations through:
  - Influencing policy
  - Representing members at various decision-making forums, bodies and groups
  - Building strategic alliances with member groups as well as those outside of the Cancer52 umbrella
  - Providing a conduit to and from the rare and less common cancer communities, government, decision-making forums, bodies and groups
  - Enabling our members to maximise the benefits they bring to the patients and people they represent

## Why us?

- We are:
  - a multi-stakeholder coalition that engages continually with its members to ensure our policies are member driven
- We have:
  - the ongoing authority to speak on behalf of our members

- unparalleled expertise from individuals within our membership
- presence and influence beyond the UK, particularly in Europe

## Our vision

- To become the 'go to' organisation of choice for rare and less common cancers for all stakeholders

## Our Aims

- We strive to reduce deaths in and improve the quality of life for people with rare and less common cancers
  - Ensuring an equitable share of attention, investment and voice
  - Improving equity of treatment and supportive services
  - Stimulating and encouraging research
  - Engaging with members and all relevant stakeholders to share expertise and improve outcomes

## Our objectives (to end 2013)

- Representation and engagement
  - To ensure representation on every relevant cancer policy-making body
  - To engage with all organisations that influence the experience and outcomes of people with rare and less common cancers
- Investment
  - To increase our core revenue to £100k minimum so we can ensure continued growth of our infrastructure in order to achieve our aims
  - To generate an investment of £50k in the organisation's projects
- Membership targets
  - Increase our membership to 80 member organisations from existing level of 61
- Build our profile
  - To help achieve our vision of becoming the 'go to' organisation of choice
  - To evaluate potential for increasing our presence in social media and mainstream media against investment and resource available, and to engage where we can



# The big numbers

## Rare & less common cancers and the 'big four'

Cancer52, whose aims include ensuring an equitable share of attention, investment and voice for rare and less common cancers, has compiled the following key facts which illustrate the current differences between the big four cancers (breast, bowel, lung and prostate) and the rare and less common cancers.

This imbalance is one that Cancer52 seeks to redress.

- i. 84,049 (53.5%) of all cancer deaths in the UK in 2010 were from less common cancers. 73,226 were from the 'big four' of breast, bowel, lung and prostate.<sup>1</sup>
- ii. This contrasts sharply with the percentages of cancers diagnosed in the UK during 2009. 46% of the 320,467 cancers diagnosed during 2009 were less common cancers and 54% were the 'big four'.<sup>2</sup>
- iii. More rare and less common cancers are diagnosed at Accident and Emergency departments than the big four cancers. The average percentage for all cancers is 24%, and of the rare and less common cancers only melanoma, uterine, bladder and oesophageal cancers fell below that average. For all cancer types, patients are much less likely to survive the next year if they are diagnosed through emergencies.<sup>3</sup>
- iv. the National Cancer Patient Experience Survey 2011/12 showed that patient experience for rare and less common cancers is generally poorer than that for the big four (breast, lung, bowel and prostate)<sup>4</sup> in key areas, summarised below.
  - a. Access fast: seeing GP only once or twice before referral
  - b. Being told and understanding explanations of which cancer they had
  - c. Choice of treatment issues, views taken in to account
  - d. Given the name of a Clinical Nurse Specialist – biggest single predictor of difference between patients
  - e. Giving information on financial support and benefits
  - f. Lots of information questions
  - g. GP staff doing everything they could to support them post discharge
  - h. Care plans
  - i. Being treated as a person rather than a set of symptoms



1. <http://www.cancerresearchuk.org/cancer-info/cancerstats/> accessed 5th October 2012
2. <http://www.cancerresearchuk.org/cancer-info/cancerstats/> accessed 5th October 2012
3. [http://www.ncin.org.uk/publications/routes\\_to\\_diagnosis.aspx](http://www.ncin.org.uk/publications/routes_to_diagnosis.aspx) accessed 5th October 2012
4. National Cancer Patient Experience Survey 2011 / 12 The National Cancer Patient Experience Survey provides detailed information on cancer patients' experiences of cancer services – allowing the NHS locally to see how it is performing and to focus on areas where improvement is needed, including better information for patients and better support during inpatient stays. The 2011/12 survey was completed by more than 70,000 patients and was published on 17th August 2012.

# Highlights of the year

During the course of 2012 Cancer52 made great strides in developing its structure, presence and profile.

A summary of key deliverables is given below.

- Cancer52's first briefing at the House of Lords at the end of 2011 put the organisation on the map and drove interest and funding.
- Formalisation of status gave Cancer52 a new lease of life in its ability to work in partnership with its members, whilst not placing it in 'competition' with those organisations, all of which are charities.
- Establishment of the board and strategy group allowed the organisation to benefit from the skills and experience of strong senior individuals who are established and credible in their own right.
- Membership of Cancer52 increased by a third over the year, from 45 to 61.
- Cancer52 is now a member of the European Cancer Patient Coalition, Eurordis, National Voices and the Ethical Medicines Industry Group (EMIG)

The quarterly all-member meetings of Cancer52 were regularly attended by between 30 and 40 member organisations. An excellent set of speakers presented during the course of the year, provoking great levels of discussion and debate.

- Cancer52 gained a 'seat' at the following:
  - the National Awareness and Early Diagnosis Initiative (NAEDI) forum
  - the NAEDI board
  - the Department of Health (DH) constellation of symptoms awareness expert group

- the DH working group on a GP learning module for rare cancers in children and young people
- the DH Value Based Pricing stakeholder event and follow up technical workshop
- the National Cancer Survivorship Initiative
- the London Health Improvement Board (LHIB) Pan-London working group on earlier diagnosis of cancer
- the steering group for the Quality in Care Excellence in Oncology Awards
- Cancer52 made formal responses or statements on the following:
  - DH proposals to secure shared decision making
  - DH consultation on the UK Plan for Rare Diseases
  - its support for CRUK's joint statement on the EU Clinical Trials Regulation
  - in partnership with National Voices and Genetic Alliance UK, Cancer52 fed back to DH Value Based Pricing consultation meeting
  - its position on Value Based Pricing
- Cancer52 generated coverage in The Times and The Guardian, and speaker platforms at the NCIN conference, Eyeforpharma conference, and presented Professor Sir Mike Richards CBE with a Lifetime Achievement Award
- Cancer52 hosted a second House of Lords briefing in October 2012 with the highest calibre of speakers
- Cancer52 now has a social media presence on Facebook, LinkedIn and Twitter. Launched on 26th November 2012 the organisation had 21 followers by teatime that day



Professor Sir Mike Richards



Dr James Larkin

## Our thanks to

- Our funders: Novartis, Pfizer, BMS, Sanofi, Napp Laboratories
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- Our volunteers, Catherine Waldon, Heather Massie, Rachel Hunter

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