

Kelmtejn

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- Caritas
 Malta
 Epilepsy
 Association
- A better life for people with epilepsy

Kontenut Photo at the last committee meeting. Diskors tal-President waqt l-AGM **Notice Board** 2020 National Epilepsy Conference AGM-12th JULY 2019 **ESPLORA-Family Science Day** Common Epilepsy Myths, Debunked CMEA activities July-August 2019



President Mr. Frank Portelli

Viċi President

Membri tal-Kumitat 2019 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

Disinn:

Kevin Attard / Noel Portelli

photo taken at the last Committee meeting





Għeżież membri, kollegi u ħbieb, bħal ma rajtu mir-rapport amministrattiv ix-xogħol li wettaqna matul is-sena 2018 kien wieħed bla waqfien bħalma kienu fis-snin ta' qabel. Naħseb li nkun qed ngħid sewwa li rega' kellna jew aħjar għandna problema bil-pożizzjoni ta' segretarja.

Dal-aħħar snin kellna ħafna bdil f'din il-pożizzjoni. Ħafna drabi dawn qed iħallu din il-ħidma minħabba pressjoni ta' xogħol li ġgib magħha din il-pożizzjoni. Irridu npoġgu ma mejda u naraw kif ser nitekkiljawha bis-serjeta'.

Naħseb ukoll li rega' wasal iż-żmien li bħala kumitat nergħu niltaqgħu darba fix-xahar. Naħseb li fl-ewwel ġimgħa ta' kull xahar ikun tajjeb, għax b'hekk inkunu nistgħu niddiskutu il-kwantita' ta' emails li qed nirċievu. Il-volum ta' emails qed ikun esaġerat u għalhekk ma nistgħux inħallu li jakkumulaw iżjed minn xahar.

Nixtieq insemmi li wara ħafna ħidma lestejna l Epilepsy Toolkit u dan intlaqa' tajjeb ħafna u qed ikollna ħafna talbiet għalih. Hawnhekk irrid nirringrazzja lil sħabi kollha tal-kumitat ta' l-għajnuna li tajna lil xulxin biex dan seta' jseħħ. Irrid inżid ngħid ukoll li il-pictorial guide fuq l-epilessija 'Epipicto' qed joqrob lejn tmiemu wkoll. Il-ħidma fuq dan il-proġett mhux dejjem kienet ward u zgħar u issa li resqin lejn l-aħħar qed insibu hafna ntoppi. Hawnhekk irrid nirringrazzja lil-istaff tal-EUPA tal-għajnuna li dejjem tawna u li dejjem insibuhom f'każi bħal-dawn.

L-Għaqda tagħna dieħla fit-23 sena tat twaqqif tagħha. L-għan prinċipali tal-Għaqda huwa li nkabbru l-għarfien u nippruvaw nagħmlu l-kwalita ta' ħajja aħjar għal-persuna blepilessija u l-familja tagħha. Għal- dan il-għan l-iktar li qed nikkonċentraw huwa fuq skejjel għax nemmnu li jekk nedukaw l-istudenti tal-llum, il-ġenerazzjoni t'għada titla edukata u l-istigma tonqos żgur. Kull okkażjoni li jkollna biex inxerrdu l-awareness kemm fuq radios, gazzetti u televiżjoni qatt ma nitilfuhom. Aħna nagħmlu in-service course lit-teachers, taħditiet kwaħi lil kulħadd, pulizija, tobba, nurses, dentist, social workers, carers etċ.

Nagħlaq billi nagħmel appell biex tagħmlu mill-aħjar biex l-attendenza għal- dawn il-laqgħat tkun wahda aħjar, għax b'hekk tagħmlulna kuraġġ biex inkomplu fl'impenn tagħna. Żgur li siegħa u nofs darba kull xagħrejn kullħadd jaffordja jekk tagħmlu daqxejn ta' sforz. Nixtieq nara iktar zaghzagh mhux biss f'dawn il-laqghat izda wkoll fil-kumitat ghaliex dawn iż-żgħażagħ iridu jkunu il-futur u s-sisien ta' din l-Għaqda. Nagħlaq billi nirringrazzja lilkom kollha b'mod speċjali lil membri kollha tal-kumitat tax-xogħol li għamlu u mhux biss iżda għamluh mill-qalb.

Fl-aħħarnett iżda mhux I-inqas irrid nirringrazzja lil-Prof. Janet Mifsud tax-xogħol bla waqfien li tagħmel mhux Malta biss iżda madwar il-globu. Mhux ta' b'xejn ħadet I-Ambassador for Epilepsy Award li se jiġi ppreżentat lilha ġewwa Bangkok it-Tajlandja propju din il-ġimgħa.

Grazzi ħafna.

Frank Portelli

NOTICE BOARD

SEPTEMBER 27

GUEST SPEAKER



MR. ANTHONY GATT Director, caritas malta

A CONTINUATION OF MR. GATT'S TALK ON THE 10th May with the subject

Coping with Stress

DON'T MISS THIS OPPORTUNITY

Anthony was born in 1976, is from Valletta and is married and has five children between the ages of 3 and 14. He is a Counselling Psychologist and has been formally working in the helping and social sector since 1999. In his youth he was immersed in voluntary work and served for 10 years within the Diocesan Youth Commission. After obtaining a bachelor degree in psychology, incidentally his first empolyment was with Caritas (Malta) as a Volunteer's Coordinator. He then worked with at-risk youth within Sedga Agency which lead him to pursue a Master degree in Counselling Psychology at the Univesity of British Columbia in Vancouver, Canada. On completion of his professional training he worked as a pyschologist in the drug rehabilitation sector with Sedga and also worked privately for a number of years before returning to Caritas (Malta). For the last three years he acted as Clinical Coordinator of the range of drug rehabilitation services and programmes within Caritas (Malta). Since 2004 Anthony has been a visiting lecturer at the University of Malta and has lectured in indivdual and group counselling and psyhotherapy, humanistic psychology and organisational psychology. Over the years Anthony has also set on several church and state boards: The Diocesan Therapeutic Board, the Malta Psychology Profession Board, and the Prison Addiction Rehabilitation Management Board. For several years he formed part of the council and also served as secretary of the Malta Chamber of Psychologists. Inspired by the church's social teaching based on the calling "whatever you did for one of the least of these brothers and sisters of mine, you did for me,' and Pope Francis's vision of deep love and care for the person in need, Anthony finds himself at home within Caritas. For him Caritas is a home and refuge for persons who feel alone, poor, heavy laden and desperate. A Home that provides solace, dignity, hope and healing. A home where the person discovers or re-discovers his/her intrinsic value and connectedness with the rest of the community. In August 2018, he was appointed by Archbishop Charles J. Scicluna as the new Caritas Malta Director, a role which he is fulfilling with passion, dedication and great perseverance..

Anthony's family and vocation fill his life to the brim. He cherishes his wife Marisa in whom he finds substantial support, family time, playing with his children, contact with nature, camping and adventure sports, savouring life in its simplicity. He enjoys a good laugh and loves to bring it about in others.

This meeting will be held at 6pm at Caritas Malta, 5 Lion Street, Floriana.

Whatever is discussed during these meetings is kept confidential.

2020 National Epilepsy Conference



Dolmen Resort Hotel Qawra - MALTA

email:maltaepilepsy@gmail.com







Annual General Meeting - 12th July 2019





The meeting started at 6:00 pm. 15 minutes were allowed as stipulated in the statute.

- Attendees: 9 persons were present, 5 committee members plus 4 members.
 A TV crew from Super One took some video and did some interviews with
 several committee members as well.
- Opening: Mr. Frank Portelli welcomed and thanked all those present. He
 explained that the AGM was called as a necessary part of our new status as an
 NGO. He declared the AGM open.
- Administrative Report: Ms. Claudine Aitken read the administrative report for the year. The report was approved. The approval was proposed by Ms. Robin Pinkston and seconded by Mr. Karmenu Vella. Approval was unanimous.
- Reading of Minutes: Robin Pinkston read the minutes of the last meeting.
 The approval of the report was proposed by Dr. Anna Micallef and seconded by Ms. Helen Attard. Approval was unanimous.
- Financial Report: Then Mr. Frank Portelli presented the Financial report for the year ended 2018. The finances were reviewed by Dr. Ivan Paul Grixti, CPA. The approval was proposed by Mr. Franz Attard and seconded by Mr. Manuel Camilleri. Approval was unanimous.

Conclusion by President- Frank Portelli

Mr. Frank Portelli gave a concluding address and encouraged us to continue working hard together for "a better life for people with epilepsy in Malta." There was a short report on recent initiatives regarding the Embrace seizure alert device and the ongoing work to bring buccal midazolam to Malta by Robin Pinkston.

Dr. Anna Micallef motioned that we adjourn, and Ms. Robin Pinkston seconded.

The next Member's Meeting is Friday, Sept 27 th at 6:00 pm and will be held at Caritas Malta, 5 Lion Street, Floriana.

Esplora - Family Science Day

CMEA were invited to have a stand at Esplora on Tuesday, 13th August during the activity Family Science Day. There was a lot of interest in our activities during the day. Children were treated to interactive games on how the brain works. The epilepsy toolkit was distributed to the parents and teachers who accompanied the children. CMEA would like to thank Esplora for this unique opportunity.









Our stand at Esplora with some Committee Members and volunteers



On Saturday, 14th September we witnessed the launching of the Epipicto pictorial guide for adults with epilepsy at the Grandmaster Antoine de Paule Hall in San Anton Palace, Attard. A full feature of this event will be published in the next newsletter.



Extract from

https://health.clevelandclinic. org/13-common-epilepsy-mythsdebunked/

COMMON EPILEPSY MYTHS, DEBUNKED

The truth about an often misunderstood condition

Some myths about epilepsy are centuries old, but they still persist. Epilepsy Center Director Imad Najm, MD, dispels 13 of the most common myths about epilepsy. Here are some of them:

Myth 1: If you've had a seizure, you have epilepsy.

Fact: A person is diagnosed with epilepsy when he or she has two or more unprovoked ("out of the blue") seizures that occur more than 24 hours apart. But when something provokes a seizure, such as binge drinking, sleep deprivation or a new medication, these are not related to epilepsy.

Myth 2: People with epilepsy are mentally ill or emotionally unstable.

Fact: Epilepsy is an umbrella term covering many types of seizure and epileptic disorders. It is a functional, physical problem, not a mental one, and it has many unidentifiable causes.

Myth 3: People with epilepsy aren't as smart as other people.

Fact: Epilepsy has little to no effect on a person's ability to think, except during some seizures, during a short period following some seizures and sometimes as a side effect of certain anti-epileptic medications.

Myth 4: People who have seizures can't handle high-pressure, demanding jobs.

Fact: They often can, and they do. Most professions — including those in the highest tiers of business, government, justice system, sports and medicine — can accommodate a person with epilepsy.

Myth 5: It's easy to tell when a seizure is about to happen.

Fact: We can't yet predict when seizures are beginning, although some patients say they can feel a brief sensation within seconds of a seizure — which we call an "aura." Research is ongoing and include training dogs to detect the onset of seizures.

Myth 6: Seizures hurt.

Fact: A person is unconscious and not in any pain during most seizures. Afterward, the patient could feel discomfort if he or she falls down, has muscle aches or if he or she bit their tongue (during a grand mal seizure).





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3 Ways to Support Someone With Epilepsy

Those who are climbing the epilepsy mountain are strong, inspirational individuals. While I do believe each one of us can handle our battle, it's important to have a strong support system. I wouldn't be where I am in my epilepsy fight without my family, friends and doctors. They provide me with a sense of comfort, and I know I can go to any one of them when I feel down. We are strong people, but we are strengthened by the people who are carrying us. If you care for, know someone or just see a person battling epilepsy, these are a few ways you can offer them support.

1. Listen.

It may sound simple and a little cheesy, but it helps a lot of us in the epilepsy community. When you're supporting someone with epilepsy, listen to them first. When I call or text my friends, I tend to just vent stuff out to them about my seizures. They are patient with me and let me finish my venting. It's a way for us to express what's on our minds, whether it's good or bad. When I'm supporting others in the epilepsy community, I always let them start the conversation first. They will get their thoughts and emotions out there, and then I can be there for support the rest of the way.

2. Change the topic.

Epilepsy is a full-time job no one signed up for. It's always good to change up the topic when talking with someone with epilepsy. With a few exceptions, not many people like to talk about their seizures all the time. If you're out or on the phone with someone battling epilepsy, change the topic to something totally different! For me, it would be sports for sure. I have had times when I texted friends telling them to talk about any random topic just to take my mind off everything. I've also done the same for friends of mine who have seizures. It's no fun talking about them daily and sometimes we just need a break!

3. Reassure them they are not alone.

Like I mentioned before; we are only as strong as those around us. Sometimes we need to be reminded we are not alone in our fight. From family to friends to the entire epilepsy community, no one battling epilepsy has to go through it alone. There were definitely times when I forgot about this and had to be reminded.

When supporting someone with epilepsy, you aren't just helping one person, you are helping the entire epilepsy community. It may get hard at times as we go through rough patches, but these tactics should help you as you support your loved one, friend etc. with epilepsy. Now go out and be that support system for the epilepsy community. We thank you in advance for your help!

CMEA activities July 2019 to August 2019

Date and time	Event	Attended by
12th July 6:00 pm	CMEA AGM	CMEA committee
13 th July 7.30pm	filming and interview with One Tv reporter on One news 7.30pm	Janet Mifsud, Frank Portelli, Manuel Camilleri
30th July 17.30pm	Meeting with Mrs Muscat at the Meeting Place	Frank Portelli, Caroline Attard, Noel Mercieca, Manuel Camilleri
2nd August 2019	Meeting at Esplora	Janet Mifsud, Frank Portelli
7th august 2019	Janet interviewed on Rasimb Ras TVM	Janet Mifsud
13th August all day	All day Stand at Esplora	Janet Mifsud, Frank Portelli, Manuel Camilleri, Caroline Attard, Matthew Attard, Cole

II-Progett Epipicto

II-proģett Epipicto jiĝi fi tmiemu fl-14 ta' Settembru ģewwa Malta. Fuq dan is-suġģett tisimgħu aktar fl-edizzjoni li jmiss.



Fiex tikkonsisti dil-gwida bl-istampi?

Dan huwa tagħrif illustrat dwar I-epilessija, magħmul b'mod sempliċi u li faċli wieħed jagrah u jifhmu.

Għal min hi mmirata dil-gwida?

Għall-adulti bl-epilessija li għandhom livell baxx ta' litteriżmu, kif ukoll għal dawk il-persuni li jsibu diffikultà biex jikkomunikaw bil-lingwa.

Msieħba tal-proġett

Epipicto huwa proģett li jgħaqqad 5 assoċjazzjonijiet Ewropej li jaħdmu fuq I-epilessija:

Caritas Malta Epilepsy Association

Stichting Epilepsie Instellingen Nederland (SEIN)

Epilepsy Connections (Scotland)

Epilepsie Dachverband Österreich (EDO)

Interessenvereinigung für Anfallskranke in Köln e.V.

Għal aktar informazzjoni żuru s-sit tagħna:

www.epipicto.eu

jew ikkuntattjaw l-imsieħba fil-proġett fuq: epipicto@gmail.com