

Letter to the Editor

Dear Editor,

Ethical Issue in Use of Expensive Drugs for Treatment of Rare Metabolic Diseases in Hong Kong

In the past forty years, we have witnessed the dramatic change in the clinical management of rare metabolic diseases in Hong Kong. Before specific drug treatment was available, families with children with rare metabolic diseases had under great difficulty and experienced the inevitable downhill course and death of these children. With the advent of specific and new drug treatment, the prognosis of these unfortunate children has changed but an ethical issue arises as to who should pay for the cost of the treatment. Most if not all of these families cannot afford to pay for the huge cost involved and should public resource be used to treat just a small number of patients. It is known

that public resource is used to treat these patients in Taiwan and Japan and Parents' Support Group in Hong Kong has urged the local Government to do likewise. I think there should be more public and open discussion on the issue before a concensus is reached and as a child advocate, our College might consider whether it should be involved in this hot subject.

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