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Stroke
association

Stroke Association:

History
perspective
1898-2012

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Part 2

Contents

Part 2

1. 'We dream of a seamless service': stroke services in the 1990s	44
Snap shot from the 1994 Annual Report	44
Snap shot from the 1995 Annual Report	45
Snap shot from the 1996 Annual Report	46
2. A financial turning point	48
Snap shot from the 1997 Annual Report	48
Snap shot from the 1998 Annual Report	49
Snap shot from the 1999 Annual Report	50
Snap shot from the 2000 Annual Report	51
3. 'A hundred years of caring'	50
Snap shot from the 2001 Annual Report	53
4. A new vision for the Stroke Association	54
Snap shot from the 2002 Annual Report	54
Snap shot from the 2003 Annual Report	55
Snap shot from the 2004 Annual Report	56
Snap shot from the 2005 Annual Report	57
Snap shot from the 2006 Annual Report	59
Snap shot from the 2007 Annual Report	60
Snap shot from the 2008 Annual Report	61
5. Expansion across the United Kingdom	62
Snap shot from the 2009 Annual Report	62

6. The Stroke Association in Northern Ireland	63
7. The Stroke Association in Scotland	64
Snap shot from the 2010 Annual Report	65
8. The Stroke Association in Wales	67
Snap shot from the 2011 Annual Report	67
9. The Isle of Man and Jersey	69
10. Europe and the wider world	70
11. Stroke Association Community Services 2004 to 2012	71
Snap shot from the 2012 Annual Report	72
12. Life After Stroke	74
13. The Stroke Association and research in the Twenty first century	75
Snap shot from the 2013 Annual Report	75
14. A new brand	77
15. Endeavours over more than a century	78
16. Acknowledgements	79

1. 'We dream of a seamless service': stroke services in the 1990s

While all this reorganisation was going on, the Association continued its efforts in funding research and lobbying for stroke services. A new initiative STROKE was launched at the end of November 1990 aimed at revising the notion, still very widespread, that stroke was an unfortunate but unavoidable consequence of ageing. The first Family Support Organiser started work in Sefton on Merseyside and Salford in 1990 and another in North Wales the following year.

The Family Support Service had been born out of a two-year pilot scheme offering support for a new kind of stroke club, but Mo Wilkinson identified the real need as support and information for families in the early days after stroke, when they struggled to deal with the loss of family life as they had known it, with changed roles and responsibilities within the family. These services were funded through contracts with the Health and Social Services.

Snap shot from the Annual Report 1994

Jean and Jim feel that Mary, a Stroke Association coordinator, has helped them come to terms with their emotions and bring their true feelings out in the open without embarrassment or self-pity. During the 20 weeks Jean spent in hospital they both remember Mary popping in. Gradually Mary became a trusted friendly face that the family liked to have around.

"Mary told me from the start that our lives would be turned upside down," remembers Jim. "It went over my head at the time, along with everything else I'd been told. Looking back, it obviously had more impact than I thought, because I did begin to think pretty early on that it was okay to feel that our lives were being shredded!"

"Talking to Mary makes me feel as though I am off-loading a part of myself, which leaves more of me to devote to Jean," said Jim.



The Volunteer Stroke Scheme was renamed the Volunteer Stroke Service at the start of 1991 as a better reflection of its activities. Regional Stroke Centres were opened in Salford, Cardiff and Evesham, and the Association set up its Stroke Family Support Service with Jenny Spreadborough as Director. Many of the services originally set up at this time still exist and have been commissioned throughout that time. A Stroke Association survey conducted over 1992 to 1993 found that hospital stroke services were neither widespread nor uniform, which was an unacceptable situation. In particular, the survey found that only 3% of those looking after stroke patients in hospital were specialists in stroke medicine: 'the development of a new sub-specialty of stroke medicine might improve leadership, organisation, and service planning, leading to better patient care' (Ebrahim and Redfern 2000: 106).

The Stroke Association had been fundraising for a chair in stroke medicine since 1989, and a grant from the Wolfson Foundation, together with local fundraising, made possible the creation of the first ever such chair at Nottingham; Peter Fentem was inaugurated as the first Professor of Stroke Medicine in November 1992. The Stroke Association also funded six pilot consultant stroke physician posts, and within seven years nearly 100 people were training to be stroke physicians and stroke medicine was at last fully established as a separate medical specialty. Many of the current stroke physicians developed their expertise by working within the teams led by these individuals.

One of the Association's longest running campaigns is *Know Your Blood Pressure*, which was launched in 1993 with the support of celebrities Jenny Seagrove, Annette Crosbie and Richard Whiteley, although the Association had been stressing the importance of blood pressure for at least three decades, having produced a leaflet on 'Does blood pressure matter?' in the 1960s. The campaign was undertaken in partnership with Rotary International Britain & Ireland, the Emergency Medical Services and St Andrew's First Aid. By 2011 no fewer than 742 *Know Your Blood Pressure* events were taking place across the United Kingdom.

Snap shot from the Annual Report 1995

The Stroke Association published the results of survey of 1,000 people about their awareness of blood pressure on 'Know Your Blood Pressure Day' – 6 July 1994.

'Know Your Blood Pressure Day' was launched by the Under Secretary of State, The Hon. Tom Sackville, MP, who led fellow MPs from all parties to get their blood pressure checked.

- 43% of those interviewed knew that high blood pressure is associated with stroke.
- 41% believed stress is a risk factor in stroke – in fact there is no evidence to prove this.
- 50% did not know that stroke affects the brain.



Following the pioneering work by Valerie Eaton Griffith with the Volunteer Stroke Scheme, the work of two women in the north of England stands out in the development of services within the Association. Mo Wilkinson, who had been part of the Eaton Griffith team, went on to become Regional Manager for Northern England in 1981, and then, when the huge growth in services in the 1990s necessitated the subdivision of that great area, she became Divisional Manager for North West England and Trent, based in Salford. Her seminal role in developing Family Support Services led to her appointment to a national post as Assistant Director of Community Services with responsibility for strategic planning and services development. One of the early Family Support Services was in Cheshire, which brought Elaine Roberts into the Association as part-time Family Support Organiser, setting up a new service and dividing her time between the Stroke Association, community nursing and the Marie Curie Cancer Foundation for six months before taking the leap into the charity completely. She became Regional Manager for South Cheshire in 1998, an area which was later enlarged by the addition of Staffordshire. When Mo Wilkinson retired in 2005, the Association's infrastructure changed once more, and Elaine was appointed Director of Operations for the North of England. The late 1990s saw major innovations, including the adoption of Dr Ann Ashburn's vision of a Stroke Therapy Research Unit to explore the methodology of research in the field of rehabilitation for stroke patients.

Snap shot from the Annual Report 1996

Following a stroke, John, from London, has been dysphasic – without the ability to speak, read or write. Once a week, John attends a Dysphasic Support Group meeting where a volunteer helps him to communicate his thoughts, wishes and feelings.

“Because of the group, John is much more aware of what is going on around him, and it gives him a break to go to a carers support group,” said Monica, John's wife.

New services in the past year have started in Guildford, Bromsgrove and Redditch and Morecambe Bay. There are now 116 staff and 108 Dysphasic Support Services throughout England and Wales.



This took shape as the Stroke Association Therapy Research Unit (SATRU) and was up and running at Hope Hospital in Salford by 1996, with Dr Valerie Pomeroy as Director. The idea of having Stroke Association District Stroke Services Coordinators had been given a trial in East Lothian and Leeds East and was soon extended, for the aim was to bridge the gulf between hospital and life back at home, and in C Alan Wood's words 'we dream of a seamless service' across the country. Family Support made a huge difference: 'Just knowing there is someone there, even though you may not need them' as one stroke patient described the service.



(© Mrs Bridget Robbie) Alan Wood receiving his award for services to the Stroke Association from HRH The Duke of Kent

2. A financial turning point

By 1998, however, the Stroke Association's finances were in a serious condition, after a period of huge growth in services and several years of deficit. In 1992, the Association had 100 staff and an annual income of £4.5 million, whereas only six years later there were 462 members of staff and an annual income of £10 million. The Director General Dr Sylvia McLauchlan had resigned in 1997, and the remarkable C Alan Wood, who had chaired the Executive Committee since 1992, worked three to four days each week at the Association's offices for several months until a new Director General could be appointed. This was Margaret E Goose, a former NHS manager, whose title was to be the more modern Chief Executive and whose careful hand would guide the Association into the new millennium.

Margaret Goose was the Association's first non-medical head of staff. Before taking up post she visited Stroke Association services in the north, when her previous job was based in Leeds, and she had met both Mo Wilkinson and Elaine Roberts. She inherited major problems, for the Association was half a million pounds in the red, and she realised that services desperately needed restructuring. There were 26 regions with staff structures in England and Wales, an arrangement which was uneconomical.

Snap shot from the Annual Report 1997

A week after the birth of her first baby, Caroline, 30, had a stroke.

"The Central Advisory Service was brilliant," she said. "They pointed me in the right direction to get the things I needed to help me start walking again."

Information Centres and the Central Advisory Service offer confidential advice on all aspects of stroke to patients, carers, relatives and friends. A network of 32 Information Centres operates throughout England and Wales. Over the past year 39,500 enquiries were answered, 44% of enquiries were from stroke survivors or carers, 40% from health professionals and 16% from the general public.



Towards the end of 1998 the Association was fortunate enough to bring a chartered accountant Norman Connor on board, first as Locum Director of Finance for eight months, after which he was persuaded to stay on for another year and then persuaded to remain permanently as Director of Finance. This was very different from the quiet life that Norman had envisaged when he had taken early retirement but it proved intensely satisfying. In what has been described as a rescue mission, he set about identifying where the money was going and what could be done to halt the flow, as well as creating a vision of how the Association should manage its income. It was clear to him that too great a proportion of income was being spent on the community services of which the charity was rightly so proud: the Dysphasia Support Service and the Family Support Service.

These services were delivered through contracts with the National Health Service and Social Services and were intended to be self-supporting, but in reality many were not receiving enough money, with the result that the Stroke Association was subsidising the NHS and local government.

Snap shot from the Annual Report 1998

When a stroke left Mohammed Afzal, 70, wheelchair-bound, his whole family was thrown into turmoil.

“He was at the centre of our family and did everything for us all,” said his daughter Nigar. “Then suddenly after the stroke, he was dependent on us rather than the other way round. We all had to adapt.”

Things were made easier by a Family Support Organiser. She helped the whole family cope with the transition from hospital to home and arranged aids and adaptations to enable Mohammed to be as independent as possible.



Council agreed that it was necessary to reduce expenditure whilst continuing to increase income. Margaret Goose decided that a mechanism for staff consultation was required and a Staff Consultative Forum was established with elected representatives from across the organisation. Individual letters were posted to all members of staff in November 1999 and in the December edition of *Teamwork*, the staff newsletter, she elaborated on the current situation. At the same time a new strapline was announced, which would appear beneath the Association's logo: 'Caring for today – Researching for tomorrow – Working for change'.

A team consisting of Trustee Michael Gatenby as Chairman, Chief Executive Margaret Goose, Director of Services, Ben Jabuni, Assistant Director of Services Mo Wilkinson, and Director of Finance Norman Connor embarked on the arduous process of reviewing every contract, with the determination and hard work of all the regional managers. In most cases the NHS agreed to increase its contribution and only a very few contracts were lost. Whereas in December 2001 there were 139 services in a state of deficit, by March 2003 that deficit had been eliminated in England and by September in Wales as well.

The Association's income at last exceeded its expenditure. It was also recognised that the way in which the Association's services were managed throughout England and Wales needed to be tightened up. The number of regions had been reduced to 16, each with its office and staffing structure, and this was further reduced by careful amalgamation in 2005 to nine larger regions in England plus Wales, 10 in all. Thus the Association's regions for services at last dovetailed with the government's Voluntary Sector Compact areas.

Snap shot from the Annual Report 1999

Difficulties with language are one of the most distressing after-effects of stroke. It can be embarrassing, frustrating and upsetting. Around 20,000 people a year face these problems. Our Dysphasia Support service helps people regain their confidence and skills.

Our trained Dysphasia Support volunteers work alongside speech and language therapists helping individuals at home or in groups. They provide individually tailored help and support as people struggle to relearn these vital skills.

- 7,895 people receive support from our Dysphasia Support Service.
- Our Oxford Dysphasia Support Service celebrated 25 years. Started in 1973, today there are 34 volunteers helping 42 people aged 45-91.
- Over 4,000 volunteers around the country help the charity in a variety of ways.



An important step forward for people who had had a stroke was the Association's work in trying to ensure that every hospital had a stroke unit. A survey was undertaken to identify those hospitals lacking such a unit, and their Chief Executives were telephoned personally by Margaret Goose to discuss what was needed: a dedicated ward with a trained stroke physician. The result was seen in the National Stroke Sentinel Audit, organised by Dr Tony Rudd (later the national Clinical Director for Stroke) at the Royal College of Physicians, which showed demonstrable annual improvements. In addition, the Association supported and encouraged the development of specialist stroke nurses, funding the first of their annual conferences.

The Association's Strategic Review of 1996 had noted that the needs of young (55 and under) people who had had a stroke were not being met, and it was decided in 2000 that the best way forward was to provide a Young Stroke service (in Cardiff), which aimed to facilitate people doing things for themselves, complementing work of other organisations such as Different Strokes.

Snap shot from the Annual Report 2000

In the past year we have:

- handled over 18,000 enquiries through our Stroke Helpline
- committed over £20 million to research.

During the next year we intend to:

- draw up a strategy in relation to young people who have strokes, including children
- pursue our role in relation to prevention of stroke
- set up a national marketing campaign to increase our Dysphasia Support services across the country
- extend our donor base
- work with the NHS to ensure that planned services meet the needs of people affected by stroke.



3. 'A hundred years of caring'

During the centenary year in 1999, the logo for the Stroke Association had a special strap-line of 'A hundred years of caring', and a booklet with the same title was produced which traced the Association's achievements back to 1898. The blue butterfly had been adopted as emblem for Stroke Week in 1998, and it continued in use through the centenary year as a symbol of joyful rebirth. The choice of the butterfly was also influenced by the recent publication of a remarkable book, *The Diving Bell and the Butterfly*, written by Jean-Dominique Bauby after a massive stroke, by means of blinking his left eyelid.

It was a busy year with many special events taking place. Many were the inspiration of Professor John Marshall, a long-standing and much respected Trustee who was then the chairman of the Executive Committee. A Centenary International Scientific Conference was held, attended by 300 delegates, and the papers were published as *Stroke: past, present and future*, edited by Professor Walter Holland who was the chairman at the time of the Research & Development Committee (Holland 2000). Holland's hope was that the centenary and its conference would 'influence those responsible for the delivery of services to rectify the unacceptable variations in the provision of effective services, and will also lead to an increase in funds for stroke services and research and thus to a better outcome for people affected by stroke.' (2000: 124).

Contributions spanned prevention, management and treatment of stroke, the use of imaging, therapy and rehabilitation, stroke services and the history of stroke. Another 1999 publication was *Stroke Care – A Matter of Chance*: a national survey of stroke. In effect, this updated a survey carried out by the Association in 1992–93, when it was found that less than half the consultants who responded to the survey had access to stroke units in their local hospitals.

Patients in Scotland and Northern Ireland were twice as likely as those in England to be managed by organised stroke services. The Stroke Association itself invested almost £500,000 in the development of a Home Therapy Service, which was piloted in Leeds, Sunderland and County Durham in March 1999. In addition, during the centenary year, the Stroke Association helped to fund research into carotid endarterectomy, treatment with thrombolytic drugs and a conversation-based aphasia therapy. Other centenary events included a new film called *A hundred years of caring*, in which people who had had stroke spoke about their experience, Professor Philip Bath described stroke illness, information and Family Support services provided by the Stroke Association were explained, and Dr Valerie Pomeroy of the Salford Therapy Research Unit described how problems of balance and walking were being explored.



During the centenary year of 1999 the blue butterfly was used as a lapel badge.

Snap shot from the Annual Report 2001

"Before my stroke I was a sales director with a brand new company car. After my stroke, I lost everything: my job, my car, my home and my girlfriend. I was homeless for a while and hit rock-bottom."

When Bernie Nolan, 43, finally moved into a bungalow, the Stroke Association helped him with a grant for furniture and a fridge freezer. "The money was helpful but the most important thing was knowing someone out there cared," said Bernie.

The physical and emotional difficulties caused by stroke are often exacerbated by everyday problems such as paying the bills.



There was also a Young Stroke Centenary Conference, the culmination of the Association's concern for people of working age who suffered stroke. A special Thames Bridges Centenary Bike Ride took place, the eighth to take place since it was first devised as a fundraising event by Andrew Allum, whose father had suffered a stroke. Andrew had the ingenious idea of a ride which included as many crossings of the Thames as was possible in London (by the twentieth ride in 2012, 25,000 people had taken part and more than £2 million had been raised).

Another event was a Thames Boat Trip with a jazz band to entertain volunteers from the Greater London area, and many other regional fundraising events were held, including golfing at Durham and skating at Bournemouth.

A Centenary Celebration lunch for long-serving staff and volunteers was held in Birmingham in November, at which they were thanked for their commitment and dedication on video by HRH The Duke of Kent, the Association's long serving President, and in person by Valerie Eaton Griffith and Patricia Neal. Afterwards a special Life After Stroke Centenary Awards was hosted by the broadcaster Angela Rippon.

The year of celebrations was rounded off by a visit by Her Majesty The Queen, the Association's Patron, to the Stroke Rehabilitation Ward at Nottingham City Hospital in December. Media coverage of all these events was invaluable in raising the profile of the Association across the country.

4. A new vision for the Stroke Association

Margaret Goose retired as Chief Executive in 2004, her services to stroke care and health services management having been recognised by the award of an OBE. The baton was passed to Jon Barrick, who for 15 years had been Director of Community Services at the Royal National Institute of Blind People. The RNIB was another charity with a very long history stretching back to 1868, and it had a wide range of services concerned with welfare and rehabilitation, including housing services in connection with which Jon Barrick produced a handbook on building and interior design for visually impaired people (RNIB 1996). Stroke was for him a new challenge and he was determined to increase the impact of the Association both nationally and internationally. He describes the charity when he arrived as 'a sleeping giant' and he was soon implementing ways in which the organisation, already full of potential, might be activated to take on a larger role in the charity world as well as in stroke itself.



Jon Barrick

Snap shot from the Annual Report 2002

Joan had a stroke that left her with severe problems expressing herself. Joan's attendance at the South Birmingham dysphasia support group changed her life.

"When I first went to the group I couldn't say a thing. Going there brought me out of myself and helped me start speaking again," says Joan, 69.

Dysphasia – problems with speech and language – affects a third of stroke survivors. Our dysphasia support services help around 8,000 people a year. We would not be able to carry out this without the help of our 3,000 specially trained volunteers.



Staff structure was good and the new Chief Executive was cheered to realise what excellent people he had inherited, but there was a need to make all in the Stroke Association believe in the need to make the charity fully professional and to rally around a new strategy for growth which was agreed with Trustees in 2005 for the next five years.

After the travails of getting the finances in order over the previous seven years, there was inevitable resistance from the more conservative Trustees to the idea of a believable growth strategy. Jon Barrick was insistent that a process was necessary for remaking the culture to get the charity to perceive itself as a potential giant that enabled staff to perform better. So the first of three senior staff conferences was delivered in 2005 with the Chairman, Professor Averil Mansfield, and a couple of other Trustees attending. The result was a hugely successful get-together that harnessed staff enthusiasm and energy, helped towards creating an impetus for the new strategy and, importantly, made Trustees realise how driven and talented the Association's staff were. This smoothed the way towards a new relationship between Trustees and staff, one in which Trustees were prepared to delegate and to see their role as one of monitoring and enabling strategy rather than of direct involvement in day-to-day affairs.

Snap shot from the Annual Report 2003

Key stats:

- Over 54,000 people signed a petition, calling for improvements in stroke services which was presented to No 10 Downing Street.
- MPs and Peers with an interest in stroke sought our support in forming an All Party Parliamentary Group for Stroke.
- Through our partnership with the Clinical Governance Support Team we are helping shape the national agenda. This has led to the establishment of a unique, multidisciplinary development programme designed to push forward changes in stroke care.



Partnership working with other bodies involved in stroke was one important way forward. Jon Barrick proposed that the only way in which the Stroke Association could achieve national stroke strategies was to unify as many as possible in the stroke world to achieve a common set of messages and positive energy towards this essential precursor to improved stroke care. This was an era when the majority of people suffering stroke did not spend the majority of their time in a hospital stroke unit, indeed many hospitals had no stroke unit at all. Stroke was not treated as a medical emergency and less than half the population even knew what a stroke was.

On Jon's appointment work started immediately, and behind the scenes the Stroke Association began working supportively with the National Audit office to agitate for an enquiry into stroke care, as well as working with politicians of all parties to get them to realise that the poor quality of stroke care was a national scandal.

At Westminster the first All Party Parliamentary Group on Stroke was held in 2004, and from amongst its membership was to come a number of politicians who became staunch supporters of the need to transform stroke care. A Stroke Association Manifesto on these issues was published for the first time in 2005, to influence all the prospective candidates. Then the first breakthrough occurred as the National Audit Office published its report in November 2005, *Reducing Brain Damage, Faster access to better stroke care*. The Association was also helped in its fight to get more attention by the fact that it won the Best Medical Charity Award from the Healthcare Journalists in recognition of the improvement in our campaigning and awareness-raising activity.

Snap shot from the Annual Report 2004



"I was walking to work and I lost the feeling in my legs from the waist down, and I just sort of collapsed on the floor. I didn't think it was anything serious, I just thought my legs had gone to sleep, said Clare.

The following year Clare suddenly I went blind for a second, then her vision came back but she felt light-headed.

"I went into hospital and they ran lots of tests, and when the tests came back they saw I had suffered a series of mini-strokes. I didn't think these things happened to young people – I was 23."

I was psychologically affected by it – I wish I had taken counselling. I'd say to anyone in my situation that they should not panic, and take the support offered. Don't think your life is over if you have a stroke. Don't sit there in your grief; get on with your life.

With these encouraging signs work was pushed forward on building a stroke cause movement. During 2005 Professor Averil Mansfield and Jon Barrick gained Council agreement to the first all-encompassing Stroke Association strategy to cover the period 2005 to 2010. This both united staff around a common direction and enabled the big vision for the stroke movement to be pursued more widely.

For example, during the difficult financial years, relationships with independently organised stroke clubs had become strained as little resource was available to cultivate mutual understanding. By 2005, there were 540 stroke clubs across the United Kingdom. As a way of improving relations with stroke clubs, a national Stroke Club Conference was organised for the first time in 2005. Jon Barrick and Professor Mansfield attended this conference and the suspicion of the Association's intentions was palpable. Jon addressed the delegates, conscious that as he did so that 'the ice began to crack', as he outlined the need for all to work together to achieve greater things in the stroke world than could be achieved alone.

A commitment to closer support and working with clubs was made, and from this came the affiliation scheme that was to become so successful, together with a Stroke Club Consultation Group set up to enable two-way dialogue which would advise the Association. By 2009, 350 of these clubs had affiliated and 200 + delegates were regularly attending the annual Stroke Club Conference.

Snap shot from the Annual Report 2005

The Stroke Association was awarded a three-year grant from the Department of Health to fund a 'Stroke prevention in South Asian communities' campaign, as there is a higher risk of stroke amongst people of South Asian (as well as African Caribbean) origin than amongst white Europeans.

The grant enabled us to build partnerships with existing Asian healthcare and voluntary organisations to help us develop information containing practical steps that people can take to reduce their risk, written and recorded in Punjabi, Bengali, Gujarati, Urdu and Hindi.



The Stroke Association called on the government for a mandatory warning to be applied to food packaging when food contains more than a third (2g) of the recommended daily amount of salt consumption.

Meanwhile Joe Korner, recently recruited as Communications Director (January 2005), and his team introduced the Stroke is a Medical Emergency campaigns, which led into the FAST campaign shortly after, which was a very clever and easily remembered way by which people could recognise stroke: **F**acial weakness, **A**rm weakness, **S**peech problems, **T**est all three symptoms (the T was later adjusted to Telephone 999). FAST underlined the fact, not always appreciated, that stroke really is a medical emergency.

In 2009 the Department of Health for England turned the FAST campaign into a national stroke awareness campaign, and the first four months produced an increase of 55% in the number of emergency 999 calls for stroke in England. This campaign was quickly picked up worldwide and is still a fundamental public health message in many countries today.

At the time there was some heated debate amongst some Trustees as to whether this campaign should be advanced, as it would lead to people arriving at hospitals that were poorly equipped or resourced to deal with stroke as an emergency. Eventually the day was won for the moral position that we had to argue for best quality care and educate the public as to what should be offered. This was to become a critical moment in the progress of the campaign for National stroke strategies and the improvement of acute care provision.

The next element of unifying the stroke world was to ensure that the stroke care professionals were supported when they advocated better care, and to provide opportunity to align alongside them in dealings with the Department of Health and Politicians. The Stroke Association had delivered a scientific conference for many years, which generally attracted around 300 participants and enabled the showcasing of funded projects and research findings. Additionally a conference for stroke care nurses and therapists was delivered annually.

In 2005 the Stroke Association hosted a meeting of all the stroke care professional bodies and the stroke charities from across the UK to propose the reallocation of the resources from these conferences to a single unified multidisciplinary conference, to enable science and good practice activity to come together in one place. It was essential to the success of this idea that the British Association of Physicians would throw their weight behind this, and they did, agreeing to share one third of the financial risk or surplus from the venture. 26 organisations spanning the whole of medical, therapy, charity and social care joined up. Thus the UK Stroke Forum and its conference were born, organised and managed by a steering committee composed of all the charities and stroke care professional bodies in the UK.

This forum was good in itself, but in addition, and despite the fact that its articles stated that it was not to be a campaigning body, the bringing together of all people interested in progressing stroke care inevitably led to discussion of controversial issues. None was more vital than progressing towards a comprehensive national stroke strategy for each country.

2006 saw another step forward with a joint campaign under the slogan 'Getting back to work after stroke' with the charity Different Strokes. Stroke moved high up the political agenda after the Westminster Public Accounts Committee deemed the National Audit Office report the most damning report on a health issue it had ever received. The year was rounded off by winning the best Healthcare and Medical research Charity award at the 2006 Charity Awards.

Snap shot from the Annual Report 2006

Our campaigning and awareness raising activities are central to achieving our vision of a world where there are fewer strokes and all those touched by stroke get the help they need. In 2005/06, we promoted key messages around stroke prevention and lobbied.



Staff from the Stroke Association contributed to the development and writing of the English National Stroke Strategy published by the Department of Health, which included quality marker performance and milestone targets, ring-fenced funding and, amazingly, goals on long term support in the community. Nearly everything which was written in the Stroke Association's 2005 Manifesto was included in this breakthrough Government strategy. This achievement was recognised by the Stroke Association being shortlisted as Britain's best charity for the first time in its short 15 year history, an honour to be repeated three more times in the next seven years but not yet with the distinction of actually winning the award.

Jon Barrick was acutely aware that funds were needed to drive forward the Stroke Association's role in stroke progression, and so fundraising was given a much greater prominence within the organisation. A concerted effort was made to professionalise and improve voluntary fundraising. A number of fundraising elements were present, direct appeals, regional fundraising, event fundraising, corporate fundraising, fundraising from Trust funds, and a legacy officer working to the Director of Governance. Jon immediately set to work to introduce major donor activity, and the longer term goal of professionalising all the Association's fundraising activity. A legacy team within fundraising was created, and led in particular by Charis Hingorani, and the very talented major donor leader John Harvey was recruited.

The legacy team built a long term campaign encouraging supporters to leave a gift to the Association as a legacy and, as a result, we have increased the number of legacy pledgers (i.e. people who tell us they have left a bequest to the Association in their will) from around 300 to 3,000 in 2014 since 2005. Legacy income advanced to approaching £9 million in 2013/14.

A programme aimed at developing a bigger and stronger network of support from more affluent supporters was initiated. The team adapted existing events like the Life After Stroke Awards and an annual operatic event, performed by the DIVA opera company, to good effect and this enabled the support of high net worth and highly influential individuals to the stroke cause, which has added many million pounds of contributions to the funding of research and other projects.

Snap shot from the Annual Report 2007

Andrew was 47 when he had a stroke. After three months in hospital he was referred to his local Communication Support Service. He attended his first group less than two weeks after being discharged.

Andrew said that when he first left hospital he found it very hard emotionally. Then someone from The Stroke Association came along and said, "I can help you". This was his first sign of hope.

At the time Andrew said he felt that he was getting better slowly and attended our Merton and Sutton Communication Support Service because it helped him to practise a bit at a time. He also said that it was a huge relief to be with others who understand and can help.



By 2014, under Jim Swindells, Fundraising Director, all fundraising databases had been integrated allowing for sophisticated segmenting of supporters and better attention to donor support which will provide a solid platform for fundraising into the future. Another priority for Jon Barrick was to make the Stroke Association UK-wide rather than working just in England and Wales, and in this he was supported by Professor Mansfield. This would enable broader campaigning on national stroke strategies and leverage of improvement by comparing country to country, and importantly by showing the Government that the Stroke Association was interested not in complaining but in giving something positive to make a difference.

Without a UK-wide presence the possibility of stroke being able to stand shoulder to shoulder with cancer and heart diseases was politically remote, as was the chance of winning major corporate business support from the big players. Jon Barrick believed that not being UK-wide was holding back the basis for achieving better quality stroke activity. Professor Mansfield's support was critical because, as we shall see, other Trustees were hostile to the idea of expansion across the UK. Professor Averil O Mansfield had been a Trustee since 1992 and from 2003 to 2008 was the much respected Chair of Council.

Most importantly, she and Jon Barrick understood their respective roles and the role of the Trustees, and they worked well together with a common belief in the strategy that had been devised. After she became Chairman, Professor Mansfield took the time to visit every regional office of the Stroke Association in order that staff could meet her personally. From stroke patients she often encountered the complaint that after leaving hospital they felt that they had fallen into a chasm left by lack of services, and thus all efforts to improve and expand the Association's provision of services had her full support.

Snap shot from the Annual Report 2008

Stephen was an international HGV driver when he had a stroke in 2000 at the age of 43. The arterial disease that caused his stroke also resulted in the loss of his left leg.

He said, "If I hadn't started going to the group I wouldn't have even been able to leave the house."

Stephen began attending Positive Action for Stroke, a Stroke Association service that helps stroke survivors back into community life, in Maesteg, in November 2006. There he was encouraged to express himself artistically and his paintings and drawings have amazed everyone. At the 2007 Life After Stroke Awards, Stephen was awarded the Susie Hulks Memorial Award in recognition of his extraordinary artistic achievement.



In 2009 Professor Averil Mansfield was succeeded as Chairman by Sir Charles George. In that year the number of Stroke Association community contracts to deliver stroke services rose from 140 to an astonishing 250, the momentum from the National Stroke Strategies in each country giving a huge boost to the quality of care. The services also made good sense from the perspective of the public purse, by helping to keep people from returning to hospital, keeping families together and delaying the need for residential and nursing home care. Under Sir Charles the number of Stroke Association long term support groups rose from five to 95, and there was a huge development of quality assurance activity, with the Association gaining external validation through Charter Mark, which evolved in CSE, customer service excellence, Investors in people and passing the NHS Information Standard requirements for all its information products. Also on the instigation of the new Chairman the prevention of strokes appeared much more strongly in the 2010 to 2015 strategy than it had before.



Professor Averil Mansfield and Professor Sir Charles George.

5. Expansion across the United Kingdom

The Stroke Association as it evolved in the early 1990s covered England and Wales but not Scotland or Northern Ireland, where the respective Chest, Heart and Stroke Associations continued their work in all three fields. An essential element of Jon Barrick's first Strategic Plan as Chief Executive in 2004 was the aim to make the Association UK-wide in its remit.

The Association needed to make sure there was a consistent voice for stroke throughout the nation. But this was a difficult and unwelcome decision for some Trustees who felt that historically Scotland and Northern Ireland had been yielded to their respective Chest, Heart and Stroke Associations. It was a divisive moment which led to the resignation of three long-standing members of Council: the Treasurer, Peter Lumsden, the former chair of the Research and Development Committee, Professor Walter Holland, and Dr Ashley Miller, who could not condone what they saw as a reversal of promises to sister charities. Walter Holland had been a committed member of Council for 30 years and, as we have seen, he had not approved of the change in England from Chest Heart and Stroke Association to the Stroke Association in 1992. Now he felt that the decision taken then by Scotland and Ireland to remain as Chest Heart and Stroke charities should be honoured along with London's promises not to encroach on their activities. He had been chairing the Research Committee of Northern Ireland Chest Heart and Stroke since 2001 and felt that he was well placed to gauge whether there was need for the Stroke Association in Northern Ireland.

Yet without a presence in these two major areas of the UK, it was difficult to raise funds from corporate donors who were themselves UK-wide in remit. As in 1992, fundraising needs were paramount. For Jon Barrick, the future benefit for people who had had a stroke was far more important than promises made years ago, and charity law enabled Trustees to review their strategies in the light of changed circumstance.

Snap shot from the Annual Report 2009

Anna was celebrating her 32nd birthday when she had a stroke. It changed her life overnight, leaving her with aphasia and slight paralysis to the right side of her body. It was a huge knock to her confidence when she had to stop the job she loved as a research nurse.

Anna joined our Newtownabbey Conversation Group and received support from our Family Support Service, helping to increase her confidence and communication skills. She felt so passionate about raising awareness of stroke that she signed up as a media volunteer and, in December 2008, was offered a job developing user involvement at the Stroke Association.

"If I could describe the first five years since my stroke it would be like I was treading water and I had to remind myself to breathe in and out. But since discovering the Stroke Association, I have been given armbands!"



6. The Stroke Association in Northern Ireland

Commenting on a consultation document 'Improving Stroke Services in Northern Ireland' in 2008, the Royal College of Physicians of Edinburgh made the point that Northern Ireland had a long history of stroke service development and in many respects had long led the way, but that this was no longer the case and Northern Ireland was now lagging far behind the rest of the UK in providing effective stroke treatment. There was a clear need for the Stroke Association to have a presence in Northern Ireland alongside the existing Northern Ireland Chest Heart & Stroke Association charity. This presence was achieved by means of a merger with a small charity called Speechmatters, which had evolved from Action for Dysphasic Adults in 2001 to provide speech and language services for people who had experienced a stroke.

The merger took place in 2006, and the joint body became officially The Stroke Association Northern Ireland in January 2009. The merger was negotiated through Eric McCullough, the then Chairman of Speechmatters, and Jackie White, the CEO and prime mover in this venture, who had the vision for a better future for people with aphasia and stroke under the wing of the Stroke Association. Jackie was succeeded by Tom Richardson as Director, Northern Ireland, who set about moving the main office into a more central position in Belfast. A new Northern Ireland Advisory Committee was set up, chaired by Professor Bob Stout and consisting of members who had worked in stroke medicine, general practice, nursing, public health, allied health professions, social care, business, human resources and finance.

Tom Richardson had retired from a career with Baxter Healthcare and wished to move into the voluntary sector, and this new challenge was ideal for him, particularly with Damien Coyle of the old Speechmatters as his Deputy Director. The Northern Ireland Stroke Strategy had been launched in 2008, and in February 2009 the new Association led on hosting a number of service user consultation events across Northern Ireland, involving more than 500 people who had experienced a stroke and their

carers, in order to help mould the implementation of the Strategy, particularly in stroke services.

Thus in Northern Ireland the Association inherited partnership benefits and it has been able to build other partnerships, such as those with the British Heart Foundation and Northern Ireland Chest Heart & Stroke (NICHHS) with whom it sits on the Northern Ireland Assembly All Party Group on Stroke and Heart Disease. Such partnerships have greatly eased the way, and the Stroke Association Northern Ireland has been careful not to expand its services at the expense of NICHHS. In addition, Speechmatters provided a doorway into speech therapy services, and new self-management pathways have been established both for Speech and Language Therapy Services and for the Information, Advice and Support Service.

In 2011 the Stroke Association in Northern Ireland facilitated the partnership between the Northern Ireland Multidisciplinary Association for Stroke Teams (NIMAST) and the UK Stroke Forum to join forces with a one day stroke conference hosted by the Stroke Association. While the conference focused on local issues, it attracted national and international speakers on improving stroke care. By 2012 the Association had 20 communication support programmes in place across the country and could call upon more than 350 volunteers. The Northern Ireland Life After Stroke Awards were also established that year. One area that still has to be addressed is that of stroke research, where a stronger sense of direction is needed and will continue to require concerted effort. The Association continues to work with all stakeholders to promote and progress stroke research in Northern Ireland. By 2014 the Association had a presence in every part of Northern Ireland with services growing to 25 communication support programmes.

7. The Stroke Association in Scotland

The first move in Scotland was made in 2006, when Jon Barrick and Professor Averil Mansfield attended a meeting with David Clark of Chest, Heart and Stroke Scotland in Edinburgh to discuss how the two charities might work side by side without conflict. Reassured that this was possible, though recognising that David Clark had made it clear that collaboration might be difficult, the Stroke Association went ahead with its plans, which were based primarily on adding to the stroke survivor voice in Scotland, advocating particularly in the sphere of social care which was not a focus of priority for CHSS. There were also fundraising needs given the extensive research spend of the Association in Scotland. Maddy Halliday was appointed as Director and an office was opened in Links House in Leith, Edinburgh, in 2007.

In line with regional governance in England, the new Director was to report to the UK Director of Services, but the special country status of her remit was acknowledged by setting up an advisory Scotland Committee. The Association had an impressive record of funding stroke research in Scotland and this would continue, but the task in relation to services and policy was to identify areas not already covered by CHSS. Unfortunately there was considerable opposition both from CHSS and from other people who were reluctant to countenance a Stroke Association presence, and progress was slow.

There was little sign of any reciprocal help to balance all the vital research funding. It took two years, for example, before Maddy Halliday was invited to join the Scottish Stroke National Advisory Group, apparently on the grounds that the Association had no services to offer as yet. As Director, Maddy Halliday had the vision to identify the gaps in services provision in Scotland and the ideas to fill them, but initially little financial power to put them into action.

Nonetheless, much was achieved even in the first year by a small team consisting of the Director, Communications Manager, Fundraising Manager and Administration Assistant. The Communications Manager was Angela MacLeod, now the longest serving member of staff in the Edinburgh office. Angela had first-hand experience of stroke, having suffered one herself in 2002, and was committed to the idea that people must be at the forefront of the Association's efforts. She and Maddy Halliday created innovative ways in which people who had had a stroke could be involved in the Association's activities as volunteers: the Scottish Reference Group for People affected by Stroke, for example, which is a volunteer advisory panel of people who are active on the Association's behalf at external events.

Unfortunately liaison with existing stroke clubs proved difficult, for most were not interested in affiliation with the Association, and there was no financial capacity to provide new clubs in areas where they were lacking.

Snap shot from the Annual Report 2010

Robert had a minor stroke at the age of 55. Seven months later he had a major stroke which left him paralysed on his left side and unable to walk.

Although many stroke survivors describe the physiotherapy they receive as a lifeline, helping them to regain confidence and independence, many do not receive the physiotherapy they need once they return home after their stroke.

A student physiotherapist provided Robert with therapy when he was in the stroke unit to help with his left arm weakness, but he received no more therapy after he left hospital. So when he heard that The Stroke Association was joining forces with the Chartered Society of Physiotherapy to raise awareness of the positive benefits of physiotherapy, Robert completed our campaign survey with the help of his wife.

"All of the physical improvements that I have made have been down to me and the support of my wife. On the positive side, I have been attending a communication group run by The Stroke Association. This has really helped my problems with speaking."



Whereas in England the NHS commissions services through a tendering process, the situation in Scotland is rather different in the sense that stroke services have been funded through direct grants to Chest Heart and Stroke Scotland. The Stroke Association specialises in post-hospital discharge services for stroke survivors and their families and has improved these over the years, and it felt particularly frustrated that its innovatory work could not gain an audience.

A particular disappointment for the Association has arisen from one of its best initiatives: the FAST campaign. Approaches were made with regard to joint working but these were dashed when it was announced that Chest Heart and Stroke Scotland was to deliver its own campaign, rather than working with the Association. Expanding services in Scotland generally has been difficult for the Association, but some headway has been made. A pilot scheme for stroke awareness training for social care workers was put in place in one local authority and there were soon plans to extend the training across the country. A major campaign, 'Back to a Life', to improve communication support services was launched in November 2008, after a survey had been undertaken to assess the extent to which stroke patients were receiving the speech and language therapy necessary to recovery after a stroke.

This was a collaborative project between the Association, the Royal College of Speech and Language Therapists, Chest Heart and Stroke Scotland and Speakability, and the survey of almost 300 stroke survivors with communication problems was carried out over several months.

There was clear need for improvement in the provision of services and for raising awareness among professionals of the impact that stroke can have on stroke patients in terms of communication. 2008 also saw the start of an advocacy project for disabled people, and the following year another collaborative event, User Involvement in Stroke Research, brought together the Scottish Stroke Research Network, the Stroke Research Programme at Glasgow University, Chest Heart and Stroke Scotland and the Stroke Association. In 2012 the Association's project on Stroke Advocacy and Self-directed Support attracted funding from the Scottish Government to 2015. One outcome was published in 2014: *Stroke, Advocacy and Self-directed Support: a guide for health and social care professionals*.

The Know Your Blood Pressure campaign got under way in Scotland in 2011 by means of a partnership with St Andrews First Aid, training some of their volunteers who would then become trainers themselves, and later training some of the Association's own volunteers in Scotland. In addition, St Andrews First Aid distributed the FAST leaflet to all those who participated in first aid training.

There is a strong and long standing tradition of medical research in Scotland, and despite perceptions that it was an English charity, the Stroke Association had been funding stroke research for many years before it had a presence in the country. For example, in the 1990s Professor Keith

Muir and his team in Glasgow received funding for their investigations into the use of graded compression stockings for stroke patients (Muir et al 2000). By 2011 eight research awards had been made for stroke research in Scotland, and the UK Stroke Forum had been held in Glasgow three years running. Professor Muir and the neurologist Professor Charles Warlow were founder members of the Scotland Committee, which has been chaired since 2010 by Dr Michael Cornbleet, a retired clinician with special interests in cancer who was formerly a senior medical officer with the Scottish Executive Health Directorate.

Dr Cornbleet sees the greatest achievement of the Association in Scotland, as in the rest of the United Kingdom, as the increased public awareness of stroke. It remains to be seen how the relationship between the Stroke Association and Chest Heart and Stroke Scotland will develop, and how the provision of services may be shared or advanced, but many people would now argue that there is no harm in innovative competition between health charities. It is certainly felt to be time that the Health Directorate in Scotland looked beyond a single charity for the provision of stroke services.

8. The Stroke Association in Wales

The CHSA (Chest Heart and Stroke Association) was present in Wales as the Volunteer Stroke Scheme (now Communication Support) in the late 70s and early 80s funded by the NHS. There were then perhaps seven staff in Wales. It became the Stroke Association in 1992 when Volunteer Stroke Scheme (VSS) Groups existed in Swansea, Cardiff, Newport, and Rhondda. There was an Information Centre and Helpline in North and South Wales in 1992 to join the London, Birmingham and Liverpool offices. Swansea, Haverfordwest and Llandrindod Wells Centres opened in 1995, by which time VSS had changed name to Dysphasia Support and there were Family and Carer Support staff in Cardiff and Swansea. By then there were about 25 staff in Wales with a Regional Manager North and South. All except the five Information Centres (who were funded by the Association) were funded by the Local Health Boards.

Snap shot from the Annual Report 2011

Alfred, 64, was an ambulance driver in the Welsh Ambulance Service, so when he realised that he was having a stroke he knew he must phone for an ambulance straight away.

He was told that he wouldn't walk, talk or use his right arm again. However, with the help of The Stroke Association's Buckley Communication Support Service in North Wales, his condition improved dramatically.

"I try and help people by showing them that, with help, you can get better. Alfred said, "When I say to them that the doctors told me I would never talk again, it makes them realise they can get better too."



Following the governance review of 2005, Wales had become a single region within the Stroke Association, replacing the earlier division into North Wales (with North West England) and South Wales (with South West England), but in practice there were still divisions between north and south for another decade. Once the Association was set upon becoming UK-wide, there was a new emphasis upon country status for Wales as well as for Northern Ireland and Scotland, although historically the situation in Wales was very different as it had always been covered geographically by the Stroke Association.

Work behind the scenes and with the stroke care profession in Wales eventually saw the Wales Government publish a National Directive for improvement in stroke services in 2008. This response by Welsh Government was a result of a damning audit report by the Royal College of Physicians. The Stroke Association played an important role in lobbying for these changes. Indeed in 2009 the Association provided evidence to the National Assembly Inquiry that investigated stroke services across Wales which would eventually lead to the National Stroke Delivery Plan that was launched by the then Health Minister in 2012 at the Stroke Association's Bridgend Community Services. This showed that a UK-wide charity that had built great local relationships could use examples of progress in one country to leverage progress in another. 2008 was also an important moment for Y Gymdeithas Strôc (the Stroke Association in Welsh) as they moved from below par accommodation in Cardiff, to a new purpose-designed building, reflecting the forward movement of the Association generally. The regional manager for Wales was replaced by the new post of Director Cymru in 2008, which was held initially by Wendy Davies but then in 2010 by Ana Palazón, who had previously spent 15 years as Director of Help the Aged in Wales. An advisory Wales Committee was set up with Association Trustee, Carol Caporn, in the chair (succeeded in 2011 by Stuart Fletcher), and their first meeting was held in October 2009.

Ana Palazón has succeeded in creating an all-Wales team and the old north/south divide is fast disappearing. Whilst some services were lost as a result of the recession of 2008 to 2012, all Wales service coverage has been preserved, providing direct services to almost 50% of stroke survivors in Wales and campaigning on a national and local basis with almost 50 staff and nearly 400 volunteers. Given the state of public funding, the growth in contracted services will have to be complemented by the development of community initiatives. To achieve this, the number of affiliated stroke clubs and of volunteers supporting the Association will be essential.

9. The Isle of Man and Jersey

The Isle of Man has its own Manx Stroke Foundation, which was founded in 1997 by a small group of health professionals, with help from Mo Wilkinson and the Stroke Association, to offer support to people after stroke. The first President was Dr Edgar Mann, who served for eight years until Dr G S Khurajam took over in 2005. The latter year also saw the long-desired introduction of the Stroke Association's Family Support and Communication Services supported by the Foundation and funded by the Department of Health and Social Security for the Isle. The foundation is a very active Stroke Club in Onchan, open to the Foundation's members, who number around 100. A major donation of £21,000 from Zurich International enabled the Foundation in April 2011 to make a grant of £10,000 to the Stroke Association specifically for stroke research along with other regular generous donations over the years to the Stroke Association.

In Jersey funding for services had to be sought from donors, and Lloyds TSB enabled Stroke Association services to be introduced in 2007, in the form of a visiting service from St Helier, under the umbrella of the South Central/South West England region.

10. Europe and the wider world

Over the last decade or so, the Stroke Association has worked to become recognised as a major player in matters of stroke world-wide. As one example of partnership working outside the United Kingdom, Mo Wilkinson had used her experience of developing stroke services to help to set up the Japan Stroke Association in 1997. Closer to home, the Stroke Alliance for Europe (SAFE) was founded in 2004 with the aims of promoting awareness and prevention of stroke, to improve access to services and to promote research into stroke, and its members represent groups of patients across Europe. The Stroke Association is one of the British members, and its Chief Executive, Jon Barrick, has acted as Secretary to SAFE since 2007. Since 2006 the Stroke Association has supplied the secretariat for SAFE. In 2014 he was elected President of the board of SAFE. He also sits on the Board of the World Stroke Organisation (WSO), which was established in 2006 with the aim of improving access to services and promoting research internationally. In 2011 the Stroke Association produced a Toolkit on how to develop stroke support organisations for the World Stroke Organisation and SAFE, which is now available in many languages and has formed the main reference point for many individuals trying to start up a new stroke organisation in their country.

11. Stroke Association Community Services 2004 to 2012

By now, Community Services covered Dysphasia support services, Family support services, Education/Training and Information Service, Hospital Information Points, the Young Strokes pilot service and the Welfare grant service. Regional helplines were merged together into a single UK-wide helpline in 2006, run from London, the only move against the tide of the Association's decentralising strategy.

One of the key figures in the Association in the first decade of the new century was Joe Korner, who became Director of External Affairs in January 2005, heading a department which spans policy development, campaigning, publications and events. Joe came from a background of dedicated campaigning from the peace movement in the 1970s to the Muscular Dystrophy Campaign of the early 2000s, and he had a personal stake in stroke illness with close relatives having succumbed to it. He saw the need to challenge public concepts about stroke and within a month of his appointment he had produced a manifesto identifying the pathway forward for stroke services, which was sent to every Member of Parliament.

This was used in the government's National Audit Office Review of Stroke Services in November 2005, which was damning in its view of the lack of stroke services in Britain. The National Audit Office review led on to the notion of a much-needed National Strategy for Stroke Services, and work was soon underway with an advisory group which included Jon Barrick, Elaine Roberts, and Joe Korner from the Stroke Association. The Strategy was launched in December 2007 at the UK Stroke Forum in Harrogate, where the Secretary of State for Health, the Right Honourable Alan Johnson MP announced that funds of £115 million would be made available for the NHS to enable local health authorities to develop and implement a stroke strategy. A proportion of the funding was set aside as ring-fenced funding available for three years, starting in April the following year, and this gave the Association the opportunity to identify areas where services were inadequate, both geographically and in their range.

By then Chris Clark had joined the Stroke Association as Director of Operations. Originally a hospital administrator, he had switched to the charity sector first to work with St Christopher's Hospice in London and then to serve for six years as Chief Executive of Action for ME (Myalgic Encephalomyelitis), before coming to the Association in January 2007. His major task was to reboot services, and he began by holding an internal conference in the Cotswolds for regional managers to agree new goals based on a commitment to identifying the needs of stroke survivors and their families and to innovating high quality services to meet those needs. Everyone was asked to speak of past successes and failures and the lessons that had been learned. These 'case studies' helped to stimulate new thinking and to motivate and empower managers, positioning them to take advantage of the opportunity created later by the stroke strategy.

After the launch of the National Stroke Strategy, the preparatory work undertaken at the Cotswolds meeting bore fruit with a rapid expansion, doubling the number of services to over 300 and the number of stroke survivors in direct contact with locally based staff to 35,000. Over 3,000 volunteers worked with the 600 locally based staff to provide care and support, often using their own experiences to encourage and give hope to others.

By 2009, from £12million in 2003 the Stroke Association turnover had reached £29million, with the two most substantial areas of income now being service income and legacies.

Snap shot from the Annual Report 2012

Jacqui Nestor didn't know she had dangerously high blood pressure until she had it checked at one of our 'Know Your Blood Pressure' events.

She was urged to see her GP and further tests showed that she had a leaky heart valve. Jacqui is now on medication to control her blood pressure and has changed her lifestyle to reduce her risk of stroke.

Around 40% of strokes could be prevented by controlling high blood pressure.

The Scottish Football Association helped us to promote the campaign by taking the blood pressure of referees at a Scottish Cup Semi-Final game, and showing our campaign messages on the big screen. This resulted in widespread media coverage across Scotland.'



The National Stroke Strategy was essentially for England, and Wales had its own strategy launched in 2007 as *Improving Stroke Services: a programme of work*. This was followed in 2008 by *Improving Stroke Services* in Northern Ireland. Scotland had had a *Coronary Heart Disease and Stroke Strategy* since 2002, and this was updated in 2009. The outlook for stroke patients had vastly improved across the UK, although inevitably among people who had suffered stroke and their carers there was bitterness that the Strategies had not come sooner, as they realised that their experiences could, and should, have been so much better.

For the Association's fundraising team, the task became one of 'surfing the wave', creating a programme of regular campaigns aimed at raising public awareness of stroke as a medical emergency. Income from contracted services in 2008 and 2009 far outstripped expectations and at last the geographical coverage of stroke services was improving and becoming less of a 'postcode lottery'. Unfortunately this story of expansion was to change, for the three years of ring-fenced funding promised by the Government in 2007 suffered the effects of Britain's financial recession, and at the end of the third year's funding the debt crisis and restrictions on public funding struck at the very point when it had been hoped that Local Authorities would find the money to continue the service. There was a real risk that much of the good work would be undone and the Association might experience major cuts in the number of services.

Elaine Roberts, Director for the North of England, and Judy Walker, Director for the South of England, combined forces to help their managers to defend their services. It was vital that the Association should demonstrate not only the value of its services but the financial benefit to the state of providing high quality and effective services. Regional Managers and their hard pressed Assistant Managers worked heroically to show commissioners what would have happened to individuals if the Stroke Association had not been there in the first place and how this would have affected their lives. They found commissioners prepared to listen sympathetically to well-argued cases, and the amazing result was that out of more than 300 services, only nine were lost. Jon Barrick was able to report to Council 'We have emerged from the first round of threats to our services more or less intact'. Nonetheless during these years to 2012 the Stroke Association battled with the general recession, with its income flat-lining, but somehow staff morale remained good and a lot of activity was directed to getting the Association ready for a big move forward when the recession ended. In 2012/2013 the Association came through with a good £33million plus turnover figure and this was replicated in 2013/2014.



Blood pressure being taken during the 'Ask First' campaign in 2011, part of the long-running Know Your Blood Pressure campaign.

A new campaign was launched in November 2006 aimed at providing more information for stroke patients: 'Nobody told me'. This was followed by a campaign to celebrate good practice in what can be achieved with an integrated stroke care pathway after the patient leaves hospital: *Getting Better: improving stroke services across the United Kingdom*. After a major trial funded by the Association, the National Audit Office emphasised the importance of Early Supported Discharge for patients in hospital after a stroke in its *Progress in improving stroke care (2010)*. Although the Association's survey of 1,100 stroke patients, 'Moving On', showed that one in five stroke survivors was not provided with the necessary physiotherapy. Nonetheless a pilot service was set up in Durham to test how well Early Supported Discharge might work as a care pathway in which less disabled patients can be discharged earlier from hospital providing that the necessary therapies are in place outside. Its success led to ESD becoming an essential part of stroke care practice in many stroke units throughout the country.

The Stroke Association's first radio advertising campaign, 'Ask First', was launched in 2011. Its object was to make people aware of strokes related to atrial fibrillation, by describing the symptoms of this condition which causes around one in six strokes and explaining that atrial fibrillation can be easily diagnosed and treated. That same year, the Association hosted the first UK Stroke Assembly, now an annual conference for people who have suffered stroke and their carers. This is a collaborative venture with a steering group composed of representatives from InterAct Stroke Support, the Stroke Club Consultation Group, Speakability, NIHR Clinical Research Network and the Stroke Association.

12. Life After Stroke

A phrase used originally by Valerie Eaton Griffith, this was the title of a section of the National Stroke Strategy and on Joe Korner's recommendation it became perhaps the most evocative of all Stroke Association slogans. Positive and encouraging, it sums up the Association's approach to the future for people who have suffered stroke and the process of rehabilitation – in Elaine Roberts' words, 'walking alongside holding the bicycle seat and knowing when to let go'. The Association renamed its Rehabilitation and Support Services as Life After Stroke Services, and resolved to create a Life After Stroke Centre at Bromsgrove in Worcestershire.

The Chairman Sir Charles George took a keen interest in the project aiding in particular the fundraising side of the activity. This was one of his strengths and he delivered big support in growing the major donor activity and income possibilities. By February 2012 more than £1million had been raised for the project, which aimed to offer a permanent space for local people who had had a stroke to participate in our services, from communication support to reablement activities and which would be the first facility of its kind in the United Kingdom. It was opened on 15 May 2012 by HRH The Duke of Kent and has proved an enormous success, providing a warm and welcoming environment for people who have had stroke, their families and carers, and a place where healthcare professionals can get together and share their knowledge.

Strategically the Life After Stroke Centre at Bromsgrove provided important expansion space for additional staff as the Association's headcount continued to grow, and by 2013 a multimedia centre was being opened on the premises enabling the production of digital video, graphic and audio material. The opening of Bromsgrove also launched a major Life after Stroke campaign for greater efforts to be made to ease the way for people who had had a stroke, and *Struggling to recover: Life after Stroke campaign briefing* graphically described the experiences of eight stroke patients after leaving hospital. This was, as Jon Barrick wrote in his introduction, an uncompromising 'call to action for all who care about stroke survivors to deliver on promises already made' (SA 2012:5).

Another innovation launched in May 2012 was Stroke Awareness Month, which has become an annual event. Linked to Life after Stroke was the Short-changed by stroke campaign, which drew attention to the financial impact of stroke on people of working age and their families, when income swiftly decreases as expenses increase, and the benefits system is inadequate in supporting these younger stroke survivors to live a dignified and independent life.

13. The Stroke Association and research in the Twenty first century

Like most charitable organisations, as the Stroke Association grew in size and complexity the role of its Trustees became inevitably distanced from the practical running of the charity. Their role should be in strategy and in particular the strategy of research funding. As always the Association was well endowed with leading medical advisors and the Trustees included some of the finest clinicians and researchers in stroke medicine.

As we have seen, research was one of the aims of the Association from its earliest beginnings as the National Association for the Prevention of Consumption, and direct funding of research goes back to the 1930s, with stroke becoming a focus as early as 1962. After the historic decision to become the first major charity devoted to stroke, the Association invested more than £40million in stroke research in the 20 years between 1991 and 2011, mostly research into prevention and rehabilitation. Its future aspiration is to grow large enough to be able to devote an even larger proportion of income to research.

It was not until 2008 that the Association launched its first fundraising appeal specifically for research, thereby increasing public appreciation of its role in funding research. This was led by Professor Hugh Markus on behalf of his research project on the use of stenting in the prevention of stroke, and the appeal raised a record £200,000, demonstrating that research was not a difficult subject for fundraising. The following year, the Princess Margaret Fund was launched, with the help of Viscount Linley, Princess Margaret's son, as Patron of the fund, specifically to fund ground-breaking research into stroke, with the aim of raising £10 million over the next five years. In addition, the Association entered into collaborative projects with the Wellcome Trust, the British Heart Foundation and the Alzheimer's Society, to fund joint research grants and fellowships.

Snap shot from the Annual Report 2013

About 40% of children with sickle cell anaemia (SCA) will have small silent strokes before they reach the age of 14 but, currently, the only way to identify them is with a brain MRI scan.

Funding was identified for Dr David Rees and colleagues at King's College London to develop new blood tests designed to detect silent strokes in children with SCA.

This project will study the blood of 50 children with the genetic condition to develop a simple blood test to identify silent strokes early so that treatments can be started to prevent further strokes from happening.



Since the mid-1980s the Association had held annual Scientific Conferences for researchers, and these evolved under Professor Peter Fentem's guidance into the UK Stroke Forum in 2006, an important annual event bringing together research workers from across the country. Another important event of 2006 was the creation of the UK Stroke Research Network by the Department of Health with considerable input from the Stroke Association. The Network has stimulated more and better clinical trials with the participation of ever increasing numbers of stroke patients. Importantly for the Association, co-funding research in this way with the Department of Health allows a limited research budget to have a greater impact. By the time that *Saving lives: 20 years of investing in vital stroke research* was published by the Stroke Association in 2011, the budget had increased from £1 million in 1991 to almost £3 million a year.

There is an inevitable danger that conflicting interests may arise in decisions about which research programmes to support. For this reason the Research Strategy Committee was established in 2004, with input from knowledgeable staff and from people who had had strokes themselves. It was chaired for the first few years by Professor Peter Fentem, who had held the first chair in Stroke Medicine at Nottingham, and currently by Professor Marion Walker, who holds the chair of Stroke Rehabilitation at Nottingham.

The Committee's priority has been to fund clinical research into stroke prevention, emergency treatment, brain research, rehabilitation and community care. The Stroke Association's Therapy Research Unit at Salford had made huge advances in the way in which rehabilitation research was carried out, and after the Unit closed, the work was carried on by a new Stroke Association Research Rehabilitation Centre in Southampton, established in 2004 under the leadership of Professor Ann Ashburn. Here the focus of research was on the understanding of balance and mobility after stroke.

It is important that the results of stroke research are disseminated to those outside the world of research, and one way in which the Stroke Association achieves this aim is the annual Keynote Lecture. HRH The Duke of Kent had always been an active and involved Patron of the Stroke Association, and in October 2005 the first of a series of lectures in his name was given at the Royal College of Surgeons in London. Always held at prestigious venues, these lectures have been very important in raising funds from major donors.

14. A new brand

Twenty years after its inception, Sir Charles George and Jon Barrick introduced discussion about the possibility of the Stroke Association refreshing its image to aid the push forward on top of earlier achievements. Market research had shown that 40% of people did not know that the Association was a charity and a third of major funders of research did not know that the Association was involved in funding research. The need for a re-brand could not be clearer.

By dropping 'The' from their title, the name of the Association became simply 'Stroke Association' in 2012, a name which is brief and to the point and above all easier to find in directories. From the original twelve-word long title in 1898, 'National Association for the Prevention of Consumption and other forms of Tuberculosis', the various name changes have become not only shorter but more and more focused, reflecting the aspirations of a charity moving with the times. Along with the name change came a new logo and a striking use of colour in the now familiar brush strokes of yellow and purple.

The logo features the word 'Stroke' in a large, bold, purple brush-stroke font. Below it, the word 'association' is written in a smaller, lowercase, sans-serif font.

Stroke Association Logo

The logo shows the Welsh word 'Strôc' in a purple brush-stroke font, followed by a vertical line and the English word 'Stroke' in the same font. Below 'Strôc' is the word 'cymdeithas' in a smaller, lowercase, sans-serif font. Below 'Stroke' is the word 'association' in the same font.

Stroke Association Logo (bilingual)

The use of the colours and the handmade font were deliberately crafted to make the organisation appear and be more hopeful and user friendly. Purple was chosen as the main colour, but reinforced by golden yellow, with the process blue being kept to maintain the link with the more medical/professional aspects of the associations work and the previous logo.

The word 'stroke' was bedded on top of association, indicating that the Association would support and be an ally to all involved in stroke, a graphic representation of the new brand promise. The logo was designed to ensure stroke would be visible on lapel badges from at least 9 feet away, and to stand out on publications, particularly where lots of other logos were also being attached. After some discussion it was agreed that Wales should have a bilingual version of the new logo.

After the re-brand, the Association moved up to 49th place in the Charity Brand Index, and there was a 4% increase in public awareness of the Association.

Snap shot from the Annual Report 2014

"After my stroke, I set myself a goal to walk again. I wanted to do 'Step out for Stroke' to raise money for the Stroke Association but, also, to challenge myself. On the day I walked half a mile, it took me a really long time but I did it!" Said Rachel, a stroke survivor.



15. Endeavours over more than a century

The long history of the Stroke Association makes it one of the most enduring health charities in Britain. Its focus has changed from tuberculosis to chest and heart diseases in 1958, to chest, heart and stroke illness in 1976 and finally to stroke illness alone in 1992, but its primary concerns have remained remarkably constant: education and awareness, practical care and rehabilitation of the patient, advice to government, encouragement of research, and a warm humanitarian approach. In the early years it was not perhaps appreciated that paid staff and effective fund-raising were the keys to realising the Association's aims, but that changed in the 1930s. There was also a somewhat conservative approach to new developments in preventative medicine, but that too gave way to a more positive and courageous outlook in the mid twentieth century.

The Association certainly showed its mettle in deciding to focus on stroke at a time when stroke illness was widely regarded as untreatable, and its recognition of the needs of people who have suffered stroke and the needs of their families has been unsurpassed. There is so much of which the Stroke Association can be rightly proud, from the growth of services to the ever-increasing funding for vital research, fostering public awareness of stroke and encouraging cooperation between professionals at the UK Stroke Forum.

There has been an important increase in public understanding in recent years, which means that the Association can move on from explaining stroke to persuading people that prevention and treatment of stroke are possible – just as, a century ago, the same progression was being made in the field of tuberculosis. Over the course of its long history, the Association has been fortunate in the high calibre and dedication of those who have served it and ensured its success.

16. Acknowledgements

I am indebted to the staff of the Wellcome Library, in particular archivist Amanda Engineer, and to staff in the London Metropolitan Archive and the Library of the Royal College of Physicians in Edinburgh for their friendly help. For the more recent history of the Association I have had the benefit of conversations with staff, Trustees and Committee members, past and present, for which I am most grateful: Jon Barrick, Holly Bowden, Chris Clark, Norman Connor, Dr Michael Cornbleet, Professor Peter Fentem, Margaret E Goose, Maddy Halliday, Professor Walter W Holland, Joe Korner, Professor Averil O Mansfield, Elspeth Molony, Professor Keith Muir, Ana Palazón, Richard Polson, Tom Richardson, Elaine Roberts, Mo Wilkinson, the late C Alan Wood and his daughter Bridget Robbie, and Morag Younie. Chris Holme was kind enough to share his recollections of the CHSA centenary conference. Mo Wilkinson has kindly allowed the inclusion as Appendix 1 of her fine tribute to Patricia Neal. I am particularly grateful to Mo Wilkinson and Chris Clark for reading and commenting on a draft of the services section of this paper and to Jon Barrick for his very helpful comments on the entire paper and for his invaluable additions to the text for the years after 2004. Jaslinder Bansal has shown me much kindness on my visits to Stroke House. Matthew Molony kindly helped with photographs of artefacts. Fenella Brown and her design team have transformed the bare bones of my text into this attractive book, and I am greatly in their debt.

I am especially grateful to my daughter, Elspeth Molony, for volunteering me for the task of writing the Association's history and to Jon Barrick for entrusting it to me.

This history of the Stroke Association 1898 to 2012 was written by Anna Ritchie and from 2013 onwards by Jon Barrick.

About the author

Dr Anna Ritchie, OBE, BA, PhD, FSA, Hon FSA Scot.

Anna Ritchie is a retired archaeologist, whose passion has always been to interest others in their past. She is a former Trustee of both the British Museum and National Museums Scotland, and a former member of the Ancient Monuments Board for Scotland.

Anna has spent many years teaching undergraduates and life-long learners in the Universities of Edinburgh and Cambridge, and her published books range from Neolithic Orkney to St Columba's Monastery on Iona.

As a volunteer with the Stroke Association, it has been her pleasant and deeply interesting task to write its history.

Contents

Part 3 - Appendices and references

Appendix 1	81
Appendix 2	84
Appendix 3	85
Documentary sources	88

Appendix 1

Patricia Neal 1926 – 2010, Honorary Vice President, The Stroke Association Tribute by Mo Wilkinson, September 2010

Had it not been for the tragic life events that changed the fate of American actress Patricia Neal in 1965, the Stroke Association would not have developed in the way that it did, from a small chest and heart charity, into a national leader in stroke care and research.

On the 17 February 1965 whilst bathing her daughter Tessa, Patricia suffered the first of a series of three massive strokes. She was 39 years old, an Oscar winning actress married to the writer Roald Dahl and was in the early stages of pregnancy with her fifth child. She was in a coma for 21 days and was not expected to live. When Patricia regained consciousness and learned that her baby was safe, the doctor told her husband that he didn't think that he had done either of them a favour by fighting to save her life. At that point she could not walk, talk or even think and had no control over what she could or could not do. She later described her feelings at that time of being trapped inside of herself, a prisoner in an oppressive, small and terrifyingly lonely place with the world around her strange and hostile.

After a month in hospital in America, where the family had been staying during the shooting of a film Patricia was starring in, they returned to their home in England, a quiet country house in Great Missenden. As soon as they arrived home, Roald, never one to sit back and let things take their natural course, decided that Patricia had to get better. He had married a glamorous and exciting woman and he wanted her back. So, he organised an army of friends and neighbours to visit her in hourly shifts for six hours a day, five days a week. They played dominoes, helped with cooking and other skills that had been lost and provided activity and stimulation to encourage Patricia out of the apathy and inertia she was suffering.

After several months she began to show signs of progress but her language was still severely impaired by the strokes. Doctors had warned that after the first six months she would not make any further progress. Patricia also believed that she had recovered as much as she possibly could and was tired of the daily grind and hourly routine of volunteer activities and rehabilitation. She was depressed. She had lost her place as a mother in her children's lives. Roald, out of necessity, had taken over the running of the house. She had no role. Everything was being stripped away and she felt suicidal, so Roald agreed to stop the daily ritual of volunteers coming to the house until after the baby's birth.

Their daughter Lucy was born on the 4th of August, and much to their relief, she was a healthy and beautiful baby. The birth heralded the beginning of a new regime for Patricia. Roald, tenacious as ever, had discovered that someone by the name of Valerie Eaton Griffith lived in the village and that she was recovering from a severe illness herself. Much to Valerie's surprise, Roald telephoned her and asked if she would be prepared to see Patricia daily and take over from the army of volunteers that had previously worked with her. With no experience whatsoever, and not having met either Roald or Patricia before, Valerie found herself agreeing to take on the task. Roald had shrewdly thought that Valerie, because of her own illness, would come equipped with insight into the isolation and oppression that Patricia felt. He was right, and there was an immediate and powerful rapport between the two women. Valerie recognised that what Patricia needed most of all was to be treated with simple human respect.

Valerie was a totally untrained amateur and worried about having no professional guidance, but never the less she put aside her fears and began an amazing journey with Patricia. They had no map; they called it a treasure hunt. Five days a week Patricia was taken to Valerie's house where for hours each day Valerie would search intuitively for ways of connecting to the buried knowledge and humour in Patricia's damaged brain. She used games, word puzzles, cards, dominoes, pictures and news items about celebrities in magazines and newspapers. She used anything that was relevant to Patricia's world that brought a spark of recognition in her eyes, made her laugh or would hold her interest for a few minutes. It was not easy. There was much repetition. Maintaining concentration and interest was exhausting for both of them but slowly Valerie learned what made Patricia tick and devised a programme to appeal to her interests and intelligence. She discarded anything that bored her or was too difficult. Her aim was to build Patricia's confidence and belief in herself again as she struggled in the darkness.

For two long years they worked together in this way. Valerie's stubborn perseverance matched by Patricia's strong instincts for survival brought about an amazing degree of recovery to the point where Roald pressured Patricia to return to her acting career, even though she had still not regained some physical abilities and had considerable communication and memory problems. She was sick with fear at the prospect, but with Valerie's support she went back to work and was soon nominated for another Oscar.

Patricia and Valerie's emotional and traumatic journey together also created a life-long bond and love between them. And, little did they realise as they stumbled through those gruelling and sometimes hilarious daily sessions that they were developing, by trial and error, a model of amateur rehabilitation that would be used in the future by thousands of stroke sufferers throughout the country, paid for by the NHS and become an integral part of stroke rehabilitation.

With Patricia spending more time filming in America Valerie went on to help the writer Alan Moorehead who had also suffered a stroke, but gradually she began to concentrate on her own life again. However, she couldn't stop herself thinking about what she had learnt and how she could use the knowledge to benefit other stroke sufferers from a wider cross section of society. She knew there was a need from the thousands of letters Patricia and Roald had received and from the many stroke sufferers she had met. Patricia was privileged and had high expectations from life, as did Alan Moorhead. Also, Patricia's husband although a devoted family man, had the ability to become emotionally detached and objective about doing what he felt would ultimately bring about the best possible outcome for his wife, who often referred to him as Roald the rotten when he drove her to the edge of her limits. In retrospect she knew that his determination was her salvation.

For others without that driving force behind them Valerie decided that she would like to pilot a service using volunteer helpers to test out the potential benefits of a structured support system for those with communication difficulties after stroke. It would be based on her experience with Patricia and grounded in the philosophy of building self-confidence first for maximum possible recovery. She understood the inextricable link between the two but wanted to test this out with a more diverse group. In 1972, to this end she boldly took her ideas to the Department of Health and Social Security. The Department was interested but felt the need for a trial before considering it further. Within months Valerie managed to persuade the Chest and Heart Association to sponsor two pilot schemes.

After about 18 months both pilots were fulfilling all of their aims. Evaluation and independent witness from health professionals showed positive results in both schemes. Every member showed improved social skills, which had an impact on their quality of life and helped reintegration into normal social activities. Also, there was less stress on families. The results were published in the British Medical Journal in 1975. The Scheme then spread and proved its adaptability in both urban and rural settings. It was known as The Volunteer Stroke Scheme and was so successful that in 1976 the Chest and Heart Association became The Chest, Heart and Stroke Association.

Both Patricia and Valerie were very proud to be appointed Honorary Vice Presidents during this period in recognition of what they had achieved. Patricia did all she could to support the work of the Association and headed up the first ever Stroke Campaign in 1986 when she gave a very moving speech that will be etched on the memory of all who heard her. It was one of the most effective campaigns ever launched for stroke, which brought awareness and enlightenment about stroke prevention and treatment to the public's attention for the first time.

By 1990 the focus of the Association's work was on stroke with around a hundred stroke services working in cooperation with NHS Speech and Language Therapists covering the length and breadth of the country, as well as new services to support families and the setting up of Information Centres outside of London. At this point the Association decided to concentrate all of its attention and resources solely on Stroke and became The Stroke Association. Since then it has become a national and international force in combating the devastation that stroke illness can bring to a family and been at the forefront of research as well as lobbying and campaigning for better services at government level.

Patricia's story raised the level of awareness about the consequences of stroke illness when little was known about rehabilitation and she became a symbol of strength and courage for many as she used her high profile to maximise the work of the Association and fight for better care for stroke survivors. She continued to support the Association in many ways until a few years ago when frail health curtailed her frequent visits to the UK. Being an actress, she described her life as something compared to a Greek tragedy. She and Roald suffered the loss of a child. Their only son acquired brain damage as the result of an accident involving a New York taxi. Her strokes followed, and then she endured a painful divorce from her husband of 30 years who soon after married one of her best friends. Despite all of these sorrows her resilience, compassion for others and her refusal to succumb to self-pity has left a legacy of hope to many of her fellow stroke survivors in the knowledge that her journey demonstrated that recovery is a process that can continue for a lifetime.

She died in the bosom of her family aged 86 years old and on the eve of her death said to them 'I've had a lovely time'.

Appendix 2

Association officers and accommodation

Chairmen of Council

1899	Sir William Broadbent
1907–1909	Sir Herbert Maxwell
1909–1920	Lord Balfour of Burleigh
1920–1933	The Hon Sir Arthur Stanley
1933–1938	Sir Robert Philip
1938–1974	The Marchioness of Titchfield/Duchess of Portland
1974–1984	Lord Hill of Luton
1984–1985	Lord Cameron of Balhousie
1985–1993	Lord Smith of Marlow
1993–2003	Lord Skelmersdale
2003–2009	Professor Averil O Mansfield
2009–2013	Sir Charles George
2013–present	Sir David Varney

Secretary-General

1939–1958	Dr J Harley Williams
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Director Generals

1958–1973	Dr J Harley Williams
1973–1985	Sir Ernest Sidey
1985–1993	Sir David Atkinson
1993–1997	Dr Sylvia McLauchlan

Chief Executive Officers

1997–2004	Miss Margaret E Goose
2004–present	Jon Barrick

Appendix 3

Archive in Stroke House

SA MS 1

National Association for the prevention of Consumption and other forms of Tuberculosis, Minutes of Annual General Meetings and Extraordinary General Meetings 1899–2001.

SA Ms 2

Board of Directors of Health Horizon Ltd Minutes, April 1967 – August 1997.

SA Ms 3

Share Register of Health Horizon Ltd/Stroke Association (Trading) Ltd.

SA Ms 4

CHSA Annual General Meeting Minutes 23 July 1991 – 2 September 1998 (these are duplicates of those in Ms 1, though they are signed).

SA Ms 5

CHSA/SA Council Minutes 1981–present

SA MS 6

CHSA Stroke Committee/SA Research & Development Committee Minutes 1982–2003

SA Ms 7

CHSA Executive Committee/SA Executive Committee Minutes 1981–present

SA Ms 8

Letters to Sir William Broadbent from Lord Lister (Professor of Surgery at King's College, London) and Sir Francis Knollys, Secretary to the Prince of Wales.

SA Ms 9

Documents relating to the change of name from National Association for the Prevention of Consumption and other forms of Tuberculosis to National Association for the Prevention of Tuberculosis

SA Ms 10

Printed agenda for EGM on 16 December 1949, concerning excluding age limit imposed on members of Council by the Companies Act 1948

SA Ms 11

Documents relating to the change of name from The National Association for the Prevention of Tuberculosis to The Chest, Heart and Stroke Association, 1958

SA Ms 12

Printed offprint from Transactions of the 24th Annual Conference of the National Association for the Prevention of Tuberculosis, London, June 29th÷July 2nd, 1938. 38 pp: 'Proceedings at the annual Care Committee and seal sale meeting, Wednesday, June 29th, 1938'.

SA Ms 13

Documents relating to the Spero Fund for the Industrial Welfare of Tuberculous Persons

SA Ms 14

Documents relating to Health Horizon Ltd

SA Ms 15

Four copies of document 61274, Memorandum and Articles of Association of the Chest, Heart and Stroke Association, according to Special Resolution passed on 14 April 1976. One copy contains certified loose extracts from the Memorandum.

SA Ms 16

Letters and documents concerning the Exchange Control Medical Advisory Committee, 1955

SA Ms 17

Personal papers of Dr Harley Williams, concerning financial matters.

SA Ms 18

Typed extract from Council Minutes of 5 March 1959 concerning new seal for CHSA and its use.

SA Ms 19

Resolution for Council 16 March 1972, proposing the creation of a General Committee

SA Ms 20

Photographic and other material

SA Ms 21

Legal document for lease of rooms at BMA House, Tavistock Square

SA Ms 22

Copies of Memoranda of Agreement between CHA/CHSA and individual authors of publications 1969–1980

SA Ms 23

Correspondence anent an anonymous gift to the Association of £5000, 1977–1979.

SA Ms 24

Documents relating to CHA retirement benefits plan.

SA Ms 25

Copy of Charitable Collection (Regulation) Bill 1938.

SA Ms 26 Certificate of membership of NAPT in The British Film Institute, 1935.

SA Ms 27 Photocopy of Deed of Settlement 1970 for the establishment of the Care Cards Association of Charities.

SA Ms 28

Legal agreement between the British Heart Foundation and the Chest and Heart Association 1962, relating to research.

SA Ms 29

Joint funding Papers for East Birmingham Volunteer Stroke Service 1983–7.

SA Ms 30

Insurance papers.

SA Ms 31

Birth and marriage certificates.

SA Ms 32

Audio tape attributed to Dr Harley Williams.

SA Ms 33

Seal Sale Committee Minutes 1952–1961.

SA Ms 34

The British Stroke Foundation, AGM minutes August 1992–September 1996.

SA Ms 35

Northern Ireland Committee Minutes 2007–2012.

SA Ms 36

Research Strategy Committee Minutes 2004–2007

SA Ms 37

Scotland Committee Minutes 2008–2013

SA Ms 38

Wales Committee Minutes 2009–2011

SA Ms 39

Jersey Committee Minutes

SA Ms 40–43

SA archive held in Salford, Manchester, material given to Mo Wilkinson by Valerie Eaton Griffith, concerning the Volunteer Stroke Scheme.

Documentary sources

Archive

Minute books and other material relating to the history of the Stroke Association between 1899 and 1991 are housed in the Wellcome Library for the History and Understanding of Medicine, 183 Euston Road, London NW1 2BE (cat no SA/NPT), with the exception of the Minutes of Annual General Meetings from 1899 onwards and Council Minutes from 1981 onwards which are in the archive in Stroke House, 240 City Road, London EC1V 2PR (see Appendix 3).

References

Aberdeen, Countess of (ed) 1909 *Ireland's Crusade against Tuberculosis: being a series of lectures delivered at the Tuberculosis Exhibition 1907*. Dublin: Maunsel & Co.

Bauby, J-D 1997 *The Diving-bell and the Butterfly*. Paris: Éditions Robert Laffont.

Breathnach, C S & Moynihan, J B 2012 'The frustration of Lady Aberdeen in her Crusade against Tuberculosis in Ireland', *Ulster Medical Journal* 81, 1: 37–47.

Broadbent, M E (ed) 1909 *Life of Sir William Broadbent Bart., K.C.V.O.* London: John Murray.

Bryder, L 1988 *Below the magic mountain: a social history of tuberculosis in twentieth-century Britain*. Oxford: Clarendon Press.

Bynum, H 2012 *Spitting blood: the history of tuberculosis*. Oxford: Oxford University Press.

CHSS Chest, Heart & Stroke Scotland 2000 *Tuberculosis in the 21st century*. Edinburgh: Scottish Medical Journal, Symposium supplement.

Clayson, C 1957 *Sir Robert Philip and the conquest of tuberculosis*. Memorial Lecture, University of Edinburgh.

Clyde, N P R 1961 *'Stroke' illness: help for patient and family*. London: CHA.

Durrant, J 1981 *Eighty Years On*. London: CHSA.

Ebrahim, S & Redfern, J 2000 'Stroke care: a matter of chance', in Holland (ed) 2000: 103–6.

Griffith, V E 1970 *A stroke in the family*. London: Penguin. (Reprinted 1975. London: Wildwood House.)

Griffith, V E 1975 'Volunteer scheme for dysphasia and allied problems in stroke', *British Medical Journal* 13 Sept 1975, 633–5.

Griffith, V E 197? *Volunteer Stroke Scheme Handbook*. Typescript, circulated internally, SA Ms 41.

Griffith, V E 1989 *'So they tell me': an encounter with stroke*. Privately printed.

- Griffith, V E & Miller, C L 1980 'Volunteer stroke scheme for dysphasic patients with stroke', *British Medical Journal* 281, 13 Dec 1980, 1605–7.
- Griffith, V E, Oetliker, P & Oswin, P 1983 *A time to speak: positive ideas for helping Stroke Patients with speech and associated problems at home and in groups*. London: CHSA.
- Holland, W (ed) 2000 *Stroke: past, present and future*. Oxford: Oxford University Press.
- Holland, W W 2000 'The role of The Stroke Association in research and development', in Holland (ed) 121–4.
- Holme, C I 1997 *Trial by TB: a study into current attempts to control the international upsurge in tuberculosis*. Edinburgh: Proceedings of the Royal College of Physicians of Edinburgh 27, 1, supplement 4.
- Holme, C I 2000 'Trial by TB: historical perspective and current challenge', in CHSS: 4–5.
- Maxwell, Sir H 1932 *Evening Memories*. London: Alexander Maclehose & Co.
- Morris, M (ed) 'The Scourge of Tuberculosis', *The Practitioner* June 1898: 561–716.
- Muir, K W, Watt, A, Baxter, G, Grosset, D C & Lees, K R 2000 'Randomized trial of graded compression stockings for prevention of deep vein thrombosis after acute stroke', *Quarterly Journal of Medicine* 93: 359–64.
- Murray, W A 1982 *A life worth living*. Haddington: D& J Croal Ltd.
- NAPT 1957 *Sir Robert Philip 1857–1939: memories of his friends and pupils one hundred years after his birth*. London: NAPT.
- Neal, P 1988 *As I am: an autobiography*. London: Arrow Books.
- Philip, Sir R 1926 'The actual place and function of the tuberculosis dispensary in the Tuberculosis Scheme', *Brit Medical Journal* 10 July 1926: 55–7.
- Philip, Sir R 1934 'Musings in the garden: fifty years' association with the tubercle bacillus', *Brit Medical Journal* 23 June 1934: 1105–10.
- RNIB 1996 *Building Sight: handbook of building and interior design solutions to include the needs of visually impaired people*. London: HMSO.
- S A Stroke Association 2011 *Saving lives: 20 years of investing in vital stroke research*.
- S A Stroke Association 2012 *Struggling to recover: Life After Stroke Campaign briefing*.
- Wallace, A T 1961 'Sir Robrt Philip: a pioneer in the campaign against tuberculosis', *Medical History* 5: 56–64.
- WHO World Health Organisation *The Global Plan to Stop TB 2011–2015: transforming the fight towards elimination of TB*.
- Williamson, J 2000 'Tuberculosis re-visited: how we nearly conquered tuberculosis', *Scottish Medical Journal* 45, 6: 183–5.
- Wilson, C 2005 *If preventable, why not prevented? The work of the National Association for the Prevention of Consumption and other forms of Tuberculosis between 1898 and 1914*. London: Wellcome dissertation, UCL.
- Wittkower, E D 1949 *A psychiatrist looks at tuberculosis*. London: NAPT.

We are the Stroke Association

We believe in life after stroke. That's why we support stroke survivors to make the best recovery they can. It's why we campaign for better stroke care. And it's why we fund research to develop new treatments and ways of preventing stroke.

**We're with you every step of the way,
together we can conquer stroke.**

Stroke Helpline: 0303 3033 100

Website: stroke.org.uk

Email: info@stroke.org.uk

From a textphone: 18001 0303 3033 100

We are a charity and we rely on your support to change the lives of people affected by stroke and reduce the number of people who are struck down by this devastating condition.

Please help us to make a difference today.



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Together we can conquer stroke

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