

# DYSTONIA

# NEWS

SPRING | 1 - 2023



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DYSTONIA  
EUROPE

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Dear readers,

Spring is here, the summer holidays are coming soon, our team is in full preparation for the Dystonia Days which will be held on June 2nd and 3rd in Dublin in collaboration and with the support of Dystonia Ireland. We will be happy to meet the representatives of the national member associations again, to learn from each other and from the scientific interventions and to have face-to-face exchanges.

We hope that many of our members will be present.

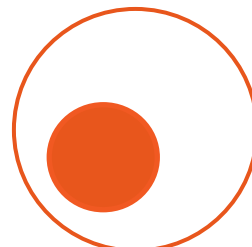
This meeting will be an opportunity to celebrate the 30 years of Dystonia Europe and to remember the evolution of our great association, the progress and the achievements. Also, to recognize those who have served us.

You will read in this edition that it was also the 30<sup>th</sup> anniversary of the Norwegian association, Norsk Dystoniforening. We wish them all the success in the future!

Our members and team have taken up their activities, which are starting up intensively in Europe with the return of face-to-face meetings.

Now enjoy reading our newsletter with articles on research, information and Jan's testimony on DBS, the current news is important.

Now wishing you all a lovely summer and take care of yourself!



**Edwige Ponseel**  
President  
Dystonia Europe

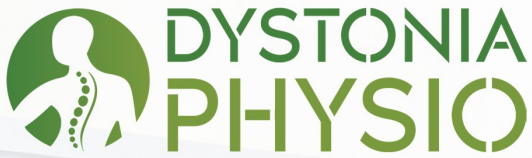
# DIET AND DYSTONIA

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## 30 Years of Dystonia Europe

This year Dystonia Europe is celebrating its 30<sup>th</sup> Anniversary.

Our organisation was formed as an association of national dystonia patient groups in Spoleto, Italy, on 18 June, 1993. The name was European Dystonia Federation (EDF). This process had taken almost a year, with the first contacts at a workshop in Munich, followed by two preparatory meetings in Barcelona and Paris. The 10 founding members were: Germany, the UK, Spain, Sweden, Norway, France, Italy, Croatia, the Netherlands and Denmark.

Today we are 23 member organisations from 20 countries in Europe. On the weekend of 2-3 June we will meet in Dublin to celebrate the 30 years of our organization. We are looking forward to a very special weekend in Dublin.

Unfortunately one of our founders Alistair Newton cannot join us in Dublin but he has sent the below message. We thank Alistair for all that he has done throughout the years for not only dystonia patients but also for the European neurological patient community.



**Back row:** Didi Jackson, Germany; Alistair Newton, UK; Feli Justo Alonso, Spain; Alan Leng, UK; Gunilla Noren, Sweden.  
**Front row:** Tore Wirgenes, Norway; Jean-Marc Bildan, France; Laura Latini, Italy; Maja Relja, Croatia; Beppy Smitshoek, Netherlands.  
**Absent:** Kai Naunung, Denmark

**Photo right:** Our founding President, Alistair Newton received the honour of becoming a Member of the Ancient Order of the British Empire (MBE) for services to dystonia and other neurology patients across Europe. The Award was presented in February 2019 at a ceremony in Buckingham Palace, London, by Prince William, Duke of Cambridge.

## Greetings from The Founder President

Dear Friends,

I send my very best wishes to you all as you celebrate Dystonia Europe's thirtieth anniversary! Many, many congratulations and thanks to the large number of people who have contributed so much to the successes of our organisation over those thirty years.

This must include not only our DE Board members, staff, advisers, and their families and friends who support them. We must also thank the many members of the medical profession and the pharmaceutical and medical device industries who all have given so much help over such a long time.

In January 1993, when we brought together delegates from the few national dystonia patient groups which existed at that time, we had no idea how the world of dystonia would be thirty years later! Then, we were dealing with an illness which had still to be properly defined by scientists, diagnosis was very difficult to find, and the first effective treatment had only very recently become available. Today, there is still a long way to go in all these aspects, but the position is immeasurably better than it was. We have much greater understanding of the condition and a much stronger working relationship with the medical professionals and other stakeholders.

After so many years of close involvement with EDF and DE, first as President and then Executive Director, I have retained a close interest over the past decade since I retired, and I look forward to reading about the successes which still lie ahead in the next ten years and beyond.

**MBE Alistair Newton**





30<sup>TH</sup> ANNUAL DYSTONIA EUROPE CONFERENCE

**D-DAYs 2023**

DUBLIN, IRELAND

Saturday 3<sup>rd</sup> June 2023



**DYSTONIA**  
EUROPE



Organized in parallel with the 6<sup>th</sup> International Dystonia Symposium



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## Prof Dr Dirk Dressler Introduces New Botulinumtoxin in India

India, too, is now producing its own botulinumtoxin drug. It was recently introduced in the presence of Professor Dr Dirk Dressler in Mumbai. 'We are glad that now also India belongs to the exclusive club of countries producing botulinum toxin drugs', said Dressler. The product development and the installation of the manufacturing process was supervised by Dr Balram Singh, an eminent botulinumtoxin researcher who had been working with botulinum toxins in the United States for decades.

'With Dr Singh the project is backed up by one of the worldwide most experienced botulinum toxin researchers with whom we had been working for years,' Dressler explained. A special feature of this drug is its extremely broad indication spectrum.

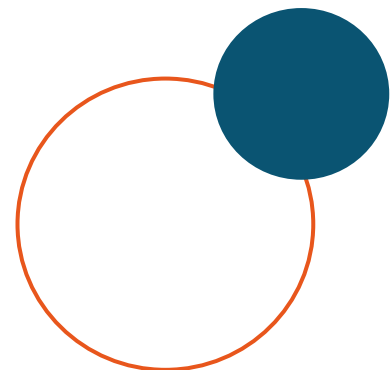
Dressler explained: 'This will change botulinum toxin therapy in India forever. This is a milestone in our goal to bring botulinum toxin therapy to all patients in need, regardless where they live.'

The new Indian botulinumtoxin drug, marketed under the trade name of Zarbot®, is manufactured by Gufic Biosciences Ltd. of Mumbai. Gufic is a family-owned pharmaceutical company, which was founded two generations ago in Gujarat in North West India and is now specialised in producing lyophilized drugs.



first from right: Prof Dr Dirk Dressler

third from right: Dr Balram Singh



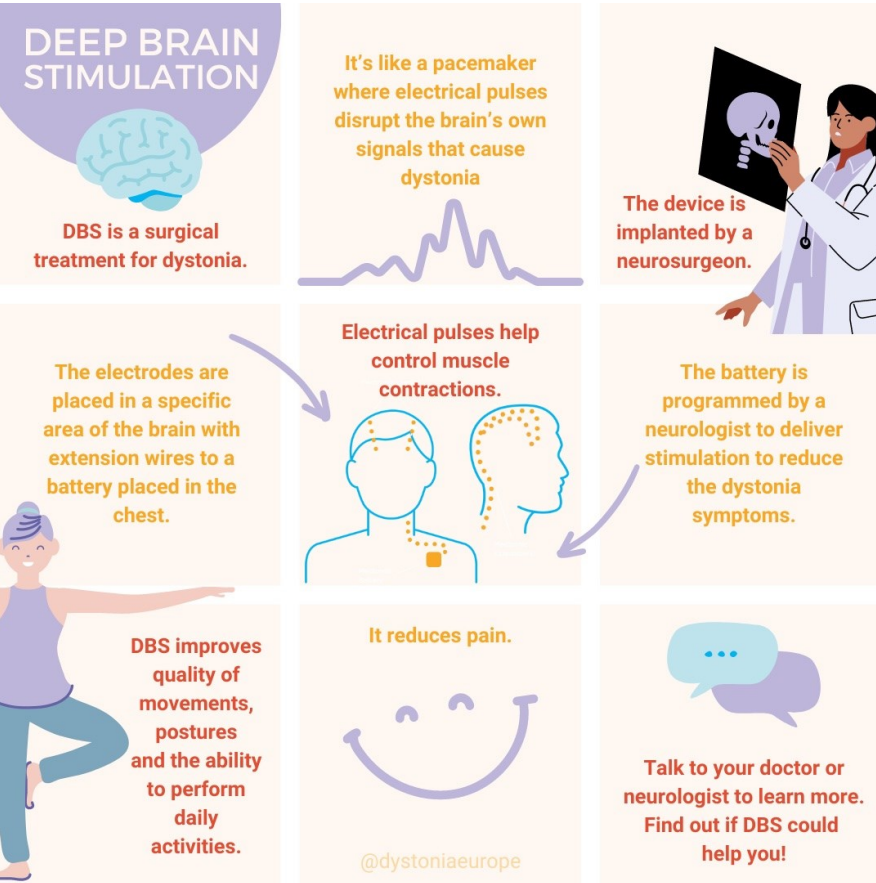


## Dystonia Infographics

One of the main activities for Dystonia Europe is to spread information and raise awareness of Dystonia.

Therefore we have decided to develop a series of infographics describing dystonia treatments and various types of dystonias in an easily accessible way.

We hope you like them and we appreciate your help with sharing these.



## Dystonia Webinars

On several occasions we have asked you, our followers, what you want to see and hear from Dystonia Europe. And the list is long. Many of you wish to hear from other dystonia patients and how they manage their dystonia. You also want to have information on treatments and research. We have therefore decided to start organizing webinars again on various topics and with the possibility to ask questions.

The first one will take place on 19 June and there will be the opportunity to listen to a neurologist describing what DBS is, an expert on the research and what's coming next in the field of Deep Brain Stimulation treatment, and last but not the least a dystonia patient, whose life was completely changed after the DBS therapy.

If you have ideas for future webinars let us know and drop us a note on [sec@dystonia-europe.org](mailto:sec@dystonia-europe.org)

## Patient Live Webinar on DBS

19 June, 2023  
18:00 - 19:15 CET  
on Zoom



### 1st Talk

DBS, benefits for dystonia patients, who is it for?

Prof Laura Cif



### 2nd Talk

Latest technologies in DBS  
Thomas Brionne, Medtronic



### 3rd Talk

The Patient Experience with DBS

Jan Bodenbach

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**Monika Benson**  
Executive Director  
Dystonia Europe

## Winter Think Tank 2023

Dystonia Europe Winter Think Tank 2023 was held in Brussels on 1<sup>st</sup> March. Members of the Think Tank are our Platinum sponsors: Ipsen, Merz and Medtronic and all DE board members and staff. At this meeting Medtronic was unable to attend.

Our President Edwige Ponseel attended via zoom and welcomed all to the Think Tank meeting and then everyone introduced themselves. Executive Director Monika Benson gave an update on the activities that DE is involved in. The activities on social media are increasing steadily as are our followers.

We discussed some of our projects which were well received by our sponsors and they gave us some great input and ideas.

We also worked in groups and did brainstorming on some projects. Again our sponsors were a huge help with one sponsor in each working group, we came up with some really good ideas on how to raise awareness, empower health care professionals and empower patients. These ideas will be discussed fully at a later date.

Finally we presented the Dystonia Awareness Videos to the Think Tank participants who were all moved by these short video clips that give a realistic and emotional insight into how it is to live with different types of dystonia. Each year Dystonia Europe is involved in Dystonia Awareness Month (DAM) in September and this year we plan to use these video clips that will soon be finalized. We are already looking forward to our next TT in October using zoom.



**From left:** Monika Benson, Merete Avery, Jukka Sillanpää, Catalina Crainic, Sissel Buskerud, Susanne Proeschel - Ipsen, Gill Ainsley, Oleks Gorbenko - Ipsen and Abdullah Alghourani - Merz

## Board Meeting Update

Dystonia Europe had an online board meeting using zoom on the 20<sup>th</sup> January and another (also on zoom) on the 19<sup>th</sup> April.

On the 28<sup>th</sup> February we had a board meeting face-to-face in Brussels. Some topics on the agenda were the Video Awareness Project and the upcoming Dystonia Days and Annual General Assembly on the 2<sup>nd</sup> and 3<sup>rd</sup> June, which will be held in Dublin, Ireland alongside the 6<sup>th</sup> Samuel Belzberg International Dystonia Symposium 1<sup>st</sup> – 3<sup>rd</sup> June.

Other information and discussions were on topics such as Dystonia & Diet Survey, Cervical Dystonia Patient Journey, the Positive Twist Podcast, the Dystonia Physio Exercise Hub, the David Marsden Award, which is now given yearly to promote research, and more. The winner of the David Marsden Award will be announced this summer and we will have an article on this in our next newsletter.

As well as having a very full and productive meeting it was lovely to see each other face-to-face again.

**Merete Avery**

Operations Manager  
Dystonia Europe



**Back row from left:**

Jukka Sillanpää, Merete Avery, Eelco Uytterhoeven, Catalina Crainic.

**Front from left:**

Sissel Buskerud and Monika Benson



# Dystonia Awareness

## Dystonia Awareness Videos

Last year late President Adam Kalinowski was leading the project of developing five dystonia awareness videos together with producer Andrew Keogh from Ireland. These videos are now being finalized.

The very first showing of them will take place at the Dystonia Day in Dublin on Saturday 3 June.

They are also being translated to several European languages to be ready for the big launch during Dystonia Awareness Month 2023. We hope you will like these videos and help to share them in your networks and communities that you belong to.

We will use the hashtag **#dystonialife** for the videos since they are showing everyday life activities and how dystonia patients experience them.



## The Positive Twist Podcast

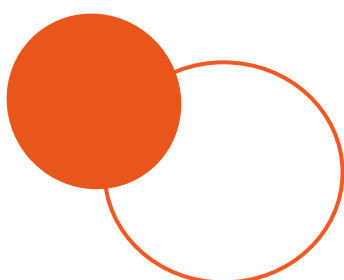
Season two of our successful podcast The Positive Twist will be launched end of June. We have 5 new episodes to be published at the end of each month until October. We have met with both dystonia patients, board members of Dystonia Europe and medical experts in this season. You will find the podcast on Spotify or on our website <https://dystonia-europe.org/media/podcast/>

Here you also find all episodes of the first season. We are really interested in hearing your feedback on which guests you would like to hear from in our third season that we have started to plan.

Write us on [sec@dystonia-europe.org](mailto:sec@dystonia-europe.org) or connect with us on social media.



**Monika Benson**  
Executive Director  
Dystonia Europe



# EPF Annual General Assembly and 20th Anniversary

## EPF 20<sup>th</sup> Anniversary

Marco Greco, President of European Patient Forum (EPF) opened the meeting 28<sup>th</sup> April 10.30 am. in Brussels. Dystonia Europe is a full member of EPF and was present at the meeting. Looking back the organisation has grown tremendously during the 20 years since it was founded in 2003. Reflections were made on advocacy in the past and in the future. EPF covers the gap between EPF members and the EU Institutions. A patient organisation that was not disease specific was needed. The voices of the patients must be present before decisions related to health care are made at EU level and EPF represents the patient voice on EU level.

In the evening the 20th anniversary celebration was marked by dinner and music. The meeting and dinner were very positive and there was a lot of networking between the patient organisations.

## EPF's Annual General Meeting 2023

On the 29 April 2023 representatives from EPF member organisations from across Europe gathered for the Annual General Meeting. During the event, EPF's board members, together with the Secretariat, reported on 2022 activities and gave an overview on the current and upcoming work plan for 2023.



### Networking with other organisations

#### From left:

Merete Avery, Dystonia Europe

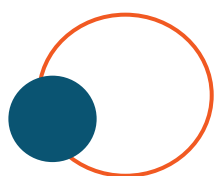
Katerina Koutsogianni-Tzigounak, The Greek Umbrella Patient Organisation

Sanna Kaijanen, The Finnish Federation of Hard of Hearing

The AGM plays a crucial role in the democratic and governance process of the organisation and is a good opportunity for members to have an overview on EPF's activities.

### Reporting and upcoming activities

The Annual Report reviewed EPF's collective accomplishments, showcased focus areas for 2022 in terms of policy and advocacy, presented the ongoing projects' highlights, featured communication milestones, and outlined the main activities carried out in the capacity building and membership areas. The annual report and the financial report were approved during the meeting by the members' unanimous vote.





Later, the members were presented with EPF's work plan for 2023, including the policy areas that EPF will cover this year, ongoing involvement in projects, the foreseen capacity building activities, and expected communications outcomes and deliverables. The work plan received a unanimous favourable vote from members, together with the 2023 Budget.

The EPF Youth Group contributed to the annual overview by presenting their achievements for 2022 and upcoming events and activities for 2023.



### New EPF Members

This year, EPF welcomed the Latvian Network of Patient Organizations and [Sjögren Europe](#) as Associate Members. The [National Association of Patients' Organizations](#) (NAPO), after joining last year as an associate member, has now become a full member, after meeting all the requirements and receiving a positive vote from the EPF membership.

### The EU Pharmaceutical Reform

To conclude the event, Julie Spony, EPF Policy Officer, delivered a much-anticipated overview of EPF's position on the recently published revision of the pharmaceutical legislation. The presentation walked the audience through the legislation's relevance to the patient community, while highlighting EPF's key recommendations.

You can read more about EPF and their work here <https://www.eu-patient.eu/>

**Merete Avery**  
Operations Manager  
Dystonia Europe



## Thank You Joke, Welcome Astri

At the beginning of May EFNA held its 22<sup>nd</sup> Annual General Assembly in Amsterdam, The Netherlands. Representatives from several neurological umbrella organizations such as Parkinson's Europe, Pain Alliance Europe, Ataxia Europe, Restless Legs Europe etc attended the meeting.

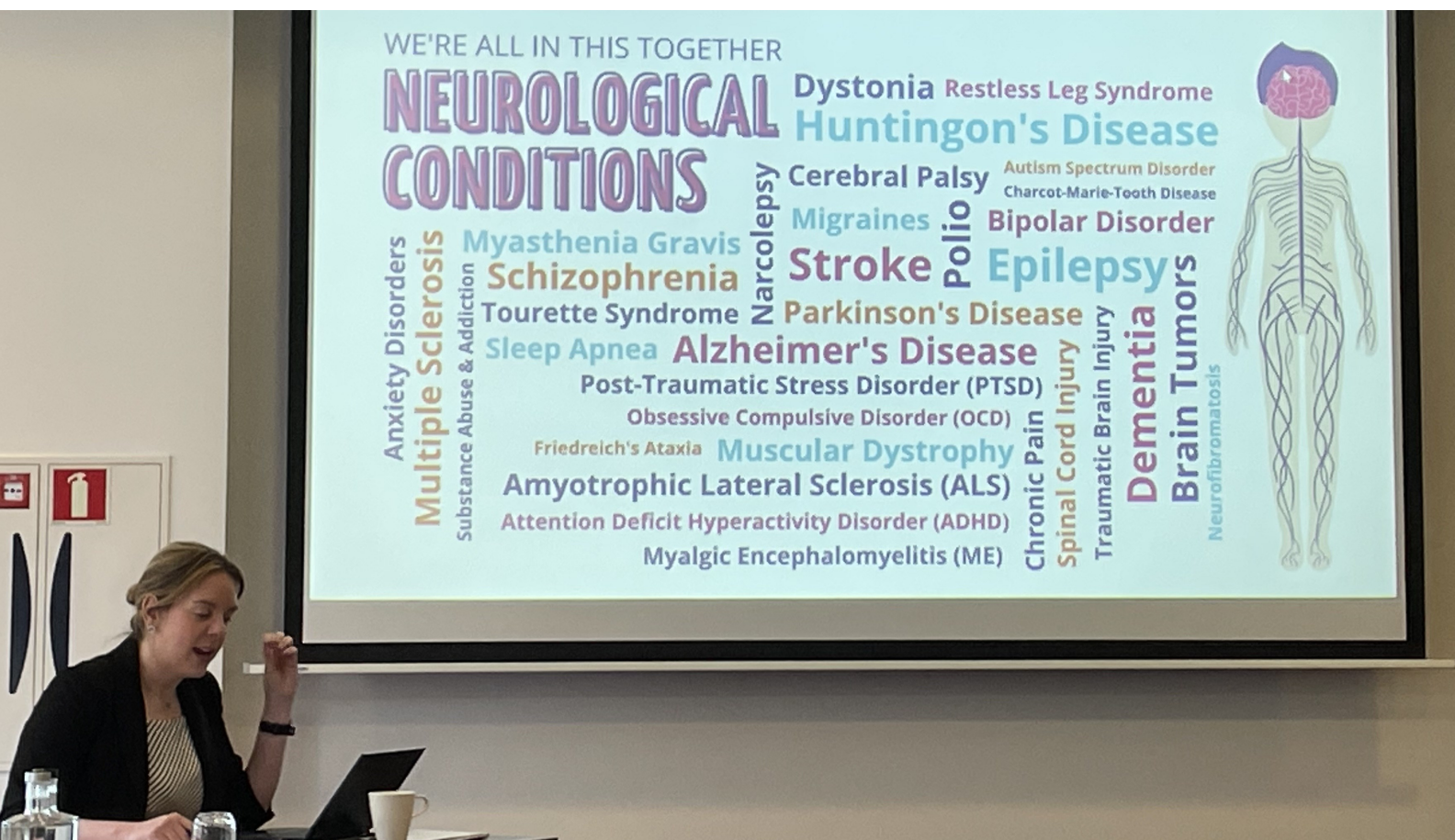
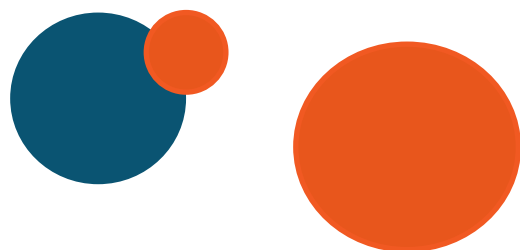
There were roundtable discussions on the IGAP\* initiative and how to implement this across Europe. The formal meeting followed after lunch with presentations of the Annual Report of 2022 as well as the final accounts, which were all approved.

EFNA was formed in 2001 to unite neurological umbrella organisations and to work together on the European level on shared interests such as awareness, advocacy and empowerment.

For the last 6 years EFNA was led by President Joke Jaarsma from the Netherlands and now it is time for her to step down. Joke is herself a neurological patient since she is suffering from restless legs syndrome. She has been active in both Restless Legs Europe and the national restless legs association in the Netherlands. She also served as the Treasurer in the European Brain Council for many years.

We thank Joke for her dedication and hard work for neurological patients across Europe.

*\* Neurological disorders are a significant public health challenge and addressing them has become a global priority with the adoption of the Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders 2022–2031 (IGAP) in 2022. The European Federation of Neurological Associations (EFNA) recognizes the critical importance of implementing the IGAP and calls attention to two specific IGAP targets that are essential prerequisites for the successful rollout of the plan.*  
<https://www.efna.net/wp-content/uploads/2023/03/EFNA-POSITION-PAPER-ON-IGAP-TARGETS.pdf>







**Monika and Joke**

Now we welcome Astri Arnesen as the new EFNA President. Astri represents Huntington's disease and she is also the President and the Executive Director of Huntington's Europe.

At the meeting in Amsterdam it was also the occasion for Dystonia Europe Executive Director Monika Benson to step down from the EFNA board after serving the maximum period of years.



**Joke and Astri**

**Monika Benson**  
Executive Director  
Dystonia Europe





# The Norwegian Dystonia Association Annual General Assembly and 30th Anniversary



In a meeting room, decorated for the Anniversary, the President Johan Arnfinn Warvik of the Norwegian Dystonia Association (NDF), welcomed about 60 members attending the Annual General meeting and 30<sup>th</sup> Anniversary Celebration at Quality Hotel Olavsgaard, Skjetten, Norway.

Many attended which indicates that the organisation is very active and important for many. In addition Johan Arnfinn was happy to announce that the association has an increasing number of members.

The local activities are also increasing, which is according to the goals of the association. To achieve this the board has among other things a strategic plan to hold board meetings alongside local meetings which has shown to be successful.

The association now has 640 members and for many of them the Newsletter 'Dystoni-nytt' which is published twice a year, is the most important channel for information. Due to this the board have worked on renewing the newsletter and Johan says they are very happy with the result.

Johan also said that in future the association will address more rare types of dystonia, as in recent years the focus has been on cervical dystonia. As a part of this NDF will arrange a conference for Spasmodic dysphonia, also known as laryngeal dystonia, at Olavsgaard 6th and 7th September this year.

Physiotherapist Johanna Blom gave the main presentation at this meeting. She presented the tool she has developed with the support of Dystonia Europe and Eelco Uytterhoeven, a digital platform with exercises for cervical dystonia. This platform is free to use for physiotherapists. They can create personal training programs for their patients. Today the platform consists of 115 exercises. The presentation was very well received by all participants. Many used the opportunity to ask questions and Johanna answered them all..

**Photo top right:** Registration, Vigdis Viken, John Berget, Aud Engen and Teija Pekonen

**Below:** Johanna Blom explains The Physio Therapy Exercise Hub





## AROUND EUROPE AND BEYOND | NORWAY

*– A fantastic presentation — some of the best I have heard at dystonia meetings. The way Johanna gave this lecture, it is clear that she has a genuine interest in helping dystonia patients. Quoted after the presentation by Siv Berit Sjøen.*

The second speaker was Aud Engen, who has the more rare diagnosis blepharospasm in addition to oromandibular dystonia which in combination is called Meige syndrome.. Aud has symptoms and is affected by the condition, but botulinum toxin injections do help..



Aud Engen receives a gift after sharing her patient story.  
From left: Johan Arnfinn Warvik, Sissel Buskerud and Aud Engen

After the presentations the Annual General Assembly was held with presenting and approval of the annual report 2022 and finances 2022. NDF has good finances, and both were approved unanimously.

Johan was re-elected as President – with applause. He had planned to step down after serving as President for 6 years, but said he was willing to do two more years as there were no other candidates.



Pia Vejle, Denmark and Anita and Steinar, members of NDF



Scandinavian friends of Norwegian Dystonia Association  
From Left: Bengt-Erik Calles, Sweden, Pia Vejle, Denmark, Ulf Borg, Sweden, Jukka Sillanpää, Finland and Johan Arnfinn Warvik, NDF.

During the Anniversary dinner, we enjoyed a buffet of cold and warm food served by the clever chefs at Quality Hotel Olavsgaard. Gifts were presented along with kind words to the board from Merete Avery, Dystonia Europe and the invited guests from our neighbouring countries; Bengt-Erik Calles, Swedish Dystonia Association, Jukka Sillanpää, Finnish Dystonia Association and Pia Vejle, Danish Dystonia Association.

All spoke well of the work done in Norway and thanked everyone for their good cooperation.

It was a very positive meeting. Rolf Villanger made it even more successful with a word puzzle that he had made for us to solve in groups.

**Vidar Bjørkli**

Norwegian Dystonia Association  
Translated from Norwegian to English  
Merete Avery



Rolf Villanger, Norwegian Dystonia Association



## Training for Physiotherapists in Sweden



Johanna Blom

During the last week of March the second part of the workshop “Physiotherapy and Cervical Dystonia” took place at the Scandic Plaza Hotel in Umeå, Sweden. The first part of this training took place last October.

Together with Göran Olsson from Swedish Dystonia Education, Physiotherapist Johanna Blom welcomed the participants to Umeå.

Johanna started the day with a short summary of cervical dystonia – symptoms and characteristics. Focus for the first day was on medical history and examination of the patient. When meeting a cervical dystonia patient for the first time it is important to ask thoroughly about the dystonia. What does the patient feel? When did the dystonia start? Is there dystonia in the family? What makes it worse or better? How is the dystonia in different positions? The 13 participants had been divided into 5 groups at the first meeting. Each group was given the assignment to work with a dystonia

this work to the group with video recordings and analyses. Each group had done an excellent job with their patient and his/her dystonia.

At the end of the day Monika presented her own ‘Living with dystonia story’ sharing how the first strange symptoms appeared about 20 years ago and how she is managing her dystonia today.

On the second day Dr. Ghada Loutfi from Umeå University Hospital delivered a presentation on Dystonia and Brain Plasticity. Neuroplasticity is the brain's ability to change and adapt due to experience. It is an umbrella term referring to the brain's ability to change, reorganise, or grow neural networks. This can involve functional changes due to brain damage or structural changes due to learning.

Then followed presentations from all groups again with the focus on how to treat cervical dystonia patients. The groups showed videos of their patients and how different exercises can show a positive result.

At the end of the day the participants each received a diploma. There was much positive feedback and one participant said: “very good course which is immediately clinically useful.”

We thank Desitin and Ipsen for their support and making it possible to realise this important workshop and of course Physiotherapist Johanna Blom for sharing her skills and expertise.

**Monika Benson**  
Executive Director  
Dystonia Europe





## Updates and News in the Children's Joy Association - Romania

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Update of the new activities that are taking place at the level of Association Children's Joy in Romania.

Under the umbrella of MC Gym Motion, together with our partner Iguana Fight Team and Children's Joy Association, we obtained a grant of €100,000 non-reimbursable, from European funds, for a period of at least 3 years which will allow us to move the headquarters to a new location with better conditions and specially designed for sports activities, kinetotherapy and psychology, fitness, wellness, contact sports for the general public and special activities for people with dystonia or other neurological diseases.

“Through the MC Gym Motion project, we want to encourage sports performances and to promote physical and emotional health. We choose inclusion, equality and equity in society” said Catalina Crainic.

Also in the same place Catalina Crainic, President of Association Children's Joy, will carry out her post graduate studies in psychology under supervision (within the psychology cabinet with a certificate of free practice for clinical psychology and psychotherapies) for one year until passing the degree of autonomous psychologist.

Through this project we want to contribute to the rehabilitation of people with dystonia using sports and physical therapies but also contributing to their integration and removing stigma with the help of therapeutic methods specific to psychological programs. Resulting in the improvement of both the physical and emotional state of the participants.

The psychology activities that will target the members of the association will remain on the basis of volunteering. Moreover, in another work place near MC Gym Motion, group activities for both adults and children will take place. These programs are established one day of the week free of charge for people with dystonia or other neurological diseases but also other vulnerable target groups who are interested in participating.

Services included in the basic activities will be:

- support groups
- rehabilitation groups through physiotherapy
- sports programs developed for neurological diseases<sup>txt</sup>
- arts programs
- virtual therapy.

In addition to the activities being open to the general public they will also benefit the dystonia community.



**Catalina Crainic**  
Board Member  
Dystonia Europe

### Jan Bodenbach

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Jan Bodenbach

It was a cold Friday night when my body began to take away everything that was important to me. Friends, sports and school, in short, everything that was important to me as a teenager.

I thought I had twisted my back while playing tennis and that the back pain was due to that. But when the orthopaedist couldn't find a solution and I went from being a normal 15 year old boy to being a patient in a wheelchair within 5 days, I knew I had a long road ahead of me.

At that time, in the spring of 2012, I didn't realise how complicated the diagnosis would become.

What puzzled all the experts and doctors was the fact that I developed such symptoms over a few days/weeks. My entire left side was affected rapidly. Back muscles, hands, legs and feet, everything was cramping and contorting me into positions that the human body was not designed for.

I had to forget about school. At first I tried to read textbooks lying on my bed. But eventually the medication affected me so much that my concentration decreased significantly. I couldn't remember anything anymore! The desired high school diploma was out of reach.

What remained was the desperate search for the cause. After 3 months in the clinic and many desperate attempts with Levodopa and Artane to control the symptoms, we were just as clueless as before. No one was willing to make a diagnosis, and no one wanted to commit.

On June 25, 2012, one day after my birthday, I had an appointment with Prof. Dr. Volkmann, who was not only our last hope but also an expert in movement disorders. After a 5-minute visit, he knew: This is dystonia, and the only thing that can help is deep brain stimulation. Of course, we did further tests and final diagnostics. We also did a genetic test, but the result was not decisive for the treatment.

After a week at the University Hospital in Würzburg, it was clear: we were going to implant a brain pacemaker due to generalised dystonia on August 8, 2012.

The 12-hour surgery went without major complications although it was, of course, a great strain on me. At that time, I weighed only 43 kg and was marked by months of living in this crooked position. Everything was exhausting and only possible with the help of my parents.

On August 14 2012 exactly 6 days after the procedure, I walked upright and without a wheelchair for the first time across the clinic floor and into the arms of my parents.

An incredible feeling that should give me the momentum for everything that was to come next.

In addition to the fact that generalised dystonia was confirmed by the genetic test, the stimulation effect was quickly observed, and we had to find and stabilise my dystonia in the long term.



But what was to come was almost a small miracle. For me, my family, my friends, and in a way, even for the doctors.

Meanwhile, I decided to end my school career and look for an apprenticeship and my 'dream job'.

I started an apprenticeship as an event manager, moved from Rhineland-Palatinate to Lohne-Dinklage in Lower Saxony. My professional passion is motorsports, and I travelled to world championship races or the famous 24 Hours of Le Mans with Porsche and BMW.

Hope gave me strength through all the setbacks, but above all, it was cycling which I loved since childhood. After the pacemaker was implanted, I needed to focus on improving my fitness, balance, and orientation. There is no free evening that I do not spend on my racing bike. Cycling is my outlet. When I'm stressed, I hop on my racing bike and just ride.

In 2022, I had a big goal: to participate in the Hamburg Cyclastics (100 km cycling race through the metropolis in northern Germany) as a 100% treated dystonia patient and become the first to officially achieve this feat.

In the end, the result exceeded my expectations. With an average speed of more than 37 km/h, I not only successfully completed the Cyclastics, but I also achieved my personal best in the world record attempt.

And what am I doing today, at this moment? I have changed jobs and now work in marketing at the German air rescue organisation "DRF Luftrettung" while preparing for the next cycling challenges. I enjoy spending time with my dog Luna and try to cherish every day as a gift!

I want to show others that although diseases and therapies can be difficult to manage, we can still accomplish things that may seem impossible to us, and everyone can. As long as we have dreams, it's worth fighting for them!

**Jan Bodenbach**

Jan Bodenbach before the DBS surgery



Jan Bodenbach after the DBS surgery





Claudia Schmid

## Meet Claudia, Switzerland

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### What is your name?

My name is Claudia Schmid. I have passed the big 6-0, and I have been married to my childhood sweetheart for the past 45 years now. We have 3 children, who are grown-ups and don't live at home anymore. We have lived the past 20 years in a beautiful house with a garden in the countryside. I am educated as a historian and work as an art educator and curator in a museum. When I was diagnosed with dystonia, I soon started getting involved in the work of our patient organisation, later being elected to the board of the Swiss Dystonia Association and I am now Vice-President.

### What are the benefits of working within a patient organisation?

A patient organisation can have a greater influence in health care structures than individuals working alone. Participation is central. Ideally carers and patients should talk to each other on equal terms. It is rarely possible for carers to know the patient's side, and experience of living with dystonia. Often carers only know the facts from the medical books. Patients can bring a lot of experience with them and are thus able to contribute significantly.

Therefore it is important for two-way communication between patients and medical practitioners. Part of my work is also to engage the public, provide information, and encourage people who are interested in research in dystonia.

### How do you like spending your free time?

I like sports, not only because it keeps me healthy, but also because it is good for the brain. When climbing in the mountains I have to plan my route, where to place my feet and hands to ascend efficiently. There are also mental health benefits that come from being patient and present and the sense of accomplishment you experience when you reach the top.

In addition to adventurous activities, I also enjoy my quiet time: reading, drawing or being creative. And I am a big fan of English gardens (although my own garden is still very far away from my dream). But hands in dirt, head in the sun feed not just my body, but my soul.

### What keeps you motivated on the tough days?

I try to see things positively. And I try to follow the Serenity Prayer, commonly quoted as follows: "Grant me the serenity to accept what I cannot change, the courage to change what I can, and the wisdom to know the difference." There is so much for which I am grateful. Sometimes I must complain, but I am conscious my complaints are at a high level.

### What makes you angry or frustrated?

I often frustrate myself with my own ambitions and perfectionism in my work. But also, the fact that I try my best to help others, but struggle to accept help from others. My other frustration is intolerance and negativity in people. We all have different qualities and should remain as tolerant and positive as we can for each other.

**Claudia Schmid**  
Swiss Dystonia Association  
Switzerland



# Dystonia Matters Live 2023

Join Dystonia UK in 2023 in the iconic city of Newcastle for the largest community event for people living with dystonia in the UK.

Dystonia Matters Live is free to attend and suitable for anyone with an interest in dystonia. Adults, professionals, kids, carers and families are all welcome! Taking place over 2 days, we've created a relaxed format with plenty of breaks allowing you to pop in and out for the sessions most relevant to you.

## What's on @ Dystonia Matters Live 2023?

- The Main Stage: Talks & Q&As from experts & patients from across the dystonia community
- The Acoustic Stage: Workshops & Masterclasses
- The Main Stage - At night: 40th birthday celebrations!
- Chill Out Room
- Stalls
- Goody bags
- Entertainment
- And lots more!

Featuring...  
~ Tully Kearney MBE,  
GB Paralympic Gold & 7x  
World Swimming champion  
& Dystonia UK Patron



[www.bit.ly/DMLive2023](http://www.bit.ly/DMLive2023)

Friday 30th June & Saturday 1st July

INNSiDE Newcastle



Book now

Tickets now available - free (excl. £25pp refundable deposit) for everyone!

## Calendar 2023

### May

31 Dystonia Coalition Meeting, Dublin, Ireland

### June

1-3 6<sup>th</sup> International Dystonia Symposium, Dublin, Ireland

2 Dystonia Europe 30<sup>th</sup> Annual General Assembly, Dublin, Ireland

3 Dystonia Ireland and Dystonia Europe Dystonia Day 2023, Dublin, Ireland  
Presentation David Marsden Award 2023, Dublin, Ireland  
Dystonia Europe 30<sup>th</sup> Anniversary Dinner, Dublin

19 Patient Live Webinar on DBS

### July

1-4 EAN Congress 2023, Budapest, Hungary

22 World Brain Day, online

### August

27-31 International Congress of Parkinson's Disease & Movement Disorders, Copenhagen, Denmark

### September

16-17 Dystonia Days 2023 in Pori, Finland

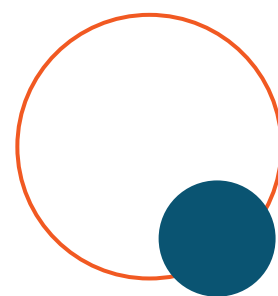
19-21 ERN-RND Annual Meeting, Leuven, Belgium

27-30 ESSFN Congress, Stockholm, Sweden

### October

2-3 Nordic Conference on Rare Diseases, Stockholm, Sweden

24 Dystonia Europe Think Tank Meeting, online





## Members

Dystonia Europe consists of 23 national member groups from 20 European countries and they are:

Austria, Belgium, Croatia, Czech Republic, Denmark, Finland, France, Germany, Ireland, Italy, Norway, Poland, Romania, Slovenia, Spain, Sweden, Switzerland, The Netherlands, Ukraine and United Kingdom.

## Medical & Scientific Advisory Board

Prof Alberto Albanese – Milan

Prof Alfredo Berardelli – Rome

Prof Kailash Bhatia – London

Prof Marina de Koning-Tijssen – Groningen

Prof Joachim Krauss – Hannover

Dr Francesca Morgante – London

Prof Tom Warner – London

Dr Jean-Pierre Lin – London

Prof Maja Relja – Zagreb

Prof Marie Vidailhet – Paris

Prof Marjan Jahanshahi – London

Connecting  
People  
for Dystonia

## Staff



**Monika Benson**

Board Member  
Executive Director, Sweden

Monika was elected President of EDF, now Dystonia Europe, in 2007. She was re-elected for a second term in 2010. Monika stepped down as President in 2013 after serving the maximum period of 6 years. She took over as Executive Director after Alistair Newton's retirement. Monika has cervical dystonia and was a board member of the Swedish Dystonia Association for 10 years. Monika has been working as a coordinator of work-shops, courses and lectures at a school in Lund, Sweden.



**Merete Avery,**

Operations Manager, Norway

Merete was appointed to the board of Dystonia Europe in 2013 and was Secretary from 2013-2015. Merete was appointed President at the Board Meeting, following the GA, in Rotterdam 2015. She stepped down as President in 2019 after the maximum period of 6 years in the DE Board. She was diagnosed with cervical dystonia in 2006 and was Chairwoman of the Norwegian Dystonia Association between 2010-2013. Merete has been working with customer service, accounting and finance in Molde, Norway.

**Edwige Ponseel**

President

Edwige is the President of the French Dystonia Association, AMADYS.

The objectives of the association are to provide support to dystonia patients, to raise public awareness, to promote research and to organize meetings and events. Edwige works full time in the purchasing and marketing department of an American company, in the European headquarter near Paris. She was diagnosed in 1994 with cervical dystonia.

She was elected to the DE Board at the General Assembly in Rome in 2017. She was reelected at the last GA in London and for a 3rd period in 2021. From December 2022 she is the President of Dystonia Europe.

**Gill Ainsley**

Vice President and Secretary

Gill is very interested in raising awareness of dystonia and in research that would lead to a cure for dystonia. Gill's first language is English, she is also a skilled computer operator. Gill's profession is engineering and she worked for many years as an Electromagnetic Compatibility Test Engineer on aircrafts. Gill was nominated and elected as Board Member to Dystonia Europe in 2019 and re-elected in 2021.

Gill is the Vice President and Secretary of Dystonia Europe.

**Sissel Buskerud**

Treasurer

Sissel is the Vice President of the Norwegian Dystonia Association (NDF). She was also Treasurer for many yrs. in NDF until 2020. Sissel has a university degree in accounting and finance and she has experience for more than 25 yrs. as CFO—Chief Financial Officer for a Norwegian Security Company. Sissel was elected to the DE Board at the GA in London in 2019 and re-elected in 2021. She has Cervical Dystonia.

Sissel is the Treasurer of Dystonia Europe.

**Catalina Crainic**

Board Member

Catalina Mariana Crainic is the President of the Romanian Dystonia Organisation, Asociatia Childrens Joy and a Board Member of National Alliance of Rare Diseases, Romania. Catalina is a psychologist with right of free practice, working as psychologist for Asociatia Children's Joy and Mrd Clinical Psychology and Psychotherapy. Catalina has broad training, within Art and Painting and also in Educator Recovery within the field of Social and Pedagogical for people with special needs. She also has training in Rare Diseases for Journalists and Effective Communication with the press, representing patients organisations. Catalina was elected to the DE Board in 2019 and re-elected in 2021.

**Jukka Sillanpää**

Board Member

Jukka has been the President of the Finnish Movement Disorder Diseases' Association since 2018. The main targets of the association are to provide the members with support and to increase dystonia awareness among the healthcare professionals in Finland. Jukka has also been a Board Member of the Finnish Parkinson Association since 2020. Jukka has a university degree in accounting and finance. He has much experience in management and financial accounting as well as business planning in his working life. He has a lot of experience in different roles in many associations. Jukka has Cervical Dystonia. Jukka was elected to the Dystonia Europe board in 2021.





**Alistair Newton**

Advisor, UK

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 was the Executive Director between 2001 and 2013. He was appointed to the Dystonia Europe Board with special responsibility of the Dystonia Research Network. Alistair also co-founded EFNA – the European Federation of Neurological Associations – in 2000, where he acted as Treasurer and Secretary-General until 2011. In 2003, he was involved in the founding of the EBC – the European Brain Council, where he was a board member and a treasurer for many years. He is now an advisor to DE on special projects.



**Maja Relja**

Advisor, 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. Between 2011 and 2017 Maja was the Vice President of DE. At present she is the project leader of the Value of Treatment project regarding dystonia.



**Eelco Uytterhoeven**

IT Advisor, The Netherlands

Eelco has been a professional IT-consultant and developer since 1999. For the last few years, since 2016 he has been working as a freelance developer on several internet projects related to Dystonia Europe. Since the beginning of 2016 he is responsible for the maintenance and further development of the MyDystonia platform. Together with the board Eelco wants to raise the professional level of the IT projects of Dystonia Europe and assist in creating new possibilities for the future.



## Contact

### President

Edwige Ponseel

### Executive Director

Monika Benson

### Operations Manager

Merete Avery

### Registered Office

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### Photos from Dystonia Days and portrait photos:

Stephan Röhl, [www.stephan-roehl.de](http://www.stephan-roehl.de)

## Meet us @



### Website:

<http://dystonia-europe.org>

### Facebook:

<https://www.facebook.com/dystonia.europe>

### YouTube:

<http://www.youtube.com/user/DystoniaEurope>

### Twitter:

<https://twitter.com/dystoniaeurope>

### Instagram:

<https://www.instagram.com/dystoniaeurope/>

### LinkedIn:

<https://linkedin.com/company/dystonia-europe/>

We have good working relations on a variety of topics with: DMRF – Dystonia Medical Research Foundation, FDR – Foundation for Dystonia Research, Dystonia Coalition, EFNA – European Federation of Neurological Associations, EBC – the European Brain Council, EAN – European Academy of Neurology, MDS – International Parkinson and Movement Disorder Society.

We thank all our partners for their support and collaboration.

## **Donation and Support**

Dystonia Europe welcomes and greatly appreciates any donations/support from organisations and individuals to further develop all the work for dystonia in Europe by funding research, awareness and education. If you would like to support the work of Dystonia Europe please contact us at [sec@dystonia-europe.org](mailto:sec@dystonia-europe.org) to discuss the possibilities.

You can also use the donate button on the Dystonia Europe website, which will take you to the following page: <https://dystonia-europe.org/donate/>

Thank you for supporting Dystonia Europe!

## **Disclaimer**

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