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Affiliated to



Caritas
Malta
Epilepsy
Association

A better life for people with epilepsy

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MEMBERS' MEETINGS

FRI - 10th SEP 2021

Annual General Meeting

FRI - 12th NOV 2021

Member's Meeting

**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



Laqgħa Annwali Ġenerali

biż-Zoom nhar il-Ġimgħa 10 ta' Settembru 2021 fis-6.00 p.m.

aktar dettalji jinagħaw aktar il-quddiem

Ara l-formola ta' nominazzjoni f'paġna 4



Kelmtejn mill-President

Gheżież membri, għaddew xahrejn oħra mill-aħħar li kellimtkom. Nispera li tinsabu tajbin u li l-ħajja għalikom issa ġeġja lura għan-normal.

Bħalma rajtu kif erġejna f'tit ir-restrizzjonijiet il-każi mill-ewwel reġġu bdew tielgħin. Għaldaqstant nerga nishaq sabiex ma tillaxkawx avolja l-każi reġġu għall-darb'oħra qed ibattu iżda nirrepeti sabiex dejjem osservaw id-direttivi tad-Dipartiment tas-Saħħa.

Nixtieq nagħmel f'tit enfazi fuq il-laqqgħa li jmiss. Il-laqqgħa li jmiss se tkun il-Gimgha 10 ta' Settembru, 2021 din se tkun il-Laqqgħa Annwali Ġenerali. Għall-raġuni ta' sigurta u saħħa ta' dak li jkun din ukoll ser issir permezz ta' zoom. Kemm jista' jkun qedin nevitaw li niltaqqgħu wiċċ imb'wiċċ. F'din il-laqqgħa il-kumitat preżenti irid jirriżenja u jittella' kumitat ġdid permezz ta' elezzjoni. Għandna wkoll xi tibdiliet żgħir fl-Istatut li biex iseħħu jkollna bżonn l-approvazzjoni tagħkom. Inhegġigkom sabiex mhux biss tattendu u tipparteċipaw iżda wkoll toħorġu għal-kumitat. Napprezzaw ħafna li jkollna membri ġodda b'deġat ġodda u kompletament innovattivi.

Immedjatament wara dawn il-kelmtejn ma din in-newsletter għandkhom issibu formula sabiex tinnominaw u anke tissekondaw lil xi membri li jkun wrew ix-xewqa li joħorġu għal-kumitat. Minn hawn nawgura lil kumitat il-ġdid li jaħdem minn qalbu, fis-serenita' u fuq kollox bħala team. Kif ukoll l-ispirtu ta' familja waħda jibqa' jirrenja fil-kumitat il-ġdid. Din il-formula ser tkunu ircevejtuha b'email minn qabel sabiex tintbghat lura lilna f'tit ġranet qabel il-laqqgħa u b'hekk inkunu nafu min għandu l-intenzjoni li joħroġ għall-kumitat.

Nixtieq niżvela magħkom li din is-sena peress li għalaqna 25 sena mit-twaqqif qedin nippreparaw ktejjeb li jinkludi il-ħidmiet li għamilna kif ukoll bosta ritratti. Ir-ritratti jibqgħu verament memorja sabiħa ħafna. Dan il-ktejjeb ser ikun dedikat Għal-Mario u Victoria Dimech, President u Segretarja u li ħallew din id-dinja għall-ħajja aħjar. Kemm Mario kif ukoll Victoria iddedikaw ħafna mill-ħin tagħhom għal-Għaqda tagħna u dan kien apprezzat mhux biss hawn Malta imma anke wkoll barra minn xtutna.

Nispera li fi f'tit xhur oħra nergħu lura għan-normal, b'laqqgħat u taħditiet minn professjonisti u fuq kollox wiċċ imb'wiċċ. Anke aħna forsi nergħu naqbd u ir-ritmu li kellna u nibdew naġhtu iktar taħditiet u presentaions.

Bħalma tafu għalkemm qedin niltaqqgħu biz-zoom xorta nagħmlu minn kollox sabiex ikollna kelliema profesjonisti sabiex ikellmuna f'dawn il-laqqgħat. Ħafna drabi ma tkunx faċli li ssib dawn in-nies u naġhmlu ħafna tentattivi biex fil-laqqgħa jkollna professjonisti.

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

Inselli Għalikom,
Frank

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A better life for people with epilepsy

Formola Nominazzjoni għal-Kumitat 2021 – 2024

Din il-Formola trid tintbagħat: Caritas Malta Epilepsy Association b'email fuq: maltaepilepsy@gmail.com Sa nhar iT-Tnejn 6 ta'Settembru, 2021

Nominat

Isem _____

Kunjom _____

Indirizz _____

Tel/Mob _____

Firma _____

Sekondat

Isem _____

Kunjom _____

Indirizz _____

Tel/Mob. _____

Firma _____

Epilepsy and you

Free



The course takes:
2 hours per week for 8 weeks

Access the course online from any
computer, tablet or smartphone

Cost: **Free**

Register an interest

Course overview

Epilepsy and you is an online self-management course that gives people the skills to manage their epilepsy.

Our learning platform saves your progress as you go, so you can work through the course at your own pace.



This course has been produced under the terms of [Epilepsy Action's information quality standards](#) and is accredited by QISMET.

Updated | August 2019

To be reviewed | August 2022

Course description

Epilepsy and you is an online course that gives people the skills to manage their epilepsy.

During the course, you will:

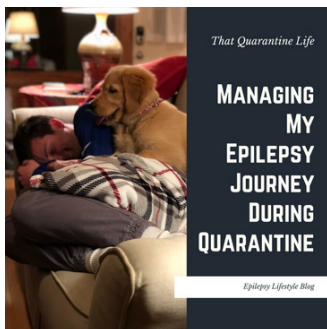
- Become an expert in your own epilepsy
- Gain new skills
- Make real changes to help you manage your health and wellbeing

People who have completed this quality accredited course feel better and more confident about managing their epilepsy every day – feeling more in control and less alone.

"As a result of this course, I'm trying to get out and about more and not let this condition control me" Course participant

to apply click on link below

https://learn.epilepsy.org.uk/courses/epilepsy-and-you/?utm_source=tiles&utm_medium=online&utm_campaign=epandyoumember2018



As epilepsy warriors, there's something we can all agree on; our journey is long and tough. We deal with so much on a daily basis that we can get completely worn out by days end. Now, were any of you prepared for what happened about five months ago? The answer is simple, no. Not only do we have to manage our epilepsy, but now we have to navigate the coronavirus. With little to do over the past few weeks, I thought I would put this piece together. Welcome to 2020!

It's funny because I felt like the coronavirus pretty much stopped my life on a dime. New experiences, memories, etc. were all going to be put on hold right? Not at all! My friend groups jumped on the opportunity to make the most of this situation with plenty of FaceTime calls. We would spend hours on the phone reliving old memories or making jokes about each other now as we managed our way through quarantine. What I loved was that despite being confined to our homes, we were making new memories that will definitely last a lifetime. Whether it was a group FaceTime call or a quick phone call with a friend, we made sure not to let this affect our ability to be with each other. Take some time to call one of your friends and have a nice long conversation reliving your past or joking around to make memories for years to come.

One thing I was taught was to always try and help people as much as you can, and being at home I found one opportunity that hit home. When I realized that local epilepsy foundations had to close their doors and go the virtual route to be with their patients I wanted to step in. It's not the same talking with a counselor over the phone than in person. As time progressed, I decided to help out some local epilepsy foundations by holding virtual interviews. Conducting those interviews showed how important foundations are to the community. I couldn't be more grateful for

the directors I met and the information they provided epilepsy patients around the world. It was something all of us were blessed to be a part of. Helping people in any way you can will go a long way especially now.

"We're requiring you to stay six feet apart." How many times have you heard this? Being six feet apart doesn't mean you can't pick up your phone and check in with your epilepsy friends. One night I spent an hour just messaging my epilepsy friends around the world checking in. That one night messaging people has led to more conversations with new people to this day. Everyone, especially now, could use a nice conversation. The best part about our community is that we don't always have to talk about epilepsy. Yes, support is always needed, but just being there to talk is more important. I encourage everyone to pick up your phone or computer and message someone to see how they're doing.

Throughout these past few months, I've been able to really reflect on my epilepsy in general. Can I find any triggers? What time of day do they occur? Am I handling my seizures good? These are all questions that I've thought about and have pretty much answered. While I can't find any triggers or a specific time of day they occur, I do know that just trying to figure that out shows me I'm handling them well. The quarantine life has taken a toll on my epilepsy, but by no means have I let it affect my quality of living through this. Epilepsy may suck, but corona is a once in a lifetime event.

Like with any big life challenge, light will show at the end of the tunnel. This is truly a mystery for everyone, but we all overcome it. I have no doubt that we will be living our life not six feet apart. And for the record, the first thing I will be doing when all of this is over will be heading to an Eric Church concert!

Social Media Campaign that International Bureau for Epilepsy and International League Against Epilepsy have developed to shine a light on Epilepsy



Epilepsy is not contagious. You cannot “catch” it by being near someone who is having a seizure.

Educating people about this and other myths can help improve the lives of people with epilepsy.



The stigma of having epilepsy can prevent children from attending school and adults from finding jobs. Stigma also affects relationships and friendships.

Educating communities about epilepsy can reduce this stigma and improve quality of life.



Globally, about 5 million people are diagnosed with epilepsy each year – about the same number of people as the entire population of Sydney, Australia.



Birth-related injury, nervous system infection, stroke, and traumatic brain injury account for nearly 1 in 4 cases of epilepsy worldwide.

Strategies to prevent these injuries and infections can dramatically reduce the number of people developing epilepsy.



As many as 70% of people with epilepsy could live seizure free if they had access to appropriate medicine. Most do not.

Making anti-seizure medication more available and affordable would allow more people to get the treatment they deserve.



EXERCISE AND EPILEPSY pt 1



Exercise improves fitness, energy and mood and relieves stress. Improving overall health and wellbeing in this way can help reduce seizures and the impact of epilepsy for some people. It can also help people feel more in control of their health.

How can exercise help epilepsy?

Exercise helps people to stay fit and healthy. If you have epilepsy, this may help to reduce the number of seizures you have. Exercise can also improve mood and relieve stress. As stress is a common trigger for seizures, exercise may help to prevent seizures for some people.

There are many ways to be active, including some that people may not realise actually count.

Exercise releases 'feel good' hormones into the brain, helps to keep your muscles active, reduces fat levels in the body, and increases oxygen flow to your brain. It can also increase your bone density which can help to prevent osteoporosis (where bones become fragile and are more likely to break).

The NHS recommends exercise as one of the five steps to mental wellbeing. Being active may help you feel more positive and able to get the most from life.

Research in exercise and epilepsy

Research in the USA has shown that people with epilepsy exercise less than those without epilepsy.

A study in Norway of women with uncontrolled epilepsy, showed that regular sessions of aerobic exercise (for example running, walking, swimming, cycling) for 60 minutes, twice a week, for 15 weeks, resulted in a significant reduction in the number of seizures they had. They also had fewer muscle pains, sleep problems and fatigue, and had lower cholesterol and better oxygen flow around the body.

Some specific diseases that are linked to a lack of exercise, poor diet and being overweight include cardiovascular disease (which can lead to heart attacks and strokes), type 2 diabetes, hypertension (high blood pressure), osteoporosis and certain cancers. A lack of exercise can also be linked to increases in depression and anxiety.

Studies show that people with epilepsy are at an increased risk of developing most of these conditions, so being active and maintaining a healthy diet can help your overall health.

Can I do exercise if I'm tired or ill?

You may not feel like doing exercise if you are tired due to seizures or because of the side effects of your medication. However, even gentle exercise can actually boost energy levels.

Some people with epilepsy may worry about doing in exercise in case they hurt themselves during a seizure. In fact, research shows that although seizures can happen during exercise, the positive effects of exercise may help to reduce seizures for some people with epilepsy.

May - August Activities 2021

<i>Date</i>	<i>Activity</i>	<i>Participants</i>
31 May 2021	Meeting for disability organisations at Ta' Qali	Frank Portelli
3 June 2021	Meeting to discuss 25 year anniversary book by zoom	Frank Portelli, Janet Mifsud, Robin Pinkston, Claudine Aitken
27 June 2021	group photo at UoM	Frank Portelli- President, Janet Mifsud- Advisor, Claudine Aitken-Secretary, Robin Pinkston, Noel Portelli, Manuel Camilleri, Caroline Attard, Adriana Caruana Soler, Noel Mercieca
9 July 2021	Members meeting by Zoom - Seizure related injury: an overview of first aid recommendations by Dr Trevor Abela Fiorentino	Frank Portelli- President, Janet Mifsud- Advisor, Claudine Aitken-Secretary, Robin Pinkston, Noel Portelli, Manuel Camilleri, Adriana Caruana Soler, Caroline Attard; members
30 July 2021	Meeting to discuss 25 year anniversary book by Zoom	Frank Portelli, Noel Portelli, Janet Mifsud
4 August 2021	Meeting with European Regional Executive Committee and other IBE European Chapters by Zoom	Frank Portelli, Janet Mifsud, Claudine Aitken
6 August 2021	Meeting about nurse specialisation call with Sarah Fleri and Rodianne Micallef Cann. Meeting at Ta' Xbiex	Frank Portelli, Noel Mercieca, Janet Mifsud
26 August 2021	CMEA committee meeting to discuss 25 year anniversary book by Zoom	Janet Mifsud, Claudine Aitken, Robin Pinkston, Adriana Caruana Soler, Frank Portelli, Caroline Attard, Noel Portelli, Manuel Camilleri, Matthew Attard

