

Genetic Counseling and Education

AB125. Down syndrome parents support group in Thailand: twenty-five years experiences

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Background: Down Syndrome (DS) is a genetic disorder caused by extra copy of chromosome 21 resulting in delayed development/intellectual disability, congenital heart diseases, congenital hypothyroidism etc. It is a common disorder with incidence of 1:800 live births. Shock and grief occurs when physician inform parents of their infant's diagnosis. Infants with DS were abandoned due to lack of education among doctors, nurses and parents. Therefore, an educational program for parents, medical professionals and teachers was established at Siriraj Hospital since 1987.

Methods: The program aims as follows: (I) to educate parents of children with DS (II) to share experiences and to provide emotional support (III) to raise awareness among the government and the public, and to provide an appropriate knowledge and up-to-date information (IV) to empower parents to voice their demands and basic rights.

Results: The support group has employed certain practical

and viable means. Particular efforts can be highlighted as follow: (I) having produced educational materials; (II) having provided counseling and emotional support in time of crises, especially at the time of birth. The early stimulation programs are available and sustained throughout; (III) having run Down Syndrome Annual Meeting at Siriraj Hospital since 1991; (IV) having organized Down Syndrome Annual Provincial Lecture Tour in collaboration with regional hospitals since 1997, 16 tours have been launched; (V) having worked with Ministry of Public Health since 1991. The proposal of establishing Child Development Center for the improvement of quality of life of children with DS has been accepted and become materialized; (VI) having joined other disabilities group and finally the Educational Act of 1999 was passed.

Conclusions: Some of these efforts could be regarded as proud success. However being far from having realized all the objectives, undoubtedly there are much works to be done, and sustained support very much sought.

Keywords: Down syndrome (DS); Thailand; parent support group; educational program

doi: 10.21037/atm.2017.s125

Cite this abstract as: Wasant P. Down syndrome parents support group in Thailand: twenty-five years experiences. *Ann Transl Med* 2017;5(Suppl 2):AB125. doi: 10.21037/atm.2017.s125