

# european dyslexia association

a.i.s.b.l.

**20<sup>th</sup>** 

**Anniversary Report** 

1987 - 2007

# Published by

# European Dyslexia Association 2007

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Compiled by

Robin Salter ©

Past President of EDA

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# **CONTENTS**

	<u>Page</u>
Addresses	1
Marcel Seynave – Father of the EDA	2
Preface - SR Michael Kalmár, <i>President</i>	3/5
President or Chairman? - Robin Salter, a Past President	5
Past Presidents	6
First Board Members	7
Present Board Members	8
Past & Present Board Members	9
Treasurers }	
Secretaries }	10
Editors 'EDA NEWS' }	
Origins	11
Board Meetings - Robin Salt	12/13
Aims, Vision and Mission	14
Dyslexia - a definition	15
Financial Fortunes of EDA - Steve Alexander, Treasurer	16
Members (current)	17/19
Some Achievements	20
Projects in Hand & Acknowledgements	21
Conferences & General Assemblies	22
Two Former Presidents have their say	
Gyda Skat Nielsen	23
Alan Sayles	24/25
Current EDA Publications available	25
Some familiar faces	26/27

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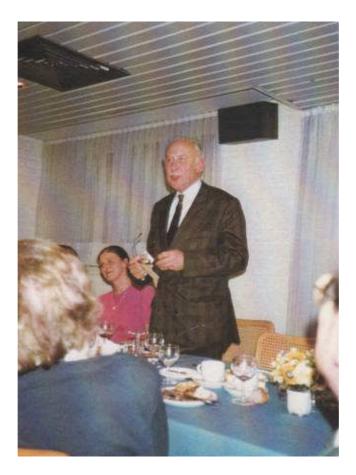
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# **'FATHER' OF THE EDA**



**Marcel Seynave** 

First President of EDA 1987 - 1993

**Monsieur Marcel Seynave** (*Belgium*) put into practice the idea of forming a European-wide association for dyslexia so that all countries in Europe could agree as to what 'dyslexia' meant and to speak with one voice on behalf of all dyslexic children and adults. In this he was ably supported by his wife, **Madame Liliane Seynave**.

## PREFACE



SR Michael Kalmár President of EDA

It is well known that looking forward will not be very successful without a good understanding of the past and an analysis of what were the initial catalysts for change which led to the present world of dyslexia that we live in. There is no better way to describe the origins of the **European Dyslexia Association** (*EDA*) than to repeat the words from the 10<sup>th</sup> Anniversary Report of our founding 'Father', **Marcel Seynave**, our first President. This may be found on **page 11**.

There is no-one more competent than **Robin Salter**, a Founding Member of our Association, its first Treasurer and second President, to describe how our organisation has been able to develop from its inaugural meeting on 18<sup>th</sup> October 1987, as he led the association for a long time during its first twenty years and still takes part in the EDA's affairs albeit in different roles. You will find his report on pages 12/13.

Amongst other things, my duty as the **Chairman\*\*** of the **Board of Directors** of the Association consists of coordinating thoughts, views and trends regarding the understanding of dyslexia in Europe, to arrange discussion about it between the members of our organisation and to draft and formulate consensus documents about what we have achieved and what remains to be done to ensure that all people with dyslexia reach their full potential. The British Dyslexia Association defines itself as the voice of people with dyslexia in England; the **European Dyslexia Association** is the voice of people with dyslexia across Europe.

In the last year the Board of Directors – in close cooperation with member organisations and various scientists – has formulated a new definition of dyslexia, new Statutes, a mission statement and a vision, which will be discussed again and hopefully will be

unanimously approved by the 20 <sup>th</sup> General Assembly of the *EDA* on November 15<sup>th</sup> 2007.

These documents are the "ideological" background for the future of the *EDA*. They express our developed understanding and views. They are based on the following principles:

- Dyslexia is not a condition, but a specific learning difference. Attitudes to dyslexia
  and ignorance combine to create barriers for people with dyslexia in every
  society, regardless of their age, language, socio-economic position, level of
  intelligence and their individual efforts.
- In our lives we all are determined to ensure that our needs are met. We people
  with dyslexia should not need charities and helping hands to respond to our
  difference, which is evidenced in difficulties in acquiring the use of reading,
  spelling and writing. Access to appropriate education, adequate employment and
  a full life is a human right for all.
- The world of dyslexia is made up of academic scientists and institutions that focus on disabilities, as well as teachers and therapists, etc., who all have an important contribution to make. But only people with dyslexia can evaluate whether their needs are being met by the services of professionals, and which approaches work best.
- Every child, adolescent and adult with dyslexia has the right to access and to receive appropriate identification, support and opportunity to achieve his full potential in education, training, employment and all aspects of life.
- The European Dyslexia Association represents the people with dyslexia in Europe. It is the European umbrella organisation **of** and **for** national and regional associations of people with dyslexia, children's parents and professionals; legally, it is a charity formed under Belgian law in 1987.
- The EDA therefore exists to make a positive difference in the lives of dyslexic people in Europe. It is based on truly democratic principles to ensure that member organisations are fully involved in helping to make that difference, and in shaping the EDA to be pro-active.
- The EDA facilitates the exchange of information and good practice through international networking and lobbying in partnership with member organisations, governmental bodies and professionals working within the dyslexia community.

• The EDA challenges prejudice and ignorance to ensure that people with dyslexia are empowered to reach their full potential.

This statement of principles may lead to continuous up-dating and discussion and, hopefully, to greater awareness of the wants, needs and requirements of those living in Europe with dyslexia. I am confident that there will be significant progress in the next twenty years, but even then there will remain much to be done.



## **President or Chairman?**

(See page 3, 3rd paragraph above)

There has often been confusion in the past over the two titles used by the EDA of **President** and **Chairman**. In many 'European' countries, the head of an organisation is the 'President' who will also chair its meetings. In other countries (for example, the UK) the title 'President' is often reserved for the founder of an organisation and is usually a non-executive role whereas the 'Chairman' is in charge of an organisation and is always the person (or Vice-Chairman) who will chair meetings.

To make it clear, for all countries, the person in charge of the EDA is the President who will also chair its meetings.

A large number of confusions arose at the start of the EDA due to the different meanings and subtleties of the different languages, quite apart from the mis-translations.

This has been a problem with the EDA's Statutes. The words that we agreed at the first inaugural meeting in October 1987 were written down in English – the language it was agreed would be used by the EDA for speech and communication. For the Arrêtte Royal under Belgian Law, the English was translated into French with slightly different words and meanings – and none of the English speakers realised there were changes! It was the French translation which was legally adopted in our Statutes.

## Robin Salter

# **PAST PRESIDENTS**



Marcel Seynave (Belgium) 1987 - 1993



Robin Salter (United Kingdom) 1993 - 1999



Gyda Skat Nielsen (Denmark) 1999 - 2000



Alan Sayles (Ireland) 2000 - 2006

# FIRST EDA BOARD



# <u>1987</u>

Marcel Seynave (Belgium) Alan Sayles (Ireland)
Dr Lisa Dummer-Smoch (Germany)

Gyda Skat Nielsen (Denmark) Aaldert van der Horst (The Netherlands)
Turid GammelsrØd (Norway)

Robin Salter (United Kingdom) Dr Anne-Marie Montarnal (France)

# PRESENT BOARD MEMBERS



SR Michael Kalmár (Austria) 1999 President



Prof. Marta Bogdanowicz (Poland) 1989 Vice-President



Karin Brünger (Germany) 2000 Vice-President



Steve Alexander (United Kingdom) 2003 Treasurer



Maria Potamitis (Cyprus) 2003 Secretary



Carina Carlsson (Sweden) 2003



Dr Marija Kavkler (Slovenia) 2003



Raymond Claes (Luxembourg) 2006



Lars Sander (Denmark) 2007

# PAST & PRESENT BOARD MEMBERS

The purpose in producing this list of Past and Present Board Members is to remind everyone just how representative across Europe the *European Dyslexia Association* has been over the past twenty years, and to provide a record for the future.

Marcel Seynave	Belgium	1 <sup>st</sup> President	{ 1987 - 1993 { 1987 - 1997
Turid GammelsrØd	Norway Join	t 1 <sup>st</sup> Vice-President	{ 1987 - 1997 1987 - 1991
Alan Sayles	Ireland Join		{ 1987 - 1997
		.th —	{ 1999 - 2006
Lian Dummar Cmach	C a ### a ## /	4 <sup>th</sup> President	{ 2000 - 2006
Lisa Dummer-Smoch Aaldert van der Horst	Germany The Netherlar	, do	1987 - 1993 1987 - 1993
Anne-Marie Montarnal	France	1 <sup>st</sup> Secretary	1987 - 1995
Robin Salter	United Kingdo	m 1 <sup>st</sup> Treasurer	{ 1987 - 1993
	3	2 <sup>nd</sup> President	{ 1993 - 1999
		4 <sup>th</sup> Treasurer	{ 2000 - 2002
Gyda Skat Nielsen	Denmark		{ 1987 - 2000
	5	3 <sup>rd</sup> President	{ 1999 - 2000
Marta Bogdanowicz	Poland	3 <sup>rd</sup> Vice-President	{ 1989 -
Andras Mate	Hungary	3 Vice-President	{ 1991 - 1991 - 1993
Katrin Sellin	Germany		1997 - 1993
Peter Havas	Hungary		1993 - 1997
Nada Lovric	Croatia		1993 - 1997
Berit Bogetvedt	Norway		{ 1992 - 1997
		2 <sup>nd</sup> Secretary	{ 1993 - 1997
Koos Henneman	The Netherlan		1993 - 1998
Eleni Grammaticos Herbert Gunther	Belgium	3 <sup>rd</sup> Secretary	1997 - 2000 1997 - 1999
André Poncelet	Germany Belgium	3 <sup>th</sup> Treasurer	1997 - 1999
Michael Kalmar SR	Austria	o measurer	{ 1998 -
monaci ramar cir	71001110	5 <sup>th</sup> President	{ 2006 -
Suzanne Bertschinger	Switzerland		(1999 - 2002
		4 <sup>th</sup> Secretary	{ 2000 - 2002
Karin Brünger	Germany	4 <sup>th</sup> Vice-President	2000 -
Gavin Reid Teresia Hegedüs	Hungany		2001 - 2002 { 2001 - 2004
reresia riegeuus	Hungary	5 <sup>th</sup> Secretary	{ 2001 - 2004
Steve Alexander	United Kingdo		{ 2002 - 2004
	o mada migue	6 <sup>th</sup> Treasurer	{ 2004 -
Carina Carlsson	Sweden		2003 -
Marija Kavkler	Slovenia		2003 -
Maria Potamitis	Cyprus	_th	{ 2003 -
		5 <sup>th</sup> Treasurer	{ 2003 - 2004
Raymond Claes	Luxembourg	6 <sup>th</sup> Secretary	{ 2005 - 2006 -
Lars Sander	Denmark		2007 -
	_ 3		= 3 • ·

# **TREASURERS**

Robin Salter	(United Kingdom)	1987 - 1993
Koos Henneman	(The Netherlands)	1993 - 1998
André Poncelet	(Belgium)	1998 - 2000
Robin Salter	(United Kingdom)	2000 - 2002
Maria Potamitis	(Cyprus)	2003 - 2004
Steve Alexander	(United Kingdom)	2004 -

# **SECRETARIES**

Dr Anne-Marie Montarnal	(France)	1987 - 1993
Berit Bogetvedt	(Norway)	1993 - 1997
Eleni Grammarticos	(Belgium)	1997 - 2000
Susanne Bertschinger	(Switzerland)	2000 - 2002
Teri Hegedüs	(Hungary)	2002 - 2004
Maria Potamitis	(Cyprus)	2005 -

# **MINUTING SECRETARY**

Jennifer Salter (United Kingdom) 1993 - 1999

# **EDITORS 'EDA NEWS'**

Marcel Seynave	} (Belgium)		1988 - 1993
Marcel Seynave	} (Belgium)		{
	}	Joint	{ 1993 - 1995
Anne-Marie Montarnal	} (France)		{
Elaine Miles	(Wales)		1995 - 1999
Robin Salter	}		{
	} (United Kingdom)	Joint	{ 1999 -
Jennifer Salter	}		{

#### **ORIGINS**

# Extract from the 10<sup>th</sup> Anniversary Report 1997

In 1986 the association, APEDA\* Belgique, invited Dr. Albert Galaburda, the Head of Research at the Harvard Medical School in Boston, Massachussetts in America to participate in a conference on developmental dyslexia in Brussels. The conference was organised for the benefit of its members and the scientific world. APEDA-France and the German association, Bundesverband Legasthenie (BVL), took the opportunity to invite Dr Galaburda to make another conference for their respective organisations at a later date.

So it was that I was invited to attend the congress of BVL in Hannover as the President of APEDA-Belgique and I travelled with Dr Galaburda. During our conversations, he was quite surprised at the diversity of approaches in Europe towards dyslexia which he believed were influenced by the Anglo-Saxon theories of Piaget. Dr Galaburda then suggested the idea of creating an association to agree a common approach for the benefit of dyslexics in Europe.

Two years previously in 1984, there had been a study organised in England by the British Dyslexia Association with delegates from Belgium, France and Germany at which the same idea had been germinated; but at that time nothing was done!

At the congress in Hannover, there was a reunion of the contacts made in Britain between the delegates from France, United Kingdom, The Netherlands, Belgium and Sweden. I proposed I should take the first necessary steps for the creation of a European Association for dyslexia.

Living in Brussels, it was easy for me to establish contacts with the European Community. Mr Daunt, the Director at that time of the Bureau of Action for Handicapped Persons, showed great interest in the initiative. So it was that I obtained from the European Commission a financial subvention to cover the entire costs of preparation and organisation of the first assembly.

**European Dyslexia Association**, an international association under Belgian law was founded at Brussels on <u>18 October 1987</u>. Twenty-five representatives from dyslexia associations in the following eight countries set the course for the future of the **Association**.

\* I'Association de Parents d'Enfants en Difficulte d'Apprentissage for Belgium Association for Children & Adults with Learning Difficulties for Ireland British Dyslexia Association for United Kingdom Bundesverband Legasthenie for Germany Landsforeningen For Ordblindesagen for Denmark Norsk Dysleksiforbund for Norway Balans/Stichting Dyslexie for The Netherlands Union Nationale France Dyslexie for France

In December 1988, the European Commission officially recognised the 'European Dyslexia Association (EDA)' as a Non-Governmental Organisation representing dyslexia and its specific learning difficulties.

**Marcel Seynave** 

## **BOARD MEETINGS**



Robin Salter (United Kingdom) President 1993 - 1999

The Board of Directors has endeavoured to meet three times a year over the last 20 years whilst trying to spend the minimum amount of money in doing so. Time is often added at conferences and on other occasions.

Meeting occasionally would not be enough to organise and administer the demands of the growing EDA so the use of the telephone and development, initially of the **fax**, then of the **Internet** and **Worldwide Web** has enabled the Board to keep in touch and discuss important and urgent matters without always having physically to meet.

In the early days, the Board obtained subventions from the European Union (EU) and from projects (still an important source) to pay for travel costs whilst actually staying on most occasions in the houses of EDA members in the towns where meetings or conferences were being held. This was a valuable time for the Board Members (each from a different country) to get to know their hosts and their local customs – meeting over the breakfast table is a wonderful way of getting to know people and their habits! The social connection of physical contact over business and the evening dinner has always been an important aspect of cohesion and understanding the different cultures and way things are done differently in the Member States of the European Union.

Without such contact and face-to-face discussion it would be very difficult to obtain any consensus of views and ideas, for example, of the definition of 'dyslexia'. Mistranslation and the different meaning applied to certain words, such as 'prevention', has always been a problem and caused many a strong argument!

The initial funding obtainable from the EU was reduced as the EU itself tried to solve its own problems of controlling finance, so the rules constantly changed to the point when the EDA was unable to gain as much money as it needed, as it did not have a salaried staff and central office. Attempts were made to overcome this difficulty by opening an office in Brussels which proved unworkable without the substantial funding needed to support a central administration. No-one likes to give money for 'administration' but it is the single most important cost for any organisation and without it growth is very limited.

The success of the EDA in surviving as a valid, value-added and necessary organisation for those disabled by Dyslexia is really due to the generous *voluntary* work, time given and financial support provided, respectively, by each President and the Board Members over the last twenty years.

It has to be said that the Board Members, whoever they are or have been, have gained an enormous amount of knowledge, widening of horizons, and great interest and fun by their experience as Board Members. Their individual contributions have been invaluable to the EDA and the 'Europe-trotting' has made a major contribution across Europe in helping to bring the EU Member States closer together with greater cohesion and understanding of each other. These individual **voluntary** efforts should be recognised by the EU, the Member States' respective Governments, and the EDA Members themselves.

The difficulties experienced in the creation of the EDA have been virtually the same as those in the creation of the EU itself, although on a smaller scale!

The Board Meetings of the EDA have been held in all of the following countries, which bear witness to the wide experience of the Board Members in meeting and discussing relevant issues with Members of EDA in their own countries. It has always been an essential part of the work of the Board in meeting people on their own territory to discuss matters at first hand.

# Board Meetings and General Assemblies have been held in: (often several times in the principal cities)

Austria: Vienna

Brussels Louvain la Neuve

Croatia: Zagreb Limassol

**Denmark:** Copenhagen Horsholm

France: Le mesnil St. Denis Paris Strasbourg St. Gildas de Rhuys

Germany: Aachen Berlin Darmstad Freiburg Hannover Lubeck Munich

Greece: Aegina Athens

Hungary: Budapest Ireland: Dublin

Italy: Bologna Milan Rome

Luxembourg:LuxembourgNetherlands:AmsterdamNorway:Oslo Tromso

**Poland:** Gdansk

Scotland: Edinburgh Stirling

Slovenia: Ljubljana

Spain: Barcelona Madrid

Sweden: Malmö

United Kingdom: Bath Bedford London Manchester Oxford York

There have also been visits to other countries/cities for specific projects or for talks given by Board Members.

## AIMS of the EDA

- To assist and develop support for dyslexic people in their educational, social and cultural integration into society.
- To promote co-operation between parents, teachers and other professionals.
- To publish news of its activities and to encourage research into cause(s), diagnosis, intervention and remediation.
- To carry out comparative studies and to co-operate world-wide with other organisations with similar aims.

<u>The following Vision and Mission Statements are to be proposed for adoption at the General Assembly on 17<sup>th</sup> November 2007:</u>

# <u>VISION</u>

Every child and adult with **dyslexia** has the right to access and to receive appropriate identification, support and opportunity to achieve their full potential in education, training, employment and in all aspects of life.

#### MISSION

The **European Dyslexia Association** is an umbrella organisation for national and regional associations of people with dyslexia, children's parents and professionals.

It facilitates the exchange of information and good practice through international networking and lobbying in partnership with its member organisations, governmental bodies and professionals working within the dyslexia community. The EDA will challenge prejudice and ignorance to ensure that people with dyslexia are empowered to reach their full potential.

Revised March 2007

#### 'DYSLEXIA' - A DEFINITION

Over the years, there have been almost as many definitions of '**Dyslexia**' as there are 'experts'! The **European Dyslexia Association** has endeavoured to obtain a consensus in Europe for a definition which all European dyslexia associations can accept. It is not an easy thing to do, as some countries have put more emphasis than others on the different symptoms of the 'generic' term '**dyslexia**' which covers so many aspects of a dyslexic person's developmental experience and problems.

After considerable consultation, the following 'definition of dyslexia' is generally accepted by the *European Dyslexia Association* for practical purposes:

'Dyslexia is a difference, which makes the acquiring and using of reading, spelling and writing skills difficult. This difference is neurological in origin.

The cognitive difficulties underlying these differences can also affect organisational skills, calculation abilities and other cognitive and emotional abilities.

It may be caused by a combination of difficulties in phonological processing, working memory, rapid naming, sequencing and the automaticity of basic skills.'

Researchers acknowledge that there are many possible causes of dyslexia, including genetics.

There is no relationship between a person's level of intelligence, individual effort or socio-economic position and the presence of dyslexia.

Alongside these issues is the ongoing challenge for people with dyslexia in navigating through life in a largely non-dyslexia friendly world.

Furthermore, across Europe the diversity of languages and the multilingual demands, socio-cultural backgrounds as well as educational opportunity, have a significant influence on the manifestation of difficulties and life-chances for dyslexic children, adolescents and adults with dyslexia.

## THE FINANCIAL FORTUNES OF THE EDA



Steve Alexander (United Kingdom) Treasurer

The EDA receives its strength from its membership organisations but our members also provide much of the financial support. In a full year (and if everyone paid) we receive approximately 9,000 euros from membership fees. For a variety of reasons not everyone pays straight away and it can take a little time to attract this much needed financial backing.

However, the EDA in pursuit of its objectives on behalf of its members may spend up to 20,000 euros per year. This expenditure includes maintaining our web-site as an important source of information giving, bringing together each association's President in order to mandate the EDA actions and of course in this year (2007), to help support our International Conference in Luxembourg.

In order to balance our books, we need to fundraise. Our sphere of influence is growing in Europe and increasingly with the EU government. This I am sure has aided our fundraising success in EU funded projects. I would briefly like to mention two in particular.

The first is the INCLUDE project (<a href="http://www.includedyslexia.info">http://www.includedyslexia.info</a>) which is a European collaboration between the UK, Greece, Hungary, Poland and Romania. It brings together leading experts in the field, providing identification and support for dyslexic individuals. This site is designed to provide access to the web-based tool developed out of this project that will help identify dyslexic adults, their strength and needs, and help them progress via both training and employment situations through online support and coaching in order to provide the opportunity to develop to their maximum potential.

The second is entitled Collaborative Additional Language Learning for Dyslexics (<a href="www.calldysc.eu">www.calldysc.eu</a>). This project, put simply, is about how dyslexics respond to language learning using mobile technology (e.g. phones). To achieve this, the project uses sound pedagogical principles to develop software dedicated to the project that may be used on a variety of mobile phones.

The EDA wants to achieve even more to ensure that dyslexic people across Europe receive the support and intervention they need. Clearly to deliver our ambitious programme for change we need financial support through membership fees and general fundraising. If you have any ideas on how we can raise more money then please get in touch on <a href="mailto:Steve.Alexander@pre-school.org.uk">Steve.Alexander@pre-school.org.uk</a>

# **MEMBERS** (current)

( <u>Status</u> : E = Effective Member (voting)		A = Adherent Member) (non-voting)	
<u>organisation</u>	<u>status</u>	email address/website	
Arbeitskreis Kind und Schule (ARKUS)	E	arkus@aon.at www.arkus-lienz.at	
Initiative Lega Vorarlberg (LEGA)	Е	Karin.trommelschlaeger@vup.at www.lega.at	
Kärntner Landesverband Legasthenie Österreichischer Bundesverband	Α	drastridkoppduller@yahoo.com	
Legasthenie (ÖBVL)	Е	info@legasthenie.org www.legasthenie.org	
Steirischer Landesverband Legasthenie (STI	LL) E	hermine.posch@aon.at	
BELGIUM  Belgique Association Française de Parents en Difficultés d'Apprentissage du Language écrit et oral (APEDA Belgique)  Dyslexia International Tools and Technologies (DITT)  Europe's Children Our Concern (ECOC)	E E A	secretariat@apeda.be www.apeda.be admin@ditt-online.org www.ditt-online.org ecoc@ecoc.be www.ecoc.be	
CROATIA Hrvatska Udruga za Disleksiju	E	ada.pavlic-cottiero@zg.t-com.hr	
CYPRUS Cyprus Dyslexia Association North Cyprus Dyslexia Association	E A	dyslexiacy@cytanet.com.cy dyslexia_ncda@hotmail.com	
CZECH REPUBLIC Czech Dyslexia Association Základni škola profesora Zdeňka Matějčka (Czech Dyslexia Center)	E A	zelinkova@mymail.cz zsdysmost@volny.cz	
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FINLAND Erilaistenoppijoiden liito/Förbunder for all Inlärning (FINDER)	Е	airi.valkama@erilaistenoppijoidenliitto.fi www.erilaistenoppijoidenliito.fi	

FRANCE		
Association Française de Parents d'Enfants en Difficultés d'Apprentissage du		
Language écrit at oral (APEDA France)	Α	apeda@hotmail.fr
Coordination des intervenants aupres des		
Personnes souffrant de Dysfonctionnements neuropschologiques	F	ariel.conte@tiscali.fr
(CORYDYS)	_	www.coridys.asso.fr
,		
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Bundesverband Legasthenie und Dyskalkulie e.V. (BVL)		bvlvorstand@t-online.de www.bvl-legasthenie.de
(= -)		
GREECE		
Association of Parents of Dyslexic and with	Е	milianilia Ovahaa ar
Learning Difficulties Children of Thessaloniki and Northern Greece	E	milionilia@yahoo.gr www.dyslexia-qoneis.gr
The socioniki and Northern Greece		www.dysicxia goneis.gr
<u>HUNGARY</u>		
Dyslexias Gyermekekert Egyesulet	E E	dyslexia@t-online.hu
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IRELAND		
Dyslexia Association of Ireland	E	info@dyslexia.ie
ITALV		
ITALY Associazione Italiana Dislessia	Е	info@dislessia.it
7.0000iaziono italiana Biologgia	_	www.dislessia.it
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Lithuanian Dyslexia Association	Α	redag@takas.lt
LUXEMBOURG		
Dyslexia & Special Needs Group (DYSPEL)	E	rclaes@pt.lu
		www.dyspel.org
MALTA The Division Association	_	day, and a second transfer and
The Dyslexia Association	E	dowager@maltanet.net
THE NETHERLANDS		
Stichting Dyslexia Nederland	E	henneman@euronet.nl
Vereniging Balans	Е	info@balansdigitaal.nl
NORWAY		
Dysleksiforbundet I Norge	Е	post@dysleksiforbundet.no
,		
POLAND	_	no umb a Quair and a ni
Polskie Towarzystwo Dysleksji	E	psymbg@univ.gda.pl
SCOTLAND		
Dyslexia Scotland	Α	info@dyslexiascotland.org.uk
		www.dyslexiascotland.org.uk

## **SPAIN**

Associacio Catalana de Dislexia E <u>catalandyslexia@hotmail.com</u>

#### **SLOVENIA**

Association for Helping Children and Youth
with SLD (BRAVO)

E drustvo.bravo@quest.arnes.si

## **SWEDEN**

Dyslexia statt Ordblind = Parent's Association E <u>dyslexi@fdb.nu</u> (FOB)

Förbundet Funktionshindrade Med Läs-och

Skrivsvårigheter (**FMLS**) E <u>info@fmls.nu</u> www.fmls.nu

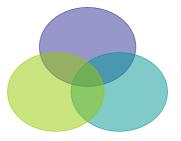
The Swedish Dyslexia Association A <a href="mailto:svenska.dyslexiforeningen@neuro.ki.se">svenska.dyslexiforeningen@neuro.ki.se</a>

## **SWITZERLAND**

Verband Dyslexie Schweiz E <u>sekretariat@verband-dyslexie.ch</u>

#### **UNITED KINGDOM**

British Dyslexia Association (**BDA**) E <u>admin@bdadyslexia.org.uk</u> <u>www.bdadyslexia.org.uk</u>



#### **SOME ACHIEVEMENTS**

This is a small selection from the growing list over the past 20 years

- membership has increased from the original 8 members to the current 40 members in 25 countries. There are currently a further 15 organisations in another 6 countries which are in discussion with the EDA about membership
- many new associations have been supported and assisted in their formation with information and organised meetings
- achieved consultative status as an NGO of the European Union
- achieved consultative status with the International Federation of Library Associations & Institutions (IFLA)
- organised and supported many conferences in Europe (and the USA) including campaigns for Early Recognition of Dyslexia, Teacher Training, Access to Information, No Matter which Country Dyslexia is Everywhere
- produced the first Dyslexia Primary School Provision in Europe
- organised the first European Conference for Young Persons with Dyslexia
- organised the first cross-border meeting for many years between any organisations in Cyprus and Northern Cyprus which led directly to the formation of the North Cyprus Dyslexia Association
- organised an East/West programme of cooperative meetings between five European countries entitled INCLUDE under the Leonardo EU programme
- produced a number of publications, including the first Guidance Criteria for the Training of Teachers of Dyslexic Students which had widespread support in many of the European countries – still valuable information today
- published the EDA's 10<sup>th</sup> Anniversary Report
- assisted in obtaining publication (with World Dyslexia Network Foundation) of the first International Book of Dyslexia (now in its 2<sup>nd</sup> and enlarged edition) covering dyslexia in over 60 countries of the world
- brought *Dyslexia* to the attention of teachers across the European Union
- published the book by Prof. Marta Bogdanowicz and Alan Sayles entitled *Rights of the Dyslexic Child in Europe*
- joined in EU projects with other countries under the Leonardo and Socrates programmes to spread further knowledge about dyslexia in Europe
- joined British Dyslexia Association and International Dyslexia Association (USA) in organising regular Multilingual Conferences
- introduction of a *European Dyslexia Week* in first week of October each year
- regularly published its journal EDA NEWS and created two websites

#### SOME PROJECTS IN HAND or PLANNED

- The 2<sup>nd</sup> All European Dyslexia Conference and EDA General Assembly in Luxembourg in November 2007 with amendments to the EDA Statutes
- Preparation for the 4<sup>th</sup> Multilingualism & Dyslexia Conference in conjunction with British Dyslexia Association & International Dyslexia Association scheduled for March 2009 in Brugges, Belgium
- Preparation of a Questionnaire for the Rights of Dyslexic Adults and Students in Europe which it is hoped will result in similar publications to the Rights of the Dyslexic Child in Europe published in 2005
- Continuation of the INCLUDE Leonardo programme
- Continuation of the Collaborative Language Learning for Dyslexics programme

## <u>Acknowledgements</u>

# **Christine Campbell**

Christine was an Irish teacher in Brussels and was asked to act as Secretary for the initial meeting of EDA at The Europa Hotel in 1987.

Looking back, Christine was never given the formal acknowledgement she deserved for acting as Secretary and for initially translating the Statutes and Bye-laws of the EDA into French. It was no mean task trying to understand the English, ideas and intent of the different delegates from the initial countries. It was she who sometimes told us we were not meaning the same thing whilst saying the same words.

It is hoped this acknowledgement will go some way to correcting an omission.

## Ian Smythe

lan has been a hidden and valuable force behind many of the British Dyslexia Association's projects. He created the World Dyslexia Network Foundation and was a leading force in the publication of the *International Book of Dyslexia*. His knowledge of dyslexia internationally is probably greater than that of almost anyone else.

Whilst having no formal position with the EDA, it is believed right that all the work he has done for the EDA over the years should be acknowledged. This has included work for the first website, the setting-up of the INCLUDE Leonardo Programme and the Collaborative Language Learning for Dyslexics programme, besides giving a great deal of expert advice.

His contributions to the work of the EDA and dyslexia generally, is here acknowledged.

# **EDA CONFERENCES & GENERAL ASSEMBLIES**

The EDA has supported conferences in many countries but it has also organised, solely or jointly with others, a number of conferences across Europe.

The EDA's own Conferences and General Assemblies for the first ten years are referred to in the EDA's 10<sup>th</sup> Anniversary Report of 1998. The EDA Conferences and General Assemblies held in the last 10 years were as follows:

## **Conferences**

<u>Conferences</u>			
Multilingualism & Dyslexia In conjunction with British Dyslexia Association & International Dyslexia Association (USA)			17/19 June 1999 Manchester UK
Multilingual and Cross-Cultural Perspectives on Dyslexia In conjunction with British Dyslexia Association & International Dyslexia Association (USA)			27/29 June 2002 Washington DC USA
First All-European Dyslexia Conference In conjunction with Startdyslexia			2/4 October 2003 Budapest Hungary
5 <sup>th</sup> World Congress on Dyslexia <i>In conjunction with George Th.Pavlidis</i>			23/25 August 2004 Thessaloniki Greece
<ul> <li>3<sup>rd</sup> International Conference on Multilingualism &amp; Dyslexia</li> <li>In conjunction with British Dyslexia Association</li> <li>&amp; Cyprus Dyslexia Association</li> </ul>			14/16 July 2005 Limassol Cyprus
1 <sup>st</sup> Presidents' Meeting			29 April 2006 Brussels Belgium
2 <sup>nd</sup> Presidents' Meeting  General Assemblies			9/11 March 2007 Luxembourg
6 <sup>th</sup>	Luxembourg	Luxembourg	7 March 1999
7 <sup>th</sup>	United Kingdom	York	22 April 2001
8 <sup>th</sup>	Hungary	Budapest	5 April 2003
9 <sup>th</sup>	Cyprus	Limassol	16 July 2005
1 <sup>st</sup>	Extraordinary General Assembly	Luxembourg	10 March 2007
10 <sup>th</sup>	Luxembourg	Luxembourg	17 November 2007

## TWO FORMER PRESIDENTS HAVE THEIR SAY



Gyda Skat-Nielsen (Denmark) President 1999 – 2000

I was one of the founding Board Members of EDA representing Denmark in 1987 and am delighted it has grown steadily ever since.

In an area of education which was primarily based upon helping dyslexic children, I was always concerned to raise awareness of the problems of dyslexic adults, most of whom would not have been recognised as being dyslexic, but only as having reading or learning difficulties. The EDA has continued to press for the need for <u>all</u> dyslexic people to have their specific problems recognised and for help to be given. Because of my job as a librarian, my term of office as President of EDA enabled me to make a practical contribution by seeing the EDA become a Consultative Member of the **International Federation of Library Associations and Institutions (IFLA)**. I have always been interested in making books accessible to all adults, as well as children, no matter what disability they may have so it was a privilege to see the EDA helping to play an important role in this worldwide international association.

Perhaps the greatest campaign for which I was responsible was in 1993 with Robin Salter (the then EDA Treasurer), when we created **The Year of Early Recognition of Dyslexia** campaign ('Early help – better future') which sought to raise awareness of the importance of early diagnosis and intervention of dyslexia. The campaign details were initiated on a beach on the Greek Island of Aegina after a dyslexia conference in Athens! It was the EDA's first major pan-European campaign and proved successful in bringing greater awareness of the problems of dyslexia to areas where there was little or no help for dyslexic people. The EDA produced a report of the campaign in 1993 (ISBN 1 899655 00 X)

I am also pleased to have been a Board Member when the EDA's **Teacher Training campaign** of 1997 was introduced. It was always the case that in order to recognise and remediate the problems of dyslexia, it was necessary for all teachers to know enough about the diagnosis of dyslexia to ensure that the appropriate help was provided. This pan-European EDA initiative helped to raise awareness for teachers and produced the EDA's publication **Guidance Criteria for Training Teachers of Dyslexic Students** in 1997 (ISBN 1 899655 16 6).

It has been a special pleasure for me to be one of the promoters of closer cooperation between countries and regions, for example, in the Eastern and Western part of Europe and in Cyprus.

The EDA has undertaken a number of projects in the last 20 years and held Conferences and General Assemblies in a number of countries. It has given me the opportunity to make many lasting friendships across Europe so you can see I enjoyed my thirteen years as an EDA Board Member; I wish the European Dyslexia Association continued success in the future.



Alan Sayles (Ireland) President 2000 - 2006

It is hard to believe that it is twenty years since that October when Anne Hughes and I, as representatives of the Dyslexia Association of Ireland, attended a weekend-long meeting in the Europa Hotel in Brussels. Like the other delegates from dyslexia organisations in Belgium, Denmark, France, Germany, Great Britain, the Netherlands, and Norway, we were not sure what to expect from Marcel Seynave's invitation to form a European organisation to support people with dyslexia and their families.

However, despite our varying cultures, languages and indeed our understandings of dyslexia, under Marcel's gentle but persuasive leadership, we managed to write a constitution and a set of bye-laws and thus induce the birth of the European Dyslexia Association.

Apart from a brief and unsuccessful initial attempt to retire, I served on the executive of the association for over eighteen years. From October 2000, on the unexpected retirement of Gyda Skat Nielsen, I had the honour of being the fourth president of the EDA until a change in my professional life led to my retirement in January 2006.

I have countless memories of meetings where board members worked long hours selflessly for the cause of dyslexia. After a full week's work, and often at their own expense, members flew across Europe to attend weekend-long meetings in cities of which they sometimes saw little. Yet they were always willing to do more and were always cheerful about it. In fact, if it wasn't for the good humour, we wouldn't have survived.

While there were many highlights to my time as president, there are some in particular, of which I am most proud. I believe they were all significant in advancing the work of the EDA.

First was the launch of the annual European Dyslexia Week in 2002. Prior to that year, a number of members, particularly the British Dyslexia Association and the Dyslexia Association of Ireland, had been organising their own national campaigns. However now, with the support of the EDA, many members use this agreed week to promote the awareness of dyslexia in their own country. I still strongly believe that a united effort such as this is crucial. Despite all of our campaigning, lack of awareness is still the root cause of many of the problems associated with being dyslexic in our society.

Secondly was the 2004 publication of the EDA book – '*Rights of Dyslexic Children in Europe*'. Most of the research for this book was the work of my able first vice-president, Marta Bogdanowicz. It was the first major publication of the association and remains a valuable reference.

(continued on page 25)

Finally and probably most important, was the EDA's venture into organising conferences. October 2003 was the month of the first conference hosted solely by the EDA. After many months of planning and in particular the hard work of Michael Kalmár and Teri Hegedüs, the All-European Conference on Dyslexia took place in Budapest, Hungary. While financially, this event was a strain on the association, it proved to be an outstanding success in furthering the reputation of the EDA. This venture was followed in July 2005 by the EDA's hosting of the Third International Conference on Dyslexia and Mulitlingualism in Limassol, Cyprus. This was a major undertaking of international importance. While the EDA received the support of the British Dyslexia Association and the American International Dyslexia Association, it just could not have been done without the significant efforts of the Cyprus Dyslexia Association. Hopefully, the EDA will continue to take a leading role in bringing together international presenters and delegates to share their knowledge of dyslexia.

I thoroughly enjoyed every minute of my time with the EDA. While the work was always demanding and time-consuming and often frustrating, I now feel somewhat guilty in that I may have gained more than I gave. In my eighteen years plus with the association, I had the opportunity to travel throughout Europe, to learn about education in a variety of settings, to meet the leading researchers in the field of dyslexia and, most importantly, to make innumerable friends. That has made it all worthwhile.

I wish the present president and board members the best of luck in their work and I thank them for all they have done and will continue to do to support people with dyslexia and their families.



# **CURRENT EDA PUBLICATIONS AVAILABLE**

- EDA NEWS the journal of the EDA published 3 times a year
   Joint Editors Jennifer & Robin Salter
   eda@kbnet.co.uk
- The Rights of the Dyslexic Child in Europe by Prof. Marta Bogdanowicz and Alan Sayles. This publication is the result of a Questionnaire to EDA Members 2006
- Guidance Criteria for the Training of Teachers of Dyslexic Students published in 1997 ISBN 1899655166
- A Report on the Year of Early Recognition of Dyslexia published in 1993
   ISBN 1899655 00X
- The International Book of Dyslexia (jointly with the World Dyslexia Network Foundation) first published 1997. (The 2<sup>nd</sup> Edition in two parts was published by John Wiley & Sons Ltd in 2004)

Part 1 ISBN 0-471-49841-6 Part 2 ISBN 0-471-49646-4

## **SOME FAMILIAR 'OLD' and 'NEW' PERSONALITIES**



left to right York 2001
Teri Hegedüs, Karin Brunger, Susanne Bertschinger
Alan Sayles, Marta Bogdanowicz, Gavin Reid



left to right

Eleni Grammaticos, Gyda Skat Neilsen

André Poncelet, Jennifer Salter, Berit Bogetvedt



left to right Scotland 1995 Marcel Seynave, Gyda Skat Nielsen a Scottish Piper, Anne-Marie Montarnal, Peter Havas, Robin Salter



left to right
Simona Tancig, Alan Sayles, Marija Kavkler
Michael Kalmár, Marta Bogdanowicz
Karin Brünger, Steve Alexander,



Early Recognition Campaign Co-ordinators Paris 1991 left to right

Francoise Biemel, Peter Havas, Gyda Skat Nielsen Sandra Marone, Jill Carlisle, Paul Erik Pagaard Katrin Hermann, Ann Power, Alice Tzen Anne-Marie Montarnal, Suzy de Maerschalk Berit Bogetvedt, Marta Bogdanowicz, Robin Salter



'Rights of the Dyslexic Child in Europe' publication of the book 2006 Alan Sayles and Marta Bogdanowicz



Creation of North Cyprus Dys.Ass. 2000 Left to right Michael Kalmár, Ersin Ozdoyjan, Dina Zakou Alan Sayles



Styrian Dys.Ass. Opening New Library 2002 left to right
Hermine Posch, Christel Otto, Petra Rouschal Michael Kalmár, Elisa Reinsberger



Left to right Luxembourg 1999 Jennifer Salter, Herbert Gunther, Michael Kalmár Karin Brünger, Robin Salter



left to right Aachen 1990 Patricia Sayles, Alan Sayles, (?), Joep Dumont Koos Henneman, Nada Lovric



Madame Liliane Seynave 1990



Two 'Originals'
who encouraged EDA
Lotte Schenk-Danzinger
(Austria)
Marion Welchman MBE
(United Kingdom)
1990



Anne-Marie Montarnal First EDA Secretary 1987 – 1995