

INTERNATIONAL EPILEPSY NEWS

ISSUE 1 - 2020

Epilepsy and Covid-19

International Epilepsy Day report

Report from Cameroon

INTERNATIONAL EPILEPSY NEWS

ISSUE 1 - 2020

FROM THE EDITOR

The last few months have seen the world and how we live in it change beyond our wildest nightmares. None of us could have imagined how so many of us would have to change how we live our lives because of a virus that has brought such misery to almost every country in the world. The IBE website has a new section that provides information on COVID-19 and epilepsy and you can find out more on page 4 of this issue.

On a brighter note, we bring you information on how International Epilepsy Day 2020 was celebrated in early February - with almost 150 countries participating.

Most of us could consider a steady hand as being essential for an artist - but not so for Niloofar from Iran. Find out more and see some of her work on page 14.

Kenneth Ninying from our chapter in Cameroon reports on a very successful workshop for young people, funded by IBE. We hope that some of the recommendations will be taken on board by the community in Nseh village.

IBE is very pleased to send its congratulations to Helen Cross, ILAE President-elect, who is making history as the first woman to be appointed to the position.

Finally, on a sad note, we publish the obituary of Henry Stokes Brown from the IBE chapter in Guatemala who died in March. May he rest in peace.

Happy reading!

Ann Little
Editor



CONTENTS

4
COVID-19
IBE website
resources



10
OBITUARY
Remembering
Henry Stokes
Brown



12
RARE AND
COMPLEX
EPILEPSIES
Report from
ePAG Epilepsy



15
YES FORUM
Report from
Cameroon
workshop



6
IED REPORT
International
Epilepsy Day
around the
world

11
ILAE
PRESIDENT
ELECT
Prof Helen Cross

14
MEET
NILOOFAR
Talented artist
from Iran

16
8 FEBRUARY
2021
Save the date
for International
Epilepsy Day!

EDITOR: Ann Little

REGIONAL SUB-EDITORS:

Action Amos, Hassan Hosny, Tomás Mesa,
Natela Okujvava, Susan Pietsch-Escueta,
Man Mohan Mehndiratta, Ding Ding

ADVISORS: Martin Brodie, Mary
Secco, Anthony Zimba



International Epilepsy News is published
by the International Bureau for Epilepsy,
7 Priory Office Park, Dublin A94 FN26,
Ireland. www.ibe-epilepsy.org.

All rights, including moral rights, reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, without the prior permission in writing from the publisher. The Editor reserves the

right to edit content for reasons of space or clarity. The views expressed in this magazine are not those of the publisher. Articles covering medical aspects of epilepsy are not intended to be taken as advice; they are not intended to replace medical care.

PRESIDENT'S MESSAGE

DEAR FRIENDS

When I wrote my last message to you for IE News, the world was in a very different place. Since then, everything has changed. We have watched in horror as first China and then the rest of the world has been invaded by COVID 19, a virus to which none of us has immunity. As I write, more than 2 million people worldwide have been infected, and 135,000 people have died, with number growing daily.

How long this virus will continue to plough an unchecked course through the world's population before we have a weapon such as a vaccine with which to fight it, is not known. And when we do come out at the other end of this nightmare, the world will be a very different place. In the meantime, we must take all the precautions to which we are directed by our national governments in order to safeguard ourselves and our loved ones.

If you have epilepsy or care for someone with epilepsy, you are probably aware that there is no evidence that COVID-19 has a direct effect in worsening seizures. However, in some places continued access to antiseizure drug may be causing problems and, if diagnosed with the virus, the medication taken to lessen the symptoms may worsen the seizures. The stress to which we are all exposed will also have a negative impact on our health and peace of mind. And, of course, with medical personnel redirected to deal with the virus, there are likely to be delays in clinic appointments.

I don't need to tell you that, like other organisations around the world, COVID 19 has had a major influence on IBE's plans for this year and many of our activities will have to be curtailed, postponed or cancelled. Most of the regional congresses scheduled for this year including the 11th Latin American Epilepsy Congress in Medellin, Colombia in May and the 1st North American Epilepsy Congress in Toronto, Canada in September, have been postponed till 2021. The 13th Asian & Oceanian Epilepsy Congress in Fukuoka, Japan in October may still happen, if things settle down over the summer. This means that our Golden Light Awards and the special IBE programmes at the postponed congresses will not now take place until next year. We have received nominations for the Golden Light Awards in Medellin, and we will carry these over to 2021.

The 34th International Epilepsy Congress, which was planned for Paris 2021, will now happen in 2022. This important biennial global congress has always been the event at which we hold our General Assembly and manage the handover of the Board, with one term ending and the next beginning. We are now looking at how best to react to this unprecedented change and will be coming back to you soon with a revised plan.



While face-to-face meetings and travel have now been paused, with an associated temporary reduction in staffing levels, IBE still remains 'open for business'. We will continue communicating with our chapters and take the opportunity to plan for bigger and better events when we come out at the other end of this global crisis.

Our Promising Strategies Program 2020, with funding from the BAND Foundation, will soon announce projects in Africa, which have been selected for support. International Epilepsy News will continue to be published and our websites and social media platforms will remain active. Planning for International Epilepsy Day 2021 will soon get underway following our usual timescale.

The advocacy project in Africa, involving chapters in six countries, is still active and will conclude in the coming months. We will bring you the results on Phase 1 of this important activity as soon as we can. And we will, of course, continue to plan for 2021!

While I am disappointed that IBE had to cancel some of our most important activities for this year, I appreciate that our chapters around the world are experiencing similar difficulties. These are trying times for all of us, but we need to prioritise the safety of our families and all those who are dear to us. This must remain foremost in our minds for the present. It will be a tough time for us all, and tougher still for those who have family members or friends who have succumbed to the virus. However, with a shared and positive focus we can get through this challenge and look forward to brighter times ahead.

Stay safe!

Martin Brodie
President

COVID-19 & Epilepsy Information



<https://www.ibe-epilepsy.org/covid-19-epilepsy-information/>

At this point in time, we are all aware of the most important weapon we have in the fight against the corona virus Covid-19, which is to wash your hands and to wash them correctly. There is also a wealth of information available about the virus, the staggering number of people who are dying each day from this deadly pandemic including many in the healthcare sector who are working tirelessly to help those who become dangerously ill; the shortage of sufficient protective clothing; and the great efforts being made to find a vaccine as quickly as possible. Much of the information is accurate and informative but there is also a lot of mis-information around, including myths on how to protect oneself against the virus. There are also a number of evil scammers around who are preying on the human misery and fear the virus is creating to try to steal our money. We need to be especially careful at this time to keep ourselves safe.

For people with chronic medical conditions, including epilepsy, this is a particularly worrying time. There is an urgent and ongoing need to know if or how Covid-19 might impact those with a comorbidity. However, thankfully, there is a range of accurate and

reliable information available and IBE has created a special page on its website to act as an information directory. The page hosts links to information in general about Covid-19, including links to excellent resources on the WHO site which is available in many languages. There is also a range of informative posters and documents available for download.

Did you know that there has been a special story book created for children aged 6 - 11 years to help children to understand and come to terms with the virus? Through Ario, a friendly orange dragon, the facts are told in entertaining and easy to understand language. My hero is you is also available in a number of languages, other than English: <https://interagencystanding-committee.org/iasc-reference-group-mental-health-and-psychosocial-support-emergency-settings/my-hero-you>.

The section relating to the virus and epilepsy has links to information provided by a number of IBE chapters. Like the rest of our special Covid-19 page, the list is growing as more chapters share information with us.

As we wait for this terrible time to pass, stay safe.

Information from International Health Authorities

- World Health Organisation (WHO)
- FDA (US Food & Drug Administration)
- European Medicines Agency (EMA)
- European Academy of Neurology (EAN)
- European Patients Forum (EPF)
- Johns Hopkins University

Epilepsy specific information

- EpiCARE European Reference Network (ERN)
- Dravet Syndrome UK
- EpiCARE European Reference Network webinars

Information from IBE chapters

- Epilepsy Action, UK
- ANPE, Spain
- Epilepsy Foundation, USA
- Epilepsy Society, UK
- Caritas Malta Epilepsy Society
- Epilepsy South Africa



My hero is you
Illustrations from the children's book

My hero is you
Illustrations from the children's book





International
Epilepsy Day

2020



Participation Around the World

International Epilepsy Day events were seen in 142 countries or regions around the world, making International Epilepsy Day 2020 the biggest yet! A big THANK YOU! to all those who helped make the day a great success.

- Albania
- Angola
- Antigua and Barbuda
- Armenia
- Aruba
- Austria
- Australia
- Argentina
- Bahrain
- Bangladesh
- Barbados
- Belarus
- Belgium
- Bermuda
- Bolivia
- Bosnia and Herzegovina
- Botswana
- Bulgaria
- Brazil
- Brunei
- Darussalam
- Burkina Faso
- Canada
- Cambodia
- Cameroon
- Cayman Islands
- Chile
- China
- Colombia
- Congo
- Costa Rica
- Cote d'Ivoire
- Croatia
- Cuba
- Cyprus
- Czech Republic
- Denmark
- Dominican Rep
- Ecuador
- Egypt
- El Salvador
- England
- Estonia
- Fiji
- Finland
- France
- Gabon
- Georgia
- Guatemala
- Guyana
- Ghana
- Greece
- Hungary
- Honduras
- Hong Kong, SAR
- Iceland
- India
- Indonesia
- Iran
- Iraq
- Ireland
- Israel
- Italy
- Jamaica
- Japan
- Jordan
- Kazakhstan
- Kenya
- Korea (Rep of)
- Kuwait
- Latvia
- Lebanon
- Lesotho
- Liberia
- Lithuania
- Luxembourg
- Macedonia
- Malawi
- Malaysia
- Maldives
- Mali
- Malta
- Mauritius
- Mexico
- Moldova (Rep of)
- Mongolia
- Morocco
- Myanmar
- Namibia
- New Zealand
- Nepal
- Nicaragua
- Niger
- Nigeria
- Norway
- Northern Ireland
- Oman
- Pakistan
- Panama
- Puerto Rico
- Peru
- Poland
- Portugal
- Qatar
- Romania
- Russian Federation
- Rwanda
- Saudi Arabia
- Scotland
- Serbia
- Sierra Leone
- Singapore
- Slovakia
- Slovenia
- South Africa
- Spain
- Sri Lanka
- Suriname
- Swaziland
- Switzerland
- Sweden
- Syrian Arab Rep
- Taiwan, China
- Tanzania
- Thailand
- The Philippines
- Togo
- Tunisia
- Turkey
- Turkmenistan
- Trinidad & Tobago
- UAE (United Arab Emirates)
- Uganda
- Ukraine
- Uruguay
- USA
- Uzbekistan
- Venezuela
- Vietnam
- Wales
- Yemen
- Zambia
- Zimbabwe

International Epilepsy Day Events

Once again, events were held around the world this year to mark International Epilepsy Day 2020, raising awareness of and educating the public about epilepsy as well as providing support to members of the epilepsy community. Below are a selection of images to illustrate the variety of events that took place. You can find out more by visiting www.internationalepilepsyday.org/events.



Association "AHMED" D'aide Aux Enfants Avec Epilepsie, celebrate the day in Tunisia.



CODEF marked International Epilepsy Day by raising awareness among students and teachers in schools in the Western region of Cameroon.



International Epilepsy Day is celebrated in Lagos, Nigeria.



Epilepsy Liga (Belgium) brought a giant brain to the Central Station in Antwerp, showing passers-by how our brains work and what types of epilepsy exist!



Colourful celebrations again this year in Sendai Japan at the Epilepsy Hospital BETHEL



Vida Saei celebrates International Epilepsy Day in Tehran with the Iranian Epilepsy Association.



TURNING PURPLE!

A highlight of International Epilepsy Day 2020 was seeing a number of landmarks and buildings around the world turn purple to mark the day!

The Lega Italiana Contro de l'Epilessia (LICE) coordinated events in Italy that included having the Colosseum in Rome (above) and a fountain in Trieste (below) lit up in purple to raise awareness.

Tower 42, the fifth tallest skyscraper in London, projected the international epilepsy Day logo from the top of the building as well as raising awareness among all inside the building through electronic posters and signage in lifts.

We hope to see more landmarks lit up to mark International epilepsy Day in 2021!





OBITUARY

Henry Berrisford Stokes Brown IBE Guatemala

El miércoles 18 de marzo de 2020, la comunidad neurológica de Latinoamérica y especialmente del IBE, perdió a Henry Berrisford Stokes Brown, uno de sus más apreciados integrantes, excelente esposo, padre, neurólogo y amigo.

Siempre se destacó como un notable estudiante: obtuvo el primer puesto de grado en secundaria, en la Escuela Normal Central para varones 1957-61, graduado simultáneamente de Maestro de Educación y Bachiller en Ciencias y Letras en 1961; obtuvo también el Primer Puesto de Promoción en la Facultad de Medicina USAC años 1962-1969, así como el premio Guillermo Salazar y Premio Flores por haber sido el Mejor Estudiante de toda la Universidad de San Carlos de Guatemala en el periodo 1962-1969

Antes de concluir su carrera universitaria, fue Capitán de la Selección de Fútbol de Guatemala, que ganó el campeonato Norte, CA y del Caribe en 1967, por lo que recibió la Ordel del Qietzal, que siempre portó orgullosamente donde quiera que se presentaba.

Su vocación, sin embargo, estaba en la Medicina. Tras convertirse en médico por la Universidad de San Carlos, se hizo neurólogo y posteriormente neurofisiólogo en la Universidad de Vanderbilt en Nashville, Tennessee, donde recibió el Premio Hillman como Profesor más destacado de la Facultad de Medicina en 1973.

Regresó a su país para abrir camino para la Neurología y la epileptología y vio la necesidad de formar recursos humanos en el campo de las neurociencias: Neurología, Neurofisiología y Neuropsicología, dirigiendo estos cursos por muchos años. Fue neurólogo y Jefe de Servicio del Hospital General San Juan de Dios por 45 años donde su consulta estaba siempre muy concurrida pues mucha gente buscaba ser atendida por él.

Se dedicó así mismo a atender pacientes en lugares remotos y llevarles información en su idioma para varios padecimientos neurológicos principalmente la epilepsia. Siempre que participaba en algún evento como conferencista o comentarista, llevaba con él un video-camarógrafo que filmaba sus participaciones, muy numerosas por cierto, creando un amplísimo acervo educativo.

A lo largo de su carrera fundó y presidió diversas asociaciones médicas., entre otros el Capítulo Guatemalteco del IBE y también el de la ILAE

On Wednesday March 18, 2020, the Latin American neurology community lost one of its most honoured members, Henry Berrisford Stokes Brown, who was also a beloved husband, father, and friend.

Always an outstanding student: he was already obtaining first grades at secondary school and he graduated simultaneously with Master in Education and Bachelor of Science and Letters degrees in 1961. He was awarded first promotion position at the University of San Carlos de Guatemala School of Medicine where he studied from 1962 to 1969 as well as the Guillermo Salazar and Flores Prize as Best Student of the entire university in the period 1962-1969.

Before concluding his university career, he was Captain of the Guatemalan Soccer Team, which won the Copa de la Confraternidad Centroamericana in 1967, for which he received the Ordel del Qietzal, which he always carried proudly wherever he went.

His vocation, however, was in medicine. After graduating as a doctor at the University of San Carlos, he became a neurologist and later a neurophysiologist at Vanderbilt University in Nashville, Tennessee, where he received the Hillman Prize as Outstanding Professor at the School of Medicine in 1973.

He returned to his native Guatemala to improve neurology and epileptology services and saw the need to provide neurology training. He led courses in neurology, neurophysiology and neuropsychology for many years. He was a neurologist and Head of Service at San Juan de Dios General Hospital for 45 years where his consultations were always very busy because many people sought to be attended by him.

He dedicated himself to caring for patients in remote regions; bringing them information in their language for various neurological disorders, mainly epilepsy. Whenever he participated in an event as a lecturer or commentator, he brought with him a videographer who filmed his numerous presentations, thus creating a vast educational heritage.

Throughout his career he founded and presided over various medical associations, among others the Guatemalan Chapter of the IBE and also that of the ILAE.

He held an annual congress in Guatemala City, to which he invited

Anualmente hacía un congreso en la Cd. de Guatemala, al que invitaba especialistas de otros países y al concluir los llevaba a sus actividades informativas itinerantes semanales, al lugar que coincidía con la fecha del congreso. Quienes asistieron con él a estos eventos, cuentan que era una real aventura acompañarlo, atravesando a veces selvas y ríos para llegar a la gente, convocada por su sola presencia.

Para estas comunidades, creó información grabada en audio y/o video, tanto en español como en otras lenguas habladas en las diferentes regiones que visitaba.

Representando a Guatemala, formó parte del Comité Latinoamericano del IBE desde su formación en el año 2000, presidió el IV Congreso Latinoamericano de Epilepsia efectuado en su país en 2006 y colaboró con publicaciones latinoamericanas acerca de la epilepsia.

Fue autor de numerosos libros y artículos pero destacó siempre la información para el público, a la que siempre se enfocó.

Dedicó su vida a los pacientes, a sus numerosos alumnos pero también a su familia: su esposa Hortence y sus cinco hijos. Una de sus hijas se dedica a la Neuropsicología y otra siguió sus pasos en la especialidad de Neurología, lamentablemente fallecida de forma prematura.

Henry siguió siempre adelante, asistiendo a actividades académicas nacionales e internacionales y dando siempre lo mejor de sí.

Compartió generosamente con sus alumnos y su comunidad sus grandes conocimientos y cosechó muchos reconocimientos, pero principalmente muchos amigos que recuerdan su capacidad, su amable personalidad y su peculiar imagen, que llevó con mucha prestancia y orgullo todos los días de su vida.

Descanse en paz.

specialists from other countries. When the congress was finished, he would bring the specialists to his weekly mobile information events. Those who attended these meetings with him say that it was a real adventure to accompany him, sometimes crossing jungles and rivers to reach people, summoned by his presence alone.

For these communities, he created information recorded in audio and/or video, both in Spanish and in other dialects spoken in the different regions he visited.

Representing Guatemala, he was a member of the IBE Latin American Committee since its formation in 2000, chaired the 4th Latin American Epilepsy Congress held in his country in 2006 and collaborated with Latin American publications on epilepsy. He was the author of numerous books and articles but always focussed the information for a public readership.

He dedicated his life to his patients, to his many students, but also to his family: his wife Hortence and their five children. One of their daughters specialises in neuropsychology and another who followed in his footsteps in neurology, sadly pre-deceased him at a young age.

Henry has always kept going, attending national and international academic activities and always giving his best.

He generously shared his great knowledge with his students and community and garnered many recognitions, but mainly many friends who remember his ability, kind personality and special image, which he carried with great care and pride every day of his life.

May he rest in peace.

Provided by Dra. Lilia Núñez Orozco, President of the IBE Mexican chapter, on the request of the Latin American Regional Committee

HELEN CROSS ILAE President-elect

IBE sends it warm congratulations to Prof Helen Cross who has been elected as ILAE President 2021-2025. She will make ILAE history when we assumes her role next year, as its first female President.

Prof Cross is the Prince of Wales's Chair of Childhood Epilepsy, Head of Developmental Neurosciences Programme and Honorary Consultant in Paediatric Neurology at UCL Institute of Child Health, Great Ormond Street Hospital in London, UK and her work has particularly focussed on optimising outcomes in the early onset epilepsies, which includes the ketogenic diet and epilepsy surgery in children.

Prof Cross is one of the main leaders in the European Reference Network, EpiCARE, and is currently ILAE Treasurer.



RARE AND COMPLEX EPILEPSIES

Patients' journey highlights the needs to which EpiCARE should try to respond

Report provided by Isabella Representative of Patient Advocacy Group EpiCARE, Chairman Dravet Syndrome European Federation

During the Annual Meeting of ERN EpiCARE, Lyon 14-15 February 2020, the Patient representatives (ePAG Patient Advocates) presented the patient journey of rare and complex epilepsies by asking the ERN EpiCARE to try to give answers in the next two years.

A "Patient Journey" is a personal testimony that reflects the natural history / needs of patients for a specific rare disease.

Baseline reference document for ERN Members to develop a healthcare pathway and guidelines to address the needs identified.

It has been used to engage wider patient community to consolidate common needs for specific rare diseases. 'Information Key' to access self-care and management information.

The 4 windows presentation gave space to the different key issues: Seizure control, early and correct diagnosis, support for the family, syndromic and comorbidities, appropriate rehabilitation program.

Although very different from each other, rare and complex epilepsies face similar difficulties in the various stages of the development of the disease. Since they are rare pathologies and not always easy to detect if not from expert centres, increasing the diffusion of adequate information on the recognition of symptoms becomes the main point to start from.

Our Aims, Your Aims: Quality care throughout life to enable children and families to lead healthy lives!

Seizure control is the key for many Rare & Complex Epilepsy syndromes; however it is only one aspect of the single and ERN EpiCARE needs which go beyond seizure control and think about the full spectrum of needs of this patient community.

Here are the 5 fundamental requests :

1. Seizure Control: We need to develop common prescribing guidelines and sharing experience with the best possible control of seizures with medication/surgery and with the best impact for the treatment in the quality of life. For this reason the Epicare group is working on new clinical trials, pathology records and evaluation of drug repositioning.
2. Early and Correct diagnosis: Develop 'red-flags' or a 'hallmark' guide to support earlier diagnosis. Champion better information, education and dissemination to neurologists and paediatricians. The group is working on the publication of information leaflets for each specific pathology, identifying common questions to compare different aspects of the pathologies. In addition, regularly organized webinars will allow to increase knowledge within the network.
3. Support for the families: The cornerstone to optimise families' ability to best cope and autonomy. By assessing the impact on the family's lives, develop family-centred guidance



Be part of something amazing TODAY, for a brighter future for all of us TOMORROW!

for family support. More information about SUDEP. This point is fundamental to the daily life of families. We should study together how to direct suggestions and appropriate responses.

4. **Syndromic and comorbidities:** More attention on the complexity of symptoms, not just the sei-zures. Recommendations for a multidisciplinary team approach. Develop 'standards of care' to optimise care for all aspects of life. Reduce inequalities for therapies and treatment opportuni-ties across EU. The guidelines and diagnostic and therapeutic rehabilitation plans being imple-mented may highlight these aspects and the importance of a mul-tidisciplinary approach and the possibility of access (by all European Union countries) to approved current therapies.
5. **Adequate Rehab Programme:** It is mandatory to run alongside pharmacological pathway with recommended transition pathway and more awareness of the epilepsies for adult neuro's SYN-DROMES vs SYMPTOMS.

The entire group of patient representatives is convinced that working together with Doctors, Researchers and patient in the next two years we could present answers to these 5 important issues. The goal, while waiting for an effective treatment, is to achieve the best quality of life possible today, putting all the knowledge and tools at our disposal. Together we will succeed.

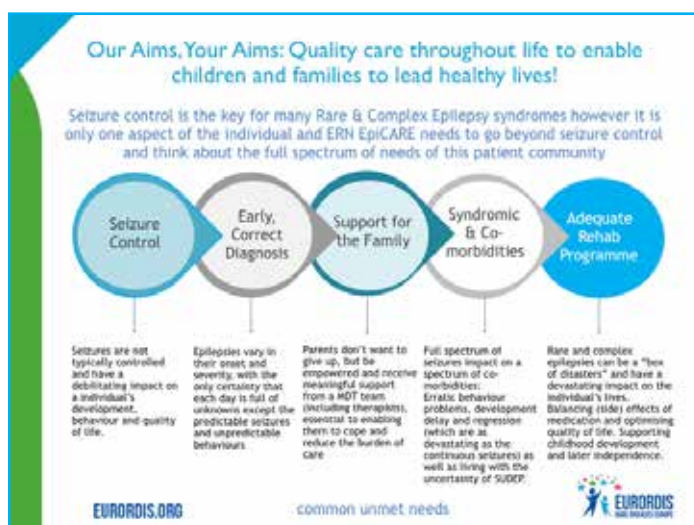
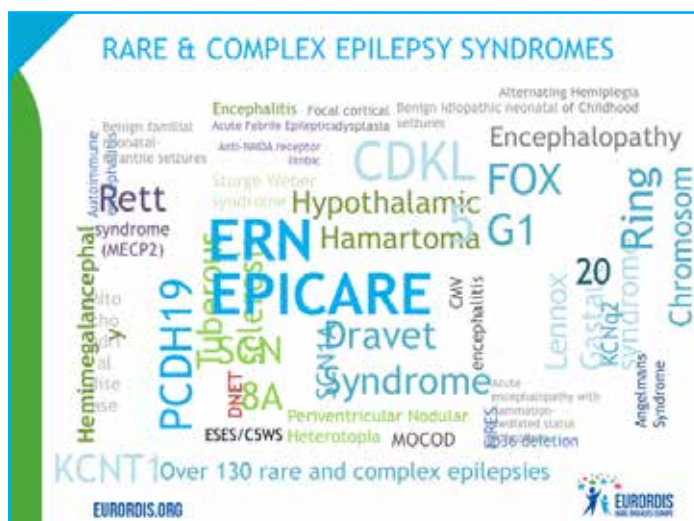
You can contact us on anything EpiCARE EPAG related by email-ing us at: ep-ag.epicare@gmail.com -

LIKE our Facebook page to follow us on social media -: <https://www.facebook.com/epag.epicare>

More info : <https://epi-care.eu/epag/>



© EpiCARE



My name is Niloofar



This is how Niloofar introduced herself to us at IBE. The talented artist from Iran wrote to tell us how she has not allowed epilepsy to affect her artistic talent.

“I’ve had epilepsy since birth but I don’t remember my seizures because I was unconscious when they happened,” she explains.

The daughter of artistic parents - both her mother and father are also artists - Niloofar grew up surrounded and influenced by art and says:

“My life is shaped by colour! I was introduced to the world as a painter when I was just eight years old.”

Niloofar has a bachelor’s degree in Art from the University of Tehran. She has had exhibitions both in Tehran and in nine other countries. Now she wants to further her artistic studies abroad and is fluent in both Italian and English.

The most amazing thing about Niloofar’s ability to create works of art with incredibly fine detail is that she is able to do so despite a side effect of her epilepsy medication that results in hand shake. This must surely be a major challenge.

Her artistic style reflects Iranian culture. She produces some smaller pieces but has also had her work mounted on the walls of homes. From the images Niloofar sent us, it is obvious that each



piece has painstaking detail that even an artist with very steady hands would struggle to produce.

“Epilepsy didn’t stop me from developing my talent and I hope that I can show my work to the world because I am an artist just like any other artist. I am no different to others,” Niloofar told IBE.

If you can point Niloofar in the right direction for having an exhibition overseas or accessing an art course abroad, let us know and we can put you in touch.

“I hope my friends with epilepsy will never be disappointed with life,” are Niloofar’s closing words.



COMMUNITY INCLUSION OF PERSON WITH EPILEPSY IN NSEH VILLAGE, CAMEROON

Kenneth Ninying from Community Development and Epilepsy Foundation (Codef) in Cameroon sent us this report on a forum funded by the IBE Young People with Epilepsy Support (YES) program

INTRODUCTION

The aim of the forum, funded by IBE, was to bring together a cross-section of the community members to discuss community inclusion of people with epilepsy. The project's objectives were:

1. To sensitize community leaders on the abilities of people with epilepsy and challenges they face in their villages
2. To educate communities about epilepsy

PARTICIPANTS

The 58 participants from Nseh communities included:

- 30 traditional leaders
- 15 parents/caregivers
- 10 persons with epilepsy
- 2 church representatives
- 1 school representative

NEEDS AND ABILITIES

Epilepsy education sessions covered topics such as what is epilepsy, causes, and seizure first aid. Other activities included participants breaking out into working groups to identify needs, abilities and challenges affecting people with epilepsy in the community. Those charged with looking at the needs of people with epilepsy listed the following as important:

1. Availability of anti-epileptic drugs as well as drugs for other health issues such as HIV/AIDS
2. Ongoing epilepsy education, including in schools
3. Income generating activities
4. Personal accommodation

The group looking at the abilities of people with epilepsy discussed education and the need to provide for access to schools; support to create small income businesses, and the ability of some people with epilepsy to become educators on the topic.

CHALLENGES

Not surprising, the group looking at challenges reported the highest number

of issues of all three group. They identified challenges as follows:

- Stigmatization: some community members constantly refer to people with epilepsy as “fainting sick” people.
- Discrimination: some Christians do not want people with epilepsy to sit near them in church.

Some cannot drink from the same cup that a person with epilepsy has used or even use the same spoon.

- Isolation: some family members sometimes do not want a person with epilepsy to live with them but to live with a traditional herbalist.
- Myths about epilepsy: that the saliva of a person with epilepsy can be transmit epilepsy.
- Cultural misinterpretation: in many villages people with epilepsy are referred to as witches or wizards
- Abandonment: sometimes when a person with epilepsy has a seizure in public, passersby will not go to their aid, even if they fall onto the road and are in danger of being run over.
- Lack of income: many people in the community think that people with epilepsy should not be allowed do business or to have a job that would allow them to earn a living. Some even say that they should not be allowed to earn money when their parents can look after them.

RECOMMENDATIONS

The closing plenary session discussed and agreed a number of recommendations to



improve the quality of life of people with epilepsy:

- The government should incorporate epilepsy in the health delivery system of Cameroon especially at the district health services.
- Traditional leaders should learn and know more about epilepsy to stop the stigmatization and discrimination of people with epilepsy in their communities even using traditional injunction orders.
- Support should be provided to home guardians of those caring for people with epilepsy.
- The Ministry of Social Affairs should provide persons with epilepsy with national disability cards that would allow them to benefit from reduced transport costs, education and medical bills.
- Community solidarity must be mobilized. Community based surveys were required to determine any other problems faced by people with epilepsy.
- Support the participation and involvement of people with epilepsy in community activities.
- Educate people with epilepsy on their human rights.



International Epilepsy Day

Monday, 8 February 2021

SAVE THE DATE!

