

Partnerships for Dystonia in Europe

DYSTONIA EUROPE

Annual Report 2011 - 2012



DE delegates from all over Europe gathered in Bol, Croatia 2012

www.dystonia-europe.org

Our mission

is to promote awareness and education, stimulate research for better treatments, and ultimately to find a cure, in order to improve the quality of life for people living with dystonia.

“Work with Dystonia Europe to provide information, raise awareness, increase research and improve everyday life of patients and their families”

Contents

Message from President and Executive Director	3
Boards & Team	4
Board Review	5
Communication Resources	5
Activities	6
2012 & Beyond	9
Financial Report 2011	10
Members	11
Partners & Sponsors	11
Contacts	11

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Dystonia

is a chronic neurological movement disorder affecting one or more muscle groups, causing sustained muscle contractions and leading to twisting and repetitive movements or abnormal postures.

Dystonia can affect both men and women of all ages. When onset occurs in childhood it is often particularly disabling. The best medical estimates suggest that there are more than half a million people living with dystonia in Europe. Treatments exist to minimize the symptoms but there is still no cure.



Monika Benson and Alistair Newton

As we publish our Annual Report and embark on a new year, we look back on the past twelve months and gratefully acknowledge the many successes achieved.

The 5th International Dystonia Symposium and other meetings in Barcelona in 2011 were a tremendous move forward for the world of dystonia in many ways. This was, by far, the largest ever international gathering of Dystonia specialists, who had gathered to learn about the latest research and treatment, and the event had an immediate impact on knowledge and understanding of dystonia.

Dystonia Europe was transformed into the platform at the European level for all dystonia stakeholders including patients and their families, the medical and scientific professions, foundations and the pharmaceutical and medical device industries.

Important steps forward were taken by projects such as COMPASS, intended to develop the structure and funding basis of the organisation, and Dystonia Europe was elected the grantholder of the newly formed Dystonia Europe Research Network. A new Communication strategy has been a major part of our work over the year and will continue in 2013, leading up to the 20th Anniversary of our founding.

We would like to thank all of our member organisations and our partners for a very successful year and we look forward to continued collaboration with you.

It is only by working in partnership in various initiatives to bring developments in research and treatment, and to increase awareness and understanding of dystonia among the public and the medical profession, that we will bring substantial change and stimulate improvements in the lives of people affected by dystonia.

Monika Benson
President

Alistair Newton
Executive Director

Board of Directors

Dystonia Europe is governed by a volunteer Board of Directors.



*Monika Benson, President.
Sweden*

Monika was elected president of EDF, now Dystonia Europe, in 2007. She was re-elected for a second term in 2010. Monika has cervical dystonia and is also a board member of the Swedish Dystonia Association. Monika has been working as a coordinator of work-shops, courses and lectures at a school in Lund, Sweden.



*Maja Relja, Vice President.
Croatia*

Maja is a professor of neurology, in charge of the movement disorders section at Zagreb University Hospital. She founded the Croatian Dystonia Association and has served as its president for over 20 years. In 2011, she was elected to the board of Dystonia Europe, and appointed Vice President in 2012. She also serves on the DE Medical and Scientific Advisory Board and is heavily involved in the COST-funded Dystonia Research Network.



*Marina de Koning-Tijssen,
Board Member. Netherlands*

Marina is a professor in charge of the movement disorders department at Groningen University Hospital and has been committed to supporting the Netherlands dystonia patient organisation for a number of years as a member (and chair) of its Scientific Advisory Board. She was elected to the board of Dystonia Europe in 2011, is a member of our Medical and Scientific Advisory Board and heavily involved in the COST-funded Dystonia Research Network.



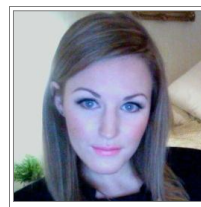
*Sölvi Engeland, Board member,
Web-master & Newsletter. Norway*

Sölvi was elected to the board of EDF, now Dystonia Europe, in 2009 and she was re-elected for a second term in 2012. Sölvi was diagnosed with cervical dystonia and blepharospasm in 1989. Since 2001 she is also a board member of the Norwegian Dystonia Association. Sölvi's professional training is within management, strategy, sales and marketing. Sölvi is responsible for the Dystonia Europe website and the Newsletter.



*Alistair Newton, Executive Director.
Scotland*

After several years as Vice Chair of the Dystonia Society in the UK, Alistair founded European Dystonia Federation, now Dystonia Europe, in 1993. He served 8 years as President and has been our Executive Director since 2001. Alistair also co-founded EFNA – European Federation of Neurological Associations - in 1999, where he acted as Treasurer and Secretary-General until 2011. In 2003, he was involved in the founding of EBC- the European Brain Council, and has been a board member and Treasurer ever since. Alistair has had cervical dystonia for 30 years.



*Amanda Benson, Communication
Advisor, Sweden*

Amanda Benson is a communication and social media consultant with a business degree from Lund University in Sweden. She runs her own business – B|Social Sustainability and Social Media Consulting and advises DE on various communication matters.

Medical & Scientific Advisory Board

The Medical and Scientific Advisory Board (MSAB) is comprised of 12 dystonia specialists, in a number of aspects of dystonia. These experts give scientific support to the DE managing board and participate in various meetings.

Prof Alberto Albanese – Milan
Prof Alfredo Berardelli – Rome
Prof Kailash Bhatia – London
Prof Andreas Ceballos-Baumann – Munich
Prof Rose Goodchild – Leuven
Prof Marina de Koning-Tijssen – Groningen

Prof Joachim Krauss – Hannover
Dr Jean-Pierre Lin – London
Prof Maja Relja – Zagreb
Prof Eduardo Tolosa – Barcelona
Prof Marie Vidailhet – Paris
Prof Tom Warner – London

Board Review

The DE board lost two long-serving directors in 2012 – the first due to the very sad passing of Dr. Anthony G. Butler who had served on the board a total of 9 years. In springtime, our Treasurer Herman de Craecker, had to resign due to health reasons. Our Executive Director, Alistair Newton, was asked to act as supervisory treasurer until a new treasurer can be

found. In addition the Board lost Dr. Göran Bylund who retired at the 2011 General Assembly. Steps are being taken to recruit new Board members, to replace these much-missed colleagues and friends. Three board meetings were held during the year. Two in Brussels - January and May, and one in Bol, Croatia in September.

Communication Resources

Newsletter

The newsletter was issued twice during the year: in winter and in summer. Since there is a new Dystonia Europe profile with different colours and logo, the newsletter has a new look from summer 2012, and the publication is now called Dystonia Europe News.

Website

The new website has been developed by communication advisor Amanda Benson and was launched in the autumn.

Publications

A leaflet about Dystonia Europe has been produced and was distributed at the MDS in Dublin, EFNS in Stockholm and at the COST Training School in Croatia.

Social Media

The Dystonia Europe Facebook page was launched in February and has more than 250 followers.

5th International Dystonia Symposium October 20-22, 2011 in Barcelona



The 5th International Dystonia Symposium, October 2011, in Barcelona

This successful conference was a collaboration between EDF and the Dystonia Coalition, attracting more than 560 participants from 39 countries. They included a mix of researchers, clinicians, medical students and physiotherapists. Several dystonia patient organisations from the US and EDF funded scholarships for young researchers to be able to participate. The scientific programme included 53 speakers with sessions over three days. Over 100 posters were displayed, with details of the latest studies on dystonia. It was the biggest international scientific event solely on dystonia ever to have been held anywhere in the world. Its success is already stimulating even greater interest in dystonia among scientists in many countries and has brought the dystonia community even closer together. All of this can only push forward research on dystonia and the possibilities for faster results in improving treatments and finding a cure.

Annual Conference and General Assembly 2011

The Annual Conference and General Assembly of members was held on Sunday October 23, alongside the 5th International Dystonia Symposium (IDS5) in Barcelona. Around 35

people participated in the meeting and only delegates from Portugal and Denmark were not present. Invited speakers were Professor Buz Jinnah, Professor Alberto Albanese, Dr. David Bradley and Amanda Benson, and delegates had already been able to attend the later sessions of IDS5 to hear the top-class speakers from across the world.

After the Sunday presentations had been made, the formal part of the General Assembly took place. The meeting approved the proposal that membership fees should remain at the present level and be reviewed in 2012. Then the

delegates agreed the Board's proposals for modernising the name and the approach of the Federation.

Dystonia Europe is now the platform at the European level for all dystonia stakeholders and membership is open to all organisations with an interest in dystonia.

Professor Maja Relja representing the Croatian Dystonia Society and Professor Marina de Koning-Tijssen of the Netherlands Society, were unanimously elected to the Managing Board. The Polish Dystonia Society had applied for membership and this was approved by the meeting.

It was announced that the General Assembly of 2012 would be held in Croatia.

COMPASS

In October 2011 Medtronic Foundation gave a grant for this project aiming to develop various partnerships such as with members, sponsors, the medical profession, as well as to strengthen and broaden the communication channels, all in line with the new statutes. The project manager is Monika Benson.

The activities have so far resulted in:

- Stronger links to industry and partners through face-to-face meetings and joint activities.
- Visits to several member groups to establish closer contact within DE and to identify possible

new board members. Meetings took place in Switzerland, France, Germany, Italy and Ireland.

- The establishment of contacts for development of new national patient groups in Czech Republic, Russia, Romania, Hungary, Estonia and Latvia. Participation at a dystonia patient meeting in Lithuania in August of 2012.
- The launch of Dystonia Europe on social media.
- Involvement in the COST funded research project The European Network for the Study of Dystonia Syndromes.

So far the project has developed according to the plan and funding has been secured for the project to continue.

International Cervical Dystonia Patient Survey

The survey was developed in collaboration with DMRF and supported by Ipsen Pharma, with a launch on-line in mid April. By September about 900 dystonia patients from more than 25 countries had answered the survey giving their expectations on treatment and relationship with their neurologist. Due to the very high response rate for such a project it was decided to keep the survey on-line until end of 2012.

The first results were presented by Executive Director Alistair Newton to an audience of around 700 movement disorder specialists at the 17th MDS congress in Dublin in June. Early results show that there is still a need to inform clinicians more effectively about the needs of dystonia patients and how this can be improved. Further discussions will be held to discover how this gap in knowledge can be addressed and how to improve the situation in the future.

The final results will be shared with the countries which have been involved and the results will be published in appropriate journals in 2013.

The David Marsden Award

The award of 2011 was generously sponsored by Ipsen Pharma and won by Dr. David Bradley of St Vincent's University Hospital in Dublin, Ireland. The presentation of the award was made by EDF President Monika Benson during the 5th International Dystonia Symposium in Barcelona at which Dr. Bradley also presented his paper: "Temporal discrimination threshold as an endophenotype in adult onset primary torsion dystonia."

The European Network for the Study of Dystonia Syndromes

Dystonia Europe was elected Grantholder of this COST-funded four-year-project. President Monika Benson is a member of the Managing Committee. The project is aimed to promote networking among dystonia experts around Europe, and to raise awareness of dystonia among the public. Nineteen countries are so far part of the project and the eight members of the steering committee lead the work of the four working groups: genetics, animal models, clinical, e-infrastructure. The responsibilities of Dystonia Europe, as the Grantholder, cover activities such as organisation of meetings and all aspects of the finances of the project.

In February 2012, the President and the Executive Director participated in a one-day work-shop at the COST office in Brussels. The Management Committee has held two meetings: one in November 2011 for the launch of the project and one in June in Dublin. Working group 3, clinical studies, held a meeting in Brussels in May. In June all working groups met in Dublin alongside the Movement Disorder Society (MDS) annual congress.

A training school was held in September in Bol, Croatia. 34 participants received grants. Six exchange grants to allow young specialists to study in other countries will be announced during the autumn of 2012. An action web-site is being developed.

Participation at meetings & congresses

Medical meetings

Throughout the year President Monika Benson and Executive Director Alistair Newton have participated at various medical meetings arranged by the industry (Medtronic, Ipsen, Allergan) to present the work of Dystonia Europe.

Congresses

International Symposium on Dystonia and Dystonic Syndromes at the Palacky Univeristy in Olomouc in December 2011. This 2-day conference allowed for meetings and discussions with dystonia experts from the main university hospitals of Czech Republic and how to proceed with the formation of a dystonia patient group.

The 17th Movement Disorder Society Congress in June in Dublin. Dystonia Europe provided information from a stand in the exhibition hall. The Executive Director presented the first results of the International Cervical Dystonia Patient Survey at the Ipsen symposium. Participation at meetings alongside the congress included Alistair Newton giving a presentation at an Allergan meeting and Monika Benson presenting Dystonia Europe at the Dystonia Ireland conference.

EFNS congress in Stockholm

September 8-12 in Stockholm. Dystonia Europe was present in the exhibition hall. There was also information about the congress on rehabilitation and treatment in Hannover. The Good Life session organised by EFNA on the Sunday afternoon highlighted Musicians' dystonia and was hosted by Professor Eckart Altenmüller together with some musicians.

European partnerships

EFNA

European Federation of Neurological Associations (EFNA) now has a new President, Audrey Craven of the European Headache Alliance. DE no longer has representation on the EFNA Board, but participates in various activities.

EBC

Among the lobbying and other activities of the European Brain Council (EBC) the main effort currently is to make 2014 the Year of the Brain. This will be an important milestone in the work to help people living with brain illness in Europe. Confirmation of the main activities planned will be available in the early months of 2013.



Participants of The European Network for the Study of Dystonia Syndromes gathered before the MDS congress in Dublin for their first meetings.

The work and activities for 2012 and 2013 will involve the following:

The European Network for the Study of Dystonia Syndromes

The responsibility for DE continues, as Grant holder of the Action, and the network scientists, with the DE Board, are actively examining the basis on which the Network might come under DE's 'umbrella'. Successful meetings of the Network Workgroups were held during the MDS congress in June, and proposals are already in hand for collaborative research projects. A Training School was held in Croatia for younger dystonia specialists, with more than 30 grants to individuals to allow them to attend. This will be an annual feature of the Network, along with the award of slightly larger grants to allow young scientists to spend periods in the labs of other dystonia specialist groups in other countries.

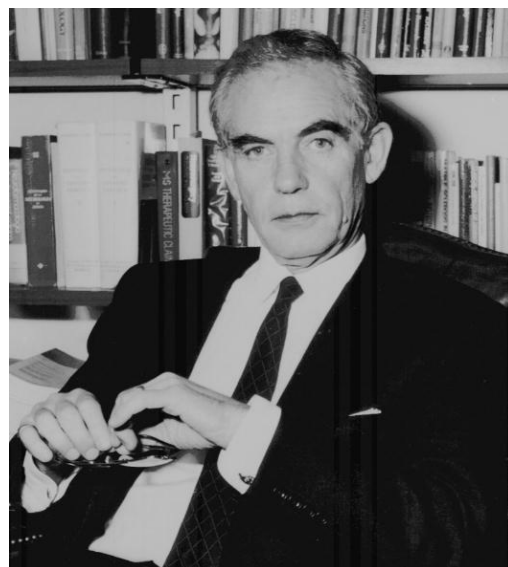


"Dystonia Stories" – is an awareness campaign generously sponsored by Merz Pharma, that will run all through 2013, the year of the 20th anniversary of Dystonia Europe. The meetings in Croatia were documented on photo and on film. Participants at the meetings, such as patient leaders from all over Europe, medical experts, students and representatives from the pharma and medical device industries were interviewed about their relationships with dystonia. The campaign will run on the Dystonia Europe website, through the different social media channels and in the DE newsletter starting beginning of 2013. Member organisations can also use the materials for their national activities.

The David Marsden Award 2013

The award will be increased to € 10 000 from 2013, and will once again be supported by Ipsen. The award is intended to encourage research into dystonia in all European countries, especially by young scientists under the age of 40.

The award will be presented at the Dystonia Europe annual meeting in Edinburgh, Scotland.



Professor David Marsden

20th Anniversary of the organisation will be celebrated at the next annual meeting that will take place in September 2013 in Edinburgh, Scotland.

COMPASS

New funding has been sought and approved for the project to be continued into 2013. The project involves: identifying new funding resources, new board members and help developing dystonia patient groups in other countries. Patient meetings are being planned in Moscow, Russia, in Bucharest, Romania and in Prague, Czech Republic.

EUROPEAN DYSTONIA FEDERATION aisbl**Annual Accounts for the period 1 January to 31 December 2011****Income and Expenditure Account**

INCOME	€
Membership fees	1,500.00
Core grants	23,000.00
Sponsorship - 5th International Dystonia Symposium	180,269.81
Other Income	4,905.80
Total Income for year to 31 December 2011	209,675.61
EXPENDITURE	
Core Costs (Office, board meetings, staff, travel, etc)	40,578.14
Project costs	138,308.72
Total Expenditure for year to 31 December 2011	178,886.86
RESULT OF THE YEAR	30,788.75

Balance Sheet

Cash at bank and in hand	131,071.31
Result of previous years	100,282.56
Result of the year 2011	30,788.75

Accounts audited by MATS s.a., Chartered Accountants and Tax Advisors, Waterloo, Belgium

Members

11

Dystonia Europe consists of 18 national Dystonia organisations from 16 European countries and they are:

AUSTRIA, BELGIUM, CROATIA, DENMARK, FRANCE, GERMANY, IRELAND, ITALY, NETHERLANDS, NORWAY, POLAND, PORTUGAL, SPAIN, SWEDEN, SWITZERLAND, UNITED KINGDOM

Partners & Supporters

In order to continue its operations, Dystonia Europe relies on partnership with external organisations. However, to ensure our independence, we do not accept donations that are dependent on policies set by others. The DE Board is careful to ensure that any funds received do not influence our organisation's ethical position or credibility.

Dystonia Europe would like to thank all its partners, sponsors and supporters for their continued interest and partnership. We look forward to working closely with them all in the future.

They are: DMRF – Dystonia Medical Research Foundation, FDR – Foundation for Dystonia Research, Dystonia Coalition, EFNA – European Federation of Neurological Associations, EFNS – European Federation of Neurological Societies, EBC – European Brain Council, MDS – Movement Disorder Society, Medtronic Foundation, Allergan, Ipsen Pharma, Medtronic, Merz.

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