

Down Syndrome Parents' Support Group in Thailand Siriraj Hospital, Fifteen Years Experience: A Review

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Down Syndrome Parents' Support Group Siriraj Hospital was established on February 14, 1993. It consists of a group of pediatricians, nurses, parents of children with Down Syndrome (DS) who received care at the Genetics Clinic, Division of Medical Genetics, Department of Pediatrics, Faculty of Medicine Siriraj Hospital. The objective is to educate parents with DS children whose diagnosis of DS given at birth causing grief and disappointment which led to abandonment of these children at Siriraj Hospital almost every other month (fifteen years ago) due to lack of education on the part of the medical professionals. Down Syndrome Parents' Support Group Siriraj Hospital received financial support from Terres des hommes of the Netherlands in the first 6 years. Later it received partial financial support from a government agency; however, the majority of the funding came from private donations. Throughout the years, the group had several successful activities: Siriraj Down Syndrome Annual Meeting since 1991 (total of 17 years) and Down Syndrome Provincial Lecture tour, so called "Down Sunjorn" since 1997. The latest in 2008 (the tenth) which was organized with major provincial hospitals of the Ministry of Public Health (MOPH). Moreover, the group took part in (1) working with the Ministry of Education for Thailand Educational Act B.E. 1999 which promotes integration of DS children into normal schools all over the country; (2) working with the Department of Maternal & Child Health, MOPH started the Child Development Center in the provincial community hospitals where the service was lacking; (3) working with Ministry of Social Development' and Human Security to initiate an educational program for the DS families in the rural areas (from 2001 - 2006) to help educate families with DS children and raise awareness for their educational & legal rights. In the past 15 years, there was no more abandonment of DS children at Siriraj Hospital and others; these children received better care and improved quality of life.

Keywords: Down syndrome, Parents, Self-help group

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How people cope best with children with Down Syndrome is an essential medical and social question. To answer it involves multi considerations, be they medical, social, attitudinal, parental, etc. In medical terms, Down Syndrome is a common genetic disorder with an incidence of 1: 800 live births. Though delayed development/mental retardation are its norm, in some cases congenital heart disease, congenital

hypothyroidism, gastrointestinal anomalies, and other physical defects may also often occur. Hence, medical care, both in alleviation and partial/complete cure, are the top priorities. However, sufficient and necessary knowledge and skills to undertake such tasks are rather confined within hospitals of a few medical schools. In addition to those in Bangkok, the rest are in 3-4 big cities. People in the rural areas have great difficulties to obtain reasonable medical care. There are no reliable statistics to reveal the scale of the medical needs for people with Down Syndrome. However, what could be a reliable statement is that the medical provision for them is definitely deficient.

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From the parent's perspective, Down Syndrome's birth brings shock and grief, if not devastation in some cases. Medical knowledge is not of much help at the earlier stage, as infant's diagnosis and prognosis are not what parents expect to hear. However, the medical aspect is only a part of the whole picture. Due to lack of proper understanding of the medical personnel and of education among the parents and the public, infants with Down Syndrome irretrievably suffer. In the past (almost twenty years ago) the rate of abandonment was alarmingly high. At Siriraj Hospital (the largest hospital in Thailand, 2300 bed capacity) alone at least one case occurred in almost every month. It is too easy to hold the parents totally responsible for their seemingly unethical action. On top of their desperation, family and social pressure could well be overwhelming. By and large, the public attitude towards the disabilities is very much in want.

As the public attitude is not conducive to needy supports, there had been little demand made on the state agencies. The social spending in general and the budgeting for the cause of disabilities in particular are relatively at a low key. Justified or not, their reasoning often made a reference to the financial constraints of the country. The people with disabilities are in the minority, the majority are more entitled to the limited resources, etc.

However, to conclude that the society is not of a caring kind is to beg questions, not offering explanations. It has been widely recognized that compassion can be overflowing in many areas, but why not with the disabilities is perplexing. Perhaps the question of prejudice can be accountable for misapprehension.

Following from the brief forgoing accounts, if left to their own courses, the situation could increasingly grow worse. Joining some other efforts and organizations of similar mission, an educational program for parents of Down Syndrome children, medical professionals, and teachers was established at Siriraj Hospital, Bangkok since 1991.

In view of the insufficient state care system for people with disabilities, there was a compelling reason for the civil society itself to shoulder the task. It was natural that as a pediatric geneticist at Siriraj Hospital, Dr. Pornswan Wasant and Dr. Chaiyan Rajchagool - sociologist and also father of a Down Syndrome child-took an initiative of the idea for a working body that came to be later known as the "Down Syndrome Parents' Support Group". With the

cooperation and help from concerned organizations and enthusiastic people such as Siriraj Hospital staffs, parents, nursing personnel from Siriraj's Child Development Center, teachers of special children from (then) Rajabhat Suan Dusit-late Dr. Orn-anong Yen-utok, the Support Group was then founded and officially inaugurated on February 14, 1993. Subsequently the Group had greatly benefited from the generosity of 'Terre de hommes', a Europe-based outstanding charity and development organization. Since its inception, it has been continually in operation.

Aims/Goals

Its aims are to achieve a composite set of integrated goals that can be outlined as follows:

1. To educate parents of children with Down Syndrome (DS) to raise their children to reach their maximum potentials.
2. To share experiences of having children with special needs and to provide emotional support by means of breaking the parents' isolation and to help children in difficult situations, especially in the provinces.
3. To raise awareness among the government and the general public towards a better understanding and greater social acceptance/incorporation, simultaneously also to provide appropriate knowledge and to disseminate up-to-date information about the children with special needs in general and the children with DS in particular.
4. To empower parents of children with DS to voice their demands and basic rights in education/schooling, health care and vocational pursuits.

What we have achieved in the past 15 years:

In the course of more than 15 years, the Support Group has employed certain practical and viable means within its capacities to work towards the above goals. Particular efforts have been invested in its competent fields of activities that can be highlighted as follows (Fig. 1, 6):

1. Having produced educational materials, e.g. pamphlets, newsletters, and videos for educational purposes among medical professionals, nursing/education personnel as well as the public. The list includes four videos entitled "Opportunities to grow", "Children with Down Syndrome", "School for Success", and "Introducing Children with Down Syndrome". Most recently with the support of the Society of Maternal & Child Health, the newsletters "Children

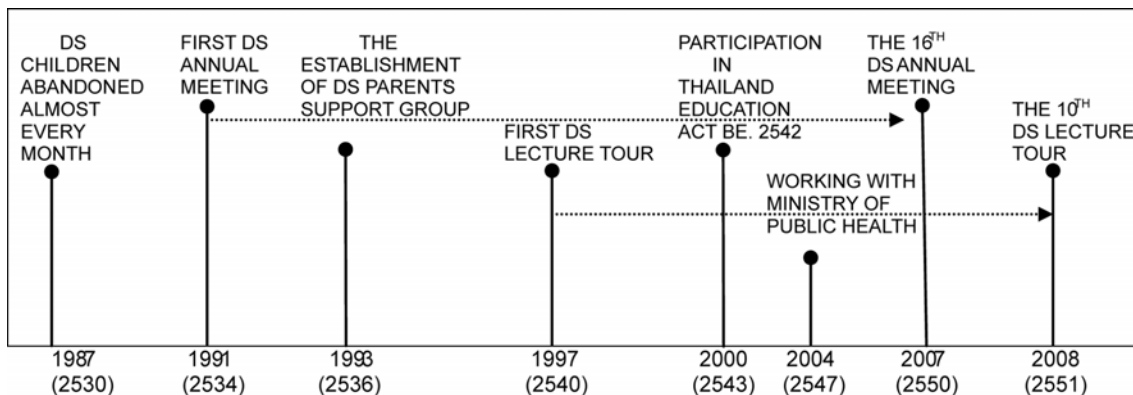


Fig. 1 Milestones of Down Syndrome Parents' Support Group Siriraj Hospital

with Down Syndrome”, issued in the past 15 years have been compiled into a book form.

2. Having provided counseling and emotional support in time of crises, especially at the time of birth of a baby with DS that could bring grief and tremendous emotional shock to people concerned. Additionally the early stimulation programs tailoring for DS babies and children are available and sustained throughout (Fig. 2-4).

3. Having run ‘Down Syndrome Annual Meeting’ at Siriraj Hospital on a regular basis since 1991, to educate pediatricians, house staffs, nursing personnel and parents of children with Down Syndrome. The principal target group is the parents of children with Down Syndrome (Bangkok and its adjacent provinces) whose up-to-date information and positive attitudes are essential to raise their children to being capable of self-care and independent lives. The 16th Annual meeting was held on May 18, 2007 at Siriraj Hospital (Fig 6, 7).

4. Having organized ‘Down Syndrome Annual Provincial Lecture Tour’ (nicknamed ‘Down Sun-jorn, literally “Down on tour”) in collaboration with hospitals and health institutions in the provinces outside Bangkok. Since 1997, ten tours have been launched (Fig. 10-14).

The First in 1997 with Cholburi Provincial Hospital [covering five provinces of Cholburi, Rayong, Chanthaburi, Trat, and Chachaengsao or Region 9 under the Ministry of Public Health (MOPH)].

The Second in 2000 with Sakon Nakhon Provincial Hospital (covering six provinces of Mukdahan, Kalasin, Khon Kaen, Loei, Nongkai, and Udonthani or Region 11).



Fig. 2 Counseling, Genetics Clinic



Fig. 3 Early stimulation program (1-3 years)

The Third in 2001 with the Child Development Center, Chiang Mai (covering eight provinces of Chiang Mai, Chiang Rai, Mae Hongson, Lumpun, Lampang Phayao, and Phrae, Nan or Region 1).



Fig. 4 Preparation for Kindergarten (3-6 years)



Fig. 5 The Establishment of Down Syndrome Parents' Support Group and its activities



Fig. 6 Educational Program for Parents and Medical Professionals Siriraj Hospital Down Syndrome Annual Meeting (since 1991)



Fig. 7 Siriraj Hospital Down Syndrome Annual Meeting 2006



Fig. 8 Working with Ministry of Public Health



Fig. 9 Participation In Thailand Educational ACT B.E. 2542

The Fourth in 2002 with Hat Yai Provincial Hospital (covering seven provinces of Songkhla, Pattalung, Trang, Satool, Yala, Patani, and Narathiwat or Region 19).

The Fifth in 2003 with Ayuddhaya Provincial Hospital (covering five provinces of Nondhaburi, Pathumthani, Ang-Thong, Ayuddhaya, and Samut prakarn or Region 4).

The Sixth in 2004 with Sappasittiprasong Provincial Hospital (covering seven provinces of Ubon Ratchathani, Amnaj Charoen, Srisaket, Yasothon, Nakhonphanom, Roi et, and Mukdahan or Region 14).



Fig. 10 Down Syndrome Provincial Lecture Tour Eastern (1997), Northeastern (2000), Northern (2001) Thailand

The Seventh in 2005 with Ratchaburi Provincial Hospital (covering four provinces of Ratchaburi, Supanburi, Nakhon Pathom, and Kanchanaburi or Region 6).

The Eighth in 2006 with Nakornrachasima Provincial Hospital (covering four provinces of Nakornrachasima, Chaiyaphum, Buri Ram, and Surin or Region 13).

The Ninth in 2007 with Petchaburi Provincial Hospital (covering four provinces of Petchaburi, Prachuap Khiri Khan, Samut Songkhram, and Samut Sakhon or Region 7).

The Tenth in 2008 with Surathani Provincial Hospital (covering three provinces of Surathani, Chumporn, and Ranong or Region 15).

5. Having worked closely with the Department of Maternal & Child Health, Ministry of Public Health since 1996. As an accomplished outcome, the proposal of establishing “Child Development Center” for the improvement of quality of life of children with DS in every province in the country had been accepted and



Fig. 11-12 Down Syndrome Lecture Tour – Northeastern Thailand 2006



Fig. 13-14 Down Syndrome Lecture Tour – Southern Thailand 2008





Fig. 15 Children with Down Syndrome



Fig. 16 When a DOWN becomes a STAR

became materialized (Fig. 8). One main aim is to educate the public health professionals and officials to establish a Child Development Center at the community level, so that parents of children with DS will be able to help their children in their respective localities.

6. Having joined other disabilities groups (autism, visual impairment, hearing impairment, cerebral palsy and others from 1994-1999); demanding for basic rights to education, jobs and, social participation and finally the Educational Act of 1999 (B.E.2542) (following the Disability Act of 1991 (B.E.2534)) was passed by the Thai government (Fig. 9). Nowadays, children with Down syndrome are accepted and integrated into the regular school system and benefits these children's learning potentials.

Some of these efforts could be regarded as proud successes (Fig. 15, 16). However, being far from having realized all the objectives, undoubtedly there is much work to be done, and sustained support very much sought after.

Conclusion

Remarkable progress had been made in the past 15 years regarding the management and care of children with Down Syndrome in Thailand. Educational programs for health professionals and teachers all across the country have made a great impact towards the quality of life of children with Down Syndrome. Today more and more children with Down Syndrome enjoy integration with normal children in regular schools and social activities. The work of Down Syndrome Parents Support Group Siriraj Hospital will

continue with great determination to benefit children with Down Syndrome and their families in years to come.

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ชมรมผู้ปกครองเด็กกลุ่มอาการดาวน์ในประเทศไทย-ประสบการณ์ 15 ปี ของโรงพยาบาลศิริราช พิจารณาบทความ

พรสวรรค์ วสันต์, ไชยันต์ รัชชกุล

ชมรมผู้ปกครองเด็กกลุ่มอาการดาวน์โรงพยาบาลศิริราช ก่อตั้งขึ้นเมื่อวันที่ 14 กุมภาพันธ์ พ.ศ. 2536 โดยเป็นการรวมกลุ่มของกุมารแพทย์ พยาบาล พ่อแม่ และผู้ปกครองที่มีลูกเป็นกลุ่มอาการดาวน์ และได้รับการดูแลรักษา ณ คลินิกพันธุกรรม สาขาเวชพันธุศาสตร์ ภาควิชากุมารเวชศาสตร์ คณะแพทยศาสตร์ศิริราชพยาบาล โดยมีวัตถุประสงค์ที่จะให้ความรู้แก่พ่อแม่ที่มีลูกเป็นกลุ่มอาการดาวน์ ซึ่งเมื่อได้รับการวินิจฉัยจากแพทย์ว่าลูกของเขาเป็นกลุ่มอาการดาวน์ ก็มีความตกใจและเสียใจมาก หลายรายยอมรับลูกที่เป็นกลุ่มอาการดาวน์ไม่ได้ และเด็กถูกทอดทิ้งที่โรงพยาบาลศิริราช ประมาณเดือนเว้นเดือน เนื่องจากแพทย์ พยาบาล ขาดความรู้ที่ถูกต้องในการให้คำปรึกษาแนะนำทางพันธุศาสตร์ และการดูแลเลี้ยงดูเด็กกลุ่มอาการดาวน์เหล่านี้ ชมรมผู้ปกครองเด็กกลุ่มอาการดาวน์โรงพยาบาลศิริราช ได้รับการสนับสนุนจากองค์กร Terre des hommes ประเทศเนเธอร์แลนด์ใน 6 ปีแรก ต่อมาได้รับการสนับสนุนบางส่วนจากองค์กรของรัฐ แต่ส่วนใหญ่การสนับสนุนได้มาจากเงินบริจาคชมรมฯ มีกิจกรรมหลายอย่างที่ประสบความสำเร็จเป็นอย่างดี ได้แก่ งานชุมนุมเด็กกลุ่มอาการดาวน์ประจำปีของโรงพยาบาลศิริราช ตั้งแต่ปี พ.ศ. 2534 (รวมเป็นเวลา 17 ปี) และโครงการ ให้ความรู้สู่ชนบท “ดาวน์สัญจร” ซึ่งเริ่มต้นตั้งแต่ปี พ.ศ. 2540 ครั้งล่าสุดเมื่อปี พ.ศ. 2551 (นับเป็นครั้งที่ 10) โดยจัดร่วมกับโรงพยาบาลศูนย์ของกระทรวงสาธารณสุข ผลงานสำคัญของชมรมฯ ได้แก่ 1) การมีส่วนผลักดัน ให้มีพระราชบัญญัติการศึกษาแห่งชาติ พ.ศ. 2542 ซึ่งเปิดโอกาสให้เด็กกลุ่มอาการดาวน์ได้เรียนร่วมกับเด็กปกติในโรงเรียนใกล้บ้าน และสนับสนุนนโยบายของกระทรวงศึกษาธิการให้มีการอบรมครูการศึกษาพิเศษทั่วประเทศ 2) การผลักดันให้กรมอนามัย กระทรวงสาธารณสุข จัดประชุม (ระหว่างปี พ.ศ. 2547-2549) เพื่อให้ความรู้แก่ แพทย์ พยาบาล และบุคลากรสาธารณสุขทุกภูมิภาคของประเทศ และสนับสนุนให้จัดตั้งคลินิกพัฒนาการเด็กขึ้นในโรงพยาบาลชุมชนในชนบททั่วประเทศ 3) ทำงานร่วมกับสำนักงานส่งเสริมและพัฒนาคุณภาพชีวิตคนพิการแห่งชาติ กระทรวงการพัฒนาสังคมและความมั่นคงของมนุษย์ โดยจัดทำโครงการ ให้ความรู้สู่ชนบททุกภูมิภาคของประเทศ (พ.ศ. 2544-2549) เพื่อให้องค์ความรู้ในการดูแลคนพิการทางสติปัญญาและการเรียนรู้ รวมถึงสิทธิและโอกาสที่กฎหมายได้บัญญัติให้อำนาจไว้

ในระยะเวลา 15 ปีที่ผ่านมา ไม่มีเด็กกลุ่มอาการดาวน์ถูกทอดทิ้งที่โรงพยาบาลอีกต่อไป เด็กกลุ่มอาการดาวน์ได้รับการดูแลรักษาและมีคุณภาพชีวิตที่ดีขึ้น แพทย์ พยาบาล ให้ความเอาใจใส่และดูแลสุขภาพของเด็กเหล่านี้ดีขึ้น ครูและโรงเรียนให้โอกาสเด็กกลุ่มอาการดาวน์พัฒนาอย่างเต็มศักยภาพ สังคมทั่วไปก็ให้การยอมรับที่ดีขึ้นอย่างเห็นได้ชัด