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Affiliated to



Caritas  
Malta  
Epilepsy  
Association

*A better life for people with epilepsy*

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## ***Vagal Nerve Stimulation (VNS) and epilepsy: what does it involve?***



The Caritas Malta Member's meeting held on Wednesday, 6th November from 6:00 pm-7:30 pm at Caritas was encouraging as 21 people interested in Vagus Nerve Stimulation were treated to a presentation by LivaNova Neuromodulation specialist Mr. Massimiliano Boffini from Italy. Dr. Boffini has a Ph.D in Robotics, Cognition, and Interaction Technology from the Istituto Italiano di Tecnologia (IIT) in Genova.

He began his presentation by presenting the prerequisites for being considered for Vagal Nerve Stimulation (VNS). In order to be eligible, the patient must have been on at least two different Anti-Epileptic drugs and still not be fully controlled. They must also have been screened to see if they are a candidate for potential brain surgery and have decided against it or ruled it out. This does not mean that they could not decide to choose that route later on.

The Vagal Nerve Stimulator is a small medical device that is implanted near the heart in a similar fashion to a pacemaker and then a lead wire is run up and around the vagal nerve which is located behind the carotid artery. It delivers electrical impulses on a regular basis to the vagus nerve and can also be activated by a person with epilepsy or a caregiver on an as needed basis. One version of the VNS includes the ability to detect a spike in heartrate that often precedes a seizure. The earlier the seizure is detected and the vagus nerve stimulated, the better the results as far as preventing or mitigating the effects of the seizure.

## 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

*Disinn:*  
Kevin Attard / Noel Portelli



## KELMTEJN MILL-PRESIDENT

Gheżież membri, nixtieq naqşam magħkom dawn il-ftit ħsiebijiet. Għandi l-pjaċir ninfurmakon li il-proġett tal-Unjoni Ewropeja, li bdejna kwazi sentejn ilu, issa wasal fi tmiemu. Il-ktejjeb diġa għe ppubblikat b'erba' lingwi u kull ma jonqos huwa biss ir-rapport finali. Dan qed jiġi ppreparat minn Professor Janet Mifsud u diġa' avvanzat ħafna fih.

Dan il-proġett kien jismu Epipicto u jikkonsisti fi ktejjeb b'ħafna stampi u ftit kitba. Dan għe mfassal apposta għal-dawk il-persuni li għandhom livell baxx ta' edukazzjoni. L-introduzzjoni ta' dan il-proġett bdiet propju hawn Malta f' Novembru tal-2017. Fih ħadu sehem Skozja, Olanda, Awstrija, Germanja kif ukoll Malta. Dam għaddej sentejn shaħ u minbarra zoom meetings kwazi kull xahar, saru meetings darbtejn ġewwa Malta, il-ftuħ u l-għeluq, kif ukoll laqgħat oħra ġewwa l-Iskozja, Awsrija, u l-Ġermanja.

Il-prodott finali b'erba' lingwi għe pprezentat lil media u l-pubbliku ġewwa l-palazz ta' San Anton. Il-kummenti li kellna fuq dawn il-kotba kienu verament tajba, kemm verbalment kif ukoll fl-evaluation forms. Hawnhekk nixtieq niringrazzja lil-President Dr. George Vella talli offrila l-post kif ukoll grazzi kbira tmur għal-istaff tiegħu u ħaqghom verament prosit. Il-post intgħogħb ħafna speċjalment mill-barranin, u l-mawra mal-palazz għet apprezzata ħafna. L-ikel ukoll kien verament tajjeb.

L-erbgha 6 ta' Novembru kellna taħdita mill-professur Massimiliano Boffini, dwar il-Vagal Nerve Stimulator. Massimiliano Boffini huwa Medical Science Liaison Manager Neuromodulation jaħdem mal- LivaNova. Twieled ġewwa Pavia, l-Italja u għix ġewwa Genova fejn għab Ph.D fir- Robotics, Cognition u Interaction Technology fl' Istituto Italiano di Tecnologia. Minn Settembru 2016 sar il- Field Clinical Manager Eastern Europe, Israel & Africa in LivaNova Neuromodulation Franchise.

Għal din il-laqqgħa kellna konkorenza tajba ħafna għax attendew 21 persuna. Għaldaqstant nixtieq nagħmlilkom appell sabieħ tattendu dejjem għal laqgħat li jkollna. Dawn il-laqgħat ma jsirux ta' spiss għax darba kull xahrejn niltaqgħu. Għalhekk daqsxejn ta' sforz żgħir jagħmel id-differenza għax lilna tagħmlulna kuraġġ kbir. Wara kollox siegħa malajr tgħaddi.

Minn hawn nixtieqilkom il-festi t-tajba.

Grazzi ħafna.

Frank



## Il-Milied it-Tajjeb

Caritas Malta Epilepsy Association tibgħat l-isbaħ xewqat għall-Milied hieni u s-sena ġdida mimlija hena, paċi u risq lill-membri kollha u lill-familji u qraba tagħhom.



## Avviżi Importanti



Segwi intervista ma' Manuel Camilleri membru tal-kumitat CMEA nhar it-Tlieta, 17 ta' Diċembru fuq Net TV wara l-aħbarijiet fuq il-programm "Fid-Dettal" ipprezentat minn Louise Tedesco

**Jannar**

**8**



Infakkrukum li l-ewwel l-laqqgħa għall-membri għas-sena 2020 ser issir nhar l-Erbgħa 8 ta' Jannar għewwa l-Caritas Malta, 5 Triq l-Iljun, Floriana fis-6 ta' fl'għaxija. It-taħdita ser titmexxa mis-sur Oliver Scicluna, Kummissarju għad-Drittijiet ta' Persuni b'Diżabilità. Inhegħgukom sabieħ tattendu.



### Training for staff at Dar tal-Providenza

CMEA were asked to provide 4 sessions of training in epilepsy - 2 in English and 2 in Maltese - for nearly 100 staff members and care workers at the Dar tal-Providenza, L/O Siggiewi. The sessions organised by Ms Remona Cuschieri and were held on 18th and 21st November

2019. The speakers were Frank Portelli, Caroline Attard, Manuel Camilleri and Janet Mifsud. The participants were all very attentive and the feedback was very positive, even among those staff members who had already attended similar sessions a few years ago. It was a real pleasure to note the dedication with which this staff care for the residents in this home.



# Training Teachers & Staff of De La Salle College

Teachers and staff of De La Salle College were trained in recognizing different types of epilepsy and seizure first aid on Tuesday, September 24th by the Caritas Malta Epilepsy Association (CMEA). Following the session a more in-depth training was given to the Year One teachers and staff.

The training was led by Janet Mifsud, Advisor CMEA. CMEA President Frank Portelli brought greetings and invited participants to join the CMEA mailing list for future opportunities and further information. Robin Pinkston shared her experience as a mother of a child with epilepsy as well.

The participants were given several literature such as diaries, the Epilepsy Toolkit funded by CRPD, and the recently launched EPIPICTO pictorial guide funded by Erasmus+.

If you or your school would like to have a similar training or if you would like more information contact CMEA at [maltaepilepsy@gmail.com](mailto:maltaepilepsy@gmail.com).

A big thank you to De La Salle College for the initiative shown to join in with CMEA's vision of "a better life for people with epilepsy."



## Training at Dar il-Fjuri Gozo

Today 11 Nov 2019, myself, Frank and Manuel gave a training session to 11 care workers in the Gozo Home for Persons with disability, Dar il-Fjuri in Victoria.

The careworkers were very motivated and asked a great deal of questions. It was really very evident that they love

their work and are really committed to their clients. indeed they are very keen to learn more on how they can help. It seems that, while it is true they are not medical professionals, they would appreciate getting more information on the medical issues related to their clients especially since they are with them 24h and also are responsible for giving medicines to them. It was a real pleasure to train them.

The Caritas Malta Epilepsy Association in conjunction with four other European epilepsy organisations (Epilepsie Dachverband Österreich (EDO) Austria; Epilepsy Connections (Scotland); Interessenvereinigung für Anfalls Kranke in Köln e.V (Germany); and Stichting Epilepsie Instellingen Nederland (SEIN)(Netherlands) launched a pictorial guide for adults in epilepsy, funded by the EU Erasmus+ programme. This launch was held at San Anton Palace, Attard on 14 September 2019, under the auspices of HE The President of Malta, Dr George Vella and in the presence of Hon Dr Michael Falzon, Minister for the Family, Children's Rights and Social Solidarity and Mgr Fr Charles Cordina, Caritas Malta.

Epilepsy is one of the most common chronic neurological disorders affecting around 1% of the population worldwide. The aim of EPIPICTO is to develop a pictorial guide for persons with epilepsy in marginalised communities, who might have difficulty communicating their ideas due to language or other barriers, are at the risk of social exclusion such as migrant persons, persons living in isolated areas in Europe and persons with low literacy levels and low health literacy. This final event was held to disseminate the final guide in order that it may be used among various endusers, such as other NGOs, respite care workers, social workers and health care professionals who were also invited to the launch.

In his opening address President Vella thanked CMEA for taking on this very important initiative. He highlighted the importance of each person, whatever the medical or social condition and the importance of education in reducing stigma.

The Minister for the Family, Children's Rights and Social Solidarity, Michael Falzon, argued that we cannot deny the stigma related with epilepsy, especially within marginalised communities such as migrants. As policy makers we need to look to the future and consider the cost of 'getting it wrong', while ensuring that we continue to support people with epilepsy from early stages.

Mgr Charles Cordina provided an overview of the services Caritas Malta provides and explained how Caritas motto is "to be on the side of the people in need". The project was thought for the inclusion in the community of persons on the margin of society, socially excluded.

Mr Frank Portelli, CMEA President and Prof Janet Mifsud, CMEA Advisor explained that the EU literacy report showed that up to 20% of European adults have poor literacy skills, and from experience many people living in rural areas have little or no access to education. Poor literacy skills lead to poor health-seeking behaviour and contributes to the enduring stigma of epilepsy. The initial aim of the pictorial guide is to ensure that adults with epilepsy living in Europe who have a poor literacy standard, or those immigrants who find the foreign language barrier an issue in learning about epilepsy or helping others to understand the disease, will have access to tailored information. The project will contribute to the social inclusion of these persons by using a pictorial guide to overcome language barriers and literacy issues. This will improve their access to social, health, education and employment services and help them to better manage

their epilepsy. All this will result in a better quality of life for these persons.

The format of the guide will be readily adaptable to be rolled out in other regions of the world, where illiteracy rates are considerably higher than in Europe. The guide will be free to use, and freely available to download on this EPIPICTO website. It will ensure better communication between persons with epilepsy and the various professionals they may come in contact with. The target participants of this final event are persons who work with people with epilepsy, persons with epilepsy themselves, and carers/relatives of persons with epilepsy.

It is so far available in 11 languages: English, Maltese, Dutch, German, Russian, Spanish, Italian, French, Chinese, and Arabic and Mandarin. A limited number of hardcopies will also be made available.

EPIPICTO brings together five European epilepsy organisations from Austria, Germany, Malta, the Netherlands and Scotland:

- Caritas Malta Epilepsy Association [www.caritalmalta.org/services/epilepsy](http://www.caritalmalta.org/services/epilepsy)
- Epilepsie Dachverband Österreich (EDO) [www.epilepsie.at](http://www.epilepsie.at)
- Epilepsy Connections (Scotland) [www.epilepsyconnections.org.uk](http://www.epilepsyconnections.org.uk)
- Interessenvereinigung für Anfalls Kranke in Köln e.V. [www.epilepsie-selbsthilfe.de/koeln](http://www.epilepsie-selbsthilfe.de/koeln)
- Stichting Epilepsie Instellingen Nederland (SEIN) [www.sein.nl](http://www.sein.nl)

For more information, please visit our website [www.epipicto.eu](http://www.epipicto.eu) or email us [epipicto@gmail.com](mailto:epipicto@gmail.com)



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## TALK WARDIJA SPECIAL SCHOOL



Nhar il-Ġimgħa 22 ta' Novembru, konna mistiedna sabiex nagħtu *talk* ta' 75 minuta ġewwa l-iskola tal-Wardiya. Għal- din it-*talk* telgħu Manuel u Frank. Kien hemm viċin is-60 *teacher* u LSE's. Mill-bidu kellna problema teknika bil-*computer* u għalhekk ma stajniex nuru l-ebda video.

Bdejna s-sessjoni bi 'brainstorming' bħas-soltu u imbagħad komplejna bil-*powerpoint presentation*.

L-interest ta' dawn l-għalliema kien enormi u bdew jistaqsu mistoqsijiet kontinwament, tant hu hekk li l-aħħar biċċa tal-*presentation* lanqas komplejnietha għax is-sessjoni spiċċat fuq nota ta' mistoqsija u twegiba. Tista' tgħid li kull min kien preżenti għamel iktar minn mistoqsija waħda donnhom ippreparawhom minn qabel.

Il-ħin għadda f'kemm ili ngħidlek u spiċċajna hemm iżda aħna wegħdniehomm li lesti nerggħu immorru sabiex nuruhom il-videos li għandna u kif ukoll inkomplu nwiegħbu l-mistoqsijiet.

L-*evaluation forms* kienu pożittivi ħafna u kien hemm numru mhux hażin li kitbu li xtaqu jaraw il-videos.

# CMEA activities September 2019 to November 2019

<b>Date and time</b>	<b>Event</b>	<b>Attended by</b>
3rd September 2019	CMEA committee meeting	CMEA committee
13th September 2019	EPIPICTO transnational meeting at San Anton Palace	Epipicto partners & various guests
14th September 2019	EPIPICTO final multiplier event	Epipicto partners & various guests
16th September 2019	Meeting at Caritas Malta with Counselling and Social Unit work	Caroline Attard
23rd September 2019	Interview on PBS Radio News line about EPIPICTO project	Janet Mifsud
24th September 830-945am	Epilepsy introduction and first aid training for staff (70)-De La Salle College	Robin Pinkston, Janet Mifsud, Frank Portelli
27th September 2019 6pm	CMEA members meeting-Guest speaker Dr. Anthony Gatt, Director Caritas Malta	committee members & CMEA members
16th October 2019	CMEA committee meeting	Frank Portelli, Manuel Camilleri, Caroline Attard, Robin Pinkston, Adriana Caruana Soler, Janet Mifsud
16th October 2019	Training to MUSEUM female members	Janet Mifsud, Frank Portelli, Manuel Camilleri
18th October 2019	Training to pharmacy III year students	Janet Mifsud and Caroline Attard
6th November 2019 6pm	CMEA members meeting - Dr Boffini	Committee members & CMEA members
11th November 2019 am	training in Gozo to support workers	Janet Mifsud, Frank Portelli, Manuel Camilleri
18th November 2019	Training Wardija School 1pm to 2.30pm	Janet Mifsud, Caroline Attard, Frank Portelli,
21st November 2019	Dar tal Providenza talks	Janet Mifsud, Frank Portelli, Manuel Camilleri
22nd November 2019	Training Wardija School 1pm to 2.30pm	Frank Portelli, Manuel Camilleri
11th December, 2019	Intervista ma Manuel Camilleri fuq Net TV jixxandar fil-progamm "Fid-Dettal" 17 Dec wara l-ahbarijiet - tipprezenta Louise Tedesco	Manuel Camilleri



At Dun Victor Grech's 90th Birthday Celebrations