Patient Spotlight - The Conlon Family, in Michael Conlon’s words

In 1982, I was in year 3 of primary school in Belfast, Northern Ireland. One day my mummy picked me up early from school to take me to meet my sister Alicia, in Year 1, at her school. As a child I recall in those moments thinking, great, a day free of school, amazing!

But when we left Alicia’s school we went straight to our local hospital. We were put into a room and examined by a doctor. We were asked questions like, “do you have a lot of falls?”; “do you fight with your friends?” – my answer to all these questions was “no”. I remember the look of worry on my young, 24-year-old mummy’s face, and I will never forget the look of scorn the doctors and nurses directed at her. At the time, we were confused, we could not comprehend why such unusual questions were being asked - I was 7, and Alicia was 5! Then they asked me if my mummy ever hit me, well, I remembered laughing and replying with a big NO! I had never been physically punished.

Hours later, the nurses shared that our blood results had come back, and Alicia’s test showed a low platelet count. Though we did not understand what this result meant, we did learn that it meant we would no longer need to stay overnight at the hospital. It turned out that all of this questioning was the result of a social worker raising concerns after having visited Alicia’s school for a general check-in when she noticed Alicia had a lot of bruising. As an adult looking back, I know the social worker was doing her job and making sure we were safe. However, I can’t even begin to imagine the despair my mummy must have felt throughout the ordeal.

Thereafter, Alicia began to visit the hospital once a month for routine blood tests. For years she was being managed by a simple “watch and wait” approach for an unnamed platelet disorder.

When Alicia was about 12, her doctor suggested removing her spleen to help regulate the platelet count. He could not be sure this splenectomy would be effective, and it meant Alicia would be on medication for the rest of her life. There was lots of discussion in the house at the time and my mummy ultimately decided that if they were not sure this would regulate her blood, then it was not worth the risk combined with lifelong medication.

In 2000, not long after Alicia had her first son Pól, the doctors had a new treatment suggestion: a bone marrow transplant with me as the donor. In parallel, her doctor asked if we would give permission for our DNA sequencing results to be uploaded into a database at Great Ormond Street Hospital. Though the internet was in its infancy at this time, somehow the database in London was shared with other research hospitals around the world. Eight other families were identified with mutations in the RUNX1 gene. One Australian family’s doctor provided key, timely information to the doctors in London that stopped our potential bone marrow transplant in its tracks. A pair of siblings had undergone transplants and while they recovered and blood counts came into the “normal” range for a while, they both contracted a form of leukemia in their 40s.

From top, clockwise: Michael Conlon and mother, Alicia and Piaras, Alicia.
To say my sister is an expert in the disorder would be an understatement. When her original doctor retired, he brought Alicia in so she could explain her case history to her new doctor. Over the years, Alicia has spotted many traits or irregularities. She has mentioned them to her doctors by saying something like “this might sound stupid, but have you checked this or noticed that...”. Many of her theories have proven to be new areas for investigation.

At some point, Alicia mentioned to her consultant that my daddy also had bruising, and he was then invited in for an examination. It turned out he had the same issue as Alicia, but still at that point the disease had no name; we were told it is just an unexplained irregularity. Our daddy was always sick. He did not have the best diet, was a recovering alcoholic and a heavy smoker. Health scares were the norm, so years later when he was diagnosed with Myelodysplastic Syndrome (MDS; which was then considered a pre-leukemia, but now considered a type of blood cancer in itself), we were not as shaken as one would expect. He was told that with his form of leukemia he could live to be an old man. That didn’t happen; within six months he had Acute Myeloid Leukemia (AML) and died at the age of 49.

A few years later, Alicia had another boy called Piaras. Piaras had the bruising. We were all still relaxed about Alicia’s blood disorder, having grown up with it. The only major side effect we connected to it was bruising, periods of tiredness and the fact that Alicia and Piaras had to attend the dental hospital rather than a regular dentist’s office. A routine appointment at the dental hospital for Piaras showed some bruising of his gums, and his dentist sent him directly to the hematology unit on site. It was then that we were told he had MDS, and given our daddy’s history, treatment was needed immediately.

A search for a bone marrow donor was instigated, and a match was found with relative ease. A transplant date was secured but required the family to move to Bristol, England, to be near the hospital. For the first time we were scared but had hope that this was perhaps the cure, and saw this as a great opportunity for a transplant at a young age while his body was at its strongest - an opportunity that his grandfather did not have.

The transplant was successful, and Piaras flew back home to Belfast. He seemed well for a while, but he picked up graft-versus-host disease which required his physicians to suppress his immune system. At this point, he picked up a virus that his body could not fight, and he passed away at eight years old. As he was passing, Piaras generously expressed with great maturity that he hoped his experience would help future children avoid similar suffering. You can only imagine the devastation and impact this had on our family. This blood disorder was now a great threat, to Alicia and any future children that might be born into our family.

Alicia did not think she would have any more kids, and this was certainly not on my radar. I’m 45 now and love the freedom of being a guncle (a gay uncle). I always look at people with kids in awe, as I just do not know how they do it, especially when their kids get sick.
Five years after we lost Piaras, Alicia unexpectedly became pregnant with a baby girl. Toni is now three years old and she too has the blood disorder. You can imagine that after losing a child, and then having a new one with the same disorder, Alicia does not get much sleep. She continues to advocate for Toni’s wellbeing; this includes a recent demand that Toni receive a platelet transfusion for a 10-hour surgery when the hematology consult did not think it was required. She knew even if Toni’s platelet levels were high, they would not function as expected.

Early last year, Alicia spent hours on the internet searching medical terms that she could not pronounce but could spell, in order to find not so much a cure, but hope. That is when she came across the RUNX1 Research Program. She could not believe it, we could not believe it: there were other families brought together through this program! Now we have hope again, not just for Toni but also Alicia and all the others that this program supports - once you have hope, you have a reason not to give up.

- Michael Conlon

“As he was passing, Piaras generously expressed with great maturity that he hoped his experience would help future children avoid similar suffering.”