

25 Years of
**CARITAS
MALTA
EPILEPSY
ASSOCIATION**
1996 - 2021

A better life for people with epilepsy



**25 Years of Caritas Malta Epilepsy Association 1996 – 2021:
A better life for people with epilepsy**

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This book is dedicated to **Mario** and **Victoria Dimech**. Mario was President of the Caritas Malta Epilepsy Association (CMEA) from 2000-2016, while Victoria was the CMEA Secretary from 2006-2016. Very sadly, they both passed away too soon in 2018 and 2016 respectively. Their commitment, hard work and dedication to CMEA were vital in the early years of the Association. They are greatly missed and this book is a testament to their ongoing legacy to the work CMEA undertakes to improve the lives of all with epilepsy in Malta.



pharmacology of chiral antiepileptic drugs and continues to invest in students as she coordinates the pharmacology study units at the University of Malta.

These many contributions have led to her appointment on prestigious boards, committees and organizations, and scientific committees, with numerous invites to present at key epilepsy conferences. She has contributed extensively to several IBE/ILAE commissions as the General Secretary of EUREPA, a member of several ILAE and IBE task forces, and even as Vice President (Europe) of the International Bureau for Epilepsy for two terms (2009-2017).

Her academic achievements and participation and leadership in many EU funded epilepsy related projects led to a tremendous honour when, in June 2019 in Thailand, she was presented with the Ambassador for Epilepsy award by the International League against Epilepsy.

Well done Professor Janet Mifsud! We love and appreciate you, and we look forward to many more years working alongside you for “a better life for people with epilepsy.”

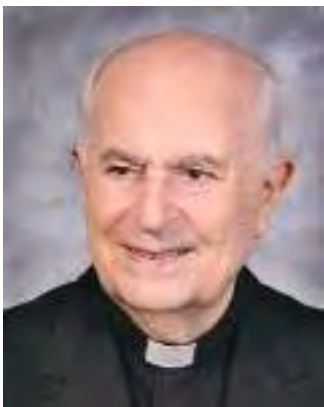
The Caritas Malta Epilepsy Association would like to take this opportunity to thank Professor Janet Mifsud for her ongoing work in the epilepsy field for more than twenty-five years. Her name is synonymous with the epilepsy community, not only locally but globally. She was one of the founding members of the Caritas Malta Epilepsy Association and is currently serving as advisor, but she also is actively involved in areas such as public relations and even secretarial work.

She keeps our group united as a team and even more as a family. In Malta, she spearheaded the introduction of epilepsy in the curriculum of several health care professional degrees. She has helped to organize numerous national and international conferences in Malta relating to epilepsy. Professor Mifsud has also been involved in the epilepsy field on European and International levels. She has conducted multiple research initiatives in respect to anti-epileptic drugs, especially through the involvement of persons with epilepsy themselves. She earned her PhD in 1995 on the

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Mgr Dun Victor Grech,
Founder & Former Director, Caritas Malta

I am honoured to write a forward to the commemorative book which aims to highlight the activities of Caritas Malta Epilepsy Association in Malta and abroad during these last 25 years.

This big adventure demanded courage, dedication and life-long commitment. The members of this voluntary association have learned to move beyond self-centredness to connectedness with others.

I have had various constructive discussions with the founding members of this Association as a former Director of Caritas Malta. There has always been a climate of mutual acceptance and understanding. The shared values and ideals of this family of volunteers coupled with dedication, loyalty, deep sense of mission and professional support, have helped enormously when dealing with the consolidation and development of CMEA.

We have learned along the years that we have no word which offers meaning to people's lives in difficult mental health impairment unless we have been touched by their doubts, anxieties and pain.

The scenario of research, diagnosis, therapy and treatment of persons suffering from epilepsy has changed and improved considerably in the last 25 years. However, our basic commitment should be to place the person at the centre of any authentic mental-health care programme because no human life is destined to be deprived of a happy and decent living.

I wish to pay tribute to the founding members and hard-working volunteers of this Association and to the timely insight, inspiration and professional support of Professor Janet Mifsud.

The CMEA has, throughout these 25 years, contributed significantly to the International Epilepsy Fora and specifically to the International Bureau for Epilepsy. I admire these achievements and the compassionate services rendered to society.

I wish CMEA to remain a fresh voice, strong and vibrant in supporting the estimated 4000 persons with epilepsy and their families in Malta and Gozo.

The journey is long and painful but rewarding.

Mgr. Victor Grech



Martin J. Brodie, President
International Bureau for Epilepsy, 2017-2021

It is with great pleasure that I pass on my warmest wishes to all my friends in Caritas Malta for reaching the important milestone of 25 years of supporting and caring for people with epilepsy in Malta. I remember clearly my visit to Malta as a speaker at the National Epilepsy conference on the 9th February 2008. I am greatly impressed by the wide range of activities and achievements undertaken over the last 25 years, which are too many for me to list. A number of these have been under the auspices of the University of Malta.

It gives me great pleasure to add my own few words of support as the president of the International Bureau for Epilepsy. I would particularly like to highlight the contributions of CMEA to people with epilepsy across Europe. In particular their participation in European and International congresses has greatly helped our worldwide agenda move forward, not just in Malta but also elsewhere in the region. It is my sincere hope that the next 25 years will see CMEA continue to grow and prosper in their essential role of supporting people with epilepsy and those who care for them.

Congratulations to you all!

Martin J Brodie



**Dr Francesca Sofia, President,
International Bureau for Epilepsy, 2021-2025**

I owe Caritas Malta Epilepsy Association (CMEA) a great debt of gratitude for believing in me and nominating me as president of the International Bureau for Epilepsy, which eventually allowed me to be elected for the term 2021-2025. I remember well the first (virtual) meeting when I presented my vision and plans to Frank Portelli, Claudine Aitken, Robin Pinkston, Caroline Attard, Manuel Camilleri, and Adriana Soler. I knew I was in the presence of giants, people who had been dealing with epilepsy for a long time without ever giving up, and to whom I must have seemed like a novice.

After all, it had been only six years since I had started my journey within an epilepsy association in Italy and three since I had joined the IBE as a volunteer. However, it was immediate to find our common ground that of the firm determination to achieve a better life for people with epilepsy.

But my gratitude goes far beyond that. I am grateful for the very existence of CMEA which over the past 25 years has truly made a difference to people with epilepsy in Malta as is evident from this commemorative book.

I believe this is an important read for anyone who cares about people with epilepsy. The history of CMEA, its accomplishments, and the dedication of all those involved with it show that it is possible to overcome many of the obstacles that stand in the way of people with epilepsy, through determination and commitment.

Over the past 25 years, CMEA has been able to successfully embody two core principles: community service and advocacy. In doing so, it has supported the community from within while paving the way for the social change we all hope for. Yet CMEA has gone beyond its geographical boundaries by becoming an active member of the international epilepsy community and exporting the ideas and skills of its generous volunteers and ambassadors.

This book celebrating its twenty-fifth anniversary is not only a memorial document, it is a source of inspiration and a guide for all those who believe that a better life for people with epilepsy is possible.



Anthony Gatt,
Director, Caritas Malta

I first crossed paths with the Caritas Malta Epilepsy Association in 1999 when I was engaged by Caritas Malta as a Volunteers Coordinator. It was a pleasure to offer my support to the committee of volunteers responsible for CMEA.

I was struck by the passion, enthusiasm and love that those responsible had for the members. I also had the opportunity to get to know the late Mario Dimech who was always thinking of new ideas how to support persons with epilepsy. After a year in the role I had left Caritas and furthered my studies in psychology. Little did I know then that I would return to Caritas in 2015 as a Clinical Coordinator of Caritas Drug Rehabilitation Programmes. Less did I imagine that in 2018 I would be appointed Director of Caritas Malta.

As Director of Caritas Malta I came across the Caritas Malta Epilepsy Association the second time round. Not only did I find the same passion, enthusiasm and love in the current committee, but also an organisation that had flourished and established itself as a fine supporter and advocate for persons with epilepsy. It had also engaged more persons and more volunteers to reach out further.

From the encounters I had with CMEA I wish to share one episode that will remain etched in my heart and a memory that will keep popping up as soon as I think of the CMEA. As director I was invited for the support group meeting a number of times.

With my background as a psychologist, the topic I would be invited to focus on is coping. While I facilitated one of the groups I clearly recall a young woman who had attended the support group for the first time and plucked up the courage to express, for the first time, that she was diagnosed with epilepsy. She had received the diagnosis some 6 months earlier and was afraid to share it even with her family. She had carried the worries, fears alone and that day the support group was a safe place to unload a burden that she was carrying alone and crushing her emotionally.

I recall how she wept in the group and with each cry she was relieving herself of such an emotional burden. Then after the group members listened carefully, with much care and sensitivity some of members (young and old) shared their own journey. Some had faced painstaking and incredibly challenging journeys. I could see this young woman feeling calmer and calmer as she attentively listened to stories of these other members. The sense of being alone in the world for this person was completely shattered. Much soothing came from that support group for this young woman. This is only one episode from 25 years of work.

I take the opportunity to express my heartfelt appreciation for the current President Mr Frank Portelli and the current committee for their dedicated work. I also thank Prof Janet Mifsud for her pioneering work and the critical contribution in the setting up of the Caritas Malta Epilepsy Association and its growth. May the invaluable work of the Caritas Malta Epilepsy Association continue on.



Frank Portelli, President
Caritas Malta Epilepsy Association

A journey of a thousand miles starts with a single step. Our journey started twenty five years ago. Rita Muscat together with a friend took the first step, when they came up with the idea of forming an epilepsy group. They contacted Bernardette Briffa from Caritas Malta who not only encouraged them but also approached Janet Mifsud, who had just returned from finishing her PhD in the UK on medicines used in epilepsy. Janet immediately accepted and helped these first volunteers to set up a support group. This all began in 1996. In 2001, we became an association and joined the International Bureau for Epilepsy as full members.

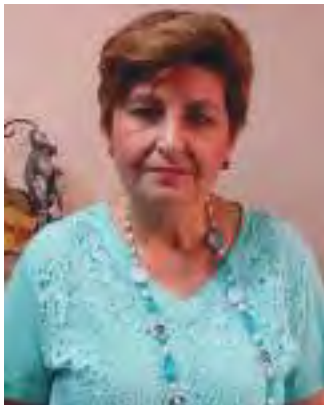
Our first president was the late Mario Dimech who held this post for several years. A couple of years later even his wife, the late Victoria Dimech joined our Association. I would add that they both were a central fulcrum and pillar for our Association. The popularity and success of CMEA kept increasing and both Janet and Victoria were elected to posts in the IBE. Today, two of our committee members Claudine and Robin are also occupying posts within the IBE. Mario and Victoria kept on contributing

to CMEA until their health permitted them to do so. I would also like to mention Joe Camilleri from Gozo. who rarely missed a meeting even though he had to travel from Gozo. We can rightly say that Joe was our ambassador for epilepsy in Gozo.

Twenty five years later, CMEA is still a 100% voluntary organisation, yet we are more professionally organised, thanks to the good will, time and support of all the Committee members. We have an ongoing very good relationship with all neurologists, doctors and even the Health Department to ensure that new epilepsy drugs or novel equipment are available to the epilepsy community in Malta, without delay.

I must also give a special thank you to all three directors of Caritas Malta we have worked with, namely Monsignor Dun Victor Grech, Mr Leonid McKay and Mr Anthony Gatt for their ongoing support and encouragement. A special thanks also goes to the staff at Caritas Malta with special mention to Geraldine Gatt, Marica Cassar, Bernardette Briffa, Victoria, Joe Grech and Stephen Farrugia. I would also like to thank Anthony Buttigieg for the ongoing management of our website and mailing list.

Finally, but not least, I want to express my sincere thanks to our current and past committee members for always working hand in hand and thus creating a magnificent team. To conclude, the letter I does not fit in the word **TEAM**, so this achievement was not the result of an individual effort, but due to a team effort. Other than a team I consider it as one big family and I am proud to be a part of this family and this augurs well for the next 25 years of CMEA.



**Rita Muscat, Founder Member
Caritas Malta Epilepsy Association**

I have epilepsy. My seizures are of the focal type, that is they affect only part of the brain. In 1977, I started working in a factory, however, I did not tell my employer that I have this condition. In fact, I had to be careful because I was working on a sewing machine. However, I used to feel my fits coming from before (auras), so I had the chance to get my feet off the pedals. That way, I wouldn't be hurt.

I worked in this factory for nine years. After it closed down, I spent a lot of time looking for another job. However, all prospective employers closed the door when I told them I had epilepsy. This is because everyone thought that epilepsy is the same in everyone, that is the grand mal (tonic clonic) that affects the whole brain. I had already shown everyone that I could work on a production machine, like anybody else. So, I went to the employment agency, JobsPlus (then called ETC) in Hal Far. When I told the clerk about the problem, he opened a whole drawer of papers. The papers belonged to all those who had epilepsy and who were looking for work. He told me that it was difficult to find work due to this condition.

I was so angry that I went to talk to a friend named Vivienne. She suggested I go to Caritas Malta. There I met Bernardette and Rosette and we talked and formed a small support group. After a while Janet, who had studied about epilepsy, also joined us. It was 1996 and this is how the epilepsy association began in Malta. In the beginning, we were only a few people in the meetings, but the word spread and we grew.

I didn't give up. I kept looking and looking for work and I succeeded and I started working again. Everyone has the right to work, including persons with epilepsy. My advice is that employers should give us a chance and not judge. First see how well the person works, whatever the condition they have.

I am really happy that out of my difficulties, the association that has helped so many people and families for the last 25 years began and grew. However, much remains to be done. More knowledge on epilepsy is needed to reduce the stigma that still exists.

HOW DID THE CARITAS MALTA EPILEPSY ASSOCIATION BEGIN ?

It is estimated that there are more than 4,000 people who have epilepsy in the Maltese Islands. The Caritas Malta Epilepsy Association (CMEA) began as the Malta Epilepsy Support Group in 1996, when Rita Muscat who was a volunteer at Caritas Malta, approached Bernadette Briffa, Head of Family Unit at Caritas Malta at the time. Rita suggested the setting up of an epilepsy support group. Coincidentally, Janet Mifsud had just returned from finishing her PhD in the UK on medicines used in epilepsy, and she got to know about this initiative. She joined as an advisor to the group in March 1996. Caritas Malta proved to be the ideal home, since the premises was free and central for those who did not drive.

The Steering Committee (core group) at the time was made up of eight voluntary members and the focus during the monthly meetings was on support and helping persons and family members of persons diagnosed with epilepsy. Isabelle Mifsud acted as secretary and took minutes for the first meetings held between 1996-1999. Close links were slowly established with the consultant neurologists in Malta, who supported the setting up of the group. It was only in 2000 that the organisation became more formalised and Caritas Malta Epilepsy Association (CMEA) was formed. Mario Dimech was chosen as its first leader and Godwin Cachia volunteered to become the secretary in January 2000. It was also agreed from the very beginning that the members of the core group (later the committee) of the epilepsy group would do so in a voluntary capacity and that all membership would be free. Any funds raised would thus go directly into activities for persons with epilepsy and their relatives and preparing educational material on epilepsy in Maltese and English.

CMEA's contribution to the international epilepsy fora, and specifically the International Bureau for Epilepsy, began when Mario Dimech and Frank Portelli represented

CMEA during the 7th European Conference on Epilepsy and Society in Athens, Greece, in 2000. There they had the opportunity to meet up with Phil Lee from Epilepsy Action UK who was, at the time, the President of IBE. In 2001, the name was formally changed to Caritas Malta Epilepsy Association (CMEA) and an application was made to join the International Bureau for Epilepsy. CMEA formally joined IBE as a full chapter on 31 May 2001 during the International Epilepsy Congress in Buenos Aires, Argentina. A logo, a hand holding a flame, was also chosen.

Subsequently, as the Association grew, there were also several constructive discussions with the Caritas Malta leadership, such as Mgr Dun Victor Grech, Mr Godfrey Kenely and Mr Anglu Fenech on how this growing CMEA would function within the main Caritas Malta entity. This open discussion and close collaboration has continued with subsequent Directors of Caritas Malta, such as Mr Leonid McKay and Mr Anthony Gatt and all the staff at Caritas Malta including Ms Bernardette Galea, Ms Geraldine Gatt, Ms Marica Cassar, Mr Joe Sammut, Ms Ritianne Cassar, Mr Maurice Xuereb, Ms Pauline Cilia, Mr Stephen Farrugia, Mr Albert Buttigieg, Ms Eleanor Borg, Ms Josette Vassallo and Ms Sylvia Galea. CMEA would not be where it is today without the input of these persons.

CMEA's breakthrough on a national basis came when the first National Conference on Epilepsy was organised by CMEA on 3 November 2001. It was not an easy task, but over 200 persons attended this first conference and its success really proved to be a key impetus to the growth of CMEA. This was the first of several national conferences subsequently organised every two years.

Mr Mario Dimech remained President until 2016, when he had to retire for health reasons. Mr Frank Portelli was appointed President in his place and still holds that position.

In 2006, Victoria Dimech was appointed Secretary of the Association. She remained in this position until 2014, and then again in 2016 for a few months until she had to retire for health reasons. Lourdes Cini was secretary in 2015-2016, Matthew Attard in 2017 and Noel Portelli in 2017-2018. Subsequently Robin Pinkston and Claudine Aitken took the conjoint role of secretary in 2018. Joe Camilleri was appointed our representative in Gozo in 2008, until his sad passing in 2011. Janet Mifsud was appointed advisor in 2000.

On an international level, CMEA's contribution grew. Janet Mifsud was elected Vice President Europe of IBE from 2005 to 2013. Victoria Dimech was elected member of the European Regional Executive Committee of IBE in 2009 until 2013. Janet Mifsud was given the award as International Ambassador for Epilepsy in 2019. In 2020, Robin Pinkston was nominated as IBE representative on the European Federation of Neurological Associations (EFNA), while in 2021 our contribution to the European Fora continued when Claudine Aitken was elected as a member of the European Regional Executive Committee of IBE.

CMEA has become more professionally organised in recent years, despite still being a 100% voluntary organisation. It has participated in three EU funded projects and obtained two national PEKTUR funds. Its first website was set up in 2007. In 2018, CMEA was rebranded with a new logo, letterhead and website and a regular attractive newsletter, as well as social media accounts such as Facebook® and Instagram®.

CMEA continues to reach out to persons with epilepsy and their families, promoting education and local awareness about epilepsy, especially because of the stigma experienced by people with this condition in society, particularly in employment. In 2018, thanks to CRPD PEKTUR funds and to

a collaboration with Epilepsy Action UK, CMEA developed an ongoing **strategy** for the next decade, specifically:

- **A vision** to ensure a better life for people with epilepsy in Malta
- **Its goals** are to make Malta epilepsy aware; to improve healthcare for people with epilepsy; and to offer practical support to people with epilepsy at key points of need. CMEA also aims to facilitate social acceptance of epilepsy, as a serious yet treatable brain disorder.
- **Its strategic** tools include education, training, communication, and commitment. Raising public and professional awareness and dispelling myths about epilepsy is one of CMEA's key objectives through media, talks, publications, epilepsy toolkits; information leaflets in English and Maltese, and epilepsy diaries and ID cards.

CMEA is still a 100% voluntary organisation 25 years later, and it is committed to work to achieve the vision of a better life for people with epilepsy. This twenty-fifth year anniversary book aims to highlight just some of the activities CMEA has undertaken during these years. All these have been carried out with a sense of dedication, commitment and support for all persons with epilepsy and their families in Malta and Gozo.



Present CMEA Committee 2021: 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, Manuel Camilleri.

ADMINISTRATIVE ACTIVITIES AND MEETINGS

The first Malta Epilepsy Support Group used to meet originally once every month. In 2000, when CMEA was set up, the need was felt to have dedicated committee meetings, separate from the whole group meetings, to facilitate the administrative work and coordination needed to ensure that the group was better organised. In fact, in recent years the CMEA Committee has sometimes met even twice a month. It has been estimated that over 300 committee meetings have been held in these 25 years.

These meetings were needed in order to reach out to key stakeholders and policy makers, prepare educational material, posters and videos, organise national events and training sessions, and participate in European projects and international fora and conferences. In 2017, CMEA worked hard and successfully obtained a Certificate of Enrolment by the Commissioner for Voluntary Organisations.

Communication lines have now greatly improved. In 2016, the need was felt for a dedicated email address maltaepilepsy@gmail.com to be set up so that anyone interested can contact CMEA in full confidence. Since 2016, there have been over 12,000 exchanges using this email address.

In 2019, it was also decided to set up a google drive for the better organisation, access and storage of all the material, communications, minutes of meetings, photos, events and activities. This will ensure that institutional memory of CMEA will last past the term of its present committee members.

With respect to meetings for members, nearly 200 meetings have been organised since 1996. Originally these were held once a month (every fourth Tuesday of the month).

In 2003, a decision was taken to organise these meetings every second Friday of alternative months in order to ensure a better attendance. These meetings began as support sessions with members sharing experiences and problems in a confidential and safe environment. CMEA has always emphasised that everything said during these meetings is exchanged in a fully confidential manner, and that no one is allowed to pass on information shared during the group meetings.

Meetings are normally held in Caritas Malta premises. When this was not available, meetings were also held in The Meeting Place in Marsa and a few meetings were also held in Gozo. From March 2020 to date, due to present pandemic restrictions, all meetings are being held online, yet attendance has still been good.

On other occasions, various professionals were invited to give talks in their area of expertise. CMEA has been fortunate to have excellent speakers in its meetings. These have included, among many others, Mgr Dun Victor Grech; Fr Alex Cordina; Dr Norbert Vella, Consultant Neurologist; Dr Doriette Soler, Consultant Neuropaediatrician; Dr Karl Chircop, Family Doctor; Mr Joe Camilleri, KNPD; Representatives from Police Headquarters re driving; Dr Elena Tanti Burlo, Psychologist; Dr Martin Micallef, Psychologist; ETC representatives; Dr Anton Grech, Consultant Psychiatrist; Ms Jackie Scerri, Pharmacist; Dr Josanne Aquilina, Consultant Neurologist; Dr Noel Vella, Occupational Health Department; Mr Anthony Gatt, Director Caritas Malta; Dr Audrey Camilleri, dentist; Mr Oliver Scicluna, Commissioner, CRPD; Dr Ray Galea, Consultant Gynaecologist; Ms Clarissa Captur, Pharmacist; Ms Marion Sammut, Pharmacist; Dr Adam Bartolo, Dentist; Dr Anna Micallef, Family Doctor; Dr Stephen Attard, Resident Specialist Neuropaediatrics;

Mr Sandro Fabri, EEG technician; Ms Moira Grixti, Nurse; Dr Sarah Sultana Grixti, gynaecologist; Mr Kevin Schembri, Consultant Cardiothoracic Surgeon. Sister Rita Zammit-Pace FMM, Pastoral Counsellor / Group Leader also held therapy sessions in 2001 for members of CMEA.

More recently Verena Portelli, Gestalt Psychotherapist, held very interesting resilience sessions for family members of persons with epilepsy. There have also been invited international speakers such as Prof Sanjay Sisodya from University College London and Dr Massimiliano Boffini, VNS specialist.

For some time, CMEA was also invited to attend weekly at the Neurology Clinical Outpatients at St Luke's Hospital, to provide information to persons with epilepsy attending the clinics. These formal meeting activities have been complemented with informal get togethers such as Christmas parties, hikes, barbecues and more recently picnics.

CMEA also cooperates and is a member of various umbrella organisations in Malta. These include the Federation of Organisations for Persons with a Disability and the Malta Health Network.

It also contributed to updating the access exam arrangements for students with epilepsy at the University of Malta in 2018. CMEA's hard work was recognised when its President, Frank Portelli, was nominated as Volunteer of the Year in January 2020 and received a certificate by HE President of Malta, Dr George Vella.

In September 2021, CMEA began to meet at the new Caritas Community Building in Blata-I-Bajda. This is a renovated building with several meeting rooms and other facilities which now serve, in an excellent manner, the needs of the wider Caritas Family, including those of CMEA and its members.



CMEA Committee meeting 29 September 2021 in the new Caritas Community Centre: Frank Portelli, Kevin Attard, Janet Mifsud, Robin Pinkston, Adriana Caruana Soler, Caroline Attard, Manuel Camilleri and Anthony Gatt, Director Caritas Malta.



Office of the Commissioner
for Voluntary Organisations

Certificate of Enrolment

Caritas Malta Epilepsy Association

c/o 5, Linn Street, Floriana FRN 1514 - Malta

Association
(classification)

Having satisfied the Commissioner for Voluntary Organisations that it qualifies in terms of Article 3¹ of the Voluntary Organisations Act, 2007 (Act No. XXX of 2007), has been enrolled as a Voluntary Organisation and its name entered in the Register of the Voluntary Organisations as follows:

Registration Number: VOV/1395²
Principal Purpose: Law, Advocacy and Politics
Date of Enrolment: 31st May 2017³
Enrolment Classification: Civic and Advocacy Organisations

The Organisation is herewith eligible for the privileges granted to voluntary organisations in terms of Article 4 of the said Act⁴. In terms of Article 4 (7) of the Act⁵, all persons to whom this certificate is provided are requested to provide the Organisation with full recognition of its status as a voluntary organisation consistent with all provisions of the applicable law⁶.



Professor Kenneth Wain
Commissioner for Voluntary Organisations

Date: 31st May 2017⁷



31 May 2017, Certificate of Enrolment, Commissioner for Voluntary Organisations



April 2011, CMEA Committee Meeting, Gozo: Mario Dimech, Frank Portelli, Victoria Dimech, Janet Mifsud, Mandy Vella, Joseph Camilleri and Manuel Camilleri.



4 April 2013, CMEA Committee Meeting, Caritas Malta, Floriana: Manuel Camilleri, Janet Mifsud, Godwin Cachia, Victoria Dimech, Frank Portelli, Adriana Caruana Soler, Mario Dimech, Caroline Attard.



December 2015, Meeting with Mr Leonid McKay, former Director, Caritas Malta, Floriana: Manuel Camilleri, Janet Mifsud, Leonid McKay, Frank Portelli, Matthew Attard, Caroline Attard, Mario Dimech, Adriana Caruana Soler.



June 2010, CMEA Committee Meeting: Mario Dimech, Janet Mifsud, Frank Portelli, Manuel Camilleri, Joseph Camilleri, Mandy Vella, Victoria Dimech.



April 2018, CMEA Picnic Ta Qali: Caroline Attard and Robin Pinkston.



April 2018, CMEA Picnic Ta Qali: Kevin Attard, Michael Attard and Frank Portelli.



9 January 2020, Frank Portelli nominated as volunteer of the year: Dr Noel Camilleri, HE Dr George Vella, Frank Portelli, PS Clifton Grima.



24 January 2020, CMEA Committee Meeting: Adriana Caruana Soler, Matthew Attard, Manuel Camilleri, Caroline Attard, Janet Mifsud, Frank Portelli, Robin Pinkston.

EDUCATIONAL MATERIAL AND DISSEMINATION ACTIVITIES

From the very beginning, CMEA realised that if its outreach strategy was to succeed, it was necessary to have information on epilepsy in English and Maltese, targeted to the local audience. In 1996, internet facilities were not yet available in Malta and few people had a computer. Few people had a mobile phone, and smart phones still did not exist. Awareness thus had to be raised through printed material and press releases to all newspapers and radios, using fax machines. CMEA also began to issue a regular newsletter in 2003. This newsletter was originally photocopied, hand folded one by one and circulated by post. In 2018, the layout was revamped and the newsletter renamed **Kelmtejn**. It is now much more attractive and professional. So far there have been over 60 issues and it is being circulated electronically to its members.

The first educational booklets were prepared by the Health Promotion Unit, within the Ministry for Health. These addressed **Epilepsy in Adults (1996)** and **Epilepsy in Children (1997)**. Thanks to a few sponsors, CMEA managed to obtain funds to print leaflets in English and Maltese in 2000 on various subjects such as **What is Epilepsy?; Epilepsy In The Home; Epilepsy In Later Life; Epilepsy And Leisure; Women And Epilepsy; Epilepsy In Children; Anti-Epileptic Medication; Epilepsy And Work; Parents With Epilepsy; Driving and Epilepsy**. The first video in Maltese was funded by a PEKTUR fund in 2001 and was entitled **L-Epilessija, Tista' Tgħix Hajja Normali**.

In 2000 and 2004, **Epilepsy Diaries** and **Identity Cards** in English and Maltese were also printed. In 2008, the American Foundation for Maltese Charities funded a teachers' pack entitled **Living Beyond Epilepsy, A Resource for Educators**. **First Aid in Epilepsy** posters were printed in 2010. The **Epilepsy Toolkit** in English and Maltese was funded thanks

to a CRPD PEKTUR grant in 2017. More recently in 2019, **Pictorial Guides For Adults With Epilepsy** in English and Maltese were prepared and printed thanks to an Erasmus+ funded project EPIPICTO. CMEA is presently updating the epilepsy diary and identity cards.

These awareness raising activities led to members of CMEA participating in various programmes on local TV, radio and even newspaper interviews. CMEA representatives have been invited on all local TV and radio stations and in practically all chat shows such as *Mit-Tnejn sal-Gimgħa*, *One TV*; *L-Għodwa t-Tajba*, *PBS*; *Min-Baqa' d-Dar*, *PBS*; *Susan Mulvaney RTK*; *TVAM*, *PBS*; *Kikkra Te*, *Net TV*; *Dwarna*, *TVM*; *Espresso One TV*; *Illum ma' Stef*, *TVM*; *Campus FM* radio; *Radju Marija*; *Radio Cottonera*; *Cittadini Attivi*, *F Living TV*; *Bejnitna*, *Net TV*; *Għazliet*, *Net FM* and even in the main *TVM 8pm* news. The various members have also contributed to articles in the printed press, including *I-Orizzont*, *il-Gens*, the *Times of Malta*, *Malta Independent*, *Malta Today* and *In-Nazzjon Tagħna*. Dissemination activities have also been held with student associations such as the *Malta Medical Students Association*; *Esplora*, the interactive science centre in *Bigħi* and *International Epilepsy Day* activities in Malta.

CMEA had its first website in 2007 as part of the Caritas Malta site <https://www.caritasmalta.org/epilepsy>. The site was recently revamped in 2020 and the website managers are Mr Stephen Farrugia and Mr Anthony Buttigieg. The site now contains all CMEA contact information, educational material, activities and events, information on national conferences, useful links and live updates of its Facebook® and Instagram® accounts which were set up in 2018 and 2021 respectively. CMEA also hosts a closed Facebook® page for youths with epilepsy who wish to share their

experiences among peers.

As part of the build up to International Epilepsy Day in February 2021, promotional videos **Voices for Epilepsy** and educational graphics for Facebook® and Instagram® were recorded in conjunction with the Communications Office at the University of Malta <https://www.um.edu.mt/newspoint/news/2021/02/voices-for-epilepsy>.

In addition, several government buildings in Valletta and some local councils were lit up in purple in order to raise more awareness about this condition.



27 July 2011, Launch of CMEA Teacher's Resource Pack: Joe Sammut, Caritas Malta; Victoria Dimech, CMEA; Dun Victor Grech, Caritas Malta; Hon. Dolores Cristina, Minister for Social Policy; Manuel Camilleri, CMEA; Frank Portelli, CMEA and Mario Dimech, CMEA.



27 July 2011, Launch of CMEA Teacher's Resource Pack: Hon. Dolores Cristina, Minister for Social Policy; Manuel Camilleri, CMEA; Frank Portelli, CMEA and Mario Dimech, CMEA.



March 2011, European Epilepsy Day, University of Malta: Medical Student representatives; Dr Peter Micallef, Parliamentary Secretary Ministry of Health; Janet Mifsud, CMEA; Manuel Camilleri, CMEA; and Frank Portelli, CMEA.



March 2011, European Epilepsy Day, University of Malta: Dr Peter Micallef, Parliamentary Secretary Ministry of Health; Giulia Mifsud, Manuel Camilleri and Frank Portelli.



13 August 2018, Dissemination at Eplora, Bighi, Kalkara: Matthew Attard, Frank Portelli, Caroline Attard, Manuel Camilleri, Janet Mifsud.



12 April 2014, MMSA event held at The Point, Sliema: Group photo with Minister for Health, Konrad Mizzi and Parliamentary Secretary Dr Chris Fearne.



25 January 2015, International Epilepsy Day, St James Cavalier, Valletta: Mario Dimech, Adriana Caruana Soler, Frank Portelli, Caroline Attard, Janet Mifsud, Manuel Camilleri, Matthew Attard.



25 January 2015, International Epilepsy Day 2015, Upper Barrakka Valletta with gun salute: Adriana Caruana Soler, Janet Mifsud, Caroline Attard, Matthew Attard, Manuel Camilleri, Mario Dimech, Frank Portelli.



April 2018, Manuel Camilleri with HE Archbishop of Malta Charles Scicluna on occasion of Maundy Thursday.



April 2018, Manuel Camilleri with HE Archbishop of Malta Charles Scicluna on occasion of Maundy Thursday.



2018 on Radio RTK. Interview with Mr Albert Buttigieg on *Spalla ma' Spalla* with Frank Portelli and Matthew Attard.



8 February 2021 Interview on Kikkra Te programme, Net TV, Frank Portelli and Janet Mifsud.



8 February 2021 Interview on Espresso 11am One TV with Claudine Aitken and Frank Portelli.



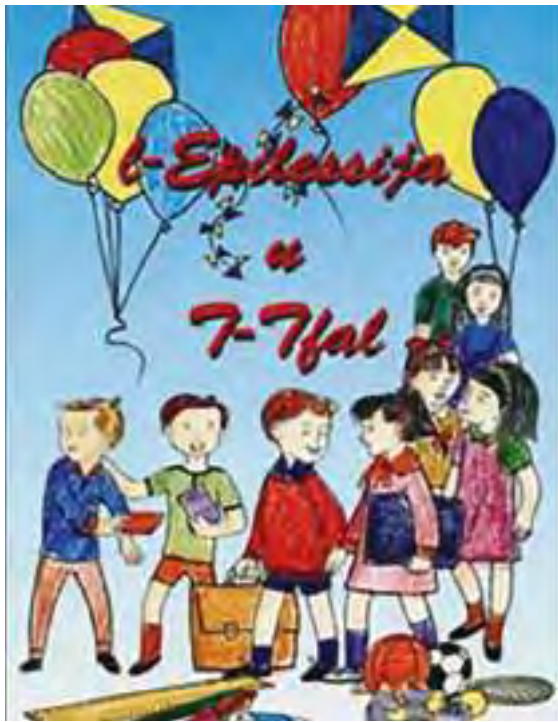
6-8 February 2021 Auberge de Castille Office of Prime Minister, lit up in purple for International Epilepsy Day.



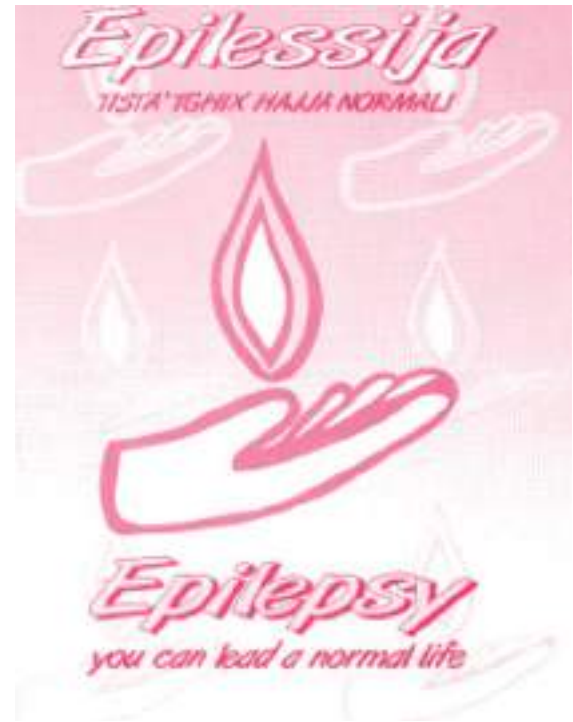
6-8 February 2021 Cavalier House Ministry for the Inclusion and Social Wellbeing, lit up in purple for International Epilepsy Day.



6-8 February 2021 Palazzo Ferreria, Ministry for Social Justice and Solidarity, the Family and Children's rights, lit up in purple for International Epilepsy Day.



L-Epilessija u t-Tfal. 1996.



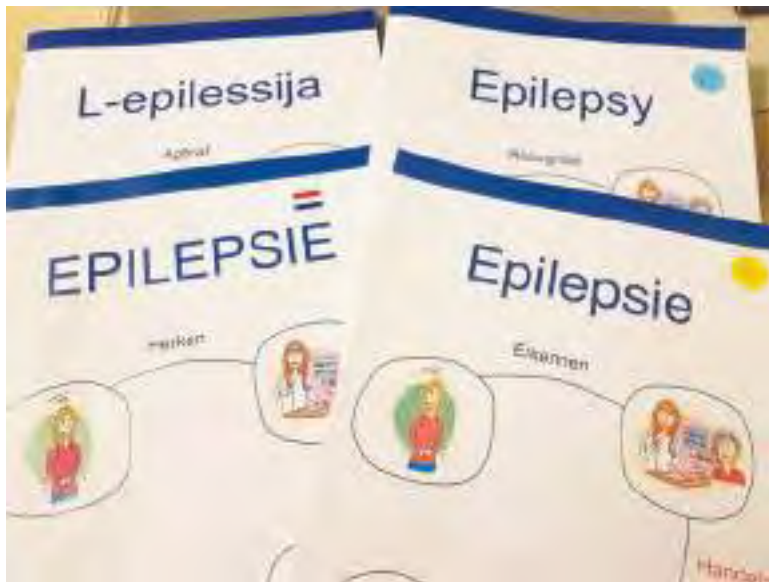
L-Epilessija: Tista' Tghix Hajja Normali. 1997.



Living Beyond Epilepsy, A Resource for Educators, 2010 (front cover).

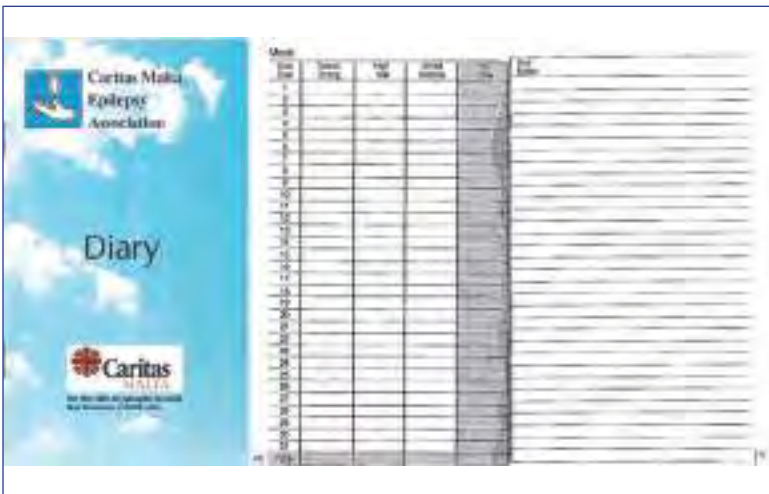


Living Beyond Epilepsy, A Resource for Educators, 2010 (inside contents).



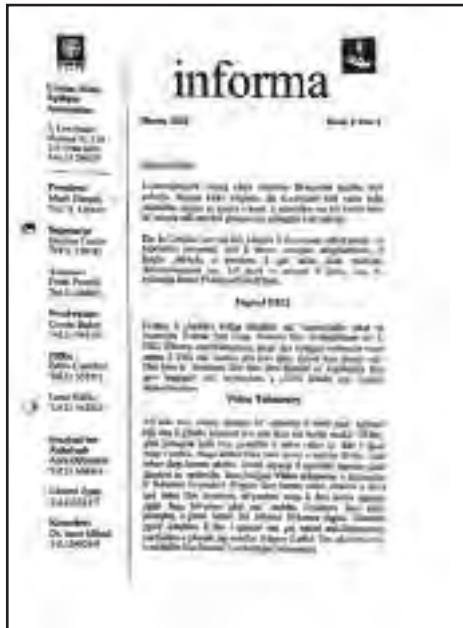
EPICTO – Pictorial Guide to Epilepsy guides in English, Maltese, German and Duch, 2019.

Epicpto Logo and the pictorial guide issued between five countries.



Epilepsy Diary 2005.

Epilepsy Identity Card 2006.



First CMEA Newsletter issued in March 2002.



CMEA Newsletter issued in May 2002.



TRUST poster explaining Seizure First Aid 2010.



Kelmtejn Newsletter issued in May 2021.



Kelmtejn Newsletter issued in July 2021.



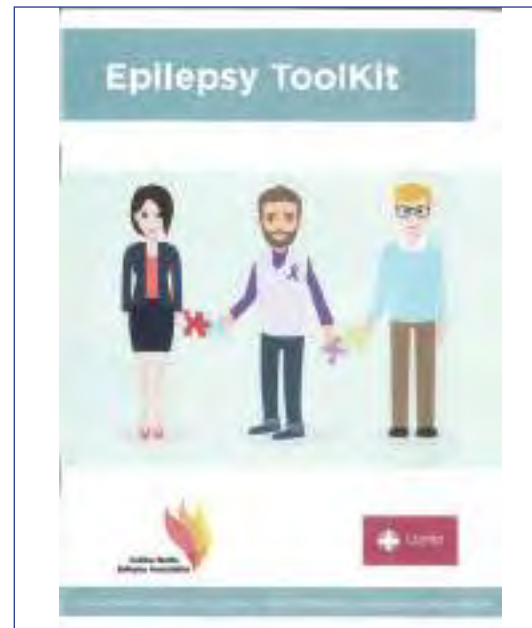
TRUST poster explaining seizure first aid 2020.



CMEA bookmarks, 2020.



TRUST bookmarks, 2011.



Epilepsy Toolkit printed in Maltese and English, 2018.



First educational leaflets in Maltese printed in 2000.



Poster used for International Epilepsy Day, 8th February, 2021.



Members' meeting - 13th November 2021 - Coping with Stress: The role of Gestalt psychotherapy during these trying times.



Members' meeting - 15th January 2021 - The role of resilience in our life journey with epilepsy - how can we become stronger together.



Members' meeting - 12th March 2021 - When sparks fly.



Members' meeting - 14th May 2021 - Treatment of drug resistant epilepsies: an update from a local perspective.



Members' meeting - 9th July 2021 - Seizure related injury: An overview of first aid recommendations.

TRAINING AND TALKS

CMEA regularly organises various free training courses in English and Maltese for teachers, social workers, police recruits and other persons who wish to know more about epilepsy. These training sessions serve as key multiplier events to inform those in a position to create change and raise more awareness about epilepsy. These training sessions are tailored to the requirements of the audience, but they generally include an overview of what epilepsy is, a description of the most common seizures, videos on different types of seizures and first aid in epilepsy as well as personal experiences. This training is also complemented with the distribution of free educational material. Feedback and evaluations have shown that these sessions are very well received, especially since a huge effort is made to ensure that the language used is one which can be understood by lay people without a medical background.

Talks have been given to teachers, Learning Support Educators and students in primary and secondary schools (state, private and church); University students; local councils; parish councils; scouts; mother and baby clubs; youth centres; church organisations such as Caritas Malta staff, MUSEUM members, and staff at special schools such as Mtarfa and Wardija. CMEA has also been regularly invited to train care workers in Dar tal-Providenza and Dar tal-Kaptan; staff at St Vincent de Paule Residence for the Elderly; social workers employed with Agenzija SAPPOR and APPOGG; St John Malta; Inspire Foundation as well Arka Foundation and Oasi Foundation in Gozo.

From 2005 to 2017, CMEA has also contributed to the annual 3-day in-service training sessions offered to teachers. Seminars for heads and assistant heads of both public and private schools were also held during the scholastic year 2005/6.

A key training session was an interactive meeting held for family doctors in conjunction with the Malta College of Family Doctors in 2005. It was a very fruitful meeting and it was felt that this initiative enhanced the treatment and the management of people with epilepsy even further. Training was also held for ETC staff in June 2012. Training to police recruits has been given on an annual basis since 2011.

In 2019, CMEA provided face to face training to over 20 different organisations, with around 430 individual participants. The evaluation forms showed that after training, those participants who were well informed about epilepsy, increased from 30% to 86%. Those participants who knew what to do if someone had a seizure increased from 32% to 72%.

From March 2020 to date, these training activities have been held online. This could not fully replace face to face training and we look forward to being able to offer such trainings again in the near future.



15 November 2011, Training for Police Recruits, Fort St Elmo, Valletta: Manuel Camilleri, Janet Mifsud, Frank Portelli with participants.



8 November 2011, Training for Police Recruits, Fort St Elmo, Valletta: Mario Dimech addressing participants.



14 October 2016, Training for Esplora staff, Villa Bighi Kalkara: Matthew Attard addressing participants.



July 2017, In-service course for teachers, Maria Regina Blata-l-Bajda: Dr Anna Micallef and Frank Portelli addressing teachers.



July 2017, In-service course for teachers, Maria Regina Blata-I-Bajda: Dr Stephen Attard addressing teachers.



July 2017, In-service course for teachers, Maria Regina Blata-I-Bajda: Marion Sammut addressing teachers.



6 June 2018, Training for St Vincent de Paule Residence for the Elderly staff: Frank Portelli addressing participants.



13 March 2019, Inspire staff training: Janet Mifsud addressing participants.



23 May 2019, Training to Police recruits, Police Academy, ta' Kandja: Manuel Camilleri addressing participants.



29 May 2019, Training to Police recruits, Police Academy, ta' Kandja: Robin Pinkston addressing participants.



24 September 2019; Training at de La Salle College Primary School: Robin Pinkston addressing participants.



16 October 2019, Training to female MUSEUM members, Floriana: Manuel Camilleri addressing participants.



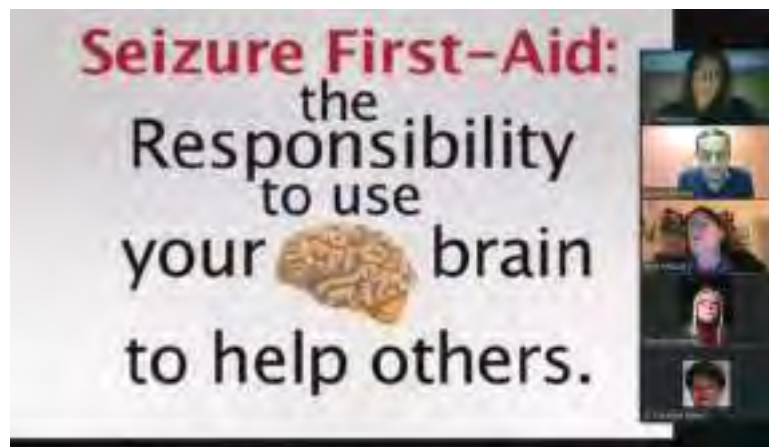
11 November 2019, Training to Gozo care workers: Frank Portelli and Manuel Camilleri addressing participants.



18 November 2019, Training to staff at Dar tal-Providenza: Janet Mifsud addressing participants.



22 November 2019, Training to staff in Wardija School: Manuel Camilleri addressing participants.



28 April 2021, online training to St John Malta on Seizure First Aid.

**LOBBYING ACTIVITIES
AND MEETINGS
WITH KEY STAKEHOLDERS
IN MALTA**

In order to catalyse change, the epilepsy message needs to arrive to key stakeholders, policy makers and those in a position to make decisions in Malta. Since 1998, CMEA has worked hard to ensure that one to one meetings are held on a regular basis with Presidents of Malta, Prime Ministers, Ministers of Health, Ministers for Education and Employment as well as Ministers for Social Policy and Social Inclusion and their counterparts across the political spectrum. The aims of these meetings have been various, but they mainly served to sensitise these policy makers on the number of persons with epilepsy in Malta and the difficulties they and their families face in the educational systems and in the workforce. CMEA has also donated its publications to the President's Library in San Anton Palace.

Discussions on improving health care and medical treatment for persons with epilepsy are ongoing with the Ministry for Health. As early as 2001, CMEA began to lobby hard with the Ministry for Health to ensure a reliable supply of antiepileptic medication and to ensure that video telemetry will be available in Malta. This finally came to fruition in the new Mater Dei Hospital in 2008. Vagal nerve stimulation (VNS) became available in 2019. Recently, the focus is on the feasibility of having buccal midazolam available in Malta for first aid in epilepsy and cannabidiol for certain rare types of epilepsy syndromes. CMEA members also regularly meet up with Consultant Neurologists (adult and paediatric), as well as support staff such as EEG technicians, nurses and pharmacists. It also advised the Occupational Health Unit on driving regulations for persons with epilepsy in Malta in 2006.

Meetings have also been held with several Maltese members of the European Parliament across the political spectrum. UK MEP John Bowis visited Caritas Malta and

attended the CMEA conference in 2003. US Ambassador to Malta HE Douglas Kmiec visited Caritas Malta in 2010. CMEA also participated in various fairs, including the 5th Edition of Il-Volontarjat (Caring Awareness Fair) held at the Trade Fair Grounds, Naxxar in 2002 which was attended by HE President Guido de Marco; had a stand at the Malta Trade Fair in 2011 and contributed to the Malta Health Network Stand outside the Parliament Building in 2019.



May 2002, Disability Fair, Naxxar: Manuel Camilleri, CMEA; HE Prof Guido de Marco, President of Malta; Godwin Cachia, CMEA; Janet Mifsud, CMEA.



November 2002, Visit by MEP John Bowis to Caritas Malta: Connie Baker, CMEA; Mario Dimech, CMEA; John Bowis, MEP; Frank Portelli, CMEA; Anna Debattista, CMEA and Godwin Cachia, CMEA.



June 2009, President's Palace Valletta: Courtesy visit to HE President of Malta. Manuel Camilleri, CMEA; Mandy Vella, CMEA; Frank Portelli, CMEA; HE Dr. George Abela, President of Malta; Victoria Dimech, CMEA; Mario Dimech, CMEA; Janet Mifsud, CMEA and Joseph Camilleri, CMEA.



June 2009, President's Palace Valletta: Courtesy visit to HE President of Malta Dr George Abela. Janet Mifsud, CMEA; Frank Portelli, CMEA; Joseph Camilleri, CMEA; Victoria Dimech, CMEA; HE Dr. George Abela, President of Malta; Olaf Terribile, OPR; Manuel Camilleri, CMEA; Mandy Vella, CMEA and Mario Dimech CMEA.



17 October 2010, Caritas Malta, Floriana: Mons. Victor Grech, Director Caritas Malta; US Ambassador Douglas Kmiec; Janet Mifsud, CMEA; Mario Dimech, CMEA; Victoria Dimech, CMEA; Frank Portelli, CMEA; Rose Ann Toledo, Caritas Malta; Manuel Camilleri, CMEA.



17 October 2010, Caritas Malta, Floriana: Victoria Dimech, CMEA; Janet Mifsud, CMEA; US Ambassador Douglas Kmiec; Mario Dimech, CMEA; Manuel Camilleri, CMEA; Frank Portelli, CMEA.



28 June 2011, Meeting Hon. Dolores Cristina, Minister for Education, Work and the Family visiting the CMEA stand, Trade Fair ta Qali: Minister Dolores Cristina, Frank Portelli, CMEA; Mario Dimech, CMEA.



31 July 2014, Meeting with HE Marie Louise Colerio Preca, President of Malta, San Anton Palace, Attard: Caroline Attard, Manuel Camilleri, Frank Portelli, Mario Dimech, HE Marie Louise Colerio Preca, President of Malta, Alex Attard, Matthew Attard, Janet Mifsud, Albert Buttigieg.



30 May 2019, Meeting with HE Dr George Vella, President of Malta and Mrs Vella: Janet Mifsud, Robin Pinkston, Frank Portelli, HE DR George Vella, Mrs Vella, Manuel Camilleri, Noel Camilleri.



November 2019, Malta Health Network Stand outside Parliament Building Valletta: MHN representative; Robin Pinkston, CMEA and Frank Portelli, CMEA.



February 2019, Presentation of Epilepsy Toolkit to HE Marie Louise Colerio Preca, President of Malta, Library San Anton Palace, Attard: Caroline Attard, Robin Pinkston, Anthony Gatt, Director, Caritas Malta, Frank Portelli, HE Marie Louise Colerio Preca, President of Malta, Oliver Scicluna, Commissioner CRPD, Manuel Camilleri, Matthew Attard, Anna Micallef.



February 2019, Meeting at Office of the Prime Minister, Auberge de Castille, Valletta: Noel Mercieca, Robin Pinkston, Frank Portelli, Matthew Attard, Caroline Attard.



February 2019, Meeting at Office of the Prime Minister, Auberge de Castille, Valletta: Noel Mercieca, Hon Dr Michael Falzon, Minister for Social Solidarity and the Family; Frank Portelli, Hon Dr Joseph Muscat, Prime Minister, Matthew Attard, Hon Dr Chris Fearn, Minister of Health; Robin Pinkston, Caroline Attard.



Online meeting with Hon Julia Farrugia Portelli, Minister for Inclusion and Social Wellbeing, on the occasion of International Epilepsy Day, February 2021.



Meeting with Dr Adrian Delia, Leader of the Opposition on the occasion of International Epilepsy Day, February 2018.



Press Conference for International Epilepsy Day, Caritas Malta, February 2019.



Manuel Camilleri, CMEA, being interviewed by a journalist, 2018.

NATIONAL EPILEPSY CONFERENCES

In June 2001, the CMEA committee felt the urgent need to hold a national conference, in order to enhance its campaign in spreading better knowledge and understanding of epilepsy in Malta and Gozo. Such a national conference would also attract the attention of the media and would improve the public awareness of the needs of people with epilepsy with policy makers, health authorities and the public at large. In order to ensure that each conference was given the appropriate esteem, the President of Malta at the time was always invited to open the conference. The relevant Ministers of Health, Education, Employment and Social Policy were also always invited to participate and address each conference.

To date, CMEA have organised ten National Epilepsy Conferences. These are organised every two years, generally in February or March, close to International Epilepsy Day. These conferences have covered a wide range of topics, suggested by the members themselves. Some conferences have targeted the needs of children with epilepsy and the education sector and helped to sensitize teachers and learning support educators (2003, 2010). Others have addressed the social impact of epilepsy (2006, 2014, 2016) and the stigma that exists locally in regards to epilepsy, particularly with employers (2012). A key interdisciplinary conference was held in 2008 with the participation of over 150 health care professionals including family doctors, pharmacists, EEG technicians and nurses.

Each conference has also had at least two invited international keynote speakers. These have included key representatives from IBE, top adult and child neurologists from UK, Italy and the Netherlands, an EU Health Commissioner, MEPs and invited international persons with epilepsy who shared their experiences.

An average of 150 persons attend each conference, giving

a total of over 1500 persons who have attended our conferences in these last 25 years. The registration fee has always been kept at a minimum in order to facilitate participation by anyone who wished to attend.

The conferences held to date have been the following:

- **Epilepsy in the Open, Experiences from Malta. 3rd November 2001**
- **Malta, Epilepsy and Children - Together We Will Succeed. 22nd February 2003**
- **Caritas Malta Epilepsy Association - Ten years of work: The Social Impact of Epilepsy. 18th February 2006**
- **Epilepsy and the Nursing Profession. 16th November 2007**
- **Epilepsy: a Multidisciplinary approach. 9th February 2008**
- **Epilepsy is more than just seizures. 22nd February 2014**
- **Epilepsy - How do we overcome stigma? 25th February 2012**
- **What is epilepsy? Improving our knowledge. 20th February 2010**
- **Living with epilepsy: Step by Step. 13th February 2016**
- **Epilepsy: Finding Help. 22nd February 2018**

Unfortunately, the 2020 conference had to be cancelled just four days before it was due to be held due to restrictions in force as a result of the emerging COVID-19 pandemic. Four international speakers had been expected to address this conference. CMEA is looking forward to being able to organise its next national conference, once health restrictions are lifted.

**3 November, 2001 CMEA Conference:
*L-Epilessija fil-Miftuh Esperjenzi f'Malta***

International Bureau of Epilepsy

International League Against Epilepsy

Seminar 3 ta' Novembru 2001
New Dolmen Hotel, Bugibba

L-Epilessija fil-Miftuh: Esperjenzi f 'Malta



Organizata
mill-Caritas Malta Epilepsy Association
u Epilepsy Society of Malta

Bl-ghajjuna ta'

The British Council

MALTACOM

AIR MALTA

L-Universita ta' Malta

Malta College of Pharmacy Practice



Mr Phil Lee President IBE addressing the participants during the plenary session



3 November 2001 Malta National Epilepsy Conference -L-Epilessija fil-Miftuh Esperjenzi F' Malta: morning panel Mgr Dun Victor Grech, Director Caritas Malta; His Excellency Prof Guido Demarco, President of Malta; Prof Janet Mifsud, CMEA; Mr Carmelo Abela, Shadow Minister for Education; Mr Phil Lee, President, International Bureau for Epilepsy; Mr Martin Micallef, Psychologist.

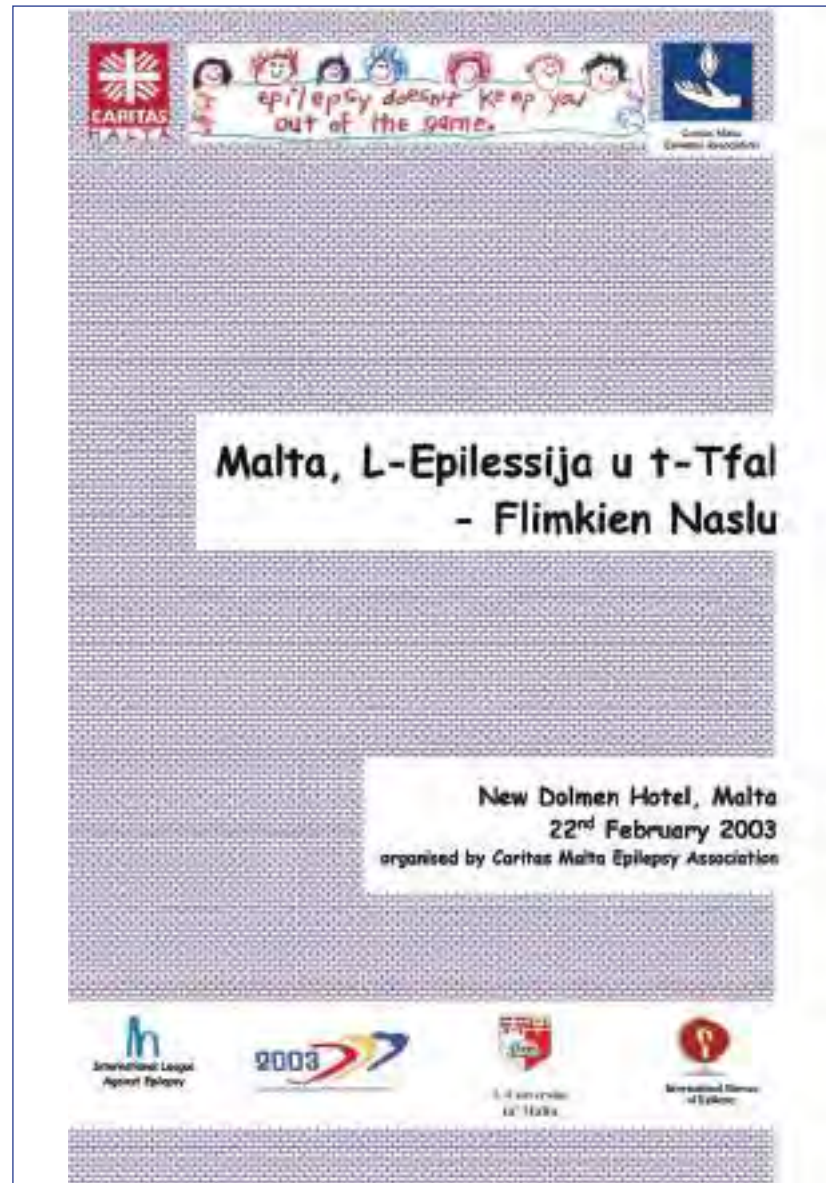


3 November 2001 Malta National Epilepsy Conference-L-Epilessija fil-Miftuh Esperjenzi F' Malta-speakers and organising committee: Mr Manuel Camilleri, CMEA; Louis Vella, CMEA; Mr Mario Dimech, President CMEA; Hilary Mounfield; CEO Epilepsy Action Scotland; Phil Lee, President, International Bureau for Epilepsy; Prof Janet Mifsud, CMEA; Ms Connie Baker, CMEA; Rita Muscat, CMEA; Mr Godwin Cachia, Secretary CMEA; Mr Frank Portelli, Treasurer CMEA.



2001 Malta National Epilepsy Conference-L-Epilessija fil-Miftuh Esperjenzi F' Malta-afternoon panel: Dr Martin Micallef, psychologist; Dr Anthony Galea Debono, consultant neurologist; Janet Mifsud, CMEA; Dr Doriette Soler, Consultant neuropediatrician; Ms Hilary Mountfield, Chair EREC; Ms Anna Callus, UM; Mr Phil Lee, President IBE.

22 February, 2003 CMEA Conference:
Epilepsy and Children - Together we succeed





Mario Dimech, President CMEA, addressing participants at 2003 conference.



Ms Connie Baker, member CMEA reporting from the workshops.

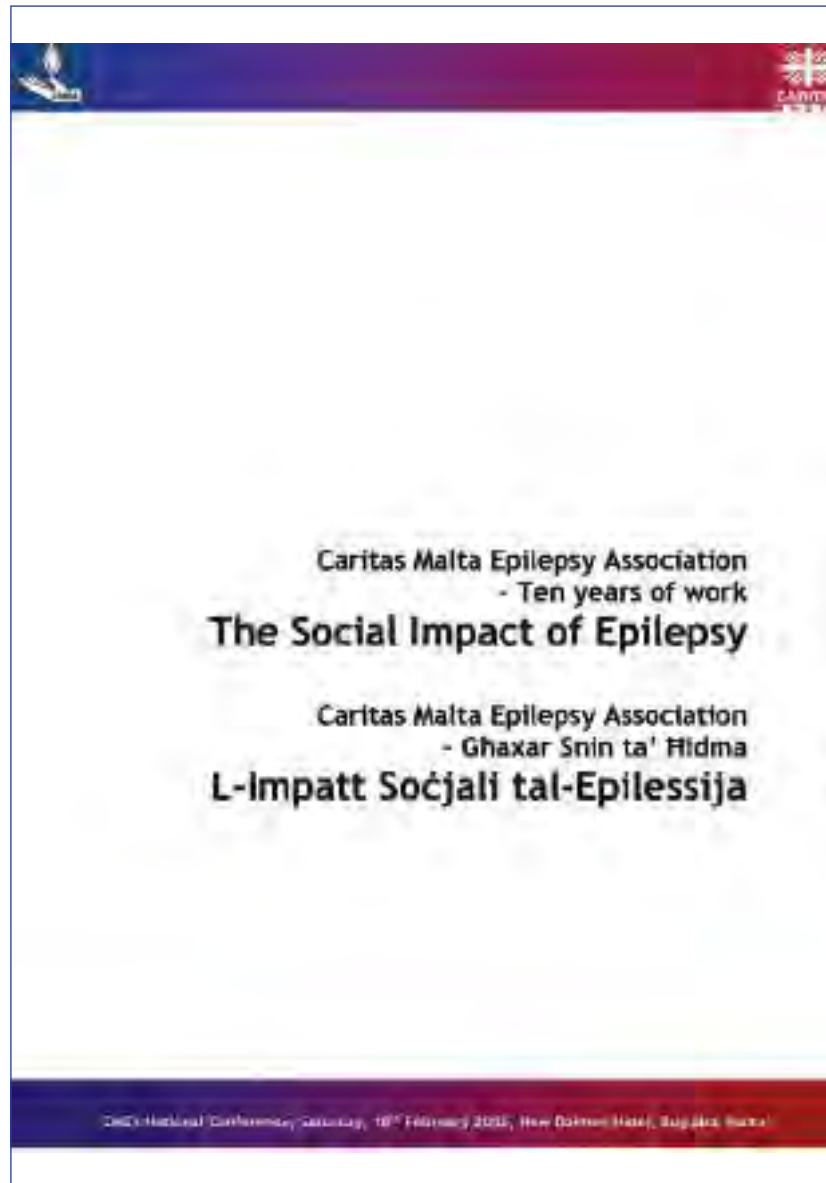


22 February 2003 Malta National Epilepsy Conference Epilepsy and Children-Together we succeed: Joseph Camilleri, Commissioner KNP, Fred Bezzina KNP, Mario Dimech CMEA, Connie Baker CMEA, Mr Albert Rutter, UNESCO Malta, Prof Charles Farrugia, Chair, UNESCO Malta; Sister Gezwina Mangion, Dar tal-Providenza.



Janet Mifsud CMEA; Lino Sghendo UM; John Bowis MEP; Connie Baker CMEA; Godwin Cachia CMEA; Anna Debattista CMEA; Paul Bartolo UM; Doriette Soler Paediatric Neurologist; Frank Portelli CMEA; John Chaplin IBE; Manuel Camilleri CMEA; Anthony Buttigieg UM; Mario Dimech CMEA; Anna Callus UM; Anthony Camilleri, UM; Sharon Agius UM; Victoria Dimech CMEA.

18 February, 2006 Malta CMEA Conference:
Ten Years of Work - The Social Impact of Epilepsy





Mgr Dun Victor Grech, Director Caritas Malta, addressing the participants.



Mario Dimech, CMEA; Dun Victor Grech, Director Caritas; Malta, HE Dr. Eddie Fenech Adami, President of Malta; Janet Mifsud CMEA; Prof. LW Sander, UK; Clarissa Captur UM.






18 February, 2006. Malta National Epilepsy Conference: Ten Years of Work - The Social Impact of Epilepsy. Participants.



Anna Callus UM, Maire Tansey, Ireland; Dr. Ray Galea, MoH; Mario Dimech CMEA; Janet Mifsud CMEA; Prof. LW Sander, UK; Clarissa Captur, UM.

9 February, 2008 CMEA Conference:
Epilepsy a Multi Disciplinary Approach




Epilepsy: a Multidisciplinary Approach

**National Conference
organised by the
Caritas Malta Epilepsy Association**

in conjunction with
Epilepsy Society of Malta
Malta College of Family Doctors
Malta College of Pharmacy Practice
Malta Union of Midwives and Nurses
Dept of Clinical Pharmacology, University of Malta

**9th February 2008
Dolmen Resort Hotel, Bugibba, Malta**





Mario Dimech, CMEA; Dun Victor Grech, Director Caritas Malta; HE Dr. Guido De Marco, President of Malta; Janet Mifsud, CMEA; Prof. Maria Cordina President, Malta College of Community Pharmacists, Dr. Mario Grixti, President Malta College of Family Doctors.



Lino Sghendo, UM; Dr. Doriette Soler Paediatric Neurologist; D. JK Soler General Practitioner; Michael Lawrence CMEA; Martin Micallef, Psychologist.



Dr. Doriette Soler Paediatric Neurologist; Dr. Anthony Galea Debono, Consultant Neurologist; Dr. Josanne Aquilina, Consultant Neurologist, Dr. Norbert Vella, Consultant Neurologist.



Ruth Theuma, Pharmacist; Dr. Norbert Vella, Consultant Neurologist; Mario Dimech; CMEA. Prof. Martin Brodie, Scotland.

20 February, 2010 CMEA Conference:
What is Epilepsy? - Improving our knowledge





Prof Brian Neville, Emeritus Professor of Paediatric Neurology at University College London, addressing the participants during the plenary session.



Dun Victor Grech, Director Caritas Malta; Dr. Joe Cassar, Minister for Health; Mario Dimech, CMEA; Dr. Doriette Soler, Paediatric Neurologist; Prof. Brian Neville, UK; Clarissa Captur UM.




Caroline Attard, CMEA; Sister Gezwinia Mangion, Dar tal-Providenza; Victoria Dimech, CMEA; Dr. Doriette Sole, Paediatric Neurologist; Rick O'Shea, Ireland; Anna Callus UM.






20 February, 2010. Malta National Epilepsy Conference: What is Epilepsy - Improving our Knowledge. Participants.

25 February, 2012 CMEA Conference:
Epilepsy - How do we overcome stigma

L-Epilessija - Kif negħlbu l-istigma
Epilepsy - How to overcome stigma



National Conference
organised by
Caritas Malta Epilepsy Association
Saturday, 25 February, 2012
Dolmen Resort Hotel





Joe Sammut, Caritas Malta; Mario Dimech, President CMEA; Mgr Dun Victor Grech, Director Caritas Malta; Victoria Dimech, CMEA; Marica Gabaretta Caritas Malta.



25 February, 2012. Malta National Epilepsy Conference: Epilepsy - How do we overcome stigma. Participants.



Joe Camilleri, Chairman KNPD; Dorianne Pawney, ETC; Joe Farrugia, Malta Employers Association; Joe Gerada, Foundation for Human Resources; Dr. Roselyn Borg, Lawyer; Dr. Josanne Aquilina, Consultant Neurologist; Manuel Camilleri, CMEA.



Group Photo - Sitting: Hanneke De Boer, SEIN Nederlands; Frank Portelli, CMEA:
Standing: Prof. Mike Kerr, UK; Manuel Camilleri, CMEA; Janet Mifsud, CMEA; Victoria Dimech, CMEA; Mario Dimech, CMEA; Mandy Vella, CMEA; Caroline Attard, CMEA; Adriana Soler, CMEA.

22 February, 2014 CMEA Conference:
Epilepsy is more than just seizures



The poster features logos for the Government of Malta, Caritas Malta, and the Epilepsy Association of Malta at the top. The main title is 'National Epilepsy Conference'. Below it, the Maltese text reads: 'L-EPILESSIJA MHIJIEK SEMPLIĊIMENT AĊĊESSJONIJIET', 'L-istigma fl-epilessija tikkawża', 'DYSEBILITÀ, INKONFIDENZA, ANNIWALITÀ, INKONFIDENZA', 'EVALUAZIONI, SĊIJAĊI', 'PROBLEMI TAL-KOĠNOLU', 'BIEX INTEJBU L-KWALITÀ TAL-FAJJA NEHTIEĠU'. The central image shows a diverse group of people holding signs with messages like 'L-epilessija ma tikkawża l-istigma', 'Epilepsy', 'ACCINO Għall-FAJJA tal-epilessija', and 'Epilepsy is more than just seizures'. At the bottom, it states 'Saturday 22 February 2014' and 'Doimen Resort Hotel, Malta'.

National Epilepsy Conference

L-EPILESSIJA MHIJIEK SEMPLIĊIMENT AĊĊESSJONIJIET
L-istigma fl-epilessija tikkawża
DYSEBILITÀ, INKONFIDENZA, ANNIWALITÀ, INKONFIDENZA
EVALUAZIONI, SĊIJAĊI
PROBLEMI TAL-KOĠNOLU
BIEX INTEJBU L-KWALITÀ TAL-FAJJA NEHTIEĠU

Saturday 22 February 2014
Doimen Resort Hotel, Malta



Prof. Phil Smith, Consultant Neurologist, University Hospital of Wales, Cardiff UK, addressing the participants in the plenary session.



Josette Portelli, CMEA; Frank Portelli, CMEA; Manuel Camilleri, CMEA; Zvetlana Zerafa, UM; Caroline Attard, CMEA; Victoria Dimech, CMEA.



Christine Bennett, Epilepsy Specialist Nurse, UK; Prof. Roger Ellul Micallef, UM; Prof. Phil Smith, UK, Janet Mifsud, CMEA; Anna Callus UM.



Anna Callus UM; Prof. Phil Smith, UK; Prof. Roger Ellul Micallef, UM; Hon Evarist Bartolo, Hon. Minister of Education; Mons. Karm Farrugia, Caritas Malta; Mario Dimech, CMEA; Christine Bennett, Epilepsy Specialist Nurse, UK; Clarissa Captur, UM.

15 February, 2016 CMEA Conference:
Living with epilepsy - Step by step



Living with epilepsy

STEP
by
STEP.



Tgħix bl-epilessija, pass wara pass
Living with epilepsy, step by step



National Epilepsy Conference,
13 February 2016, Dolmen Resort Hotel, Malta



UNIVERSITY OF MALTA
L-Università ta' Malta



Sue Mitchell, Epilepsy Action UK; Matthew Attard, CMEA; Giuseppe Capovilla, President Italian League Against Epilepsy; Victoria Dimech, CMEA; Frank Portelli, CMEA; HE Marie Louise Coleiro Preca, President of Malta; Leonid McKay, Director Caritas Malta; Leontine Spiteri; Trudy Kerr.



Minister for Health Hon Chris Fearne with Frank Portelli.




Prof Giuseppe di Giovanni with Dr Hana Shabbi.






Mr Anthony Buttigieg, UM with Prof Anthony Fenech, UM.

22 February, 2018 CMEA Conference:
Epilepsy - Finding Help

2018 National Epilepsy Conference
Epilepsy: Finding Help
L-Epilessija: Kif insibu l-ghajnuna



Saturday, 10th March, 2018
Dolmen Resort Hotel



Claudine Aitken, CMEA; Prof Dorothee Kasteleijn, Netherlands; Leonid McKay, Director, Caritas Malta; HE Marie Louise Coleiro Preca, President of Malta; Frank Portelli, CMEA; Matthew Attard, CMEA.



Sandro Fabri, EEG Technician; Josette Portelli, Speech Language Pathologist; Erika Taylor East, Pharmacist; Dr. Jimmy Farrugia, Consultant Paediatrician CDAU; Robin Pinkston CMEA; Sarah Fleri CMEA; Dr. Doriette Soler Consultant Neuro Paediatrician, Dr. Josanne Aquilina, Consultant Neurologist.



Caroline Attard, CMEA; Janet Mifsud, CMEA; Claudine Aitken, CMEA; Hon Dr. Michael Falzon, Minister for the Family, Children's Rights and Social Solidarity.



CMEA Organising Committee: Janet Mifsud, Frank Portelli, Manuel Camilleri, Noel Portelli, Matthew Attard, Dorothee Kasteleijn (guest speaker); Caroline Attard, Claudine Aitken.

PARTICIPATION IN INTERNATIONAL CONFERENCES AND MEETINGS

CMEA has always endeavoured to increase its international networks and gain experience from colleagues in other epilepsy associations. Representatives of CMEA have thus attended practically every single International Epilepsy Congress and most of the European Epilepsy and Society Conferences since 2001. CMEA thus gained insight about recent updates on epilepsy and its' management and networked with other organisations in order to broaden its knowledge and experience. The first conference CMEA participated in was the 2000 7th European Conference on Epilepsy and Society held in Athens, Greece. In 2001, CMEA formally became a member of IBE during the *International Epilepsy Congress* in Buenos Aires, Argentina. CMEA also had the honour to host the *9th European Conference on Epilepsy and Society* on 19 and 20 March 2004, in Malta. Over 250 participants from Malta and Europe took part in this meeting.

CMEA members have also had the opportunity to attend various training courses abroad. Matthew Attard was accepted to participate in the *Training For Success* programme in Sligo, Ireland in 2005, organised by the Institute of Technology in conjunction with Brainwave, the Irish Epilepsy Association. Matthew also had an internship with European Patient Forum in Brussels in 2017.

CMEA representatives were invited to take part in other international fora. Connie Baker represented CMEA at the WHO meeting at the launch of the WHO/ILAE/IBE campaign *Epilepsy out of the Shadows* in Geneva in 2001. Frank Portelli took part in the 2005 *European Patient Advocacy Leaders' Summit (EPALS) Partnership* in Brussels and in 2006, Victoria Dimech was invited to be one of the members of the advisory board looking into the DVD *Brainstorm* in Brussels. Mario Dimech and Frank Portelli were invited to participate in *the Technology Assessment workshop* in London UK in 2012, while Lourdes Cini and Caroline Attard

took part in the 2016 *European Patients Forum: Patient and Family Empowerment for Better Patient Safety*. In 2012, Janet Mifsud and Victoria Dimech represented IBE at the *WHO Europe 62nd Session meeting held in Malta*.

CMEA representatives were also invited to participate in various large European epilepsy scientific meetings organised in Malta. The EU funded FP6 project *EPICURE, Functional genomics and neurobiology of Epilepsy: a basis for new therapeutics*, was organised in Malta in January 2008. The FP7 EU funded project *DESIRE: Research to improve diagnosis, prevention and treatment in children with difficult to treat Epilepsy* organised one of its annual meetings in Malta in October 2017. Both had over 100 participants each from over 30 countries. EUREPA, the European Epilepsy Academy organised one of its *Train the Trainer* courses in Malta in October 2008 with over 30 participants from 20 countries. Several representatives of CMEA also participated in the patient forum during the EU funded Intensive Training Network meeting *Novel Routes for the Analysis of Epilepsy* held in Malta in May 2018 which had over 80 participants from 25 countries.

Anna Micallef participated in the *Training Initiatives for Neurology Advocates Workshop* organised by European Federation of Neurological Associations held in Champalimaud Foundation, Lisbon in April 2018 and the *Science for Advocates* organised by European Federation of Neurological Associations together with Federation of European Neuroscience Societies in Berlin in July 2018.



20 May 2000, 7th European Conference on Epilepsy and Society. Athens, Greece: Frank Portelli CMEA and Mario Dimech CMEA.



21 May 2000 7th European Conference on Epilepsy and Society. Athens, Greece: Mario Dimech, CMEA; Philip Lee, President International Bureau for Epilepsy and Janet Mifsud, CMEA.



May 2001 International Epilepsy Congress, Buenos Aires: Janet Mifsud receiving the certificate confirming full membership of CMEA to the International Bureau for Epilepsy.



May 2001 International Epilepsy Congress, Buenos Aires: Hanneke de Boer, Netherlands, Chair EREC; Doriette Soler; Janet Mifsud; Ann Little, Executive Director IBE; Carolien Morton, Netherlands; Karen Lee Donaldson, EUCARE; Phil Lee, President IBE.



Poster for the 9th European Conference on Epilepsy & Society (ECES) held in Malta in March 2004.



18-20 March 2004 9th European Conference on Epilepsy and Society, Malta: CMEA members: Lino Sghendo, Frank Portelli, Janet Mifsud, Michael Alexa, Sharon Agius, Anna Debattista, Joseph Micallef Dimech.



March 2004 9th European Conference on Epilepsy and Society: Participants at 2004 ECES conference.



March 2004 9th European Conference on Epilepsy and Society: Official reception at Presidential Palace, Valletta with HE Dr George Hyzler, Acting President of Malta, Janet Mifsud, CMEA; Philip Lee, IBE; Mario Dimech, CMEA.



March 2004 9th European Conference on Epilepsy and Society 2004 9th ECES conference: Official reception at Presidential Palace, Valletta with Dr Lawrence Gonzi, Ministry of Social Policy; HE Dr George Hyzler, Acting President of Malta; Prof Roger Ellul-Micallef, Rector University of Malta.



31 May - 2 June 2005 Brussels. European Patient Advocacy Leaders' Summit (EPALS) Partnership: Tarcisio Vella, Richmond Foundation Malta, Moira Grixti, Maltese Diabetes Association, Josephine Ellul, Socjeta Azmatici Maltin, Anna Miggiani, GSK; Frank Portelli, CMEA.



31 May - 2 June 2005 Brussels European Patient Advocacy Leaders' Summit (EPALS) Partnership: Group Photo.



September 2005 International Epilepsy Congress, Paris: Victoria Dimech, Janet Mifsud, Doriette Soler with colleagues from Turkey, Italy, Uruguay, Albania, Greece, UK, Serbia.



October 2008: FP7 EPICURE project annual meeting in Malta: Victoria Dimech, CMEA; Dr Doriette Soler, Consultant Neuropaediatrician; Suzanne Lund, President IBE, Hanneke de Boer, IBE.



16 October 2008 11th European Conference on Epilepsy and Society, Marseilles, France: Joseph Camilleri, CMEA; Sharon Agius, CMEA; Mario Dimech, CMEA; Victoria Dimech, CMEA and Frank Portelli, CMEA.



October 2008: EUREPA Train the Training meeting in Malta: Verena Hézser-v.Wehrs, Janet Mifsud, Prof Peter Wolf.



June 2009 International Epilepsy Congress, Budapest Hungary: Janet Mifsud and Victoria Dimech in front of CMEA poster.



2009 Training for Success Project, Sligo, Ireland: Matthew Attard participating in the Debating Society.



2010 Participation in Training for Success, Sligo, Ireland: Matthew Attard (centre) enjoying a snorkelling experience.



12 th Epilepsy and Society Conference Porto 2010: Mario Dimech, CMEA; Victoria Dimech, CMEA; Joseph Camilleri, CMEA; WHO representative; Tarun Dua, WHO; Mandy Vella, CMEA; Manuel Camilleri, CMEA; Janet Mifsud, CMEA and Frank Portelli, CMEA.



15 February 2011 European Epilepsy Day, Strasbourg France: Victoria Dimech, CMEA; Janet Mifsud, CMEA; Nico Moshe, President ILAE; John Dalli, EU Commissioner for Health; Mike Glynn, President IBE; Emilio Perucca, Secretary ILAE and Ann Little, Executive Director, IBE.



15 February 2011 European Epilepsy Day, Strasbourg France: Janet Mifsud, CMEA; David Casa Malta MEP; Victoria Dimech, CMEA; Gay Mitchell, Irish MEP.



August 2011 International Epilepsy Congress, August, Rome Italy: Victoria Dimech; Mike Glynn, President IBE; Aisling Farrell (IBE); Janet Mifsud - presentation of Teachers Pack.



August 2011 International Epilepsy Congress, August, Rome Italy: Janet Mifsud and Victoria Dimech in front of CMEA poster.



10-13 September WHO Europe 62nd Session meeting in Malta: Victoria Dimech, Janet Mifsud meeting Zsuzsanna Jakab, WHO Regional Director for Europe at Verdala Palace.



24 - 26 September 2012 Health Technology Assessment Workshop
London School of Economics: Mario Dimech, CMEA; Panos Kavanos,
Main Tutor; Frank Portelli CMEA.



24 - 26 September 2012 Health Technology Assessment Workshop
London School of Economics: participants.



2013 Epilepsy Forum Dublin: Frank Portelli.



29 August 2013 13th European Epilepsy and Society Conference,
Ljubljana, Slovenia: Janet Mifsud, CMEA; Philip Lee, Epilepsy Action
UK; Hanneke De Boer, SEIN Netherlands; Frank Portelli, CMEA;
Mr Mike Glynn, President, IBE; Victoria Dimech, CMEA and Mario
Dimech, CMEA.



8 September 2015 International Epilepsy Congress, Istanbul Turkey: Matthew Attard and Janet Mifsud.



8 September 2015 International Epilepsy Congress, Istanbul, Turkey: Robert Cole (Australia, Treasurer, IBE); Hassan (Morocco), Thanos Covanis (Greece, President IBE); Micheal Alexa (Austria); Matthew Attard (Malta).



September 2016 International Epilepsy Congress, Prague: Janet Mifsud with tribute to Mario and Victoria Dimech.



16 September 2016 International Epilepsy Congress, Prague, Czech Republic: Manuel Camilleri, Lourdes Cini, Shirley Maxwell (Scotland), Caroline Attard, Philp Lee, Epilepsy Action UK, Frank Portelli.



3 September 2017: International Epilepsy Congress Barcelona, Spain:
Janet Mifsud and Caroline Attard.



2017 Internship with European Patient Forum, Brussels: Matthew Attard.



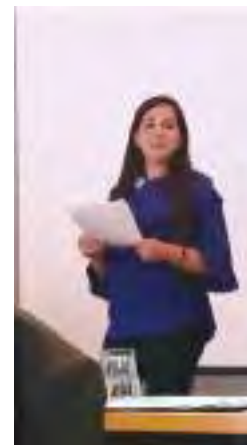
August 2018, European Congress on Epileptology, Vienna Austria:
Anna Micallef and Janet Mifsud.



August 2018: European Epileptology Congress, Vienna Austria:
Dr Stephen Attard, Malta; Prof Charlotte Dravet (France); Dr Anna Micallef (CMEA).



May 2018, Novel Routes for the Analysis of Epilepsy ITN network meeting in Malta: Frank Portelli, Anna Micallef, Caroline Attard, Robin Pinkston, Prof Frank Kirchhoff, Germany; Prof Matthew Walker (UCL, UK), colleagues from Epilepsy Action UK.



July 2018, Science for Advocates organised by European Federation of Neurological Associations together with Federation of European Neuroscience Societies: Dr Anna Micallef.



June 2019, International Epilepsy Congress, Bangkok Thailand: Janet Mifsud being given the International Ambassador for Epilepsy Award by Prof Martin Brodie, President IBE and Prof Sam Wiebe, President ILAE.

PARTICIPATION IN PROJECTS AND RESEARCH

As a 100% voluntary organisation, CMEA has sought funds from various sources and has participated in national and EU funded projects. These projects have enhanced CMEA's administrative and strategic capacity. They have also permitted CMEA to widen its national and international networks and its lobbying and outreach services.

Moreover, they led to the development of knowledge and expertise needed in the preparation of audio-visual and printed material. The participation in national projects was funded by KNPD and subsequently CRPD, while participation in EU projects was greatly facilitated through the assistance of European Union Programmes Agency. Young persons also had the opportunity to participate in the Nave Italia experience organised by Bambin Gesu Hospital in Rome, in 2014.

CMEA also continuously encourages and supports research on epilepsy in Malta. Its members have contributed to research carried out by University of Malta students in the Department of Clinical Pharmacology and Therapeutics, Department of Psychology, Department of Sociology and Department of Nursing on adherence of medicines in epilepsy, stress in epilepsy, pharmacoepidemiology of epilepsy in Malta among others.

This research has led to an increase in more information on the acute and long-term needs of persons with epilepsy in Malta and has also addressed some of the gaps in the delivery of services.

National Funded Projects

PEKTUR 2000 L-Epilepsija - Tista Tgħix Hġajja Normal

This was the first funded project which CMEA obtained, with funds provided by the former National Commission for Persons with Disability (KNPD). These funds led to the

translation and development of a video in Maltese about *Living a normal life with epilepsy*. It also included experiences of persons in Malta with epilepsy and information about CMEA. This video provided to be vital in complementing the delivery of subsequent training sessions to teachers, police officers and other audiences.

PEKTUR 2017: Epilepsy: reducing stigma by training service providers in Malta

The PEKTUR project aimed to develop new competencies through the training of service providers who come in regular contact with persons with epilepsy. This project was organised in collaboration with University of Malta and Epilepsy Action (UK).

The project aimed at enhancing opportunities, increasing social inclusion and reducing stigma for persons with epilepsy, by improving knowledge and skills of service providers. It led to the development of a training course and a tool kit in English and Maltese for training service providers in Malta through on-site visits in Malta and in UK.

Malta Arts Council "Creative Communities" MOSIACS grant

In 2018, desiring to see more cooperation and collaboration between NGOs that work with children with disabilities, CMEA, specifically Robin Pinkston and Caroline Attard worked on the Inspire Mosaic Project, funded by the Malta Arts Council "Creative Communities" grant that allowed them to bring in professional artist Mary Portelli from Gozo Mosaics.

This project involved the collection of recycled ceramics and tiles, preparing them, and producing seven lovely mosaics, and thus establishing a sense of creative community among the children from the different NGOs. The mosaics

were displayed together at the Action Planet exhibition in Spazzju Kreattiv in February/ March 2018, and the seven pieces were then donated to the participating organizations including Caritas Malta.

EU Youth project: Epilepsy Youth in Europe EYiE 2001- 2005

This EU project was co-ordinated by Prof John Chaplin in Sweden and funded the exchange of young persons with epilepsy from several countries including Iceland, Finland, Sweden, Ireland, Germany and Malta. The first meeting CMEA participated in was held in **Bethel Epilepsy Centre, Bielefeld Germany** in August 2001.

It was attended by two representatives from the CMEA youth section. During their stay, these two youths worked with other young persons from all over Europe, working on IT projects, socializing, participating in cultural activities and also sharing their experiences with respect to epilepsy and how they cope with this condition in their respective countries.

The **EYiE project** came to Malta in 2003. The Youth Section of the Caritas Malta Epilepsy Association in collaboration with the EYiE (Epilepsy Youth in Europe) and IBE (International Bureau for Epilepsy) obtained EU funding to host a Youth Exchange Project. **EYiE of Horus** was held in Malta from 31 August to 8 September 2003.

It included the participation of 40 youths from nine different countries meeting in Malta in a very friendly and educational atmosphere. It explored what it is like to be a youth with epilepsy in Europe, what it means to European society at large, and how to tackle the multicultural social exclusion these youths often experience. The workshop included a meeting with HE President of Malta Prof Guido

de Marco in the President Palace in Valletta.

Three Maltese youths, members of CMEA, also had the opportunity to participate in the **EYiE Epilepsy Youth In Europe** meeting in Sligo, Ireland from 8 to 10 August 2005. During this event, 30 youths with epilepsy learnt how to submit grant proposals and analysed how epilepsy affected various social aspects of their daily life.

EU Grundtvig Project: Curricular Education for Professionals Allied To Medicine (PAMS) working in Epilepsy 2006-2008

CMEA also co-ordinated an EU funded Grundtvig project together with Bethel Epilepsy Centre in Germany, European Epilepsy Academy (EUREPA) and Budapest Bethel Epilepsy Centre Foundation (BBEC) in Hungary.

The aim of this learning partnership was to create a curriculum in epilepsy for professionals allied to medicine, by mobilising resources and improving competence. This project thus aimed to provide European professionals allied to medicine (PAMs) with tools and methods to improve knowledge and expertise for the prevention, diagnosis and treatment in epileptology and thus help to improve the quality of care to patients with epilepsy. Meetings were held in Malta, Budapest, Berlin and Bethel Epilepsy Centre, Bielefeld, Germany.

EU Leonardo Project: The Promotion of a Good Transition of Disabled Young Persons from School to the World of Work and Adult Life (MOTION) 2013 - 2015

CMEA actively participated in an EU Leonardo project MOTION. This project aimed to increase the vocational skills and abilities of students with special needs to enter the world of work.

This project included the participation of five institutions from Turkey (3), Malta (1), Germany (1). With this project, all the participating institutions had a chance to transfer knowledge and experience related with individuals with special needs through mobilities, workshops, and seminars. This project was co-ordinated by Mamak Özkent Akbilek Special Education Vocational Training Center in Ankara, Turkey; Mamak Guidance and Research Center, Taşköprü Ticaret Odası in Kастhamonu and the C Hamburg Consulting Gbr in Gelsenkierchen, Germany.

EU Erasmus+ project: EPIPICTO: A pictorial guide for adults with epilepsy 2017-2019

CMEA has also coordinated a very successful EU Erasmus+ project called EPIPICTO <http://epipicto.eu>, A Pictorial Guide for Persons with Epilepsy. The project developed a pictorial guide on epilepsy which can aid in overcoming language barriers and literacy issues.

It is envisaged that this guide will also help adults with epilepsy to improve their health-seeking behaviour, contribute to an improved quality of life and in turn contribute towards a reduction of stigma. The guide has been prepared in 6 languages to date.

The project brought together five European epilepsy organisations Epilepsie Dachverband Österreich Austria; Interessenvereinigung für Anfalls Kranke in Köln e.v., Germany; Caritas Malta Epilepsy Association, Malta; Stichting Epilepsie Instellingen Nederland (SEIN), and Epilepsy Connections, Scotland. It included over four management meetings and four multiplier events in all the partner countries, as well as over 60 dissemination events to an estimated audience of over 10,000 persons.



Pektur and CRPD logo.



18 July 2017 PEKTUR Epilepsy Toolkit project: visit to the UK Epilepsy Society premises, Chalfont St Peter: Manuel Camilleri, Robin Pinkston, Frank Portelli.



13 October 2018: PEKTUR training by Epilepsy Action UK: Manuel Camilleri, Robin Pinkston, Frank Portelli, Dyfed Foulkes, Epilepsy Action UK, Anna Micallef, Noel Portelli, Caroline Attard, Janet Mifsud.



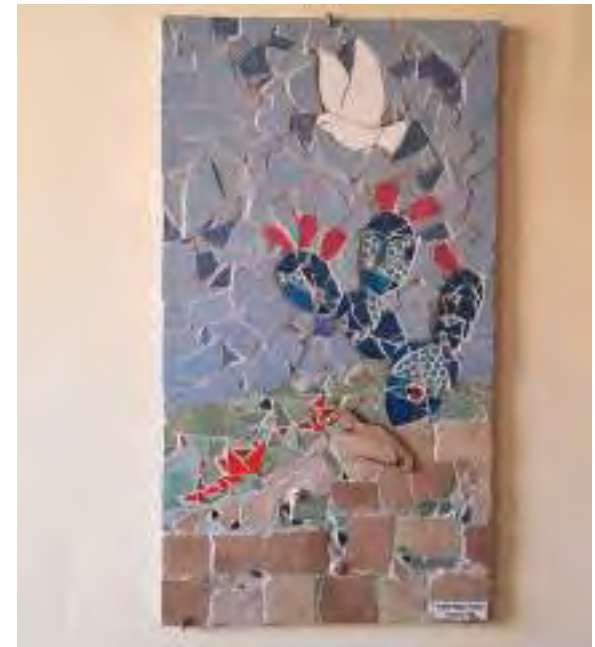
7 February 2019: Presentation of Epilepsy Toolkit to Commissioner CRPD: Anna Micallef, Oliver Scicluna, Rhoda Garland, Frank Portelli, Kevin Attard and Robin Pinkston.



Mosaic Project Logo.



March 2018, The Maltese Countryside, Panel 7; CMEA funded by a Malta Arts Council "Creative Communities" grant: Robin Pinkston and participants.



March 2018, Mosaic Project: Led by Robin Pinkston.



September 2003: 2002 Epilepsy Youth in Europe project: logo.



2 September 2003 EU Youth Epilepsy Youth in Europe (EYiE) Workshop: 39 participants from 12 European countries attended the EYiE project meeting on a courtesy visit to HE the President of Malta Prof. Guido DeMarco at the Palace, Valletta.



1 September 2003: EU Youth Epilepsy Youth in Europe (EYiE) Workshop: Maltese CMEA participants.



2005 Epilepsy Youth in Europe exchange, Ireland: The Maltese participants included Matthew Attard, Joe Camilleri and Sharon Agius.



EU Grundtvig Project: Curricular Education For Professionals Allied To Medicine (PAMS) working in Epilepsy: logo.



January 2006 EU Grundtvig Project: Curricular Education For Professionals Allied To Medicine (PAMS) working in Epilepsy, project meeting in Berlin Germany: Victoria Dimech, Janet Mifsud, Margarete Pfaflin and colleagues from the German IBE Chapter.



March 2007 EU Grundtvig Project: Curricular Education For Professionals Allied To Medicine (PAMS) working in Epilepsy, project meeting in Bethel Epilepsy Centre, Bielefeld, Germany: *Back Row:* Mr. Mario Dimech, Malta, Ms. Victoria Dimech, Malta; Ms. Petra Novotny, Germany; Dr Janet Mifsud, Malta *Front row:* Dr Csaba Borbély Hungary; Dr Judit Bekes, Hungary; Dr Margret Pfaefflin; Ms. Verena Hezser-v.Wehrs, Germany.



26 April 2007 EU Grundtvig Project: Curricular Education For Professionals Allied To Medicine (PAMS) working in Epilepsy, Malta: *Sitting* - Mario Dimech, CMEA; Victoria Dimech, CMEA; Frank Portelli, CMEA; Sharon Agius, CMEA; Clarissa Captur, UoM; Rose Caruana, translator. *Standing* - Lino Sghendo, UoM; Manuel Camilleri, CMEA; Verena Hezer vWehr, Bethel Epilepsy Centre, Germany; Judit Bekes, Hungary; Samantha Pace, CMEA; Germany; Janet Mifsud, CMEA; Petra Novotny, Bethel Epilepsy Centre, Francis Ripard, nursing manager.



EU Leonardo MOTION project: The Promotion of a Good Transition of Disabled Young Persons from School to the World of Work and Adult Life: Logo.



March 2013 EU Leonardo Motion Project. Victoria Dimech, CMEA and Mario Dimech, CMEA (centre) visiting a special school in Ankara, Turkey.



October 2013 EU Leonardo MOTION project: The Promotion of a Good Transition of Disabled Young Persons from School to the World of Work and Adult Life. Meeting in Gelsenkirchen, Germany: Manuel Camillieri and Caroline Attard with Turkish Colleagues.



October 2013 EU Leonardo MOTION project: The Promotion of a Good Transition of Disabled Young Persons from School to the World of Work and Adult Life, Visit to Bethel Epilepsy Centre. Bielefeld: Manuel Camillieri, Verena Hezser-v.Wehrs , Caroline Attard, Margarete Pfafflin.



March 2014 EU Leonardo MOTION project: The Promotion of a Good Transition of Disabled Young Persons from School to the World of Work and Adult Life, Malta Meeting: Visit of MOTION participants to HE Ayşe Sezgin, Ambassador of Turkey to Malta in her residence in Floriana.



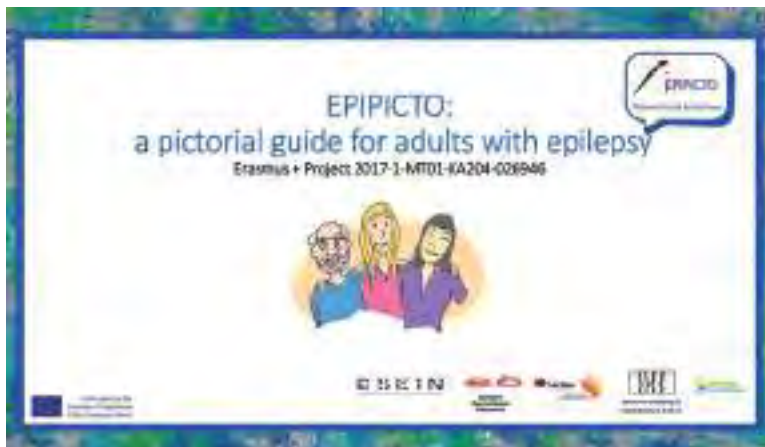
March 2014 EU Leonardo MOTION project: The Promotion of a Good Transition of Disabled Young Persons from School to the World of Work and Adult Life, Malta Meeting: Group photo at MCAST - Paola.



March 2014 MOTION project in Malta: Awarding of Certificates with Matthew Attard and Mario Dimech.



May 2014, Motion final meeting, Ankara, Turkey: Mathew Attard, Manuel Camilleri, Caroline Attard, Adriana Caruana Soler, Frank Portelli, Mario Dimech.



Epipicto Logo.



November 2017 EPIPICTO Kick off meeting, Malta: Noel Porelli, Robin Pinkston, Micheal Alexa (Austria), Caroline Morton (Netherlands), Shirley Maxwell (Scotland), Thomas Porschen (Germany), Janet Mifsud, Caroline Attard.



March 2018 EPIPICTO project meeting, Glasgow, Scotland: Management Meeting: Janet Mifsud, Caroline Morton, Netherlands; Thomas Porschen (Germany); Michael Alexa (Austria); Shirley Maxwell (Scotland).



March 2018 EPIPICTO project meeting, Glasgow, Scotland: Visit to Epilepsy Connections Office: Michael Alexa (Austria); Thomas Porschen (Germany); Shirley Maxwell (Scotland); Caroline Morton, Netherlands; Janet Mifsud, Malta.



September 2019 EPIPICTO final management meeting, San Anton Palace Malta: Michael Alexa (Austria); Jean William Barzilay (Netherlands); Shirley Maxwell (Scotland); Thomas Porschen (Germany); Frank Portelli; Janet Mifsud, Claudine Aitken.



September 2019 EPIPICTO final management meeting, San Anton Palace Malta: Fr Charles Cordina; Thomas Porschen (Germany); Jean William Barzilay (Netherlands); Frank Portelli; Hon Minister Dr Michael Falzon; Janet Mifsud; Shirley Maxwell (Scotland); Michael Alexa (Austria).



HE President of Malta George Vella addressing participants in the final EPIPICTO meeting September 2019. Photo: DOI - Pierre Sammut.



Shirley Maxwell from Scotland addressing participants in the final EPIPICTO meeting September 2019.

ABBREVIATIONS

- CRPD - Commissioner for the Rights of Persons with Disabilities
- ETC - Employment and Training Corporation
- IBE - International Bureau for Epilepsy
- ILAE - International League Against Epilepsy
- KNPD - National Commission for Persons with Disability
- UM - University of Malta
- MEA - Malta Employers Association
- WHO - World Health Organisation

CONTACT US

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Instagram: [cmea_malta_epilepsy](https://www.instagram.com/cmea_malta_epilepsy)

website: <https://www.caritasmalta.org/epilepsy>

CMEA Committee

The present CMEA committee members are:

President	Mr. Frank Portelli
Vice President	Dr. Anna Micallef
Secretary	Ms. Robin Pinkston
Treasurer	Ms. Caroline Attard
P.R.	Mr. Matthew Attard
Facebook & Youths	Ms. Adriana Caruana Soler
Member	Mr. Manuel Camilleri
	Ms. Claudine Aitken
	Mr. Kevin Attard
Psychotherapist	Ms. Verena Portelli
Advisor	Prof. Janet Mifsud
Newsletter Editors	Mr. Noel Portelli & Mr. Kevin Attard

Would you like to join us?

CMEA has a mailing list where we send out information about meetings, newsletters, and other useful information. If you wish to subscribe to our mailing list just send a blank e-mail with the word **Subscribe** in the subject field to cmeamailinglist@gmail.com. Your e-mail address will be kept confidential and will not be used for any other purpose. This e-mail address account is not monitored, e-mails sent to this address will not be read or replied to.

No one knows what
changes, big or
small,
lie ahead.
One thing is certain,
our journey
is not over.

“The journey is long and painful but rewarding”

Mgr. Victor Grech