香港中文大學 THE CHINESE UNIVERSITY OF HONG KONG





January 16, 1996

Faculty of Medicine, The Chinese University of Hong Kong Setting Up the First Seating Clinic and The Cathav Pacific Wheelchair Bank for Children with Neuromuscular Diseases

Introduction and Background

Severe neuromuscular diseases include cerebral palsy, muscular dystrophy, spinal muscular atrophies, spina bifida and many other conditions. It is estimated that for cerebral palsy and spina bifida, the incidences are 1 to 6 in 1,000 births. In spinal muscular atrophies, the incidence is 1 in 15,000 whereas for muscular dystrophy, it is nearly 1 in 3,500 boys. Data from the Prince of Wales Hospital alone show that there are a few hundred patients suffering from severe neuromuscular disorders.

Children who are severely affected and cannot walk should be provided with a proper seat and a mobility base (e.g. specially adaptable wheelchair) as soon as the diagnosis is made. The earlier the intervention takes place, the higher the chances that further skeletal deformities such as scoliosis, hip dislocations and joint contractures together with other medical complications can be prevented or minimized.

The majority of families with affected children cannot afford to buy a proper wheelchair. Formal application for financial assistance usually takes a lengthy period of time, sometimes up to a whole year. By the time the children receive the wheelchair, their condition has often deteriorated. Also, the "standard wheelchair" they receive cannot be modified to accommodate their size or deformities.

The First Seating Clinic in Hong Kong at the Prince of Wales Hospital

In 1994, the Faculty of Medicine of The Chinese University of Hong Kong set up the first seating clinic at the Prince of Wales Hospital. The clinic aims to improve the quality of life and independence for children with neuromuscular diseases through proper seating, positioning and mobility.

A clinical team was formed to provide the best assessment, planning and intervention to improve the patient's condition. This multidisciplinary team includes the following members:

- (1) Paediatric orthopaedic surgeons from the Department of Orthopaedics and Traumatology, Faculty of Medicine, The Chinese University of Hong Kong
- (2) Rehabilitation engineers from the Jockey Club Rehabilitation Engineering Centre, The Hong Kong Polytechnic University
- (3) Physiotherapists, occupational therapists, and the prosthetic orthotists from the Prince of Wales Hospital

The work of the team is

- (a) to provide detail assessments of the patient's physical status, postural and structural deformities and functional capacities so that essential information will be available for the planning of special seating and other supportive orthoses and aids
- (b) to help in the selection or modification of wheelchairs to prevent progressive deformities and to achieve maximum level of independence of the children
- (c) assessment of the seating needs in home and school environment
- (d) fitting and regular follow-up to monitor and evaluate the effectiveness of seating system provided

The Cathay Pacific Wheelchair Bank

Dimensional changes in the child virtually rule-out the possibility of prescribing a wheeled-seat which will serve that child through to skeletal maturity. A child will need a number of wheelchairs of different sizes and systems according to the changes in their physical dimensions, physiological and psychosocial needs and in their ability to propel themselves. By establishing a bank of reusable seating systems, the children in the seating clinic will be able to benefit from having the correct support at the right time. The seating systems can be recycled for use by other needy patients. It is expected that the life cycle of these systems can be in the order of 5 to 7 years, and over 300 patients would benefit from this project.

Cathay Pacific Airways has kindly agreed to donate a generous sum of HK\$ 3 million within the next 2 years 1996-97 to the Faculty of Medicine for the establishment of a Wheelchair Bank which further strengthen the service provided by the Seating Clinic at Prince of Wales Hospital. The donation would support the set up of over 150 wheelchairs of different sizes and designs in the Bank.

Unique Features about this Project

- (1) The first wheelchair bank of this kind specially established for neuromuscular disease children in Hong Kong, estimated to benefit at least 200 to 300 needy children.
- (2) A full supporting Seating Clinic Team with paediatric orthopaedic surgeons, rehabilitation engineers, physiotherapists, occupational therapists and prosthetic orthotists. Such integrated team is not available in any other hospitals or centres in Southeast Asia.
- (3) The concept of a recycling bank to maximize the usage and sharing of the adaptable seating/wheelchairs.
- (4) It can provide more advance technologically designed modular seating systems and wheelchairs for the children so that the seating adaptation can be done much more quickly and efficiently to within weeks rather than years.

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