European Down's Syndrome Association

NewsLetter

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EDSA

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Editorial

DR. JUAN PERERA

"AND THE OTHERS ...?"

The recent public appearances by people with Down's Syndrome on TV or in the cinema (Chris Burke in the series "Life Goes On"), etc., have moved parents and also many professionals (doctors, psychologists, teachers) who believed that people with Down's Syndrome were mentally retarded and incapable of looking after themselves, of having an opinion and of making decisions.

Things have changed radically in the last few years for people with Down's Syndrome.

It is a good thing that people with Down's Syndrome who express themselves normally, who are taking courses in further education or planning to study at University, should appear in public. But not all people with Down's Syndrome are like that, or can reach these levels. Because it must not be forgotten that among people with Down's Syndrome the same thing occurs as with normal people: there are more gifted people and others who are not so bright. In a graph of normal distribution, the average is the most common score in the group, and around this average are concentrated, to the right and to the left, what is known as "normality", that is to say, 68% of the cases. And at each end remain approximately 14% of the cases who exceed, either by excess or deficiency, the criteria of normality.

Television, Congresses and the news media have presented some cases which are not representative of ***"normality"*** *in Down's Syndrome. They are especially gifted cases and they have frequently benefitted from educational and training methods which are not available to everyone. True cases, and it is positive that they are presented, because they serve as a stimulus and an incentive for breaking negative social attitudes and because they aid the integration of children with Down's Syndrome.*

Normality is, however, a relative term. Forty years ago it was not normal to go swimming in a bikini on the beach. Nowadays it is completely normal. "Normality" has also changed in Down's Syndrome. Progress in genetic and neurobiology, early treatment, the psychology of learning and behaviour and modern teaching techniques have achieved a better development of each child's potential. ***Normality in Down's Syndrome has been raised to a higher level,*** *Today - following the correct techniques - most children are - for example - able to read and write fairly fluently. This was completely unthinkable just ten year ago.*

But what about the "OTHERS"? Those who unfortunately have greater limitations, those who, because of their age, their financial or family situation, have not been able to benefit from modern knowledge, those who are profoundly mentally

retarded, adults who have become psychotic or demented by Alzheimer's disease...

EDSA has been receiving complaints from parents who, with great anxiety and frustration, raise the case of their own child: Have we not brought him up properly? Have we done all we could? Are the professionals in our Association or our school out-of-date? Why is our child not like those who appear on the Telly? It is difficult to explain to a parent that their child is as far removed from "normality" in Down's Syndrome - in this case because of deficiency - as those who appear on the Telly.

For this reason I should like to strongly request that those who organize seminars, acts and congresses, and those who publish articles or those who intend to appear on television, or who have at their disposal the best services, do not forget the "OTHERS..."

I believe that we talk too much about early intervention, language or reading/writing programmes for school-age children, and about working integration projects with exceptional groups.

And who is concerned about adults, about professional training, warden controlled homes, care for the worst cases, support for parents and brother or sisters with this problem?

Dr. JUAN PERERA
EDSA Scientific Board Coordinator

SPECIAL ARTICLES
ARTICLES DE FOND

Clinical follow-up of Down Syndrome from infancy to adulthood. A present view.

A. RASORE-QUARTINO*

In recent years the epidemiology of Down Syndrome (DS) has significantly changed and the prolonged life span that ensued determined the shift from a pediatric population to one composed also of adolescents and adults. New clinical problems came out in an already difficult health background.

Moreover, early rehabilitation programs that are more and more used, have gradually changed their life style, with a progressive integration into the society, either school or work.

Clinical follow-up is therefore necessary and will be a valuable guide for the general practitioner to whom the affected people are entrusted.

The medical control must have a multidisciplinary character, concerning a number of clinical specialties, although with coordinated programs and protocols.

The main aspects of diseases frequent in DS, that should be well known, in order to set up programs of prevention or of correct treatment, are discussed here.

Congenital heart disease is the commonest severe malformation: about 50% of infants are affected, representing 7% of all children with congenital heart defects. Endocardial cushion defect, or atrioventricular canal defect, is the prevailing anomaly, averaging nearly half of the total.

An early diagnosis is desirable, since most of the anomalies are treatable by effective surgery.

Cardiac defects with increased pulmonary flow are most frequent: affected children become symptomatic at an early age, developing pulmonary artery hypertension, cardiomegaly, cyrrhosis and severe congestive heart failure.

Patients show growth retardation and recurrent respiratory infections, resulting in high morbidity and mortality. Pulmonary vascular obstructive disease is a severe complication, the development of which generally prevents the surgical correction.

Surgical mortality has dramatically decreased in recent years and the long term prognosis is good. Other congenital malformations, although rare, should be looked for accurately, since surgical repair is almost always possible. The relatively high incidence of congenital megacolon has to be reminded.

Visual and hearing defects are often present in DS children. It is well known that sensory defects greatly reduce the acquisition of mental abilities, even if appropriate rehabilitation programs are established.

As for hearing defects, beside congenital anatomic anomalies of the ear, a higher incidence of inflammatory diseases of the middle ear is described.

They are often misdiagnosed and can easily become chronic, adding to the underlying sensorineural deafness and worsening the auditory loss. From 30% to 70% of DS persons have some hearing defect.

Ocular abnormalities are also frequent. For their frequency and practical consequences, emphasis should be laid on strabismus and on refractive errors, that can impair a correct vision, so adding an organic defect to the mental deficiency.

An early diagnosis is important, as it is an early correction. Spectacles and hearing aids are generally well accepted: they are a good help for the rehabilitation process.

In DS the risk of **leukemia** is greatly increased: in infants it is 10 to 20 times higher than in non Down infants.

The ratio acute lymphoblastic leukemia/acute non lymphoblastic leukemia is similar in both populations, except in the first two years of life, when non lymphoblastic leukemia is prevalent in DS.

About 25% of all leukemias in DS are evident at birth; 15% of congenital leukemias develop in trisomic newborns, who can also show in 17% of cases a form of transient leukemia, chiefly of the myeloid type, called benign myeloproliferative disease. Its course is benign and it resolves with a spontaneous remission.

Treatment and prognosis of the various forms of leukemia in trisomic persons do not differ from non-Down persons.

Thyroid dysfunction frequently affects DS persons. Both congenital and acquired hypothyroidism are described. Congenital hypothyroidism in DS varies from 0.7% to 10%, while in the general population it varies from 0.015% to 0.020%; figures for acquired hypothyroidism are 13% to 54% in DS,

versus 0.8% - 1.1% in the general population. Hypothyroidism in DS is commonly related to autoimmune destruction of functioning thyroid tissue and a subsequent reduced synthesis of hormone. Initially only increased TSH values are detected, then hormone deficiency develops (reduced T3 and T4).

With the progression of the disease clinical symptoms appear. Unfortunately they may go unrecognised or be mistaken for the features of the syndrome itself (dullness, increased fatigability, loss of attention), mainly in adolescents and adults.

Since untreated hypothyroidism may interfere with normal neuronal function, causing decreased intellectual abilities, appropriate substitutive therapy is strongly recommended.

Persons with DS are at increased risk of developing hypothyroidism at any age, albeit with increased frequency in adulthood.

One DS person out of 12 has either compensated or subclinical hypothyroidism. Periodical controls of thyroid function are mandatory since childhood, in order to detect in time decreased activity and to start a suitable treatement.

A reduced growth is almost costant in DS. Little is known about the causes of growth retardation. Malabsorption, congenital heart disease and hypothyroidism have a role in single cases. An aetiologic relationship between mental retardation, microcephaly and growth retardation has been suggested. The brain dysfunction may be the cause of growth hormone deficiency, through the dysruption of the brain-hypotalamic-pituitary axis. Treatment with recombinant human growth hormone increases growth velocity and height in DS children.

An associated inconstant increase in head circumference has also been observed. Side effects of GH therapy (glucose intolerance, antibody formation) are of relative importance. More severe complications are related to the development of neoplasia and leukemia.

Up to now there is no convincing evidence for a substantially increased risk of leukemia in patients who have been given hGH: nevertheless particular caution should be exercised in children with a primary increased risk for malignancy, as it is true for DS children.

Intestinal malabsorption observed in DS is responsible for intestinal disturbances, sideropenic anemia and stunted growth in some children. Coeliac disease in particular seems to have an increased frequency.

Gluten intolerance, in its classic, severe form is not often seen, but atypical late forms are more often described: the clinical signs are aspecific, that is, anemia, hypovitaminosis, growth retardation. The diagnosis is based on intestinal biopsy, that shows the typical hystologic lesions of the mucosa. Screening tests are the xylose test and the dosage of antigliadin and, more recently, of antiendomysium antibodies.

Orthopedic problems in DS are chiefly a consequence of generalized muscular hypotonia.

Pes planus, subluxing patella, hips dysplasia, slipped capital femoral epiphysis, scoliosis and atlanto-axial instability are frequently observed.

A correct mobilization and sports activities are a good prevention of these disabling defects.

The risk of atlanto-axial subluxation and cord compression is present in adolescents practising with field activities specifically dangerous for the articulation, including tumbling, diving, boxing, etc.

Assessment should include neurological examination and X rays of the cervical spine in extreme flexion and extension.

Dental anomalies are a well known problem, that is generally underestimated for the actual difficulties met with in the management of mentally handicapped people. Unusual dental and oral anatomy, developmental anomalies and malocclusion are common in DS.

Dental caries, on the contrary, is less frequent than in normals.

Oral hygiene is often poor, leading to gingivitis and to subsequent periodontal disease and early and total tooth loss. Dental control should be constant since early childhood through adulthood.

Ortodontic help should be available in order to avoid the disrupting consequences of progressive dental decay.

With increasing age, the reduced immunologic competence of DS is responsible of increased infections, particularly of the skin. **Autoimmune disorders**, with protean clinical manifestations, are more frequently observed: hypothyroidism, diabetes mellitus, alopecia, chronic active hepatitis, autoimmune thrombocytopenia are only the main examples.

Neurologic problems become prevalent, including seizures, in adulthood.

There is moreover a constant, though slow and variable, decline of intelligence with age.

A reduction in thought elaboration ability, in particular for the abstract thought and in logical performances, both inductive and deductive, is likely to occur at an age of about 30.

Characteristic of aging in DS is also the dementia, showing striking similarities with Alzheimer's disease and appearing in about 30% of persons older than 30 years. Clinically, the affected patients show deterioration of mental and emotional responses, apathy or excitement, irritability, temper tantrums, loss of previously acquired vocabulary.

There is a decline in personal habits of cleanliness. The progression is often very rapid. Seizures can be an early sign of Alzheimer's disease.

At the moment there are not any procedures that could slow down the process of early aging. DS persons for whom early rehabilitation has been available are just now reaching adulthood. It is possible that intensive stimulation and social integration are beneficial in slowing down precocious aging. Recent research, that has mapped the gene for Alzheimer's disease to the long arm of chromosome 21, has brought to light the problem of presenile dementia, awaking new interest in its relationships with DS.

As a conclusion, we can state that, if a somewhat effective program of specific controls has been provided for the child with DS, this is not true for the adult.

The diseases affecting this population are often misdiagnosed.

The main difficulties of a thorough knowledge of the pathological aspects of these persons are due to the low number reaching the adult age or, more often, to the lack of relatives caring for them, thus rendering very difficult an effective clinical follow-up.

In this context, a program of periodical clinical controls in DS is proposed, pointing out some peculiar aspects in the different ages and therefore the differents demands. It is our opinion that every program should be flexible enough, in order to avoid medical dependence of DS persons.

It is also very important that general suggestions of specific controls be easily available for those who care for DS persons at any age, from infancy to adulthood, to prevent the secondary disabilities we know to occur with increased frequency and that actually can hinder a successful rehabilitation or a social integration and, after all, a good quality of life.

A short and comprehensive protocol for the clinical follow-up in Down Syndrome.

1) **Newborn**

Clinical diagnosis; communication of the diagnosis to the parents.
Cytogenetic analysis.
Clinical and neurological assessment.
Complete investigations (clinical and instrumental) for congenital malformations.
Routine neonatal screening tests.
Blood tests for anemia, policytemia, leukemoid reaction, etc.

2) **First year of life**

Clinical and neurological follow-up: every two months.
Tests for hearing defects: 6 and 12 months.
Tests for visual defects: 12 months.
Echocardiography: 6 months.
Serologic tests for thyroid dysfunction, malabsorption, anemia etc.: 12 months.
Vaccinations according to national schedules, plus optional ones.

3) **Childhood**

Clinical and neurological follow-up: once or twice a year.
Serologic tests for thyroid dysfunction, malabsorption, anemia, growth retardation, etc.: once a year.
Dental control: once a year.
Orthopedic control: once a year.
Vaccinations according to national schedules, plus optional ones.
Ophtalmologic and audiologic controls: once a year.

4) **Adolescence and adulthood**

Clinical follow-up (with emphasis on body weight): once a year.
Neurological and psychiatric follow-up: every two years.
Orthopedic control: once a year.
Dental control: once or twice a year.
Ophtalmologic and audiologic control: once a year.
Serologic tests for thyroid dysfunction, diabetes and other endocrine disorders, malabsorption, autoimmune disorders, etc.: once a year.

This paper was presented at the 9th World Congress of the International Association for the Scientific Study of Mental Deficiency, held in Goald Coast (Queensland) Australia, august 5-9, 1992.

References can be sent by request.

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NEWS FROM CONGRESSES
NOUVELLES DES CONGRES

Growth hormone treatment in Down Syndrome

An International Conference on Growth Hormone Treatment in Down Syndrome , organized by the NYS Institute for Basic Research in Developmental Disabilities, was held in New York on October 10-11, 1992.

It was the first international congress on this up-to-date but controversial subject.

Growth retardation in DS has a prenatal onset, has a wide individual variability, is accompanied by delayed bone age. It was remarked that after adolescence the stature of DS persons living in institutions does not differ from that of DS persons living in families. Microcephaly is a well known feature present in 80% of DS children. Like short stature, it is possibly due to growth hormone deficiency.

The main structural brain anomalies include cortical dysgenesis, retarded neurogenesis, maturation delay, reduced number of neurons and of the synaptic contacts. It is very important for the study of DS the trisomy 16 mouse, representing a true model system.

The importance of the somatomedins (IGFI and II) as growth regulators was stressed: IGFI in brain is a potent neuroregulator, enhancing DNA synthesis (cell proliferation and differentiation) and having a strong myelination effect. In DS low levels of IGFI are present in utero, with an incomplete shift from the fetal to the adult type. Laboratory tests suggest the presence in DS of an inactive IGFI-like protein.

A group of lectures were then devoted to GH therapy.

A small number of children with DS of different ages were treated in different centers, for periods varying from 1 to 3 and more years. GH treatment increased growth velocity and height, a near normal stature being attained.

An associated, inconstant increase in head circumference has also been observed, especially if the treatment had been started very early (before l year of age).

No correlations have been drawn between increased head circumference and mental abilities. According to the extensive experiences done in non Down children, side effects and complications are relatively modest.

Relationships between GH therapy and leukemia seem not to exist, as it was hypothesized some years ago.

The cost of the treatment is very high (15,000 - 20,000 US dollars/year). Since in DS a clear-cut and generalized GH deficiency does not exist, there is no rationale for the substitutive treatment.

Unresolved biological problems, ethical, social and economic aspects, the ignorance of long term effects, advise against the extension of the treatment to all children with DS.

More accurate studies and extensive trials are needed, before GH therapy can be considered a safe treatment for DS children.

Alberto Rasore-Quartino

International Symposium on specificity in Down Syndrome

Palma de Mallorca, 26th-27th february 1993

Objective of the Symposium

The latest research shows that mental deficiency should not be approached as a single entity but that, on the contrary, each pathology has specific characteristics each of which demands specific therapeutic methods. In the case of DOWN SYNDROME, principal genetic cause of mental deficiency, it is an extra chromosome in pair 21 which is responsible for the alterations which occur in human development.

The symposium takes the lates knowledge of the molecular structure of chromosome 21 as its starting point and endeavours **to study the consequences of genetic abnormalities** on the structure and function of the nervous system and on the learning and behaviour of people with Down Syndrome.

It will also attempt to **determine the specific therapeutic methods** which are being envolved in health care, early intervention., the introduction and development of language and the teaching of reading and writing, etc., in people with Down Syndrome.

At the same time, the Symposium wishes to collaborate on **laying down the scientific basis of the associated European Down movement** and to define the features that clearly separate it from other types of mental deficiency.

Delegates

Professionals from the different disciplines related to Down Syndrome: genetistists, doctors, psychologists, educators, logopedists, physiotherapists, social workers, etc. Without excluding those parents who are interested in following the programme.

Director

Dr. Juan Perera. President of the EDSA Scientific Board (European Down's Syndrome Association).

Programme

Friday 26th, February 1993

Morning:

8,30 h. Collection of Documentation.
9,00 h. Opening the Symposium.
9,30 h. Prof. Dr. ILYA TCHOUMAKOV (FRANCE)
Genetic specificity in Down Syndrome: the molecular structure of chromosome 21. Genetic abnormalities. State of the art.
10,30 h. Break.
11,00 h. Prof. Dr. KRYSTYNA E. WISNIEWSKI (USA)
Neuron, cerebrum and nervous system in Down Syndrome. Consequences of genetic abnormalities in the structure and function of the nervous system.
12,00 h. Discussion.
12,30 h. Projection of Videos.

Afternoon:

15,30 h. Prof. Dr. JESUS FLOREZ (SPAIN)
Cerebral pathology in Down Syndrome, learning and behaviour.
16,30 h. Break.
17,00 h. Prof. Dr. SIEGFRIED M. PUESCHEL (USA)
The morphogenetic abnormalities which form the specific phenotype of Down Syndrome.
17,45 h. Break.
18,00 h. Prof. Dr. SIEGFRIED M. PUSCHEL (USA)
Specific medical pathology (by ages) of people with Down Syndrome.
18,45 h. Discussion.

Saturday 27th, February 1993

Morning:

9,30 h. Prof. Dr. JUAN PERERA (SPAIN)
Early intervention in Down Syndrome. State of the art. Specific aspects.
10,30 h. Break.
11,00 h. Prof. JEAN A. RONDAL (BELGIUM)
Language systemic specificity in Down Syndrome.
12,00 h. Discussion.
12,30 h. Ms. DONNA ROSENTHAL (USA)
The Associated Down Mouvement in the USA; lines of work.

Afternoon:

15,30 h. Prof. Dr. SUE BUCKLEY (UNITED KINGDOM)
Learning to read and write in children with Down Syndrome. Specific aspects.
16,30 h. Break.
17,00 h. Prof. Dr. CLIFF CUNNINGHAM (UNITED KINGDOM)
Psychology of persons with Down Syndrome. Specific aspects: consciusness of individual limitations and growth towards independence.
18,00 h. Discussion.
18,30 h. Projection of video "IN THE NAME OF DOWN". TV2 Television programme "Linea 900".

Speakers

- PROF. DR. ILYA TCHOUMAKOV. Researcher on the GENETHON project. Human Genome Research Centre. PARIS.
- PROF. DR. KRYSTYNA E. WISNIEWSKI. Researcher in the New York State Institute for the Basic Research in Developmental Disabilities. NEW YORK.
- PROF. DR. JESUS FLOREZ. Professor of Pharmacology. University of Cantabria. SANTANDER.
- PROF. DR. SIGFRIED M. PUESCHEL. Director. Child Development Center. Professor of Pediatrics. Brown University School of Medicine. RHODE ISLAND.
- PROF. DR. JUAN PERERA. Director. Principe de Asturias Centre. ASNIMO (Balearic Islands). President of the EDSA Scientific Board (European Down's Syndrome Association). PALMA DE MALLORCA.
- PROF. DR. JEAN A. RONDAL. Director. Laboratoire de Psycholinguistique Université de Liège. LIEGE.

- PROF. DR. SUE BUCKLEY. Director. The Sarah Duffen Centre. University of Portsmouth. PORTSMOUTH.

- PROF. DR. CLIFF CUNNINGHAM. Emeritus Professor of Applied Psychology in the Mental Deficiency Department. School of Medicine. Nottingham University. MARPLE.

- Ms. DONNA ROSENTHAL. Executive Director of the National Down Syndrome Society (NDSS). NEW YORK.

International Down Syndrome Conference

August 11-14 1993
Walt Disney World- Swan - Orlando Florida USA

Purpose of Meeting.

The fifth International Down Syndrome Conference, sponsored by the National Down Syndrome Society in cooperation with the European Down Syndrome Association, will be held in the United States for the first time.

The meeting will offer a unique opportunity for professionals and parents from all over the world to learn, network and exchange state-of-the-art information about medical, educational and social issues concerning people with Down Syndrome.

Renowned speakers will discuss the most recent programs, services and advances world-wide which help people with Down Syndrome to achieve their potential in community life. Topics will be discussed from both a parent/advocate and a professional/service provider point of view. Special sessions for young people age 13 and older will be available simultaneously.

The National Down Syndrome Society

The National Down Syndrome Society was established in 1979 to promote public awareness about Down Syndrome, to support research about this genetic disorder, and to provide vital services for families and individuals affected by Down Syndrome. Its mission is to help people with Down Syndrome to achieve their potential in community life, and to find the scientific answers to this disorder.

Through ist toll-free hotline, information about Down Syndrome and referrals to community resources are provided to families, professionals and concerned individuals.

Program Highlights

Day One - Opening Ceremonies, Health and Research
Presentations by People with Down Syndrome from all over the World
Chromosome 21 and Down Syndrome
Neuroscience of Down Syndrome
Advances in Medical Care
Behavior Perspectives

Day Two - Education and Employment
Inclusion: From Early Intervention Through Adult Education
Computer Education Across the Age Spectrum
Perspectives on Learning
Reinforcement of Learning at Home
Reading and Writing
Vocational Training and Employement Preparation
Creative Jobs Options
Support Services

Day Three - Vision for the Future
Fostering Independence from Early Childhood
Recreation for the Younger Child
Organized Sports
Developing a Social Life
Volunteering and Extracurricular Activities
Sex, Dating and Marriage
Options for Indepedent Living
Closing Ceremonies

Poster Sessions - Presentations of Programs, Services and Products
- International Groups
- Community Organizations
- Corporations

Pre-conference symposia for parent group directors, social workers, MR/DD professionals and health care professionals.

Conference Planning Committee

Richard Bonjean - Secretary, European Down Syndrome Association, Brussels, Belgium
Inger Claesson-Wastberg - Ministry of Health and Social Affairs, Stockholm, Sweden
Dr. Anne Fowler - Assistant Professor, Bryn Mawr College, and Haskins Institute, New Haven, CT
Elizabeth F. Goodwin - President, National Down Syndrome Society, New York, NY
Nancy Hall - Executive Director, Down Syndrome Association of Los Angeles, CA
Gail Marino - President, Gold Coast Down Syndrome Organization, Boca Raton, FL
Josephine Mills - Executive Director, Canadian Down Syndrome Society, British Columbia, Canada
Bernadette Moran - President, Down Syndrome Parent Support Group of Manhattan, New York, NY
Tom O'Neill - Parent/advocate and former President, Nation. Down Syndrome Congress, Fort Wayne, IN
Dr. Juan Perera - European Down Syndrome Society, Baleares, Spain - Coordinator, Scientific Council
Donna M. Rosenthal - Executive Director, National Down Syndrome Society, New York, NY
Dr. William Schwab - Assistant Professor, Department of Family Medicine and Practice, University of Wisconsin-Madison
Fredda Stinnel - Executive Director, Association for Children with Down Syndrome, Bellmore, NY

For further information, please contact:

National Down Syndrome Society
International Down Syndrome Conference
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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) possibilites.
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.

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 puissent recevoir immédiatement l'aide et les conseils requis.
3. Promouvoir les principes de normalisation dans le sens de transformer, humaniser et rendre digne tous le 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 d'EDSA que le pluralisme culturel des nations eurpéennes 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 constituition et le rassemblement de groupes scientifiques pour parteciper par leur travaux à:
   a) la biologie des sujets Down et ses conséquences pathologiques;
   b) au développement mental à différents âges;
   c) parteciper 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 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.

MEMBRES
MEMBERS

EFFECTIFS ET ADHERENTS • EFFECTIVE AND AFFILIATE

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I wish to make a contribution of:
Je désire effectuer un versement de:

☐ 100 ecu ☐ 50 ecu ☐ 20 ecu ☐ .... ecu

I'd like to help the European Down'S Syndrome Association to attend its goals and objectives in favour of the persons with Down Syndrome

Je désire aider dans la poursuite des ses objectifs en faveur des personnes atteintes par la trisomie 21.

Name
Nom _____

Address
Adresse _____

City
Ville _____

State
Nation _____ Zip
C.P. _____

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 les 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.

AFFILIATION FORM

This affiliation form has to be sent by ordinary mail to the General Office. It's necessary it will be completed and signed by the qualified 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, first name and function)
1. .....
2. .....
II. Representative of the Association:
.....
.....
III. Official address:
.....
.....
IV.
Phone: .....
Fax: .....
seek 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 per 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 qualitées 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 qualitè de "membre affilié'. Le 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: .....
Représentant professionnel: .....
Date Signature