



# EPI-Focus

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

*Issue 14*

News from Ireland, Russia and Spain  
**International Epilepsy Day 2020**  
*Epipicto launched in Malta*

## Hear my Story workshop - Dublin



*Workshop participants pictured with three members of the IBE European Regional Executive Committee (Shirley Maxwell and Natela Okujava, second and third from left standing) and Ljubica Vrba (front left). Also pictured is Evaldas Rupkus (centre front), the workshop facilitator.*



## Message from the Chair

*Dear Friends*

Time flies and we are already wrapping up the year 2019. Let me highlight some trends and achievements of this year globally and in Europe. In January, the IBE International Executive Committee (IEC) came together with the aim of planning its strategy. Stakeholder engagement and empowering voices of young people with epilepsy in our community, training and supporting epilepsy advocates and lay experts, expanding collaborative actions together with ILAE and other governmental and non-governmental organizations, were considered as major priorities. I am happy that these plans have already turned into action.

I believe that the “Golden Light Awards” and the session featuring presentations by the awardees at International Epilepsy Congress in Bangkok in June was a big victory, inspiring young people from all over the world to stand up for epilepsy.

In October, in Dublin, the European Regional Executive Committee organized a workshop “Hear My Story” for

young people with epilepsy. By the way, the European “Golden Lights” also participated in this workshop. Participants planned four different projects and a special joint action for International Epilepsy Day next February.

European chapters of the IBE and ILAE are working together for common research projects in the Epilepsy Alliance Europe task force (EAE).

WHO, ILAE and IBE produced and launched a document of major importance, the global report “Epilepsy: a Public Health Imperative”.

The coming year promises to be even more interesting!

I wish you all a Merry Christmas and a Happy New Year, success and fulfilled hopes to our epilepsy community in 2020!

Kind regards  
Natela Okujava

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### EREC Officers

Chair: Natela Okujava, Georgia  
Secretary: Shirley Maxwell, Scotland  
Members: Francesca Sofia, Italy, Ljubica Vrba, Slovenia,  
Ex officio: Martin Brodie, President; Mary Secco, Secretary General; Anthony Zimba, Treasurer.

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EPI-Focus layout and design: Ann Little



# NEWS FROM EPILEPSY IRELAND



## Seizure Awareness Campaign

International Epilepsy Day 2019 was one of the most high profile days in recent years in Ireland with widespread coverage. Epilepsy Ireland used the day to focus on seizure awareness with Ireland rugby coach, Joe Schmidt supporting this year's campaign.

Epilepsy Ireland CEO Peter Murphy said: "We were delighted to have Joe Schmidt again supporting the need for greater seizure awareness through the T.E.A.M. campaign. Joe's association with Epilepsy Ireland has been a major factor in improving seizure awareness among the Irish public over the past five years. "There are over 40,000 people with epilepsy in Ireland, so it is vital that we all know the basics of how to respond to a seizure if ever called upon."

## Epilepsy Research Explained Event

Meanwhile, Epilepsy Ireland and FutureNeuro were pleased to co-host a Public Seminar to mark International Epilepsy Day. The seminar, which took place in the Royal College of Surgeons in Ireland, (RCSI) was for people with epilepsy, their families & carers and highlighted the latest developments in epilepsy research in Ireland and internationally.

### Photos:

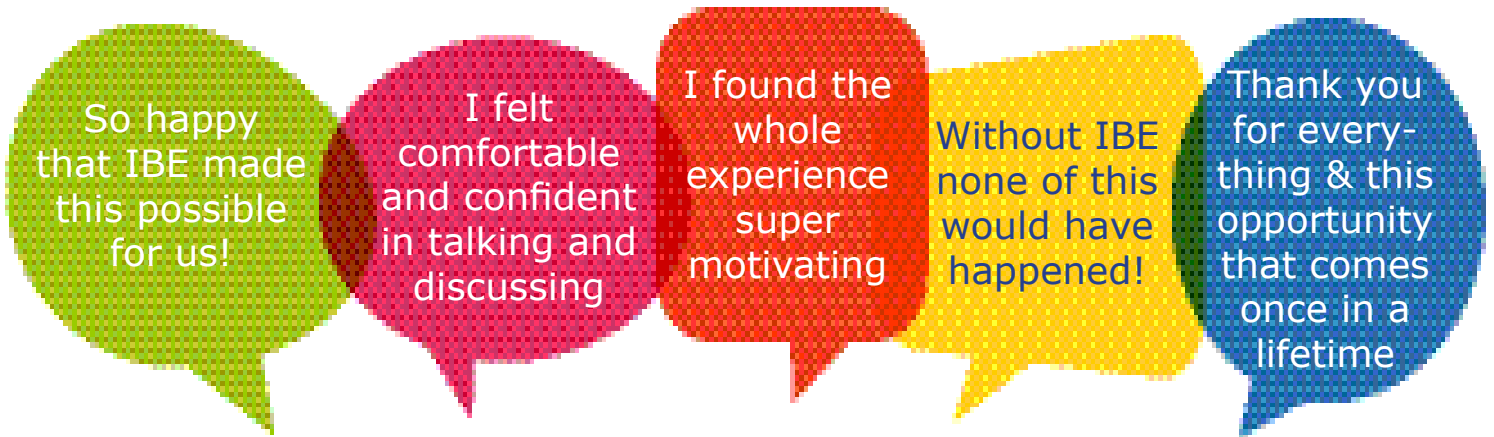
- Top: Epilepsy Ireland poster featuring Joe Schmitt
- Bottom: event on epilepsy research at the RCSI, Dublin.



# HEAR MY STORY - WORKSHOP REPORT

## Communications workshop for young adults

DUBLIN, 4TH-6TH OCTOBER 2019



### WHAT'S THE PROBLEM?

Despite the statistics, there has been much less public awareness and discussion about epilepsy compared to other conditions. This has to change and the future lies with the next generation.

There is wide recognition amongst IBE's chapters that young people are currently under-represented in their associations. This poses the risk of undermining the future potential of epilepsy associations or, at worst, putting their very future in jeopardy. It is also felt that the issues facing young people affected by epilepsy are not getting the public or political attention they should. Yet the diverse range of experience and the remarkable personal resilience that a large number of young people with epilepsy already demonstrate is going unnoticed, because many feel ill-equipped to report on their achievements.

### WHAT'S THE PLAN?

Maturing into adulthood is a difficult time for most people. For young adults with epilepsy, faced with the added issues that a diagnosis of epilepsy can bring, it can be an even more challenging time. Recognising this and in line with IBE's goal 'to provide resources for people with epilepsy and their families to maximise quality of life', the objectives of the workshop were agreed:

- To offer a platform for young people to voice the issues they face and raise awareness of these issues;
- To provide young adults with epilepsy with the skills to become epilepsy advocates, in partnership with IBE's chapters in Europe;
- To hear how young people with epilepsy perceive patient organisations and how IBE, together with its chapters, can better adapt its operations to em-

brace the views and expectations of these young people with epilepsy;

- To harness the outcomes of the workshop towards building a political campaign that could be brought to national policy makers as well as those at EU level;
- To encourage the group to channel their results into a campaign for International Epilepsy Day 2020;
- With an ultimate aim of developing a youth commission within IBE.

We were delighted that chapters from across Europe nominated their shining stars and, in the end, twelve countries were represented: Austria, Croatia, Cyprus, Denmark, England, Finland, Germany, Ireland, Italy, Norway, Scotland and Slovenia.

The workshop was led by Evaldas Rupkus, an experienced facilitator from Germany, who is an associate with People Dialogue & Change, which has a strong track record in supporting organisations to train and support a generation of young patient activists.

### WHAT'S THE PROGRAMME?

Bringing awareness to important issues such as the right to work, discrimination, social exclusion, access to treatments and fighting stigma, the opportunity to network and to work together on projects, as well as to get inspired were recognized as key factors for the group's attendance.

The definition of what it is to be an advocate was discussed and consideration given to target groups, which ranged from national governments, MEPs at EU level, right down to people with epilepsy themselves, with media, schools, employers and the healthcare system also being identified.

## Participants from 12 European countries

1. Austria
2. Croatia
3. Cyprus
4. Denmark
5. England
6. Finland
7. Germany
8. Ireland
9. Italy
10. Norway
11. Scotland
12. Slovenia



Solutions were considered and the attendees split into sub groups to develop concepts with different media products and how they might influence change. Education, employment, patient support and international networking were selected as the four projects that the group would develop after an initial prototype was conceived.

Additionally it was considered how to best utilise International Epilepsy Day to launch the projects with the support of IBE, which resulted in a fifth project for all of the group to work on together – a social media campaign that will feature each of the participants sharing personal stories about their own epilepsy journey that will include “A day in the life of...” and “Overcoming challenges that epilepsy has prevented me from trying before” or talking about the project that they are working on as a result of this workshop.

## WHAT'S THE OUTCOME?

This social media campaign will feature the next generation telling the world, in their own words, the struggles that they face in living with epilepsy and the barriers that they have overcome. Moreover, it will show that they are not afraid to be heard. Self-empowerment will be at the centre of this campaign.

It was hoped that one of the primary outcomes of this workshop would be the development of a programme that would assist young adults living with epilepsy to become epilepsy advocates, with the added potential to be replicated at a national level through IBE's chapters and with the possibility of adaptation for use in other IBE regions. Unquestionably, this has been achieved.

The success of the project is still evident in the continued active engagement of the young people in rolling out their social media project and in their interest

in further evolving the group. It was inspirational to witness how this group of young people felt that their capabilities and skills as advocates had improved as a result of the workshop. Each one returned home with the strong belief and confidence that they could make a difference.

IBE's realisation was achieved in helping young people to grow in independence with one of the attendees saying "Very often 'Thank you' is the only words that come to mind but I believe that we are all capable of making a huge difference in relation to the understanding and experience of people with epilepsy."

## AND THE FUTURE?

Without doubt, connections have been established and a network of experience has come together to create a community of advocates for people living with epilepsy. For IBE, this is a great foundation for the future and addresses IBE's goals of awareness, advocacy, empowerment and communication.

Since the end of the event, the participants have been staying in touch using Social Media as well as Zoom video calls, as they continue to work on their project for International Epilepsy Day and the longer term projects that the teams proposed during the workshop.

We now look to rolling out the initiative in other regions with the possibility of engaging the young adults from the Dublin workshop in our future endeavour.

## WHAT THE PARTICIPANTS SAID

### What were the best aspects of the workshop?

- I found the whole experience super motivating just to be in the same room as people with similar passions and aims

- I felt comfortable and confident in talking and discussing. It was easy to express myself
- Talking with others, support from peers, open honest discussion, positive participation, the planning element for the future, the social aspect and meeting others as well
- Thank you for everything & this opportunity that comes once in a lifetime
- I had a really great time, everyone was so great and I also learned a lot from each person
- I'm very glad that everyone has to talk about their own story and that there was nearly no self-pity

### What key things did you learn in this workshop?

- The divide between countries in terms of the support for people with epilepsy despite being covered by common European law
- More motivation and inspiration for projects - talking more to persons
- Importance of networking across the borders
- Disparity of epilepsy care in the EU difficulties in other countries the network that exists with the IBE supports IBE can provide inspiration and motivation from others
- The challenges others are facing, different ideas how we can aware people about epilepsy, how to start working on a project
- About other people's experiences of epilepsy in their own country
- There are a lot of differences between the European countries
- How to speak out more about epilepsy and to make a difference
- Our differences and getting some ideas and what to improve back home



# EPILEPSY

A public health imperative



## Epilepsy: a Public Health Imperative

*Natela Okujava reports*

**Epilepsy: a Public Health Imperative** is a new report on epilepsy produced by WHO, ILAE and IBE. The report is presented with five overarching topics, describing burden of epilepsy; stigma and discrimination; treatment gap; prevention possibilities; and ways to act on national, regional and global levels, in order to prioritize epilepsy care. Altogether, this document presents a comprehensive picture of the impact that the condition has on people with epilepsy, their families, communities and society. Major messages from this report are:

**BURDEN:** The burden of epilepsy is high and often neglected in public health agendas. Epilepsy is one of the most common neurological diseases, affecting nearly 50 million people of all ages around the world. The risk of premature death in people with epilepsy is up to three times that of the general population. Roughly half of adults with epilepsy have at least one other health condition. Psychiatric conditions, such as depression and anxiety, make seizures worse and reduce quality of life. Epilepsy has significant economic implications in terms of health care needs and lost productivity at work.

**STIGMA AND DISCRIMINATION:** Globally, people with epilepsy are the target of discrimination and human rights violations. The stigma of epilepsy can discourage people from seeking treatment and has consequences for quality of life and social inclusion. Improving knowledge and raising awareness of epilepsy in schools, workplaces, and communities is needed to reduce stigma. Legislation based on internationally accepted human rights standards can prevent discrimination and human rights violations, improve access to health care services, and raise the quality of life for people with epilepsy.

**TREATMENT GAP:** Three quarters of people living with epilepsy in low-income countries do not get the treatment they need. Yet, up to 70% of people with epilepsy could become seizure free with appropriate use of cost effective antiseizure medicines. A significant proportion of the burden of epilepsy could be avoided by scaling up routine availability of antiseizure medicines, possible at an annual cost as low as US\$5 per person. It is feasible to integrate epilepsy treatment into primary healthcare – training nonspecialist providers, investing in continuous supplies of antiseizure medicines and strengthening health systems can substantially reduce the epilepsy treatment gap.

**PREVENTION:** An estimated 25% of epilepsy cases are preventable. The major modifiable risk factors for epilepsy are: perinatal insults, central nervous system infections, traumatic brain injury and stroke. Preventing epilepsy is an urgent unmet need. Effective interventions for prevention are available and delivered as part of broader public health responses in maternal and newborn health care, communicable disease control, injury prevention and cardiovascular health.

**THE TIME TO ACT IS NOW:** Sustained and coordinated action to prioritize epilepsy in public health agendas is required at global, regional and national levels. World Health Assembly resolution WHA68.20 on the global burden of epilepsy and the need for coordinated action at the country level to address its health, social and public knowledge implications sets the framework for increasing investment in epilepsy. There is a pressing need for increased investment in research and to address the burden of epilepsy through integration in primary health care, ensuring that all people with epilepsy have access to quality and affordable care. The report was officially launched with overwhelming success at IEC in Bangkok on June 24, 2019.

In my personal opinion, this document is a landmark achievement of the WHO/ILAE/IBE collaborative endeavour, representing a unique source for facts and data on epilepsy all over the world, offering guidance for solving problems, organization and governance of epilepsy care from local to global levels and also telling us that “The time to act is now”! (<https://www.ibe-epilepsy.org/global-report-epilepsy-a-public-health-imperative/>).

# Asociación Nacional de Personas con Epilepsia - ANPE, Spain



On November 16, neuropsychologist, Dr Lorena Rodríguez, gave a training course on Neurodevelopment and Epilepsy at the 5th International Congress of Clinical and Health Psychology for Children and Adolescents, held in the city of Oviedo.

On June 26, we had the opportunity to be invited to participate in the Multidisciplinary Epilepsy Conference organized by the Clínica Universidad de Navarra with its headquarters in Madrid. The conference was addressed by Dr D Asier Gómez Ibáñez on the topic of neurology, who explained what epilepsy is, types, diagnosis, etc., aspects that concern all patients and family members when we encounter epilepsy for the first time.

In the area of neuropsychology, Dr María Teresa Rognoni Trueba addressed the importance of brain stimulation and early diagnosis as well as therapies for a better quality of life for people with epilepsy and their families. We also had the attendance of a representative from the area of employment who explained the shortcomings and obstacles faced by adults who wish enter the labour market.



On October 10, we had the honour of participating, together with great experts in neurology and representatives of other patient associations, in the pre-congress organized by the Madrid Association of Neurology (AMN).



ANPE, one of IBE's associate chapters in Spain, based in Madrid, shared with us some of the many events it organised during the year.

On June 13, 2019 the students of the Manolo Blahnik School of Art organised a fashion parade with the costumes and jewelry made throughout the year as an end-of-course work, which were then exhibited at the Fashion Show in the Plaza de España on the Island of Santa Cruz de la Palma (Canary Islands).

Thanks are due to the students and the Manolo Blahnik School of Art, as well as to TOUS Jewels and the Government of Santa Cruz de la Palma for their support.



On Saturday 23rd March, within the framework of Purple Day, we organised our 2nd Inclusive Education Day during which different aspects of inclusive education were approached and from different perspectives such as Education and Health, Epilepsy and Women and seeing how the contribution of all specialists influences results for the better in Educational Centers, thus improving the lives of children and adolescents with epilepsy.

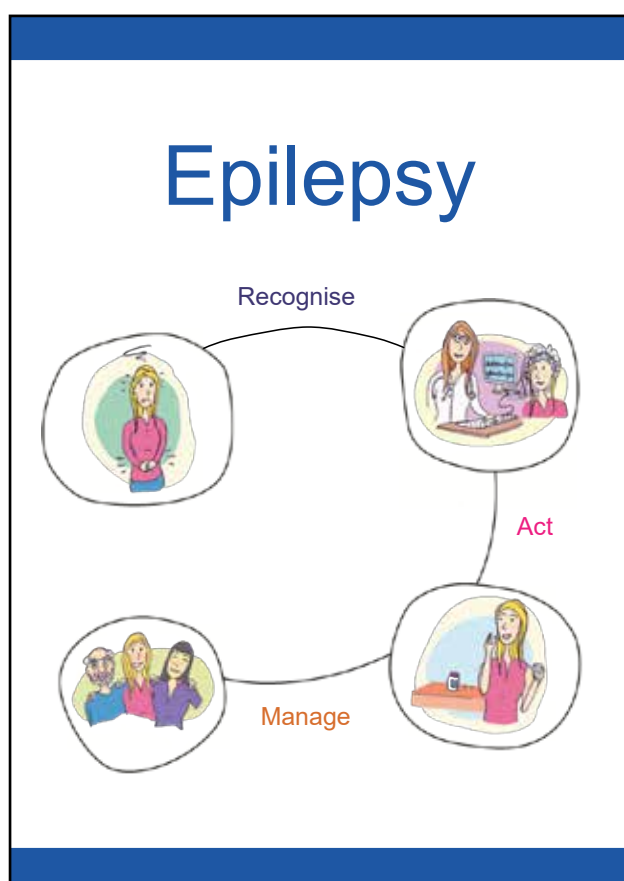


# EPIPICTO launched in six languages ...with more to come!



Five European epilepsy organisations: Caritas Malta Epilepsy Association, Epilepsie Dachverband Österreich (EDO) Austria; Epilepsy Connections (Scotland); Interessenvereinigung für Anfalls Kranke in Köln e.V (Germany); and Stichting Epilepsie Instellingen Nederland (SEIN)(Netherlands) recently launched a pictorial guide for adults in epilepsy, EPIPICTO, funded by the EU Erasmus+ programme. The launch was held at San Anton Palace, Attard, Malta on 14 September 2019, under the auspices of HE The President of Malta, Dr George Vella and in the presence of Hon Dr Michael Falzon, Minister

for the Family, Children’s Rights and Social Solidarity and Mgr Fr Charles Cordina, Caritas Malta. The aim of EPIPICTO is to develop a pictorial guide for persons with epilepsy in marginalised communities, who might have difficulty communicating their ideas due to language or other barriers; are at the risk of social exclusion such as migrant persons, persons living in isolated areas in Europe; and persons with low literacy levels and low health literacy. This final event was held to disseminate the guide in order that it may be used among various end users, such as other NGOs, respite



**About epilepsy**

**Epilepsy** is a common brain condition: parts of your brain become confused and send mixed messages to your body. This is called a seizure.

**Anyone can have epilepsy.** Sometimes it is caused by brain injury, illness / infection, stroke or genetics. Sometimes the cause is unknown.

1) In some seizures, the whole brain is affected. The person might fall down and shake, or stare.

2) In other seizures, only part of the brain is affected. The person stays awake but might not know what is happening around them.

If you have seizures, please visit a doctor. They will ask you about your seizures. You may need to have some tests.

**Medicine can help to control your seizures.**

care workers, social workers and health care professionals.

In his opening address President Vella highlighted the importance of each person, whatever the medical or social condition and the importance of education in reducing stigma. The Minister for the Family, Children's Rights and Social Solidarity, Michael Falzon, argued that we cannot deny the stigma related with epilepsy, especially within marginalised communities such as migrants.

Mr Frank Portelli, CMEA President and Prof Janet Mifsud, CMEA Advisor explained that the EU literacy report showed that up to 20% of European adults have poor literacy skills, and from experience, many people living in rural areas have little or no access to education. Poor literacy skills leads to poor health-seeking behaviour and contributes to the enduring stigma of epilepsy. The initial aim of the pictorial guide is to ensure that adults with epilepsy living in Europe who have a poor literacy standard, or those immigrants who find the foreign language barrier an issue in learning about epilepsy or helping others to understand the disease, will have access to tailored information. The project will contribute to the social inclusion of these persons by using a pictorial guide to overcome language barriers and literacy issues. This will improve their access to



social, health, education and employment services and help them to better manage their epilepsy, resulting in a better quality of life for these persons.

The format of the guide is readily adaptable for roll out in other regions of the world, where illiteracy rates are considerably higher than in Europe. The guide will be free to use, and freely available to download on the EPIICTO and IBE websites. It will ensure better communication between persons with epilepsy and the various professionals with whom they may come in contact. The target participants are persons who work with people with epilepsy, persons with epilepsy themselves, and carers/relatives of persons with epilepsy.

**Previous page:** EPICTO team: Noel Mercieca, Caroline Attard, Claudine Aitken and Frank Portelli, all from Malta; Thomas Porschen, Germany; Michael Alexa, Austria; Mr Jean Willem Braziley, Netherlands; Janette Melia, Austria; Janet Mifsud and Cole Curmi de Gray, both Malta; and Shirley Maxwell, Scotland.

**Above:** HE Dr George Vella, President of Malta addressing the participants at the EPIICTO launch.

**What to do in case of a seizure**

Stay calm. Clear a space around the person.

Put something soft under the person's head during a seizure.

When the seizure stops:

- Turn the person on their side.
- Make sure they can breathe.
- Check if they have any injuries.
- Let the person lie down until they feel better.

Stay with the person until they feel better. Take note of what has happened.

**Call an ambulance if:**

- The seizure lasts more than 5 minutes.
- The person does not wake up.
- You are worried about the person's breathing.
- The person is hurt.
- Another seizure happens soon afterwards.

**Do not:**

Do not try to stop a seizure or hold the person.

Do not move the person unless they are in danger.

Do not put anything in the person's mouth.


**At present the guide is available in 6 languages: English, Maltese, Dutch, German, Spanish and French. A further 7 language versions will be available soon: Italian, Russian, Chinese, Arabic, Swahili, Turkish and Mandarin.**

**For more information and to download the guide free of charge, please visit our website [www.epipicto.eu](http://www.epipicto.eu) or email us [epipicto@gmail.com](mailto:epipicto@gmail.com).**

### How to deal with your epilepsy



Talk to your doctor about your seizures and medication and follow their advice.



Remember to take medicines regularly.




Write down when you have seizures. This will help your doctor find the best medicines. Keep note of what might trigger your seizures.



Missing sleep can cause seizures. Try to get plenty of rest.




Eat a healthy diet.




Stress can cause seizures. You can't avoid it but you can learn how to deal with it.


### How to deal with your epilepsy




Get some fresh air and exercise every day.




Talk about your epilepsy with your friends and family.




Some people get a warning that a seizure is coming. The warning might be a smell or strange taste in your mouth.



After a seizure, you might feel tired or confused or dizzy. You will feel better soon.




If you are having seizures, you are not allowed to drive a car. Ask your doctor when it is safe to drive.




Take a balanced approach to life.


### How to deal with your epilepsy



Epilepsy is only one part of you! Try to enjoy your life. You do not need to stay at home. If flashing lights trigger seizures then be careful.




You can still study, learn or work. There are people who can help and support you.



You can have a normal life, but you may need to make some changes.

- Spend time with family and friends.
- Find a local support group.
- Don't be afraid to ask for help.
- You can have a relationship and have children.
- Women with epilepsy must talk to their doctor if they want to have children.



EPIPICTO: Pictorial Guide to Epilepsy is to help you talk about epilepsy. It is not a full guide about epilepsy. It gives some basic information and tips to live your life well. Please talk to your doctor for personal advice about your epilepsy and medication.

### About EPIPICTO



Pictorial Guide To Epilepsy



Co-funded by the Erasmus+ Programme of the European Union  
Project 2017-1-MT01-KA204-026946







EPIPICTO is a joint project of 5 European epilepsy associations:

- Caritas Malta Epilepsy Association  
[www.caritasmalta.org/services/epilepsy](http://www.caritasmalta.org/services/epilepsy)
- Epilepsie Dachverband Österreich (EDO)  
[www.epilepsie.at](http://www.epilepsie.at)
- Epilepsy Connections (Scotland)  
[www.epilepsyconnections.org.uk](http://www.epilepsyconnections.org.uk)
- Interessensvereinigung für Anfalls Kranke in Köln e.V.  
[www.epilepsie-selbsthilfe.de/koeln](http://www.epilepsie-selbsthilfe.de/koeln)
- Stichting Epilepsie Instellingen Nederland (SEIN)  
[www.sein.nl](http://www.sein.nl)

For more information, please visit our website  
[www.epipicto.eu](http://www.epipicto.eu)  
or email us  
[epipicto@gmail.com](mailto:epipicto@gmail.com)



International Bureau for Epilepsy

The EPIPICTO partners would like to acknowledge the support of the International Bureau for Epilepsy (IBE) in the dissemination of the project.

# NEWS FROM RUSSIA

**Busy time for Russian Charity Foundation "SODRUZHESTVO" ("Commonwealth")**

*Inna Airapetova sent us the details*



## International Epilepsy Day

On February 11, 2019 a charity concert and the photo exhibition "Life is Beautiful" took place in Moscow Column Hall of the House of the Unions. The concert and the exhibition were dedicated to International Epilepsy Day. This charity event was a part of the international programme "Epilepsy out of the Shadows".

In Moscow, charity concerts dedicated to International Epilepsy Day have been held annually since 2011. The main goal of the event is to raise epilepsy awareness and to help people living with this condition to improve their life quality.

The concert began with a welcome address by the Trustee of the Foundation, Deputy of the State Duma Oleg N. Smolin and the representative of the Interregional Foundation "Sodruzhestvo" Oleg I. Gorelko.

There were performances by the Folk Instrument Orchestra named after N. P. Osipov, the National Guard Forces Command Orchestra, Moscow Vocal Ensemble "Lanterns" and Folk Ensemble "Precious Stones" from the art school for children in Skhodnya, Moscow.

The photos in the exhibition were taken by young people living life to the full despite having epilepsy. The educational animated film "Epilepsy and Sport" created by IBE for International Epilepsy Day was shown. This is one in the series of Campi short videos that have been created in the past four years.

The concert took place in a very friendly atmosphere.

All money raised from selling tickets will be used to support children living with epilepsy.

The concert was supported by:

- Moscow Column Hall of the House of Unions management
- UCB pharmaceutical company, permanent partner of the foundation in creating patient programmes;
- Epilepsy Centers from Moscow

## Lecture at Moscow State University of Civil Engineering

Dr. A. M. Pivovarova spoke to students about epilepsy on March 26, 2019. Teachers and students were provided with very important information about the following:

- What is epilepsy?
- How often can you meet a person with epilepsy?
- What are the reasons for epilepsy?
- How to perform first aid if a person has a seizure.

Educational videos on these aspects were also shown. Lectures like these take place every year in different educational establishments.

## Charity Markets

Charity markets are also held annually. One took place on March 23, 2019 in the Church of Ilya the Prophet in Cherkizovo, Moscow. Dolls and souvenirs sold at the market were made by the patients' parents and by partners of "Sodruzhestvo".



MONDAY, 10 FEBRUARY 2020

## 'EPILEPSY - A GLOBAL HEALTH IMPERATIVE'



CELEBRATED IN 120 COUNTRIES WORLDWIDE

[www.internationalepilepsyday.org](http://www.internationalepilepsyday.org)

#EpilepsyDay