

Clinical Trials - The value and importance of 'new medicine' for patients and their families.

By Kate Burns, Belfast

Oisin asked me: 'If we make new medicine will Granda come back?' He is five years old. His adored Granda Paul died five months ago. He was 55 when he was diagnosed with advanced metastatic prostate cancer: the prognosis indicated that it was terminal.

At that time, Paul and I had no grandchildren. When he died almost six years later we had three, and Oisin is the eldest. The fact that Paul lived so well and for so long, and that he was able to welcome, bond with, and enjoy these three little boys, is testament to a brilliant professor and oncology team at Belfast City Hospital. It is also testament to him having taken part in two clinical drug trials during the course of his illness.

We had been unprepared for Paul's diagnosis. He had recently completed a motorbike ride out in the USA to raise funds for the Crumlin Children's Hospital in Dublin. He was a director of the Arts Council of Northern Ireland and he lived life to the full. The cancer diagnosis initially plunged the family into a series of negative emotions - shock, disbelief, despair, anger, fear and many more. He retired from work, and life soon revolved around the hospital and treatment options. We simply could not believe that this was happening.

And then something new and exciting was presented to us. Gradually through our monthly visits to the Bridgewater Suite, we learnt about the wonderful advances in medical research and the potential of being involved in a clinical trial. Paul fitted the criteria for participating. He knew these were new drugs and through random selection he might receive a placebo. He knew too that he might be trialling a new drug with potential unknown side effects. But he knew he would be monitored closely and he felt very secure.

The clinical trial brought us more than we could have ever have anticipated. It changed those negative emotions to positive ones, and now we had hope. We knew with Paul that the cancer would one day inevitably win, but the trial brought with it the potential not only to prolong his life, but to improve the quality of his life too. He also felt empowered by the knowledge that while this drug might not overcome his cancer, it might make a difference for the generations to come after him. His experiences and outcomes might help shape directions and decisions on the treatment of patients in the future. He felt privileged to be a part of this.

Being a part of the clinical drug trial also involved him in a new type of doctor-patient consultation. Paul moved from being a recipient of an established treatment regime to being a participant in the development of a new one. He felt he was working in true partnership with his oncology team. He was invigorated by a sense of active involvement in the development of a drug that might mean his children and grandchildren may not have to face what he was facing. He was excited to be at the 'cutting edge' of new drug developments and he eagerly monitored and reported back his progress on the drug. These positive emotions spilled out into the family. It was contagious and we all felt the excitement too.

In the end, the involvement in the clinical trials did improve the quality and length of Paul's life. Although he lost his battle with cancer on December 1st, 2014, he was with us for much longer than we had ever anticipated. This very special person lived long enough and well enough to become a grandfather and engage fully in the children's lives. He was able to travel the world, to motorbike

2nd place winner to the article writing competition organised by the **Health Research Board - Trials Methodology Research Network (HRB-TMRN)**

right up into the autumn of 2013, to continue fundraising for the Friends of the Cancer Centre and to raise awareness of the signs and symptoms of prostate cancer. Paul believed that life must be lived. He believed that in the race to overcome so many devastating illnesses, medical research and clinical trials hold the key to success.

So yes, Oisín is right. The message from a five-year-old is simple, but spot on. We do need 'new medicine'. It won't bring his granda back, but it will help others in the same situation. We need to continue to support clinical trials, we need brave new thinking, and we need new medicine.

The views expressed in this article are those of the author and are not necessarily shared or endorsed by The Irish Times, the HRB or the HRB-TMRN

