

1978 – 2003

The First 25 Years of Reach



It's Ability Not Disability that Matters

Reach: The Early Days

1978 – 2003: 25 years of Reach

On Tuesday 18th February 1978 the BBC broadcast an edition of Tomorrow's World featuring Dr Rolf Sorbye's myoelectric prosthetic hand being fitted to children in Sweden. All over the UK parents of children with upper limb deficiencies were asking 'why can't my child have an arm like that?' Two people in particular were so determined to achieve this for their daughters that they called public meetings to launch a campaign with other parents. Betty Southwick called a meeting at Trinity Methodist Church, Romford on October 14th 1978, and advertised it in both local and national newspapers.

Maureen Brennan called a 'Foundation Meeting' at Finsbury Leisure Centre for October 28th.

The Events Leading to the Association by Betty Southwick (written in 1979)

After seeing the Tomorrow's World programme my first action was to contact the programme producer for further information regarding the myoelectric limb, who advised me to contact the Swedish Embassy. This proved to be the only way at that time to find how to obtain the limb, as the National Health Service were very unco-operative, although I was corresponding with Elizabeth's doctor at Roehampton, namely Dr. Fletcher. Also, I wrote to all the national newspapers hoping one would take an interest, plus my local MP and the then Minister for the Disabled, Mr Alf Morris. The Swedish Embassy gave me information on the limb and Dr. Sorbye's telephone number and address, and he answered all my letters.

The first letter I received from Roehampton was from Ian Fletcher dated 18/4/78:

Dear Mrs Southwick, I received your letter this morning and as yet I do not have any more information concerning the Swedish arm than I gave you when you were here last month. Next week a small team of people will be going to Sweden to see some of the children wearing the myoelectric arm, in due course we shall be importing some of them for use.

You ask what you can do if the National Health Service rejects the hand, but the Department of Health and Social Security HAS agreed to supply this country. I should, however, warn you that there is quite a long training programme for the children who are to wear the limb and it does entail the wearing of a pack of batteries with wire leading to the arm. It is unlikely that the arm will be available in this country for quite a few weeks. Yours sincerely, Ian Fletcher, Senior Medical Officer.

Although I had it in writing that a team of people were taking up the matter I thought it best to cover against any 'let downs' so I contacted my local press for support and with the idea of helping not only my own child but also some of the others. The press ran stories about us, publicising our fundraising appeal which would pay for children to go to Sweden to be fitted, should the arm not be made available by the NHS.

Then came the blow: I received a letter from Dr. Sorbye, April 28th 1978, saying he was unable to fit Elizabeth, let alone any other child from England, but he did assure me that a clinical trial would take place in the near future and advised me to contact Elizabeth's doctor and health department. It was shortly afterwards that I read in the National Newspapers of how he had fitted one English child with the limb – Joanne Brennan. I was amazed to say the least. I then

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received a telephone call from a reporter, John Burns, of the Daily Express, asking if he could do a story on Elizabeth so as to keep the pressure on the government to carry out the trials as quickly as possible. I agreed and the article appeared June 10th 1978. The response from that one article was overwhelming, I received no end of letters from all over the country, mostly from parents of affected children. I corresponded as much as possible on a regular basis and found parents were very much unaware of just basic facts concerning their child.

Later that month I was invited to join a BBC radio chat with celebrity Monty Modlin. I contacted several other parents with whom I had now become friendly and suggested that they ring in and put questions to him regarding the myoelectric limb, as this was an 'open' chat line. It paid off. Mrs Jenny Hudson

was on the air for some time, highlighting the plight of the older child and also Mrs Hartley's sister-in-law spoke too. It couldn't have worked out any better!

On July 7th 1978 I received a letter from Dr. Fletcher asking me to bring Elizabeth (the first child to be fitted by the National Health Service) to Roehampton to be assessed for the trial. This proved successful and she was fitted with her arm on August 7th 1978. This made the front page of the Daily Express and again the letters came in. I was invited to appear on Pebble Mill at One and accepted because I wanted the media to show how well she was doing after only one month of wearing her new arm, particularly as a recent item on News at Ten had seemed to 'play down' the benefits of the arm.

Elizabeth was on form and showed how she could hold a pen and scribble using the limb only. Again I received enquiries, and a letter was circulated to all the parents who had written to me, inviting them to attend a meeting in Romford, originally this was going to be at my home, but as the numbers grew we changed the venue to a local church hall.

This informal meeting took place on Saturday 14th October 1978. Although representatives from five national newspapers attended, there was no coverage printed in the UK media. However, it did reach a South African newspaper, the Australian TV news and the Australian Woman's Own. Thus I received many personal letters from abroad.

We had heard about Maureen Brennan's meeting in Finsbury park on the 28th and several of us



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went along. By luck, I had met Hassan Waarie – who had lost both of his hands in a land mine accident and was being fitted with myoelectric hands – at Roehampton. He gave me details of where he was staying whilst receiving private treatment in England. On the day of the Finsbury meeting I went to see Hassan with my husband Alan, and Mr Roy Hill (knowing that this hand would be ideal for his son). We managed to persuade him to come along to the meeting as his prosthetic hand was of great interest to us. I felt that those present at the meeting would be as surprised as I was to learn of this device. It turned out that many of those present were unaware of this limb and since have made their own enquiries, thus some lucky children have been fitted with a smaller version. I wonder how long it would have been before the NHS informed us of this device?

Maureen Brennan

After seeing Dr Sorbye on *Tomorrow's World* Maureen Brennan began campaigning locally for funds to get her daughter Joanne seen in Sweden. Because of her efforts and the publicity she had generated, Dr Sorbye had agreed to see Joanne and Maureen began making travel arrangements. However, 3 days prior to their planned departure, Maureen received a letter from Dr Sorbye saying that the UK Department of Health had contacted him to request that he did not see British children because they were planning to make arrangements for children to be fitted in the UK. So, Maureen and Joanne were at the airport the next morning. They arrived in Sweden on May 1st, which is Labour Day, and everything was closed. We presented ourselves at the hospital the next day and Dr Sorbye was astonished to see us. When he asked, I said "letter? No, I didn't get a letter".

Once there, he agreed to assess Jo for suitability. He was just as keen as we were to get the myoelectric hand made available in the UK, so it was very important to him that the first British child fitted was of optimum suitability. We were back there again ten days later for her to be fitted and trained. At first she found it heavy, but within 2 weeks she was fine.

On their arrival home there was a great deal of media attention. Anna Ford visited the Brennans' house and interviewed Joanne in her bedroom. They were on the television news (both channels!) and in every national newspaper.



Dr Sorbye is also a psychiatrist and was very considerate of Joanne's feelings. He helped her parents to make sure she enjoyed the publicity, making her feel special, and she coped very well.

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Above: Joanne Brennan coming through Arrivals on her return to the UK

The meeting in Finsbury was attended by around 150 people, and was 'quite a lively affair'. The temporary name of The Society for Arm Amputees was adopted, a steering committee was formed, and working parties were set up to look into: the name of the Association; aims and objectives; membership; funding and finance; local branches; constitutional framework.

In January 1979 the Association adopted the name 'Reach, the Association for children with artificial arms'. During the first year Reach committee members met with the DHSS and with the Minister for the Disabled, Mr Alf Morris. A Parliamentary Question was put forward by Mr Christopher Price on December 5th 1978, regarding the delay in provision of myoelectric hands by the NHS. Paul Cook describes the occasion: 'One of the party from Reach (who shall remain nameless) got quite excited and leapt up when an

MP said something derogatory. He was promptly seized by the Sergeant at Arms, at which point his wife joined in. Both were removed and held in the cells underneath the Houses of Parliament for about three hours. Feelings often ran high, everyone wanted the best for their children.'

Paul Cook was a member of the working party set up to find a name for the association. At a committee meeting on January 13th 1979 it was decided by a majority vote to adopt the name Reach, The Association for Children with Artificial Arms. In the first issue of the newsletter it was reported that the name was chosen because 'it defines the action of the hand and arm, it suggests the search for new developments and it describes the need for contact and support of new parents of children like ours.'



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Jo with her husband in 2003



The first AGM in October 1979 was the culmination of a very busy year. A Constitution was drawn up and registered with the Charities Commission and after a good deal of work by our treasurer Dave Marchant, Charitable Status was agreed by them on October 12th 1979.

Branches were set up in several areas and the National Council agreed the following aims as a guide for branches:

- to provide a means of communication between members and other families
- to facilitate communication of knowledge
- to provide a forum for discussion of association policy
- to elect representatives to a National Council of the Association
- to raise funds for Association use
- to help members appreciate what prostheses are available

The newsletter, to be called *Within Reach*, made its first appearance, produced by editor Alan Round and 'photostatted' in black and white, it was sent to all members. Though it may have looked different to our current magazine format it contained all the elements that Reach members enjoy today.

At the time of this first AGM in October 1979 the membership stood at 95 members, made up of 84 families and 11 associates. The membership subscription was set at £3 per family.

During its second year, Reach took out a Group Insurance Policy against complete or partial loss of a child's 'good arm'. The premium was to be paid by the Association, and although modified over the ensuing years,

Regional Branches

Bristol	Ray and Sue Hendry
Cambridge	Dave Young and Jenny Hudson
Central London	Maureen Brennan
SW London	Christine Honeywill and Janet Sharpe
Essex	Paul Cooke, Carol Hartley and Betty Southwick
Luton	Ken Gale
Manchester	Francis Pajak
Southsea	Cheryl Clarke
Strathclyde	George Dougal

Original Steering Committee Members

Mrs S Adams	Mr D Marchant
Mr T Benson	Mr J Ockleford
Mrs M Brennan	Mrs C Osbourne
Mrs C Clarke	Mr F Pajak
Mr P Cook	Mr R Parsons
Mr k Gale	Mrs J Pearce
Mrs C Hartley	Mr A Round
Mr R Hendry	Mrs J Sharpe
Mr R Hill	Mrs B Southwick
Mrs C Honeywill	Mr D Young
Mrs J Hudson	

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this policy is still in place and currently all affected children above the age of two years old are covered. It is also still the case that provided the Reach child takes out membership of Reach personally on reaching 18 years of age, the cover is continuous until they reach 65.

So much of what is still at the heart of Reach was established in the very early days.

Research and Development

Reach maintained close contact with the DHSS and was developing links with other interested parties such as Hugh Steeper Ltd (now RSLSteeper) and Princess Margaret Rose Hospital, Edinburgh. A Research and Development Fund was established in June 1980 and the Reach National Council began considering possible projects to support or initiate. In March 1981 a decision was taken to fund two areas in particular: Research work in artificial hand design and development, and research into possible causes of congenital deficiency.

During 1981 representatives from Reach visited Southampton University where, in the Control Engineering Section, work had been going on for ten years or more into an adaptively controlled hand prosthesis. Here, the visitors were shown the prototype – a large hand with sophisticated sensory control functions. Professor Nightingale stressed that although reliable and robust this prototype involved considerable precision engineering; required development and miniaturisation of the control system; and would need re-designing to make it suitable for production. Messrs. J E Hangar (prosthetics manufacturers) and the Science Research Council were involved with funding the project. In December 1981 the Council of Reach made

a grant of £2,000 towards 'current materials and components linked with miniaturisation of the currently developed hand'.

Although no further financial commitment was made, Reach maintained a 'watching brief'. In 1985 a further visit was made by a number of council members. The original Southampton Hand had been put aside and work was being done to try to introduce sensory feedback into a 'Vienna Tone' hand (similar to a myoelectric controlled hand in appearance and action). The original control system had been greatly reduced to a size which could be carried on a belt together with the power source. It was stated that all work was being done on adult sizes and reduction to child-size would be very difficult.

In December 1988 a further visit was made by two Reach representatives who were shown a 'four degree of freedom' hand. The thumb, forefinger and remaining block of three fingers had separate motor power sources. Sensors detected pressure so that strength of grip can be selected, and 'slip' can be registered.

The work at Southampton showed what was technically possible but the hands developed were all research projects and unlikely to be adopted for production.

Reach announced at the 1981 AGM that it would be financing a two-year research project into possible causes of congenital upper-limb deficiency. This would be undertaken by Dr Jean Golding and her team in the Department of Child Health, Bristol University, at a cost to Reach of £6,500 per annum (in the event the final figure was £15,000).

After an initial literature review to establish what theories and findings already existed, Dr Golding enlisted the help of Reach member families. Control families with children of like

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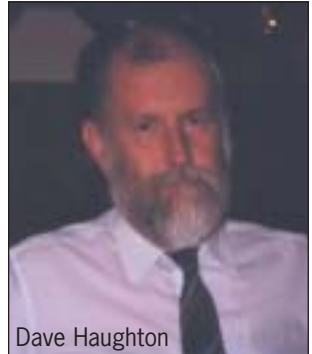
age to the Reach child but unaffected, were also contacted. Questionnaires were completed and the data analysed in an attempt to find significant factors. The final report could show no evidence of a specific cause or even support for the various suggestions commonly made to explain the deficiency. Although it did not answer the question 'why?' it did reassure parents that they were in no way to blame for their child's deficiency. It should be remembered that at that time by far the majority of Reach families had children with the commonest limb-reduction – an absence of hand and lower forearm.

Meanwhile some branches explored new initiatives. In 1982 the Bristol branch hosted an evening of music by three one-handed musicians, which included one-handed piano music and craftsmen to make musical instruments. Reach also made contact with groups in other countries – France, Italy, Hungary and Australia – whose aims seemed remarkably similar to our own.

One member, Dave Haughton, began collecting used stamps to raise money for Reach – and he still is! Dave has now been raising funds for Reach in this way for over twenty years. Many thanks Dave.

In June 1983 a very positive report from the DHSS showed that 140 small children were now being routinely fitted with myoelectric prostheses, and that younger children – those born after 1/1/1972 were now also being tested for inclusion. The number of Assessment Centres were to be increased from four to ten. The hard work of the Reach pioneers paid off not only in the short term with the provision of myoelectric prostheses for children in the UK, but also in the long term with the establishment of our Association which continues to evolve and grow with the core focus of supporting families and children with limb deficiency.

LIZ BLEACH



Dave Haughton

Reach Milestones of the Last Fifteen Years

1988 Publication of the first Reach leaflet: *The Child With a Missing Arm*, by Elizabeth Hardy, Head Occupational Therapist at the Leon Gillis Unit, Roehampton.

Change of Name to 'Reach, The Association for Children with Hand or Arm Deficiency'.

John and Brenda Bruce became the first employees of Reach, jointly filling the role of National Co-ordinator.

1991 Reach was extended with the founding of the Reach Ireland branch.

1994 Sue Stokes took on the role of National Coordinator.

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1995 A group representing Reach visited Susan Szendro in Hungary for the first time, to learn more about their annual children's camps for upper limb amputees and their physiotherapy programme. A further visit took place in early 1997 and Susan later brought a group of Hungarian children to join our first camp in 2000.

1996 The first Reach Dinner Dance, now a key feature of our Annual Family Weekend, took place in Renfrew, Scotland. This was the brainchild of trustee Elaine Clarke.

The Reach Video was made, featuring our new patron, Jeremy Beadle.



Elaine Clarke

1997 The first of our highly successful Jeremy Beadle Quiz Nights was held at the Glynhill Hotel in Renfrew, organised by Elaine Clarke and a dedicated committee of members from the Scottish Branch. This Quiz Night was then followed by others in Dublin, London and Birmingham.

1997 Reach launched a Bursary Fund in order to be able to help young Reach members with specific projects and challenges. These have included travelling, specialist adaptations to musical instruments, and participation in sports competitions. Two Reach members have benefited from the bursary in order to compete in World



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Championships. Hannah Stodel visited South Africa to compete in the World Mirror Dinghy Sailing Championships in 1999 and more recently, Amy Truesdale competed in the Tae Kwon Doh World Championships in Florida, winning the title of World Champion!

Within Reach was re-designed with help from professional publishing and design consultants, and was published in colour for the first time. The new editor – trustee Rosemary Green – led a team of volunteers who researched and wrote articles for the Reach membership. Expansion of the magazine under the leadership of a new editor allowed more time for the National Co-ordinator to work on the growing calendar of events for Reach families and children.

Mark Broomfield set up the first Reach website, establishing our web presence at www.reach.org.uk.

1998 Liz Bleach was appointed as Within Reach Editor when the job was made a paid position.

1999 Reach moved into its first commercial premises, in Wellingborough, Northamptonshire.

2000 Frank Letch proposed and then began raising funds specifically for our millennium project: the Reach Activity Week. The trip was a tremendous success and has now become an annual event for Reach members between the ages of 10 – 18.

Mark Broomfield



Clare Titman became the first Reach trustee who had 'grown up' with Reach as her family had joined when she was a small child. Following an invitation to 'grown-up' Reach members to participate in the Reach Activity Week as mentors/helpers, Clare and subsequently Alice Brient, volunteered to help run Reach.

2002 The Reach website was expanded and re-designed to reflect the growth of Reach and published material from the magazine along with the growing list of official publications. The site also included secure members' areas so that both children and parents can make contact directly on the chat boards. Sue Stokes and Liz Bleach were joined by Tim Gerrish, computer consultant, as webmaster.



Clare Titman

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Reach and Me

SUE STOKES

A good few years have passed since my first connection with Reach. My fourth child arrived at home in the early hours of Friday 4th October 1985, about 4 hours before workmen were due to knock our new extension through in to join the main part of the house. Needless to say they were sent away for a few days. Natalie decided to be slightly different in her approach to life, by being born with no fingers on her left hand. Luckily as a family we took it all pretty much in our stride, we'd been thrown curved balls before so we had got a little used to them.

Never the less, it was a shock and something totally unexpected, of all the illnesses and syndromes you become aware of whilst pregnant, limb deficiency never seems to be a consideration. As with most new mums I used to read the baby magazines of that time and in one of these was a letter from a mum in the Yorkshire area who was looking for contacts as she had a child with a hand missing. Natalie wasn't quite the same as she had most of her hand but as it was the first I'd seen anywhere related to limbs I decided to get in touch. This mum told me about Reach who at that time were – The Association for Children with Artificial Arms. I was not really encouraged to join, in fact I was almost given the impression that Reach had nothing to offer because Natalie only had a partial hand deficiency, but I decided to join anyway.

Well over a year later and it would seem that Reach did indeed have very little to offer, we hadn't met another family or attended an event of any kind, as there really hadn't been anything available. I had been receiving the Within Reach magazine though, and one edition carried an article about lack of branches and a need for new coordinators. I decided to take up the challenge and became a Branch Coordinator, probably in about 1987/8. I made contact with all members in Northamptonshire, Warwickshire and Leicestershire just to gauge the level of interest for a local meeting. I had 13 families attend a 'small' get together at my house. It was a huge success; no one could stay shy for long because there was no space to hide away in. The branch met quite regularly after that and I became more and more involved. Back then every branch was able to send a member to committee meetings of the 'Council' of Reach, the forerunner of today's Management Committee of Trustees. It seemed like a good idea at the time, a day away from 'the littlies', and some adult activity for a change so I went along. I became involved in various aspects and was probably one of the people who led Reach to becoming a wider-based association and the adjustment of our title to The Association for Children with Hand or Arm Deficiency.

From my involvement in the Council of Reach I learnt more about the work, taking on various voluntary roles for the Association. It was hard but enjoyable work trying to help Reach to grow and



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Sue Stokes takes the plunge on the zip wire at the first Reach Activity Week held in 2000

expand, especially to try and make it more than just a parent support group, trying to bring back the children themselves and offer more activities for them

I was fortunate to work alongside some of the greats of Reach – Elaine Clarke, Phil Milligan, Kathy Holdsworth, John Heigham, Graham Nind and Deborah Wilkinson, to name but a few. All had high hopes for the Association and great ideas for the future. I was encouraged by their strength and ideas. Reach seemed at one stage to have become a bit stagnant but with enough bright ideas and willing people about it was sure to go from strength to strength.

When the resignation of John Bruce happened I was offered the opportunity to take on most of the day-to-day administration, which I did on a voluntary basis to begin with. This voluntary period allowed the Committee to assess the workload and ensure it was in the Association's best interest to continue funding a full-time employed post. Once this had been established I was offered the job. This meant my stepping down as a committee member and also along the way I had been unable to keep up with running my branch too, this was passed on to other members and continues to be an active branch of Reach.

The work was carried out from my own home but as Reach grew so too did the administration and the amount of files, equipment, paper etc. I'm sure you can imagine how much room 2500 Reach magazines take up each quarter and even though most were posted out swiftly it still meant a few days tripping over boxes. For that reason, Reach moved into the 'official' market and into our first office premises in Wellingborough.

Our present resting place is down in Cornwall; this is where I spend the majority of each working day unless I am out representing Reach at conferences and meetings, or attending Reach events like camping in Wales, or being sent down zip-wires by the young Reach members who join us for our Activity Week! My office day is spent dealing with all enquiries – whether by phone, email or post – for information from new parents, professionals and existing members and I hope we are still offering members a top quality yet family-friendly service. Reach has exciting plans for the future and I am sure that I will be kept busy putting in place all the events and activities that have become established as part of our calendar.

SUE STOKES