Preface

Here is a collection of incredible stories: the stories of men, women, and children who have suffered from uncertainty, misdiagnosis, a lack of options and, in some cases, tragic loss. This is also a collection of stories of hope and the search for answers, truth, understanding, and options. Overall, they reveal the raw interface between knowing and not knowing, and our search as humans to understand and strive for the best.

We give thanks first to the brave individuals who were willing to share their stories. They offer us a window into the world of diagnostic odyssey: a sometimes quick and effective label and other times a very long and frustrating journey. These are the pioneers in a new land of promise. But they are the ultimate pragmatists as well—they need safe and accurate tests, to be used as tools in the healthcare continuum, without undertaking an advocacy role for themselves.

We offer this collection as a panoramic, qualitative view of a small subset of the experiences of real individuals engaged in real testing.