

CONCLUSIONS OF THE 6TH WORLD CONGRESS ON DOWN SYNDROME

(As presented at the closing session of the Congress)

Madrid, 23rd-26th October 1997

The aim of the 6th World Congress was to give an answer to the challenges facing persons with Down syndrome as the 21st century approaches, formulating the following proposals and conclusions:

1. The promotion of genetic investigation in order to probe deeper into knowledge of chromosome 21's identity (especially finding out what each gene lodged inside it is responsible for and how they interact), as well as to probe into knowledge of mechanisms intervening in the non-disjunction to prevent the appearance of the syndrome.
2. The study of the specificity in Down syndrome, trying to isolate typical characteristics of Down syndrome so that it is possible from specialisation to design more efficient instruments of a medical and psychopaedological nature for the rehabilitation and education of persons with Down syndrome.
3. The search for practical solutions (strategies, programmes, methods, etc) which, taking into account findings of recent scientific research, provide concrete solutions applicable to the health care, early attention, education, social and labour integration of persons with Down syndrome.
4. To specify the quality of life model proposed for persons with Down syndrome in three aspects: a) that their needs and expectations are met, b) that they develop all their potentialities and c) that they enjoy all their rights.
5. In the area of health: an endeavour must be made to spread and establish preventative medical programmes for Down syndrome everywhere in the world and also to maintain a critical attitude towards therapies not confirmed scientifically. By applying the principle "the same cases require the same treatment", organ transplants for persons with Down syndrome who require them should be encouraged.
6. Becoming aware of the important role of the family as the Down syndrome person's first natural nucleus of integration will encourage actions to be taken that are addressed towards effective training and the involvement of parents in the attention, education and social insertion of their children.
7. Specialised attention must preferentially reach those persons with Down syndrome who have other additional serious limitations or needs which prevent their effective integration. Attention could be given to them in specialised centres, with the support of the family, attaining the level of normalisation that is possible in each case.
8. In the field of education the Congress decisively supported three criteria: a) inclusion, with the proper supports, in an ordinary school, b) specific programmes and curriculum adaptations and c) the application of new technologies in the classroom as a particularly useful strategy.
9. The Congress called attention to the importance that the adult life of persons with Down syndrome has at the present time, including self advocacy, in such a way that the services provided are adapted to their rights, needs and demands, guaranteeing a positive quality of life.
10. All the means at our disposal must be used to encourage effective integration of persons with Down syndrome in school, work, culture and social life, with the understanding that non-discrimination means equal opportunities. Likewise, the change towards a better social image and participation of persons with Down syndrome in public life must be pursued.

11. Training and employment of Down syndrome persons in ordinary firms must be a priority as a source of personal realisation and autonomy and full participation in the life of the community.

12. Encouragement must be given to the worldwide creation of specific associations for Down syndrome, independent from the associations which attend to persons with mental retardation in general. These associations should claim representation and financial support from governmental departments.

13. The Down syndrome associations must ensure that parents, professionals and persons with Down syndrome are integrated in their organisations and management and they must be guided and reorganised by democratic principles.

14. The services - to create them whenever necessary - have to respond to criteria of quality, efficiency and social economy and insofar as possible they have to be rendered and integrated in the normal services of the community.

15. The training of specialists in University and in post-graduate courses is fundamental if persons with Down syndrome are to receive global and specialised attention in accordance with their needs.

Mr. S. Al Malaq (Saudi Arabia), Prof. F. Astudillo (Spain), Prof. M. Beeghly (USA), Prof. R. I. Brown (Australia), Prof. S. Buckley (UK), Prof. C. Epstein (USA), Prof. A. Fortuny (Spain), Prof. C. Garcia-Pastor (Spain), Prof. M. J. Guralnick (USA), Prof. R. Hodapp (USA), Mrs. M. Madnick (USA), Mrs. Ma M. N. Mendonca (Brazil), Mrs. J. Mills (Canada), Prof. E. Momotani (Japan), Prof. E. Montobbio (Italy), Prof. L. Nadel (USA), Prof. R. R. Olbrisch (Germany), Prof. J. Perera (Spain), Prof. S. Pueschel (USA), Prof. A. Rasore-Quartino (Italy), Mrs. P. Robertson (Indonesia), Prof. J. A. Rondal (Belgium), Prof. J. Rynders (USA), Prof. B. Sacks (UK), Mrs. M. Schoeman (South Africa), Prof. W. Silverman (USA), Prof. P. M. Sinet (France), Mrs. R. Sneh (Israel), Prof. D. C. Van Dyke (USA), Prof. J. E. Wann (Sweden), Prof. H. A. Wisniewski (USA), Prof. K. Wisniewski (USA).