

Those of us lucky enough to have children born healthy can perhaps never fully appreciate the problems of the parent whose child is not normal. And who - without experiencing it - can know the intense agony of fighting for and eventually losing that child?

Albert Keeling and his wife, Peggy, are two people who have lived through this terrible tragedy. After the death of their child in 1963, they were instrumental in the formation of the RICHARD Fund which has, over the past seven years, provided money for Research into Congenital Hydrocephalus and Radical Deformities. In the midst of their personal grief, they threw themselves into sales of work, dances, jumble sales and golf competitions to raise the money which would eventually help other sufferers.

In 1968, a special research unit was opened in Sheffield with the financial assistance of the Sir Isaac Wolfson Foundation, and the effort to raise more and more money for equipment goes on today. An association has been formed to help parents of such children along their heart-breaking path. All the answers have not yet been found, but the fact that the situation is improving all the time comes about in many ways because of a little boy called John. This is his father's story . . . . .

It was the summer of 1958, and my wife, Peggy, was expecting our second child. Our daughter was already nine years old and we looked forward to having a baby around the house again.

Mid-way through August, the doctor told us that it would be at least a month before the birth would take place, but only a few days later, while away from home on business, I had a strange premonition. I still don't know why or how I knew that something was amiss, but I packed my bags and left for home a day earlier than planned.

It was almost eight in the evening when I arrived to find an anxious neighbour with my wife, who was obviously in great pain. I rang the nursing home and was told to take her there immediately.

As often happens when a second child comes along, I had to get back to number one, who at that time was being looked after by friends. The next morning, the 'phone rang and a voice on the other end told me that although my wife was well, the baby, a boy, had been transferred from the private home in which he was born to a specialist unit, and I was advised to get there as soon as possible. The first time I saw my little John, he

was enclosed in an oxygen tent.

Two miles away, Peggy was suffering agonies of doubt, and although her role now was to supply the milk which I myself transferred to John's hospital in sterilised bottles, she insisted that this was just some kind of plot to convince her that the child was alive.

For six days, John remained in the oxygen tent. Through the plastic, I could see that he was beautifully proportioned but struggling, nevertheless, for the life which had very nearly eluded him during his difficult passage into the world.

Gradually, though, he was allowed to be in a normal atmosphere for an increasing length of time, and for eleven days I continued to go between the nursing home and the hospital to collect his supplies of milk.

It was indeed a great moment when, on the twelfth day, I was able to take my wife from the nursing home to the hospital, where, John, for the first time, was put into a pram and pushed out into the warm summer afternoon. Needless to say, our hearts were full when we were told that we could now take him home.

The days went by and John appeared to be thriving on the love and attention which he received at home. The district nurse called each day at first, and when he was six months old she was still coming twice a week.

But although Peggy and I never spoke of it to each other, our secret fears were confirmed by this nurse, when she remarked that there was something wrong about the baby's eyes.

Our family doctor called the next morning and made a simple test. He would make no comment at the time, but shortly afterwards the child specialist, who had been called in at the birth, was consulted once again.

He saw John for two hours that same afternoon, and although he maintained that there was no indication of water on the brain during the early days - and certainly no sign of the split spine which normally accompanies the condition - he nevertheless made arrangements for us to go to Sheffield Children's Hospital, where there was more specialised knowledge of both.

Only two days later, we visited one of the foremost authorities on the twin conditions. By this time, we were beginning to feel rather weary and upset. Forces beyond our

control meant that our son - although he appeared to outsiders to be a healthy specimen of child - was not, in fact, normal. Exactly what it was we didn't know. What was certain was that we would have given anything and everything we owned to make it so.

John was admitted to the Sheffield hospital almost immediately. Having seen him safely in his cot, Peggy and I returned home. We had been warned that the tests which were to take place on John during the next few days would be painful - but we knew that this was the only way. If our child was ever to live a normal life, he - and his family - had to suffer now.

My business took me to Sheffield only two days after he was admitted, and I couldn't resist the temptation to go to the hospital. There, I bumped into the man whose role in my child's life was more important than I could have ever imagined. He told me that John had been operated on the same morning. A valve had been placed in his head over the right ear, and I could see him if I wished.

I believe it was the most difficult task of my life to explain, when I arrived home, how I had found him. I had stood and looked at the pathetic shaved head with its new life-saving

valve protruding. A father like myself had developed that valve because of his own child's illness, and now it was the means of keeping my John alive - of stopping his head from growing bigger and following the normal progress of what is known as a hydrocephalic.

We were, of course, completely in the surgeon's hands. From now on, we were going to become fully conversant with the subject of hydrocephalus. Each evening we rang the hospital, and each weekend we travelled the seventy-odd miles from our home to be near John.

After three weeks, he came home again. We were frankly terrified as we placed his carrycot in the car and set off for Leicester. Words failed us as we made the two-hour journey.

Among other things, we worried about the reaction of our young daughter, Patricia. No other child we knew of had to face the sight of a brother or sister with such an obvious mark of abnormality as our John's valve - but we needn't have worried. She was happy to see her little brother home, and outwardly, at least, was calm.

There were innumerable trials ahead. Each evening, we had to carry out the "routine" job of depressing the valve twenty or thirty times to make sure that it was clear. We had to muster all our courage to do that - but when something is essential to life itself, then there is no question about it - you just go ahead.

We were fortunate in having the kind of neighbours one normally only dreams of, and during my necessary business trips away they gave Peggy the help and support she needed.

After that came visits to the clinic in Sheffield - and in a way it was an ordeal to see the other children of the same age and older with their parents, who were so obviously trying to put on a good face.

"Troubles come not single spies but only in battalions," so they say, and at this time Peggy's mother fell ill. Despite this, the day-to-day business of keeping John alive by depressing the valve went on, and he continued to progress. His blonde hair gradually covered the hideous object, and his occasional happy chuckle made life worth living for all of us.

When Peggy's mother eventually died, our family problems were intensified, since our daughter had worshipped her, but the visits to Sheffield went on. It became obvious that John had a highly retentive brain, and although at one stage his IQ was below his age group, it was soon above, and our hopes rose with every passing day which showed that John could hold his own and more with any child of his age.

We were reasonably happy with the way things were going until I returned from a game of golf one Sunday lunchtime to find him desperately ill. Peggy had sent for the doctor and throughout the day we had to keep on pressing the valve. Next day he went back to Sheffield. The skilled people there were able to get the valve working again without an operation, and with a relief which can only be guessed at by those who have not had to endure such a period, We received the news that he could come home again.

When we arrived to fetch him, John, then just three years old, was trying to walk around the ward and was laughing with the other children. Our joy knew no bounds.



Proudly we held his hand and gloated over the fact that he could show his intelligence by reciting the capitals of the World to anyone who asked, and a whole year went by without our having to take him to the clinic.

A lovable little character, he went to nursery school at 4½ and progressed to a normal primary school at five, enjoying himself immensely and competing well with the other children.

After a glorious holiday at the East Coast, we came home better for the change, but when he returned to school, John caught measles. It was just a normal childhood ailment, but not long after he went back to classes he was taken ill again, and although he managed to watch me letting the fireworks off on November 5th, he went to bed ill, and was at Sheffield again within 48 hours.

Sometimes I slept at the hospital as John's condition worsened. His outlook on life didn't alter, however, and one day he even said, "Daddy, please don't worry. I'm alright."

Another day, taking a break from his bedside, I walked and walked and eventually found myself looking into the window of a sports shop. I had no real wish to buy anything, but came away with four new golf woods. When I got back to the hospital and told John what I had done his face lighted up. "Daddy, can I play golf when I'm nine?"

At this time I seriously thought about giving my work and everything else up to stay by him. If I returned home at night, it was only in the early hours.

One Friday night, I got back from the hospital at 1 a.m., intending to take Peggy back to Sheffield with me the next day. A little after three, however, the phone rang to tell us that John was dangerously ill. When they rang later - a quarter of an hour which seemed like eternity - he was dead.

The ringing of the 'phone had wakened Patricia, and the three of us wept together. The hours dragged by until, at 7.30 a.m., we went to church.

After that came the formalities - the harsh, cold formalities - and all the time we didn't dare give in to our grief, for the sake of Patricia.

He was buried not far from our home - a five-year-old who had brought tremendous joy and utter misery into our lives by turns and left us with a feeling of unutterable loneliness.

But hope, for us, goes on - even though our son died. Our thoughts now are towards the future - and the children who through the RICHARD Fund will be able to look forward to the tomorrow which was not for John.