

*Editorial***Rare Cancers (Reply to Dr B. Jones)****M. Brada***Royal Marsden NHS Trust Sutton, UK*

The management of rare cancers is not frequently at the top of a clinical or political agenda. It is not clear whether the improvements in oncology, driven by the Calman–Hine cancer review and political directives, will have as much impact on their management and outcome as is expected for common tumours. It is therefore important to define a strategy that will allow for the standardization of care and, in particular, an improvement in outcome for tumours, some of which may be curable.

It is suggested that peer review journals, including *Clinical Oncology*, should continue publishing case reports of rare cancers as a method of disseminating useful information that will be of help in their management. There is no doubt that the rigour of evidence-based medicine required for common cancers is a dream that is unlikely to be fulfilled in rare tumours. However, lower-grade evidence within the evidence-based scale must be better than an inconsequential anecdote of a case report. The development of clinical medicine has long been guided by individual ‘clinical experience’, often based on curiosities with little relevance to the overall picture. Publishing such case reports is an outmoded and potentially misleading method of gathering objective information. This is not to say that the avid hunter of rare cases cannot have access to such information, which could be published in electronic format on the Web. In raising the status of case reports, to the equivalent of other peer review

publications would only strengthen existing beliefs and preconceptions rather than provide objective information.

There are alternatives that should help us to improve our understanding of rare tumours. We do not need to look far for a model that has led to significant improvement in the treatment and outcome of rare cancers. Paediatric oncology, through national and international groups such as the United Kingdom Children’s Cancer Study Group (UKCCSG), has made enormous strides in what are rare paediatric tumours equivalent in frequency to most adult ‘rare’ tumours. The impetus must come from the oncology community, together with appropriate academic and NHS support, to create the equivalent of the UKCCSG, with a national database of rare cancers leading to collaborative Phase II and III national and particularly international protocols. The existing funding and infrastructure of adult oncology may not be able to support studies of rare cancers and a new source of funding may need to be identified. It is hoped that the proposed National Cancer Research Network (NCRN) will include rare cancers in its remit. It is unlikely that the solution will lie in a single ‘rare cancer’ group but, with appropriate support, rare cancers could be a defined component of each (UKCCR) UK Co-ordinating Committee on Cancer Research Network Groups and this programme is already under way.