The history of Action for M.E.

2012

Action for M.E. marked its 25th birthday in 2012.

In February, we launched our Time for Action campaign, calling for an end to the ignorance, injustice and neglect of M.E., once and for all. As part of the campaign, we published a damning report about the lack of specialist NHS services for people with M.E. As a result of our survey of people who had applied for Employment Support Allowance in the past year, we also produced *Time for Action on the Work Capability Assessment*, showing that the test isn't fit for purpose.

CEO Sir Peter Spencer spoke at a Department for Work and Pensions employment conference in March to show employers how they can help people with M.E. and other fluctuating long-term conditions remain in or return to work.

During M.E. Awareness Month in May, we announced that we had awarded a total of £61,000 to three biomedical pilot research projects at Newcastle, Northumbria and Sheffield universities.

In July, the Medical Research Council issued a highlight notice inviting the submission of high-quality proposals in priority areas within M.E./CFS research, to all its research boards.

Sonya Chowdhury became Action for M.E.'s new CEO in September, after Sir Peter Spencer stood down. One of her first jobs was to meet with Prof Stephen Holgate and representatives from other M.E. charities to begin setting up a new UK M.E./CFS Research Collaborative.

Unfortunately there was a setback in Scotland in October when the Cross Party Group on M.E. was disbanded. Sonya Chowdhury, our CEO, commented: "Action for M.E. remains committed to Scotland and a collaborative approach to achieving better services and support for M.E. patients and driving research into the biological nature of this terrible condition. We will continue to endeavour to work with all key stakeholders."

Prof Julia Newton gave a presentation on M.E. research, including her Action for M.E.-funded study into muscle dysfunction, at our Annual General Meeting in November, where Chair of Trustees Alan Cook also announced the re-appointment of Trustee Tony Golding and the appointment of five new Trustees.

2011

The Medical Research Council (MRC) announced £1.5m funding "for research into the causes of Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/M.E.)" with a June deadline for submitting proposals.

In February, *The Lancet* published the initial results of the PACE trial.

NICE decided not to review its guideline on CFS/M.E. until August 2013.

Our Scottish election manifesto for M.E. received support from many potential MSPs, 13 of whom were elected. Cross Party Group on M.E. Convenor Andy Kerr lost his seat but the Group reformed under Labour MSP Mary Fee.

On 26 March, the Disability Benefits Consortium and the UK Disabled People's Council organised a Hardest Hit march and rally in London. Action for M.E. joined other people with M.E. (see photo, right) to campaign against Government spending cuts.

Mandatory work experience for some on Jobseeker's Allowance was introduced.

Representatives from Action for M.E. met senior representatives from the Department for Work and Pensions.

In May we launched our NHS services survey.

The National M.E./CFS Observatory published its fourth and fifth paper, A Disease Register for ME/CFS: Report of a Pilot Study, and The functional status and well being of people with M.E./CFS and their carers.

Clare Francis stood down as a Trustee after many years service but continues to be our President.

In June, the Government had to change its NHS reform proposals for England following widespread concern about its Health and Social Care Bill.

In July we launched this, our new website!

In August the UK's first biobank for M.E. was launched, co-funded by Action for M.E., the ME Assocation, ME Research UK and an anonymous donor.

Our AGM and Open Conference 2011 was held in October in London.

2010

In January, Kay Gilderdale - who had admitted to assisting a suicide - was cleared of attempting to murder daughter Lynn, who had had severe M.E. for many years. Lynn had taken her own life, with her mother's help, in December 2008.

Action for M.E.'s election manifesto was launched following wide consultation with people with M.E. It outlined key facts and expectations of Government in the areas of health, welfare, research, education, employment, social care and policies relating to carers. 14,000 copies were distributed across the UK. Members used the manifesto to lobby their local MPs and parliamentary candidates, to pledge their support.

A Coalition Conservative/Lib Dem Government was formed, which introduced extensive spending cuts and welfare reform, prompting a series of Action for M.E. campaigns.

The charity was awarded funding to launch a Scottish Hub for M.E. in March and in April Dr Alastair Miller replaced Professor Anthony Pinching as our Principal Medical Adviser.

NHS Scotland published the Scottish Good Practice Statement on M.E.-CFS in September, shortly before the Scottish Public Health Network published its Needs Assessment of Services for people with M.E-CFS. Action for M.E. was involved in both initiatives.

The charity held a conference - 'Work, welfare benefits and M.E - is anyone listening?', in London. The event provided an opportunity for people with M.E. to present their experience of welfare benefits to a representative of the Department for Work and Pensions and to disseminate the findings of the National M.E. Observatory.

In October Action for M.E. held its open annual general meeting in London. Our Telephone Support Line opening hours were extended from 10 hours a week to 20.

With austerity measures in full swing, Government announced plans to replace Disability Living Allowance with Personal Independence Payment.

Throughout 2010 Chief Executive, Sir Peter Spencer, met Ministers and key government figures including Paul Burstow (Minister for Care Services), Professor Malcom Harrington (who led the independent review of the Work Capability Assessment) and Chris Grayling (Minister for Employment) to raise the concerns of people with M.E.

The charity launched itself on Twitter and work began in earnest on this, our new website.

2009

Preliminary findings from the M.E. Observatory were disseminated at a meeting in April. Studies from the University of East Anglia, Hull York Medical School and the London School of Hygiene and Tropical Medicine examined the impact of living with M.E., relationships between people with M.E., health professionals and services.

Following the July publication of a green paper on proposals for a National Care Service for adults in England, Action for M.E. held a consultation with its members. The aim was to generate statistical evidence that the Government could use when considering the impact of its decisions, and to find out what issues people with M.E. wanted to highlight.

Action for M.E. launched a fan page on Facebook, offering people with M.E. a place to share stories and offer each other support.

2008

Six new trustees were appointed to the board: Chris Cundy, Lionel Godfrey, Stephen Halpern, Sarah Helton, Martin Jarvis and Chris Hoare.

Sir Peter Spencer, CEO, addressed a Royal Society of Medicine conference on CFS in London in April. He said: 'It is time to change the image of this illness, to ensure that all patients are treated with understanding, respect and a bit more kindness than they receive today."

Sir Peter was also amongst those invited to attend the first meeting of the Medical Research Council's multi-disciplinary panel on M.E./CFS, to discuss research opportunities and the way forward.

In May the charity published '*M.E. 2008: what progress?*', the initial findings of a national survey of more then 2760 people with M.E. focusing on their health and welfare.

In order to produce an informed response to the public consultation on the Welfare Reform Green Paper, published in July, Action for M.E. developed two further surveys and an online discussion forum to collate feedback on the proposals.

The resulting report, entitled *'No one written off: problems and potential solutions for people affected by chronic fluctuating conditions'*, highlighted the need for "a fundamental shift in attitudes among Department for Work and Pensions assessors to illnesses like M.E. and amongst employers to taking on people who have a disability or chronic fluctuating condition."

In September, Action for M.E. published the first issue of its e-newsletter *Keep me updated*.

The M.E. community mourned the death of Lynn Gilderdale, who took her own life after being severely affected by M.E. for 17 years.

2007

Action for M.E. celebrated its 20th birthday and Sir Peter Spencer took up the role of Chief Executive. Writing in *InterAction*, he said: "The Board of Trustees has entrusted me and my new senior team to make a really big difference for the better in your lives. I take that responsibility and their faith in me very seriously. I will not let you down."

We launched our Men and M.E. campaign after 2006's More Than You Know survey seemed to indicate that a significant proportion of men might have more difficulty than women getting an official diagnosis.

The Scottish Executive committed to funding an assessment of needs of people with M.E. in Scotland. £40,000 was allocated.

Action for M.E. did not support new guidelines on M.E./CFS for Disability Living Allowance, issued by the Department of Work and Pensions in July, rejecting the basic approach in which principles of evidence-based medicine had been too narrowly applied in circumstances where so little research evidence was available.

The National Institute for Health and Clinical Excellence unveiled its M.E./CFS guidelines for healthcare professionals, having removed the controversial recommendation that cognitive behaviour therapy and graded exercise therapy should be the "treatments of first choice" following outcry after the initial public consultation.

The National M.E. Research Observatory was launched. A collaboration between Action for M.E., the University of East Anglia, Hull York Medical School and the London School of Hygiene and Tropical Medicine, it aims to support the development of social and epidemiological research which responds to the needs of the M.E. community.

In November, BBC Radio 4 broadcast an important series of programmes which looked at different aspects of M.E. The transcripts were featured in InterAction.

2006

Chris Clark stepped down to spend more time with his family and Trish Taylor became Interim CEO.

Action for M.E.'s 'M.E. – More Than You Know' campaign was the most successful ever in terms of media coverage, highlighting the severity of symptoms, revealing that 77% of adults with M.E. had lost their jobs and announcing an updated Cost to the Nation figure of £6.4 billion.

Susan Webster was appointed as our Project Coordinator for Scotland, re-establishing our presence north of the border.

In November, Action for M.E. organised an M.E./CFS Research Summit in conjunction with the Medical Research Council, bringing together researchers and clinicians from a variety of disciplines to develop collaborative networks and research proposals.

The Gibson Inquiry called on the UK to lead the way in encouraging biomedical research.

Draft clinical guidelines published by the National Institute for Health and Clinical Excellence (NICE) and the Department for Work and Pensions caused an outcry among the M.E. community. Action for M.E. joined other charities in signing joint statements in response. The Trustees also criticised NHS Plus guidance on Occupational aspects of the management of CFS which were published in October.

In June an inquest found that Sophia Mirza had died as a result of acute renal failure due to dehydration as a result of chronic fatigue syndrome.

2005

The M.E. Alliance published a report on the importance of early diagnosis entitled *M.E. diagnosis: delay harms health*, lead by main author Dr Charles Shepherd of the ME Association (MEA). The M.E. Alliance – which included Action for M.E., Association of Young People with M.E. (AYME), Case History Research on ME (CHROME), MEA, National M.E. Centre and The Young ME Sufferers (Tymes) Trust – also made early diagnosis the theme for the 2005 May campaign.

Action for M.E. consolidated its resources into one office in Bristol.

In November, the 50th edition of *InterAction* reported that the 1% petition (asking the government to donate 1% of the cost of M.E. (£35 million) to M.E. research) had been presented to Parliament, supported by 23,000 signatures and a further 5,000 signed 1% Campaign postcards.

The magazine also outlined the implications of the second phase of funding for NHS services. By now, 50 new local multidisciplinary teams had been set up plus 13 Clinical Network Coordinating Centres (CNCCs).

Earlier in the year, a report in *InterAction* by Dr Neil Abbot, Director of Operations for MERGE (now M.E. Research UK), compared the amount of research done on other illnesses with statistics for M.E. He found that 2841 articles had been written and 146 clinical trials had been undertaken for M.E./CFS compared to 221,828 articles and 10,236 clinical trials for diabetes. Only 0.49% of all clinical trials involved people severely affected.

Our Hope for M.E. campaign inspired over a thousand members to write in to *InterAction* with their experiences of the illness.

2004

February saw the then National Institute for Clinical Excellence (NICE) announce plans to develop clinical guidelines on the diagnosis and treatment of CFS/M.E.

Tony Wright MP, Chair of the All Party Parliamentary Group (APPG) on M.E., led a debate in the Commons about common benefits problems faced by people with M.E.

In the summer, CEO Chris Clark issued a statement explaining explaining Action for M.E.'s postion on the PACE trial.

2003

On 6 February the Scottish Executive published *Developing Services for People with M.E.*, which recommended that NHS Boards work in partnership with the voluntary sector and develop strategic plans suitable for their local area.

Health Minister Jacqui Smith chose M.E. Awareness Day to announce that £8.5 million would be made available in England to develop new multi-disciplinary NHS centres for people with M.E.

The Medical Research Council (MRC) issued a 'highlight notice' which flagged up CFS/M.E. as a priority area for research.

Action for M.E. received over 2,000 signatures and 4,000 signed decorated postcards, supporting our 1% Campaign. At that time it was estimated that M.E. was costing the country £3.5 billion. The campaign asked the Government to spend just 1% of that figure, £35 million, on research into M.E.

In Scotland, Action for M.E. thanked Helen McDade for all her work and wished her well in her new job when she resigned as officer to the Cross Party Group.

2002

The report to the Chief Medical Officer of an independent Working group on CFS/M.E was published on 11 January. Highlights included recognition of the severity and impact of the illness; the need for early and positive diagnosis; a call for research on all aspects of the illness; instruction for better services at primary, secondary and tertiary level; a recommendation that health professionals should be properly trained in the illness.

Although the report was welcomed, many people were upset that the report did not clarify the clinical difference between M.E. as defined by Dr Melvin Ramsay in 1956 and CFS as defined by the Centers for Disease Control in the USA in 1994. In addition, not enough space was given to symptoms experienced by the severely affected and some people criticised the section on management, where graded exercise and cognitive behaviour therapy were placed first and pacing last.

Actress Maureen Lipman, patron of the Hull and East Yorkshire M.E. Group, joined Clare Francis, to host a VIP drinks reception on our behalf.

2001

The Cross Party Group on M.E. was formally approved by the Scottish Parliament on 28 March.

Action for M.E.'s report, *Severely affected: M.E. in the UK*, based on a survey of more than 2,300 members, was launched at the House of Commons. Two thirds of participants had received no advice from their GP about managing the illness. Around a third had to wait over a year and a half for a diagnosis. Over 50% said they had felt suicidal at some point as a result of the illness. The vast majority - 89% - had been either housebound or bedbound at some stage, 58% for over a year and around a quarter for over four years. In terms of treatment, pacing and rest were found to be the most helpful.

	Helpful	No change	Made worse
Graded exercise	417	187	610
Sleep medication	870	223	207
Pacing	1949	201	30
Pain medication	856	385	153
Dietary changes	1216	590	58
Supplements	1190	699	64
Rest inc.bed rest	1962	169	31
CBT	21	191	73

Chief Medical Officer (CMO), Professor Liam Donaldson, passed the report on to the CMO's Working Group on CFS/M.E. and to the Benefits Agency.

InterAction acknowledged the "long-standing work which has been done by others, and in particular Simon Lawrence and fellow workers at the 25% M.E. Group" who had campaigned tirelessly on behalf of the severely affected for some time.

A delegation of staff and members attracted television cameras from BBC Breakfast News and GMTV when they gathered outside Whitehall with two huge inflatable letters, M and E, wearing T-shirts which spelt out the message: Don't neglect ME.

2000

Chris Clark joined Action for M.E. as Chief Executive, from a background as a manager in the NHS.

Action for M.E. patrons Melvyn Bragg and David Puttnam hosted a VIP reception at the House of Commons.

The event was attended by a number of peers and MPs with a special interest in M.E., including Tony Wright MP, Chair of the All Party Parliamentary Group on M.E., plus Professor Anthony Pinching, Deputy Chair of the Chief Medical Officer's Working Group on M.E., celebrity chef and TV presenter Ainsley Harriott and actress Jane Lapotaire.

1999

15-year-old member Alexander Finlay was thrilled to meet actress Joanna Lumley at a fundraising drinks party hosted by Clare Francis in April.

Trish Taylor joined as a trustee, later to become chair. In 2006 she stepped in as interim CEO and was reinstated as chair in July 2007. She stood down because of ill-health in 2008.

1998

Young Action Online was launched on the Lorraine Kelly Show (pictured right) with Big Country bass player Tony Butler and Action for M.E. Children's Officer Jane Colby.

A bright yellow Stop Press! in the December issue of *InterAction* announced the membership of the Chief Medical Officer's (CMO's) Working Group on M.E./CFS: Chair Professor Allen Hutchison, Deputy Naomi Wayne, members Roma Grant, Jonathan Hull, Patricia Smith, Simon Lawrence, Mavis Moore, Dr Charles Shepherd, Dr Nigel Hunt GP, Dr Anthony Cleare, Dr Peter White, Dr Alison Round, Dr Derek Pheby, Dr Trudie Chalder. Members of the Children's sub group: Judith Waterman, Jane Colby, Dr Nigel Speight, Dr Alan Franklin, Dr Anne Macintyre, Professor Elena Garralda, Judith Acreman, Anna-Grace Lidstone represented by Alex Western, Rachel Lynds and Jill Moss.

The same Stop Press was "delighted to announce that Tony Wright, MP for Great Yarmouth, is planning to establish an All Party Group on M.E." and urged members to contact their local MPs, encouraging them to get involved.

1997

Action for M.E. celebrated “A decade of action - a future of hope” with the launch of its own website and the announcement that a new CEO, Naomi Wayne, had been appointed.

1996

Action for M.E. launched the 1996 Year of the Child and its Children’s Charter on 24 April at a press conference in central London. The event was relayed live on the ITN lunchtime news.

On 7 May Action for M.E. and the ME Association announced the results of their joint Cost to the Country survey, estimating that M.E. cost the nation £2 billion every year in lost salaries, welfare benefits, hospital consultations, prescribed drugs etc.

A controversial report on M.E. by the Royal Colleges was felt by many to be biased towards psychological factors.

1995

A year of financial crisis and unrest within the organisation. Director Nick Anderson left, after seeing the charity through a period of great expansion and current trustee, George Armstrong, stepped in to the position of Chair temporarily while the Council of Management considered its options. After nine years of campaigning, Clare Francis retired as President (temporarily as it turned out!) and Lady Elizabeth Anson took her place, with Suzy Diamond as Vice-President. Neil Conn left our Scottish Office, his health affected by the situation.

The Association of Young People with ME (AYME) was founded and went on to become the largest UK charity for children and young people with M.E.

Tanya Harrison, who is severely affected and her mum, Christine, started BRAME, the Blue Ribbon for the Awareness of M.E.

1994

Action for M.E. established a pilot national counselling service. Angela Henderson moved on, leaving Nick Anderson as overall Director. The M.E. charities filled the letters page of the Lancet, responding to a letter from Dr Simon Wessely. Dr Wessely had argued that M.E. was the same as CFS and that the World Health Organisation (WHO) International Classification of Diseases ICD 10 should reverse its recent decision to include M.E. in the section on Diseases of the Nervous System and place it instead within Other Neurotic Disorders, the section which includes CFS and depression.

Thanks to a donation from the Scottish Business Achievement Award Trust, via Alex and Jan Meddowes, Action for M.E. opened a ‘Scottish Office’ staffed by Neil Conn and Robin Irvine.

InterAction reported its first International M.E. Awareness Day, 12 May.

The Task Force Report CFS/PVFS/M.E. was published on 13 September. It concluded that there was widespread ignorance and mismanagement of chronic fatigue syndromes and that patients often encountered lack of support from doctors, healthcare professionals, education authorities and society. Recommendations: clarify the differences between various chronic fatigue syndromes; educate professionals and public to accept their existence; train relevant professionals to identify and manage them; improve services to patients; actively encourage research.

1993

The charity relaunched itself as Action for M.E. and Chronic Fatigue ('Chronic Fatigue' was later dropped), with an Action for M.E. Month in September.

The BBC broadcast Wide-Eyed & Legless (inspired by the books of Derek Longden), the first ever documentary about M.E. on national television. Maureen Lipman's husband Jack Rosenthal wrote the screenplay for the film.

Action for M.E. held a charity showing of the film at Kensington Town Hall, when Melvyn Bragg, Joanna Lumley & Maureen Lipman made speeches and helped with the auction. The charity's Medical Adviser, Dr Anne Macintyre, appeared on Channel 4's Frontline programme and the Jimmy Young radio show. 15,000 viewers and listeners wrote in for information.

A celebrity preview of Wide-Eyed & Legless held at Kensington Town Hall raised £28,000. Membership topped 6,500.

1992

A year of great gains and personal loss. Membership exceeded 4,000 and the new Campaign office was formally opened in Wells. M.E. Action joined forces with the ME Association (MEA), the International Federation of M.E. Associations (IFMEA) and Westcare, an independent Bristol-based M.E. charity, to campaign for a fair representation of M.E. in the new Disability Living Allowance (DLA) handbook.

Following intensive pressure from the MEA, M.E. Action and Westcare, the Department of Health finally agreed to set up a National Task Force on CFS/PVFS/M.E., to "provide an impetus for positive action." Richard Sykes, Director of Westcare, played an important role in bringing together the Task Force.

Tragically, after a number of personal set-backs, former Director Martin Lev took his own life. Editor Martin Arber's tribute described the Campaign's first Director as "one of the most dynamic people I'd ever met... He continues to inspire us."

1992 ended on a happier note when rock music legend Rick Wakeman (pictured right) performed a benefit concert in aid of M.E. Action.

1991

Campaign HQ moved from London to Wells as Martin Lev handed over the Directorship to Angela Henderson. He stayed on as a member of the Council.

Representatives from the Campaign and the ME Association (MEA) met Stephen Dorrell, Junior Health Minister and MP Jimmy Hood prepared to present a Private Member's Bill, "to make provision for an annual report to Parliament on matters relating to myalgic encephalomyelitis including progress made in investigating the causes, effects and treatments of the disease, diagnostic practice and information derived from national epidemiological surveys."

Martin Arber became editor of *InterAction*.

1990

With membership standing at 1600 and over 140 support group contacts nationwide, M.E. Action began to research its original hypothesis, that M.E. was caused by an imbalance in the bowel bacteria, resulting in a form of immune deficiency. Its new research arm, the M.E. Action Research Foundation, was registered as a charity in England and Wales.

Thanks to an anonymous benefactor, a powerful 90-second video was produced for cinema screening, which depicted the impact of M.E. on the life of an ordinary teenage girl. The film, deemed too distressing in its original form, was given an 18 certificate. It went on to win a prestigious British Television Advertising Award.

1989

David Puttnam, one of the best-known names in the British film industry, joined the Campaign as a Patron. Director Martin Lev's Spring column explored the possibilities of a research project which would look at detoxification, homeopathy, probiotics and nutritional therapy.

In the autumn, Ellen Goudsmit guest edited the magazine. The Council of Management now included Martin Arber, ME Association Group Leader for Redbridge, Essex, who would go on to become Editor of *InterAction*. In September, a new M.E. Action Therapy Information helpline was launched.

1988

The M.E. Action Campaign published its first newsletter, *InterAction*, emblazoned with the message: Freedom of Information. Freedom of Expression. Freedom of Action.

Clare Francis, our President, welcomed readers. As well as Clare, campaigners were listed as: trustees Sue Finlay, Mike Franklin, Dr Anne Macintyre, John Tolson. Patrons Melvyn Bragg, Leslie Kenton, Jimmy Hood MP. Director Martin Lev, Treasurer Chris

Corin. Medical Advisers Dr Anne Macintyre, Dr Belinda Dawes, Dr Milo Siewart, Dr Robin Hensman.

1987

Action for M.E., or the M.E. Action Campaign as it was called, first set up. But the foundations had been laid on 1 June 1986, when an article by our founder, Sue Finlay, appeared in the Observer.

''I had become frustrated with the lack of support and recognition amongst the medical authorities, the general public and caring agencies," Sue told *InterAction*'s former Assistant Editor, Gill Jacobs, 10 years later. "My article generated 15,000 replies which took me a year to reply to!

''I first got ill with M.E. in 1980, but looking back it was probably before that, because I had exhaustion for some time. In 1980 nobody knew what was wrong with me. I eventually contacted a psychiatrist called Dr Mark Hughson, who had similar symptoms, and who I knew about because his wife was a friend. He sent me Dr Ramsay's description of M.E. and when I read it I cried for the rest of the day because it was describing exactly what I was experiencing.''

''In the mid-80s my partner, Ian Hamilton Finlay was interviewed for the Sunday Post, a Scottish tabloid, about his work as a landscape artist. During the interview I said that I had to sit down because I had M.E. The journalist pricked up his ears and sent someone else to interview me. The resulting article prompted 80 letters from people with M.E., all in total despair.

''By chance Ann Barr, features editor of the Observer weekend supplement, was an acquaintance of my partner. I submitted my article to her in 1986, with absolutely no hope, but she 'phoned immediately and sent a photographer round straight away.

''They asked me to send a small information sheet in case there was a response so I sent 200 copies. Ann Barr said that was far too many. But by the Tuesday after publication she phoned me up, astounded, to say that they had had thousands of letters. Over the next year, as I said, there were 15,000 letters, some from abroad. This gave me a really wide perspective on the illness and its effects.

''I felt that my articles in the media, and the response, had opened up a possibility, and no-one was prepared to use it. I wanted to start a campaign, and was encouraged by a doctor in Devon to take the plunge and did so. I got some letterheads, registered the charity in Scotland, and ran it from my back bedroom. A friend sent me £500 to kick off with, and I raised about £200. I sent out information and also bought books for a postal lending library.

''I kept this up for about two years, and made useful connections, among them Martin Lev, who contacted me after the Observer article. Martin became a trustee of the M.E. Action Campaign, and we used to have trustee meetings on the moving walkways at Heathrow airport. (Martin lived at Acton, and I did a lot of travelling. Heathrow seemed a natural meeting place). Eventually I realised that the campaign needed to have more time and energy put into it. Martin agreed to take over as Director. In this way, it went from one back bedroom to another!

''Around that time Clare Francis telephoned us, offering to join us. Eventually she became our President, and much of our successful media coverage was generated by an interest in her, and her skills in communicating what she had been through. We have a great deal to be grateful to Clare for; many of our members owe their diagnosis and recognition to her.”