



Phyllis Hilton with Debra

# THE EARLY DAYS

by Phyllis Hilton, Founder of Debra

**There came a time when I felt that some good must come from my daughter Debra's suffering to make any sense of it. Debra was severely affected by dystrophic EB. An association for others with EB was the only obvious answer. But how?**

**I'd already made one attempt in 1972 but to no avail and with considerable opposition.**

It was the time when the first test tube-baby was about to be born just a few miles from our home in Rochdale. TV pictures showed bored looking cameramen from all over the world waiting for the event. What an opportunity. I drafted a statement. My daughter Linda typed all night and by 9am next morning we were busy distributing to all reporters and cameramen.

Replies from newspapers and magazines came flooding in. Granada TV and radio stations invited me for interviews and celebrities, including Bob Monkhouse and Derek Nimmo also offered help.

Most important were the letters from parents with EB. Many of these brought tears. Their joy at finding someone to share with was so encouraging, hope was born.

## **The isolation that EB can bring was at an end**

At the first radio interview I was asked if I hoped DEBRA would be nationwide. I replied, "No it will be worldwide."

And so it has turned out to be.

There was still opposition to the formation of DEBRA and there were still many difficulties to be overcome. In stark contrast the highlight for me was the first meeting in

Manchester where 78 people attended. One boy said, "I thought it was just me that had EB, but there are others like me."

Heartache and tears were washed away as sheer joy took over. Parents began to share their problems. The isolation that EB can bring was at an end.

Publicity was still a priority for fundraising, increasing awareness and reaching other parents. It came and increased. Very early on I gave a talk at a Rotary dinner, and later I was grumbling to daughter Debra that I just could not find the words to make them understand EB.

Next morning, dressings at the ready, Debra asked me to fetch our camera, then insisted I photograph a particularly stubborn raw area. "Use that to explain EB," she said. I did and people responded.

Before founding DEBRA I was intensely shy and had no fight in me whatever. Within days that changed. The motivation came from Debra who would constantly say, "Mummy, help the babies not yet born." This was usually at a difficult time when I felt like giving up. It always worked.

Debra died on 21 November 1978 (*Now established as National Debra Day*). I know her death was not in vain.

My hopes were for research, welfare, a holiday home, advice, someone on call at any time and general support for new mums. Each month brought us another step nearer our goal.

It is amazing now to see how after 15 years so many more steps have been made. Our dreams became hopes. These hopes are actually being turned into reality.

Theresa Clegg was Debra Hilton's home tutor. Some years after Debra died Theresa wrote:

"I remember the very beginnings of the Association when it was just an idea in the mind of Phyllis Hilton.

At that time she was coping admirably with her young daughter's struggle against Dystrophic EB. But a feeling of isolation and the desire for a cure for the disease gripped her.

## **An Association is needed**

'An Association is needed,' she said to me enthusiastically one day. 'An association through which help, support, friendship and a knowledge of EB can flow, through which improved medical treatment and research into a cure can be worked for.'

By dint of extraordinary effort and persistence on her part, her idea materialised. She founded DEBRA.

Now, the work which she began continues to expand, thanks to interested and dedicated people down the years.

It is tremendous to read about the research projects, the peer counselling and the welfare work; all the things which Mrs Hilton talked about to me when I was her daughter's home tutor. And to see so much has been achieved.

I think it is important to find out about 'beginnings' and having found out to remember them because they have a bearing on the present. I am sure that members of DEBRA have reason to be proud and thankful to its founder because EB sufferers worldwide can now be helped directly or indirectly through DEBRA.'

## **WONDERFUL NEWS**

**"I just want to share the good news with everyone. Louise is now two years and four months old, and has just taken her first unaided steps... Louise has EB Simplex and it has been very difficult... After all, you would be put off walking if you had sore feet all the time, especially if you are a child too young to understand why they hurt.**

**"I knew Louise would walk and I'm very proud of her."**

*Emma - an EB mother*

**PLEASE REMEMBER DEBRA IN YOUR WILL**