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Affiliated to



**Caritas**  
**Malta**  
**Epilepsy**  
**Association**

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## Żomm dawn id-dati....

*Il-Laqgħat għall-Membri,  
din is-sena 2019, huma dawn:*

- 8 ta' Marzu - (sala San Pawl, Istitut Kattoliku, Furjana)
- 10 ta' Mejju
- 12 ta' Lulju
- 13 ta' Settembru
- 8 ta' Novembru

*fis-6 ta' fl-għaxija ġewwa Caritas Floriana.*

**Kull ma jingħad waqt il-laqgħat  
jinżamm kunfidenzjali.**



## Membri tal-Kumitat 2019

*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

## LAQGĦA TAL-MEMBRI 8 ta' Marzu 2019 - 'In-Nisa u l-Epilessija'

Għeżiež Membri,

Il-laqgħa tal-membri li jmiss tal-Assoċjazzjoni tal-Epilessija tal-Caritas Malta se ssir nhar il-Ġimgħa 8 ta' Marzu 2019 fis-6pm.

Nixtiequ ninfurmawkom li peress li l-lift f'Caritas Malta qiegħed bil-ħsara din il-laqgħa se ssir fis-Sala San Pawl, l-Istitut Kattoliku, il-Furjana.

Perezzi li din il-laqgħa tikkoinċidi mal-Jum tan-Nisa t-tema tal-laqgħa hija 'In-Nisa u l-Epilessija'.

Il-mistiedna speċjali se tkun Dr Sarah Sultana Grixti. Dr Sultana Grixti ggradwat fil-medicina mill-Università ta' Malta fl-2011. Ilha taħdem fil-qasam tal-Ostetrija u l-Ginekologija mill-2013. Saret membru tal-Kulleġġ Irjali tat-Tobba fl-2016 u tal-Kulleġġ Irjali tal-Ostetriċi u Ginekologi fl-2018. Ggradwat wkoll fil-Masters fis-Saħħa Riproduttiva mill-Università ta' Malta fl-2016 u nġatat Ċertifikat fil-Medicina Interna mill-Università ta' Edinburgh fl-2013. Dr Sarah Sultana Grixti taħdem fl-Isptar Mater Dei Malta u ħadmet ukoll fil-Isptar Royal London. - Barts NHS London, UK. Hija speċjalizzat fil-medicina materna kif ukoll fuq problemi ta' waqt u wara t-tqala.

Għandna pjaċir ninfurmawkom ukoll li lil dawk kollha preżenti għal-laqgħa ser tingħata kopja tat-Toolkit ta' l-Epilessija li tnedja reċentement mill-CMEA.

Dawk interessati li jattendu għal din il-laqgħa huma mistiedna jinfurmaw lis-CMEA fuq maltaepilepsy@gmail.com. Nixtiequ nfakkrukom li l-informazzjoni kollha diskussa waqt il-laqgħa tinżamm kunfidenzjali.



## Kelmtejn mill-President

Kif tafu lkoll il-11 ta' Frar kien il-jum internazzjonali tal-epilessija. Konna qegħdin naħdmu fuq proġett, 'Epilepsy Toolkit' u meta ż-żmien beda jagħfas insistejna mal-istampaturi biex dan ikun lest għal din l-okkażżjoni. Dan fil-fatt seħħ u ftit ġranet qabel dan il-jum dan il-ktejjeb kien lest. Allura għidna li jkun opportun li nnieduh għal din l-okkażżjoni, kif fil-fatt għamilna.

Tajnieh importanza kbira kemm mal-media kif ukoll ma l-għola awtoritajiet. Fil-fatt f'dik il-ġimgħa ta' jum l-epilessija morna 3 darbiet fuq it-televizzjoni u tajna 2 intervisti għal-gažżetti. Barra minn dan ipprezentajna dan il-ktejjeb lill-Eċċellenza tagħha l-President ta' Malta, Marie Louise Coleiro Preca, lil Prim Ministru Joseph Muscat kif ukoll lil kap tal-oppożizzjoni. Ġabuna wkoll fl-aħbarijiet kemm ta' One TV kif ukoll tan-Net TV.

Hawnhekk wieħed tajjeb jgħid li dan il-ktejjeb kien possibbli bis-saħħa u l-fondi tas-CRPD li tawna fondi mill-proġett Pektur. Għalhekk kien bix-xieraq li l-ewwel preżentazzjoni ssir lil Kummissarju Oliver Scicluna ġewwa CRPD ġo Psaila Street Birkirkara.

Preżentazzjoni ohra saret ukoll lis sur Anthony Gatt Direttur ta' Caritas Malta. Barra dan kollu qassamna wkoll minn dawn it-toolkits lil careworkers tas-Support waqt żewġ taħdidiet ta' 90 minuta l-waħda lil ħaddiema tas-Support, waħda ġewwa Baħar iċ-Ċagħaq u l-oħra s-Swatar.

Għalhekk tista' tgħid li kellna 10 t'ijiem ta' ħidma bla waqfien. Nixtieq nagħlaq billi nirringrazzja lil kumitat kollu tas-sehem li taw biex dan kollu jirnexxi.

Grazzi ħafna.

*Frank*



## Strategic Development Forum

The University of Malta held a Strategic Development Forum for External Stakeholders at their Valletta campus on Thursday, January 31, 2019. Caritas Malta Epilepsy Association sent three delegates- Professor Janet Mifsud, Manuel Camilleri and Robin Pinkston. The morning began with a Vision and Mission statement from the Honorable Minister Evarist Bartolo, the Minister for Education and Employment and Prof Alfred J Vella, the Rector of the University of Malta. Prof Tanya Sammut-Bonnici, the Pro-Rector of Strategic Planning and Enterprise then introduced the leaders and themes of the various working groups. The CMEA delegates attended the Societal Impact workshop where the themes of accessibility, community, diversity, good citizenship, social engagement, social inclusion, and social outreach were discussed.

### AVVIZ

CMEA qed tfittex skrivan/a jaħdem/taħdem  
mal-gvern biex jiġi/tiġi sekondat/a għal ma'  
l-assoċjazzjoni.

Jekk taf lil xi hadd interessat ikkuntattjana  
fuq [maltaepilepsy@gmail.com](mailto:maltaepilepsy@gmail.com) għal aktar dettalji.





## Talk at Agenzija Support

Caritas Malta Epilepsy Association led a training for eleven Agenzija Support workers in Swatar on Friday, 8th February. The one and a half hour training was led by Professor Janet Mifsud and included a time for questions and answers, a power point presentation that covers basic information about epilepsy, the different types, and how to help when needed. There were also video clips of actual seizures of various types to help workers better understand. Robin Pinkston shared her experience as the mother of a son with epilepsy and Noel Mercieca shared from his previous experiences as a nurse. All eleven of the participants indicated on their evaluation forms that the session was “Good” or “Excellent” and all of them increased in their knowledge and confidence about what to do if they had a client have a seizure. We thank them for their obvious interest and support and for the work they do to help people with disabilities and their families! Education is power! CMEA held a training session for Agenzija Support workers today involving a presentation, video clips and discussions covering basic information about epilepsy. We thank the participants for their obvious interest and support and for the work they do to help people with disabilities and their families!



## Presentation to CRPD

Caritas Malta Epilepsy Association (CMEA) has launched a toolkit in English and Maltese in conjunction with International Epilepsy Day on 11 February 2019, which is celebrated worldwide on the second Monday in February. The toolkit was funded by PEKTUR, a funding scheme by the Commissioner for the Promotion of the Rights for Persons with Disability. Mr Frank Portelli, President of CMEA presented a copy of the toolkit to Mr Oliver Scicluna, Commissioner CPRD.

In his presentation, Mr Portelli explained how epilepsy is the most common neurological brain disorder, caused by abnormal excessive electric discharges. It affects over 1% of population worldwide and around 4000 persons in Malta and Gozo. Many advances have been made on its causes and several new medicines are now available which control seizures in over 70% of cases. Yet, in several countries, including Europe, persons with epilepsy still face social exclusion and discrimination. This adversely affects employment and education of persons with this condition. Over the last two decades, CMEA, which was set up by voluntary workers in 1996, and now lists almost 300 members, has been working hard to promote more local awareness about epilepsy. This toolkit is intended to provide basic information on the condition to the public and it also provides information which will help persons with epilepsy be better equipped to have a better quality of life. It is intended to complement the medical advice and instructions given by the medical professionals.

The toolkit will be used by CMEA to supplement their outreach activities and training programmes to various stakeholders.



## Preżentazzjoni tat-Toolkit lill-President

Ic-CMEA ippreżentat it-toolkit ukoll lil Eċċellenza tagħha Marie Louise Colerio Preca fil-Palazz ta' San Anton, Balzan nhar it-13 ta' Frar 2019. Il-preżentazzjoni saret fil-Biblioteca restawrata tal-Palazz msemmija għal ex-President Anton Buttigieg. Preżenti ukoll kien hemm id-direttur tal-Caritas Malta is-sur Anthony Gatt u il-Kummizzarju tad-Drittijiet għall-Persuni b'diżabilità. Kienet tassew laqgħa kordjali ħafna u il-President ukoll dawret lil dawk preżenti mal-Palazz. Hi wriet apprezzament kbir għax-xogħol li jgħamlu il-Caritas Malta, CRPD u CMEA u r-rwol importanti tal-voluntarjat fis-soċjeta Maltija.

### X'QALET IL-PRESIDENT TA' MALTA WARA L-PRESENTAZZJONI:

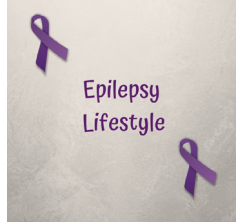
“Minn qalbi nixtieq nifraħ lil Caritas Malta Epilepsy Association għall-ħidma tagħhom sabiex nedew l-”Epilepsy Toolkit” jinkludi fih informazzjoni ġenerali fuq din il-kundizzjoni. Barra minn hekk, dan it-toolkit jinkludi wkoll informazzjoni u pariri utli għal dawk li jgħixu b'din il-kundizzjoni, u li permezz tagħhom jkun jista' jkollhom kwalita' ta' ħajja aħjar.”



## Meeting with Prime Minister

On 18 February 2019, the Prime Minister of Malta, Hon Dr Joseph Muscat hosted a delegation from the Caritas Malta Epilepsy Association. He also invited Hon Dr Chris Fearn, Deputy Prime Minister and Minister for Health and Hon Dr Michael Falzon, Minister for Minister of Family and Children's Rights to join this meeting. Mr Frank Portelli, President of the Caritas Malta Epilepsy Association led the delegation which presented the Prime Minister with an Epilepsy Toolkit, prepared entirely by the Association and funded by CPRD, the Commissioner for Rights of Persons with Disabilities and timed to be released in conjunction with International Epilepsy Day. Epilepsy, which is a hidden condition affects 1 in every 100 persons worldwide, thus making it a very common condition which can hit anyone at any age. It was very encouraging to see the needs of persons in Malta living with epilepsy being taken so seriously. Well done Caritas Malta Epilepsy Association for championing the cause and a huge appreciation to the Office of the Prime Minister for being so sensitive to the needs of the individuals and the families affected.





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## **"written by epilepsy lifestyle blog"**

Dear Epilepsy,

You're a friend of mine that has been around for quite some time now. Throughout the years, you have been one wild, inspirational, foolish and positive friend. You have taught me more about life than almost any person in my life. From being knocked down by you literally to helping others who have friends like you, I couldn't have gone through life without you. As much as I may have hated you at times, I will always appreciate you!

I was cruising through the third grade with amazing friends and teachers. Life was great; hanging with friends, playing golf, and a little school in there too. My friends and I were super excited as the school year was ending. While enjoying school and all my other activities, a new friend came into my life – you.

Your first impression on me and my family was "what the heck?" You scared everyone I knew in a matter of minutes. We didn't know how beneficial you would become later in my life.

While we didn't see much of each other in middle school and high school, you came back in my life during college. You gave me experiences I will never forget in those four years. I had to introduce you to my friends, and that was truly one of the best things ever. My friends really cared about you, so thank you for that. However, I didn't appreciate the late nights battling you. While I had support, battling you is on me. Because of you, I started a blog that has been internationally recognized and gave me a community service award. Having you in college was a big roller coaster ride for sure.

You are still by my side now, allowing me to share my experiences with others on how to battle and live with you. Although you managed to take some major things from me, you are still in my life. I look forward to the many years to come, and hope we can have fewer battles with each other!

# CMEA activities Jan 2019 to Feb 2019

Date & time	Event	CMEA representative
8th Jan	Interview on NET TV am with Matthew Attard NET TV	Matthew Attard
11th Jan	CMEA members meeting	Members
18th Jan	CMEA committee meeting	CMEA Committee members
30th Jan	interview on TVAM	Frank Portelli
31st Jan	University of Malta outreach meetings for stakeholders	Robin Pinkston, Manuel Camilleri, Janet Mifsud
4th Feb	Dwarna recording TVM2 with Mariella Dimech	Robin Pinkston, Frank Portelli, Matthew Attard
5th Feb	Interview with NET studios with Matthew Mamo	Matthew Attard
7th Feb	Presentation & launching Toolkit at CRPD premises with Oliver Scicluna	Janet Mifsud, Frank Portelli, Noel Mercieca, Robin Pinkston, Anna Micallef
7th Feb	Interview for Malta Independent	Frank Portelli
8th Feb	Training at Swatar Day Centre	Janet Mifsud, Robin Pinkston, Noel Mercieca
9th Feb	recording NET TV Mirja with Dulcima Aquilina	FrankPortelli, Manuel Camilleri, Dr Galea Debono
11th Feb	Interview on super one TV feature for news	Frank Portelli
11th Feb	Meeting Leader of Opposition Dr Adrian Delia re Interntational Epilepsy Day	Frank Portelli
11th Feb	International Epilepsy Day meeting in European Parliament in Strasbourg	Janet Mifsud with other representatives across Europe
12th Feb	Interview on Net TV - tea Room with Louise Tedesco	Matthew Attard
13 th Feb	Launch of Toolkit with HE President of Malta, San Anton Palace	Janet Mifsud, Frank Portelli, Robin Pinkston, Noel Mercieca, Anna Micallef, Oliver Scicluna, Marica Mizzi, Anthony Gatt, Geraldine Gatt , Caroline Attard, Matthew Attard, Manuel Camilleri
13th Feb	Meeting for NGOs working with children, San Anton Palace	Robin Pinkston, Noel Mercieca
15th Feb	Training, Day Care Centre, Bahar ic-Caghaq	Janet Mifsud and Noel Mercieca
18th Feb		
11am	Meeting with Prime Minister, Minister for Health and Minister for Social Affairs for International Epilepsy Day	Frank Portelli, Caroline Attard, Robin Pinkston, Noel Mercieca, Matthew Attard
22nd Feb	EUPA bilateral meeting on EPIPICTO project with Ms Janelle Camilleri	Janet Mifsud, Frank Portelli
25th Feb		
10am	Meeting with Gloria Montebello MD II student about her request to have a survey among parents of children with epilepsy on what they think about use of cannabis	Janet Mifsud and Frank Portelli
28th Feb		
6.30-8.30pm	MHN AGM life science park	Caroline Attard and Frank Portelli
28th Feb		
12-2pm	CRPD seminar on unla - Law Courts Training Room, Level -1, Law Court of Malta, Valletta	Noel Mercieca

## Talk at Aġenzija Sapport - see report on Page 5

