tile therapy, and the patient could easily argue that it was not relatively futile either, as it would keep her alive when she would otherwise certainly die. At some level, restraints must be placed on what is allowed as relatively futile care. This leads on to another problem with medical futility – the issue of resource allocation and health care rationing. The necessity for these restraints is economic – no health system can afford to provide all possible therapies to all those who request or benefit from them. The market mechanism is one way of defining those limits, but in a highly unjust fashion. A minimally adequate level of health care needs to be defined, including definitions of relative futility that go beyond individual values. Social judgements as to what is medically reasonable must underpin individual requests for treatment, just as social judgements underpin the concepts of medical expertise and rightful medical authority. It may be that these social judgements, regarding what is relatively futile, are based on group probabilities, such as not treating anyone who falls into a group with a predicted mortality of 99 per cent. Current scoring systems can be applied to group predictions, with some reservations. They may provide a means of reaching a societal definition of what is medically reasonable. Those treatments that do not receive the sanction of society, perhaps because the cost of treatment is viewed as excessive, or the benefit received is marginal, could be termed medically unreasonable – but they are not futile.

The confusion and criticisms in bioethics over medical futility have arisen because the term has been used in various clinical situations to denote physiological futility, relative futility and medical reasonableness. For the sake of clarity, it would be wise to restrict its usage to situations where it means physiological futility. A clear sense of the relevant differences between the uses of the term 'futility', the respective roles and ethical limits on physician authority and patient autonomy, and the importance of decision-making processes need to be appreciated and remembered when at the bedside.

The Bioethics Research Centre holds a list of supporting references for Dr Hall's article.

Reader's Views

Dear Editor

Please find attached a press release from North Health Ethics Committee regarding its decision to approve in March 1996 the treatment of two children with Canavan Disease by gene therapy.

In March this year, North Health Ethics Committee Y approved an application to treat two children with Canavan Disease by gene therapy. Following the granting of that approval two children who had been brought from the United States by their parents underwent gene therapy surgery at Auckland Hospital. The Committee's decision was subsequently the subject of some debate, most notably criticism by Professor Alastair Campbell in an article published in the *Listener* in June 1996.

The principal thrust of the criticism made against the Committee's decision was that the children involved were too young to give informed consent to the experimental procedures, and the Committee ought not to have relied upon the parental consent given on behalf of the children.

The Committee's decision was subsequently supported in a letter written by Dr David Seedhouse, Director, Research Unit for the Ethical and Legal Analysis of Health Care, and Professor Garth Cooper of Auckland University to the *Listener* in response to its article. Subsequently, the Committee commissioned Mr Ron Paterson, Senior Lecturer in Health Care Law at Auckland University, and Peter Skegg of the Faculty of Law of Otago University, to review the Committee's decision, and its decision-making process.

Mr Paterson and Professor Skegg carried out a comprehensive review of the Committee's handling of the application lodged by Professor Matthew During, and the objections subsequently levelled at the Committee's decision to approve the gene therapy application. In carrying out their review, Paterson and Skegg, both experienced lawyer-ethicists, examined the application and all of the information which was before the Committee at the time the decision was made, together with the current National standard for Ethics Committees and the Ethical Guidelines and relevant case law in New Zealand and overseas.

Paterson and Skegg concluded that there is no ethical requirement that children should have independent representation at Ethics Committee hearings held to consider applications seeking ethical approval for experimental treatment procedures. Paterson and Skegg were satisfied that the Ethics Committee complied with all relevant Standards in granting their approval to allow the gene therapy trial to proceed. Paterson and Skegg also determined that there was no legal requirement that children should have independent representation at an Ethics Committee hearing to determine whether ethical approval should be given to therapeutic research procedures for which their parents have given informed consent.

In coming to their conclusions, Paterson and Skegg noted that the New Zealand courts

> 'even in the context of withdrawal of life support for an incompetent patient with no prospect of recovery ... have been prepared to rely upon "good medical practice", subject to the concurrence of family and an ethics committee (with no requirement that the patient be independently represented before the committee) rather than requiring court approval ...'.

Paterson and Skegg concluded that the gene therapy application was appropriately handled by the Ethics Committee; that the parents of the children involved gave a valid consent to what they understood to be a potentially beneficial procedure and that there was no legal or ethical requirement for the children to be independently represented.

It is interesting to now see that the opinions expressed by Paterson and Skegg are consistent with those expressed by Judges of the English Court of Appeal in the recently reported *Baby T* case.

Ann Howard
Secretary
Ethics Committees