

The Charity Enterprise in Research

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The role of charities in funding, advancing and promoting research for patient benefit is one of the unique success stories of medical and health research in the UK. This year the Association of Medical Research Charities (AMRC) is marking its twenty-first year as the sector's representative body by celebrating the impact that its 114 current members – both individually and collectively – have had on research and the research environment.

Scale and diversity

Whether measured in terms of the scale of its monetary contribution to medical and health research – £791 million in 2006-07, over £5 billion over the last five years, or the breadth and type of research activity its funding supports, the charity enterprise is now integral to the sustainability of science in this country.

About seventy per cent of all charity funding currently goes to Higher Education Institutions and historically a strong partnership has existed between charities and universities in developing a strong science base in the UK. In 2006-07 alone, AMRC estimates that charities funded over 3,000 scientists at different stages of their careers and many charities and universities have been able to realise shared ambitions for scientific endeavour through the development of world class research institutes and facilities.

Even a scant review of some of the most exciting and important research developments in UK health research – from the Human Genome Project (Wellcome Trust) to the development of anti-TNF therapy for people with

severe rheumatoid arthritis (Arthritis Research Campaign) or ongoing trials of an artificial pancreas for Type 1 diabetes (Juvenile Diabetes Research Foundation (JDRF)) – underlines the central part that medical research charities have played in supporting research that has advanced our scientific knowledge and understanding and/or is helping develop new treatments, therapies and interventions. And further examples of such work – taken from our forthcoming booklet to be published this autumn showcasing the work of AMRC's members – are interspersed throughout this article.

The range of this activity reflects, of course the very diverse nature of AMRC's membership. Two of the world's largest charitable bodies funding medical research (Wellcome Trust and Cancer Research UK) are AMRC members and the British Heart Foundation and Arthritis Research Campaign are also significantly larger than most of our other members. Yet even those whose funding may only reach into the thousands rather than millions have often played a historically important role in funding and raising awareness, particularly if their field is a rare disease or condition.

Genetic research into a rare disorder has led to increased understanding of more common diseases.

Genetic research supported by Ataxia UK resulted in a landmark discovery, changing the landscape for patients and families with Friedreich's ataxia, a rare disorder of the nervous system which causes unsteadiness and lack of co-ordination.

Discovering which gene goes wrong in Friedreich's ataxia has improved diagnosis and made it possible to predict whether siblings will also develop the condition, paving the way for antenatal testing. Finding the mutation responsible means scientists can now study what the gene should normally do and have a target to treat when it goes wrong.

The charity has built on these advances by funding mouse models of Friedreich's ataxia. These are mice bred to have the same genetic defect as in the condition and which have some of the same physical characteristics. This invaluable resource is already allowing potential new treatments to be identified and tested, some of which may also be useful for more common diseases such as Alzheimer's and Parkinson's.

A bench to bedside journey to clinical trials

The Muscular Dystrophy Campaign has supported UK scientists in their efforts to find treatments and cures for over 40 types of muscular dystrophy. One of these, Duchenne, is an inherited condition, caused by an error in the dystrophin gene, resulting in progressive weakness as muscle cells break down and die. Like AMRC, 2008 marks a particular milestone for the Campaign. Twenty-one years ago, dystrophin was identified and since then research has aimed at understanding the function of this gene and its protein and developing new treatments based on this.

Now researchers are trying to find a drug that will increase levels of utrophin, a protein that is similar to the missing dystrophin. The charity's researchers at Oxford University have founded a biotech company to develop this work and clinical trials are now a realistic option. This progress illustrates the charity's aim of ensuring a smooth and speedy transition of promising technology from "bench" to "bedside."



Wellcome Images.

Quality

Together, AMRC's members represent over 90% of all funding available from the sector and their credibility – both as funders and as a voice in public debate about research – rests on their commitment to upholding the same standards in how they allocate this money.

It is a membership requirement of AMRC that all its members must abide by the Association's five principles of

peer review: accountability; balance; independent decision-making; rotation and impartiality. Members' peer review practices are audited every five years by AMRC, the last time being in 2005-06. At that time, approximately 90% of its then 112 members fully met all five of these principles. In those instances where it was felt that member charities could strengthen and improve their approach AMRC has provided feedback, guidance and training as part of its core role of supporting members.

Another membership condition of AMRC is that member charities must have a publicly available research strategy in place. Such documents are important not only as the basis for openness and transparency with the public but are helpful in setting appropriate expectations with scientists and partner organisations and institutions about a charity's research priorities and the way it works.

Similarly, while the recent Charities Act rightly puts ever-greater emphasis on charities demonstrating the public benefit of their activities, it has actually been a long-standing concern of medical research charities not just to be able to understand and show the impact of their funding but also to disseminate the results of such research as broadly as possible. AMRC and its members have now taken part in two studies by the UK Clinical Research Collaboration (UKCRC) which have helped the wider science community better understand the role they play but also inform these charities as to how the activities they fund fit with the bigger picture. (See Figure 1)

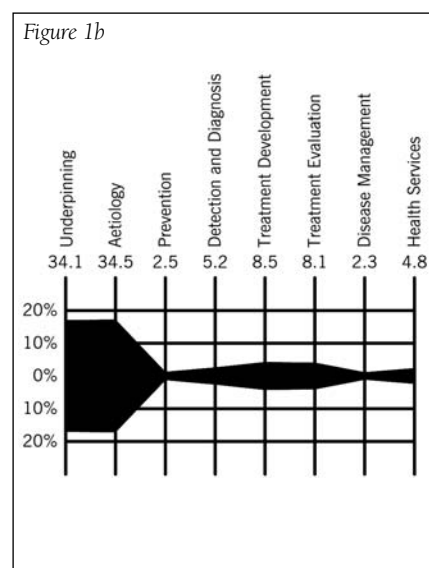
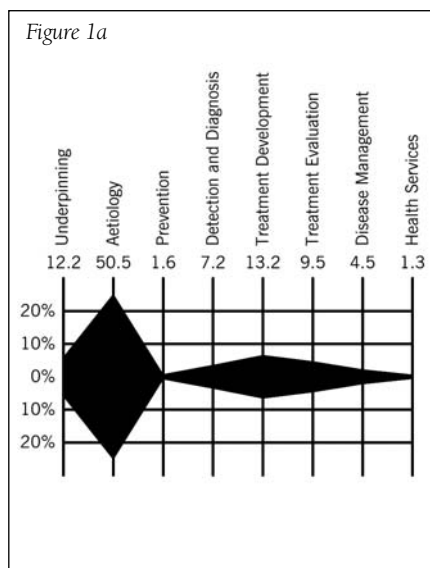


Figure 1. Proportion of Total Spend by Research Activity
Source: "From Donation to Innovation" UKCRC and AMRC, October 2007

1a. Medium and Smaller Sized Charities

Data from 29 medium and smaller sized AMRC member charities

1b. UK Health Research Analysis

Data from the 11 largest government and charity funders of health research in the UK

A unifying purpose

This overriding commitment to a common set of standards marks the UK sector out from its equivalents in

the US and abroad where the NGO sectors are more disparate, as does its unity of purpose and openness on issues such as the necessity and importance of animal research or stem cell research.

Indeed, it was concerns over attacks by animal rights campaigners on some of the shops run by an AMRC charity that was one of the key catalysts to motivating the Association's members to create a formal umbrella body in 1987 which it funds itself to look after its own interest. Twenty-one years later and this member subscription base – over 95% of all AMRC's funding comes from its members – is an important foundation of its 'independence' and credibility with those with whom it works.

Historically, another unifying cause for the sector has been its stance on non-payment of indirect costs of research funded in universities. The Government acknowledged the significant role played by charities by funders and their principled position on this issue by establishing the Charity Research Support Fund

(CRSF) in 2004 to enable universities to cover these costs. Welcome though this was, the Government's monetary commitment to the Fund up until 2010-11 lags behind the anticipated growth in charity research expenditure. AMRC and its members are increasingly concerned that as a result charity money may diminish in value relative to funds from wholly government sources and reduce the nature and diversity of funding available to researchers in the UK.

Public engagement

Finally, the all-important footnote to this story is that the charity enterprise in UK research would not be possible on the scale we now see it, were it not for the ongoing support of the British public.

Their enthusiasm and desire to support research that will ultimately lead to finding the cause and cure for diseases and conditions affecting themselves, friends or family is reflected in the upward trend in donations to medical research charities over recent years: forty per cent of all

donors gave to medical research charities in 2006 compared to just over 24% in 2003.

Medical research charities are now a trusted source of information to their respective patient constituency and are playing an ever-more important role in terms of wider public engagement on science. They are also finding new and innovative ways to bring this patient voice to bear upon issues of public debate such as the potential of 'human admixed embryos' but also in respect of their own research funding activities and related work such as the Parkinson's Disease Society's Research Network or Alzheimer's Society's QRD programme.

Conclusion

In the future, AMRC's credibility will continue to rest on the commitment of its members to funding quality research of public and patient benefit and the difference this has made not just to science but also to patients' lives in the UK. It is this 'difference' which remains our prime purpose and motivator and which we celebrate in this, our twenty-first year.

Charity-funded research as a catalyst for wider action

The earlier a stroke can be recognised, the better, yet stroke can be difficult to recognise and diagnose. In the late 1990's a team in Newcastle developed a simple test to enable ambulance staff to recognise a possible stroke. They named the test FAST (Face, Arm and Speech Test), and it looks at three issues - facial weakness, arm weakness and speech disturbance.

The Stroke Association recognised the potential of FAST and funded the team to research whether paramedics can accurately identify stroke using FAST – resulting in the establishment of FAST in ambulance services throughout the UK and as an integral part of training for paramedics.

The Association used their research findings in their 2005 'Stroke is a Medical Emergency' campaign, to increase awareness of stroke and its symptoms amongst the public, GPs and A&E staff. The Department of Health and policy makers were also targeted, to ensure adequate systems are provided to treat stroke as a medical emergency.

FAST was an integral part of the campaign, with leaflets and posters produced showing the symptoms of a stroke and stressing the importance of calling 999. These were distributed to many hospitals and GP surgeries, and now more than half the general public are aware of FAST, and the Department of Health has again funded the Stroke Association to publicise the message throughout the UK.

All Party Parliamentary Group on Medical Research

AMRC provides the secretariat for the APPG on Medical Research, which was established in 2005 by AMRC, Academy of Medical Sciences, Medical Research Council, Cancer Research UK and the Wellcome Trust. Details of the Group's previous and forthcoming meetings are published on our website at www.amc.org.uk