

## What they say...about Cancer52



### Our members...

*"I find the information and insights I get from Cancer 52 members invaluable. I feel I can talk with a stronger voice because I am a member of the Group."*

Rose Woodward  
Cancer Patient & Advocate  
Founder - Kidney Cancer Support Network

*"Being a member of Cancer 52 really sits with our ethos - we're none of us as smart as all of us. It is so important for us to know that Cancer 52 is there to support us and together we can achieve so much more when it comes to the campaigning for the bigger picture."*

Helen Bulbeck  
Director  
brainstrust - the Meg Jones brain cancer charity

*"Membership of C52 has helped us, as a new organisation, to gain: a good knowledge of the important debates around cancer issues; access to key players; a raised profile; and advice from other member organisations with greater experience. An important step forward for Cancer of Unknown Primary (CUP) in 2011 has been the inclusion of CUP data in national statistics by the National Cancer Intelligence Network and this was facilitated by C52".*

John Symons,  
Director,  
Cancer of Unknown Primary (CUP) Foundation - Jo's friends

*"Cancer 52 provides an invaluable platform for organisations representing patients with less common cancers. By working collaboratively through Cancer 52, we can ensure that the voices of patients with rarer cancers are heard."*

Alastair Kent OBE  
Chair, Rare Disease UK

*"When you represent a subset of patients suffering from a cancer which affects, but kills, those in a group totalling 3 each year, not many out there can relate to the condition you describe. Being part of an umbrella organisation that represents most or all such cancers provides perspective, depth of knowledge, and real hope that your voice will be heard."*

Susan Hay  
Chair of Trustees  
Adam's Hats

*“Rare tumour charities & patient support groups like ours are small but often closer to patients than the “big guys” and Cancer 52 gives us a strong voice so we can be heard in a noisy world.”*

Ella Pybus  
Director and founder



*“Cancer 52 plays an invaluable role in linking up a large number of small charities, all of whom have a common interest in improving the outcomes for patients with the types of cancer are at risk of being neglected.”*

Alan Moss, London Branch Coordinator  
Oesophageal Patients Association

*“By collaborating together via Cancer52 the less common cancer charities have a powerful collective voice on the issues that really matter to the patients and families they represent. Given that this amounts to over 1 million people directly affected by less common cancers, this has to be a vital organization.”*

Alexandra Ford  
CEO, Pancreatic Cancer UK

*“As a small charity the Lymphoedema Support Network values the opportunity to work with the other members of cancer 52 to ensure that the needs of those affected by the less common cancers and the side effects of treatment continue to have a voice in the wider cancer community.”*

Karen Friett  
Chief Executive  
Lymphoedema Support Network

*“To be a member of Cancer52 provides a small charity like me with the chance to network and exchange views and ideas with like minded charity groups enabling me to become the bigger voice. As Cancer 52's newest member, my first impressions of them are that they are an extremely dynamic team that will no doubt offer me many positive opportunities that without their support would simply not have been made available.”*

Dawn Green  
CEO & Founder  
Pseudomyxoma Survivor - One in a Million

## Our founders...



### Professor Sir Mike Richards, CBE

“Cancer52 has a major role in championing earlier diagnosis, better treatment and better care for the 52% of cancer patients who die of less common cancers.

“Cancer52 provided me in my role as National Cancer Director and my colleagues one representative voice to work with for less common cancers.

“We simply would not have been able to deal effectively with all the smaller cancer charities. The existence of Cancer52 means that we included the views of many more cancer organisations and patients in our work than would otherwise be possible.

### Vivienne Parry, OBE

Having brought together all the prostate cancer charities to deliver the Prostate Cancer Charter for Action in 2005, Vivienne Parry was asked by cancer tsar, Professor Sir Mike Richards whether she could help build one collaborative voice for the less common cancers.

As a result and with funding from the GUS Charitable Trust, Cancer52 was formed in 2006 with a membership of 17 organisations. Its initial remit was to ensure that less common cancers played a part in the development of the Cancer Reform Strategy, which was being developed at that time by Mike Richards. As a result, the Strategy properly reflected the needs of less common cancers which account for more than half of all cancer deaths in the UK.

Vivienne says of Cancer52 six years on, “It is great to see the membership growing, and to see that the organisation is increasingly delivering one voice for less common cancers at all levels, including national cancer policy level.

“We shouldn’t forget the pivotal role that rare cancers have played in the cancer story. Research on rare cancers revealed key cancer mechanisms which resulted in more effective drugs for common and less common cancers alike. Now rare cancers are leading the way again for cancer as a whole, showing how co-operative multi-centre pan European trials can deliver better research and better treatments’.

“I applaud the organisation’s vision of a future in which fewer people die of less common cancers and believe that Cancer52 plays a vital and growing role in keeping less common cancers on the public agenda. “

*Ms Parry is a writer and broadcaster, a Vice–Chair of UCL Council, sits on the Council of the MRC, is a judge for the Wellcome Trust Book Prize 2011 and has recently been appointed an OBE for services to the public understanding of science.*