



Caritas Malta Epilepsy Association

KELMTEJN

Diċembru 2022 – Nru. 66

**A BETTER LIFE FOR PEOPLE
WITH EPILEPSY.**

Fondazzjoni Caritas Malta

Triq Mountbatten

Hamrun HMR 1577

Tel: +356 2219 9000

V/O 1396

maltaepilepsy@gmail.com

www.caritasmalaa.org/epilepsy



Caritas
MALTA



Caritas Malta
Epilepsy Association



Content:

Kelmtejn mil-president.....	3
The 25th Anniversary	4
2022 CMEA Calender of Events.....	5
Conclusion	18

Membri tal-Kumitat:

President:
Frank Portelli

Viċi President:
Dr. Anna Micallef

Segretarja:
Ms. Robin Pinkston

Teżoriera:
Ms. Caroline Attard

P.R.
Mr. Matthew Attard

Facebook u Żagħżagħ:
Ms. Adriana Caruana Soler

Membri:
Mr. Manuel Camilleri
Mr. Kevin Attard
Ms. Claudine Aitken

Konsulenta:
Prof. Janet Mifsud

Psychotherapist:
Verena Portelli

Disinn:
Matthew Theuma



CMEA 2022 Committee (from left to right): Anna Micallef, Adriana Caruana Soler, Matthew Attard, Kevin Attard, Robin Pinkston, Frank Portelli, Verena Portelli, Janet Mifsud, Noel Mercieca, Claudine Aitken, Caroline Attard, Noel Portelli, Emanuel Camilleri.

KELMTEJN MIL-PRESIDENT

Gheżież kollegi, ħbieb u membri, nispera li tinsabu tajbin u bħas-soltu dejjem nappellalkom sabiex tibzġhu għal-saħħitkom. Nibda billi nixtieqilkom milied u sena t-tajba mimlija hena, risq u paċi. Caritas Malta Epilepsy Association issa għalqet sitta w għoxrin sena' mit-twaqqif tagħha. Ahna ninsabu kburin b'dak li rnexxielna nagħmlu u niksbu tul dawn l-aħħar snin. L-Għaqda tista' tgħid saret il-vuci ta' nies li għandhom l-epilessija.

Bħalma tafu konna hadna grant ta' kwazi hames t'elef ewro mingħand il-Ministry for Inclusion, Voluntary Organisations and Consumer Rights. L-ittra li t-talba tagħna għet milqugħa għet ipprezentata lilna mill-Onorevoli Ministru Julia Farrugia Portelli.

Dan l-ammont qed nużawh biex nipprintjaw materjal fuq din il-kundizzjoni sabiex dejjem inqajjmu iżjed għarfien. Bħalma tafu tagħmel kemm tagħmel qatt mhu biżżejjed. Tafu wkoll li minbarra dan il-materjal ahna nagħtu taħdidiet fi skejjel, lil-pulizija, nurses etc. Immorru fuq it-TV's u radios imma kif għidt qabel qatt mhu biżżejjed.

Dan il-proġett li semmejt jismu 'Freedom to Live' u mxejna mhux ħażin fih għax irid ikun lest sa nofs Frar għax inkella jista' jaqa' kollox.

Bħalissa tlabna lil kumitat, tal-'Freedom to Live' sabiex nagħmlu amendi żgħar fil-kuntratt sabiex inkunu nistgħu nippubblikaw iktar affarijiet bżonnjuzi. Bħalissa qedin nistennew tweġiba mingħandhom. Kif ikollna risposta inkomplu immedjatament.

Il-pjanijiet tagħna dejjem kienu li:

- Noffru aktar għarfien u tagħlim lil-poplu Malti dwar din il-kundizzjoni.
- Nagħmlu pressjoni akbar fuq id-dipartiment tas-saħħa sabiex jinġiebu l-aħħar u l-aqwa medicini li jeżistu kif ukoll apparat għal din il-kundizzjoni.
- Noffru support lin-nies li għandhom din il-kundizzjoni u l-familji tagħhom.
- Fl-aħħarnett imma mhux l-inqas nipplanaw iżjed taħditiet ġewwa l-iskejjel, għax l-istudenti tal-illum se jkunu l-generazzjoni t'ghada.

Jekk dawn ikunu edukati fuq din il-kundizzjoni l-istigma tkompli tonqos.

Nispera li tipparteċipaw fil-laqgħat li jkollna kull xahrejn, kemm jekk ikunu virtwali kif ukoll wiċċ imb'wiċċ. Il-preżenza kif ukoll il-parteeipazzjoni tagħkom jimlewna b'kuraġġ sabiex inkomplu bil-ħidma tagħna.

Nerġa' niehu din l-okkażżjoni sabiex nawguralkom u l-familji tagħkom il-festi tajba. Nispera li jkunu mimlija ferħ, hena, risq u paċi.

Frank



In 2022, Caritas Malta Epilepsy Association (CMEA) celebrated 25 years of work, having been set up in 1996. For this occasion, a commemorative book was prepared which covered some key aspects of these 25 years of work, lobbying, conferences and projects. We are honoured that this book was launched under the distinguished patronage of H.E. George Vella, President of Malta on Monday 14th February at 6.30pm at San Anton Palace, Attard. The book is dedicated to late Mario and Victoria Dimech, former President and Secretary respectively of CMEA.



25 years of CMEA book launch (from left to right) Ms Claire Dimech, Mr Karl Dimech, Ms Lourdes Cini, Mgr Fr Charles Cordina, Ms Caroline Attard, Ms Geraldine Gatt, Mr Anthony Gatt, Mr Frank Portelli, Ms Robin Pinkston, Prof Janet Mifsud, Mr Manuel Camilleri, Ms Verena Portelli Mr Kevin Attard.

years

25

Jan 23.

Attendance at Memorial service in honour of Ms. Natasha Dowling. Janet Mifsud and Manuel Camilleri attended.

Ms. Natasha Dowling suddenly passed away on January 13, at her home in London aged 42. Mass for the repose of her soul took place on Sunday, January 23, at Our Lady, Mother of Good Counsel church, Paceville at 5 pm. The family requested no flowers but donations to the Caritas Malta Epilepsy Association were greatly appreciated. CMEA were thus invited to set up a small stand during the service.

CMEA is extremely grateful to the generosity of the family at this very sad time. We will keep Natasha and all the family in our thoughts and prayers.

May the Lord grant her eternal rest.



Jan 25.

Presentation of the Freedom to Live grant to CMEA by the Ministry for Senior Citizens and Active Ageing and the Ministry for Inclusion and Social Wellbeing, held at 3:00 PM Awla Magna, Valletta Campus, University of Malta. Frank Portelli, Robin Pinkston and Manuel Camilleri attended.

The main aim of these funds will be:

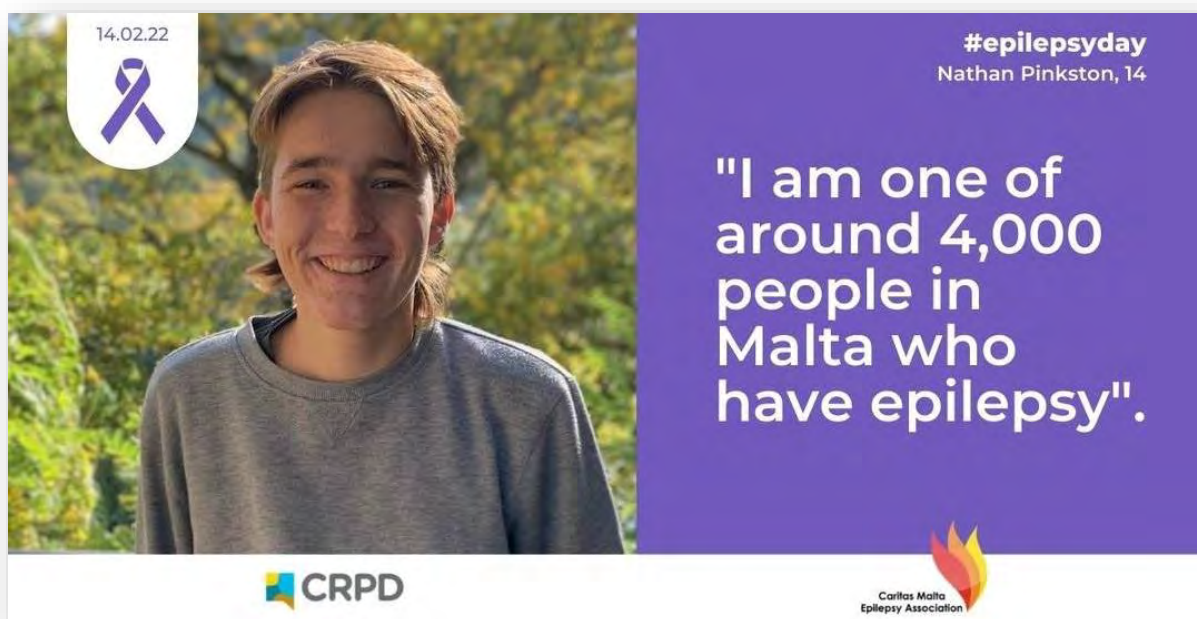
- The preparation of educational material, such as posters and leaflets in English and Maltese about epilepsy;
- The preparation of epilepsy diaries and ID cards for the use of persons with epilepsy and health care professionals;
- The use of this educational material in training sessions for various service providers;
- The empowerment of persons with epilepsy through the preparation of this material;
- More awareness raising about epilepsy in Malta which will lead to less stigmatisation and discrimination.



Feb 08.

Nathan Pinkston's participation on Commissioner for the Rights of Persons with Disability (CRPD) social media day #Epilepsy Day

"I am one of around 4,000 people in Malta who have epilepsy. Epilepsy is often called a "hidden condition" because if you are not with someone when they are having a seizure, you would never know that they have epilepsy. I started having seizures when I was three years old and there were some hard times for me and for my parents, but thankfully the past few years I have been very well-controlled by my daily medication".



Feb 12 13 14.

Buildings were lit up in purple around Malta for the International Epilepsy Day on February 12th, 13th, 14th 2022:

- Auberge de Castille
- Palazzo Castellania
- Eastern Regional Council
- Għajnsielem Local Council
- Balzan Local Council
- Zurrieq Local Council
- Attard Local Council
- Pembroke Local Council
- Palazzo Ferreria



Feb 14.

On this day, the CMEA 25 yearbook was launched at de Paule Hall, San Anton Palace, at 6:30 pm.

St. Valentine's name is immediately recognizable due to the internationally celebrated "Valentine's Day" every February 14th. However, he is also known as the patron saint for epilepsy. Some attribute this to the name "Valentine" being similar to the German word for "fallen," as many types of seizures could cause a person to fall. Others say that a bishop named Valentine healed a Roman orator's son from a seizure. Regardless of its roots, 2022 was a special year as the two holidays coincided on February 14th - Valentine's Day and International Epilepsy Day. Over 130 countries, including Malta, held special events to bring attention to epilepsy, one of the most common brain disorders affecting over 50 million people worldwide, and over 4,000 persons in Malta. Caritas Malta Epilepsy Association, which has been set up for 25 years, works hard to disseminate more information about this much misunderstood condition.

Purple is the colour associated with epilepsy. In fact, this year, over the weekend of Saturday, February 12th, Sunday February 13th, and Monday February 14th, many buildings around Malta and Gozo were lit up in purple, the international colour for epilepsy awareness. These buildings included: Auberge de Castille, Palazzo Castellania, Palazzo Ferreria, Pembroke Local Council and the Reġjun Lvant office, Zurrieq Local Council, and the Għajnsielem Local Council. The Caritas Malta Epilepsy Association is incredibly grateful for the support of The Office of Prime Minister, the Office of the Deputy Prime Minister and Ministry for Health, the Ministry for Social Justice and Solidarity, and the Pembroke, Reġjun Lvant, Zurrieq and Għajnsielem Local Council offices respectively, in this regard.

We are eagerly looking forward to International Epilepsy Day on Monday, February 13, 2023, and an advocacy campaign that we will be launching then. If you know of a building that would be happy to shine the light on epilepsy, contact us at maltaepilepsy@gmail.com.

The International Epilepsy Day for 2023 will be on Monday, February 13th.



Feb 18.

Frank Portelli attended a forum for NGO's held by CRPD at the Archbishop Seminary in Rabat between 9am and 1pm. The theme was 'A Stronger Voice for Disability'.

There were presentations of three case studies and after each case a brainstorming session was held. Later the participants were divided into three groups (workshops) one for each case. Analysis was made using the **SCAMPER** and **SWOT METHODS**.

SCAMPER: Substitute, Combine, Adapt, Modify, Put to Another Use, Eliminate and Reverse

SWOT: Strengths, Weaknesses, Opportunities and Threats.



Feb 24.

Frank Portelli attended the 50 yearbook launch for the MFOPD (Malta Federation of Organisations for Persons with Disabilities) at de Paul Hall in San Anton Palace.

Feb 28.

Malta Health Network AGM, at 6pm. Frank Portelli and Caroline Attard attended.

Mar 08.

Training at Fleurs de Lys Training Centre - Agenzija Sapport.

At 9am Robin Pinkston and Janet Mifsud gave training to around 30 Agenzija Sapport support workers at the Ċentru Taħriġ, Fleur de Lys Centre. The support workers were very interested in the subject and asked very relevant questions on Epilepsy. It was a pleasure to speak to them.



Mar 16.

Training for educators at the St Albert the Great College, at CAK Centre Birkirkara 12:30-13:30.

Robin Pinkston and Caroline Attard gave training to educators and support workers at St Albert the Great College. They were very interested and had many questions as they had some students with epilepsy.

Mar 24.

Online training for primary school children in Gharghur school 9-11am

Janet Mifsud, Robin Pinkston, Claudine Aitken were invited by Ms. Pamela Scicluna, (the Assistant Head of Gharghur Primary School) to give a short, simple, child friendly presentation on epilepsy and an accompanying video to all primary classes in Gharghur Primary School from Year 1 to Year 6, using Teams. Several cartoons were used, and a small quiz was given to consolidate the learning. The children were extremely attentive and ask very pertinent questions. It was indeed a pleasure to speak to them.

Apr 07.

Training for primary school children St Albert College- CAK Centre Birkirkara.

Janet Mifsud and Robin Pinkston gave training in epilepsy to 8-year-old children attending St Albert's College in Birkirkara. They were extremely attentive and made lots of questions and it was clear that they really want to learn in order to help their friend in the class who has autism and epilepsy. We greatly appreciate the interest the school administration took in our activities.



Apr 08.

Training to Support- Bahar ic-Caghaq Centre at Valletta Design Cluster.

Caroline Attard, Frank Portelli and Janet Mifsud gave epilepsy training to the Support Workers from the Bahar ic-Caghaq centre. The training was held at the Valletta Design cluster premises. The participants showed a great deal of interest and participated in the discussions since they have several clients who have seizures.



Apr 12.

CMEA committee meeting online

Janet Mifsud, Frank Portelli, Robin Pinkston, Adriana Caruana Soler, Noel Portelli, Claudine Aitken, Kevin Attard and Caroline Attard attended.

May 13.

CMEA Member's meeting/AGM

Frank Portelli, Robin Pinkston, Caroline Attard, Manuel Camilleri, Janet Mifsud, Kim D'Alfons attended.

May 23.

CRPD conference Mount St Joseph

Frank Portelli attended.

May 25.

Matthew Attard held training for Community Police from 10am to 10.30am at the Caritas Community Centre.

The talk with Sergeants of the Community Police section went very well. They expressed a great deal of serious interest in the subject, especially in learning about first aid both for dealing epileptic seizures and even mental health cases. The subject came up when explaining first aid measures for epileptic seizures. They would like CMEA to give more talks about epilepsy to the constables under their command in the Community Police section.



Sep 14.

Training of Police Recruits at the Academy.

Frank Portelli, Manuel Camilleri, and Robin Pinkston presented epilepsy training to the police recruits for 1.5 hours including videos and personal testimonies.

Police Constable Training

Matthew Attard was also at Caritas Community Centre that same day training Police constables.



Sep 16.

Training of Police Recruits at the Academy.

Frank Portelli, Manuel Camilleri, and Robin Pinkston returned to do the same training with the second half of the recruit class.

Oct 04.

European Federation of Neurological Associations (EFNA)webinar - Addressing gender equity in health care. CMEA Secretary Robin Pinkston represented International Bureau for Epilepsy (IBE) at this webinar.

The “Hu Kontroll” self-management classes began.

These lasted for six weeks and were organised by the Department of Health Promotion and Disease OPrevention at the Ministry of Health specifically Ms. Phoebe Woodford and Dr Mariella Buontempo. CMEA participants included Frank Portelli, Kevin Attard, and Robin Pinkston along with other members of CMEA. Matthew Attard did a fantastic job as a co-facilitator.



Ms. Phoebe Woodford, Dr Mariella Buontempo from Health Promotion and Mr Matthew Attard

Oct 11.

Malta Health Network booth at MCAST Paola.

Earl and Robin Pinkston and Caroline Attard greatly enjoyed meeting others and sharing about epilepsy and opportunities with CMEA to students, teachers, and those in attendance.



Oct 13.

Malta Health Network booth at MCAST. Robin Pinkston attended.

At the MCAST Art school during Fresher's Week, Secretary Robin Pinkston met with many students to promote epilepsy awareness and to share about volunteer opportunities. There she met Matthew Theuma, a second-year student in graphic design. He has been collaborating with CMEA to produce some graphic designs (posters, leaflets, bookmarks, etc...) and this newsletter, and he plans to continue to volunteer next semester as well. Thank you to MCAST and well done for the effort to promote community volunteer involvement by their students



MCAST

Nov 02.

Official Opening of Caritas Community Centre. Frank Portelli and Janet Mifsud attended.

We are grateful to be able to use these lovely premises! It is located in Hamrun.



Nov 08.

Robin Pinkston met with Matthew Theuma regarding volunteer work for CMEA.

Nov 11.

Member's meeting online: Peter Farrugia, Caritas psychotherapist discussed and shared on, "Dealing with complex emotions".

Nov 16.

Training of Police Recruits at the Academy.

Frank Portelli, Manuel Camilleri, and Robin Pinkston did the training unit for the new recruit class. This group really impressed us with their interest and attention.

Nov 18.

Patient Empowerment Training' programme.

Training Initiative Scheme managed by the Malta Council for the Voluntary Sector. Malta Health Network, AX Palace Hotel. Frank Portelli attended.

Nov 25.

Online meeting regarding MCAST students as volunteers. Robin Pinkston attended.

Nov 28-29.

Robin Pinkston went to Brussels for an EFNA board meeting and to attend the MEP Interest Group on Brain, Mind and Pain as EFNA presented, *“Addressing Gender Related issues and bias in the Prevention and Treatment of Neurological Conditions,”* that took place under the patronage of the Czech Presidency of the Council of EU and the European Parliament and was hosted by the MEP Sirpa Pietikainen.

Dec 06.

Staff training at Haz-Zebbug Primary School; Frank Portelli, Manuel Camilleri and Robin Pinkston have attended.



Dec 07.

December 7, 2022- International Day for persons with disabilities in the Parliament of Malta.

President Frank Portelli and PR representative Matthew Attard took part in a Parliamentary meeting. During their presentation, Matthew presented the needs for the rescue medication Buccal Midazolam, an epilepsy specialist nurse, and the timely procurement of anti-epileptic drugs or the reimbursement of their private purchase if necessary due to it being out of stock. CMEA will continue to advocate for these needs!

As you can see, in 2022, the Caritas Malta Epilepsy Association committee has been working diligently to fulfill our vision for "a better life for people with epilepsy in Malta." If you have epilepsy, know someone who does and might need some support, or would like to join us in volunteering in some way, please contact us at maltaepilepsy@gmail.com. Thank you!

C - CARITAS
M - Malta
E - Epilepsy
A - Association

