

Tragedy & Joy:

The Story Behind Leukaemia Busters

SYNOPSIS

When eight year old Simon Flavell was diagnosed in the Summer of 1988 with a fatal form of childhood leukaemia it set in motion a train of events that led to the birth of the charity Leukaemia Busters. What made Simon different from others like him was the fact that his parents were both leukaemia research scientists. Doctors David and Bee Flavell ran university research laboratories at Southampton General Hospital that lay just a short distance from the ward where Simon was receiving treatment for his leukaemia. Many years before Simon's illness struck his parents working together as a man-wife team had been successfully making antibodies for the diagnosis of leukaemia and other types of blood cancer, always hopeful that one day their creations would be developed into anti-leukaemia drugs for use in treatment. Ironically it was Simon's illness and his ultimate death that ensured this hope would become a reality.

In Chapter One (A Painful Formation) The story begins when three sets of fearful parents meet on the ward where their children are undergoing treatment for leukaemia and lymphoma. One set of parents, Doctors David & Bee Flavell are leukaemia research scientists whose laboratory lies a few hundred yards from the children's cancer ward. Together they decide to form a new charity to help fund the Flavell's work to produce and develop antibodies to improve treatment. The story behind the naming of the charity and the design of the logo by ten year old leukaemia patient Simon Flavell is told and how this was based on his love of the "Ghostbusters" films

In Chapter Two (Outpouring of Support) the events that led up to the formation of Leukaemia Busters, the people behind it and the challenges that this brought are described in graphic detail. This all occurred at the start of the office computer revolution and tells an insightful tale of how much more difficult things were before the advent of the internet. The whole process of the charity's development was influenced greatly by the relapse of Simon's leukaemia and the international bone marrow donor appeal that ensued. This was a key event that played an important role in launching the charity into the wider public eye. The chapter tells of the fight that Simon's parents put up to save his life, including the use of experimental antibody therapy, partly produced by their own laboratory, that went disastrously wrong. The chapter is replete with anecdotes that will take the reader on an emotional roller coaster ride.

Chapter Three (Experimentation) Describes the scientific reasoning behind the charity's pursuit of antibody-based treatments for leukaemia in language that is easily understood by the non-specialist. It provides insights into the scientific process for the non-specialist without losing focus or detail. In this chapter the ins and outs of the creation of a new flagship laboratory for Leukaemia Busters at Southampton General

Hospital later named *The Simon Flavell Leukaemia Research Laboratory* are described. It was from here that the charity's scientists and doctors undertook cutting edge R & D work to develop immunotoxin treatments for leukaemia and lymphoma patients that sometimes came at a high price.

Chapter Four (First Time in Man and Child: Clinical Trials) Describes the development of Leukaemia Busters portfolio of clinical trials and the wide and varied difficulties encountered along the way. The chapter informs about the difficulties encountered in obtaining regulatory permission to treat children with relapsed leukaemia and how the Leukaemia Busters team overcame these to become the first to treat children with antibody based treatment in Britain. It also tells an uncanny tale of the first six year old child from Birmingham to receive this treatment in the UK and her entirely coincidental relationship to the scientific team involved.

Chapter Five (The Challenging Years) Like all organisations Leukaemia Busters has passed through difficult times but has always found a way of resolving the issues that have on occasions threatened to derail the charity's efforts. These difficulties came largely from outside with the exception of the greatest threat that came from within and threatened to bring about a collapse of the charity. The chapter tells of these events in full graphic detail and will leave the reader in no doubt of the hazards that charities such as Leukaemia Busters must face up to if they are to survive and succeed. The anecdotes told here provide a cautionary tale for other charities to be on the lookout. Happily Leukaemia Busters has so far weathered the various storms that have rolled its way, always coming out at the other side stronger and more determined than ever.

Chapter Six (Working to Transform Future Years). This chapter summarises the positive contributions that Leukaemia Busters research scientists have made so far to the development of new therapies and our research plans into the short, medium and long term future. It also takes a broader view of what other types of treatment are in development globally and the importance of national and international collaborations to ensure that more rapid and efficient progress is made.

Chapter Seven (Epilogue) Concludes and summarises the entire story from beginning to where we are today and takes a forward look, predicting that one day in the foreseeable future leukaemia in children and adults will become a thing of the past whilst treatments will become safer and less harmful than those which exist today.