

Kelmtejn

Dicembru 2020 - Nru. 60

Caritas Malta Epilepsy Association tibghat l-isbah xewqat ghall-Milied hieni u s-sena ģdida mimlija hena, pači, risq u sahha lill-membri kollha u lill-familji u qraba taghhom.

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"Tibzghux, għax jien ġibtilkom aħbar sabiħa u ta' ferħ. Għaliex il-lum twieled għalikom u għal poplu kollu, fil-belt ta' David, is-Salvatur, li hu Kristu l-Mulej. Għandkom issibu lit-tarbija imgeżwra fil ħrieqi u minduda f'maxtura."



Caritas Malta Epilepsy Association

A better life for people with epilepsy

Kontenut

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Blood test may predict seizures
CMEA activities during 2020
Let's shine a light / Dr. George Grech

CMEA giving a helping hand during the marathon



G R A Z Z I Waqt il- Maratona inġabret is-somma sabieħa ta' EUR668,280

President Mr. Frank Portelli

Vići President Dr. Anna Micallef

Segretarja Ms. Claudine Aitken

Teżoriera Ms. Caroline Attard

P.R. Ms. Robin Pinkston

Membri tal-Kumitat 2020

4 5

7 8

> Assistent P.R. Mr. Matthew Attard

Facebook u Żagħżagħ Ms. Adriana Caruana Soler

Membru Mr. Manuel Camilleri

Konsulenta Prof. Janet Mifsud

Psychotherapist: Verena Portelli





Għeżież kollegi, ħbieb u membri, nispera li tinsabu tajbin, u jien dejjem nappellalkom biex dejjem tieħdu ħsieb saħħitkom. Min hawn nerġa' nfakkarkom sabiex tobdu d-direttivi tad-Dipartiment tas-Saħħa u tieħdu l-prekawzjonijiet kollha meħtieġa.

Din il-pandemija effettwatna ferm negattiv u xekklitna fi dmirijietna. Kellna nħassru ħafna taħditiet lil entitajiet differenti u l-ftit li għamilna għamilniehom mid-dar permess tal-kompjuter. Qed ngħid ftit għax fejn is-sena ta' qabel kienet miżuda bil-lectures u taħditiet din is-sena naqsu drastikament, anke l-konferenza nazzjonali kellna nħassru. Bħalissa għaddejjin inħhallsu l-flus lura ta' min kien ġa applika. Aħna xorta waħda għamilna ftit taħditiet u wżajna powerpoint presentations permess tal-kompjuter, u dan kollu sar mid-dar, biex kemm jista' jkun nevitaw kuntatti. Pero niggarantielkom li hemm qabża kbira bejn li wieħed ikun preżenti fiżikament quddiemek milli qed tara bniedem fuq l-iscreen.Jien m'inhiex qed ngħid li ma għamilna xejn, imma id-differenza bejn prezenza fizika u dik fuq screen hija ċara.

Il-laqgħat tal-kumitat kif ukoll tal-membri xorta waħda baqghu għaddejjin kif kien skedat għalkemm xorta waħda bil-kompjuter bi programm jismu zoom, fejn inti xorta waħda tista' tara l-dak li jkun. L-attendenza xorta waħda qed tkun fqira avolja dak li jkun jista' jingħaqad magħna mill-kumdita' tad-daru. Hawnekk nerġa' nagħmel daqsxejn ta' appell sabiex tagħmlu ftit sforz u tinaqdu magħna. Aħna dejjem ninfurmawkom meta se jkollna laqgħa permess ta' email.

Bħalissa qedin għaddejjin bi preparamenti u ħafna diskussjonijiet ħalli naraw x'nistgħu nagħmlu għal-Jum Internazzjonali tal-Epilessija li se jiġi fit-8 ta' Frar. Barra min dan qed naħdmu fuq tifkira għal egħluq il 25 sena tal-Ghaqda li ser tkun is-sena d-dieħla.

Nagħlaq billi nixtieqilkom milied mimli hena, risq u paċi. Nafu li dan il-milied ser ikun differnti mill-oħrajn għax ma nistgħux ningħaqdu u ningabru flimkien pero nibqgħu posittivi. Irridu nżommu d distanza soċjali u nittamaw li din il-pandemija tgħaddi malajr. Nerga' nappella biex tobdu d-direttivi u oqodu safe u l-bogħod mill-periklu.

Inselli għalikom.

Frank

NEXT MEMBERS' MEETING

Sessions will be held on zoom until further notice and start at 6pm. An email with login details will be sent before each meeting.



SAVE THESE DATE

Keeping contact with you

People with epilepsy and their friends and families have a lot of experience in overcoming challenges and this season of Covid 19 has been no exception. Literally almost every person in the world has had to make major adjustments in their lives. The members of Caritas Malta Epilepsy Association have risen to the challenge admirably.

Just days before the lockdown begin, CMEA had a national conference planned with everything booked, printed, prepared, and ready. Unfortunately, the conference had to be postponed and our speakers from abroad had to cancel their tickets. This did not mean that the association stopped working though! The committee members of CMEA have continued to meet online and even to consult with different groups regarding epilepsy training and guidance. A Zoom member's meeting took place in March where we heard from Dr. Josanne Aquilina, a neurologist at Mater Dei. She graciously gave time to answer questions and advise CMEA members regarding the new realities of visiting the hospital and the changes in both the ER and outpatients. Committee members were also able to contribute to a Malta EU Steering Committee and hold their Annual General Meeting in September via Zoom.

When CMEA members were asked about the effect this new reality has had on life with epilepsy in Malta, there were some positive comments. Some of our members are unable to have a driving license due to uncontrolled seizures, and they travel by bus. Although there were still some problems, overall, they concurred that there was much less traffic and fewer people traveling by bus, so transportation improved. Another positive was that the prescription process and paperwork has been eased to cut down on the amount of people visiting the hospital. This has made it much simpler for many people to access needed medications at the pharmacy of their choice. Tele-doctoring was also overall appreciated, as a lot of time and effort was saved. On the other hand, some people felt rushed, as if the doctor was in a hurry to be finished, and they did not have the opportunity to ask some questions they really wanted to ask. Several members lost jobs due to the pandemic and this of course led to a loss of income and increased stress and anxiety which tends to exacerbate seizure activity.

Like many others, the time at home and feeling cut off from others has brought challenges including some feelings of anxiety and depression. Various methods of stress relief that were shared included painting and drawing, hiking in nature, and exercising. A Gestalt psychotherapist, Verena Portelli, generously volunteered to donate some time to assist CMEA and its members in the coming months. For future meetings online and any questions, contact us at maltaepilepsy@gmail.com or https://www.caritasmalta.org/cmea/.





Members' Meeting- 13th November 2020

Coping with Stress: The role of Gestalt Physotherapy during these trying times



VERENA PORTELLI

Gestalt Psychotherapist B.Psy(Hons)(Melit.); M.Psych (Gest)

Verena Portelli led a discussion about "What is Gestalt Psychotherapy?" She asked us what our impressions were when we heard these words. She then gave a definition, and a description about the differences between a psychiatrist, a psychotherapist, and a psychologist. She shared about "How to Know When to Reach Out" and gave reasons including excessive worry and being "on edge" and finding it difficult to concentrate. It would especially be important if you find that your problems are causing you to harm others or yourself. We discussed that you do not always need to have a problem or an issue to go to psychotherapy. A few members shared some questions and Verena expertly shared some thoughts in response too.

Then we moved to 5 Myths vs Truths and heard about some common misconceptions of therapy.

After that, Verena shared about Stress and Covid 19, which was of course extremely applicable. Quarantine, Isolation, Financial stressors, fear of being infected, fear of the infection of a loved one, and the lack of control were some of the topics covered. We discussed as well how our body shows signs of stress and various coping mechanisms to take care of our mental health during these times. Routine really helps and mindfulness is helpful. She also shared helpful practical tips such as maintaining a routine, moving around, keeping in contact with friends and family, setting up appropriate work spaces and remembering that THIS IS TEMPORARY and you are not ALONE. She finished the session by asking us to share what stuck out to us and what we found helpful. We all agreed that we are VERY grateful for Verena's investment in us for this session and her offer to help with some future small groups for people with epilepsy and their caregivers.





A NEW PSYCHOTHERAPY GROUP IS BEING SET UP FOR PARENTS AND CAREGIVERS OF INDIVIDUALS EXPERIENCING EPILEPSY.

A new psychotherapy group is being set up for parents and caregivers of individuals experiencing epilepsy. This group aims to provide a safe space where group members can share their own experiences, both positive and negative, whilst being provided with emotional support from the psychotherapist facilitating the group as well as from the rest of the group.

Group sessions are different ways of getting support whilst having the opportunity to listen to others experiences. This gives room for more support and growth.

The group sessions will consist of monthly hour and a half sessions for a total of 5 sessions. The group will consist of 8 members, so if interested and would like further information, kindly get in touch with CMEA by the 04.01.2021 to reserve your spot in the group. This will be on a first come first served basis. Kindly note that these sessions will only be held depending on the response received so kindly get in touch by the above mentioned date for us to be able to provide further information.

We look forward to receiving your feedback.



Wara diskussjonijiet li kellna mal-PBS u TVM is-sena I-oħra, bi pjaċir ninnutaw li qed isiru avviżi kemm bil-miktub u kemm bil-fomm qabel jkunu ser jintuzaw strobe lights li jistgħu idejqu lil min hu sensittiv għad-dawl. Grazzi PBS u TVM.



Epilepsy & A Social Media Cleanse? Why It's Important

Fresh off of a few seizures, I wanted to share with you an experience I've been going through. For those who deal with epilepsy on a daily basis, you understand the role social media plays in your life. However, over the past few weeks social media has engulfed all of us. I decided to take a social media "cleanse". Epilepsy plays a huge part in my life and any stress from outside sources like social media can affect it. I hope you consider doing this on your own!

Why Did I Do It?

If you know me, you know that I have partial seizures that occur almost on a daily basis. We, epilepsy warriors, spend



time trying to figure out what may cause or on the other hand help our seizures. In this case, I noticed that stress was beginning to play a bigger role when it came to my epilepsy. Now, as we all know, social media is the one thing that the majority of people spend their time on. While I have been getting support on social media, it has also been very toxic (not epilepsy related). About two weeks ago, I decided to remove all social media apps from my phone. A decision that I didn't think would even last a day!

The Lessons I've Learned

I have to admit that the first few days were rough. However, once I got used to not having Facebook, Instagram, or Twitter on my phone, a little improvement happened. I was no longer tied to everything that was happening online. I was having fun with family and friends. This was slowly relieving me of stress I may have had during the day. Positivity > negativity and the best way to avoid any negativity is to get off of social media as soon as possible. Truthfully, you can feel like a young kid again (if you aren't one!) if you do this cleanse. Go outside, throw around the football, go for a hike, or grab your fishing poles and catch a few fish. Worry less about what people think on social media and impress your friends playing flag football!

**One thing to note is that I was still in contact with all of my epilepsy friends for support via text!

What Do I Expect From You?

Let me be clear, I'm one out of 2.5 billion people on social media. What I hope you do is consider finding what your main cause for your seizures are and tackle them head on. Social media may not be any cause towards your epilepsy, but remember this. Never ever compare yourself to someone on social media. Your journey is different in so many ways, and the last place you want to measure your success is on platforms like Facebook or Instagram.

You have been put on this earth for a reason. Your story will inspire and help so many people. I found that taking a break from social media could and will help me. I hope this inspires you to turn off those notifications and have some fun outside!

extract from: https://www.epilepsylifestyle.com/

Blood test may predict seizures, study suggests

18 Researchers may have found a way to predict seizures in
Jun people with epilepsy using a blood test, according to a new
2019 study in the Journal of Clinical Investigation.

Scientists at research centre FutureNeuro and the Royal College of Surgeons in Ireland (RCSI) carried out the study.

Researchers Dr Marion Hogg and her colleagues collected blood samples from 16 people with hard-to-treat focal epilepsy. The participants underwent video EEG monitoring and a second blood sample was taken 24 hours after they had had a seizure. Samples were also taken from people without epilepsy for comparison.

The study found that before a seizure happened, there was a rise in the levels of a few particles in the blood samples. The researchers explained that activity in brain cells causes chemicals called tRNAs to break down into the particles seen in the blood samples.

The findings showed a spike in the levels of these particles before a seizure came on.

Lead author of the study, Dr Hogg, said: "People with epilepsy often report that one of the most difficult aspects of living with the disease is never knowing when a seizure will occur.

"The results of this study are very promising. We hope that our tRNA research will be a key first step towards developing an early warning system."



Professor David Henshall, study author and director of FutureNeuro explained that the research paves the way for a prediction tool. He said FutureNeuro hopes to develop a device, similar to a blood sugar monitor, to predict when a seizure might occur.

You can find the full journal article on the Journal of Clinical Investigation website. https://www.jci.org/articles/view/126346

epilepsyaction extract from epilepsytoday Your online epilepsy magazine



ent nk nominated as volunteer of the year	Who is going from CMEA committee
nk nominated as volunteer of the year	
	Frank Portelli, Josette Portelli, Noel Portelli
mbers Meeting	Janet Mifsud, Frank Portelli, Robin Pinkston, Noel Mercieca, Matthew Attard, Caroline Attard, Adriana Caruana Soler, Manuel Camilleri, Claudine Aitken
nual Lunch for CMEA Committee members	
EA Comittee Meeting	Janet Mifsud, Frank Portelli, Robin Pinkston, Noel Mercieca, Matthew Attard, Caroline Attard, Adriana Caruana Soler, Manuel Camilleri, Claudine Aitken
eting with Associated Equipment re VNS speaker conference	Janet Mifsud and Frank Portelli
eting with Dolmen @ National epilepsy conference h march	Janet Mifsud and Frank Portelli
ss conference about national epilepsy conference 14th March and International epilepsy day 10th feb	Marica Cassar, Anthony Gatt, Janet Mifsud, Frank Portelli, Robin Pinkston,
EA committee meeting	Janet Mifsud, Frank Portelli, Robin Pinkston, Noel Mercieca, Matthew Attard, Caroline Attard, Adriana Caruana Soler, Manuel Camilleri, Claudine Aitken
erview TVAM 7am	Frank Portelli
erview NET radio	Janet Mifsud and Frank Portelli
icle on Nazzjon newspaper	Marica Cassar, Janet Mifsud
erview on Espresso TV programme	Frank Portelli
IN AGN	Frank Portelli, Caroline Attard
rt of COVID crisis	
om CMEA Members meeting by Janet Mifsud	Janet Mifsud, Frank Portelli, Robin Pinkston, Noel Mercieca, Matthew Attard, Caroline Attard, Adriana Caruana Soler, Manuel Camilleri, Claudine Aitken
erview recording on OneTV	Robin Pinkston
om CMEA committee meeting	Janet Mifsud, Frank Portelli, Robin Pinkston, Noel Mercieca, Matthew Attard, Caroline Attard, Adriana Caruana Soler, Manuel Camilleri, Claudine Aitken
om CMEA members meeting with Dr Josanne jilina	Janet Mifsud, Frank Portelli, Robin Pinkston, Noel Mercieca, Matthew Attard, Caroline Attard, Adriana Caruana Soler, Manuel Camilleri
om meeting with MEUSAC on armaceutical strategy	Janet Mifsud, Frank Portelli, Robin Pinkston, Caroline Attard
om Info talk Ghaqda Diakonjia Bkara	Janet Mifsud, Frank Portelli
om CMEA Committee meeting	Janet Mifsud, Frank Portelli, Robin Pinkston, Noel Mercieca, Matthew Attard, Caroline Attard, Adriana Caruana Soler, Claudine Aitken
om info talk with Appogg	Janet Mifsud, Frank Portelli, Caroline Attard, Claudine Aitken
om CMEA Committee meeting	Janet Mifsud, Frank Portelli, Robin Pinkston, Noel Mercieca, Matthew Attard, Caroline Attard, Claudine Aitken
om CMEA Annual General Meeting	
crosoft Teams meeting with Tarxien school @ dent with epilepsy.	Janet Mifsud, Frank Portelli, Robin Pinkston, Claudine Aitken
om lecture to pharmacy students	Janet Mifsud, Robin Pinkston, Claudine Aitken
ning at WE studios for Caritas Maraton	Janet Mifsud
om info meeting with Marsaskala youths	Janet Mifsud, Frank Portelli, Robin Pinkston, Caroline Attard, Claudine Aitken, Verena Portelli,
om lecture to Mpsych students	Janet Mifsud, Robin Pinkston
eting about conference reimbursements	Janet Mifsud, Frank Portelli
om CMEA Members meeting	Janet Mifsud, Frank Portelli, Robin Pinkston, Noel Mercieca, Matthew Attard, Caroline Attard, Adriana Caruana Soler, Claudine Aitken, Manuel Camilleri
om meeting with Communications Office University Aalta about 2021 International Epilepsy Day	
om CMEA committee meeting	Janet Mifsud, Frank Portelli, Robin Pinkston, Noel Mercieca, Matthew Attard, Caroline Attard, Adriana Caruana Soler, Claudine Aitken, Manuel Camilleri
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DON'TMALTA & INTERNATIONAL EPILEPSY DAYFORGETMONDAY, 8 FEB 2021





LET'S SHINE A LIGHT IN MALTA TOO

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FOR THIS OCCASION CMEA CAN ANNOUNCE THAT AUBERGE DE CASTILLE & PALAZZO FERRERIA WILL BE LIT UP IN PURPLE 6, 7, 8 FEBRUARY 2021.

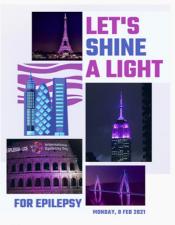
CMEA IS CURRENTLY IN DISCUSSION TO HAVE OTHER PUBLIC BUILDINGS LIT UP FOR THIS INITIATIVE.

SAVE THE DATES!

EPILEPSY IS MORE THAN SEIZURES YOU WILL BE UPDATED BY EMAIL IN DUE COURSE



Nifirħu lill Dr George Grech li ġie ppremjat bil-Premju Nazzjonali għall-Volontarjat 2020.



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mational Epilepsy Day we're asking you to encoura andmarks in your town or country to light up purple list's shine a light on epileps