



NewsLetter

Half-yearly - N° 10 - June 1998

The President's word

Several important events have taken place over the course of the last fifteen months or so, in which EDSA has participated decisively. The first and major one certainly is the noted organization of the VIth World Congress on Down Syndrome in Madrid during the month of October 1997. This Congress, most remarkably organized under the leadership of EDSA's former Chairman of the Scientific Committee and FEISD President, Professor Juan Perera, was an outstanding success with delegates from more than 50 countries and around 2000 people attending. Every one present could realize the splendid diversity and richness of the Down Syndrome movement worldwide, as well as the astonishing vitality of the research conducted almost everywhere on the development, education, and social integration of the Down syndrome persons.

A second remarkable event, that also took place in Madrid in the context of the VIth World Congress, was the long awaited creation of the International World Federation on Down Syndrome (IFDS), placed under the chair personship of Canadian Social Worker and mother of a Down syndrome adolescent, Josephine Mills.

The IFDS' major tasks will be to lead the DS movement at the world level, organizing a world congress every four years, and to coordinate the research and social actions in the various countries.

In the meantime, EDSA has been reorganizing itself particularly since the productive meeting of the board in Portsmouth, UK, last April. New and flexible statuses have been drafted, discussed, and will be proposed to the general assembly for official approval. Additional funding money obtained from the European Communities will allow us, among other actions, to reach farther towards a number of new Down syndrome associations in Central and Eastern Europe. Several Down syndrome associations, some relatively new, others in existence for quite some time have applied for EDSA membership and will obtain it at the next general assembly. EDSA, in this way, is steadily becoming fully representative of a larger Europe and is going to play a major role in the future activities of the International Association.

More immediately, the EDSA Board has appointed **three task forces** in order to advance the work on several key issues regarding the Down syndrome persons. They are (1) the promotion and coordination of scientific research on Down syndrome as to a number of important questions (genetic, medical, psychological, social, educational); (2) a review and comparative synthesis of the legal and juridical dispositions existing in the various European countries concerning every aspect of the life of the Down syndrome persons and their families; (3) the definition of a number of important needs relative to the daily lives of people with Down syndrome and their family, which could be efficiently approached in a cooperative perspective within Europe.

I warmly invite you all to join us in working for a better future for the Down syndrome babies, children, adolescents, adults, aging persons, and their families.

Professor -Dr. Jean A. RONDAL, Ph.D., Dr. Ling.
President of EDSA.

Report on the 6th World Congress on Down's Syndrome Madrid, 23rd-26th October 1997

by Maria Dolores Maurin

psychologist and psychoterapist of ASNIMO (Mallorca, Spain)

Sixty-two countries taking part, thirty guest speakers, thirty-four workshops with over two hundred speakers, twenty-three people with Down's syndrome taking part at the workshops, plus four hundred free papers, ninety scientific posters, one hundred and three associative posters, thirty commercial stands and, most of all, two thousand participants give an idea of the size and scope of the 6th World Congress on Down's Syndrome which was held from the 23rd to 26th of last October at the Palace of Congress in Madrid (Spain).

The Congress was organised by the Spanish Federation for Down's Syndrome (FISD), with the excellent technical assistance of Madrid's Viajes Iberia Congresos. It also had special contributions from the Educational, Scientific and Cultural Organisation of the United Nations (UNESCO), from the World Health Organisation (WHO), the European Disabled Forum (EDF), the Ministries for Health and Compton, Education and Culture, and Labour and Social Affairs, and also from the Town Hall of Madrid (Madrid Convention Bureau). The Complutensian University of Madrid gave its scientific endorsement and awarded the attendance certificates. Patrons were the Institute of Social Services (INSERSO), the Royal Patronage for Prevention and Attention to People with Disabilities, and the ONCE (Spanish National Organisation for the Blind) Foundation. Among the sponsors were the Madrid Savings Bank's Department of Social Work, the Sol-Melià hotel chain, Grespania, Fundacion Inocente and MRW.

It is difficult to value and express gratitude for the effort made by the Organising Committee (made up of 25 personalities from 17 countries) and by the Scientific Committee (comprising 19 scientists from 15 countries around the world), to stage a congress of such magnitude, which is held in a different place in the world every four years and on this occasion was presided by Prof. Juan Perera of Spain.

The Congress had an excellent and costly presentation in English and Spanish; 60,000 leaflets of the first announcement and 13,000 of the second were completed with an attractive web page on Internet. The Congress slogan: "Down's Syndrome: when dreams come true" took shape in the design of an attractive logo which was present at all its acts. Everyone who attended received a copy of the final programme for the Congress, a detailed 300 page publication containing summaries of all the conferences and workshops, and which served as a practical guide for all the Congress activities.

It is especially difficult and complicated to organise a world congress open to all the groups concerned with Down's syndrome: scientists, families, people with the Down's syndrome, professionals, associations, volunteers, etc. and with participants coming from so many different cultures and stages of development.

The organisation endeavoured to find a random formula of presenting the Congress, that satisfied the majority of participants: in the morning, scientific sessions of the highest level, and in the afternoon, workshops at which were presented the concrete applications of scientific advance, intervention practices, stimulating testimonies, personal experiences and debate panels.

Special mention should be made of the active presence at the Congress of the 23 people with Down's syndrome who, coming from a variety of countries, took part as speakers at the workshops, and 18 others, of very different levels, who took part in artistic performances. Gratitude must also be expressed for the 263 free registrations the organisation gave, so that many countries with depressed economies could attend. At the plenary sessions in the morning there were important news which will shortly be published, first in English and then in Spanish, in the book "Down's Syndrome: A Review of Current Knowledge", by J. Rondal, J. Perera and L. Nadel, published by Whurr Publishers of London.

At the **workshops** the organisation opted for diversifying the offer and announced the ones which were preferentially aimed at professionals, at families or at people with Down's syndrome, thus endeavouring to achieve a balance in the quality of the lecturers, variety and validity of the subjects, the participation of the greatest number of countries and the inclusion of the best free papers. The best works will be published in English in the review "Down Syndrome Research and Practice" by the University of Portsmouth, and in Spanish in the "Revista Down" of the Spanish Federation of Down's Syndrome Institutions (FEISD).

But the Congress was much more than that.

At the opening session, presided by the Spanish Minister for Labour and Social Affairs, Mr. Javier Arenas, Pablo Pineda made an excellent speech in which he asked society to respect people with Down's syndrome and "demanded" that the Minister should keep his promise after the congress and that should allocate more funds and effort to the educational, social and labour integration of people with Down's syndrome.

The Madrid City Council held a reception in the Town Hall for the speakers at the Congress and a cocktail party to welcome all participants in the Arganzuela Crystal Palace, with the performance of a delightful University student musical group.

Especially emotional, impressive and applauded were the artistic acts by all the children and young people with Down's syndrome from Peru, Brazil, Slovenia, Italy, USA and Spain, who gave performances of ballet and regional dancing, mime, Spanish dancing, piano and acting.

The Congress's official dinner was held in the Tapestry Room of

the Hotel Melià Castilla, which was filled to capacity. Prizes were awarded to scientists and leaders of the associative movements, as well as to the authors of the best free papers. The ceremony ended with the performance by the "Maria Rosa Spanish Ballet".

There were also many activities held parallel to the Congress which helped in exchanging experiences and opinions among the Congress participants in the framework of the Palacio de Congresos: a commercial exhibition with thirty stands, exhibition of scientific posters, presentation of associative posters, video sessions and meetings of a scientific and associative nature.

Those attending had high praise for the services of simultaneous translation (from English into Spanish and vice versa) at all the sessions, as well as at the press office and for the children care-centre which was organised by the Down's Syndrome Association of Madrid.

The Congress closed with a session devoted to the Associative Movement for Down's Syndrome worldwide. Representatives from Usa, Canada, Belgium, Brazil, South Africa, Japan, Saudi Arabia, Spain, Indonesia and the United Kingdom spoke of the challenges

the Down's Syndrome Associations all over the world face for the 21st century, and this was immediately followed by the official presentation of the International Federation for Down's Syndrome (FISD).

At the closing ceremony the President of the Congress, Professor Perera, read the conclusions of the Congress (which are transcribed further in this issue) and introduced those in charge of holding the next World Congress in 2000 in Sydney (Australia). The conclusions of the Congress have been published in Down's Syndrome reviews all over the world and have been translated into 18 languages.

The organisation of the Congress has received over four hundred letters of congratulations from all over the world and - why not? - a few criticisms.

The great majority say the Congress has contributed significant scientific advances, has favoured contact between parents and professionals worldwide, has presented a new and positive image of people with Down's Syndrome and has marked a guideline for the associative movement concerned with Down's Syndrome.

Highlights of the VI World Congress

by J. Perera

Director of the Principe de Asturias Centre (University of the Balearic Islands, Spain)
and President of the 6th World Congress on Down's Syndrome in Madrid

The world's most renowned scientists in disciplines related with Down's Syndrome communicated important innovations in Madrid which will be contained in a volume to be published in English by Collin Whurr of London and which will later be translated into Spanish. In this section our review sums up the most important contents of the plenary sessions.

GENETICS

- P.M. Sinet. Paris, France: after describing the genes which have been located and their possible functions, he delimited the region of chromosome 21 responsible for the most specific and frequent features of Down's syndrome ("critical region of Down's Syndrome") situated in the distal portion of the long arm. Work is being done to isolate and identify the genes present in this region, especially those related to the development of the heart, brain and skull.
- C.J. Epstein. San Francisco, USA: with some pessimism he focused on the subject of "non disjunction" since there are few short term possibilities to have any influence on it in order to prevent it. He was more optimistic on the possible palliation, in the next century, of some adverse effects of excessive genetic endowment using substances which curb determinate specific genes.

MEDICINE

- A. Rasore-Quartino, Genova, Italy: he posed a revision of the medical problems of people with Down's Syndrome in the

different stages of their life. He underlined the importance of studying the immunological system and of the development of the thymus as responsible for different alterations (thyroiditis, diabetes, respiratory infections, hepatitis, etc.). He highlighted the frequency of hypothyroidism, which increases with age, and of coeliac disease. He analysed the controversies on atlanto-axoid instability and on Alzheimer-type dementia.

PSYCHOLOGIC RESEARCH

- S.Z. Buckley. Portsmouth, United Kingdom: her contribution focused on cognitive development, its relation with language and the influence of reading to improve both processes. In Down's syndrome, development is slowed but is progressive. Speech and language patterns are decisive for developing mental skills and are the principal vehicle for exchange of knowledge, for developing thought and for reasoning and memory skills. Reading improves grammar and syntax as also short-term memory, both visual and auditive.

INTELLIGENCE AND COGNITIVE PROCESSES

- R. Hoddad. Los Angeles, USA: he approached his thesis on the existence of strong and weak points or areas in the cognitive skills of people with Down's Syndrome and he placed emphasis on the evolution of the intellectual quotient. It is a fact that IQ diminishes with age. But this does not mean that intellectual growth stops, as there is still progress in comprehension, capacity of analysis, reasoning and vocabulary. Their capacity to

communicate and their adaptation to daily life increase.

LEARNING AND MEMORY

- L. Nadel. Tucson, USA: he explained that in Down's Syndrome there is no single way of learning but multiple forms that depend on different neuronal structures. He differentiated two forms of memory: the explicit, which recalls events and facts, and the implicit, which relates to skills and habits. In each learning a specific cerebral region is involved, which develops at a different rhythm. There is greater affectation of the structures related with the explicit memory (hippocampus, prefrontal cortex, cerebellum). On the other hand, there is a better understanding of characteristics, features and values and also a better retention of motor skills.

DOWN'S SYNDROME AND ALZHEIMER

- W.P. Silverman. Staten Island, USA: a rigorous longitudinal study on the evolution of cognitive capacities of adults with Down's Syndrome points out the differences existing between normal ageing and that of Alzheimer. Of special importance is the revelation that the incidence of this dementia in adults with good intellectual functioning entering their sixties, is notably lower than that indicated in previous studies.

LANGUAGE AND COMMUNICATION

- J.A. Rondal. Liege, Belgium: he analysed the differences existing between Down's Syndrome language and that of other forms of mental retardation (Williams' syndrome, autism, etc.). In Down's Syndrome the habitual pattern of language development is followed, but with delay. As specific problems he underlined: phonetic and phonologic, morphosyntactic, lexical, semantic difficulties and for organising discourse. The special cases of good language in Down's Syndrome throw light on the function of certain areas of the brain cortex.

TEMPERAMENT

- M. Beeghly. Boston, USA: she reviewed empiric knowledge on the temperament of children with Down's Syndrome. Temperamental characteristics are rooted in biological and constitutional factors and are relatively stable during childhood, and may be modified by the influence of the environment. A study carried out with 191 children with Down's Syndrome, based on their parents' observations, contributes important data for knowing the temperament of children with Down's Syndrome.

EARLY INTERVENTION

- M. Guralnick. Seattle, USA: early intervention is positive when from a maturation perspective, it improves parents-child interaction, incorporates into the family experiences centred on the child and helps to control matters of health and safety. A subject of enormous interest is to know to what degree early intervention conditions or resolves the later development of the persons with Down's Syndrome. The reply lies in that each phase of the child suggests the appropriate model of intervention. Long-term efficacy depends on whether the programmes are integral, last for at least five years and deal with the so-called transition periods (starting nursery school, junior school, etc.).

PRENATAL DIAGNOSIS

- A. Fortuny. Barcelona, Spain: he reviewed new population-screening techniques that determine the risk rate for Down's Syndrome, and the most usual methods for diagnosing Down's

Syndrome in the uterus. Today, with the combination of the cytogenetic and geographic study, not only can the existence of the chromosomal anomaly be known, but also its possible association with other alterations not always linked to Down's Syndrome and which undoubtedly modify the postnatal perspective of this anomaly, as is the case of congenital cardiopathies or duodenal atresia.

INCLUSION

- C. Garcia Pastor. Seville, Spain: based on the comparison between inclusion (state school) and exclusion (focused more on the private school) she posed inclusion as a committed form of work in the school: orientation towards special education derives from a biological-psychological conception, in which difference is considered a deviation from the norm. The subject of special educational needs is focused individualistically: labels, limitations of opportunities, etc. She defended a school committed to the idea of including everyone, that does not choose, that does not negatively judge what is the different and that diversifies in its offers.

NEW TECHNOLOGIES

- J.E. Wänn. Borlänge, Sweden. New technologies help to equal the opportunities within reach of people with mental retardation in the world of family, school and work. Today, people with Down's Syndrome have access to modern technology that may help to compensate their cognitive deficits. He showed some tools developed at the Handitek Foundation for improving causal relations (why), spatial relations (maps), quantity relations (money, etc.) and time (clocks).

QUALITY OF LIFE

- J. Perera. Palma de Mallorca, Spain: he explained current implications of quality of life from the new definition of mental retardation proposed by the American Association on Mental Retardation and posed an integrating and comprehensive vision of quality of life for people with Down's Syndrome. We are facing the challenge of adult life. From this perspective he spoke of the challenges that people with Down's Syndrome face at the dawn of the third millennium: good health, better social image, self-advocacy, work, life with a partner and marriage.

AFFECTIVITY AND SEXUALITY

- C.D. Van Dyke. Iowa, USA: friendship, relationships and sexuality are normal aspects in adult human development. For some this means friendship, for others physical contact and for others it may mean marriage and children. In case of adults with Down's Syndrome all these aspects must be linked to appropriate programmes of sexual information, educational programmes for parents and support systems which ensure positive affective and sexual relationships, and which avoid situations of abuse or pregnancy and give guidelines for the use of sexual activity, marriage and the upbringing of children.

INCORPORATION INTO THE WORKPLACE

- E. Montobbio. Genova, Italy: the key for joining the workplace in a normalised situation is found in "mediation", which allows the individual to learn the social schemes and personal development necessary for work: and the community to leave aside prejudices and make an effort to adapt the environment (especially the workplace) to favour inclusion. The experience developed in Italy has been very positive (91% successful) and is a stimulation which is having an effect in many parts of the world.

Conclusions of the 6th World Congress on Down's Syndrome Madrid, 23rd-26th October 1997

The aim of the 6th WORLD CONGRESS was to give an answer to the challenges facing persons with Down's 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 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's syndrome, trying to isolate typical characteristics of Down's 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's 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's syndrome.

4. To specify the **quality of life** model proposed for persons with Down's 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 **preventive medical programmes for Down's 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's syndrome who require them should be encouraged.

6. Becoming aware of the important role of **the family as Down's 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's 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 a ordinary school, b) **specific** programmes and curriculum adaptations and c) the application of **new technologies** in the classroom as a

particular useful strategy.

9. The Congress called attention to the importance that the **adult life of persons with Down's 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's 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's syndrome in public life must be pursued.

11. Training and **employment** of Down's 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's 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's syndrome **associations** must ensure that **parents, professionals and persons with Down's syndrome** are integrated in their organisation 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's 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. J. Mills (Canada), Prof. E. Momotami (Japan), Prof. E. Montobbio (Italy), Prof. F. Murphy (USA), 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).

PRIZES OF THE 6th WORLD CONGRESS ON DOWN'S SYNDROME

Three groups of prizes were awarded at the Madrid Congress. The first was awarded to two scientists of world renown who have distinguished themselves in recent years for their research and publications on Down's syndrome. They were: Professor C.J. Epstein, of the University of California and Professor J. Rondal, of the University of Liège. The second group went to the leaders of the world associative movement, to reward effort and personal dedication in favour of the associative movement for Down's syndrome in the world.

They were awarded to MR. Antonio Gijón, of Spain, and Ms. Silvia García E., of Mexico. The third group of prizes was awarded to two people with Down's syndrome who, with their personal effort and work achieved goals which are an example and stimulation for all. They were: Pascal Duquesne, of Belgium and Ana Cristina Souto de Oliveira, of Brazil. There were also prizes for the three best scientific papers, and which went to Professor J. Rynders, of the University of Minnesota, Dr. Ariel Villagra, of the Polytechnic University of Madrid and Professor Svetlana Arbuzova, of the University of Donetsk, in Ukraine.

Celiac disease: a new challenge for persons with Down Syndrome.

Alberto Rasore-Quartino

Department of Genetics and Neonatology. Galliera Hospital, Genoa, Italy.

Celiac disease, or gluten-sensitive enteropathy, is a relatively uncommon disease due to gluten intolerance that causes permanent injury to small bowel mucosa, with villus atrophy, crypt hyperplasia and damage to the surface epithelium. As a consequence, malabsorption of nutrients ensues, mainly of fats, proteins, iron, folic acid and fat-soluble vitamins A and D. Clinically the disease shows different expressivity in affected persons. The first symptoms appear some time after the introduction of gluten products into the diet. Gluten is found in wheat, rye, oats and barley. These so called classic forms are characterised by early beginning, with severe gastrointestinal symptoms, frequent diarrhoea, failure to thrive, abdominal distension and pallor. The majority of affected persons, on the contrary, have a late onset, often during adolescence or even in adult age and present with scarce symptoms, not always referred to intestinal malabsorption, but to more aspecific growth retardation, anorexia, iron deficient anemia and hypoproteinemia; silent forms also exist and are more frequent than previously thought: their diagnosis can obviously be difficult. Screening tests are very important for a presumptive diagnosis: antigliadin antibodies have relatively high sensitivity and specificity, but the sensitivity and specificity of serum Ig-A endomysial antibody testing have approached 100%. A small-bowel biopsy remains nevertheless the clear-cut approach for diagnosis. Treatment requires a lifelong, strict gluten-free diet, after the establishment of which symptoms rapidly subside.

The prevalence of the disease in the general population has increased in recent years, possibly due to better diagnosis and increased awareness among physicians. It varies from 0.012% to 0.43%.

The association between Down syndrome and autoimmune diseases has long been recognised.

However, its relationship to celiac disease has only recently been reported and a definite association remains to be fully established. Since 1990 several investigations reported an increased frequency of celiac disease in Down syndrome, well above that of the general population. At present, we have different figures, ranging from 0.8% to 4.7%, depending on the authors and the populations screened.

One of the largest investigations on this subject was undertaken in Italy, with the study of 1184 persons with Down syndrome age from 2 months to 45 years. Fifty-two patients were diagnosed by intestinal biopsy as having celiac disease (4.4%). A classic form of the disease was present in 75% of the patients; atypical symptoms were observed in 10.2% and a clinically silent form in 14.2%.

It is important to stress that among the most common symptoms there were failure to thrive, anorexia, diarrhoea, vomiting, less frequently constipation and abdominal distension. Low levels of haemoglobin, serum iron and calcium were also frequently encountered. Autoimmune pathologies were found more frequently in subjects with celiac disease.

From that study, confirming a high prevalence of celiac disease in persons with DS and the detection of atypical presentation and clinically silent forms in about a quarter of cases, it is evident that a generalized screening for celiac disease in DS would be important in the perspective of improving the medical surveillance of these persons.

We strongly recommend that screening tests for celiac disease be considered in the health care protocols provided for DS, not only in childhood, but also during adulthood.

Down Syndrome behind the dikes

Saturday 13th June 1998

International Symposium

Academisch Medisch Centrum (AMC) - Amsterdam

PLENARY SESSION

09.30 Reception

10.00 Opening

Prof. dr. H.S.A. Heymans, Emma Children's Hospital,
AMC, Amsterdam

10.10 I'm nineteen now. When I was born, there was no
Stichting Down's Syndroom. Flashback

Peetje Engels, Schinnen, The Netherlands

10.20 The present state of medical aspects in Down
syndrome

Prof. dr. A. Rasore-Quartino, Ospedale Galliera, Genova
Italy

A review of the state of the art of medical research will be
given with special emphasis on preventive medicine aspects.

10.45 Coffee break

11.15 Promoting the development of children with Down
syndrome: the practical implications of recent psychological
research

Prof. S. Buckley, Ph. D., University of Portsmouth,
Portsmouth, England

A review of the state of the art of psychological research
will be given with special emphasis on practical aspects, e.
g. early reading.

11.45 Language in Down syndrome: current perspectives

Prof. dr. J.A. Rondal, Université de Liège, Liège, Belgium

A review of the state of the art of research into language
and communication with special emphasis on practical
intervention techniques.

12.15 Discussion

In the afternoon there are two parallel sessions, namely:

10 years Stichting Down's Syndroom.

Its significance for research.

A number of short presentations relating to investigations
that have been carried out upon the request of, under the
guidance of, with the aid of, in using a population from the
Stichting Down's Syndroom.

This session is specifically intended for researchers of various
disciplines and will be held in English. For Dutch participants
there is simultaneous translation into Dutch.

10 years Stichting Down's Syndroom.

Recommended practice in The Netherlands.

A number of more extended presentations in Dutch that
are closely related to the themes addressed in the morning
and will illuminate the situation in The Netherlands in
particular. This session with workshop-character is particularly
intended for parents.

Fourth European Down Syndrome Conference

Creating Challenges

Malta, 10-13 March 1999

First Announcement and call for papers

The Fourth European Down Syndrome Conference with
the theme **Creating Challenges** will be held in Malta from
Wednesday March 10 through Saturday March 13 1999.

The Conference aims at bringing together persons with
Down Syndrome, parents, professionals and others interested
in the field in an atmosphere of mutual respect and
collaboration. The programme will consist of a number of
plenary and specialist sessions.

Topic areas: Genetics; Breaking the news; Health and medical
issues; Early interventions; Nutrition; Language; Parental
experiences and aspirations; Community and home - based
services; Enabling independent learning; Vocational
education and work opportunities; Inclusion in school and
communities; Educating for independent living; Leisure;
Dating, sexuality, marriage and family planning; Late
adulthood; Ethical and legal aspects; Information technology.
Preference will be given to the presentation of papers and
posters based on the latest research and good practice in
the various topic areas.

You are invited to submit papers for presentation at the
Conference as well as propose themes for symposia, thematic
sessions and plenary sessions.

Papers and non-scientific papers are welcome for presentation
as independent papers or as part of a thematic session.
Interactive poster sessions will be given special prominence.
Associations, agencies and individuals are invited to present
posters featuring their activities.

If you are interested in receiving the Second Announcement
brochure and registration document, please contact the
Conference secretariat:

Down Syndrome Association

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Persons and organizations who provide advice and any kind of support to the persons with Down's syndrome and/or to the members of EDSA.

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