

PREFACE

The death of any child is a tragedy; a promise of life stolen. A child suffering from and then dying of cancer seems hideously cruel. There was a time in Europe when the loss of an infant or child was commonplace due to endemic infections or malnutrition. This still happens, disgracefully so, on a prodigious scale in less developed regions of the planet. But here, with social and economic advances over the past century or so, these ravages of early life have been driven back and what comes to the fore is something that somehow seems far less “natural” and more insidious — cancers, of which leukaemia is the most common. Fifty years ago, for any child, a diagnosis of leukaemia was literally a death sentence and there was near universal pessimism in the medical community over any prospect for effective treatment. But today, some 80% or more of children are cured of leukaemia — by artful combinations of drugs and chemotherapy. Legitimately, this is widely regarded as one of the real triumphs of modern medicine and science. This extraordinary turnaround did not happen overnight and its slow incremental success is a testament to courage, persistence, belief and ingenuity. But it is not, or not yet, an unmitigated triumph. Up to 20% of patients still succumb to the disease, more still in countries that lack access to state of the art diagnostic and therapeutic tools. And for children to achieve sustained remissions and likely cure, there is a two to three year ordeal of toxic treatment, obnoxious side effects and some risk of long term collateral damage. The treatment, though efficacious, is, in biological terms, still crude: effectively, blanket bombing of a target by a blind marksman. And for

the parents of such children, there is the passive agony of watching the child you adore, teeter on the edge of an abyss. So much has been achieved but so much remains to be done. Fortunately, the remarkable advances in genetics, cell and molecular biology over the past two decades have unravelled the underlying mechanistic faults in DNA and cells that cause the disease. This lays the foundation to move forward so that we can deliver more targeted, less toxic therapy and ultimately unravel causes of leukaemia.

Embedded in the saga of childhood leukaemia are some extraordinary stories of human endeavour and resilience which are best told as personal narratives. In this book, we venture to compile perspectives of a kind that rarely go hand in hand. We portray the experience of childhood leukaemia as journeys taken by a clinician, a biologist, a child psychologist, a patient, and the parents of children with leukaemia. It might be considered incongruous, or even insensitive, to place alongside each other tales of hard-nosed laboratory science and personal grief. We hope not, but judge for yourself. There is also an issue of whether the particular stories told are “typical”, whether it be that of the clinician or parent, etc. They are, we feel, indeed representative but at the same time, unique and special. The only alternative would have been to have multiple versions. This we feel would have been at the expense of real engagement and impact.

We hope these stories will give some comfort to families faced with a diagnosis of leukaemia in a child and for others, more fortunate, we offer them as windows into a world that can hardly be imagined as well as a celebration of the human spirit and how ordinary people deal with extraordinary circumstances.

The narratives are illustrated with evocative paintings on childhood leukaemia by a remarkable artist, Susan Macfarlane. Sadly, Susan died in 2002 and we are grateful to her sons, Euan and Angus Mackay, for their permission to reproduce some of her extraordinary paintings here, all of which derive from the exhibition ‘Living with Leukaemia’, commissioned by Dr. Geoffrey Farrer-Brown. The

descriptions of the paintings in the legends below each image are, appropriately, in Susan's own words.

This book is dedicated to Georgie, and to other children who, like her, didn't make it through.

**Mel Greaves
London**