

National Reye's Syndrome Foundation of the UK



Historical Statement by Audrey & Clifford Harrington – circumstances which brought about the establishment of the National Reye's Syndrome Foundation of the UK charity in 1983 - and the introduction of warnings on aspirin products sold in the UK with effect from 1986

It was October 1981 and the Harrington family were looking forward to the autumn half term coming up in just two weeks time. It had been a very different start to the school year as Katherine (Katie) had transferred schools leaving her sister Nicola (Nicky) at the local village school. Katie had successfully won a much prized place at the Colchester High School for Girls. She was extremely able and had an IQ of 140+. The daily journey to Colchester was exciting but tiring and each night there was homework to be completed. So a welcome week at home to recharge the batteries was greatly anticipated

The weekend of 9th/10th October was a typical weekend. Katie had a Guide Jumble sale in the village hall on the Saturday, homework in the evening and church on the Sunday – except Katie did not feel so well when she woke on Sunday morning. She had a headache and was aching a little so we decided a quiet day resting at home would be wise.

On the Monday morning neither girl was well. Katie had a slight temperature and headache and Nicky was complaining of earache. A visit to the doctor gave the diagnosis that the girls had a viral infection and Nicky had an ear infection. The GP advised that they should both have four hourly aspirin and Nicky was prescribed an antibiotic for her ear infection.

The next day both girls seemed much better and were happy to sit together sewing and playing happily. It was therefore very likely that by Thursday they would both be back at school but this was not to be. Nicky continued her recovery and indeed returned to school on Thursday but on the day before Kate vomited twice she had a strange rash on her tummy. Whilst Nicky was at school, Audrey Harrington called the surgery and asked for a home visit for the doctor. Katie's vomiting was becoming more frequent and she was becoming disorientated. The anti vomit tablets given for Katie were poured into her Mother's hands by the doctor in order that treatment could commence immediately. The pills (maxolon) did not work and another GP was called again that evening as Katie was now clearly very sick unaware of her surroundings as her condition deteriorated rapidly.

The senior partner from the local surgery was on call that night and he immediately advised that Katie had to go to hospital and an ambulance was called. The nightmare had begun as in her Daddy's arms she was taken to the waiting ambulance.

The young doctors on call in the local hospital were thorough but perplexed. They asked about the number of pills given to Katie in order to stop her vomiting. The GP was telephoned as there was an apparent discrepancy in the number of pills he said he dispensed and the number that were taken to the hospital and the number that Mrs Harrington said she had given to Katie – about 10 were “missing”. Could it be that Katie had helped herself to more tablets? Could Mrs Harrington have made a mistake? The emergency advisory telephone service at Great Ormond Street was calledan

antidote to drug overdose was prescribed.....it did not work. By this time Katie was very agitated and she began to slip into a restless sleep.

The questions to the parents were relentless, inquisitorial and demanding but no light could be shed on what was causing Katie's condition. The consultant was called and he suggested a lumbar puncture should be performed.

In the morning the parents were told that Katie had encephalitis with three possible outcomes.....she could live and make a perfect recovery; she could live but be severely damaged – mentally, physically – or both; or she could die – the paediatrician was “unable to say which of the three it would be” and “he had to go on his rounds” and so he left.

Later that day arrangements were made to transfer Katie to the Hospital for Sick Children – Great Ormond Street. Within an hour of her arrival her condition was diagnosed – Katie had Reye's syndrome – a disease that affects the liver and the brain. We were told that her condition was serious but there was nothing that the doctors could do that they would not do to restore her to the little girl she once was.

A sensor pressure was placed in Katie's head to monitor the pressure in her brain. We were told that it was vital to keep the pressure down and her body was placed into hibernation – cooled artificially to protect the brain as much as possible.

For four nights and days Katie fought bravely but on 20th October, having been told by the doctors that there was no brain activity - her heart stopped and the fight against this overwhelming condition ended for Katie. Our bright, bubbly, beautiful little girl left us with an enormous hole in our lives that remains to this day.

Whilst at Great Ormond Street we were asked whether Katie had been given aspirin for the flu – indeed she had 4 tablets over two days – well within the therapeutic dose. We asked the reason for the question and were told that in America it was thought there might be a link between Reye's syndrome and the taking of Aspirin. Indeed we were told that this rare condition was much more common in the USA and there was a charity set up to help spread awareness of the disease and to support families whose children suffer from Reye's syndrome.

During the weeks following Katie's death we searched the libraries locally in order to find out more about this devastating illness. A consultant friend of Katie's grandfather offered to undertake some investigation into the illness on our behalf. His speciality was radiography and he had never heard of Reye's syndrome. He told us that his enquiries had revealed that Reye's was a familial condition – we should watch our remaining daughter as it was likely that she too could have inherited this devastating condition. As you can imagine we were distraught!

As a nuclear engineer and having both a naturally and trained enquiring mind, Clifford decided to seek out information from outside the UK. His enquiries led him to the National Reye's Syndrome Foundation based in Columbus Ohio, USA. Within days of writing to this organisation we received a mountain of literature. The symptoms described in those documents, the onset and subsequent progress of Reye's syndrome were matched identically to what had happened to Katie. Indeed there was another shock for us. In 1979, 2 years earlier, the Surgeon General of the United States had issued a warning that Aspirin

should not be given to children and young people under the age of 19 years when they have flu or chickenpox due to the risk of Reye's syndrome.Two years before Katie had contracted Reye's syndrome.....why had such a warning not been issued in the United Kingdom?

We continued to make enquiries and search out documents on Reye's syndrome and the more we read the more we were convinced that Aspirin had a part to play in the onset of Reye's syndrome. Furthermore we learnt of another case of Reye's when a few weeks after Katie became ill another girl from the same school a year older than Katie contracted Reye's Syndrome. Furthermore we learnt that Reye's syndrome could be managed successfully if doctors in emergency and paediatric units recognise the condition and commence treatment to manage it at an early stage. We were sent copies of "Consider Reye's" posters that are on display in hospitals throughout the USA warning doctors to think of Reye's syndrome as a possible condition with children presenting with vomiting and signs of brain dysfunction. We could not understand why such a warning on the potential dangers of aspirin when given to children who have flu or chickenpox had not been given in the UK. If only such a poster had been available to the doctors in Chelmsford maybe Katie would have been alive.

We contacted local and national newspapers and articles on Reye's syndrome began to appear. In particular a reporter from the London Evening Standard contacted us and agreed with us that the American findings were too important to be lightly dismissed. As a result of this publicity other parents made contact with us telling us of similar tragic stories of how their children too had contracted Reye's syndrome. As I recall the majority of children had ingested aspirin or used bonjela. Most of the children had died, some had survived damaged and very few had survived with no adverse effects. We began to think that Reye's Syndrome was not as rare as we had been led to believe. Indeed had Katie died in the hospital at Chelmsford her death would have been recorded as Encephalitis. We wrote to the then Secretary of State for Health one Kenneth Clarke, MP to ask him why parents in the UK were not being warned of the risk of giving aspirin to children with flu and chickenpox. His brief and dismissive reply was that such a warning was not applicable in the UK and not relevant. We wrote to the Committee on Safety of Medicines sending a copy of the Surgeon General's warning and once more our request to give the same warning on Aspirin in the United Kingdom was dismissed.

We met with an executive of the local NHS Health Trust who was anxious to learn more about this devastating illness. He advised that we should make contact with the Public Health Laboratories (PHL's) in Collindale, North London.

In the early part of 1983 we met with Dr Susan Hall an Epidemiologist and Dr Martin Bellman a paediatrician who at that time was conducting a study into encephalopathy in children. We hoped they would explain why the aspirin warning was being ignored in the UK. Armed with our posters, the leaflet that contained the surgeon general's warning, leaflets published by the National Reye's Syndrome Foundation and various other pieces of medical literature we presented our case and asked these eminent doctors why nothing was being done in this country to warn parents of the dangers in giving aspirin to children.

We were told the USA epidemiological studies that had reached the conclusion regarding Aspirin and Reye's Syndrome were flawed and had been the subject of much criticism and as a result could not be relied on to give the same warning in the UK. The Committee on

Safety of Medicines would not wish to cause the public to panic by giving false information. We asked why the study could not be repeated in the U.K and were told that there was no money for such a study. We asked the anticipated cost of such a study and were told in the region of £350,000. We asked "If we find the money.....will you undertake the study correcting all the criticisms that were perceived in the findings of the USA?" Drs Hall and Bellman agreed that if they had the money they would be happy to conduct such a study. However they warned that funding for such research was extremely hard to come by and I am not confident they believed the money would ever be found.

At that meeting we showed the doctors the poster that was currently on display in all paediatric wards and Accident and Emergency units in the U.S.A. It advised doctors and health care staff to "Consider Reye's" if a child presented with certain symptoms. Dr Bellman thought the poster was good but was too "Americanised" to be acceptable in the U.K. We asked where we could get advice that would make the poster more appropriate for the United Kingdom. It was suggested that we should contact a Dr Alex Mowat – Head of the Hepatic Children's Unit at King's College to assist in this regard.

We left the Public Health Laboratories disappointed but totally committed – that however long it would take – we would get the funding for that study. It was at this time that we began to consider the setting up of a National Reye's Syndrome Foundation in the United Kingdom. Quite how we were going to do this we did not know but friends in our village were supportive and a meeting with a firm of accountants who had dealings with the setting up of the Anthony Nolan charity was arranged. If we were going to form a charity we were determined it would be done properly.

We were put in touch with a firm of solicitors based in Southend-on-Sea (Tolhurst Fisher) to whom we wrote explaining the reasons for our wanting to form a National Reye's Syndrome Foundation of the U.K. and why. We also explained that we had little money and asked what the costs would be. We were overwhelmed to receive a reply that "the legal expenses would be covered – whatever they may be".

We met with Dr Mowat who readily agreed to re-write the Consider Reye's Posters. Our brother in law persuaded his employer 'Initial Towels' to pay for the printing and the local health trust helped to supply addresses of hospitals where there were accident and emergency or paediatric units. We asked whether he would be willing to serve on the Scientific Advisory Board of the charity and he agreed. He also suggested various high profile medics whose particular speciality would provide invaluable support, advice and credence to the Foundation. Whilst encouraging he warned us that he had seen so many parent groups set up following the tragic loss of a child only to fall with the passage of time before achieving their goal. Whilst we heard what he said we were determined that we would continue for however long it took to establish whether there was a link with the ingestion of Aspirin and the onset of Reye's Syndrome.

The aspirin we gave to Katie was purchased from a local Boots store in the small market town near to the village where we live. We therefore wrote to the Chairman of Boots. We explained what had happened to Katie and we sent copies of the leaflets we had received from America. We told him of the study that we wanted conducted in the U.K. and of the vital need to know whether or not the taking of aspirin was associated with the onset of Reye's Syndrome. We explained the need to raise £350,000 in order that the Public Health

Laboratories could conduct a risk factor study into Reye's Syndrome and asked whether Boots would be able to provide some of that funding. We were pleased to be invited to a medical conference organised by the Aspirin Foundation to be held at the Royal College of Medical Practitioners where Dr Hall was presenting a paper on the risk associated with aspirin and Reye's Syndrome. At that meeting we were introduced to the Chairman of Boots. He was extremely kind and said our letter had impressed him – we had not been accusative but had presented an honest and well made case – and then he dropped his bombshell – if we could persuade the Aspirin Foundation to provide half of the funds required - Boots would provide the other 50%!

We decided to strike whilst the iron was hot – with Dr Hall's paper fresh on the minds of the members of the Aspirin Foundation we wrote to ask for the funding! On what would have been Katie's 13th birthday – 29th April 1983 we received written confirmation that both the Aspirin Foundation and Boots would jointly share the Public Health Laboratories' costs of conducting a Risk Factor Study into the ingestion of Aspirin and the onset of Reye's Syndrome.

Dr Hall wasted little time in advertising for a Research Nurse and ten families were identified to be interviewed to set up the protocol on how the research would be based and appropriate questions identified. The surveillance began in the summer of 1983. All we could do was wait.....

We became impatient as we considered that children were being exposed to the dangers of Aspirin. Doctors did not want to cause a panic or adversely affect the study. However we believed that no child would die if he or she was not given an aspirin for flu or chickenpox but by that time we strongly suspected that Katie most certainly had. So we continued to speak to anyone who would listen be it local or national press, radio or television. We wrote to Members of Parliament and in particular Jack Ashley, MP took up our cause appearing with Audrey on breakfast TV in March 1985.

In June 1986 – before the three years of the Risk Factor Study was completed, we were informed that the results were proving an overwhelming statistical link between the taking of Aspirin for a viral infection and the onset of Reye's Syndrome. The Committee on the Safety of Medicines could no longer delay giving a warning. As a consequence the Aspirin Foundation agreed to voluntarily withdraw paediatric aspirin from the shelves.

It gave us no sense of satisfaction, just overwhelming sadness, that such a warning from the USA had been so lightly dismissed in the United Kingdom.

Clifford and Audrey Harrington

June 2011