European Down's Syndrome Association

NewsLetter

Half-yearly - N° 1 - June 1991 / Semestriel - N° 1 - Juin 1991

EDSA

Editorial

ALBERTO RASORE-QUARTINO

This issue of EDSA Newsletter is the first number of a new journal devoted to the problem of Down's Syndrome. In the special preliminary issue published in the month of october 1990, the meaning and the purposes of EDSA were explained by its President, Mr Jean-Yves Perchat. In this issue, it seems important to relate the intentions and the strategies of those who thought it necessary to publish a new journal.

Interest in Down's Syndrome is increasing both in the scientific and in the social world. As a proof of that, international conferences are more often dedicated to the syndrome and parents associations arise everywhere. A journal is a good tool for gathering informations and latest trends in scientific research, but the different kinds of persons to whom this special journal is addressed, namely the families, the medical and social teams and all lay people that are in some way connected with Down's Syndrome, make it a complex task. Therefore, this should be not only a scientific journal, collecting news related to the multifaceted aspects of the syndrome, but it will be the voice that collects the experiences, the demands, the requests coming from the different parts of Europe, so that everybody can share the experiences of other people. European unity is becoming a reality, but that Europe that was supposed to be limited to the western area of the continent will rapidly extend to the eastern half of it. Different cultures in managing Down's Syndrome shall meat and the best of them should be chosen. Problems will possibly be more severe in the near future, due to the language confusion. Common solutions must be taken, in order to create more favourable conditions to the living of handicapped persons. Everybody's engagement must be a common source of enrichment for all. The more active the participation of the associations will be, the more important the political decisions of EDSA in the new Europe will be.

It is our belief that the Newsletter will become the specific voice of the persons with Down's Syndrome in Europe, in order to assert their right to existence, within a society without barriers and to achieve a better quality of life for all. ■

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MEMBER OF ILSMH

SPECIAL ARTICLES
ARTICLES DE FOND

Congenital heart disease in Down's Syndrome

PROF. O. CONOR WARD

Congenital heart disease is seen in 50% of patients with Down's Syndrome. The reason for this is beginning to emerge and the gene locus on chromosome 21 which is responsible for the occurence of congenital heart disease is now being defined; children with down's Syndrome have a wide variety of abilities. Congenital heart disease is not specifically linked to a clinical presentation of either mild, moderate or severe handicap and it affects children with all grades of Down's Syndrome.

Congenital heart disease occurs because of a failure to complete a complex process through which the heart must develop in order to achieve its final form.This complex process begins early in foetal life and the initial primitive heart tube folds on itself to make a right and a left loop which is then subdivided by the ingrowth of dividing partitions to form four separate chambers and two main arteries.

The commonest congenital heart defects in Down's Syndrome are atrio-ventricular canal defects, ventricular septal defects, atrial septal defects, persistent ductus arteriosus, and the tetralogy of Fallot.

In atrio ventricular septal defect, the abnormality which is most characteristic of Down's Syndrome the dividing partition of the heart is defective both between the atria and the ventricles while in addition the mitral valve, which separates the left atrium from the left ventricle is defective. This is the most serious of the defects which may affect a child with Down's Syndrome. Surgery is possible and the operative mortality varies between 10 and 30%. Additionally surgery may fail to restore completely normal anatomy. If surgery is to be undertaken it must be carried out early in life because children with Down's Syndrome have a special tendency to develop pulmonary vascular disease and when pulmonary vascular disease occurs, limiting blood flow to the lungs the condition is irreversible and surgery does not affect the outcome. Patients with pulmonary vascular disease develop blue discoloration from low tissue oxygen saturation and they experience some reduction in exercise tolerance. With modern medical management however a Down's patient with pulmonary vascular disease should be expected to live into the third or the fourth decade.

Ventricular septal defect in childhood is uniqu insofar as it is the only condition in which sponta neous improvment an indeed complete closure may be seen. Patients with Down's Syndrome follow the same course as other children and spontaneous closure of the defect between the two ventricles may occur. As in the case of atrio ventricular canal the risk of pulmonary hypertension has to be born in mind and for this reason a Down's child may have to be brought forward for sugery at an earlier age. Atrial septal defect is the least serious of the septal defects. Two types of defect occur. These are described as primum and secundum defects, a reference to the embryological structures responsible for the abnormalities. Unfortunately the primum type of defect is the commoner one in Down's Syndrome. This lies at the lower border of the atrial septum and because of its position it creates a distortion of the mitral valve. Repair carries a very low mortality but longterm follow-up often shows that mitral valve function fails.

Persistent ductus arteriosus is a very minor malformation. The ductus arteriosus is a bypass vessel joining the aorta, the left heart artery and the pulmonary artery, the right heart artery. It has a function in the foetus before birth but it should then close. Persistent patency is an indication for sugery but the risk is negligible. The final common abnormality is the tetralogy of Fallot. This is a complex disorder in which the outlet from the right ventricle into the pulmonary artery is narrowed and in addition there is a defect in the ventricular septum which allows blood from the right ventricle into the aorta and to cause a blue discolouration, described as cyanosis, followed later by thickening of the ends of the fingers and toes, described as clubbing. Two types of surgery may be undertaken for this condition. Palliative surgery, in which a vascular graft is made between the aorta and the pulmonary artery in order to increase pulmonary blood flow provides effective relief of symtoms in many patients and for prolonged periods. The surgery may be repeated if necessary. The alternative is radical surgery, which is undertaken to cor-

rect the structural abnormalities as far as this is possible. In some children with Down's Syndrome the tetralogy of Fallot is associated not with a ventricular septal defect but with an atrio ventricular canal defect, which makes the repair more difficult.

Children with Down's Syndrome survive cardiac surgery with little or no increase in immediate mortality. The presence of Down's Syndrome in itself is not a reason for rejecting surgery. It is important however to view each child on an individual basis, taking into account the immediate operative risk and the long-term natural history of their condition. It is widely accepted that children with Down's Syndrome who live into adulthood have less than the normal expectation of live. Additionally 10 to 30% of adult survivors with Down's Syndrome will have a quality of life which is impaired by the early onset of Alzheimer's Disease. Alzheimer's Disease is related to a gene locus on chromosome 21, the abnormal chromosome in Down's Syndrome. Future development may make it possible to identify more accurately the position of this gene locus and so to know which children with Down's Syndrome are at greatest risk for the development of Alzheimer's Disease in the future. This would be an additional consideration in relation to surgery, particularly as modern medical treatment could be expected to ensure the survival of patients into the third and the fourth decade without surgery.

Congenital heart disease in Down's Syndrome may present with clinical evidence, such as breathlessness, poor feeding and poor colour and medical examination, clinical, by EKG and heart x-ray may indicate a diagnosis. Congenital heart disease may however be clinically silent and so echocardiography should be undertaken early in life in order to make certain that no unsuspected defect passes unnoticed. there is a tendency for minor defects of the mitral valve to become manifest later and although these do not affect the patients life in the short-term it is important that they should be recognised as the abnormal valve may be a vulnerable site for infection if the patient has a blood borne bacterial invasion. An infection of this kind, called infective endodcarditis may occur after dental extraction and similar procedures and so it is important to be certain that no minor congenital heart defect becomes apparent at a late stage. Cardiological review as 10 to 15 years is therefore essential.■

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SPECIAL ARTICLES ARTICLES DE FOND

The Doman-Delacato treatment for children with Down's Syndrome

DR. J. PERERA · DR. G. RUL.LAN · DR. J. VENY

The Doman-Delacato treatment is frequently offered to parents in certain European countries as a particularly effective early treatment for children with Down's Syndrome. It seems to us to be the appropriate time to comment on the treatment and to present the criteria of the American Paediatric Academy, that has been adopted recently by the National Down's Syndrome Congress in the U.S.A. and published in "Down's Syndrome News" (September 1989).

WHAT IS THE DOLMAN-DELACATO METHOD?

It is the method developed by G.J. Doman, physiotherapist, and C.H. Delacato, educational pschycologist who worked with Temple-Fay in the Norwood Rehabilitation Center in Philadelphia and used Fay patterns in the treatment of cerebral lesions.

Practising neurosurgery caused Temple-Fay to become interested in the phylogenetic aspects of movement and he instigated the use of primitive reflexes to facilitate function. His treatment programme followed the different stages of locomotion adopted by animals as they ascend the phylogenetic scale.

In 1963, the Rehabilitation Center was reorganised and became the Institute for the Achievement of Human Potential - I.A.H.P.

The basis for evaluation and treatment in the IAHP is the concept of "neurological organisation" (the degree with which the nervous system, and more specifically the brain, provides the organism with the

capacity required to relate successfully to the exterior environment"). The nervous system would be composed of hierarchical levels which, phylogenetically and ontogenetically, would be developed from the lowest to the highest level.

Thus, in order to measure the degree of "neurological organisation", the " Doman-Delacato Development Profile" was developed, divided into six areas of competency. Three of them receptive (visual, auditory and tactile), and three expressive (mobility, language and manual ability). There are seven levels in each area. The ages of attaining these levels being based on the works of Gessell. And, the greater the discrepancy between the neurological age measured by the "profile" and the chronological age, the greater the degree of neurological disorganisation.

The results of this evaluation form the basis for the development of the treatment programme. Starting from the point that the cerebral functions are similare to a cybernetic system, the sensorial **input** and the motor **output** can be measured with the profile. The basis of the treatment is an increase in function, intensity and duration of the sensory stimuli. Subsequently motor responses will be required. The treatment programme is designed to be applied by the parents and is rigidly structured. A typical treatment programme starts at 7.30.a.m. and finishes at 9.0.p.m.

One axiom is that as "the brain is the part with the lesion", the treatment must be "directed at the brain", and that this may be achieved by means of the stimuli which are being administered.

Great attention is being paid to development in hemispherical dominance by means of a series of stimuli and adopting it during sleep is even being postulated. An improvement is being sought in cerebral circulation, increasing the carbon dioxide in the air inhaled by the child, making the child breathe in a plastic mask for periods of time. Certain devices are designed to induce the child to crawl or move on all fours (an inclined surface, slide, tunnel, etc..). The scheme is strictly maintained in that the child may not execute an advanced motor pattern without previously executing the preceeding patterns with an acceptable level of **performance.** (Toledo Gonzalez, M.)

When programming the treatment, no distinction is made between the different types of neuromuscular alterations nor the degree of gravity of the motor or mental incapacity. It is a method principally designed and utilised with cerebral paralysis and applied secondarily to children with Down's Syndrome or other types of neurological deficiencies.

CONTROVERSY

Since its commencement the Doman-Delacato method has been the subject of considerable controversy. It seems to us to be the oportune moment to start by presenting, here, the principal conclusions of a communique issued to the scientific world by the ten most important American an Canadian medical associations in the "Developmental Medecine and Child Neurology" Journal, (1968,243-246).

1. "The theory of neurological organisation which forms the basis of the Doman-Delacato treatment cannot be verified from the data available in scientific literature. This theory is supported by certain imprecise, contradictory concepts whose scientific value is debatable at all levels.

2. The spectacular results published in the press are not conclusive. Some of the cases were, in fact, particular children who presented postraumatic cerebral lesions that, often, improve whithout specific treatement. All the studies designed to reproduce the results supposedly achieved, for example, at reading level, have not been succesful.

3. At the present time, there is no data which would enable it to be said that the eventual progress observed in some children after the treatment is not a result of growth or of certain effects not specifically arising from intensive stimulation.

4. If the theory and the treatment are to be taken seriously, it is absolutely essential that its avocates provide a sound basis for their work, a basis supported by a series of scientific studies".

This above statement from leading scientists of medical associations of international repute was issued in 1968 and continues to be valid today.

The American Pediatric Association has revised and updated the 1968 statement and has reached the following conclusions and recommandations in 1989:

PRESENT SITUATION OF THE REPUTED THERAPEUTIC RESULTS

The results published by or for the Institutes have carried little conviction. Many reports on improvements in the capacity to read after treatment have been presented as a vindication of the theory, but statistical analysis shows little demonstrable improvement. Controlled studies of the Dolman-Delacato treatment with respect to the reputed improvement in reading have shown that the benefit is slight or non-existent.

It has been shown repeatedly that some of the children with problems, whose improvements have been related to the treatment, had been badly diagnosed or had been the subjects of unduly pessimistic prognoses. The maturation course of these children is variable and may lead to the declaration, without foundation, that the improvements were the result of a specific treatment. Some of the more dramatic cases publicised by the Institutes have been children with traumatic cerebral lesions or secondary to encephalitis, which would have improved substantially, without any treatment.

Preliminary precautionary statements have insisted on the necessity of carrying out well-controlled studies on the effects of the treatment. The realisa-

tion of a study on all the aspects covered in the statements of the Institutes involves many theoretical and practical problems. When a well-designed and complete study (financed by State and private organisations was in the final stages of programming, the Institutes withdrew their initial agreement to participate in it. In the face of this failure, it is up to them to assume the responsibilty of demonstrating their reputed results, particularly since a smaller, recent controlled study has shown that the treatment of the Institutes does not provide a notable improvement.

To sum up, the "Institutes for the Achievement of Human Potential" differ substantially from other groups which treat the problems of development in that, 1) their statements of cures are excessive, and, at the same time, are, little documented, and 2) an excessive demand is placed on parents to follow exactly, down to the last detail, a method that is not proven.

In the majority of the cases, an improvement observed in patients utilising the treatment, could be explained by the evolution of growth and development, by the intensive practise of certain isolated skills or the non-specific effects of an imtense stimulation.

Doctors and physiotherapists should familiarise themselves with the particular aspects of the controversy and with the data which is available. Based on the analyses, studies and reports, both earlier and more recent ones, we must conclude that the treatment of the Institutes has no greater merit, that statements of its efficacy are not proven and that the demands on the families are so great that in some cases, the treatment may be prejudical.

CONCLUSIONS

Once more, we believe it is important that the parents, doctors and physiotherapists clearly realise that the effectiveness of a treatment does not depend on its cost nor on the efforts demanded of those who apply it. And that , nowadays more than ever, it should be born in mind, what Jesus Florez so roundly declared, that "**the only therapeutic method of indisputable merit lies in the educational action**, instituted early, constantly maintained and happily carried out".■

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ASNIMO, Balearic Islands, Spain.

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.

SPECIAL ARTICLES ARTICLES DE FOND

Le rôle des parents

A.M. KRINS-HERMAN

Devenir parents est un événement extraordinaire. Comme tous les futurs parents, nous avons vécu 9 mois de rêves et d'espoirs. C'est pourquoi nous sommes effondrés lorsqu'on nous annonce le diagnostic de trisomie 21. Notre bébé est handicapé, il est né différent.

Tous les couples, à ce moment, sont désemparés, découragés, parfois honteux et craintifs, parfois, aussi, susceptibles et dépressifs mais, toujours, ils sont tristes et révoltés car ils subissent une coupure avec la vie normale, une coupure de toute relation, une coupure de tous sentiments, de toutes sensations.

Il faudra un temps plus ou moins long avant que ne se cicatrise quelque peu cette profonde blessure.

Avant de pouvoir prendre des décisions concernant leur bébé, il est nécessaire que les parents reprennent confiance en eux. Ils ont besoin de retrouver leur relation de couple, d'apprendre et de comprendre leur enfant né différent.

A ce moment, ils doivent recevoir une information objective et complète sur la trisomie 21 mais aussi sur les possibilités de leur bébé, ses difficultés, ses aptitudes et sur les diverses possibilités éducatives.

Il faut les aider à penser positif; nos enfants sont porteurs de tendresse, de sensibilité, de franchise, de volonté. Il faut les aimer, les respecter mais aussi les motiver, les solliciter et, surtout, ne pas les couver pour leur permettre de grandir. Très tôt, il faut les pousser à l'indépendance pour que leurs acquis se transforment en plus d'autonomie, en plus de confiance en soi.

Aidés par des professionnels, il faudra, à partir de programmes structurés, apprendre à intervenir adéquatement dès le plus jeune âge tout en établissant un réel partenariat avec les professionnels, chacun ayant une partie du chemin à parcourir pour permettre a l'enfant de progresser.

"Si supprimer le handicap est impossible, en reculer les limites, ensemble, parents et professionnels, nous le pouvons" (M. Della-Courtiade).

Si nous voulons que nos enfants soient pleinement intégrés dans la société, il faut les stimuler à faire seuls ce qu'ils peuvent faire sans notre aide. Ce n'est pas chose facile; les parents ont parfois l'impression de perdre leur temps. Il faut, cependant, être conscient que le temps gagné ici et maintenant en agissant à leur place est du temps perdu pour notre enfant dans cette immense bataille qu'il doit poursuivre inlassablement pour se réaliser pleinement. Faire à sa place ce qu'il est capable de faire c'est retarder son évolution, c'est retarder le développement de son intelligence, de son langage, dè sa motricité, de sa socialisation. Plus que pour nos autres enfants, il faudra permettre, interdire, récompenser mais aussi sévir. Il faudra être ferme et lucide.

Le projet de vie conçu pour notre enfant doit s'insérer dans notre vie familiale, sociale et professionnelle. Ceci va demander quelques ajustement une remise en question de notre organisation afin de préserver l'épanouissement et l'équilibre de l'ensemble de la famille. La participation active du père dans l'éducation des enfants est certainement un des facteurs essentiels qui favorisera l'équilibre des familles. Il ne faudra pas confier trop de responsabilités aux frères et soeurs, qui doivent vivre leur vie d'enfant, d'adolescent et même d'adulte avec sérénité. Pour le couple, il y a indubitablement un effort constant à fournir.

Toutefois, nous sommes des "parents ordinaires". Il ne nous est pas demandé de devenir des "supers parents", nous avons le droit à l'erreur, à la lassitude, au découragement, au ras-le-bol. Ne pas vouloir devenir des "super parents", c'est aussi la possibilité de redevenir des parents heureux, donc plus disponibles à chacun.

Les grands-parents sont des personnes ressource des plus efficaces et des plus aimantes. Il sera utile de partager avec eux les informations que nous détenons afin de les aider à modifier l'image ancienne de la trisomie 21.

Ils ne doivent plus penser "pauvre petit, il ne sait pas", cela serait dangereux pour l'évolution de notre enfant. La famille élargie peut également jouer un rôle très intéressant dans l'accueil de l'enfant handicapé, réduisant de façon considérable notre isolement.

Tout au long de ce cheminement, nous serons parfois tentés de faire glisser notre responsabilité vers les professionnels par crainte de ne pas être suffisamment compétents. Ce serait une erreur. Il est, cependant, indispensable d'établir un partenariat avec ceux qui vont intervenir en fonction des besoins et différentes périodes de la vie de notre enfant. Mais, ne l'oublions pas, nous restons les seuls éléments permanents dans leur vie.

Tout ce qui concerne notre enfant, quel que soit son âge, est de notre responsabilité. Aucune décision

le concernant ne peut être prise sans consultation et sans notre accord. Petit à petit, grâce au partenariat avec les professionnels, les parents vont améliorer leurs compétences. Ils pourront, dès lors, juger de la qualité des services proposés. C'est en se formant qu'ils percevront le mieux les demandes de leur enfant et qu'ils y répondront avec efficacité.

Notre société s'ouvre et doit s'ouvrir aux personnes handicapées, car une société qui exclut les différences, qui exclut la personne handicapée, est une société immature; c'est une société qui se prive d'une partie d'elle-même. d'une partie porteuse de valeurs qu'elle ne retrouvera pas ailleurs.

En tant que parents, nous détenons des moyens qui seront déterminants pour l'évolution de notre enfant, pour son intégration. Mais il faut lui faire confiance. Avec nous, avec des professionnels compétents "il y arrivera".

AM. KRINS/HERMAN
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en demandant R. Bonjean, Secrétaire Général

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rue Victor Close 41 · B 4800 Polleur Verviers
or call 32 (0)87 22.33.55
asking for R. Bonjean, Secretary General

MEMBRES EFFECTIFS
Associations établies dans les pays de la Communauté Européenne et qui ont pour objet social de s'occuper spécifiquement des personnes ayant le Syndrome de Down et ce, dans une perspective compatible avec l'objet social de EDSA.

MEMBRES ADHERENTS
Associations établies dans des pays qui ne font pas partie de la Communauté Européenne tout en étant des pays d'Europe et qui ont le même objet social de s'occuper spécifiquement des personnes ayant le Syndrome de Down.

MEMBRES ASSOCIES
Ce sont des personnes physiques ou des associations susceptibles d'apporter avis, conseils... dans tous les domaines concernant les sujets ayant le Syndrome de Down.

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.

MEMBRES MEMBERSHIPS

EFFECTIFS ET ADHERENTS · EFFECTIVE AND AFFILIATE

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ASSOCIÉS · ASSOCIATE

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Syndrome specificity in the Netherlands

SHARING THE SAME OBJECTIVES

While the down's Syndrome Conference in Liège of November 1987 can be considered the cradle of EDSA, it was not before January 1989 that its charter was officially executed. Yet, even before that time EDSA clearly had a very distinct influence, at least in the Netherlands. There, in March 1988 the foundation charter of the Stichting Down's Syndrom SDS (Down's Syndrome Foundation) was executed. The backbone of the latter was a Dutch version of the EDSA objectives of 1987, differing only slightly from a litteral translation. In addition, its plan of work was heavily influenced by discussions with EDSA-board members-to-be.

Although not the very first, surely SDS was one of the first syndrome-specific organizations in the Netherlands in the field of mental handicap. Furthermore, it was the one with the largest growth potential, simply because of the relative incidence of Down's syndrome. Within the SDS parents and professionals are organized alongside each other and have access to the same information.

Until that time in the Netherlands there only had been various non-syndrome-specific organizations of professionals and the one hand and parental organizations based on religion and ideology on the other. The latter were traditionally organized very broadly as umbrella organizations for all types of handicaps. They co-operated in the form of a Federation. Their main interest was in organizing general care facilities, not in development, education or integration of individual people. As a consequence they did not consider it their task to build up specific knowledge about particular syndrome. Furthermore, because neither the term Federation nor the names of the composing organizations did reflect a specific syndrome, they proved to be difficult to find for new parents.

On the other hand, since 1988 parents of young children with Down's syndrome could find the SDS fairly well (resulting in an estimated pick-up rate of well over 50%). As a consequence the large membership of the Federation was ageing, whereas the SDS grew rapidly, right from the start. The success of the SDS, with that of other syndrom-specific organizations, made the Federation reconsider the situation, which resulted in their creating a working party on "Specific Information" already within a year after the start of the SDS and very much after its example.

INTRODUCING EARLY INTERVENTION

Peculiarly, the first main achievement of the SDS was non-syndrome specific: the large scale introduction of the concept of early intervention. The SDS did so by producing a Dutch version of the Australian Macquarie Program, promoted it heavily in the general lay press and on radio and TV and made it available to hundreds of parents. Before that time, in the Netherlands, not only were structured early intervention programs for children with handicaps totally unheard of but, in addition, there existed a fair amount of resistance against their approach. As a result professional interest in early intervention only slowly followed after that of the parents.

In the course of 1989 the working party on "Specific Information" of the Federation expressed its interest in early intervention and its willingness to participate in the setting up of a demonstration program initiated by the SDS. Meanwhile, the SDS continued the dissipation of syndrome specific information as well as on early intervention to parents and in an increasing amount to professionals too. Here it must be said, that the contacts within EDSA and the resulting exchange of information proved of enormous importance for the quality of the work the SDS did.

IN PARLIAMENT

As a result the SDS became well-know and that, in turn, led to its activities being praised in a working party of the Dutch Parliament in the spring of 1990. During that particular session a partial financial support for the SDS by the Dutch government was proposed, provided a structural relation would be made between the Federation on the one hand and the SDS on the other. In the late summer of 1990 preliminary talks between the Federation and the SDS made clear, that the large Federation and the much smaller SDS hardly had any overlap in their activities at all and therefore could very well supplement each other's activities. In addition, the SDS with its relatively young membership could very well play a leading role, which could be of great value for other syndromes as well. An example of that is the creation of several interdisciplinary Down's syndrome teams by the SDS that is now well on its way.

JOINING FORCES

So, it was decided to join forces and to co-operate instead of compete. Since then the SDS receives its (partial) financing from the Government via this Federation, whereas the bureau of the latter has happily taken over some more burocratic work of the SDS. In the actual policy field co-operation is rapidly increasing and, although it is not clear where exactly this will lead to in the end, somewhere between a total amalgamation of the SDS and a syndrome-specific reorganization of the Federation, it works very well now and holds promises for the immediate future.

Erik de Graaf,
president of the Stichting Down's Syndroom (SDS)

Fédération espagnole d'institutions pour le Syndrome de Down

A Madrid s'est constituée récemment la FEDERATION ESPAGNOLE D'INSTITUTIONS POUR LE SYNDROME DE DOWN. Vingt institutions (associations ou fondations) de toutes les régions d'Espagne se sont unies avec un objectif commun: améliorer la qualité de vie des personnes atteintes du syndrome de Down.

Cette initiative promue par EDSA et qui peut servir d'exemple à d'autres pays européens, a surgi de la conviction des parents et des professionnels qu'il est nécessaire d'appliquer des solutions spécifiques afin d'aborder le problème concret des personnes atteintes du syndrome de Down de manières systématiques, expertes et différentes de celles qui s'appliquent, en

BUTS ET OBJECTIFS D'EDSA

1. Répandre à travers toutes les nations européennes le principe que chaque personne ayant le Syndrome de Down a le droit de recevoir les soins de santé et l'éducation demandés par sa condition afin d'atteindre le meilleur de ses possibilités.
2. Stimuler dans chaque pays européen l'implantation d'un réseau d'associations locales faites de parents et de professionnels. Ces groupes seront à même de mieux atteindre et résoudre les besoins locaux, de telle sorte que les familles de chaque nouveau-né avec le Syndrome de Down puisse recevoir immédiatement l'aide et les conseils requis.
3. Promouvoir les principes de normaLisation dans le sens de transformer, humaniser et rendre digne tous les services utilisés par toutes les personnes avec le Syndrome de Down.
4. Encourager le développement de programmes et services appropriés aux personnes avec le Syndrome de Down.
5. Organiser l'échange des informations au sujet de ces programmes mis en route. C'est l'intime conviction de EDSA que le pluralisme culturel des nations européennes enrichira les actions personnelles et collectives en faveur des personnes atteintes du Syndrome de Down.
6. Introduire dans toutes les nations des programmes spécifiques et adaptés aux personnes ayant le Syndrome de Down.
7. Encourager la constitution et le rassemblement de groupes scientifiques pour participer par leurs travaux à:
a) la biologie des sujets Down et ses conséquences pathologiques;
b) au développement mental à différents âges;
c) participer à des programmes d'éducation et d'intervention adaptés aux conditions spécifiques de chaque sujet Down;
d) son intégration dans son environnement, sa communauté et au travail.
8. Etudier et de recommander des législations adaptées à chaque pays européen, dans le but de garantir et assurer les services en faveur des personnes atteintes du Syndrome de Down tout au long de leur vie.

général, à d'autres types de moins valides.

Les Associations cherchent des solutions concrètes afin d'améliorer la santé des personnes atteintes du syndrome de Down, afin d'étudier leur développement intellectuel, pour leur apprendre à parler, à lire, à écrire, afin qu'ils obtiennent un plus grand degré d'autonomie personnelle, et qu'ils sachent profiter des loisirs, et s'intégrer dans les milieux scolaires, sociaux et de travail. Ils se sont unis en une Fédération Nationale pour transmettre ces inquiétudes aux organismes publics, échanger des connaissances et des expériences, élaborer des programmes spécifiques d'éducation, promouvoir des études scientifiques, stimuler des projets d'intégration, organiser des programmes et des cours de formation pour le personnel qui s'occupe des personnes atteintes du syndrome de Down et pour- entre beaucoup d'autres objectifs - obtenir des subventions et des recours qui rendent effective la vie des institutions.

La Fédération Espagnole d'Institutions pour le syndrome de Down veut connaître et maintenir des relations avec d'autres Fédérations de différents pays d'Europe et est ouverte à l'échange d'informations et d'expériences.

Le Président de l'Assemblée de Gestion est Mr. JUAN PERERA. ASNIMO. Km 7,5 Ctra. Palma-Alcudia, 07141 Marratxi (Baléares). Espagne. Tél. 34-71-79.50.54 Fax 34.71.79.48.98

Spanish Federation of Down' Syndrome associations

The FEDERATION OF DOWN'S SYNDROME ASSOCIATIONS was recently established in Madrid. Twenty bodies (Associations and Foundations) from all over Spain have joined forces to pursue a single common objective to improve the quality of life of people with Down's Syndrome.

This initiative promoted by EDSA, and which could act as an example for other European countries, has arisen from the conviction of parents and all those professionally involved with Down's Syndrome patients of the necessity of applying specific solutions to tackle the specialised problems of such people in a systematic and expert manner, in a way which is diferent from those applied, in general, in other types of disabilities.

The Associations are looking for specific solutions to improve the health of people with Down's Syndrome, in order to study their intellectual growth, to teach them to speak, to read and to write so that they can aquire a greater degree of personal independence, so that they may know how to enjoy their leisure time so that they may become integrated in scholastic, social and occupational spheres. And therefore, they have united in one single National Federation so that they can present these preoccupations to public bodies, so that they can draw up spécific educational programmes, promote scientific studies, encourage integration projects, organise training programmes and courses for the personnel who care for people with Down's Syndrome and- among many more objectives - to obtain subsidies and resources which will support the work of the Associations.

The Spanish Federation of Down's Syndrome Associations is very interested in getting to know and developing relationships with other Federations in other European countries and would welcome the interchange of information and experiences.

The president of the Administrative Board is JUAN PERERA, ASNIMO, km.7,5 Ctra. Palma-Alcudia. 07141 Marratxi, (Baleario Islands) Spain. Tél. 34.71.79/50/54. Fax 34.71.79/48/98.

INFORMATIONS

International workshop on "Developmental and aging in Down Syndrome"

(Satellite of the 4th IABG Congress)

Organized by G. Albertini (I) and N. Fabris (I)
Prometed by INRCA, Ancona
and the "Bambino Gesù" Institute, Rome
Rome, Italy, June 24-25,1991

The workshop will focus on the physiopathological aspects of Down's syndrome subjects with particular emphasis on the developmental aspects as well as on the precocious appearance of age-related diseases, such as senile dementia, diabetes, hypertension, infections and neoplastic pathologies. The biological substrates for the age-related pathologies and the bio-psychological and medical approaches for their control will be discussed. For further information please contact:

Prof. G. ALbertini
Ist.Scientifico "Bambino Gesù"
Lungomare G. Marconi, 36 00058 S. Marinella, Italy
Tel: (766)535444 - Fax (766)735037

NEWS FROM CONGRESSES
NOUVELLES DES CONGRES

National Health Care Conference of the National Down Syndrome Society

On march 15 and 16,1991, the National Health Care Conference of the National Down Syndrome Society was held in San Diego, California.

It was, as NDSS Executive Director, Donna M. Rosenthal said, the first national conference to focus entirely on health problems of people with Down Syndrome, throughout their life, from birth to old age. The speakers were all renowned physicians specialized in the different arcas of treatment of people with this genetic disorder.

The first session was devoted to understanding of the chromosomes and genes affecting DS (Dr. Julie Koremberg), to the current and future modes of prenatal diagnosis (Dr. Mark Bogart) and to mechanisms of non-disjunction (Dr. Terry Hassold). In the second session, some current problems and controversies on the development of speech and language in children with DS were discussed by Dr. Jon Miller. In the next two sessions, clinical advances in DS care were deall with. More specifically, single system disorders were discussed. Dr. Langford Kidd spoke of cardiorespiratory disorders , Dr.Ernest McCoy of endocrine and metabolic disturbances, Dr. Ira Lott of neurological disorders, Dr. Liebe Sokol Diamond of orthopedic disorders, Dr. Marshall Strome of ear and nose problems, Dr. Edward Sterling of dental problems. All of them gave good accounts of next trends in research and treatment of each field. An interesting and current subject, plastic surgery, was discussed by Dr. Jeffrey Posnick, who clearly pointed out its failure in effectively altering the face of the child with DS. New trends in the care of infectious diseases (dr. David Lang) and of hematologie and oncologie disorders (dr. Alvin Zipursky) were also discussed, while Dr. Siegfried Pueschel summarized the reasons of a comprehensive approach to the whole individual with DS. Finally, some problems of present interest in the adults were treated: sexuality in its many aspects (Dr. William Schwab) and aging, its relationships with the normal course and the pathological aspects observed in Alzheimer's disease (Dr. Krystyna Wisnieski). As a conclusion, Dr. Ira Lott summarized the recommendations of the panel speakers for proposing a timetable for intervention strategics throughout the life of persons with DS.

From this very interesting and up to date Conference, the developing interest for a global approach to DS can be inferred. The importance of a thorough knowledge of the different clinical aspects of DS lies in the possible interventions, able to prevent secondary disabilities, so to help rehabilitation and social integration for a better quality of life of all persons with this genetic disorder.

Prof. Alberto Rasore-Quartino
Dept. of Pediatrics
Galliera Hospital, Genoa, Italy.

BOOK REVIEW
REVUE DE LA LITTERATURE

Molecular Genetics of Chromosome 21 and Down Syndrome

Editors: David Patterson and Charles J. Epstein (*Wiley-Liss, New York, 1990*).

The etiological relationship that for many years has been established between chromosome 21 and Down Syndrome has greatly stimulated the interest of scientist towards the molecular analysis of this chromosome.

A great deal of informations on the molecular structure of chromosome 21 has been achieved and the data outnumber at present these on any other human chromosome. It is because of the great of new data produced in a short period of time on the matter that the book edited by David Patterson and Charles J. Epstein bears great interest and will undoubtly prove useful.

The book, which is composed of two parts, updates us on the present level of research on chromosome 21. The first part examines recent approaches to the physical and genetic structure of chromosome 21 and spans from the physical mapping of specific fragments to the identification of genes based on their tissue specific expression.

The ultimate purpose of this type of research is to determine the relationship between genotype and phenotype in Down Syndrome.

The second part focuses on some quite specific aspects. Several chapters are dedicated to single genes of the chromosome 21 which have been extensively studied and appear to be related to particular clinical features of Down Syndrome, such as immunological depression, increased incidence of leukemia, cerebral lesions analogous to those of Alzheimer's diesease.

This book will undoubtly prove useful to several groups, including clinicians caring for individuals with Down Syndrome and geneticists studying the organization of human genome and interested in the relationship between the alterations in gene dose and the consequent abnormalities of development and function.

Dr. Paolo SCARTEZZINI
Pediatric Dept. E.O Ospedali Galliera
Genoa Italy

INFORMATIONS

Annual meeting
European society of human genetics
July 13-16, 1991
Leuven, Belgium

Adresses

For scientific and organizational information:
Prof. J.J. Cassiman
Secretariat, M. De Dobbeleer
Center for Human Genetics
University of Leuven
Campus Gasthuisberg
Herestraat 49
B-3000 Leuven, Belgium
Tél. 32-16-21.58.60
Fax 32-16-24.38.01

The conference will take place in the center of Leuven, exact location and a map will be sent to all registered participants.

PROGRAM

Saturday July 13, 1991, 15.00-17.00 Workshop on new technical developments

Sunday July 14, 1991, Plenary session: Highlights from the clinical and basic research of the Center for Human Genetics - Leuven.

Monday July 15, 1991 , 8.00 - 9.00 Curbstone consultations. Dysmorphology · Risk calculations · Software sharing · Problems of genetic counselors · Educational packages. Plenary session: Molecular and clinical analysis of malformation syndromes.

REGISTRATION FEE

Received before June 1, 1991
for members of the European Society of Human Genetics: 3.500 BF. For non-members: 4.500 BF
Received after June 1, 1991
Members: 5.000 BF. Non-members: 6.000 BF
Payment: Please send Eurocheque or international cheque payable to:
C.M.E. - EUR. CONGR. HUM. GENET.-LEUVEN - BELGIUM
The participants name and address must be marked on the cheque. Credit cards are not accepted.

CANCELLATIONS

A 70 % refund will be allowed for cancellatio received before July 15, 1991. No refund will be allowed after this date.

AFFILIATION FORM

This affiliation form has to be send by ordinary mail to the General Office. It's necessary it will be completed and signed by the habilited members so say the law of the Association if this affiliation form concerns effective member or adherent member. It will be signed personally if it concerns an affiliate member. The affiliate form means the adhesion to the law of EDSA.

INFORMATION

I. The undersigned: (name, firts name and function):
1. .....
2. .....

II. Representative of the Association:
.....
.....

III. Official adress:
.....
.....

IV.
Phone: .....
Fax: .....

seck to join EDSA as:
1. Effective member* 2. Affiliate member* 3. Associated member*

We join a copy of the law of our Association.
*Cross out the wrong information.

INFORMATION FOR CORRESPONDENCE

Name and address:
.....
.....

Action of the Association (or brochure):
.....
.....

Number of members: .....
Down's syndrome people's age (if personal affiliation) .....
Representative parent: .....
Representative professional: .....
Phone: .....
Fax: .....

Date Signature

DEMANDE D'AFFILIATION

La demande d'affiliation doit être retournée par envoi ordinaire au secrétariat général, dûment complétée et signée par les personnes habilitées, conformément aux statuts s'il s'agit d'une demande d'affiliation en qualité de "membre effectif" ou de "membre adhérent". Elle doit être signée par la personne elle-même s'il s'agit d'une demande d'affiliation en qualité de "membre affilié". La demande d'affiliation implique l'adhésion aux statuts d'EDSA.

RENSEIGNEMENTS:

I. Le(s) soussigné(s): (noms, prénoms et fonctions):
1. .....
2. .....

II. Représentant l'association:
.....
.....

III. Siège social:
.....
.....

IV.
Téléphone: .....
Fax: .....

sollicitons l'adhésion à EDSA en qualité de:
1. Membre effectif* 2. Membre adhérent* 3. Membre affilié*

En annexe, nous vous adressons copie des statuts de notre association.
*Biffer la, les mention(s) inutile(s).

INFORMATION POUR CORRESPONDANCE

Nom et adresse:
.....
.....
.....

Téléphone: .....
Fax: .....
Représentant parent: .....
Représentative professionnel: .....

Date Signature