

# Kelmtejn

Lulju 2019 - Nru. 56



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Caritas
Malta
Epilepsy
Association

#### Kontenut Blood tests may predict seizures... Kelmtejn mill-President Notice Board CMEA Advisor receives award Coping with stress/CMEA picnic **Police Training Course** A work in progress ...... Why I never gave up...... CMEA activities May-June 2019

# A better life for people with epilepsy

Meeting with HE Dr George Vella, President of Malta and Mrs Vella in The Palace, Valetta on 13th May, 2019

The members of CMEA were very cordially greeted by HE and Mrs Vella. During the discussions with him, he was very interested as a former family doctor in our activities. He also very kindly offered the use of meeting rooms in San Anton Palace for some of our activities.

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

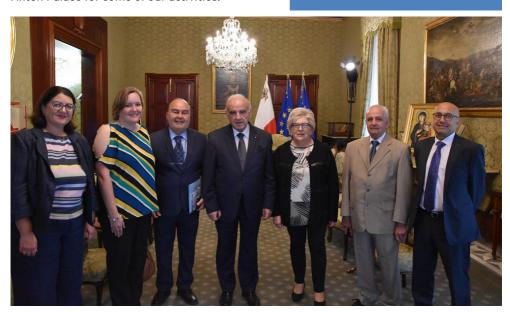
Membru

Mr. Manuel Camilleri

Konsulenta Prof. Janet Mifsud

Disinn:

Kevin Attard / Noel Portelli



From left Janet Mifsud, Robin Pinkston, Frank Portelli, HE Dr Vella, Mrs Vella, Manuel Camilleri, Noel Mercieca



Għeżież membri,

Inħarsu naqra lura u naraw flimkien x'sar matul dawn is-sitt xhur li għaddew mill-Assocjazzjoni tagħna.

B'impenn kbir u dedikazzjoni u grazzi għal fondi minn CRPD tlesta il-ktejjeb "Epilepsy Toolkit" b'verżjonijiet kemm bil-Malti u kemm bl-Ingliż. Dan il-ktejjeb jagħti informazzjoni utli għal meta xi ħadd jiġi 'ċċertifikat għall-ewwel darba bl-epilessija. Huwa mmirat għal ġenituri, kuraturi, għalliema/LSE's, pulizija u għal minn iħaddem. Dan il-ktejjeb qed jitqassam b'xejn lill kull min jattendi għal laqgħat tal-membri li jsiru kull xagħrejn. Għalhekk inħeggukom tattendu waħda minn dawn il- laqgħat biex tiġbru kopja. Il-laqgħa li jmiss ser issir nhar il-Ġimgħa 12 ta' Lulju ġewwa l-Meeting Place il-Marsa.

Ta' sodisfazzjon ukoll kien in-numru kbir ta' intervisti fuq it TV u Radju bi programmi interessanti u nformattivi dwar I-Epilessija. Tajna wkoll zewģ 'training sessions' ta' siegħa w nofs il-wahda lil rekluti ġodda fil-korp tal-Pulizija. Dawn saru għal-laħħar gimgħa ta' Mejju.

Inħarsu I-quddiem għal dawn is-sitt xhur li ġejjin u nħabbru li fi ftit xhur oħra inniedu ktejjeb ieħor taħt proġett bl-isem ta' Epipicto u ffinanzjat mill-EU. Dan il-proġett wasal fl-aħħar fażi tiegħu. F'Settembru se jkun hawn żewg laqgħat hawn Malta flimkien ma' rappresentanti minn 4 pajjiżi ohra. Dan il-ktejjeb se jkun fih aktar stampi milli kitba u hu mmirat għal dawk li jsibuha diffiċli biex jaqraw. Dan il-proġett qed jinħadem b'kollaborazzjoni bejn ħames pajjiżi – Malta, il-Ġermanja, I-Olanda, il-Belġju u I-Awstrija. Wara I-laqgħa ta' kortesija li kellna mal-Eċċellenza tiegħu il-President ta' Malta, Dr. George Vella hu offrilna li nagħmlu dawn il-laqgħat ġewwa I-Palazz ta' San Anton u diġa lħaqqna arranġamenti mal-istaff tiegħu. Minn hawn nirringrażżjaw lil-President ta' dan il-ġest sabiħ.

Ma nistax nagħlaq u ma nsemmijx il-premju li ħadet Prof. Janet Mifsud. Din ħadet il-premju 'Ambassador for Epilepsy' minn fost ħafna li ġew nominati. Dan l-award kella titla' għalih Bangkok ġewwa t-Tajlandja. Minn hawn niehu din l-opportunita' biex għan nom tal-membri kolla nifirħula mill-galb.

Kif taraw il-ħidma tagħna ma tonqosx biex inqajjmu għarfien fuq din il-kundizzjoni. Inħeġġukom bħala membri tippartecipaw aktar għax flimkien nistaw nagħmlu differenza.

Grazzi u narawkom fil-laqgħa li jmiss!



#### NOTICE BOARD

# Laqgħa Annwali Ġenerali

Caritas Malta Epilepsy Association il-Ġimgħa 12 ta' Lulju, 2019, ġewwa l-Meeting Place, Balbi Street, Marsa, ħdejn l-iskola Tereża Nuzzo.

Żomm dawn id-dati.... II-Laqgħat għall-Membri, din is-sena 2019, huma dawn:



- 12 ta' Lulju
- 13 ta' Settembru
- 8 ta' Novembru

fis-6 ta' fl-għaxija ġewwa The Meeting Place Marsa (ara paġna 8).

Kull ma jingħad waqt il-laqgħat jinżamm kunfidenzjali.

Messaġġ li rċevejna wara llaqgħa tal-membri tal-10 ta' Mejju:

"Ftaħt qalbi u ħassejtni nistrieħ. Naf li dak li ntqal waqt il I-laqgħa ħa jibqa mistur."

## DONAZZJONIJIET

Jistgħu jsiru donazzjonijiet biex jappoġġaw il-kampanji edukattivi u l-konferenzi tagħna f'dan il kont:

Bank of Valletta

Beneficiary: Caritas Malta Epilepsy Association

Account No: 40012251483

IBAN: MT44VALL22013000000040012251483

SWIFT CODE: VALLMTMT

Grazzi mill-Qalb

## CMEA advisor awarded International Ambassador for Epilepsy Award 2019

Prof Janet Mifsud, Advisor CMEA, has been awarded the International Epilepsy Ambassador Award, by the International Bureau for Epilepsy (IBE) and International League Against Epilepsy (ILAE), during the recent International Epilepsy Congress, held in Bangkok Thailand.

This prestigious award was given to Professor Mifsud for her advocacy and research work in epilepsy on an international and local level. She set up the Caritas Malta Epilepsy Association (IBE) in 1996 and Epilepsy Society of Malta (ILAE) in 1997. She has led several epilepsy-related activities in Malta, including the introduction of the understanding of epilepsy in the curriculum of several health care degrees.

Prof Mifsud has worked in the epilepsy field extensively at European and international levels. She is involved in several European epilepsy research projects and served as IBE Vice President (Europe) for two terms. She is presently a member of the IBE Education Commission and the IBE/ILAE Epilepsy Advocacy European Task Force.



Photo: (Left to right):

Professor Martin Brodie, President International Bureau for Epilepsy; Prof Janet Mifsud; Prof Sam Wiebe, President International League Against Epilepsy.



## Coping with Stress - Mr Anthony Gatt

The Caritas Malta Epilepsy Association held its bi-monthly Member's Meeting on Friday, 10th May at the Marsa Local Council Hall. Mr. Anthony Gatt, the Director of Caritas, led a group discussion regarding handling stress and there was a real sense of community as people found freedom to share their difficulties with others who understand what it is like to live with epilepsy.

Many thanks to the Local Council in Marsa as there was a last minute adjustment in location and they gave us use of their beautiful facilities as well as to Mr. Gatt for his expertise.

### CMEA picnic for members and friends

Friends and Members of the Caritas Malta Epilepsy Association enjoyed a picnic at Ta' Qali together on Saturday, 18th May. While the picnic began a bit cool and windy, the sun then showed up and we enjoyed a lovely afternoon of fellowship and eating. Some people played football and baseball while others enjoyed relaxing and visiting. A special bonus was celebrating Kevin Attard's birthday the previous day with THREE different types of cake! Happy Birthday Kevin! Plans are underway for a summer time BBQ so watch this space so you will not miss it!







### 39th Police Basic Training Course on epilepsy

On May 23rd, 2019, three members of the Committee from the Caritas Malta Epilepsy Association were delighted to conduct a one and a half hour training course on epilepsy with the new recruits of the Police Corps at Ta' Kandja.

In this first session 30 recruits attended; 12 of these came from the island of Gozo. Professor Janet Mifsud, Manuel Camilleri and Matthew Attard delivered this informative session. Matthew gave a very valuable insights from his experience as a security guard.

The second session for another group of cadets was held on the 29th May. The trainers from CMEA were Robin Pinkston and Manuel Camilleri assisted by Professor Janet Mifsud. This was another informative and successful presentation.





**Extract from:** 

# Epilepsytoday

Your online epilepsy magazine by Epilepsy Action UK

#### A work in progress: what research says about employment and epilepsy

People with epilepsy often report that they struggle to find or stay in a job. A new piece of research has looked into why this might be and what tools would help to reassure employers and empower people with epilepsy looking for work.

Getting a job is something most of us strive for. Work can be a way to earn a living and offer a feeling of security. But it's also about more than that. It's an opportunity for us to follow our interests and ambitions. It is linked to our confidence and self-esteem. And it can add to our social life and create a routine for us.

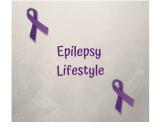
Finding a job is undeniably an important part of life for many of us. So, it makes it even more of a serious problem that people with epilepsy report facing challenges in this arena. Past research has confirmed this. It has shown that people with epilepsy are more than twice as likely to be unemployed as people without the condition.

Epilepsy Action wanted to better understand the reasons for this and what can be done to improve the situation. To do this, the organisation requested a piece of research from the Institute for Employment Studies (IES). This aimed to find out what barriers exist for employers and people with epilepsy and find ways to tackle them.

The IES researchers interviewed six employers and four experts in employment, clinical practice and research. They also held focus groups with people with different forms of epilepsy and different employment experiences. They wanted to compare epilepsy and other long-term conditions when it comes to employment support. They also set out to find out what information would reassure an employer. Finally, they wanted to know what employment support would be useful for people with epilepsy.

#### follow this link to continue reading this article:

https://www.epilepsy.org.uk/news/features/work-progress-what-research-says-about-employment-and-epilepsy-69567?utm\_source=eactionMay19&utm\_medium=email&utm\_content=WIP&dm\_i=720,6AHBR,8JOLYH,OTY7A,1





#### Why I Never Gave Up On My Epilepsy Fight & You Shouldn't Either

Living with epilepsy is never easy. There are days when I feel like there's no way I can accomplish anything because of my seizures. It's the feeling of almost giving up on my fight against my epilepsy. However, I know that it's not in my blood to give up and quit. I was taught to use my strength and fight back. Although there are days when I feel alone, I quickly realized that I had family, friends, and a community helping me in my battle against my epilepsy. Strength, faith and love is what keeps me going.

It was a typical school day, having fun with friends and learning some valuable lessons from teachers. Late in the day, I experienced something not many people get to. I walked out of my classroom into the hallway, and in a matter of minutes my life changed forever. The next thing I remember is waking up in the ambulance with my teacher and the emergency nurse. My family and friends were at the hospital waiting for me to see what exactly happened that day. My first experience with epilepsy hit me hard and shook me up. What my epilepsy didn't know was that I'd fight back harder.

After my first seizure I knew that I needed to fight back harder and not let it beat me. Through past experiences and lessons taught by my parents, I knew I had the strength to overcome this challenge. Epilepsy tested me early throwing me to ground numerous times. This time around though I had friends by my side and knew I was not alone. My first punch back at my epilepsy was figuring out my aura. I may have been a little kid, but I was a smart one who wanted to get a head start on my epilepsy, literally. From this point on I always knew when my grandmals were coming. Nice try epilepsy!

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#### CMEA activities May 2019 to June 2019

Date and time	Event	CMEA committee
10th May 6pm	CMEA Members meeting	How to cope with stress Mr Anthony Gatt, Director Caritas Malta
13th May 2019	Meeting with Dr George Vella, President of Malta, The Palace Valletta as part of MFOPD	Frank Portelli
18th May 12noon to 2pm	CMEA Family Picnic - Ta' Qali	all members invited
21st May 10am	Meeting at Dolmen re 2020 conference	Janet Mifsud+ Frank Portelli
22nd May 10.00am	Meeting Anglu Fenech re quotes from Dolmen	Frank Portelli
22nd May, 10.45am	Deposited some copies of the toolkit at the Malta Public Library and the Book Council	Frank Portelli
22nd May 12 noon	Meeting UoM re website	Janet Mifsud + Frank Portelli + Noel Portelli + Anthony Buttigieg
23rd May 1030-1200	Training Police Recruits Hal Farrug	Janet Mifsud + Frank Portelli + Matthew Attard
28th May 2019	Meeting EUPA re EPIPICTO - Mtarfa	Janet Mifsud + Frank Portelli
28th May 2019	Meeting Dolmen re organisation of conference	Janet Mifsud + Frank Portelli
29th 1230-1400	Training Police Recruits Hal Farrug	Janet Mifsud + Robin Pinkston + Manuel Camilleri
30th May 10am	Meeting with Dr George Vella, President of Malta, The Palace Valletta	Janet Mifsud + Frank Portelli + Robin Pinkston + Noel Mercieca
5th June 1.30pm	Meeting with Mr Carmel Marsh, Office of the President re EPIPICTO meeting	Janet Mifsud + Frank Portelli
22nd June	International Epilepsy Conference in Bangkok, Thailand	Janet Mifsud

# **Epilepsy**

Epilepsy is now a daily part of life for so many Research never ends, medications there are plenty There are no golden rules of when or where Just a forgone conclusion that some will stare

It may begin in childhood or your later years Seizures and headaches causing many tears Will this be a good day or the same as before? Try to make it home, without falling to the floor

Not allowed to be alone, privileges taken away Coming around from a seizure, hearing it'll be OK Medication changes, trying to find the right dose Not even sure of all the medicines real purpose

Anger and depression that comes with all you lose From this crazy situation that you didn't choose Told you can't drive; you must learn how to adapt Yet in the hold of epilepsy it's easy to feel trapped

Live a normal life until the next seizure comes around Listening to the doctors about how a cure will be found People point out, you're no longer who you used to be Yet inside you're just the same, except for the epilepsy

by Andrew Burns Benson