



Caritas Malta Epilepsy Association
5 Lion Street,
Floriana, FRN 1514
Tel: +356 2133 1000
V/O 1396
maltaepilepsy@gmail.com
www.caritasmalta.org/epilepsy

Affiliated to



Caritas
Malta
Epilepsy
Association

A better life for people with epilepsy

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SAVE THESE DATES

MEMBERS' MEETINGS

FRI - 14th MAY 2021

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

Membru
Mr. Manuel Camilleri

Konsulenta
Prof. Janet Mifsud

Psychotherapist
Verena Portelli

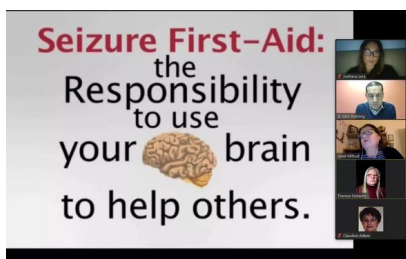
Disinn:
Kevin Attard / Noel Portelli

Training on epilepsy to ST John Malta volunteers

On 20 April 2021, CMEA members provided training through a webinar to around 40 volunteer members of St John Malta on Epilepsies and Seizures made simple: what should the first aider know?

The feedback was very positive and CMEA looks forward to collaborating with St John in the great volunteering work they do around Malta and Gozo.

We would like to thank Mr James Cilia and Dr Trevor Abela Fiorentino for facilitating this event.





KELMTEJN MILL-PRESIDENT

Eżgħiež membri,

Għaddew xahrejn mill-aħħar komunikazzjoni li għamilna magħkom permezz tan-newletter. F'dawn l-aħħar gimgħat jidher li l-każi tal-pandemija taffew xi ftit. Madankollu jien nibqa' nhegġgħkom sabiex tibqgħu tużaw il-prudenza u dejjem ssegwu l-istruzzjonijiet tal-Awtorita' tas-Saħħa. Diġa għandna prova li kif nillaxkaw ftit il-każi jerggħu jiżdiedu.

Infakkarkhom li għal-laqqgħa li jmiss, propju nhar il-Ġimgħa 14 ta' Mejju il-laqqgħa xorta waħda ser issir biz-zoom u mistiedna ewlenin ser ikunu Dr. Doriette Soler u Dr. Stephen Attard. It-tnejn li huma, huma magħrufin sewwa fil-qasam tal-epilessija fit-tfal. Il-laqqgħa ser titmexxa minnhom u s-sugġet hu 'Treatment of drug resistant epilepsies'. Din il-laqqgħa żgur li se tkun waħda mhux biss interessanti iżda wkoll se tkun ta' ħafna għajnuna. Se jkun hemm ħin allokat għal-mistoqsijiet. Inhegġgħkom sabiex tingħaqdu magħna billi tibgħatu email fuq mataepilepsy@gmail.com halli nkunu nistgħu nibgħatulkom il-link għal- meeting.

Minn hawn nixtieq nieħu din l-opportunita' sabiex nifraħ lil-żewġ membri tal-kumitat tagħna li ġew appuntati fuq bordijiet internazzjonali. Dawn huma is-sinjorina Claudine Aitken, li hija s-segretarja tagħna u li nħatret membru fil-European Regional Executive Committee (EREC). Kif ukoll lis-sinjura Robin Pinkston li hija nkarigata mir-relazzjonijiet pubbliċi fl-Għaqda tagħna. Robin ingħaqdet fuq il-bord tal-EFNA, European Federation of Neurological Associations fejn se tirrappreżenta lil-International Bureau for Epilepsy. Hawn nixtieq nawgura l-ħidma t-tajba lit-tnejn li huma u ninsab ċert li minbarra li se jagħtu kontribut siewi fuq dawn il-bordijiet, din se sservihom ta' esperjenza kbira li minnha jgawdu huma kif ukoll l-Għaqda. Qabel nagħlaq nixtieq infakkarkom li għal-laqqgħa tal-10 ta' Settembru ser ikollna l-Laqqgħa Annwali Ġenerali. F'din il-laqqgħa ser ikollna xi amendi żgħar fl-istatut għall-approvazzjoni tagħkom. F'din l-istess laqqgħa ser issir elezzjoni għal- kumitat, peres li qabel il-laqqgħa il-kumitat preżenti irid jirriżenja. Għal-din l-elezzjoni jkollna formoli ta' nominazzjoni li jridu jaslu għandna sa 3 t'ijiem qabel il-laqqgħa. Inhegġgħkom sabiex tagħtu l-kontribut tagħkom mhux biss billi tattendu u tipparteċipaw fil-laqqgħat, iżda billi toħorġu għal-elezzjoni tal-kumitat. Nieħdu pjaċir ħafna jkollna membri kif ukoll idejat godda fil-kumitat. B'hekk tkunu qedin tagħmlulna kuraġġ inkomplu f'ħiedmietna.

Grazzi ħafna

Frank

CMEA MEMBERS MEETING

**Friday, 14th May 2021
at 6:00pm**

Treatment of drug resistant epilepsies:

An update from a local perspective:

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

This month's guest speakers are Dr Stephen Attard, Resident Specialist Paediatric Neurologist and Dr Doriette Soler, Consultant Paediatric Neurologist at Mater Dei.



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They will discuss the 'Treatment of drug resistant epilepsies: An update from a local perspective'. This talk will include a brief outline of the main forms of treatments for pediatric epilepsy patients in Malta, including topics such as medications, epilepsy surgery, the ketogenic diet, Vagus Nerve Stimulation (VNS), and the new Epidiolex, and Cannabidiol.



After the presentation they will be available to answer some questions. Please note that they will not be able to answer questions related to individual cases. Questions related to an individual case will need to be directed towards the patient's doctor.

If you would like to reserve your place in this meeting, please send an email 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.





KNOWING YOUR LIMITATIONS

while living with epilepsy

Limitations, we all have them whether we're living with epilepsy or not. As we get older we tend to understand what our personal restrictions are. Living with epilepsy does bring a little more limitations, but by no means does that mean you have to avoid doing things you love. Throughout my years living with epilepsy I've tested my limits and continue to every day. Limitations are good, but they do not have to hold you back from living your life.

"Make sure you stay around here when you head out." This is one of many limitations I have that my dad put in place when I take the jetski out. At first, I was upset, but now I understand why he wants me close by. I've had many close calls on the jetski, but nothing like what happened last year. In early spring, I took the jetski out. With no boats on the lake I decided to go for a nice cruise away from our cottage. What could be better than enjoying the beautiful scenery of the lake from the jetski? I was enjoying every minute of it until a few waves knocked me off. I thought okay I've fallen off before so I will just get back on, no big deal. However, the way I fell off had me too far from the jetski to swim after it. I was in the 50 degree water for about 15 minutes until someone on shore came and helped me. Although I didn't have any seizures through this, it made me realize that I could have and it would have been tragic. It's important to know your safety limitations.

"Don't swim without one of us here." Another one of my dad's favorite limitations. This one made total sense right from the beginning,



but can be frustrating. Yes, you always want someone there to watch you while you're in the water, but if you just want to jump off the dock once, it's a little inconvenient. However, like anything, you need to make the best of it. I found that I could use this as a way to drag my siblings, cousins, or friends into the water with me. If I need someone to watch me swim, they're definitely coming in with me! Some limitations are common sense, but you can also have fun with them.

"I think it's time to give up snowmobiling." This unfortunately was said by me. Since I was a little kid, I loved to snowmobile. Whether it was in the backyard or on the groomed trails. It was a few years ago when I realized that snowmobiling on the trails wasn't going to be in my best interest anymore. If I was to have a seizure on those narrow trails, I would fly over the handlebars and hit a tree easy. Just because I gave up driving a snowmobile doesn't mean I can't still enjoy it. I still go with my cousins and dad as the passenger. If I really have the urge to drive, we'll find an open area of beautiful fluffy snow for me to tear up! Some limitations you find out yourself from experience, but don't let it stop you from enjoying it.

These are just a few of my top limitations. As you can see, it's both other people and myself that create these restrictions. However, I still enjoy all of these activities maybe even more than before. Know your limitations, but don't let them take away the things you love to do.

About EREC



European Regional Executive Committee

The Regional Executive Committee for Europe consists of the Chair, Vice Chair, Secretary and three Members, all of whom are elected by the Full Members in the European Region. The IBE President, Secretary General and Treasurer are also ex-officio non-voting members of this committee.

The purpose of the Regional Executive Committee is to facilitate joint activities in the region and to arrange regular (at least annual) meetings of the Regional Committee. These meetings usually take place at the time of the International Epilepsy Congress and the European Epilepsy & Society Congress.



Claudine Marika Aitken
Secretary of Caritas
Malta Epilepsy
Association

Claudine Marika Aitken is the incoming member on the European Regional Committee of the International Bureau for Epilepsy (IBE) for the years 2021-2025. She will be taking up this role in September 2021.

She has been involved with Caritas Malta Epilepsy Association since 2016. In 2018, she was elected as Secretary of Caritas Malta Epilepsy Association. She is a registered nurse by profession and has extensive experience in both the adult and paediatrics emergency departments and in the Child Development Unit. Her interactions at the workplace, have confirmed her belief that the active participation of persons with epilepsy, their families and carers is conducive to an enhanced provision of healthcare and optimal outcomes.



CONGRATULATIONS

Claudine & Robin
on being elected to
serve in their
respective roles

About EFNA



Robin Pinkston
 PRO of Caritas Malta
 Epilepsy Association

The new board members of EFNA

European Federation of Neurological Associations

The European Federation of Neurological Associations (EFNA) brings together European umbrella organisations of neurological patient advocacy groups, to work with other associations in the field of neurology, including the European Academy of Neurology (EAN), in what has been termed a “Partnership for Progress”.

Robin Pinkston joins the EFNA board as representative of the International Bureau for Epilepsy (IBE).

As the mother of a son with epilepsy for the past ten years, Robin has been active in the Caritas Malta Epilepsy Association (CMEA) as an advocate for a “better life for people with epilepsy.” She has witnessed firsthand the need for more awareness and training to reduce stigma and the difficulties associated with enabling access to the latest medications.

Alongside CMEA, Robin managed an EU Creative community for the Inspire Mosaic Project, encouraging participants from multiple NGOs to produce art from recycled tiles. She is a firm believer that we have a stronger voice working together.

She and her husband are Americans, but have lived in Malta since 1998, where her husband is a pastor of an evangelical church. They have two other children who are grown and living in the USA and Germany.



Do I need to think about safety differently from other people?

Epilepsy can come with some risks to your safety. However, by putting some safety measures in place, you can lower this risk. There are many activities and situations that carry some sort of risk, even if you don't have epilepsy. But people still do these activities – otherwise no-one would ever cross the road! Like anyone else, you might decide the benefits of doing a particular activity outweigh the activity's risk.

How could my seizures put me at risk?

If you have epilepsy, your seizures can put you at greater risk of accidents or injuries. During an epileptic seizure, you might fall down, lose consciousness, or have muscle movements that you can't control. All of these can put you at risk of physical injuries such as:

- Bruises
- Burns and scalds
- Cuts
- Drowning
- Fractures
- Head injuries

Which are the riskiest situations?

- Heights
- Traffic
- Water
- Sources of heat or power



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Does everyone with epilepsy have the same level of risk?

Not everyone with epilepsy has the same level of risk. For example, someone who has seizure control may not be at any more risk than a person who doesn't have epilepsy.

But someone who has lots of unpredictable tonic-clonic seizures may be more at risk.

The risk of accidents or injuries depends on:

- What happens during your seizure
- Where you are
- What you are doing
- Who you are with

As well as accidents or injuries, you can also be at risk of sudden unexpected death in epilepsy (SUDEP). Some people seem to be more at risk than others. Epilepsy Action has separate information about this, including ways those risks can be reduced.

How do I decide if there's a risk for me?

A risk for one person with epilepsy may not be a risk for another person. Some people prefer to take some risks. Other people prefer to stay as safe as possible. You'll need to find a balance between your quality of life and staying safe. And then you can make a choice that is right for you.

What do I do if someone else sees the level of risk differently?

It is likely that different people will see risk differently. This is especially likely with members of your family. It is understandable if they feel anxious for you. But once you're an adult, the choice between quality of life and safety has to be yours. It may help to let them know you're aware of their anxiety. And it would be good to see if, together, you can find a way for them to feel less anxious. This might include agreeing to take a friend with you somewhere, or texting them every so often while you're out, for example. See safety outside the house for more suggestions.

How do I do a safety check?

A safety check helps you decide whether something is safe for you personally. And if there are risks, it helps you work out what could be done to make that activity safe enough for you to do. It doesn't need to be complicated. All you need to do is:

Think about your seizures – what happens, how often they happen, specific triggers
Keep a seizure diary or download an app to help get any information about patterns or triggers. Knowing about triggers and patterns can offer some useful information about how to make an activity safe for you

Think about what the risks would be if you had a seizure

Make a plan to do things that reduce those risks

Here are some questions to help with a safety check:

Safety check questions

What is the activity/situation?

- When and where will the activity happen?
- Will there be other people with you?
- Will there be any potentially dangerous tools or equipment involved?
- How far would you be from help, if you needed it?

What is it about your seizures that may put you at risk?

- What happens when you have a seizure?
- How long do your seizures last?
- How often do you have seizures?
- Do your seizures follow any kind of pattern?
- Do you have any triggers?
- Do you get a warning before a seizure?
- How quickly and well do you recover from a seizure?

What can you do to make this activity safer for you?

- Do you need someone to be with you?
- Do you need any extra equipment?
- Do you need the activity to be changed in any way?
- Do you need any changes to the environment?

Do you have to decide not to do the activity?



CMEA activities 01 January to 15th May 2021

Date	Event	Attended by
8 Jan 2021	CMEA committee meeting	Janet Mifsud, Robin Pinkston, Caroline Attard, Anna Micallef, Noel Mercieca, Noel Portelli, Frank Portelli, Verena Portelli, Adriana Caruana Soler, Manuel Camilleri
12 Jan 2021	Zoom meeting with James Moffett, Communciations office, University of Malta @ International Epilepsy Say	Janet Mifsud, Noel Portelli, Frank Portelli
14 Jan 2021	Manuel interview with FB page People of Malta	Manuel Camilleri
14 Jan 2021	Staff training for Attard School	Janet Mifsud, Robin Pinkston, Claudine Aitken
15 Jan 2021	Interview with One TV 2pm	Janet Mifsud, Frank Portelli,
15 Jan 2021	CMEA members meetings 6pm	Committee members
25 Jan 2021	filming of research at University 2pm for UM website etc	Hana, Cristina, Frank Portelli, Robin Pinkston
26 Jan 2021	filming of personal experiences at University 10am for UM website etc	Matthew Attard
27 Jan 2021	Meeting with Minister Julia Farrugia	Janet Mifsud, Frank Portelli, Claudine Aitken, Adriana Caruana Soler.
29 Jan 2021	filming at University 11.30am for UM website etc	Anna Micallef
2 Feb 2021	Xaghra school training	Janet Mifsud, Claudine Aitken, Frank Portelli
2 Feb 2021	Kikkra Te	Janet Mifsud, Frank Portelli
4 Feb 2021	Interview on Telefonata l'Boghod (10am-1130am)	Janet Mifsud, Claudine Aitken
4 Feb 2021	Illum ma Steph 4pm TV	Janet Mifsud, Frank Portelli
5 Feb 2021	Campus FM Breakfast 8am sharp	Janet Mifsud, Frank Portelli
8 Feb 2021	article on Times of Malta	Janet Mifsud
8 Feb 2021	article on The Malta Independent	Janet Mifsud, Claudine Aitken
8 Feb 2021	TVAM 8am	Janet Mifsud, Frank Portelli
8 Feb 2021	Espresso 11am	Frank Portelli, Claudine Aitken by skype
8 Feb 2021	follow up Kikkra Te 4pm	Janet Mifsud, Frank Portelli
8 Feb 2021	Popolin TV 7pm	Janet Mifsud , Frank Portelli
11 Feb 2021	follow up Interview with One TV	Matthew Attard (recording)
12 Feb 2021	Training for Police recruits 9.30am to 1pm	Janet Mifsud, Frank Portelli, Caroline Attard, Claudine Aitken
16 Feb 2021	Interview with Joe Dimech PBS (radio) 9am	Janet Mifsud (recording) aired Friday, 19 February
17 Feb 2021	Meeting with CRPD commissioner 1.30pm	Robin Pinkston, Janet Mifsud, Frank Portelli, Caroline Attard, Matthew Attard, Anna Micallef, Noel Mercieca, Bernard Busuttill, Rhoda Garland,
1 Mar 2021	MHN meeting	Caroline Attard, Frank Portelli
3 Mar 2021	invite on Net Radio	Frank Portelli, Noel Mercieca
12 Mar 2021	CMEA members meeting	Committee members
24. Mar 2021	Meeting re. new setup of diary	Frank Portelli, Anna Micallef, Noel Portelli
29 Mar 2021	Meeting with James Cilia and Dr Trevor Abela Fiorentino ST John Malta for training	Janet Mifsud, Robin Pinkston, Noel Mercieca, Frank Portelli, Adriana Caruana Soler, Manuel Camilleri, Caroline Attard, Noel Mercieca, Claudine Aitken
29 Mar 2021	Urgent committee meeting for updates	all committee members
12 Apr 2021	Lecture to Diploma in Community Access for Disabled People	Janet Mifsud, Robin Pinkston, Frank Portelli, Adriana Caruana Soler
20 Apr 2021	Training for St John Malta - Epilepsies and Seizures made simple: what should the first aider know?	Janet Mifsud, Claudine Aitken, Robin Pinkston, Adriana Caruana Soler, Frank Portelli
7 May 2021	Committee Meeting	Frank Portelli, Robin Pinkston, Noel Mercieca, Adriana Caruana Soler, Manuel Camilleri, Claudine Aitken, Janet Mifsud,
15 May 2021	Members meeting on Treatment of drug resistant epilepsies: An update from a local perspective - speakers Dr Doriette Soler, Dr Stephen Attard Members meeting	CMEA members.