

Adam goes to the States to receive blood infusions. 'He's as right as rain when he comes back from the States,' his mum says. 'The infusions have had a profoundly good effect on him'



THE WARNING SIGNS YOUR CHILD MAY BE ILL

Below are some conditions that may be warning signs of a primary immunodeficiency in both adults and children

Eight or more new ear infections within one year

Two or more serious sinus infections within one year

Persistent thrush in the mouth or on the skin after the age of one

A family history of primary immunodeficiency

Two or more months on antibiotics with little benefit

Failure of an infant to gain weight or grow normally

Two or more deep-seated infections such as meningitis, cellulites, sepsis or osteomyelitis (bone infection)

Source: Primary Immunodeficiency Association of Ireland (www.piai.ie).

effect on him. He's become more active since he started the treatment three years ago and the behaviour difficulties have all gone away, except for some occasional tics when he is feeling unwell."

Adam receives treatment in the US because specialist care is needed for the administration of his infusions and at present there is no paediatric immunologist working in Ireland. There are plans, however, to recruit such a specialist in this country and if it goes ahead it will mean the end of tiring transatlantic journeys for Judi and her son.

Adam also receives general paediatric care at Our Lady's Hospital in Crumlin, which Judi highly praises. "The communication between Our Lady's and the American hospital is excellent. With Adam's illness, it's been one of those things that you don't understand how terrible it is unless it touches you and then you suddenly realise how great a place like Our Lady's is and how worthwhile

it is to support it."

Support is also on hand from the Primary Immunodeficiency Association of Ireland (PIAI), which was set up in 1997. "Our purpose is to create awareness of these deficiencies, especially amongst GPs, but also amongst the general public," says the group's secretary, Maria Nolan. "A lot of people aren't being diagnosed with the condition when getting proper treatment could give them a much better quality of life."

At present, Irish children with immune problems are treated at the Rainbow Clinic at Our Lady's Hospital for Sick Children, Crumlin. But the PIAI is concerned that those children are coming into contact with children suffering from infectious diseases.

"We feel that the two groups sharing a waiting room is totally wrong," says Maria Nolan. "Children with a PID are supposed to be cared for in a way so they don't come in contact with infectious diseases as their immune systems don't have the mechanisms to

fight infections."

The hospital, however, says it is following what is accepted as best practice in other countries such as Britain.

At present PIDs are incurable but fortunately there has been a lot of new research into immune deficiencies and treatments. At last count, the World Health Organisation had identified 70 different deficiencies and new types are still being identified thanks to genetic research.

One of the rarest kinds is Severe Combined Immune Deficiency (SCID), which usually results in the onset of serious infections within the first few months of a baby's life. Illnesses can include life-threatening bouts of pneumonia, meningitis or bloodstream infections and babies have to be kept in a sterile space, commonly called a 'bubble'.

SCID is often called 'bubble boy disease' because of a famous case

in the US. A baby called David Vetter was born with the disease in Texas in 1971 and was immediately placed within a sterile plastic isolator because of the threat of fatal infection. Doctors assured his parents that this would be a temporary measure until a cure for SCID was found — but David lived in a bubble home for the next 12 years.

Although he adjusted as best he could, it was a lonely existence for the child without physical contact with others or personal freedom. His story became a source of fascination for the media and members of the public. In 1983, a bone marrow transplant was arranged for David and in the months afterwards it looked like he might be able to leave the bubble and lead a normal life. Sadly, complications set in and he died in 1984, aged 12.

Even though the image of the boy in the bubble is still associated with primary immunodeficiencies, the treatment options have evolved since the 1980s and bone marrow transplants are proving to be very successful in treating

SCID.

One of the biggest factors in combating immune problems, whether they are severe or manageable with medication, is to keep the mind focused on positives rather than negatives. It's the approach that Judi Costello and Adam take with his PIDs.

"Adam knows he is the most important member of the team fixing him," she says. "He's very proactive about doing things like washing his hands when he comes in from playing, eating the right foods and keeping his happiness levels up."

Despite missing some school because of his condition, the boy is catching up quickly. "The whole experience has had a profound effect on us but my family have been really supportive and Adam's dad is phenomenal," says Judi. "Other parents may have a child who is constantly ill and feel like they don't know what to do for them. I'd advise them to find out more about immune deficiencies and make sure they get help for it."