

# INTERNATIONAL EPILEPSY NEWS

ISSUE 3 - 2019



**A TARTAN FOR EPILEPSY**

*Hear my story workshop*

**PLANS FOR 2020**

# INTERNATIONAL EPILEPSY NEWS

## ISSUE 3 - 2019

### FROM THE EDITOR

As we publish this issue of IE News, we come close to the end of another year at IBE. It is only on looking back that we can see how much has been achieved and how busy we have been since January 2019.

In the last few issues we have brought you reports on International Epilepsy Day 2019, our Promising Strategies Program and our newest initiative, EpilepsyNEXT. There were congresses in Marrakech, Bangkok and Entebbe, with special programmes for people with epilepsy and their care providers, the Golden Light Awards and our General Assembly in Bangkok.

In this issue of IE News we unveil the new epilepsy tartan, we report on the very successful Hear My Story workshop for young adults that took place in Dublin in October, there is a very interesting report on a visit to Eswatini made by members of the African Regional Committee, and we introduce you to three new applicant chapters. Of great significance is the inclusion of epilepsy on the agenda for the WHO Executive Board meeting next February and your help is sought on this. And we also give you a sneak preview of some of the activities planned for 2020.

In the meantime, I wish you all a very Happy New Year.

Happy reading!

Ann Little  
Editor



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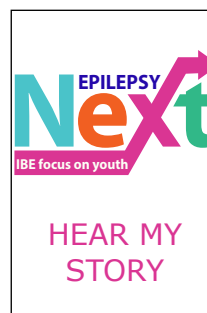
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intended to replace medical care.

# PRESIDENT'S MESSAGE

## DEAR FRIENDS

Across Scotland, the country in which I was born and raised and where I have spent most of my life, New Year's Eve is known as Hogmanay. This is a time for major celebration across the country and, in particular, in the Highlands and Islands. Historians believe that Hogmanay has Viking origins from their winter solstice celebration marking the passing of the shortest day and the start of the return to longer hours of daylight. The festival would have been brought to Scotland by blonde invaders arriving from Scandinavia during the 8th and 9th centuries.

Hogmanay is full of traditions. One of the best known is 'first-footing'. This is the welcoming of the first visitor of the New Year, who usually brings gifts of black bun and whisky. To be welcomed, they should be tall, dark and male. The dark hair is thought to be a necessary throwback to the Viking days, when a big blonde bearded stranger arriving on your doorstep with an axe meant trouble and probably not a very happy New Year!

At IBE, we are hopeful of a good year for all people with epilepsy across the world and I am looking forward to seeing our plans for 2020 take shape. It promises to be a year full of positive action, as we work hard to meet the priorities outlined in our strategic plan.

Of major importance is the WHO Executive Board meeting in Geneva in February. It is an impressive achievement, particularly for those involved in the IBE/ILAE Global Outreach Task Force, that epilepsy is included on the agenda. You will all have received the message from Mary Secco, our secretary general and co-chair of the task force, urging you to approach your health ministers to seek their support for a Global Action Plan for Epilepsy. Some of you will have already done so and received a positive response. But we need more member states to stand up in our support!

Also, in February, International Epilepsy Day will be celebrated around the world. This is an excellent opportunity for all stakeholders, including people with epilepsy themselves, to highlight the gaps that hamper the provision of optimal care, both medical and social, in their country. Good news sharing is also welcome!

As we move through the year, we will have three opportunities to recognise young adults with epilepsy, who have made their mark in the world, as we present our Golden Light Awards. These will be highlighted at three regional congresses – in Medellin, Colombia in May, in Toronto, Canada in September, and in Fukuoka, Japan in October. Chapters in these regions will be receiving invitations to nominate local candidates for the award. I hope many of you will do so. They are our future!



Thanks to new support provided by the BAND Foundation, we will be funding a number of new projects in the African region as part of our Promising Strategies Program, which has been running since 2006. Apart from these activities, we also have plans to roll out more events under the banner of our EpilepsyNext programme, including the launch of YEAH – the Young Epilepsy Advocates Hub. Watch this space for more news on this initiative!

But for now, it just remains for me to wish you and your family a joyful Hogmanay and a healthy and happy new year. And if you happen to spot a tall dark male, make sure he drops by just after midnight on the 31st December. I used to be dark, but never tall and so it won't be me! All the best for 2020. May it be a year of success and achievement for all our IBE members.

With best wishes

Martin Brodie  
President, IBE



# A Tartan for Epilepsy

Think of tartan and you probably think of Scotland. You might also think of men proudly sporting kilts in their clan colours. And there is also an element of romance associated with the cloth – think Braveheart!

Now epilepsy has its own tartan, providing a new opportunity to highlight our identity and to help in our work to raise awareness and reduce the stigma and discrimination that so often affect people with epilepsy. At present, we are considering how to use the design to best advantage. But, no, the wearing of kilts will not become a prerequisite for IBE membership!

This great addition to the epilepsy arsenal is thanks to the generosity of Robert Pool, a tartan designer from Scotland, who has registered a new tartan pattern for epilepsy. Robert, whose grand-daughter has epilepsy, registered the tartan with the Scottish Register of Tartans (SRT) - Scotland's official tartan register- in July 2019. The SRT is administrated by the National Archives of Scotland (NAS), a statutory body based in Edinburgh that aims to promote and preserve tartans. Any design submitted for registration to the SRT must first be approved by the NAS. Thankfully, the epilepsy tartan passed the test!

The naming and registration of official clan tartans began in 1815, when the Highland Society of London (founded 1778) decided that all clan chiefs each “be respectfully solicited to furnish the Society with as much of the Tartan of his Lordship’s Clan as will serve to Show the Pattern and to Authenticate the Same by Attaching Thereunto a Card bearing the Impression of his Lordship’s Arms”.

The tartan clothing that we associate with Scotland today can be traced back more than 400 years to the 16th century where they became standard clothing pieces in the Scottish Highlands identifying clans. However, following a very famous battle

between English and Scottish armies in 1746, known as the Battle of Culloden, changed this albeit temporarily. The English defeated the Scottish and a law was introduced that forbade clan members from carrying a weapon or wearing clan tartan.

Thankfully, tartan was returned to popularity in Scotland following a visit by George IV to Edinburgh in 1822. Wearing tartan, the king encouraged everyone, in particular those in high office, to don their tartan clothing. During the reign of Queen Victoria, the popularity of tartan continued to grow, the queen herself having been noted for her fondness for almost everything that came from Scotland. Since then, tartan has become a major addition to the Scottish economy, to which any visitor to a Scottish souvenir shop will attest!

Although many of us will still associate tartan with identification of clans, tartans don’t have to be associated with a family name. The epilepsy tartan is just one example of this. The epilepsy tartan is also not the first design registered by Robert. In January 2019, he registered a tartan to celebrate the 30th anniversary of the internet and the invention of the World Wide Web by Sir Tim Berners-Lee in 1989

and he also created a design to mark the 50th anniversary of the launch of the Apollo 11 spaceflight and the first moon landing by the Apollo Lunar Module ‘Eagle’ on the 20th July 1969.

So, for the epilepsy tartan, the sky is now the limit!



Above: Mel Gibson as Braveheart in tartan  
Below: Epilepsy tartan registration certificate



# IBE CONTINUES TO GROW!

Recently, IBE has welcomed the applications of three associations, two based in the European region and one in the African region to become IBE Associate Chapters. The applications have been approved by the International Executive Committee as Provisional Chapters. During the next General Assembly, taking place in 2021, IBE voting chapters will be invited to ratify these and other membership applications.

## Dravet Syndrome European Federation (DSEF)

Founded in 2014, the Dravet Syndrome European Federation (DSEF), a non-profit organisation, is a federation of European organisations active in the field of Dravet Syndrome. Together they have built a strong European community of people living with Dravet Syndrome, providing the community with a voice with which to fight against the impact of Dravet Syndrome.

Dravet Syndrome is a rare genetic disease starting in infancy characterised by drug-resistant epilepsy associated with complex neuro-motor development disorders, behavioural delay and intellectual disabilities. Initial seizures are most often prolonged.

Development remains on track initially, with plateaus and a progressive decline typically beginning in the second year of life. Individuals with Dravet Syndrome face a higher incidence of SUDEP.

Unless a cure or better treatments for Dravet Syndrome are found, individuals with this disorder face a diminished quality of life. Current treatment options are extremely limited and the prognosis for these children is poor.



## Purple Bench Initiative (PBI)

The Purple Bench Initiative seeks to reduce stigma in Uganda through active awareness in schools, institutions and communities. It seeks to educate the masses to dispel myths and misconceptions, advance involvement and boost efficiency/production while establishing a firm foundation that enables those affected to enjoy basic human rights and live dignified, meaningful and highly impactful lives.

The Purple Bench Initiative (PBI) was started by Nina Mago who has lived with epilepsy since childhood and has experienced the stigma and discrimination associated with it. She realized this is a result of ignorance on the part of school administration

and on the part of fellow students.

She identified a gap in social support for people with epilepsy and to create awareness about epilepsy so as to reduce stigma and discrimination towards them, their family and caregivers. PBI works with individuals to identify support groups, and works with caregivers to improve their livelihoods through income generating projects. PBI encourages individuals to come out of the shadows and talk about their condition as a basis for advocacy for improved medical services.



## RING20 Research and Support UK CIO

RING20 Research and Support UK CIO is a UK based patient group supporting families, individuals and professionals who are affected by Ring Chromosome 20 Syndrome – [r(20)]. The group has two aims: to promote and (where possible) fund research, to better understand the diagnosis, treatment, management and care for those living with r(20); and to provide a vital support and information network to families who often feel isolated given the rarity of the disease. It currently supports over 100 families from across the globe; quite an achievement considering there are reportedly only

150 cases cited in medical literature worldwide.

These statistics are likely due to the diagnostic challenge – recommended epilepsy panel testing for exomes or genomes or even CGH array, will not pick up the ring chromosome in the mosaic form. A karyotype has to be requested for chromosomal mosaicism so a doctor needs to be aware of the signs and symptoms of r(20) to request this, which rarely happens. For this reason r(20) is likely under-diagnosed and under reported. The aim is to change this through education and awareness.



# 3 NEW CHAPTERS





# WHO Executive Board 2020: *a golden opportunity for epilepsy*



There is a great deal of symbolism associated with sculptures and artwork that you will find in the city of Geneva. The main image above shows a 60-metre long ceramic fresco, the work of Hans Erni, who was 100 years old when the mural was inaugurated at the United Nations in Geneva in 2009. He died in 2015, at the age of 106. His mural is devoted to peace and is found at the entrance to the Palais des Nations, the European headquarters of the UN.

Even more prominent is the Broken Chair monument, a 12-metre high wooden chair with, as its name suggests, a damaged leg, that stands in the middle of a roundabout as you approach the area where the UN and WHO buildings are located. You cannot

miss it and, for those seeing it for the first time, it's difficult to drag your eyes away. Designed by another Swiss artist, Daniel Berset, it was made by a carpenter called Louis Genève to symbolise opposition to land mines and cluster bombs. Its purpose, was to encourage as many Member States as possible to sign the Ottawa Treaty on landmines in December 1997.

More than 20 years later, there is the potential to see the chair in a broader context; not just the association with land mines and cluster bombs but as a symbol of things that are broken or unwhole and that need to be fixed or completed. For the epilepsy community, it could represent a call to the WHO Executive Board on the need for an

Action Plan for Epilepsy to address what is missing in providing the best possible healthcare and support to people with epilepsy across the world. As the date of the annual WHO Executive Board meeting approaches, we now have a golden opportunity to work on this. But it needs the great efforts of us all.

In February, the WHO will hold its annual Executive Board meeting in Geneva. The great news is that, thanks to the efforts of IBE and ILAE and its membership, Epilepsy will be an item on the Agenda. This marks another step towards the development of an Action Plan for Epilepsy and, at this point, it would be a disaster if we were to trip.

To help us succeed, the support of the WHO Members States at the 146th Session of the WHO Executive Board will be required in order to translate our aspiration into reality. To attract this support, letters from your national Ministries of Health and Missions in Geneva are vital. And you can help with this by writing to the relevant offices in your country asking for support. The important wording is:

***“To request the director-general to develop, in full consultation with Member States, and in full collaboration with UN organization and non-state actors, a global Action plan to address epilepsy covering the period until 2030 for consideration by the World Health Assembly through the Executive board”.***

Already the draft agenda for the WHO





Executive Board is available, with Epilepsy listed as Agenda Item 11. In addition, there is a Report, prepared by the WHO Secretariat, to accompany the agenda item. In the report, recent collaborative achievement of WHO, IBE and ILAE – the Global Epilepsy Report: making epilepsy a global health priority, and a Side event held during the 72nd World Health Assembly – are referred to.

This is an opportunity that we must grab with both hands. If we lose it, we may not get the chance again – or at least not for some time. If you would like to have a template letter that you could adapt to send to your national Ministry of Health, together with a list of Member States, please contact the IBE office at [annlittl@ibe-epilepsy.org](mailto:annlittl@ibe-epilepsy.org).

So, how did we get to this point? Certainly not without a lot of effort and hard work! It all began five years ago, in late 2014, when China made a formal request to WHO to have epilepsy included in the agenda of the 136th WHO Executive Board meeting in 2015. The Chinese authorities then began the process of drafting a draft Resolution that might be acceptable. Russia then liaised with the Chinese delegation in advancing drafting of the Resolution. Discussion on agenda item on epilepsy and the draft Resolution at the 136th board in February 2015 were extremely fruitful, with 28 countries making positive statements. Then, in May 2015, the 68th World Health Assembly (WHA) Resolution was unanimously approved with the support of 42 countries and 19 co-sponsors.

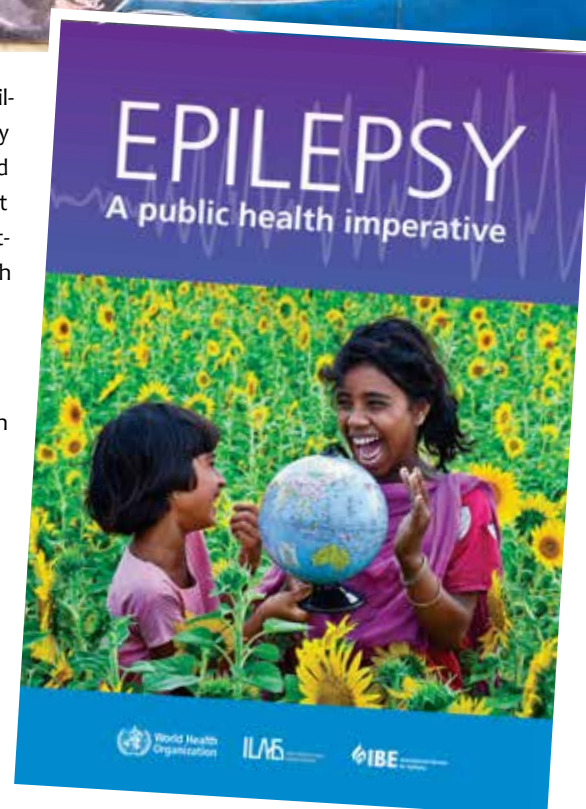
The next major achievement was the publication this year of the **Epilepsy: a public health imperative**. The report was launched in June at a special session held during the 33rd International Epilepsy Congress in

Bangkok. The report highlights the available evidence on the burden of epilepsy and the public health response required at global, regional and national levels. It is an important milestone in reinvigorating the and translating the World Health Assembly resolution into action.

In recent years the need for the Action Plan for Epilepsy has become more obvious and, for this to happen, inclusion on the agenda of the WHO Executive Board was vital. A great deal of work was done on this in 2017 and 2018. Then, in January 2019, during the 144th Session of the WHO Executive Board, an initiative of the Russian Federation, supported on site by Chile, China, Indonesia and Jamaica and in advance in writing by Russia, Croatia, Romania and Honduras, led to the inclusion of epilepsy in the Agenda of the 146 Executive Board to take place in 2020.

We also took advantage of the 72nd World Health Assembly in 2018 to request a slot for a much-coveted Side Event. This we managed to achieve and the event was extremely successful, attracting more than 120 participants from 39 different Member States. The application for the Side Event, submitted by the Russian Federation, was co-sponsored by China, Columbia, Croatia, Guyana, Kazakhstan, Honduras, Mexico, Slovenia, Tunisia and Zambia. Philippines and Malta officially requested to participate. From the Non-State Actors, the ILAE, IBE and the WFN were official contributors.

Now we have a unique opportunity to advocate for the development of an Action Plan for Epilepsy at the 146th WHO Executive Board meeting. The momentum should not be lost! It is essential for representatives of

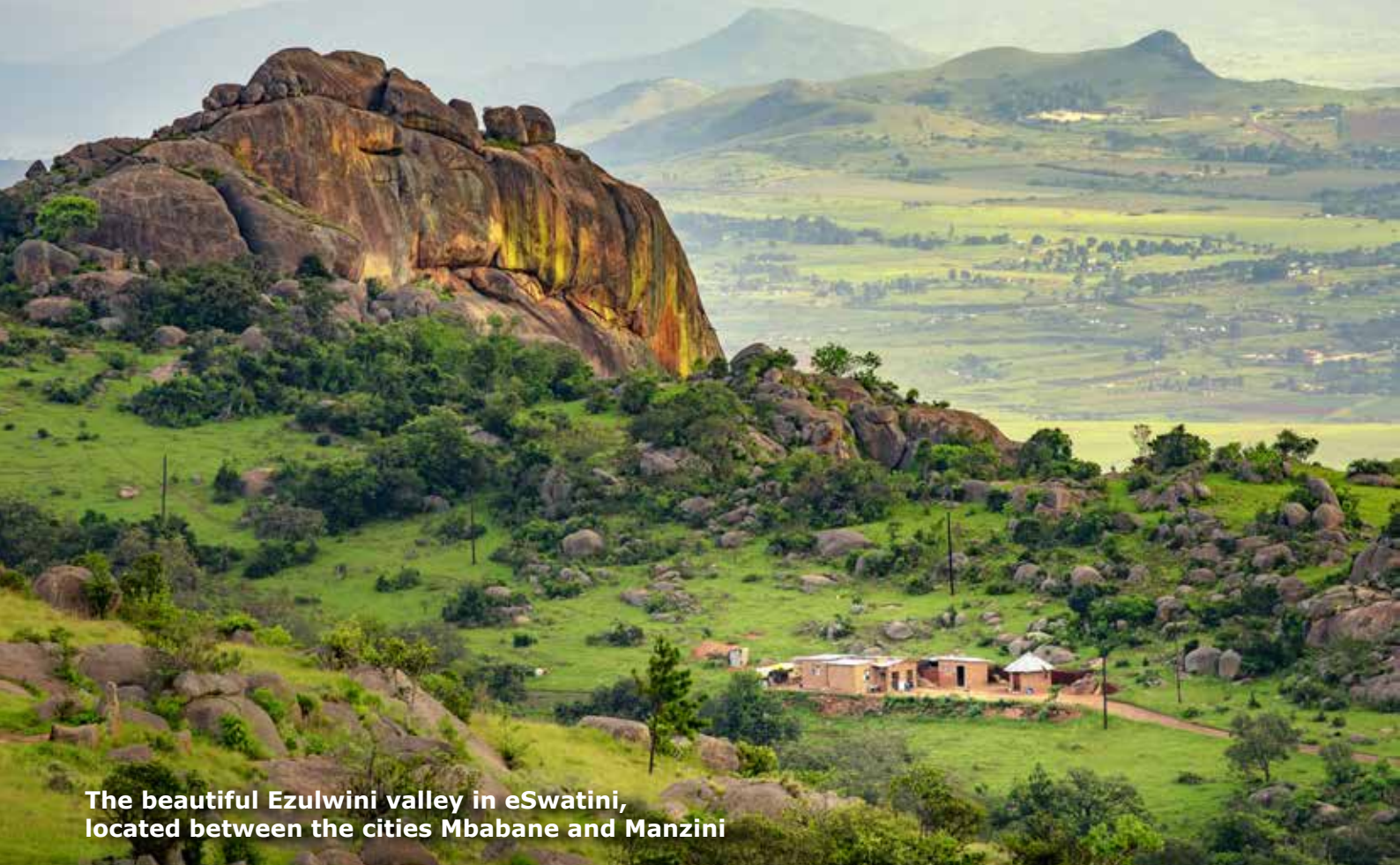


countries to be willing to make a statement at the board meeting, indicating that an Action Plan is needed. An intervention by Representatives of those countries who are Members of the WHO Executive Board is crucial.

Also, as mentioned earlier official letters from the Member States to the WHO, advocating for the Action Plan, are very much needed and SOON. A template letter is available from the IBE office ([annlittl@ibe-epilepsy.org](mailto:annlittl@ibe-epilepsy.org)). The letters should be sent to [hqgoverningbodies@who.int](mailto:hqgoverningbodies@who.int). Please copy Mary Secco ([mary@epilepsysupport.ca](mailto:mary@epilepsysupport.ca)) and Alla Guekht ([guekht@gmail.com](mailto:guekht@gmail.com)) with any letters you might send.

Together, with our combined efforts, we can make a difference!





The beautiful Ezulwini valley in eSwatini, located between the cities Mbabane and Manzini

# A visit to Eswatini

Betty Nsachilwa, Secretary, IBE African Regional Executive Committee reports on a productive visit



## BACKGROUND

On the invitation of Eswatini Epilepsy Organization (EEO), a visit to the Kingdom of Eswatini was undertaken by IBE Vice President Africa, Mr Action Amos, and Ms Betty Barbara Nsachilwa, Secretary, IBE African Regional Executive Committee in mid-November 2019. The purpose was two-fold:

1. to propose establishing an African Epilepsy Trust Fund (AETF)
2. to monitor progress of the Africa Epilepsy Advocacy (AEA) Project.

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The visit included discussions with His Royal Highness Prince Bandile, the Honourable Minister of Health, World Health Organization Country office, and the Epilepsy Association of Eswatini.

## DISCUSSIONS

On the first day of the visit, a presentation on the proposal to create African trust fund was made to members of Eswatini Epilepsy Organization, explaining why a trust fund was essential, its structure, how it would be funded and the benefits of having such a fund for African epilepsy associations.

There was also need to consider the legal process for registration, leadership and location of a secretariat. It was also revealed that the fund would be expected to raise a total sum of US\$200,000 in its initial stage. The proposed patron was the Patron of Eswatini Epilepsy Organization, His Royal Highness Prince Bandile. A Board of Trustees would be appointed with two members of the AREC being part of the Board. The raised funds would be disbursed for critical issues under education, health and economic empowerment.

The meeting was attended by, Mr Majahonkhe Mngometulu, Chairperson of the Board; Ms Phindile M. Gamedze, Board Member, Mr Mbusomuni Mahlalela, National Director EEO; Mr. Abraham Ntshalintshali, Member EEO; Mr Mzwandile Dlamini, Corporate and Strategy Officer & EEO Liaison Officer; Mr Nhlanhla Dlamini, Accounts Clerk.

## MEETING AT WHO OFFICE

In the afternoon, the team visited the



World Health Organization office for a meeting with Dr Kevin Makadzange (HPR Officer). The meeting focussed on the significance of the advocacy project and appealed to WHO to assist Eswatini Epilepsy Organization in its efforts to have a National Action Plan on Epilepsy introduced. Dr Makadzange was also told about the proposed African trust fund and asked that whenever there was need to engage WHO, the country office would be contacted.

Dr Makadzange commended the efforts of Eswatini Epilepsy Organization and indicated that WHO was well aware of the recommended actions following the WHA 68.20 Resolution of 2015. However, WHO Eswatini office would wait for the Ministry of Health for a response and action. With regard to the 73rd WHA in 2020, the Eswatini WHO Office would wait for instruction from the Regional Office. The country office agreed that an Action Plan on Epilepsy was important to alleviate the challenges faced by persons with epilepsy.

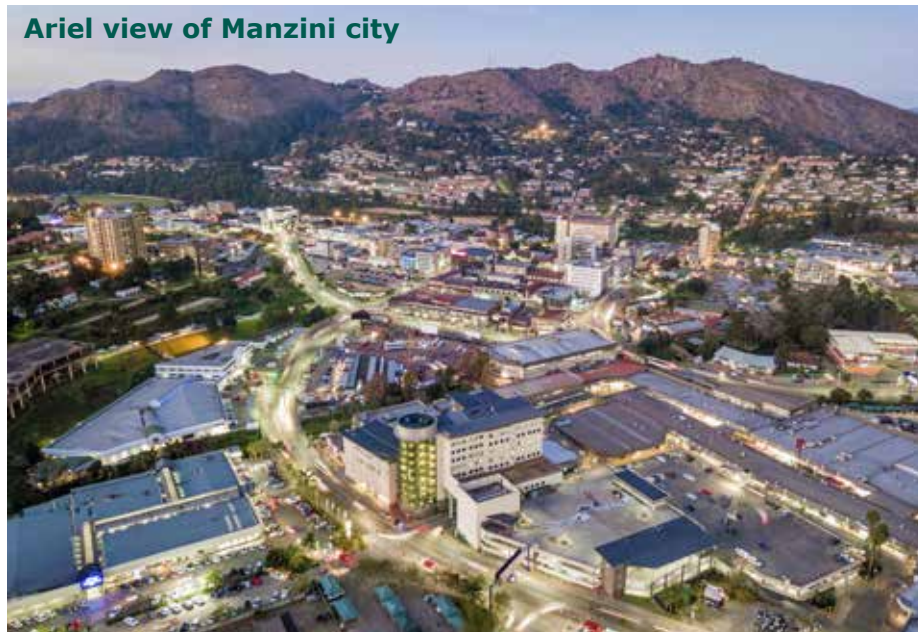
## HIS ROYAL HIGHNESS

The team met with His Royal Highness Prince Bandile at the Royal Villas. Mr Amos presented the main points of the trust fund Concept Note, emphasising three areas of action - education, health and economic empowerment. An initial fund of US\$200,000 to 300,000 was proposed, with Eswatini to host the fund Secretariat, since the prince had agreed in earlier correspondence to champion the cause.

Ms Nsachilwa elaborated on the significance of the Africa Epilepsy Advocacy Project (Utetezi), explaining that the project was to support the implementation of the WHA Resolution WHA 68.20 of 2015. Together with five other countries, Eswatini was one of the selected countries for the first phase of the project. The next phase would see other countries selected.

His Royal Highness was impressed with the work done to date and said he had been inspired by the recent established Malaria Trust Fund in the Kingdom of Eswatini. He agreed to be patron of the fund and that Eswatini would host it. He was pleased that five of the six selected countries implementing the Advocacy Project were based in the Southern Region and were members of the Southern African Development Community (SADC), another important organ where the topic of Epilepsy should be on the agenda. He emphasized the need to

## Ariel view of Manzini city



have epilepsy highlighted at SADC level.

The meeting agreed to the following steps:

1. To consider the legal procedures for registration of the AETF
2. To draft a Constitution
3. To establish the fund Secretariat in Eswatini
4. To propose names for the Board of Trustees
5. To consider suitable sponsors

## MEDIA INTERVIEWS

Mr Amos and Ms Nsachilwa were interviewed on a morning show at the Eswatini National Broadcasting station. The show discussed the challenges of having epilepsy and what actions had been done so far to alleviate the suffering of persons with epilepsy. The Chairperson also revealed the proposed establishment of the AETF to resolve challenges faced by people with epilepsy in Africa and encouraged the formation of National Action Plans on epilepsy

**PHOTOS:** Opposite page, front left to right: Mr Abraham Ntashlintshi, EEO; Dr Magagula, Director Ministry of Health; Mr Action Amos; His Royal Highness Prince Bandzile; Senator Lizzie F Nkosi, Hon. Minister of Health; and Ms Phindile Gamaedze, Board Member EEO. Back row: Ms Betty Nsachilwa, AREC; Dr Simon M Zwane, Principal Secretary Ministry of Health; and Mr Mbusomuni Mahlalela, Director EEO.

**Below, from left:** Mr Action Amos, HRH Prince Bandzile and Ms Betty Nsachilwa.

**Bottom, from left:** Mr Abraham Ntashlintshi; Mr Action Amos; Dr Makadzange HPR, WHO Eswatini Office, Ms Betty Nsachilwa



as a stepping stone to successful quality health care.

The Live Radio interview with the 'White Hippo' was organized by Mr Mzwandile B Dlamini, Corporate Strategy Officer and Liaison Officer for the EEO Advocacy Project. The interviewees were Mr Action Amos, Ms Betty B Nsachilwa and Mr Mbusomuni Mahlalela National Director. The interview addressed issues on causes of epilepsy, action to raise epilepsy to an understandable platform, the Advocacy Project and the trust fund.

## ESWATINI MINISTRY OF HEALTH

The team was privileged to have a meeting with the Hon Minister of Health, Senator Lizzie F Nkosi; Principal Secretary, Dr Simon M Zwane; and Director, Dr Magagula. His Royal Highness who joined the meeting at a later stage. Those present were informed that the visitors were representing the International Bureau for Epilepsy (IBE) through the IBE Africa Regional Committee and were visiting Eswatini to propose the establishment of a trust fund and to monitor progress on the implementation of the Resolution of WHA 68.20 of 2015.

The Minister asked about the work of AREC. On advocacy and the trust fund, she enquired whether there was seed money or any other funding for the fund; how contributions would be made to fund; how IBE/AREC related to the African Union and other organs on the continent. The Minister also asked why Eswatini, with a small economy, was chosen to hold the fund Secretariat.

iat. She considered that the Patron could be a Patron even with the office elsewhere but still accomplish his role. She also stated that the mandate to establish such a fund takes some time, giving an example of the challenges experienced in the establishment of the Malaria Trust Fund.

Mr Amos outlined the work of the IBE African Regional Committee and assured the Minister that the proposed trust fund would raise its seed money through pledges, fundraising and donations. The meeting was also informed that IBE Chapters in Africa were supported with limited grants for projects. The political will and passion were motivating factors in choosing Eswatini to hold the secretariat with much of the proposal coming from His Royal Highness.

On the invitation to raise other issues, Mr Amos and Ms Nsachilwa spoke of inadequate supplies of anti-epilepsy medication; improvement in collection of statistics on epilepsy; the Ministry to support the Eswatini Epilepsy Organization (EEO) to work with other stakeholders in coming up with a National Action Plan; and an appeal to have one of the EEO members accompany the Ministry of Health to the World Health Assembly (WHA) in 2020.

The meeting agreed on the following:

1. His Royal Highness to be the Patron of the trust fund, with a Secretariat in Eswatini.
2. To provide credentials to the person nominated to attend the WHA, but without the provision of financial support.

3. The Ministry to collaborate with the EEO, as far as limitations allowed, in accomplishing the Advocacy Project.
4. The appointment of a Focal Point to work with the EEO.

## FINAL WORDS

The visit to Eswatini was fruitful, considering that the visits to the intended offices were fulfilled and the message conveyed as planned. The African Epilepsy Trust Fund concept was adopted and a Constitution write up to ensure the legal process commences.

Eswatini Epilepsy Organization was encouraged to mobilize persons with epilepsy into support groups and to advocate both at grass root and national levels. Members of Eswatini Epilepsy Organization were asked to oversee a successful stakeholder consultative platform for the Advocacy Project and to ensure feedback to the Ministry of Health which was interested in seeing positive results. Eswatini Epilepsy Organization would present their proposed National Action Plan during a Workshop to be held with stakeholders.

With regard to the Utetezi (Advocacy) Project, the Liaison Officer needed to learn more about epilepsy in order to give correct information to the public and the organization to explain procedures on how they will carry out the awareness programme. There is need for continued guidance and monitoring to ensure a well-recognized program on epilepsy based on partnership with other stakeholders.

## About Eswatini

Eswatini or eSwatini in Swazi, and also known as Swaziland, is a landlocked country in Southern Africa. It is bordered by Mozambique to the northeast and by South Africa to the north, west and south. It is one of the smallest countries in Africa but with a diverse climate and topography that belies its size.

The population is composed primarily of ethnic Swazis. Its present boundaries were drawn up in 1881 in the midst of the so-called 'scramble for Africa' by European powers. Swaziland was a British protectorate from 1903 until it regained independence in 1968. In April 2018, the official name was changed from Kingdom of Swaziland to Kingdom of Eswatini. The government is an absolute diarchy since independence, ruled jointly by the King and Queen Mother.

Eswatini is a developing country with a small economy and with most employment provided by agriculture and manu-

facturing. It is a member of the Southern African Development Community (SADC), the African Union (AU) and the United Nations.

The biggest problems faced by Eswatini relate to health issues – HIV/AIDS and tuberculosis. It is estimated that at least 25% of the adult population is HIV-positive. It has the highest prevalence of HIV among those aged 15 to 49 years in the world.

As of 2018, Eswatini had the 12th lowest life expectancy rate in the world at 58 years. As a consequence, its population is young, with more than a third under the age of 14 years.



Eswatini marked in red with Mozambique to the north east and South Africa on its remaining borders





## NEWS FROM EpiCARE

European Reference Network for rare and complex epilepsies

<https://epi-care.eu>

### EpiCARE on the Red Carpet in Cannes!

The European Commission's EU Protects campaign featuring an inspiring and touching video on an EpiCARE ERN patient case with the contribution of the network coordinators and other members was awarded a Silver Dolphin prize at the Cannes Corporate Media & TV Awards. The short film shows how collaborative work between ERN EpiCARE members from Finland, UK, France and Sweden helped 4-year-old Onni from Finland, who was diagnosed with hypothalamic hamartoma, by finding the right course of treatment. The Cannes Corporate Media & TV Awards are presented annually to honour the world's finest corporate films, online media

productions and documentaries in one of the most

important film centres: Cannes, France. The international competition is open to film producers, clients, agencies, TV stations, as well as students. The coveted Dolphin Trophies in Gold, Silver, Black, Blue and White are awarded at Palm Beach, Cannes in autumn each year.

Watch it at <https://www.youtube.com/watch?v=DB48vKXT67o>.



### Rare2030 project launched

Professor Alexis Arzimanoglou from HCL - Hospices Civils de Lyon, EpiCARE coordinator, and Isabella Brambilla, EpiCARE patient representative (Epag Epicare & Dravet Italia Onlus) attended the Rare2030 panel of experts meeting in Brussels.

This is a two year project that will end in a presentation to parliament at the end of 2020 with recommendations on the most critical areas needing sound policy.

#### WHY IS Rare 2030 IMPORTANT?

Since the adoption of the Council Recommendation on European Action in the field of Rare Diseases in 2009, the European Union

has fostered tremendous progress to improve the lives of people living with rare diseases. Rare 2030 will guide a reflection on rare disease policy in Europe through the next ten years and beyond.

Rare 2030 is a foresight study that gathers the input of a large group of patients, practitioners and key opinion leaders to propose policy recommendations that will lead us to improved policy and a better future for people living with a rare disease in Europe.

### VALENCIA, SPAIN Strategic plan for epilepsy

After two years of collaborative work by all stakeholders, a four-year strategic plan was launched in the Valencian region that addresses the gaps in epilepsy healthcare provision. The main goals of the plan are:

1. To improve the healthcare in patients with epilepsy by means of a comprehensive approach
2. To improve intersectoral and institutional coordination in the healthcare of patients with epilepsy
3. To improve epilepsy care in special population groups

The plan aims to reduce the 'treatment gap in epilepsy' and defines strategies to prevent and reduce the incidence of the disease. Patient empowerment is a key part of the plan to ensure that needs

are met and to avoid discrimination in schools, employment or the social arena.

The achievement of the objectives of plan will be monitored by a list of predefined indicators and a coordination committee.



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



**Above:** EPIICTO 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.

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

Five European epilepsy organisations: Caritas Malta Epilepsy Association, Epilepsie Dachverband Österreich, Austria; Epilepsy Connections, Scotland; Interessenvereinigung für Anfalls Kranke in Köln e.V, Germany; and Stichting Epilepsie Instellingen Nederland, Netherlands, recently launched a pictorial guide for adults in epilepsy, EPIICTO, funded by the EU Erasmus+ programme. The launch was held at San Anton Palace, Attard, Malta on 14 September, 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 EPIICTO 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 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



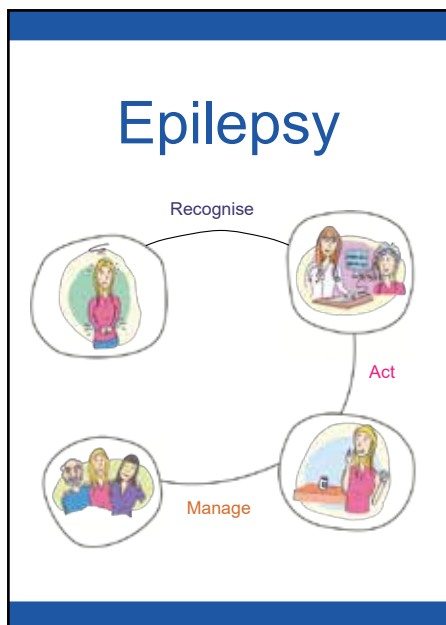
stigma. The Minister for the Family, Children's Rights and Social Solidarity, Michael Falzon, argued that we cannot deny the stigma related with epilepsy, especially within marginalised communities such as migrants.

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,





## 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.**

## 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.

5 min

## 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.

## 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.

where illiteracy rates are considerably higher than in Europe. The guide will be free to use, and freely available to download on the EPIPICTO 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.

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

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)

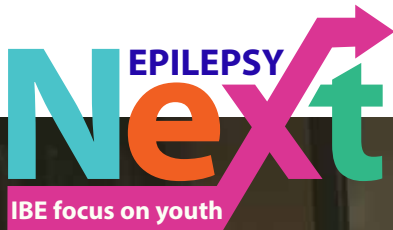
For more information, please visit our website  
[www.epipicto.eu](http://www.epipicto.eu)  
or email us  
[epipicto@gmail.com](mailto:epipicto@gmail.com)

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

The eight page guide relies heavily on images to convey its message. The minimal text is already available in six languages.

# HEAR MY STORY

## Communications workshop for young people



### BACKGROUND

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.

### 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 embrace 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 an IBE youth council.

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, which took place in Dublin in early October, was led by Evaldas Rupkus, an experienced facilitator from Germany, 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.

### 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. 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,



## 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



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.

## 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 adaption 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.”

## 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,

So happy that IBE made this possible for us!

I felt comfortable and confident in talking and discussing

I found the whole experience super motivating

Without IBE none of this would have happened!

Thank you for everything & this opportunity that comes once in a lifetime

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.

## PARTICIPANTS COMMENTS

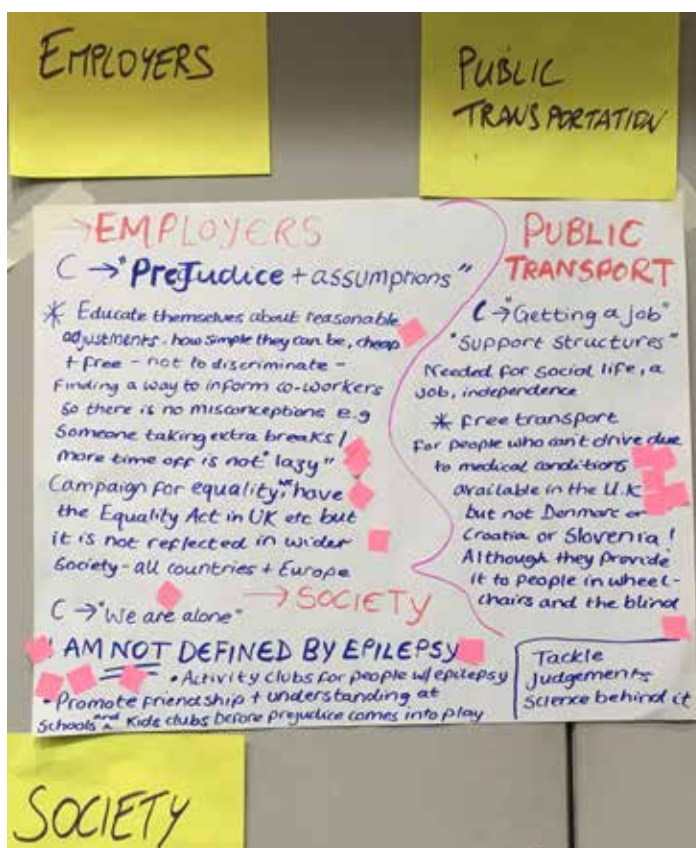
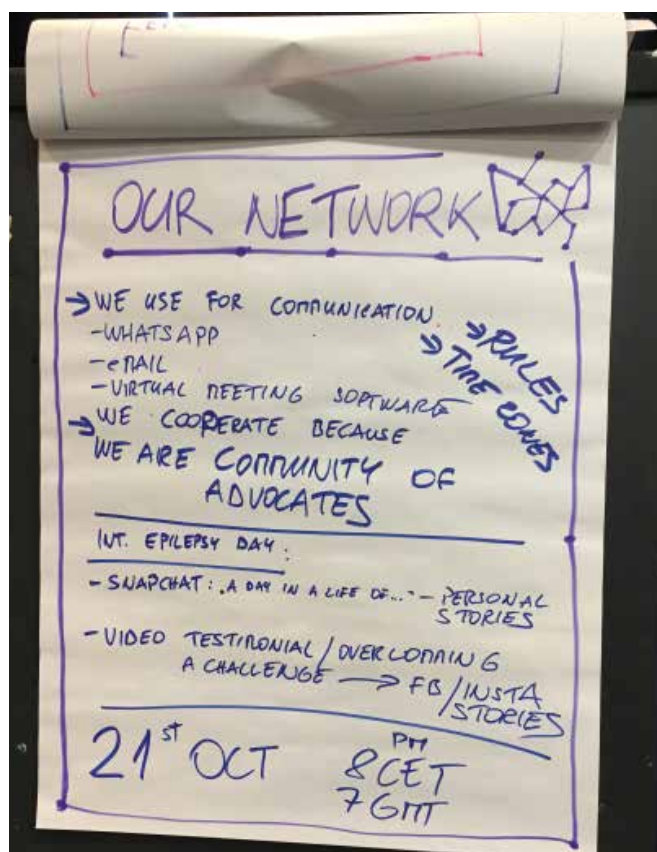
### What were the best aspects of the workshop?

- 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.



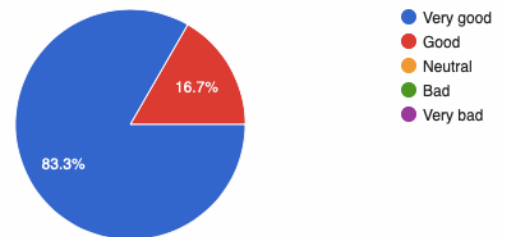


# WORKSHOP SURVEY

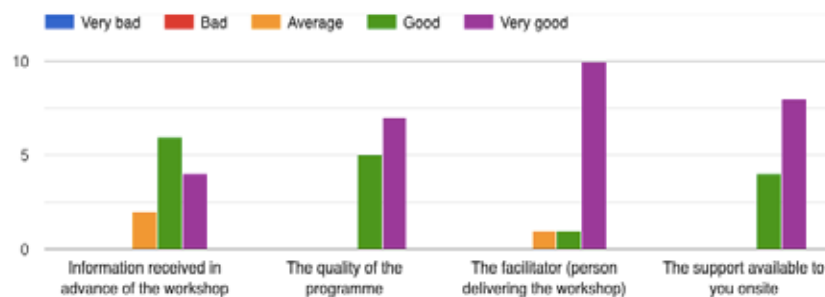
## The results in graphics

### Overall how would you rate this workshop?

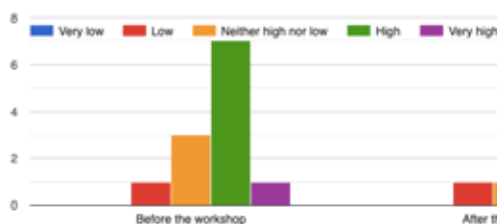
12 responses



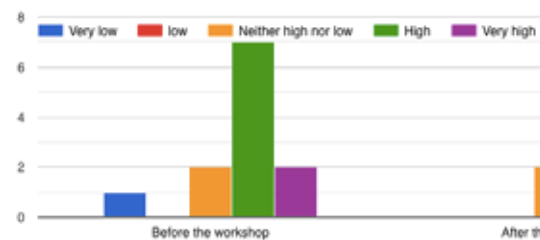
### How do you rate:



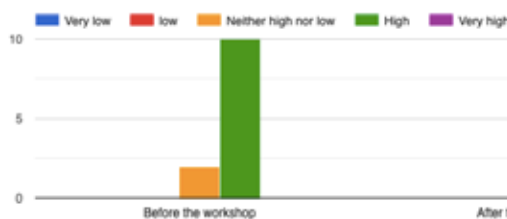
### To what extent do you have the necessary personal and cultural competencies to be an epilepsy spokesperson? (e.g. communication skills, teamwork abilities)



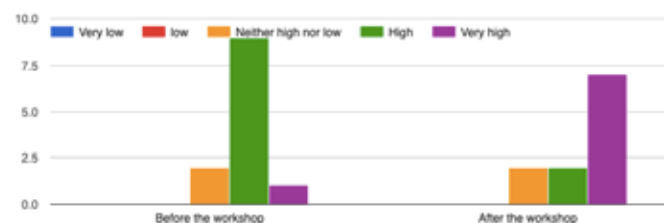
### How much do you understand advocacy/speaking out and the purpose of advocates?



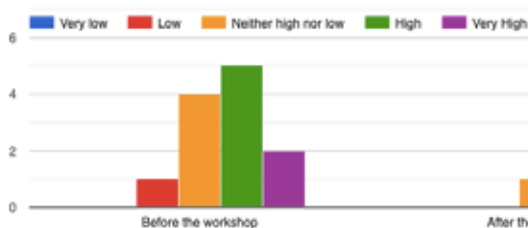
### How would you rate your ability to represent the views of other people living with epilepsy?



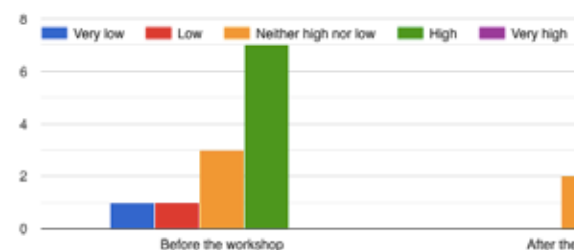
### How empowered do you feel to make a positive change on epilepsy awareness?



### How do you rate your confidence in working on an epilepsy project?



### How do you rate your skills in working on an epilepsy project?





# PLANS FOR 2020

## PROMISING STRATEGIES 2020

We are delighted to announce that, thank to financial support from the BAND Foundation, we will have significant funds to offer for projects carried out under the Promising Strategies Program next year. Focus will be on projects in the African region but we hope also to be able to support some projects in other regions through IBE General Funds. You will be hearing more about this in early January!



Those of us who were at the International Epilepsy Congress in Bangkok last June, will have been humbled by the eight young adults who received an International Golden Light award at the Opening Ceremony and who shared their remarkable stories during a special congress session earlier in the day.

For 2020, there will be three further opportunities to recognise more young adults who have achieved great things, despite a diagnosis of epilepsy, and thus are a "shining light" for others.

The IBE Golden Light Awards will be

presented at three regional congresses taking place during 2020 - at the 11th Latin American Epilepsy Congress, Medellin, Colombia (23rd - 26th May); 1st North American Epilepsy Congress, Toronto, Canada (25th - 27th September); and the 13th Asian & Oceanian Epilepsy Congress, Fukuoka, Japan (8th - 11th October).

To be considered for an award in 2020, candidates must be between 18 and 40 years of age on 1st January 2020, and be nominated by the IBE chapter in which they are involved (as a member, volunteer, board or staff member).

Each IBE chapter (full, associate and provisional) is entitled to nominate one person to be considered for the award at the congress taking place in the region in which they are based.

The award consists of a glass plaque, and a lapel pin which is hoped the awardees will wear with pride. Support is also provided to attend the congress at which the award will be presented.

Information on the 2020 awards will be circulated to chapters in the coming weeks. This is a golden opportunity for you to promote the work of your young advocates!



## GOLDEN LIGHT AWARDS





# International Epilepsy Day

## ART COMPETITION

Thank you to all those who entered the IBE Art Competition for International Epilepsy Day 2020. With the theme Friendship and Inclusion, there was a fantastic response from all ages and from across the globe. In all, we received more than 200 entries in three categories: under eight years, eight to 15 years, and 16 years and over.

Early in the New Year, once the judging panel has completed its difficult deliberations, we will be announcing the winners and providing a link on the International Epilepsy Day website [InternationalEpilepsyDay.org](http://InternationalEpilepsyDay.org) so that you can enjoy all of the wonderful artwork that was submitted.

This wonderfully colourful work of art was submitted by Chi Tin Cheng, aged 11 years from Hong Kong. The title of the picture is 'Love what we have'.

## InternationalEpilepsyDay.org MONDAY 10th FEBRUARY 2020 RESOURCES TO HELP YOU GET INVOLVED!

Check on the Resource page of the website where you will find downloads to help you get involved on International Epilepsy Day:

<https://internationalepilepsyday.org/resources/>

where you will find logos, social media icons, selfie cards and posters. There are also resources in 12 different languages.

### Catch up with Campi

Check out the three new Campi videos that we've made for 2020 at:

<https://internationalepilepsyday.org/campi/>

There are now eight in the series. And if you would like to translate them to your language, or add subtitles, we are here to help!

Finally, do keep us posted on activities planned by your association - we would love to promote them on the website.



## SHARE YOUR VIDEO STORY

The Hear my Story workshop participants are making personal videos to share on social media on International Epilepsy Day. You too can get involved by telling the world about your epilepsy journey. Your video can be shared through your personal social media accounts, if you are happy to do so. You can do this directly to Instagram, Twitter and Facebook. You can also upload your video to YouTube.

Please make sure you tag your video with the '#epilepsyday' hashtag. You may also like to include other keywords such as #epilepsy, #epilepsyadvocate, #patientexperience, and any other words you find appropriate.

Please tag the appropriate International Epilepsy Day social media account so we can find and share your messages:

**@intepilepsyday – Twitter/Insta**

**@epilepsyday – Facebook)**

If you are not a social media user, but would like to be involved, you can email your videos directly to us here. We will not share your name or personal details, unless you give us specific permission to do so.

Not sure how to get started? We've prepared some tips for you, which you will find on this link. <https://internationalepilepsyday.org/online-awareness/video-advocacy-for-epilepsy-awareness>





MONDAY, 10 FEBRUARY 2020

## 'EPILEPSY - A GLOBAL HEALTH IMPERATIVE'



CELEBRATED IN 120 COUNTRIES WORLDWIDE

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

#EpilepsyDay