



photo by Massimo Cassar

Caritas Malta Epilepsy Association
Fondazzjoni Caritas Malta
Triq Mountbatten
Hamrun HMR 1577
Tel: +356 2133 1000
V/O 1396
maltaepilepsy@gmail.com
www.caritasmalta.org/epilepsy

Affiliated to



Caritas
Malta
Epilepsy
Association

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SAVE THESE DATES MEMBERS' MEETINGS

FRI - 9th JULY 2021

FRI - 10th SEP 2021

FRI - 12th NOV 2021

**please send an email to
maltaepilepsy@gmail.com
for further details.**

Membri tal-Kumitat 2021

President
Mr. Frank Portelli

Viċi President
Dr. Anna Micallef

Segretarja
Ms. Claudine Aitken

Teżoriera
Ms. Caroline Attard

P.R.
Ms. Robin Pinkston

Assistent P.R.
Mr. Matthew Attard

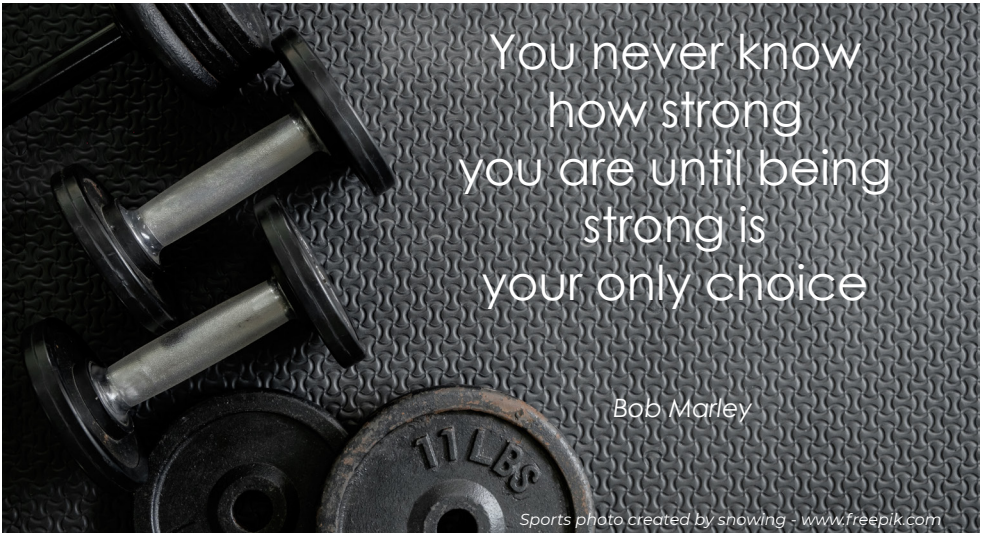
Facebook u Żagħżagħ
Ms. Adriana Caruana Soler

Membri
Mr. Manuel Camilleri
Mr. Noel Mercieca

Konsulenta
Prof. Janet Mifsud

Psychotherapist
Verena Portelli

Disinn:
Kevin Attard / Noel Portelli



You never know
how strong
you are until being
strong is
your only choice

Bob Marley

Sports photo created by snowing - www.freepik.com



KELMTEJN MILL-PRESIDENT

Għeżież membri,

Għaddew xahrejn oħra mill-aħħar li kellimtkom. Nispera li tinsabu tajbin u li l-ħajja għalikom issa ġejja lura għan-normal.

Bħalma tafu bħalissa qedin jitneħħew ħafna mir-restrizzjonijiet għax in-numru tal-każi naqas sew. Nerga nirrepeti biex ma tillaxkawx avolja l-każi qed ibattu iżda dejjem osservaw id-direttivi tad-Dipartiment tas-Saħħa. Nispera li sal-laqqgħa tal-10 ta' Settembru nkunu nistgħu niltaqgħu wiċċ imb'wicc. Din ser tkun il-Laqqgħa Annwali Ġenerali għalhekk inhegġigkom sabiex tattendu. F'din il-laqqgħa il-kumitat preżenti irid jirriżenja u jittella' kumitat ġdid permezz ta' elezzjoni. Għandna wkoll xi tibdiliet żgħira fl-Istatut li biex isehħu jkollna bżonn l-approvazzjoni tagħkom. Inhegġigkom sabiex mhux biss tattendu u tipparteċipaw iżda wkoll toħorġu għal-kumitat. Napprezzaw ħafna li jkollna membri ġodda b'idejat ġodda u kompletament innovattivi.

Il-laqqgħa li jmiss ta' nhar il-ġimgħa, 9 ta' Lulju fis-6.00pm ukoll se ssir biz-zoom. M'hemmx għalfejn ngħidilkom li dak li jingħad jibqa' kunfidenzjali. It-sugġett ta' din il-laqqgħa se jkun: *'Seizure related injuries: An overview of first aid recommendations'*. Il-kelliem se jkun Dr. Trevor Abela Fiorentino u ninsab ċert li din it-taħdita mhux biss se tkun interessanti iżda utli u bżonnjuża wkoll, għalhekk nirrakkomandalkom sabiex tingħaqdu magħna.

F' dawn l-aħħar xahrejn ma tantx kellna laqqgħat u nista' ngħid li l-ħidma tagħna naqset konsiderevolment. Nispera li sal-aħħar tas-sena ir-ritmu jerġa' jaqbad u s-sena d-dieħla nerġgħu lura għan-normal, b'laqqgħat u taħditiet kontinwi.

Bħalma tafu il-laqqgħat li qedin nagħmlu huma virtwali iżda dawn qatt ma jistgħu jieħdu post il-laqqgħat li jsiru wiċċ imb'wiċċ. Il-problemi li niltaqgħu magħhom meta jsiru virtwali mhumix f'tit, għax daqqa wieħed ma jkunx jista' jikkonnettja, oħra il-video ma jkunx tajjeb u ħafna drabi anke problemi bl-awdjo ikollna.

B'dana kollu xorta nagħmlu minn kollox sabiex inġibu kelliema profesjonisti sabiex ikellmuna f'dawn il-laqqgħat. Ħafna drabi ma tkunx faċli li ssib dawn in-nies, għax ħafna drabi jkollhom clinic jew ikollom xogħol ieħor. Ġieli kellna nirrikorru għal iktar minn 4 professjonisti sabiex nakkwistaw is-servizz ta' wieħed minnhom.

Nagħlaq billi nhegġigkom sabiex tattendu għal-Laqqgħa Annwali Ġenerali tipparteċipaw u tibzghux toħorġu għal-kumitat. Kif għidtilkom idejat ġodda dejjem huma apprezzati. B'hekk tkunu qedin tagħmulna kuraġġ inkomplu f'din il-ħidma li bdejna 25 sena ilu.

Inselli Għalikom,

Franke

**CMEA
MEMBERS MEETING
Friday, 9th July 2021
at 6:00pm**

The Caritas Malta Epilepsy Association is glad to invite all interested parties to an online member's meeting via Zoom.



Seizure related injury: An overview of first aid recommendations

Research into medical and safety risk related to seizures has demonstrated that seizure-related injury is in most cases non-fatal. Nevertheless, seizures resulting in an injury are still a relevant concern for persons who suffer seizures and their families. In this session, we will be discussing the main and most common injuries that are associated to seizure episodes and the appropriate first aid that is recommended in these situations, using the most recent first aid guidelines.

This month's guest speaker is **Dr Trevor Abela Fiorentino** Dip.Nurs., B.Sc.(Hons.), M.Sc.(Melit.), Ph.D.(Cov.), R.N.

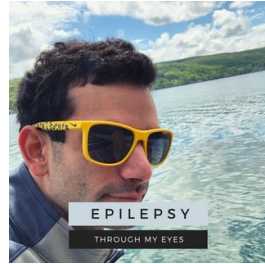
Trevor is a nurse by profession. His clinical background is in emergency nursing with a special interest in pre-hospital emergency care. Trevor is a lecturer in emergency nursing and resuscitation at the Faculty of Health Sciences, University of Malta. He completed doctoral studies in pre-hospital emergency nursing at Coventry University (UK), and is involved in research on first aid and immediate care education and training. Due to his academic involvement and clinical experience in the area of emergency and immediate care Trevor is a technical advisor in first aid for St John Malta and a member of the clinical working group of Johanniter International (JOIN), working on the development of International First Aid Guidelines.

If you would like to reserve your place in this meeting, please send an email to Caritas Malta Epilepsy Association at maltaepilepsy@gmail.com. The primary language of this meeting will be Maltese so if you do not understand it, feel free to join and have a family member or friend in your bubble ready to provide translation for you. Don't miss this opportunity to hear from our local experts!

Please note that, as usual, the meeting will be held in full confidentiality.



Epilepsy Through My Eyes



For 18 years, it has felt like I have been playing a round of golf every day. It unfortunately has just been my epilepsy. From preparing for numerous doctors appointments to handling clusters of seizures, epilepsy has taken a toll on me both mentally and physically. Every epilepsy journey is different, but I want to show you epilepsy as I see it through my eyes.

We Get Scared

At nine years old, the battle became real. Waking up in that ambulance after my seizure was the first sign that it was time to go to work, both me and my family. Epilepsy provided me with challenges in my early years. None compared to the ones during my college years and into my working life. Engraved in my mind forever will be the night I was taking punch after punch from my epilepsy in my dorm room. My emergency meds weren't working and I quickly began looking up rides to the emergency room. Seizures at work? Unfortunately yes. I've been dealt with days of cluster seizures hitting up to 20. It's experiences like these that make us want our epilepsy to go away forever.

It's An Everlasting Journey

Epilepsy is not a sprint, it's a lifelong marathon. Whether you're two weeks or 20 years seizure free, epilepsy to me is everlasting. Take a look at your phone's calendar, odds are you probably have a few epilepsy related appointments. For some, it could be simple check-ins while others are circling that big day for their brain surgery.

Year after year, we spend time talking with doctors, professionals, or counselors about our epilepsy. Do we enjoy it? Probably not. However, this is what helps us manage our epilepsy and adjusted lifestyle.

Find The Positives

What I wish everyone could see is that there are positives while living with epilepsy. We have such a strong community that is ready to help each other whenever they need it. Our community thrives when someone shares their amazing epilepsy story. It takes courage to share it, and we all applaud them for sharing it with everyone. I've made friends throughout the world within our community and I know each and every one of you can connect with people across the world. Our community makes us stronger and gives us the ability to inspire others day in and day out.

Everyone has a different perspective on epilepsy, but I've always been open about how I live with my epilepsy. This is how I see epilepsy through my eyes and live with it on a daily basis.

Drug treatment of drug resistant epilepsies: an update from a local perspective

Report of CMEA Member Meeting 14th May 2021



Dr Doriette Soler

The guest speakers for this meeting were Dr Doriette Soler, Consultant Paediatric neurologist and Dr Stephen Attard, Resident Specialist Paediatric Neurologist, both at Mater Dei Hospital.

They gave a very helpful 20-minute power point presentations on the various antiepileptic treatments currently being used in Malta. They discussed new medicines, vagal nerve stimulation and the ketogenic diet which is facilitated in collaboration with a trained dietician. It is to be noted that not every type of epilepsy can be managed by these new treatments. They also explained that although there is not a designated epilepsy nurse, there is a nurse who is somewhat acting in that way as she assists in the paediatric neurology department.

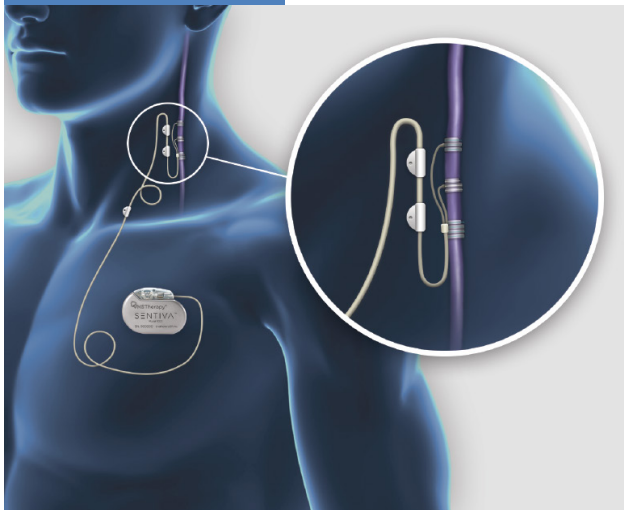
Due to COVID restrictions, the neurology department now also has an I-Pad to which patients and parents can send updates, videos of seizures, and requests for prescriptions and receive an answer within a few days.

At the end of the discussion Dr Soler and Dr Attard also kindly answered several questions from the participants.

CMEA would like to forward their thanks to Dr. Soler and Dr. Attard for their kind service to our children and for their time in sharing with us their expertise



Dr Stephen Attard



Vagus Nerve Stimulation (VNS) Placement

Epilepsy Foundation

Photosensitive Epilepsy



Dorothee Kasteleijn-Nolst has worked in the field of photosensitive epilepsy for more than 30 years. Her newly published book, ***The Importance of Photosensitivity for Epilepsy*** (<https://www.amazon.nl/Importance-Photosensitivity-Epilepsy-Dorothee-Kasteleijn-Nolst/dp/3319050796>) is a detailed and comprehensive study of all aspects of photosensitivity.

As an epileptologist working at the children's department of the Dutch Epilepsy Centre Meer & Bosch (later known as SEIN) in the 1980's, Colin D Binnie, a world renowned British electroencephalographer, taught me to read EEGs and how to optimize epilepsy care with proper use of the EEG. It is fascinating to see the dynamics of the epileptogenic brain-print in relation to its clinical expressions or... in other words: it is possible to see the underwater process in people with epilepsy and this helps to better diagnose, choose the best treatment and evaluate the effect of treatment.

With Peter Jeavons and Graham Harding as protagonists, special interest in photosensitive epilepsy was transferred through Colin Binnie to the Dutch centre. I had several adolescents under my care who were photosensitive and, with EEG registrations with intermittent photic stimulation (IPS) and black and white striped pattern stimulation, I understood that photic stimulation creates a kind of "stimulus and answer game", being different from the general "wait and see policy" in epilepsy diagnostics in general. This has led me to choose photosensitivity as my PhD subject. Between 1981 and 1989 I investigated 100 patients with a photosensitive EEG response and 100 age and sex matched epilepsy patients without such a reaction. Thanks to the advice of Pierre Vinken, former CEO of Elsevier, who had worked at Meer & Bosch as a neurosurgeon, my thesis was published as supplement of *Acta Neurologica Scandinavica* (Photosensitivity in epilepsy: electrophysiological and clinical correlates, *Acta Neurol.Scand.*1989;125:3-149).

After receiving the Gowers Prize Young Physician's award in 1986 on the topic of "Photosensitive patients: symptoms and signs during IPS and their relation to seizures in daily life", I was sure that the subject of photosensitivity was seen as important by the epilepsy community. And so, an international network of physicians interested in the subject arose, leading to standardization of stimulation procedures. This procedure helps in getting maximum information with the least risk of provoking seizures in susceptible patients. It also made international research efforts feasible, such as the Nintendo European videogame study¹.

Further spreading of knowledge on photosensitivity (how to recognize, diagnose and treat patients in the EU community) was



Technically better color TVs with remote control became the norm in the 80s, yet, despite this, the public recognized that certain commercials with flicker and striped patterns, were provocative

made possible thanks to the Marie Curie Excellence Grant of the European FP6- research program. Central to this endeavour was University Sapienza in Rome, Italy and my work still continues to be teaching, advising and further unravelling epilepsy in general thanks to photosensitive patients!

How photosensitivity first became more widely known in the lay epilepsy community

With the introduction and spread of TV screens in the home in the 1950s- 60s, persons with epilepsy started to recognize that coming close to the TV screen for on and off switching of the TV provoked seizures. The TV produced not only a 25/30 Hz constant

extract from International Epilepsy News



Wednesday 1st September 2021

IBE Day at the 34th International Epilepsy Congress

Three (3) two-hour virtual sessions

Time: 07:00 EST, 13:00 CET/CAT, 16:30 IST, 19:00 CST, 21:00 AEST

If you are unsure about the start time for where you live, contact us at annlittle@ibe-epilepsy.org for help.

PROGRAMME

1. Making Epilepsy a National Health Priority - intersectoral collaboration

Chairs: Mary Secco, IBE Secretary General and Action Amos, IBE Vice President Africa

Topics and speakers:

- 10-year intersectoral global action plan on epilepsy and other neurological disorders (IGAP) *Tarun Dua, WHO Brain Health Unit*
- Improving care for children with neurological disorders in resource poor settings
Jo Wilmshurst President International Childhood Neurology Association
- Improving access to essential medicines
Gaby Ooms, Health Action International
- Putting epilepsy on social policy and development agendas
John O'Toole, Division for Inclusive Development, UN Dept of Economic & Social Affairs
- Leveraging the IGAP to improve care for people with epilepsy
Alla Guekht, Chair ILAE Global Advocacy Council
- Working with donors
Gardiner Lapham, Trustee BAND Foundation
- Epilepsy Advocates Toolkit
Karen Robinson, Epilepsy South Africa
- Global health in epilepsy database
Karen Parko, ILAE North America

2. Empowering Youth to Raise their Voices

Chairs: Lorraine Lally (Ireland) and Scarlett Paige (Australia), co-chairs of the IBE Youth Team

Topics and speakers:

- Epilepsy & Pregnancy: launching IBE's new toolkit
Lorraine Lally and Gus Baker, Chair Epilepsy & Pregnancy Campaign and Secretary General-elect
- Meet the International Golden Light Award Winners 2021
Presentation of 19 awardees
- Hear my Story
International Golden Lights, from IBE's seven regions, share their personal stories:
 - *African region: tbc*
 - *Eastern Mediterranean: Mohsen Fariborzi (Iran)*
 - *Europe: Lynna Held (Germany)*
 - *Latin America: Luiza Gatto (Brazil)*
 - *North America: Cassidy Megan (Canada)*
 - *South East Asia: Vinay Jani (India)*
 - *Western Pacific: Meng-Leo Chou (Taiwan China)*
- Introduction to the IBE Global Youth Team
Lorraine Lally and Scarlett Paige
- Questions and Answers session

3. Psychologic treatment and self-management of epilepsy

Chair: Gus Baker (UK)

Topics and speakers:

- The comorbidities of epilepsy: a review
Gus Baker (Chair, IBE Research Team and Secretary-General-elect)
- The psychological management of epilepsy: The Turkish experience
Nuran Aydemir (Turkey), Co-chair IBE Research Team
- Self-management programmes in children: The Scottish experience
Liam Dorris (Scotland)
- Psychological treatment of epilepsy: The Mauritian experience
Devishada Dassyne (Mauritius)
- Self-management programmes: The US Experience
Rosemary Kobau (USA)

REGISTRATION IS FREE BUT YOU MUST REGISTER TO ATTEND!

To register, please click **HERE** <https://www.surveymonkey.com/r/C9MV3FR>



L'Epilessija M'Intix waħdek

Tixtieq tkun taf aktar ?

Nilqgħu

suggerimenti dwar suggetti
fuq l-epilessija li tixtiequ li
jiġu diskussi waqt il-laqqgħat
tal-membri

ibgħat imejl bl'idejat tiegħek lil

maltaepilepsy@gmail.com

kull ma jingħad f'dawn il-laqqgħat jibqa' kunfidenzjali