



NewsLetter

Half-yearly - N° 8 - May 1996

The Sixth World Congress on Down Syndrome. Madrid instead of Paris

ERIK DE GRAAF, Vice-President

The previous (5th) World Congress on Down syndrome in Orlando in 1993 was organised by the American National Down Syndrome Society (NDSS) in co-operation with EDSA. During the preparatory stages of the congress in Orlando it was decided that the order of the organisations responsible should be reversed for the next congress: EDSA would lead its organisation and the NDSS would co-operate with EDSA. Within the membership of EDSA, the French umbrella organisation for Down syndrome, FAIT 21, made a strong plea to organise the 6th congress in Paris, with FAIT 21 in charge of the actual organisation in situ. As such the French set to work and did a lot of promotional work for what was going to be widely known as 'the Paris congress'. Everything was well under way and in full control.

The message from EDSA's Secretary General Richard Bonjean that FAIT 21 all of a sudden had cancelled the Paris congress for political and economic reasons reached me in the car and caused a moment of dangerous instability. Why? ? What to do? ? As soon as possible EDSA called an extraordinary meeting of its Board of Directors in Verviers (Belgium), on november 11th, 1995, in order to assume responsibility for and re-co-ordinate the organization of the congress.

After listing all the alternatives, at this meeting a strategic plan was drawn up and approved with several simultaneous and successive options. In the meantime EDSA had to bear in mind that it was already agreed in Orlando to organise the 7th World Congress in Sydney (Australia) in the year 2000. This meant that possible other organising parties after FAIT 21 would have much less time to set up a totally new organisation because two world congresses, say, less than two years apart was (and still is!) considered unacceptable. Yet, postponing the 6th Congress to 1997 was considered a viable option.

The strategic plan from the EDSA Board Directors considered the following alternatives:

- 1a. to propose to the organizing committee of the International Conference of Down Syndrome in Roma, Italy, to be held from October 23rd to 25th 1996, that this conference could be transformed into the 6th World Congress.
- 1b. to investigate the possibility of organising the 6th World Congress near Eindhoven (the Netherlands) under the responsibility of the Dutch Down Syndrome Foundation (Stichting Down's Syndroom)
- 1c. to investigate the possibility of organising the 6th World Congress in Madrid (Spain), firstly to coincide with the IV International Symposium which the Asociación Síndrome de Down de Baleares (ASNIMO) has been organizing every two years.
2. to investigate the possibility of organising the 6th World Congress in Belgium under the auspices of the Belgian Association of Parents of Children with Down syndrome (APEM) and the University of Liège.
3. To cancel the 6th World Congress entirely.

Already during the extraordinary meeting, option 3. was ruled out as totally unacceptable. Next, around Christmas 1995, given the very short time available, it proved impossible to reach a satisfactory solution to transform the Roman congress. For the Dutch option, the actual organisation was carried out quite far in December 1995 and January 1996. However,

it proved impossible to find sufficient funding to give the final green light. In the meantime, the Belgian option turned out not to be fruitful. The positive results from the Director of EDSA's Scientific Board, Juan Perera in Spain (option 1c.) led to the final cancellation of options 1b. and 2.

The issue at present

Since the beginning of 1996 Juan Perera has been working intensively to be able to host the 6th World Congress on Down Syndrome in Madrid. Responsible for the organisation in situ is the Spanish Federation of Down Syndrome Institutions (FEISD). The actual work will be largely done by the Spanish National Institute of Social Services in Madrid. This organisation will run the Congress secretariat and publish the proceedings. Furthermore, it contributes in the financing of the congress. The venue will be the Palacio Municipal de Congresos in Madrid. This is the latest generation intelligent building, equipped with all the necessary technical advances for the organization of congresses. In the early preparatory stages of what all of us now have to be made widely known as 'the Madrid Congress' the option of coincidence with other related congresses in Spain was left, whereas 'the Madrid Congress' was moved to October 1997.

Finally, now that everything is so well under way (again), the entire Board of EDSA is eagerly looking forward to welcome all persons interested in Madrid: 'bienvenidos' (an attempt to say 'welcome' in Spanish).

Madrid Centre for the VI World Congress on Down Syndrome

The VI World Congress on Down Syndrome will be held in Madrid from 23rd to 26th October 1997 and is being organised by the Spanish Federation

of Down Syndrome Institutions (FEISD) under the patronage of INSERSO (National Social Services Institute). This is the result of the cancellation for

political and financial reasons of the Congress which should have taken place in August of this year in Paris.

The World Congress on Down Syndrome is organised every four years in a different place in the world. The last one was held in 1993 in Orlando (USA) and the Congress for the year 2000 has already been arranged to take place in Sydney (Australia). The decision was recently taken by the Board of Directors of EDSA (European Down Syndrome Association), who shared with New York National Down Syndrome Society (NDSS) the ultimate responsibility for organising the World Congress.

The World Congress is undoubtedly the greatest and most important Down Syndrome meeting at world level. The aim is to present and discuss worldwide advances in the different disciplines concerning Down Syndrome in the last four years and for this leading figures in each speciality have been invited to participate. However, it is also being organised with the intention that people with Down syndrome, families and professionals from all over the world meet in a forum of communication and discussion.

The scientific and organising committees for the Congress have been formed under the presidency of the Spanish professor Juan Perera. The structure of the Congress is now being finalised and will be as follows: in the mornings, two plenary sessions, each with three conferences at the highest scientific level addressed basically to professionals; and in the afternoons, workshops and round tables addressed to the practical aspects and experiences of special interest to parents and professionals, with the participation of persons with Down Syndrome. Open conferences, posters and exhibition stands are also planned.

The aim of the Congress title: "DOWN SYNDROME: Sueños hechos realidad - DOWN SYNDROME: When dreams come true" is to transmit a message of innovation and hope,

emphasizing and informing on the scientific advances which are making it true that people with Down Syndrome receive social recognition, go to a normal school, learn to read and write, have a job and, in short, have a better quality of life.

Simultaneous translation at least from English into Spanish and vice versa is guaranteed at the Congress. From French, German and Italian into Spanish and vice versa it will also be possible in any of those languages which have at least one hundred delegates.

For the first time the last day of the Congress will be dedicated to the world of the Down syndrome association movement, when it is planned to have continental meetings, presentation of the large world federations, association posters, as well as the official presentation and constitution of the FIDS (International Down Syndrome Federation) and the election of the first Board of Directors at its General Assembly.

The Congress will also have an interesting social programme which includes the inauguration ceremony, Congress dinner with show, presentation of prizes and awards, as well as an extensive programme of excursions, parties and tours of Madrid and surrounding areas.

The first worldwide issue of the programme, with fifty thousand copies, will be ready in May, coinciding with the opening of the Congress's Technical Secretariat.

We suggest that you make a note of the dates in your diaries and start saving. There will be travel and accommodation allowances for families and a magnificent atmosphere in a world without frontiers where the only protagonists will be the persons with Down Syndrome.

*The VI World Congress
Organizing Committee*

International Down Syndrome Federation

Federación Internacional para el Síndrome de Down

Fédération Internationale Syndrome de Down

The Fids is Born

The FIDS is a fact. On February 15th 1996 last the constitutional act for the INTERNATIONAL DOWN SYNDROME FEDERATION was signed in Mexico.

At the V World Congress on Down Syndrome held in August 1993 in Orlando (USA) the need was confirmed to form a body to represent, promote and defend interests and rights of persons with Down syndrome at world level.

Forming part of this management committee were Josephine Mills (President of the Canadian Down Syndrome Society), Donna Rosenthal (Executive Director of the National Down Syndrome Society of New York), Silvia García Escamilla (President of the John Langdon Down Institution of Mexico), Penny Robertson (President of the Australian Down Syndrome Society) and Juan Perera (Vice-president of the Spanish Down Syndrome Federation).

The committee received very specific instructions from the Assembly at the World Congress in Orlando: to prepare for presentation at the Assembly of the VI World Down Syndrome Congress, draft by-laws, identity document (constitutional act), a plan of action and a budget. Throughout 1994 and 1995 the committee met in Orlando, Vancouver, Palma de Mallorca and Dublin. On the occasion of the 3rd European Down Syndrome Congress in Dublin an initial draft of the aforementioned documents, with a three month period for sending any suggestions and amendments, was discussed and approved at an open Assembly attended by 37 countries.

In the meantime, there was news that for economic and political reasons the VI World Down Syndrome Congress to be held in Paris was postponed without

specifying any date. The committee studied the situation and considered that for operational and efficiency reasons it was not convenient that the formation of the FIDS should also be postponed. A committee meeting was called from 12th to 14th February in Mexico and after a long discussion, which incorporated the amendments to documents presented in Dublin, it was agreed to approve and register the FIDS in Vancouver (Canada) as a non profit making International Down Syndrome Federation, with the management committee members as its founders.

The FIDS has begun to work and the Vancouver Secretariat (3580 Slocan Street, Vancouver, BC V5M 3E8 CANADA, Tel. (604) 431 -9694, fax (604) 431-9248, E-mail: josephine(@sfu.ca) is informing the principal Down Syndrome Federations and Associations in the world and is also inviting them to become members.

The management committee approved the by-laws based on those of other large and experienced world federations, as well as a budget for 1996, an initial and priority plan of action, a promotion leaflet and membership form. Among the priorities for 1996 are the following: to attract members, publication of a NEWSLETTER, Internet connection (Web page), to call a General Assembly and seek resources and sponsors.

The first FIDS General Assembly will take place at the VI World Down Syndrome Congress, which will finally be held in Madrid in October '97, where there will be also the election of the first Board of Directors and representatives from each of the six regions in which the world has provisionally been divided (Africa, Asia-Pacific, Latin America, Europe, Middle East and North America).

The FIDS is a fact and has started work with clear and concrete objectives: to assist the specific Down syndrome association movement throughout the world, to promote and protect the rights of everyone with Down syndrome, to circulate the right information on Down syndrome, to organise a World Congress every four years and to represent

the Down syndrome association movement before international institutions such as UNESCO, OMS, FSE, UNICEF, etc.

Juan Perera
President - EDSA Scientific
Advisory Board

The adolescence of children with Down syndrome and the role of parents. Some aspects.

Dr. Anna Zambon Hobart*

Boys or girls with Down syndrome can, like all teenagers, feel the need to become less dependent on their parents and to try and understand their own identity with regard to their contemporaries. These needs are too often ignored.

The capacity to be independent is not simply a matter of knowing how to do things, but depends most of all on the confidence we do or do not have in our own abilities and on our own self-respect. These aspects of our growth are rooted in infancy and in our parents' capacity to let us try and do things on our own. Otherwise we grow up insecure and in need of someone to protect us, to accompany us and do things for us.

To be sure, boys or girls with Down syndrome can increase the need many parents feel to control and protect, but we should never forget that the more adolescents are allowed to become self-sufficient in an over-protective family nucleus the more they will be capable of living as independent and responsible adults. After many years of observing how not only social inclusion but growth towards an active and intelligent working life were possible, we must make an ever greater effort to see that persons with Down syndrome are given the chance to be successful, to make choices, to prove how wrong the pessimistic theories of the past have been.

During adolescence boys or girls want to lead a life that is at least partly independent of their family, want therefore to go out alone, have friends, dress as they like and choose where they want to go and the things that interest them most. For

many parents it is hard to accept these changes and the child's requests risk being taken for rebellious behavior to be discouraged rather than accepted as normal aspects of his/her growing up. Many times we have heard anguished mothers say their babies are no longer "docile" like they used to be, that they insist upon going around in ridiculous clothes or to school by themselves or refuse to go swimming or answer back like they never did before. The vetoes which distress children most regard their capacity to do things on their own. The distress stems from their inability to prove to their parents or to themselves that they are capable grown-ups and no longer babies. Adolescents with Down syndrome can react to excessive parental control in different ways. The best way is for them to explain to and to show their parents that they deserve their trust. People with Down syndrome have more trouble getting parents to understand these things, but they can. I remember one boy who ran away from school an hour before lessons were over in order to show his mother he could get home on his own, was able to take a bus and get back without her help. Since then the mother respected her son's need for independence; he had found a "painless" way of solving the problem. I could give many more examples of how boys and girls with Down syndrome succeed in changing their parents' attitudes for the better.

Other adolescents, feeling stifled by situations which do not allow them to grow up, can devise more drastic and dramatic solutions to their feelings of helplessness and frustration. They can stop communicating or

start doing and saying things which distress or upset their parents who become infested, as it were, by the same feelings of helplessness. We have seen however that distressing behavior in persons with Down syndrome can vanish as if by magic if they are shown respect and engaged in adult discussion. But above all the behavior changes when parents succeed in improving the quality of the sons' and daughters' life, both creatively and socially.

Thanks to AIPD training courses in Rome for aiding the independence of adolescents, and the activities of Stelletta, a coop of persons with Down syndrome for the making and selling of pottery, we have been able to observe the relationships which the children gradually form, many of them brought together for the first time with other persons with Down syndrome. (In Italy we are very proud of having abolished special schools as early as the 1970s; our children are fully included in regular schools so that social inclusion has been an accepted fact here more than elsewhere for over twenty years.)

So after adolescence, when social inclusion becomes more difficult, young adults with Down syndrome found themselves for the first time in groups of their own kind, and established loyalties, friendships, antagonisms, rivalries and competitiveness. Authentic love affairs blossomed as well and couples formed with all the possessiveness and jealousy, all the self-absorption, fidelity and "betrayals" of any steady couple and with all the feelings of exclusion and envy, or of solidarity on the part of others. As with any group. One still quite common prejudice is that persons with Down syndrome do not fall in love or do not desire the company of their own kind. I remember one mother telling me how "awful" it was the first time she saw her daughter at a dance with boys with the syndrome. She talked about it with tears in her eyes for never before then had she been faced so directly with her daughter's reality. But when I asked her how her daughter took it, she said she had the time of her life and danced all night.

Which brings us to the subject of identity, that is to the child's awareness and acceptance of the syndrome. I feel the subject should be dealt with at elementary school level, as soon as a child shows signs of uneasiness about his capacities compared to those of his classmates. Many parents tell me their children, in the elementary school years, were specifically worried about the trouble they had doing homework. I remember one seven-year old girl, Caterina, who had already learned how to syllabify and was struggling to learn how to read whole words. One day she said to her mother in tears: "I do, I do, but I can't!"

At that moment the mother realized her daughter was asking why she was having such a trouble compared to her younger brother and her classmates. The mother explained very clearly and simply that she had Down syndrome, which made it harder for her to learn to read and write, so she had to work more than the others. But she also told her she was very clever because she was in any case going ahead, reminding her of her 'prowess' in other fields, and besides everybody has problems; the important thing is to do one's best.

The child felt reassured because she was given a reason for her problems. She also realized she could talk about them to her parents, and trust them because they would encourage her to carry on without playing down her difficulties and telling stories.

Very often boys or girls already in their teens or even adults have never spoken about Down syndrome with their parents, most of whom feel their children are incapable of understanding. Or they can notice their children are aware of their condition, but do not know how to talk about it. It is certainly not easy, but it might be useful to consider what Down syndrome means for parents and to what extent they have succeeded in dealing with and accepting, to the best of their ability, their children's problems. Why, for example, do some parents find it unbearable for their children to associate with other people like themselves? Why this rejection of other persons with exactly the same number of chromosomes? Helping their sons and daughters make friends with other adolescents with Down syndrome can give them a chance to explain what it is that makes them different from others. Telling a child: "You have Down syndrome and that's why you have some difficulties," means reassuring her that her parents have accepted the reality she has to live with forever. It also means strengthening her sense of identity, allowing her to attain a clearer and more confident relationship to herself. There are children who come to our Association for the first time, see the pictures of persons with Down syndrome on the walls and read the word Down in the pamphlets lying around and they show interest without the least embarrassment. Pointing to the pictures they say: "Look, she's Down like me."

Others instead tell their flustered parents they want to go away because they're "not Down." I remember one father who, there in our presence, for the first time discussed the matter with his son clearly and calmly. There was nothing wrong, he said, about having Down syndrome like lots of other children who were on the ball like him, despite the trouble they had learning some things. The boy responded:

yes, it was all true, he was on the ball. At that moment, for the first time, father and son had a heart-to-heart talk and both accepted a reality which the father had never been able to talk about and the son consequently felt obliged to reject.

Many brothers and sisters and friends willingly go on accepting a person with Down syndrome into their group also during adolescence. Many children with Down syndrome willingly go on meeting friends different from themselves like when they were smaller and were always the first to be invited to friends' parties. A few days ago a mother told me her son, one of the Down syndrome youngsters employed by McDonald's in Rome, was invited to a discothèque by two waitresses and came home at three in the morning after dancing all night.

But some young adults feel very uncomfortable around friends without the syndrome, felt excluded for a number of reasons, either because the others were all paired off or because they couldn't take part in the conversation and in group activities the way they would have liked to, or for other reasons their parents sometimes could not understand. The result was that they ended up withdrawing from the group and keeping to themselves.

Lack of friends and social exclusion is a very common problem among adolescents and adults. Parents and de facto family members represent the only company they have, at that very age when they should have a group of their own and a social life outside the family. We have long advised parents to encourage persons with Down syndrome to meet, to form more equal relations, a true friendship or even a love affair. In a group with people of his own kind a person with Down syndrome can, perhaps for the first time in his life, freely choose a friend to become more intimate with, and seeing himself reflected in the other accept his own identity with greater equilibrium. During school years, choices were most likely made for him or her by parents or classmates. But in a group of persons with Down syndrome a boy or a girl can choose along more personal lines the person to help or be helped by, the friend to phone, to go out with, to see a film or have a pizza.

Many children, in accepting Down syndrome in others, accept it in themselves too. Some parents, at the idea of encouraging meetings with other children like their own, protest: "What? You mean after all we've done in Italy for inclusion, we're supposed to meet up now with other handicapped people?" What we're suggesting, however, is certainly not a return to segregation, but a realistic way of dealing with the demands of many adolescents

who want to live like other adolescents, want to go out, want to have those friends and sweethearts it would be hard to find among people without Down syndrome. When the alternative is staying at home or going out exclusively with one's parents, or when one-time friends drop out of sight, or brothers or sisters get engaged or married, what does that leave for many persons with Down syndrome? Real segregation and the loneliness of one's handicap. But with friends like themselves they can share the world of others, linger in the streets and meeting-places of one and all.

We have seen youngsters change character or their whole attitude towards life because they have fallen in love and felt loved in return. These were not impossible, made-up love affairs, but real, authentic and very beautiful relationships. We know four couples who have been together for months or over a year. Some of them save up money so that one day they can live together and travel the streets of Rome on their motorbikes.

I asked Roberto and Sara, who have been engaged for over a year, to let me publish some of the beautiful love letters they write each other almost every day. They asked me not to use their names and Roberto gave permission to publish only one letter that Sara wrote his parents. They spend almost every weekend together, sometimes at his house, sometimes at hers. They both lead active working lives like lots of young people, especially those who grew up in the generation of inclusion. There is only enough space here to quote a few lines:

Robert "... We'll get married some day. Every time it's wonderful knowing what we have in common and it's right that you dear Sara you must stay with me forever because **I LOVE YOU FOREVER AND EVER...**

I want to help you grow even more, I want to do things, to read lots of books and copy out the bit you liked best... Growing up together's wonderful and when I'm with you I learn all sorts of things and I like being in you it's wonderful being with you and when I feel your presence I'm never alone, in fact I feel I got something I feel I got you inside me... I always think about you and I see my positive side as if it were part of me... I'm sure you understand what I'm saying because the way you are the way you do things I'm sure you love what I am ... Sara I love you and I feel wonderful with you and when I feel your soul warming me and staying in my bed I feel protected. You know that when you're with me I feel your soul talking to me about love, about sex, about kids, about having a home, about having a motorbike for two and a big family."

SARA in a letter to Roberto's parents "... You got a son like no one in the world... your son makes me feel

happy... I needed to have a boyfriend because I wanted to have the first love of my life because before I didn't have anyone. My classmates were all engaged but said they were fond of me that's all. I was always alone and without anybody because they didn't want me... he 's the only person who opened me more".

These two youngsters also speak for all those persons who can't express themselves or write like them, but have the same feelings inside and the same desires.

Conclusions.

I would like to end with some advice which I hope may be useful to parents when they begin to realize their children are growing up.

First of all they should try to accept their need to grow up and have a space of their own in the family, and to organize spare-time activities which are congenial and pleasant for them.

Talking openly about Down syndrome is essential for them to be able to deal with their own identity in an at once realistic and acceptable way.

In fact parents should speak as clearly and calmly as possible, stressing all those achievements which their child should be proud of despite the difficulties of his handicap. Talking about these things is of course not a matter which can be solved overnight, but the subject should be brought up in different contexts every time the opportunity arises. Parents who have taken the trouble to explain things to their child as of the early school years when he/she begins asking questions about his/her difficulties, have helped him/her deal with reality as an adult, a reality which becomes the more acceptable the more easily it is spoken of.

In fact, the fibs, the fantasies and myths which an adolescent may invent to improve the quality of his life must as far as possible be carried back to reality. One girl fell in love with a conscientious objector who worked in a pottery coop with her and other young people with Down syndrome. She told everyone she was engaged to him and out of jealousy showed aggressiveness towards the other girls. The boy did not know what to do. He hadn't told her he had a girlfriend and didn't try and stop her because he was afraid of hurting her feelings. One evening I suggested she go out with him to meet his girlfriend. Faced with the fact that the man she loved was in love with somebody else and that the two of them would welcome her as a friend to go out with like grown-ups, she stopped acting like a little girl with her head in the clouds and accepted a reality she had not accepted before. In situations where an adolescent has neither

friends nor a satisfactory social life I think parents should encourage him to meet other persons with Down syndrome or some other disability, either at specialized centers or even privately. Among groups of young people who share activities like going to theater, dancing and so forth, some of them become friends and start making dates to meet during their free time, even spend weekends together. They choose each other, phone each other, arrange to see each other and enjoy an intense and satisfactory social life. I know several of these young people whose families took the trouble to support their need for social independence.

Lastly, parents must give their children rules of adult behavior and a sexual education.

Their behavior should correspond to that of any adolescent, so no hugging and kissing which should be reserved exclusively to members of the family and close friends. Parents should also discourage the exaggerated shows of affection towards themselves which can become annoying and slightly provocative. When people with Down syndrome start going out on their own it's important to tell them not to accept invitations of any kind from strangers.

Regarding sexual education, good books and audio-visual aids exist for children and teenagers which can help parents explain how the different parts of the body are made, how babies are born, how to avoid an unwanted pregnancy and those aspects connected with sexuality which all children have fantasies about but which they too must be informed of in a proper and appropriate way. During an AIPD meeting of adolescents and specialists dealing with sexual education, the boys and girls asked many questions and showed great curiosity about the way the body functions.

In what we hope is not a too-distant future, persons with Down syndrome will have more and more opportunities to enjoy a social life independent of the family. It will be easier for them to meet people with the same or similar problems with whom to form friendships and to fall in love like Sara and Roberto and other friends and other couples have.

When adolescents say they want to get married when they grow up and live on their own, instead of feeling anguished and helpless, parents will be able to accept the possibility that their children's dreams and desires can some day come true.

**Associazione Italiana Persone Down (AIPD), Viale delle Milizie 106, 00912, Rome, Italy*

Quality of Life

Dr. Juan Perera

We frequently hear these words: "QUALITY OF LIFE". In our Associations' by-laws, in Down syndrome care programmes and scientific literature, achieving quality of life is considered a principal objective.

However, what exactly do we mean when we say quality of life? What are the indicators in order to assess the quality of life of a person with Down syndrome? Can everyone with Down syndrome attain a reasonable quality of life or is it something reserved for just a few? Does a person's concept of the quality of life change with the passing of time?

If we are convinced that the principles of normalisation and integration must be present throughout the lives of the disabled, we have to admit right away that the indicators of quality of life for people with Down syndrome should not be any different from those which any of us consider to be quality of life.

Recent works on quality of life establish the following criteria or indicators for its assessment:

Firstly, **health and wellbeing**: that is why it is important that right from the beginning the health of children with Down syndrome is carefully looked after with specially adapted programmes and that any other problems are medically or surgically corrected or compensated. The Spanish Federation of Down Syndrome Institutions has been very much aware of this need and has published and circulated the "Programa Español de Salud para las Personas con Síndrome de Down" (Spanish Health Programme for Persons with Down Syndrome) which only purports to be a guideline for the prevention of illnesses or disorders usually occurring in persons with Down syndrome and for their health care. Good health is the basis for good development of intelligence and also the basis for positive learning later. Even more than that however, with good health it is possible to enjoy life more and wellbeing is improved.

Secondly, **the capacity to choose and be independent**. A good programme of early intervention and good attention at school should lead to an increase in the capacity of the persons with Down syndrome to choose and be independent. This means being able to have control over their own lives, being able to do what they like and want, having the capacity and opportunities to choose and plan for the future. This

affects such important aspects in life as work, home, leisure, friends, partner, religion, politics and minor everyday decisions. An overprotected education and feeling many parents still have that their children, in spite of their age, continue to be children are the worst breeding grounds for developing this aspect of quality of life.

Thirdly, **life in the community**. That is to say, adaptation to the environment. The person with Down syndrome whose aspirations are in accordance with his/her possibilities has to adapt him or herself to the community in which he or she lives: to be able to go to the cinema, to buy his/her favourite magazine, to belong to a sports club, to eat in a restaurant or to shop in the supermarket. It is very important that their social behaviour is such that it adapts to the rules the community has established for using its different services. We sometimes complain that society rejects the disabled and it is often quite the reverse. It is the disabled person himself, with his abnormal behaviour when eating, for example, or using public services, or dressing, etc. who segregates himself from the community. And the parents have a lot to do with this.

Lastly, **integration**, or as it is now called in Anglo-Saxon countries, **inclusion**. That integration is the only correct way for educating a person with Down Syndrome is no longer being debated today. We cannot talk about quality of life without integration. Integration in school at all levels and integration in the working world. The majority of persons with Down Syndrome are capable of working if we train them properly, if we adapt jobs to their capabilities and if we give them the opportunity to work. Experiences in this field show that work transforms their lives, makes them feel useful, gives them greater autonomy and more self confidence. Once again, and we will not get tired of repeating it, it is no good leaving young people at home, glued to the TV and without any alternative except to depend on their parents. What will happen when they are gone?

The fundamental obligation of parents and Associations is to work on improving the quality of life for people with Down syndrome and this is achieved by working hard from the beginning on the points mentioned above.

TOWARDS AN INCLUSIVE SOCIETY

A report on the 3rd European Down Syndrome Conference, 1995
by Joseph E. Greevy, Chief Executive,
Down Syndrome Assoc. of Ireland

THE THIRD European Down Syndrome Conference was held in the O'Reilly Hall U.C.D., Belfield, 23rd - 26th August 1995, under the auspices of the European Down Syndrome Association. The Conference was the most ambitious event on the subject ever held in Ireland. It attracted over 630 delegates including representatives from 33 countries, thus giving the event a truly international flavour. It was particularly interesting to talk to and exchange experiences with delegates from former Eastern bloc countries like Russia, Estonia, Slovakia, Slovenia and Albania, where conditions for people with learning difficulties leave much to be desired.

The Association is privileged with having Mary Robinson, as its Patron. Mrs Robinson formally opened the Conference and afterward delighted the audience by meeting and talking to as many people as possible. The keynote address was delivered by the American Ambassador to Ireland, Mrs Jean Kennedy-Smith whose family are well known internationally for their work in support of persons with a mental handicap. Mrs Kennedy-Smith has established her own Trust, very Special Arts, which has branches in many countries including Ireland. The theme of the Conference 'Towards an Inclusive Society' implied a two-way journey: society coming to meet people with Down Syndrome and people with Down Syndrome moving towards this welcoming community. The aim of the conference was to look at ways to help people with Down Syndrome more easily make their part of the journey to inclusion - to make them more ready to participate in the Inclusive Society. It is interesting to note that the International League of Societies for persons with Mental Handicap (to which the D.S.A.I. is affiliated) has been renamed 'Inclusion International'.

The Conference was designed to encourage maximum interchange between the panel speakers and the audience. A questionnaire was circulated to the members of the D.S.A.I. and as a result the following subjects were chosen Speech and Language; Education

at all Levels; Training and Employment; Genetics; Health Nutrition and Fitness and Psychological Aspects of Integration. The importance of speech and language to persons with learning difficulties was emphasized and the role of the parents encouraging their children from an early age was considered vital. The scarcity of qualified speech therapists to work with children with Down Syndrome was deemed very unsatisfactory and it was suggested that action be taken to try and remedy this state of affairs.

There is an international trend towards integration of children with learning difficulties into mainstream schools. However, the Down Syndrome Association of Ireland emphasizes the right of choice by the parent, between special and mainstream schools, the parent being the final arbiter in any particular case. Speakers from Northern Ireland and Spain gave details of the situation in their countries; and it was pointed out that in Ireland, while the principle of integrated education was accepted by the Department of Education, the support teacher service was inadequate to cope with current demands.

It was generally agreed that the provision of facilities for training and employment should be available to persons with learning difficulties after they leave school. Many avail of sheltered workshops and a few have managed to secure work in the open market. Speakers from the European Union of Supported Employment were included on this panel.

Plenary sessions on genetics and on general health nutrition and fitness were very well attended and a panelist from Russia spoke about the effects of radiation. The importance of a proper diet and of exercise for people with learning difficulties was deemed to be of great importance. A session on the psychological aspects of integration prompted a useful debate between audience and the panel. Early counselling of parents was discussed and it was noted that many parents were willing to counsel 'new' parents coming on stream. In this connection, organisations like the D.S.A.I. played a vital role.

The final item on the programme was a special panel discussion, the panellists all being young people with learning difficulties. Chris Burke (U.S.A.), Andy Trias (Spain), Emmy McAs (Canada) and Clara McNeill and Emily Moore (Ireland) spoke about their lives, their work, their recreational pursuits and their hopes for the future. One and all distinguished themselves and were a living example of the progress that has been made over the past two decades in the development and care of people with learning difficulties. A detailed report on the Conference is being prepared and will be available in the New Year.

GOALS AND OBJECTIVES OF EDSA

1. To spread throughout all European nations the principle that every person with Down's syndrome has the right to receive the health care and educational services demanded by his (her) condition, in order to achieve the best of his (her) possibilities.
2. To stimulate the implementation in each European country of a network of local groups, made up of parents and professionals. These groups should be able to better attend and resolve local needs, so that the families of every newborn with Down's syndrome may immediately receive the required support and advice.
3. To promote the principles of normalization in order to transform, humanize and dignify all human services upon which persons with Down's syndrome rely.
4. To encourage the development of programs and services that may be appropriate for persons with Down's syndrome.
5. To exchange information among the European countries on those programs that have proved to be effective. It is EDSA's conviction that the cultural pluralism of the European nations will enrich the personal and communal actions on behalf of the persons with Down's syndrome.
6. To introduce in all nations specific and comprehensive health programs for persons with Down's syndrome.
7. To encourage the constitution and convening of scientific groups, to share their study and research on:
 - a) The biology of Down's syndrome and its pathological consequences.
 - b) The mental development at different ages.
 - c) Programs of education and intervention that are suitable for the specific conditions of each person with Down's syndrome.
 - d) Integration in his (her) environment, in the community and at work.
8. To study and recommend legislation adapted to each European nation, in order to guarantee and ensure the services for the person with Down's syndrome during his (her) adult life.

EDSA Science Advisory Board

PRESIDENT

Prof. Dr. Juan PERERA MEZQUIDA - Psychologist
DIRECTOR "CENTRO PRÍNCIPE DE ASTURIAS" ASNIMO
km 7,5 Ctra. Palma-Alcudia • 07141 Marratxí, Balears, ESPAÑA
Tel.: 34 - 71 - 60.49.14 Fax: 34 - 71 - 60.49.98

CHIEF EDITOR

Prof. Dr. Alberto RASORE QUARTINO - Pediatrician & Geneticist
DEPT. OF PEDIATRICS GALLIERA HOSPITAL
Mura delle Cappuccine, 14 • Genova, ITALIA
Tel.: 39 - 10 - 5632.464 Fax: 39 - 10 - 5632-399

SCIENCE ADVISORS

BELGIUM

Prof. Dr. L. KOULISCHER
CHEF SERVICE DE GÉNÉTIQUE HUMAINE
Université de Liège - Centre de Génétique Humaine - Tour de Pathologie (B23)
B • 4000 Sart Tilman (Liège)
Belgium
Tel.: 32 - 41 - 66.25.62 Fax: 32 - 41 - 66.29.74

Prof. Dr. Jean A. RONDAL - Psycholinguist
PROF. OF PSYCHOLINGUISTICS LIEGE UNIVERSITY
Laboratory of Psycholinguistics
at. B-32 • 4000 Sart Tilman (Liège)
Tel.: 32 - 41 - 66.20.05 / 66.20.06 Fax: 32 - 41 - 66.29.44

FRANCE

Prof. Dr. B. LAURAS - Pediatrician Geneticist
PROF. SAINT ETIENNE UNIVERSITY
4, Impasse du Midi, La Flache • 42290 - SORBIERS
Tel.: 33 - 77 - 53.89.99 / 82.80.28

Prof. Dr. Patrice GARDES - Rehabilitator Department of Orthopedics
CLINIQUE BEAU SOLEIL, MONTPELLIER
1 Rue Corneille • 30900 NIMES
Tel.: 33 - 66 - 67.93.54
33 - 67 - 75.98.88 Fax: 33 - 67 - 75.97.65

GERMANY

Prof. Dr. Med. Hubertus VON VOSS - Pediatrician
DIRECTOR KINDERZENTRUM MÜNCHEN
8000 München 70 • Heiglhofstrasse 63
Tel.: 49 - 89 - 71.00.90 Fax: 49 - 89 - 71.00.9248

Prof. Dr. Etta WILKEN - Language Therapist
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Dpt. of Special Education
Bismarckstrasse, 2 • D-3000 HANNOVER 1

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X-PROF. NOTTINGHAM UNIVERSITY
154 Church Lane, Marple, Stockport-Cheshire • SK6 7LA
Tel.: 44 - 61 - 427.3024

Prof. Dr. Richard W. NEWTON - Neuropediatrician
PROF. MANCHESTER UNIVERSITY
Royal Manchester Children's Hospital
University of Manchester School of Medicine
Pendlebury, Near Manchester M27 1HA
Tel.: 44 - 61 - 794.4696

Prof. Dr. Sue BUCKLEY - Psychologist
DIRECTOR OF THE SARAH DUFFEN CENTRE
Dept. of Psychology Portsmouth University
Belmont Street
Southsea Haunts PO5 1NA U.K.
Tel.: 44 - 705 - 82.42.61 Fax: 44 - 705 - 82.42.65

Prof. Dr. Jennifer G. WISHART - Psychologist
PROFESSOR EDINBURGH UNIVERSITY
Edinburgh Centre for Research in Child Development
Dept. of Psychology, University of Edinburgh
7 George Square, Edinburgh EH8 9JZ • SCOTLAND, U.K.
Tel.: 44 - 31 - 650.3438 Fax: 44 - 31 - 650.6512

Prof. Dr. Derek CHERRINGTON - Psychologist
DIRECTOR NATIONAL CENTRE FOR DOWN'S SYNDROME
Centre for Advanced Studies in Education
Faculty of Education, Birmingham Polytechnic
Westbourne Road Edgbaston • Birmingham B15 3TN - U.K.
Tel.: 44 - 21 - 331.6021 Fax: 44 - 21 - 331.6147

HOLLAND

Dr. Marijke J. G. CREMERS, MPH
SSG
Wittevrouwenkade, 6 • 3512 CR UTRECHT
Tel.: 31 - 30 - 31.58.41 Fax: 31 - 30 - 36.70.77

HUNGARY

Prof. Dr. Sjoukje BORBELY - Psychologist
ASSOCIATE PROF. HOSPITAL BARCZI GUSTAV
Bárczi Gustáv - Institute of Psychology
1071 Budapest, Damjanich U. 41-43 • H-1443 Budapest 70 P.F. 146
Tel.: 36 - 1 - 121.3526 Fax: 36 - 1 - 142.3168

Prof. Dr. Joseph BUDAY - Anthropologist
PROFESSOR DEPT. ANTHROPOLOGY
Bárczi Gustáv - Dept. of Pathophysiology
H-1071 Budapest, Damjanich U. 41-43 • Bethlen Tér. 2
Tel.: 36 - 1 - 142.1379

IRELAND

Prof. Dr. Chris CONLIFFE - Psychologist
DIRECTOR INSTITUTE FOR COUNSELLING & PERSONAL
DEVELOPMENT
ICPD, Glendinning House, 6, Murray Street • Belfast, BT1 6DN
Tel.: 44 - 232 - 33.09.97 / 32.45.06 / 32.99.43
Fax: 44 - 232 - 24.86.07

Prof. Dr. O. Conor WARD - Pediatrician
CHIEF, DPT. OF PEDIATRICS NORTH WEST ARMED FORCES
HOSPITAL (TABUK-SAUDI ARABIA)
North West Armed Forces Hospital
P.O. Box 100 - Tabuk - Saudi Arabia
Fax.: 966 - 4 - 423.2795
Our Lady's Hospital for Sick Children • Crumlin - Dublin 12

ITALY

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PROF. OF PEDIATRICS DIRECTOR DIVISION OF PEDIATRICS
METABOLIC DISEASE. CENTER FOR DOWN'S SYNDROME.
NAPOLI UNIVERSITY
Via S. Pansini, 5 • 80131 NAPLES
Tel.: 39 - 81 - 746.2673 / 746.3500
Fax: 39 - 81 - 546.3881 / 545.1278

Prof. Dr. Carlo BACCICHETTI - Pediatrician and Geneticist
DEPT. OF PEDIATRICS - PADOVA UNIVERSITY
Via Giustiniani, 3 • 35128 PADUA
Tel.: 39 - 49 - 8213559 Fax: 39 - 49 - 8213510

Prof. Dr. Bruno DALLAPICCOLA - Geneticist
PROFESSOR OF HUMAN GENETICS ROMA UNIVERSITY
Servizio di Genetica, Laboratorio Centrale
C.R.I. Via Pansini, 15 • 00151 ROMA
Tel.: 39 - 881 - 41.04.23
Fax: 39 - 881 - 45.72.96

Prof. Dr. Salvatore SORESI - Psychopedagogue
DIPARTIMENTO DI PSICOLOGIA DELLO SVILUPPO E DELLA
SOCIALIZZAZIONE - UNIVERSITÀ DI PADOVA
Via Beato Pellegrino, 26 • 35137 PADUA
Tel.: 39 - 49 - 876.1411 Fax: 39 - 49 - 875.5025

SPAIN

Prof. Dr. José A. ABRISQUETA ZARRABE - Geneticist
HEAD LABORATORY OF HUMAN GENETICS
PROFESSOR III CICLO UNIV. COMPLUTENSE MADRID
Centro de Investigaciones Biológicas • (C.I.S.C.) Genética Humana
Serrano, 113 bis • 28006 MADRID
Tel.: 34 - 91 - 562.0307 Fax: 34 - 91 - 562.7518

Prof. Dr. Isidoro CANDEL GIL - Early Rehabilitation
PROF. MURCIA UNIVERSITY
Facultad de Psicología ASSIDO
c/ Miguel de Cervantes, s/n • 30009 MURCIA
Tel.: 34 - 68 - 29.38.10 Fax: 34 - 68 - 28.29.42

M E M B E R S

EFFECTIVE

BELGIUM

ASSOCIATION DE PARENTS D'ENFANTS MONGOLIENS-APEM
Rue de la Maison communale, 4 • 4802 Heusy

FRANCE

FAIT 21

Direction Générale

10, rue du Monteil - 42000 St. Etienne

GEIST 21 Puy de Dôme - 40, rue Julien Ferry • 63118 Cebazat

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ASSOCIATION FRANÇAISE POUR LA RECHERCHE SUR LA

TRISOMIE 21 - APET

Hôpital Necker - Enfants malades - Rue de Sèvres, 149 • 75743 Paris cedex 15

ASSOCIATION DE PARENTS D'ENFANTS TRISOMIQUES 21 DE
METZ & ENVIRONS - APET

204, avenue André Malraux - 57000 Metz

GERMANY

EUROPAISCHE DOWN SYNDROM ASSOZIATION

Siegfried von Westerburg Straße 22 • 50374 Ertstadt Lechenich

ARBEITSKREIS DOWN SYNDROME

Hegelstraße 19 • 4800 Bielefeld

SELBSTHILFEGRUPPE FÜR MENSCHEN MIT DS

Hirschenau, 10 • 90607 Ruchersdorf

GREECE

ASSOCIATION DES PARENTS D'ENFANTS TRISOMIQUES

54352 Thessalonika

IRELAND

DOWN SYNDROME ASSOCIATION OF IRELAND

South William Street, 27 • Dublin 2

ITALY

ASSOCIAZIONE ITALIANA PERSONE DOWN

Viale della Milizie, 106 • 00192 Roma

ASSOCIAZIONE COORDINAMENTO DOWN

Laboratorio Citogenetica - Via Giustiniani, 3 • 35128 Padova

ASSOCIAZIONE DOWN

Via Brione, 40 • 10143 Torino

NETHERLANDS

STICHTING DOWN'S SYNDROOM

Bovenboerseweg 41 • 7946 AL Wanneperveen

PORTUGAL

ASSOCIACAO PORTUGUESA DE PORTADORES DE TRISSOMIA 21

Rue Professor Delfim Santos, 1 - 4B • 1600 Lisboa

SPAIN

ASSOCIACION PRO SINDROME DE DOWN DE BALEARES - ASNIMO

Carretera Palma Alcudia km 7,5 - 07141 Marratxi (Mallorca Balears)

FUNDACION CATALANA PER LA SINDROME DE DOWN

Valencia 229-231 08 007 Barcelona

FUNDACION SINDROME DE DOWN DE CANTABRIA

Avenida General Davila 24 A, 1° C. 39 500 Santander

ASOC. SINDROME DE DOWN DE CADIZ Y BAHIA "LEJEUNE"

Plaza Santa Elena, 2, 2° C-D 11006 Cadiz

ANDADOWN (FED. ANDAL. DE ASOC. PARA EL SINDROME DE DOWN)

Angel, 24, 3° C 18002 Granada

ASSIDO - MURCIA

Av. da Miguel de Cervantes, s/n 30009 Murcia

ASINDOWN

c/ Camino Farinos, 2 • 46020 Valencia

AGUIDOWN

Apdo. de Correos 1094 • 20080 San Sebastian

UNITED KINGDOM

DOWN'S HEART GROUP

Ormonde, Henley Down, Nr Battle • East Sussex TN33 9BT

AFFILIATE

ARGENTINA

A.S.D.R.A.

Vera 863 • 1414 Buenos Aires

C.I.S.

DOWN SYNDROME ASSOCIATION

Ulitsa Mjawkiczja, D 13, Kw 3 • Moskau

HUNGARY

DOWN FOUNDATION OF HUNGARY

Kiraly u. 72 III, 22 • 1068 Budapest

MALTA

DOWN'S CHILDREN ASSOCIATION

45, South Street • Valletta VLT 11

MAROC

ANSHAM

rue Sanaa 13 • Rabat

POLAND

CHORYCH Z ZESPOLEM DOWNA

ul. Kilinskiego, 2 • 91421 Lodz

RUMANIA

DOWN'S SYNDROME ASSOCIATION OF RUMANIA

Rue Teiul Doannei, 14 - BL8 - AP4 - Sect. 2 • Bucarest

SLOVAKIA

SPOLOCNOST DOWNOVHO SYNDROMU

Frana Krala, 6 • 81105 Bratislava

SWITZERLAND

EDSA SCHWEIZ

Kontaktstelle - Postfach • 8702 Zollikon

ASSOCIATE

MM Richard BONJEAN

La Fermette, Rue V. Close, 41 • 4803 Verviers (Belgique)

MM Jean-Adolphe RONDAL

Université de Liège, Boulevard du Rectorat, 5 • 4000 Liege (Belgique)

MM Alberto RASORE-QUARTINO chief editor

Ospedali Galliera, Dpt. of Pediatrics, Mura delle Cappuccine, 14 • 16128 Genova (Italia)

MM Salvatore SORESI

Dipartimento di Psicologia dello Sviluppo e della Socializzazione

Università di Padova - via Beato Pellegrino, 26 - 35137 Padova (Italy)

THE INSTITUTE FOR INTEGRATION

Normalmstorg 1, S-111-46 Stockholm • (Sweden)

Dr Anamarija BREZIGAR

Dept. of Obstetrics and Gynaecology - University Medical Centre

Slajmerjeva, 4 - 61000 Ljubljana • (Slovenia)

EFFECTIVE MEMBERS

Organizations of the countries that belong to the European Community, which are involved in the promotion of the rights and welfare of persons with Down's syndrome.

AFFILIATE MEMBERS

Organizations of the European nations that do not belong to the European Community, which are involved in the promotion of the rights and welfare of persons with Down's syndrome.

ASSOCIATE MEMBERS

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.

EDSA

SECRETARY GENERAL

Richard Bonjean

Rue V. Close, 41 • B-4800 Verviers

BELGIUM

Tél: 32 (0) 87223355 • Fax: 32 (0) 87220716

MEMBER OF ILSMH