EPI-Focus

Newsletter of the IBE European Regional Executive Committee (EREC) *Issue 12*

Focus on GEORGIA

Message from the Chair

Dear Friends

We are happy to present the latest issue of Epifocus, the magazine from and for the European Chapters of IBE. This issue is packed with articles from a.o. Germany, Malta, Norway, Slovenia and Spain, showcasing recent activities. We are introducing a new Chapter Spotlight section to Epifocus. The first Chapter in the spotlights is Georgia and EREC's co-chair introduces the Georgian Chapter to us. Chapters unfortunately often aren't aware of what another Chapter does, what challenges they face and what successes they have achieved. We feel this is a nice way to start to build up interaction, to share good practices and we encourage you to contribute to this section.

I particularly want to draw your attention to an important item in this issue of Epifocus in which we reflect on the feedback received from our Chapters about our work. This feedback has been very important in shaping the discussions over the past months internally at IBE and we want to thank all of you who have been open and shared your thoughts with us.

We are also delighted to announce the launch of the website for the Erasmus+ funded European project 'Epipicto' to develop a pictorial guide to epilepsy for adults with reading difficulties. We invite you to check out the website for more information.

Through Epifocus we aim to connect with you, inspire you and help you share your experiences with others. If you are disappointed that your organisation is not in this issue of Epifocus then please let us know what you are getting up to! If you have a question for other Chapters or are looking for advice on a particular activity then please get in touch.

Please note that we also have an EREC Facebook page: IBE Europe. We are happy to share any of your stories via this Facebook page. If you haven't connected to us yet then please do! The links is: https://www.facebook.com/IBE-Europe-146539062854447/

We're looking forward to connecting with you, but in the meantime, we hope you enjoy a warm and relaxing summer!

Kind regards,

Caroline

Caroline

IN THIS ISSUE

EREC Officers

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Vice chair: Natela Okujava, Georgia
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Members: Francesca Sofia, Italy, Ljubica Vrba, Slovenia, Margaretha Andersson, Sweden
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EREC
European
Regional
Executive
Committee
IBE

Association “Epilepsy and Environment” Georgia

Report by: Natela Okujava

Epilepsy and Environment Association, a non-governmental, not-for-profit organization was launched in 1998 in Tbilisi, Georgia. Our association is of the individual membership type, with a national range of operation. In the year 1999, at the General Assembly during the 23rd International Epilepsy Congress in Prague, our association was acknowledged as a Georgian Chapter of the IBE.

Georgia is a small post-Soviet country, located in between the Caucasus and the Black sea, with 3,750,000 inhabitants. The main problems affecting epilepsy care in Georgia are: very poor financial support from the state, restricted medical insurance for epilepsy, i.e. epilepsy services are mostly financed by out-of-pocket payment, low awareness on epilepsy of primary health care physicians, as well as neurologists, limited neuropsychological services and psychosocial rehabilitation and an extremely high stigmatization level.

Our association is involved in several activities with the aim to improve quality of life of people with epilepsy and their families by reducing stigma, raising public and professional awareness, representing their interests in governmental and non-governmental organizations, improving legislation, cooperating with authorities and taking part in national, regional and international activities dedicated to the problems mentioned above.

One of the greatest achievements of our organization was to be involved in a major activity of the Global Campaign Against Epilepsy - Demonstration Project: “Epilepsy Management at Primary Health Care Level in Georgia”. The project was carried out in the capital of Georgia Tbilisi during 4 years, 2008-2011, under the auspices of WHO, ILAE and IBE. Our association was one of the local leading organisations in this project. At the request of the World Health Organization, the Epilepsy Institute in the Netherlands (Stichting Epilepsie Instellingen Nederland – SEIN) was the major international partner.

From the Demonstration Project it had become clear that the treatment gap in Georgia is over 65%, which is mainly due to incorrect diagnoses followed by inappropriate treatment. After the completion of Demonstration Project, Epilepsy and Environment Association continued to work with a number of people that had been actively involved in the project, specifically with Simon Khechinasvhili University Hospital (SKUH) and SEIN, which resulted in launch of a comprehensive epilepsy clinic in the 2014, with aim to improve the diagnosis and treatment of people with epilepsy. We hope, that opening of this international epilepsy centre contributes greatly to the scaling up of epilepsy care in the country.

In addition, Epilepsy and Environment Association is involved in educational activities focused on professional education of primary health care physicians, medical students and specialists of other medical fields like obstetrics, intensive care etc, carrying out lectures and implementing interactive modes of teaching.

International Epilepsy Day is always celebrated by giving joint talk show with participation of Georgian IBE – ILAE chapters on prime time on most popular Georgian TV channels. Educational activities focused on raising public awareness on epilepsy are carried out on a regular basis

We hope, that involvement into the European Regional Executive Committee will be a milestone for the Georgian IBE chapter, opening new possibilities to contribute towards the improvement of lives of people with epilepsy in our country and all over the world.

Photos, from top: 1. SEIN-SKUH Epilepsy and Sleep Centre in Tbilisi, International team: Standing from the left: Al de Weerd, Fia Van der Berg, Natia Chikhladze, Natela Okujava, Nick Malaskhia, Tea Gutter, Alex Tsereteli. 2. Natela Okujava, Prof Marina Janelidze and Alex Tsereteli in the life talk show on TV, devoted to the International Epilepsy Day. 3. Meeting at the Georgian National Science Foundation. From the left: Natela Okujava, Jean Willem Barzilay, Caroline Morton, Ekaterine Kldiashvili (Head, Monitoring Dept), Nino Gachechiladze. 4. Beautiful mountain scenery

IRISH SURVEY RESULTS

82% of young people reveal concerns about their epilepsy*

Report submitted by Conor Culkin, Communications Officer, Epilepsy Ireland

To mark National Epilepsy Week (May 14th – 20th), Epilepsy Ireland announced results of a survey conducted among young people aged 16-21 on their experience of living with the condition.

The results showed that:

- 65% of respondents have concerns about lifestyle issues such as drinking alcohol, socialising, sport and travel
- 56% were worried about employment
- 64% said they were concerned about anxiety issues
- 56% have confidence and self-esteem worries
- When asked what two words best sum up your epilepsy, "angry" and "annoyed" were the most common words
- 71% felt that they are able to explain their epilepsy to others

Speaking in advance of National Epilepsy Week, Peter Murphy, CEO of Epilepsy Ireland said: "The results of our survey shed new light on the experiences of the condition among young people. The teenage years can be a difficult time with exams, social pressures and transitioning into adulthood. With an epilepsy diagnosis on top of all that, you can feel like you're on an emotional rollercoaster. The survey has shown that young people often feel like the condition is a heavy burden, resulting in feelings of anger and frustration. If anyone is feeling like this, it is important you find someone to talk to whether it's friends or family or engaging with the services of Epilepsy Ireland or your healthcare team."

He adds: "Epilepsy Ireland also offers a range of services which include one to one services, a dedicated Transitional Nurse helpline (01 4554133) and our new How2Tell app which addresses the major concern of disclosing epilepsy. We also offer our pre-employment training course Training For Success. Based on campus at the Institute of Technology Sligo, the programme has helped over 250 young people with epilepsy attend since its inception in 1998. Additionally, Epilepsy Ireland also offers support groups or self-management programmes such as the STEPS programme to help teens and young people talk about the difficulties they experience."

Meanwhile, Epilepsy Ireland has released a new booklet to mark National Epilepsy Week entitled 'Moving Forward', a guide for young people with the condition. It addresses the key challenges for young people with epilepsy identified in the survey as well as for their parents and aims to support teenagers as they make the often difficult move from paediatric to adult care.

Author and Epilepsy Transition Coordinator with the National Children's Hospital Group and Epilepsy Ireland, Yvonne Owen said: "In the development of this book we have worked with many young people with epilepsy and their parents who have provided great insight about what it's like to live with epilepsy and the challenges they have to face. They have helped us to identify what young people want to know about at this stage of their lives and with their help we have developed this new resource. The booklet has information about transition and moving to adult services. There is also a section on top tips for living with epilepsy and a section for parents too. Additionally, there are lots of links to further resources included so you can find out even more information about the condition."

*Epilepsy Ireland surveyed 105 people online who have the condition from May 2nd to May 11th 2018.

ACTIVITIES IN SPAIN

Isabel Madrid Sánchez, President, brings us news of recent activities organised by ANPE (Asociación Nacional Personas con Epilepsia)

EPILEPSY DAY IN THE WORKPLACE

On this day, we intend to give information to employers and companies so that they understand that a person with epilepsy can perform a job just like anyone else. In Spain the disease is hidden because there is stigma and you cannot access a job, in addition people with epilepsy are dismissed from their job because they have a seizure. We believe that it is due to lack of information for companies.

NATIONAL EPILEPSY DAY IN SPAIN

May 24

Similar to 2017, we illuminated public buildings and monuments in orange - the color of Spain - to give visibility to those who live with epilepsy and to help to raise awareness and thereby eradicate the stigma associated with the disease. One of the most representative photos is the facade of the Congress of Deputies of Spain, the largest representation of Spanish citizens that we want to reach to inform. We had information stands in different parts of Spain.

AWARENESS DAY

This initiative allows us the opportunity to provide information and testimonies about epilepsy. On this day we meet with the Ministry of Health, Social Security and Equality and is an excellent opportunity to publicize epilepsy to public bodies.

Tuk Tuk to Turkey

SUDEP Action, one of IBE's Associate chapters in the UK, has come up with a novel way of raising awareness about SUDEP and, at the same time, raising funds.

The Tuk Tuk to Turkey initiative is the brainchild of the family of Emily Sumaria who died from SUDEP five years ago. Now her sister Amy and parents Rachel and Bharat want to generate something positive from their tragedy.

Tuk Tuk to Turkey will see the family travel from the UK through 21 European countries, to end up in Turkey. The journey will begin in September and it is hoped to complete the arduous trip to Istanbul in this low-tech vehicle within six weeks. With no suspension or shelter from the elements, and with limited horsepower, it won't be the most comfortable of journeys.

Find out more at tuktuktoturkey.com.

International Epilepsy Day in Croatia

Ana Sruk and Marija Sedlić sent us this report

Pictured from left: Prof Ivan Bielen, MD, PhD; Assist. Prof. Maša Malenica, MD, PhD; Željka Josipović-Jelić, MD, PhD; Prof. Silvio Bašić, MD, PhD; Ana Sruk, MD; Prof. Željka Petelin Gadže, MD, PhD; Ružica Palić Kramarić, MD, PhD

On February 12th 2018, we celebrated both International Epilepsy Day and Croatian National Epilepsy Day, in Zagreb City Hall Square.

The event was organized by the Croatian Association for Epilepsy, Croatian League Against Epilepsy, Referral Center for Epilepsy of the Ministry of Health of the Republic of Croatia, Referral Center for preoperative treatment of patients with epilepsy of the Ministry of Health of the Republic of Croatia, Croatian Society for EEG and Clinical Neurophysiology of the Croatian Medical Association, and the Department for Pediatric Neurology of the Pediatric Clinics University Hospital Centre "Sestre milosrdnice".

As part of the event, an educational event was held that addressed the most important facts about epilepsy, including the algorithm for first aid for epileptic seizures. For the younger participants, we presented a series of educational animated stories "Campi - the International Epilepsy Day mascot" (http://www.epilepsija.hr/?p=2427), with Croatian translation and synchronisation. Also, at the end of this section, we presented awards for the best photo as part of the national photo contest "Life is Beautiful!" (http://www.epilepsija.hr/?p=2437).

We were exceptionally honored to have a representative of the Ministry of Health, Ružica Palić Kramarić, MD, PhD, and the representative of City Office for Health of the City of Zagreb, Željka Josipović - Jelić, MD, PhD to join us and in that way emphasize the importance of this topic.

We thank all of our members, colleagues and friends for a great turnout. A special thanks to the police officers of the Zagreb Police Department who have followed the lectures with great interest and interaction. We hope that all of us will apply newly gained knowledge in our everyday life because "By spreading the knowledge about epilepsy, we are getting rid of the prejudices!".

WINTER CAMP FOR CHILDREN WITH EPILEPSY

Masa Malenica, Monika Kukuruzovic, Kristina Kuznik, Mirela Passero,
Department of Pediatrics, Neuropediatric Unit, University Hospital Center "Sestre Milosrdnice", Zagreb, Croatia

Support for children with epilepsy in Croatia has been a vital part of the Croatian Association for Epilepsy, and the organization of epilepsy camps has been one aspect of it. In December 2017 a four day long winter camp took place on Sljeme Mountain in Zagreb, the capital of Croatia. The camp was supported by the City Office of Zagreb of Health. This was the first winter camp; all previous camps had taken place during the summer months.

This year, the 20 participants were children of subnormal-intellect with active epilepsy, or well controlled with anti-epileptic drugs. Camp staff included two child neurologists, a psychologist, nurses and trained volunteers. Activities included indoor swimming, group sports (including tae-kwon do practice), outdoor fun activities and snow sports, arts and crafts, and entertainment such as disco night and movie night.

We provided teaching sessions by a child neurologist and psychologists with the goal of improving knowledge of epilepsy, the importance of medication and on managing lifestyle issues such as socialization, employment and driving. Discussion with camp participants occurred in groups or in one-on-one sessions. However, the main idea was for children to make new friends who share the same problems and to have fun in a safe environment. Our job, in addition to keeping them entertained and safe, was to get to know the patients in a different setting in order to provide individualized health care in the future.

In addition, it was a great opportunity for some parents to have their child taken care of in conditions in which they felt comfortable – meaning with the child's neurologist on hand. The impact of the educational sessions was evaluated at the beginning and at the end of the camp. Questionnaires explored stressors and methods of relaxation, bullying, concentration, knowledge about epilepsy and satisfaction with the camp.

The children were continually encouraged to improve their knowledge of epilepsy and associated lifestyle modifications to ensure good health. Our main message was for them to reach their full potential in life and to feel equal to their peers in every aspect of life. Participants enjoyed the experience and received education in a supportive environment.

Epilepsy- Finding Help

National Epilepsy Conference Malta

"Epilepsy- Finding Help" was the theme of the March 10, 2018 National Conference held by Caritas Malta Epilepsy Association in Malta (http://www.caritasmalta.org/cmea-conferences/).

Her Excellency Marie Louise Coleiro Preca, President of Malta, opened the conference with kind words about the efforts of Caritas Malta Epilepsy Association to assist and support people with epilepsy in Malta as well as to reduce stigma through educational campaigns.

Prof Dorothée Kasteleijn, Department of Neurosurgery and Epilepsy, University Medical Center Utrecht, The Netherlands then shared from her vast experience about "Finding Help: Understanding Different Types of Seizures." The audience consisted of people with epilepsy and their family and friends, caregivers, teachers, aides, nurses, pharmacists, and doctors. Her presentation was very well received and seemed to be understood by all.

A panel discussion followed with a Question and Answer time from invited guests including neurologists, the head of the Child Development Assessment Unit, a speech therapist, a pharmacist, and an EEG technician. After a delicious lunch break, participants were invited to choose one of three interactive workshops- Finding Help for Children, Adults, or Caregivers.

The day concluded with closing remarks by the Honorable Dr Michael Falzon, Minister for the Family, Children's Rights and Social Solidarity and an appeal for those present to join the Caritas Malta Epilepsy Association in assisting people with epilepsy in "Finding Help."

From top: 1. Prof Janet Mifsud, Advisor, CMEA; Frank Portelli, President, Manuel Camilleri, Committee member; Noel Portelli, past Secretary; Mr Matthew Attard, PR; Prof Dorothee Trenite Kasteleijn, guest speaker; Caroline Attard, Treasurer; Claudine Aitkens, Secretary. 2. Frank Portelli presenting a gift to Prof Dorothee Trenite Kasteleijn. 3. Conference audience.

NEWS FROM GERMANY

Arbeitstagung 2017 in Jena

Once a year a workshop organised by the German Epilepsy Association takes place at different venues and under different themes each year.

One of the aims of the workshop is to give people with epilepsy and their relatives the opportunity to gain an overview of important aspects of the conference topic, to inform themselves about new developments and to discuss the respective topics together with experts.

This year it will take place from 8th June to 10th June in Berlin.

Tag der Epilepsie – Epilepsy Day

National Epilepsy Day is celebrated every year on October 5th

It is a nationwide action day of epilepsy self-help. Its purpose is to inform the public about epilepsy, to encourage those affected, as well as their relatives, and to counteract the existing stigmatization. This year we are organising the day to take place in Trier.

Tagung zur Förderung der Epilepsie-Selbsthilfe in Jena - Conference for the promotion of epilepsy self-help

This conference in Jena, which took place in October 2017, focussed on self-help and how it can be promoted in the coming years. An important point is new media opportunities (Facebook, Twitter etc.). The question was, how can young people become enthusiastic about self-help and how can they be integrated?

The results are included in a conference brochure available at the office of the federal association in Berlin.

"Wellenreiten" - Creative workshop

This is our seminar for younger people aged between 18 and 35 years. It is a mixture of improvised theater, art and neurolinguistics. It is important to deal with one's peers who are also affected by epilepsy and to creatively deal with the disease.

It will take place from 30th August to 2nd of September in Berlin this year.

For further information, please contact:
Deutsche Epilepsievereinigung e.V. at info@epilepsie-vereinigung.de

CHAPTER

A while ago we wrote to you to ask you three questions:

1. How can IBE best support you?
2. What specific activities would you like to see IBE organise?
3. What could IBE/EREC do better?

The last question was asked specifically to gauge the reasons behind the growing senses of chapter disengagement we are experiencing.

We would like to thank all of you who responded with your feedback. While some of it was confronting to read, the message is clear and we thank you for taking the time to provide us with your views and opinions.

So, what feedback did we receive?

Respondents expressed a wish for clearer communication and position statements on important issues from IBE. There are times when IBE does not communicate often, and there are times when IBE sends out too many messages at the same time.

In addition, it isn't clear to many what IBE's strategy is, which leads to confused expectations and uncertainty as to what IBE is doing. Chapters also want IBE to be more interactive and more responsive to chapters.

Chapters would like IBE to distribute information regarding funding opportunities and to bring chapters together in joint activities, with a focus on training & international collaboration to raise awareness and competences.

We are reflecting on this feedback and will use this to review IBE's processes for the benefit of our chapters. We are excited to announce that IBE is working on organising a number of networking activities for our chapters and more news on these activities will follow very soon!

EPIPICTO GOES LIVE!

On 16 March, Epilepsy Connections' service users, volunteers and staff had a successful meeting with project partners from the Netherlands, Austria, Germany, and Malta to help develop content for Epipicto: A Pictorial Guide to Epilepsy.

The guide is for adults with epilepsy who have low literacy levels or are experiencing language barriers. The feedback from the meeting was passed on to the artist, who has started creating the pictures and text for the Guide.

The website is now live. For more information about the project please go to: www.epipicto.eu

Photo: Henrik Peersen in the Norwegian parliament meeting with parliamentarian Nicholas Wilkinson, who specialises on healthpolicies.

International Epilepsy Day in Norway

The Norwegian Epilepsy Association interviewed parliamentarians on International Epilepsy Day. Our Secretary General (pictured above) took on the role as an eager reporter with rehearsed questions and a film crew. The politicians were faced with questions on how they can contribute to epilepsy patients' needs for information.

The marking of International Epilepsy Day was framed by a social media campaign. From break of dawn until afternoon the association's Facebook site and YouTube account were continually updated with interviews with the parliamentarians. Most of the biggest political parties were represented by interviewees who work with health policies at the parliament.

Politicians and specialists on health

So why did we choose to interview these politicians as a way of marking International Epilepsy day?

"In previous years we have had debates on stage with politicians, but this year we felt that the format needed to change. Anyway, it's easier for us to go to the parliament than for all of them to come to us. Also, we wanted to have it available to our followers so that people from all over the country could participate. Later in the day we were able to bring the comments from the politicians and our followers on Facebook to a round table discussion with health specialists", Secretary General Henrik Peersen explains.

"During the day, the videos that were uploaded received many Views, Likes and Comments. Many of the comments from our followers serve as valuable feedback on what issues they face and where they believe access to information must improve.

"At the Oslo University Hospital we gathered doctors, professors, neurologists and nurses for a discussion on how the need for information should be addressed. A topic that many raised in comments on Facebook was "How can schools better help students with epilepsy with their needs and challenges?" The health specialists said health practitioners need to actively train those who interact with the child in need. Teachers and fellow student need to know the medical aspects and how to facilitate for special needs," Peersen says.

Why did we choose the topic "information" for this year's International Epilepsy Day theme?

"Together with other players, the association has conducted a survey, where it became clear that information is the most important thing patients want improved in their treatment. Oliver Henning, a neurologist at the Oslo University Hospital who is in charge of the research, says he has found statistics about the same problem in many other European countries," states Peersen.

Knows where the shoe pinches

Some of the health specialists who were present said a main problem is consultations that are too short. Thirty (30) minutes for each patient is not enough time to answer questions, give individual advice and information and do the administrative work.

Solutions that were presented were joint information meetings, which would give time for more one-on-one consultations and take some pressure off the system. More epilepsy nurses to take consultations can also be an efficient way of support and save the neurologists time.

The insights received on this day, from politicians and health specialists, is something the Epilepsy Association of Norway will bring with us as we continue our work to change rules and regulations and improve the conditions for people with epilepsy from all over the country. One of the politicians, the leader of the health committee at the parliament said in her interview:

"The first thing is that there needs to be more expertise amongst regular general practitioners, health stations and hospitals. One aspect is finding the diagnosis and the medication. Something entirely different is the whole aspect of living with epilepsy."

NEWS FROM SLOVENIA

Submitted by Ljublica Vrba

As on previous International Epilepsy Days, we organised a lot of activities to make people aware of epilepsy and the lives of people with the condition as widely as possible.

In the autumn, we wrote to all Slovenian MEPs and their assistants in Slovenia and invited them for an interview. We got answers from four of the eight MEP offices. We invited MEPs to attend the events which will take place on this year´s International Epilepsy Day in the European Parliament. At the same time we encouraged them to join the European Advocates for Epilepsy Group in the European Parliament. One of our MEPs is a member of this group since 2016, three others joined at the end of 2017.

On International Epilepsy Day (IED) we organized a press conference and as a result there were quite a few contributions to epilepsy in the media. We posted a poster about IED in health centers, hospitals and some pharmacies all over Slovenia. It was also presented on the screens in buses in Ljubljana, the capital of Slovenia.

On the eve of our Cultural Holiday on 8th February, Simona Semenic- drama writer - received the Preseren Fund Award for her book "Do you hear me?", where she describes her life with epilepsy. In Nova Gorica, a town near the Italian border, a local self help group prepared a public presentation of her book and a talk about her life with epilepsy. The attendance at the event was good with lively discussion. Simona´s presentation of the book and the discussion about epilepsy was organized several times in different places around Slovenia.

Norwegian Epilepsy Association awards NOK427,000 to science

This is a record allotment!

Five epilepsy related scientific projects were awarded through the association's Sciencefund. The projects which were granted support are going to research amongst other things; long-term effect of ketogenic diet amongst adults, how to treat pharmacoresistant epilepsy and quality of life amongst patients with brain tumor and epilepsy.

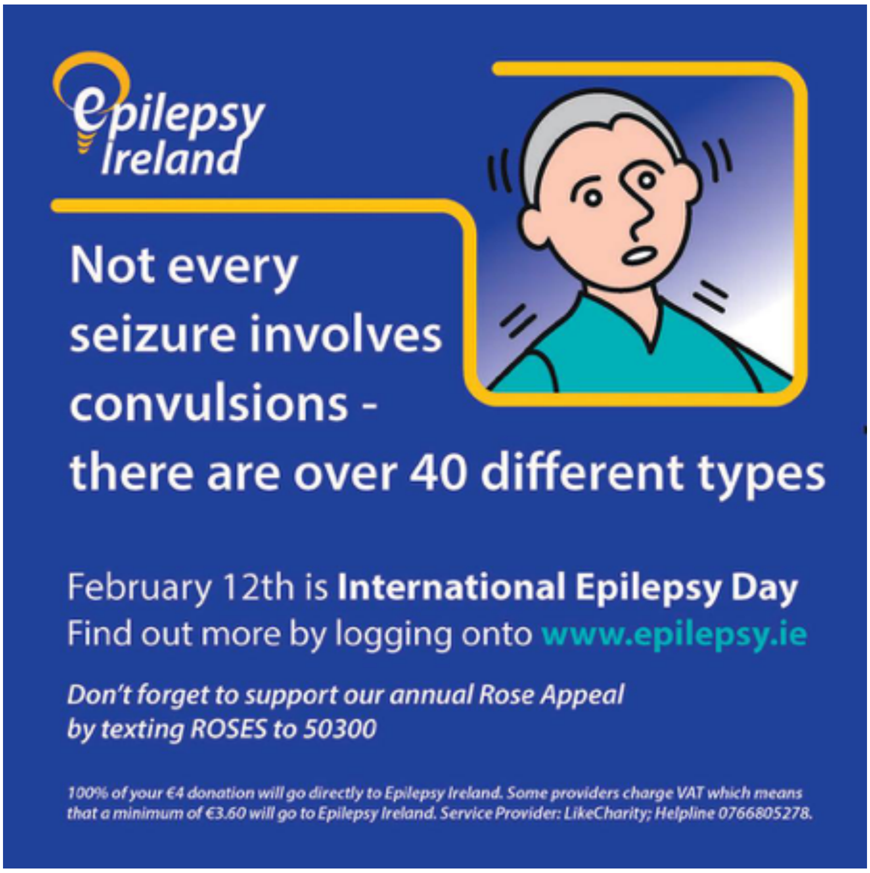
The leader of the Socialist party, Audun Lysbakken (pictured left), gave an interview about epilepsy.

As epilepsy is still a disease where patients experience stigma, it is hard to find public figures willing to step up and be open about their diagnosis. When it became known that party leader Audun Lysbakken had gone through epilepsy surgery, we sat down with him for a talk.

"It has been a positive experience because I have received a lot of inquiries from people with epilepsy, who have said they think it was a relief that someone spoke about it. It has meant that I have realized that too many experience the diagnosis as perhaps more stigmatizing than I thought. It means that it feels more meaningful to talk about it, because then it is important", Lysbakken says.

NOK 427,000 is approximately €45,000.

Irish public show their support for *International Epilepsy Day*


Epilepsy Ireland

Not every seizure involves convulsions -
there are over 40 different types

February 12th is **International Epilepsy Day**
Find out more by logging onto **www.epilepsy.ie**

Don't forget to support our annual Rose Appeal by texting ROSES to 50300

100% of your €4 donation will go directly to Epilepsy Ireland. Some providers charge VAT which means that a minimum of €3.60 will go to Epilepsy Ireland. Service Provider: LikeCharity; Helpline 0766805278.

International Epilepsy Day was one of the most high profile days in recent years with widespread coverage in Ireland. Epilepsy Ireland used the day to focus on the top five things to know about the condition, as voted by Epilepsy Ireland service users in a survey.

Top 5 things to know about epilepsy

1. Seizure first aid (a tonic-clonic seizure)
2. Not every seizure involves convulsing
3. On rare occasions epilepsy can be life threatening
4. Epilepsy in most cases does not affect your career
5. Epilepsy doesn't define who you are

Epilepsy Ireland CEO Peter Murphy said: "It's no surprise that knowing what to do if someone has a seizure was number one, but a variety of other important messages also shone through, such as knowing that not every seizure involves convulsions, that epilepsy does not have to affect your work/ career, and that while epilepsy can present many complex challenges, it does not define you as a person. I was delighted that more people than ever got involved in International Epilepsy Day showing their support in great numbers both online and all the people who sold roses for our annual appeal."

Online highlights

- El Facebook page went over 13,000 likes and Epilepsy Ireland posts reached over 80,000 people from February 6th to 12th
- Over 4,000 Irish tweets on Feb 12th and #EpilepsyDay was the most talked about topic on Twitter in Ireland for the day
- Over 4,800 page views on our website – a huge increased compared to the normal daily traffic

Broadcast highlights

- Rick O'Shea (broadcaster who has epilepsy) was on Claire Byrne Live radio show talking epilepsy
- Epilepsy Ireland Communication Officer Conor Culkin was interviewed on Newstalk on lunchtime live radio.
- Epilepsy Ireland Training Manager Paul Sharkey was interviewed on the same station by Ivan Yates.

Caption photo right: Olivia Sneyd used to the day to dress up and show support for the Epilepsy Ireland Rose appeal at Pearse Street Station (police station)

NEWS from FEDE, Spain

Spanish Summer Camp for Children with Epilepsy

For a child with epilepsy that goes to a regular school, going on a school camping trip is not so simple because many times it cannot be guaranteed that there is someone available to provide extra support (such as medication, resting, swimming, or first aid in epilepsy). As a consequence, the child with epilepsy ends up not participating in the camping trip.

On the other hand, children with epilepsy that go to a special education school often have the option of going to camps specifically organised for children with special needs and abilities (motor, cognitive, psychological, etc.). But parents usually don't send their children to these camps either because they don't think their child's condition is serious enough for them to participate in a camp for children with special needs.

Sueños de Verano Camps solve this dilemma. These camps are specifically organised for children who don't participate in school camps or in special needs camps. They are for children and youngsters from 10-16 years of age, with a certain level of autonomy for basic daily activities. Camps guarantee the management of activities by professional educators and medical supervision by a trained medical team with knowledge of epilepsy.

This year the Summer Camp will take place from 8-15 July at Sant Celoni, in the province of Barcelona, with everything the children need to enjoy sport, playful activities and games.

Next year, in 2019, the 7th edition of the Summer Camp will be held and we would like to include children from other countries in a special English-edition camp. For this purpose, we would like to invite parents and children of IBE Chapters to visit our camp in Sant Celoni this summer if they want to find out more about the camps in person. We encourage you to contact us if you need help finding accommodation in Barcelona.

For more information please contact the Federación Española de Epilepsia (FEDE) at: presidente@fedeepilepsia.org.

Give your face for epilepsy

The campaign 'Give your face for epilepsy' is an online campaign where people with and without epilepsy can submit their picture and a message of support for people with epilepsy and share this on social networks. The aim is to normalise epilepsy by means of a viral campaign, and in Spain there is already a sponsor to help spread this throughout the media.

FEDE is making this platform available to all IBE chapters and it can be adapted to suit each country, culture and language. This way each country will have its own campaign, in its own language, with its own internet domain for the campaign, and with the images uploaded by users from their own country.

For more information about the campaign please contact the Federación Española de Epilepsia (FEDE) via email at: presidente@fedeepilepsia.org.