

photo by Noel Portelli



Marzu 2021 - Nru. 61

Palazzo Ferreria

lit up in purple for International Epilepsy Day -Monday, 8th February 2021 Caritas Malta Epilepsy Association 5 Lion Street, Floriana, FRN 1514 Tel: +356 25906600 V/O 1396 maltaepilepsy@gmail.com www.caritasmalta.org/epilepsy



Caritas Malta Epilepsy Association

A better life for people with epilepsy

Kontenut

Members' Meeting Kelmtejn mill-President When Sparks Fly Covid-19 vaccines & People with epilepsy International Epilepsy Day activities & photos

Membri tal-Kumitat 202

NEXT MEMBERS' MEETING

Sessions will be held on zoom until further notice and start at 6pm. Send an email to maltaepilepsy@ gmail.com and you will receive the login details accordingly.



SAVE THESE DATES

President Mr. Frank Portelli

Viċi President Dr. Anna Micallef

Segretarja Ms. Claudine Aitken

Teżoriera Ms. Caroline Attard

P.R. Ms. Robin Pinkston

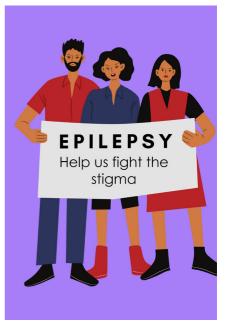
Assistent P.R. Mr. Matthew Attard

Facebook u Żagħżagħ Ms. Adriana Caruana Soler

Membru Mr. Manuel Camilleri

Konsulenta Prof. Janet Mifsud

Psychotherapist: Verena Portelli



Għeżież membri,

L-ewwelnett nispera li lkoll tinsabu tajbin u nerĝa nappellalkom sabiex isseĝwu l-istruzzjonijiet u d-direttivi talministeru tas-saĥħa. Nisperaw u nittamaw li l-affarijiet imorru aħjar issa li waslet it-tilqima.

Ma nistax ma niftaħx din l-introduzzjoni u ma nsemmix il-Jum Internazzjonali tal Epilessija. Dan l-avveniment isehh kull sena fit-tieni tnejn ta' Frar u dan jigi ċċelebrat f'din id-data mhux b'kumbinazzjoni izda ghax tkun viċin il-jum ta' San Valentinu. San Valentinu huwa l-qaddis patrun tal-epilessija. Jgħidu li San Valentinu kien fejjaq xi nies minn din il-kundizzjoni.

L-attivitajiet għal din il-ġurnata bdew minn diversi jiem qabel. Dawn l-attivitajiet saru possibbli bil-għajnuna tal-Universita' tal Malta u Uffiċċju tal-Komunikazzjoni bdew ix-xogħol minn 15 il-ġurnata qabel, u nista' ngħhid mingħajr tlaqqliq li x-xogħol li għamlu kien verament professjonali.

Malta ħadet sehem attiv fl-inizjattiva globali tal-Jum Internazzjonali tal-Epilessija, fit-8 ta' Frar 2021. Ir-rwol tas-CMEA fil-kampanja globali "Raġġ ta' dawl għall-epilessija!", kellha tenfasizza d-diffikultajiet varji ffaċċjati minn persuni bl-epilessija, kemm f'Malta kif ukoll mad-dinja kollha.

Caritas Malta Epilepsy Association ingħaqdet mal-Università ta' Malta biex iżżid l-għarfien u b'hekk tnaqqas I-istigma. L-għanijiet ta' din il-kampanja kienu tnejn. L-ewwel nett kellha l-għan li tagħti mportanza l-ħajja ta' persuni bl-epilessija u l-familjari tagħhom. It-tieni, nagħtu prominenza wkoll fuq it-tfassil ta' attivitajiet permezz tar-rwol edukattiv u ta' riċerka li twettaq l-Università ta' Malta fil-qasam tal-epilessija, u l-kollaborazzjoni mal-Caritas Malta u l-Caritas Malta Epilepsy Association f'dan ir-rigward.

L-Università organizzat kampanja ta' għarfien pubbliku fuq il-midja fuq perijodu ta' ġimagħtejn fuq Facebook, Instagram, Campus FM u fuq il-websajt tagħha. Permezz ta' din is-sħubija b'saħħitha li ilha għall żmien twil, CMEA ġiet mistiedna għal diversi programmi tat-TV u tar-radju kemm fuq stazzjonijiet pubbliċi kif ukoll privati. Ilkampanja nidiet 2 vidjows iffilmjati, prodotti u editjati b'mod espert mit-tim tal-Midja tal-Università ta' Malta.

Kien hemm bosta artikli ppubblikati fuq gazzetti lokali. Fost dawn kien hemm editorjal iddedikat għall-Epilessija u x-xogħol magħmul mis-CMEA, artiklu miktub mill-Prof. Janet Mifsud, it-tielet wieħed mil-Prof. Janet Mifsud u Claudine Marika Aitken bħala ko-awturi u artiklu mill-Ministru għall-Inklużjoni u l-Kwalità tal-Ħajja.

L-attivitajiet laħqu l-qofol tagħhom bil-Caritas Malta Epilepsy Association tingħaqad, għall-ewwel darba, malinizjattiva globali bid-dawl vjola fuq ħames binjiet Maltin; Berġa ta' Kastilja, Palazzo Castellania, Palazzo Ferreria, Cavalier House u Maison Demandols fis-6, is-7 u t-8 ta' Frar. Dan sar possibbli permezz tal-appoġġ tal-Uffiċċju tal-Prim Ministru, l-Uffiċċju tad-Deputat Prim Ministru u l-Ministeru għas-Saħħa, il-Ministeru għall-Ġustizzja Soċjali u Solidarjetà, il-Familja u d-Drittijiet tat-Tfal, il-Ministeru għall-Inklużjoni u l-Kwalità tal-Ħajja u il-Ministeru għall-Finanzi u l-Impjiegi, rispettivament. Xi kunsilli lokali ppubblikaw posters "Raġġ ta' dawl għall-epilessija!" u informazzjoni fuq il-websajts tagħhom jew il-paġni tal-Facebook u mill-inqas kunsill lokali wieħed ingħaqad malinizjattiva. Pereżempju, il-Kunsill Lokali ta' Pembroke xegħel funtana. Is-sit verament popolari 'People of Malta' wkoll tagħtna daqqa' t'id f'din il-ġurnata billi ppubblikat artiklu verament intersanti ta' membru tal-kumitat tagħna, Manuel Camilleri, li f'dan l-artiklu semma' wkoll li dik il-ġurnata kienet il-jum internazzjonali tal-epilessija. Manuel semma' wkoll s-siti kollha fil-belt li nxtegħlu vjola.

II-kampanja nidiet is-sit Instagram tal-Assoċjazzjoni. CMEA innutat żieda ta' "likes u views" fuq il-midja soċjali ta' Facebook tagħha. Numru ta' persuni kkuntattjaw lill-Assoċjazzjoni għal aktar informazzjoni u appoġġ u b'mod ġenerali kienet kampanja eċċellenti.

CMEA hija ħerqana biex tipparteċipa mill-ġdid fil-kampanja tas-sena d-dieħla u tittama li jissieħbu aktar entitajiet. Dan kollu kien possibbli għax ħdimna bħala tim wieħed, u jien ninsab kburi li nifforma parti minn dan it-tim.

Frank

Zoom Members' Meeting - Friday, 12th March 2021-6pm



WHEN SPARKS

A Free Webinar by Zoom moderated by Dr. Anna Micallef

To join send an email to maltaepilepsy@gmail.com and you will receive the login details.



Dr. Anna Micallef is a general practitioner. She graduated from the University of Malta in 2015 and spent two years working at Mater Dei Hospital. She then started the training program for Specialists in Family Medicine which she has just completed. During the members' meeting on the 12th of March Dr. Micallef will talk about "When Sparks Fly". A general overview of epilepsy from the medical point of view will be given. Epilepsy and the different types of seizures will be explained in very simple terms. The session will of course be an interactive one and questions will be addressed.

It-tabiba Anna Micallef hija tabiba talfamilja. Hija gradwat mill-Università ta' Malta fl-2015 u għamlet sentein taħdem fl-Isptar Mater Dei. Wara bdiet il-programm ta' taħriġ għall-Ispeċjalisti fil-Medicina tal-Familja li għadha kemm temmet. Wagt il-laggha tal-membri fit-12 ta' Marzu it-tabiba Micallef se titkellem dwar "When Sparks Fly". Hi beħsiebha titkellem fug I-epilessija mill-aspett mediku. L-epilessija u t-tipi differenti ta' accessioniiiet se iidu spiedati f'termini semplici hafna. Is-sessjoni naturalment tkun waħda interattiva u l-mistoqsiiiet iidu indirizzati.

IMPORTANT NOTICE





IBE and ILAE Joint Statement on COVID-19 vaccines and people with epilepsy

Vaccines against COVID19 are currently being approved and becoming available.

There is currently no evidence to suggest that having epilepsy is specifically associated with a higher risk of side effects from a COVID-19 vaccine. For people with epilepsy, the risk of COVID-19 infection and potential complications far outweighs the risk of side effects from a COVID-19 vaccine. As with other vaccines however, a fever can develop after a COVID-19 vaccination. This could lower the seizure threshold in some people. Antipyretics (e.g. paracetamol/acetaminophen) taken regularly for 48 hours after the vaccination (or for the duration of fever) will minimize this risk.

Before you receive a COVID-19 vaccine, make sure to let your vaccination provider know that you have epilepsy, as well as any other important medical information, such as:

- Allergies, especially an allergy to any ingredient in the vaccine
- Allergic reactions to prior vaccines (e.g. flu vaccine)
- Current or recent fever or infection
- All medications you are taking, especially medications that suppress the immune system (e.g. immunomodulatory or immunosuppressive medicines) or anticoagulants.
- If you are pregnant or nursing, or plan to become pregnant

As with any vaccine, you should not receive the COVID-19 vaccine if you are allergic to any of its ingredients. You should not receive a second dose if you had an allergic reaction to the first dose.

If you already received the COVID-19 vaccine, it is important to continue wearing a mask and social distance. The current vaccines reduce your risk of getting sick from COVID-19 by up to 90%, depending on the vaccine, but vaccinated people may still be able to spread COVID-19 to others without knowing they are carrying it.



CMEA Activities for International Epilepsy Day 2021

TV, Radio, Press and Social Media Events related to International Epilepsy Day			
	Date	Event	Details
1.	20 January to 8 February 2021	Numerous University of Malta - activities on Facebook, Instagram and You tube videos	https://www.youtube.com/ watch?v=TXR73X1PNOY&t=8s; https://www. facebook.com/Epilepsy.malta.association/ videos/459837115023658; https://www.facebook. com/universityofmalta/photos/pcb.39567980209 99586/3956797860999602/
2.	15 January 2021 and 10 February 2021	Interviews on One TV News	One TV
3.	27 January 2021	Meeting with Minister Julia Farrugia Portelli	Minister for Inclusion and Social Wellbeing
4.	2 February 2021 and 8 February 2021	Interview on Kikkra Te	Net TV
5.	4 February 2021	Interview on Telefonata I'Bogħod	Net Radio
6.	4 February 2021	Interview on Illum ma' Steph	TVM
7.	5 February 2021	Interview on Campus FM Breakfast	University Campus FM
8.	6 to 8 February 2021	 Lighting in purple of five Maltese buildings in Valletta: Auberge de Castille, Office of Prime Minister Palazzo Castellania, Office of the Deputy Prime Minister and Ministry for Health Palazzo Ferreria, Ministry for Social Justice and Solidarity, the Family and Children's Rights Cavalier House, Ministry for the Inclusion and Social Wellbeing Maison Demandols, Ministry for Finance and Employment 	
9.	8 February 2021	Interview with FB page: <i>People</i> of Malta which has over 80,000 followers	https://www.facebook.com/thepeopleofmalta/ posts/3198784666889669
10.	8 February 2021	Let's shine a light on epilepsy	Article on Times of Malta newspaper
11.	8 February 2021	#EpilepsyDay 2021: shining a light for more understanding and awareness	Article on The Malta Independent newspaper
12.	8 February 2021	Interview on TVAM	TVM
13.	8 February 2021	Interview on Espresso	One TV
14.	8 February 2021	Interview on Popolin TV	TVM
15.	16 February 2021	Interview on Newsline with Joe Dimech	Radio Malta 93.7FM

In-Nazzjon It-Tnejn, 8 ta' Frar, 2021

EDITORJAL U ITTRI LILL-EDITUR

Raġġ ta' dawl għall-epilessija

Jekk illum - u fil-jumejn li għaddew - ma' nżul ix-xemx tinnota lbinjiet pubblići ewlenin tal-Belt Valletta u postijiet ohra dominati millkulur vjola tahsibx li din kumbinazzjoni minghajr tifsira. Illum it-Tnejn id-dinja kollha, inkluż Malta, tfakkar il-Jum Internazzjonali tal-Epilessija, li hi waħda mill-kundizzjonijiet newroloģići kronići u prevalenti li taffettwa persuni irrispettivament mill-istatus socjali, issess u l-età tagħhom.

Kundizzjoni li għadha ģģorr stigma

Hu magħruf li l-epilessija - skont l-Organizzazzjoni Dinjija tas-Saħħa - taffettwa ftit inqas minn wiehed fil-mija tal-popolazzjoni tad-dinja, jigifieri madwar 50 miljun persuna. Ifisser ukoll li f'Malta jbatu minn din il-kundizzjoni madwar 4,000 persuna. Proprju minhabba l-fatt li din hi kundizzjoni meqjusa bhala 'mohbija', jista' jkollha effetti negattivi fuq il-hajja ta' dawk milquta u ta' dawk l-aktar grib taghhom.

Sfortunatament l-epilessija hi waħda minn dawk il-kundizzjonijiet li, kellna kemm kellna edukazzjoni u għarfien dwarhom, għadhomiġorru magħhom ċerta stigma. Sitwazzjoni li żżid mat-tbatijiet li jgħaddu minnhom dawk milquta.

Kontribut siewi mill-Caritas Malta Epilepsy Association

F'dan is-sens ma nistgħux ma nirrikonoxxux il-kontribut kbir ta' organizzazzjonijiet bhal Caritas Malta li fi hdanha, sa mill-1996, waqqfet organizzazzjoni volontarja - il-Caritas Malta Epilepsy Association proprju biex tiggieled din l-istigma u tghin mill-ahjar li tista' lill-persuni involuti u anki lil dawk gribhom. Il-viżjoni tal-assocjazzjoni fil-fatt hi 'Hajja ahjar ghal nies bl-epilessija' u l-assocjazzjoni ģiet reģistrata bhala organizzazzioni volontaria mhux governattiva fl-2017. L-ghanijiet tagħha jinkludu li jiżdied l-għarfien ta' din il-kundizzjoni f'Malta, li ttejjeb il-kura tas-saħħa għal persuni bl-epilessija, u li toffri appoģģ prattiku lil persuni bl-epilessija f'kull bżonn li jista' jkollhom.F'dan ir-rigward, is-CMEA hi involuta hafna fil-kisba ta' dan billi tuża listrateģiji li ģejjin:

· Edukazzjoni u tahrig: tipprovdi tahrig lil bosta entitajiet: bhal edukaturi, LSEs u skejjel, Agenzija Sapport, ufficjali tal-Pulizija, ħaddiema socjali u professjonisti tal-kura tas-saħħa li jaħdmu f'diversi setturi

· Lobbying u komunikazzjoni: fuq il-midja, b'diversi partijiet interessati biex tiģi zgurata kwalità ta' hajja ahjar u l-provvediment ta' kura tas-saħħa u servizzi soċjali aħjar għall-persuni kollha bl-epilessija u l-carers u l-familji taghhom.

Dawl vjola ghal aktar interess u gharfien

Din is-sena l-Jum Internazzjonali tal-Epilessija 2021 - imfakkar illum it-Tnejn - qed jara numru ta' postijiet familjari u bini famuż madwar iddinja bhall-Kolossew f'Ruma u t-Torri Eiffel f'Parigijinxteghlu vjola biex jimmarkaw il-gurnata. Caritas Malta Epilepsy Association inghaqdet ma'din l-inizjattiva globali bid-dawl vjola fuq binjiet kbar u famużi Maltin. L-assocjazzjoni nghaqdet ukoll mal-Università ta' Malta biex iżżid l-gharfien dwar l-epilessija. L-Università fil-fatt qed torganizza kampanja ta' għarfien pubbliku biex tenfasizza l-ħajja ta' persuni bl-epilessija u l-maħbubin tagħhom. Din il-kampanja se sservi wkoll bhala ghodda edukattiva bil-ghan li tnaqqas l-istigma.

Boghod mill-preģudizzjoni li ģģib l-istigma

Id-dawl vjola ta' dawn il-jiem fuq il-binjiet taghna jwasslilna messagg biex ninfurmaw ruhna aktar dwar kundizzjonijiet invizibbli bhall-epilessija. Ghax meta ninfurmaw ruhna, inkunu f'qaghda li nghinu aktar lil min ghaddej minn din il-kundizzjoni. Nghinuhom jgħixu ħajja aħjar. Bogħod mill-preģudizzji tal-misħuta stigma, li għax ma taghmilx sens, ma twassal imkien.



In-Nazzjon It-Tnejn, 8 ta' Frar, 2021

Illum jitfakkar Jum I-Epilessija

Illum it-Tnejn Malta tinghaqad mal-kumplament tad-dinja biex tfakkar il-Jum Internazzjonali tal-Epilessija.

L-Epilessija hi waħda mill-aktar kundizzjonijiet newrologiċi kronići u prevalenti li taffettwa persuni irrispettivament millistatus socijali, is-sess u l-età tagħhom. Hu stmat li f'Malta hawn 4,000 persuna li ghandhom din il-kundizzjoni.

Biex jigi mfakkar dan il-jum diversi binjiet fil-Belt Valletta xegħlu l-faċċata tagħhom bilkulur vjola fosthom il-Berga ta' Kastilja, Palazzo Castellania u Palazzo Ferreria fil-Belt Valletta. Dan sar fuq inizjattiva tal-Caritas Malta Epilepsy Association

5

Ara wkoll l-editorjal f'pagna 7 u storja umana f'paġna 16

Miģjuba bil-permess ta' In-Nazzjon



Laggħa virtwali mall-Ministru Julia Farrugia



Funtana go Pembroke mixgħula vjola għall din I-okkażjoni mill-Kunsill Lokali ta' Pembroke

Opinion

20

BE International Durea

🇯 Caritas

Epilepsy Day 2021: shining a light for more understanding and awareness



JANET MIFSUD **and** CLAUDINE MARIKA AITKEN

Most of us were transfixed in front of our television and mobile devices a few weeks ago, watching the inauguration of Joe Biden as President. Few may have paid attention to the person leading the oath which Biden repeated. That was John Roberts, US Chief Justice of the Supreme Court. A hugely important position. Yet, Roberts has also publicly stated that he has one of the most misunderstood medical conditions: epilepsy.

Ianet Mifsud, Professor, Depart-

ment of Clinical Pharmacology and Theraneutics. University of

Malta; Advisor, Caritas Malta Epilepsy Association

Claudine Marika Aitken, Secretary, Caritas Malta Epilepsy As-sociation Epilepsy is the most prevalent chronic neurological disorder with an incidence of approxi-mately 1% of the population worldwide; that is around 50 million people, with approximately 4000 persons in Malta across all ages. Epilepsy is currently defined as a tendency to have recurrent seizures (sometimes called fits). A seizure is caused when the brain activity and messaging between brain cells (neurones) becomes abnormal, leading to mixed messages being sent to various parts of the body. These appear as seizures or periods of unusual behaviour, sensations, and at times loss of awareness.

The International Against Epilepsy League classifies epilepsy in over forty different types and conditions. Epilepsy is classified "generalised" when the discharge affects the entire brain cortex. The main seizures types in this group are tonic-clonic (grand this group are tonic-clonic (grand mal) and absence (petit mal). An epilepsy is called "focal" (can also be referred to as "partial") when the electrical discharge causing it occurs in a specific area of the brain. Simple partial seizures re-with in page of conceinements sult in no loss of consciousne On the other hand, complex p tial seizures are characterised by automatisms. There are various possible aetiologies for seizures and epilepsy across various ages: prenatal or birth injury, or con-genital disorders, CNS infection or trauma, head trauma, stroke, brain tumour, and neurodegener-ative conditions.

According to the World Health Organization, 70% of persons with epilepsy can live a seizurefree life if treated properly. Cur-rent anti-epileptic medication can control seizures in about 70% of individuals. In Europe, it is esti-mated that there are 10 million persons with epilepsy. 30% of whom are refractory to the drug treatment presently available and have one or more seizures per month

Despite these medical adwhich have resulted in 70% of persons with epilepsy being seizure free, epilepsy is still surrounded by huge social burdens, misconceptions and is very rarely discussed in public. In Malta, it is a condition with is unfortunately still associated with a huge stigma. It is very rarely spoken about de spite it being more common than ALS, autism or ADHD. Epilepsy is a condition which can have a significant negative impact on the qual-ity of life a person, ramifications which are primarily due to the revailing attitudes of society at

arge. Understanding epilepsy and seizures is key to raising more awareness of this condition's im-





iolidarjetà u l-Ĝustizzja Šočjali, II-Farnilja u d-Drittijiet tat-Ttal), Palazzo Castellania iahha), Cavalier House (Ministeru ghall-Inklužjoni u l-Kwalità tal-Hajja) u Casa De eru ghall-Finanzi u x-Xoghol) ser jinxteghlu bid-dawl vjola fis-6, 7 u 8 ta' Frar 2021.

www.internationalepilepsyday.org

pact on a patient's general medical and psychological health. People with epilepsy can contribute to so-ciety as attested by various other famous famous persons who have epilepsy. This list includes Hugo Veaving, actor, Lord of the Rings; Martin Kemp, actor and Spandau Ballet bassist; Susan Boyle, singer; and Neil Young, singer.

Addressing stigma towards epilepsy by educators in educa-tional settings is a key step in ensuring an improvement to the quality of life of persons with epilepsy. A study carried out some years ago by the University of Malta and Caritas Malta Epilepsy Association (CMEA), assessed the perceived stigma to-wards epilepsy by a group of educators who attended in-service training courses on epilepsy organised by CMEA. Over 100 educators (primary and secondary school teachers, personal social development, guidance teachers and learning support educators) were asked questions about their individual perception of epilepsy, before and after the training ses before and after the training ses-sions. Before training, some of the attendees thought that all seizures make persons fall. Most admitted to being worried, afraid and taken by surprise on seeing a seizure for the first time. Some thought the all whiles with thought that all children with epilepsy had learning difficulties. These misconceptions were ad-dressed throughout the course

and a similar survey held postand a similar above new pose-training, clearly indicated that most were very keen to learn more about epilepsy, develop teaching strategies for children with epilepsy, prepare a learning environment for children with epilepsy and learn how to co-onepilepsy, and learn how to co-op-erate with parents of children with epilepsy.

This awareness cannot stop with educational institutions but must be widened to prospective employers and other social insti-tutions. Caritas Malta Epilepsy Association (CMEA) was set up Association (CMEA) was set up by voluntary workers in 1996. Now it lists almost 300 mem-bers. The Association is for per-sons with epilepsy and their families. Through education, it aims to promote local awareness about epilepsy. This is vital to tackling the experience by peo-ple with this condition in society, particularly in the employment sector. CMEA also works towards improving healthcare services, treatment and social acceptance of epilepsy, as a serious yet treatable brain disorder. It offers free training on epilepsy to all those organizations that request it.

The Caritas Malta Epilepsy As-sociation is affiliated with the International Bureau for Epilepsy which together with World Health Organization and the International League Against Epilepsy, is working on the Global Campaign

maltaepilepsy@amail.com Against Epilepsy: Out of the Shadows. This is a unique joint venture which has the mission to improve acceptability, treatment, services and prevention of epilepsy world-

These efforts are highlighted annually on International Epilepsy Day, which falls on the second Monday of February. This year it is today, 8th February 2021. More than 130 countries join together on this occasion to which the this are different and the annually on International highlight this condition, speaking vith one global voice. Malta will also be shining a light

on epilepsy today, International Epilepsy Day 2021. Several land-marks and buildings around the world, such as the Colosseum and the Eiffel Tower, being lit purple to mark the day. Malta will be joining this global initia-tive with the lighting of five key buildings in Valletta: Auberge de Castille, Palazzo Castellania, Palazzo Ferreria, Chevalier House and Casa Demandols on 6th, 7th and 8th February 2021. Caritas Malta Epilepsy Association is appreciative of the im-mense support by the Office of Prime Minister; the Office of the Deputy Prime Minister and Ministry for Health; the Ministry for Social Justice and Solidarity, the Family and Children's Rights: the Ministry for the Inclusion and Social Wellbeing and the Ministry for Finance respectively, which made this possible.

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wide

TIMES OF MALTA

Let's shine a light on epilepsy

TALKING POINT

JANET MIFSUD

Professor, Clinical Pharmacology and Therapeutics, University of Malta



hat connects this diverse group of persons: Julius Caesar, Fyodor Dostoevsky, the singer Prince, Susan Boyle and US Chief Justice John Roberts? They have all experienced one of the most misunderstood, maligned and stigmatising medical conditions - epilepsy.

Persons with epilepsy have been unfairly singled out, prosceuted and discriminated by various cultures and societies across the millennia. Persons with epilepsy have been and still are unjustly perceived as being possessed by magic or supernatural power, despite it being so common. It affects around one per cent of the population worldwide, across all ages.

This means that around 4,000 persons in Malta have epilepsy. One cannot stress enough that a person is not 'epileptic' or 'suffers from epilepsy', since such terms reinforce the stigmatisation.

Medically, we know quite a bit about epilepsy and its causes. It is defined as a tendency to have recurrent seizures (also sometimes called fits), caused by a sudden burst of excess electrical activity in the brain, resulting in a temporary disruption in the normal message passing between brain cells. This disruption may have several causes: prenatal or birth injury, congenital malformation, infection, head trauma, brain tumour or other neurodegenerative conditions. In some persons, the cause remains unknown.

Few are aware that there are several different types of epilepsy. The symptoms seen during a seizure depend on which part of the brain is affected. Epilepsy is generally associated with the tonic-clonic (grand mal) seizures that affect the whole body and is manifested by stiffness and shaking. On the other hand, in absence seizures (petit mal), the individual may just stare for a few seconds while, in focal epilepsy, only part of the brain is affected and there is generally no loss of consciousness, just some abnormal move ments of the limbs. We are fortunate that, with the medical treatment available today, 70 per cent of persons with epilepsy have their seizures controlled.

So why is epilepsy still so little spoken about? Why isn't it a 'trendy' condition but is rarely discussed in the media? Why are so few persons with epilepsy ready to



in Malta deserve better

share their experience and admit that they have it to their friends and colleagues? The biggest hurdles are the negative sociocultural attitudes towards epilepsy that still pervade educational, occupational and recreational spheres.

Some still mistakenly consider epilepsy as an illness which hinders employment. Others perceive it as lack of intelligence. Such erroneous public perceptions have been found to proliferate negative attitudes and drive persons with epilepsy to withdraw socially, in order to avoid discrimination and stigma.

Huge efforts are presently being made to address these misconceptions by the Caritas Malta Epileps Association, in conjunction with the Department of Clinical Pharmacology and Therapeutics at the University of Malta. The vision of the association is to achieve a better life for persons with epilepsy.

The Caritas Malta Epilepsy Association offers free training to educational institutions. The attitudes of educators have a big impact on any child's academic performance, social skill development and future accomplishment. This is even more important for a child with a chronic condition such as epilepsy.

Free sessions on basic information about epilepsy and first aid for seizures are also offered to other professionals such as healthcare professionals, social workers and police officers but also to the public at large.

The Caritas Malta Epilepsy Association is affiliated to the International Bureau for Epilepsy, which, together with the World Health Organisation and the International League Against Epilepsy, is working on the Global Campaign Against Epilepsy: Out of the Shadows.

These efforts are highlighted annually on International Epilepsy Day, which falls on the second Monday of February. This year it is today, February 8. More than 130 countries join together on this occasion to highlight this condition, speaking with one global voice.

International Epilepsy Day 2021 will see a number of landmarks and buildings around the world, such as the Colosseum and the Eiffel Tower, being lit purple to mark the day. Malta joined this global initiative with the lighting of five key buildings in Valletta: Auberge de Castille, Palazzo Castellania, Palazzo Ferreria, Chevalier House and Casa Demandols on February 6, 7 and 8.

The Caritas Malta Epilepsy Association is grateful for the support by the Office Prime Minister, the Office of the Deputy Prime Minister for Social Justice and Solidarity, the Family and Children's Rightsy. the Ministry for the Inclusion and Social Well-being and the Ministry for Finance respectively, which made this possible.

We can all endeavour to play our small part. We can all shine a light on epilepsy. Four thousand persons in Malta deserve better.

For more information and support contact maltaepilepsy@gmail.com

Janet Mifsud is also an advisor to the Caritas Malta Epilepsy Association.

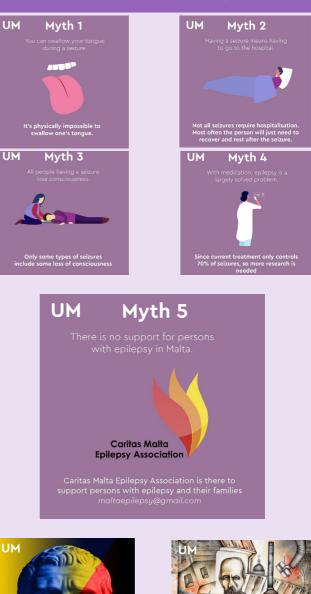
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8 February 2021 Janet Mifsud & Frank Portelli Interviewed on TVAM PBS TVM

International Epilepsy Day in conjunction with The Communications Office, University of Malta - some infographics





Julius Caesar

Fyodor Dostoevsky

International Epilepsy Day in conjunction with The Communications Office, University of Malta - some infographics



Nixegħlu d-dawl

Ftakar din id-data

➡ It-Tnejn, 8 ta' Frar 2021
 ◊ Jum Internazzjonali tal-Epilessija







Let's Shine a Light

Remember the date

Monday, 8 February 2021

International Epilepsy Day



International Epilepsy Day

From the Hon. Minister Julia Farrugia Portelli

maltatoday | SUNDAY • 14 FEBRUARY 2021

OPINION



Julia Farrugia Portelli

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The colour purple and other hues

SYMBOLIC acts of support go a long way towards creating a greater awareness of ongoing issues such as those of inclusion and social well-being. It is why as part of International Epilepsy Day last Monday we gladly shone a light for epilepsy by turning our ministry and other buildings in Valletta purple. After all, there are 4,000 Maltese citizens who suffer from this condition and who need our unconditional and non-stop backing to help them live to their fullest potential.

The cause of inclusion, however, goes beyond any colour or slogan. It is through our everyday approach to things that matter to all of us in society that we can really make sure that no sector of the Maltese population feels isolated, forgotten or even taken for granted. The rights of so-called minorities became an instant focus of political and legislative action with the change of government in 2013. The results since then have not only been palpable, but they show there is still so much to be done within our society that is undoubtedly, among the most charitable in the world: we seek to consolidate this social backbone and cement the realities and principles we have always upheld.

It happens to be Valentine's Day today, a timely celebration of romance and love which we need to extend to other values, other than their cultural, religious and commercial significance. It embraces the very concept of mutual respect which, in these days of a horrible pandemic, forms part of humanity's fightback by way of ensuring that the social well-being achieved in the past few years is protected, acknowledged and enhanced.

Love on Valentine's Day should not be limited to romantic outpourings but ideally repackaged to help each one of us to reach out to the various sectors of Maltese society, including the disabled, the emarginated and those others extracting a life on the fringes. The same noble sentiment has to go towards the thousands of carers and front-liners in our hospitals, institutions and within the brave NGO organisations where the work is often carried out at awkward and difficult moments in people's lives, most often unseen and unsung but actually working out miracles, providing hope and instilling happiness, sometimes against all odds.

There are also carers and family members within village and town homes who deserve our attention, our gratitude as we sustain the nation's determined efforts to make of inclusion an everyday reality rather than a spark – or a colour – here and there during special occasions on the calendar. To be part of society, to claim the same rights and an equal portion of that sense of well-being within it; this has to remain the objective.

Strengthening these rights and bringing to fruiton the many targets we still have to contend with, are not a burden. It is merely the onus and the responsibility that we, as privileged administrators and political protagonists, have: to make sure they propel us into achieving better things and opening better access avenues for inclusion and social well-being.

That 65% of disabled persons in Gozo went off the unemployment list in the last four years is testament to this official commitment, and, also as significant, a

we sustain the nation's determined efforts to make of inclusion an everyday a project at Zebbug Rangers FC to help reality rather than a spark – or a colour – here and there during special occasions cise and the joy of football.

There is a strong sense of positivity in our purpose as we seek to give inclusion and social well-being the permanent platform they warrant on both the national and European canvases.

Laws and directives certainly provide substantial foundations, but it is through a sense of duty and a genuine belief in love-moored principles that 21st century Maltese society can take pride in its evergreen, to use another colour, evolution.

It is a process that will always be a work in progress if we really do mean to stay in touch with that same society and its various sectors as new challenges crop up and new solutions emerge. There are 4,000 Maltese citizens who suffer from epilepsy and who need our unconditional and non-stop backing to help them live to their fullest potential

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Intervisti fuq diversi programmi tat-televiżjoni għall Jum Internazzjonail tal-Epilessija



Intervista fuq Net TV fil-programm "Kikkra Te" ma' Frank Portelli u Janet Mifsud, President u Konsulenta rispettivament ta' CMEA



Intervista fuq One TV fil-programm "Espresso" ma' Frank Portelli u Claudine M. Aitken, President u Segretarja rispettivament ta' CMEA



Intervista fuq Net TV fil-programm "Kikkra Te" ma' Frank Portelli u Janet Mifsud, President u Konsulenta rispettivament ta' CMEA



Intervista fuq One TV ma' Matthew Attard, Assistent PR ta CMEA



Intervista fuq TVM Live fil-programm "Illum ma' Steph" ma' Frank Portelli u Janet Mifsud, President u Konsulenta rispettivament ta' CMEA



Intervista fuq One TV ma' Janet Mifsud, konsulenta ta' CMEA



Robin Pinkston waqt parti minn vidjo maħdum mill-Communications Office ta' I-Universita ta' Malta u li deher fuq TVM Live.



Matthew Attard waqt parti minn vidjo maħdum mill-Communications Office ta' l-Universita ta' Malta u li deher fuq TVM Live.

Raġġ ta' dawl għall-epilessija

Diversi palazzi nxtegħlu bil-vjola għall-okkażjoni tal-Jum Internazzjonali tal-Epilessija.



Casa Demandols (Ministeru għall-Finanzi u x-Xogħol)



Palazzo Ferreria (Ministeru għas-Solidarjetà u l-Ġustizzja Soċjali, il-Familja u d-Drittijiet tat-Tfal)





Il-Berġa ta' Kastilja (Uffiċċju tal-Prim Ministru)

Cavalier House (Ministeru għall-Inklużjoni u I-Kwalità tal-Ħajja)



www.internationalepilepsyday.org malfaepilepsy@gmail.com



Palazzo Castellania (Ministeru għas-Saħħa)

Jum Internazzjonali tal-Epilessija



Manuel Camilleri membru tal-kumitat CMEA intervistat minn The People of Malta

Miġjub bil-permess ta' The People of Malta



The People of Malta February 8 at 6:55 AM · 🕄

•••

"Jiena persuna li għandi l-kundizzjoni tal-epilessija. Ngħix ħajja normali u jekk tarani ma tindunax li għandi din il-kundizzjoni. L-epilessija hija disturb newroloģiku li jaffettwa l-moħħ. Skoprejt li għandi din il-kundizzjoni meta kelli 45 sena. Kollox beda meta ta' 25 sena, kien waqa' fuqi bieb ta' garaxx. Żmien wara, kont qed nagħmel xi xogħol u kont fuq ċint, u f'daqqa waħda tani ħass ħażin u spiċcajt b'xorti tajba ġejt f'għalqa. Ħadd mis-sitt sħabi li kienu miegħi ma kien jaf xi ġrali u kif se jġib ruħu. Iddaħħalt l-isptar u minn hemm indunaw li jien persuna bl-epilessija. Minn dak inhar bdejt nieħu l-medikazzjoni u bdejt naqra dwar din il-kundizzjoni. Meta tax-xogħol saru jafu li jien persuna li għandi l-epilessija, waqqfuni. Ma qalulix li waqqfuni minħabba f'hekk. U ta' 45 sena, spiċcajt bla xogħol, nirreģistra. Dak iż-żmien kelli t-tifla għadha dieħla l-Universita'. Ma kienx żmien faċli għall-familja. Imma sibt sapport enormi mill-familja u mill-grupp tal-Caritas Malta Epilepsy Association

Din id-diżabilita' hija kundizzjoni li ma tidhirx. 70% ta' dawk li għandhom l-epilessija jgħixu ħajja normali, u l-aċċessjonijiet (fits/seizures) li jistgħu jagħtuhom huma kkontrollati bil-mediċina. Imbagħad hemm dawk it-30% li jeħtieġu attenzjoni 24/7. Ħafna persuni bħali li għandhom l-epilessija jistgħu jgħixu ħajja normali, jaħdmu, ikollhom familja u jikkontribwixxu għas-soċjetà.

Kull fejn immur, miegħi inġorr brazzuletta li fiha hemm il-medikazzjoni u l-informazzjoni meħtieġa dwar il-kundizzjoni tiegħi. Fuqi jkolli wkoll cards li juru x'jista' jsir f'każ li lili tagħtini aċċessjoni. Għall-persuni bħali, mhux tajjeb li nkunu fil-għoli, u qatt m'għandna nissakkru f'xi kamra għax jekk jinqala' xi ħaġa, ma rridux nispiċċaw waħedna. Hija esperjenza kerha immens meta persuna tagħtih aċċessjoni. U jien nissuġġerixxi li min ikollu din il-kundizzjoni, jitkellimha u mhux iżommha għalih.

Hawn Malta hawn mal-4000 persuna li rreģistraw li għandhom din il-kundizzjoni, b'oħrajn li jaħbu jew ma jurux. Kull min irid ikun jaf iktar dwar din il-kundizzjoni, għandu jersaq lejn Caritas Malta Epilepsy Association.

Illum, it-8 ta' Frar, huwa I-Jum Internazzjonali tal-Epilessija. Għal din I-okkażjoni Berġa ta' Kastilja u Palazzo Ferreria se jinxtegħlu fil-vjola flimkien ma' bini importanti ieħor madwar id-dinja." -Emanuel #EpilepsyDay

Thallix I-epilessija tikkundizzjonalek ħajtek... għix il-ħajja normali bi ftit aġġustamenti

In-Nazzjon

It-Tnejn, 8 ta' Frar, 2021

LOKALI

FL-OKKAŻJONI TAL-JUM INTERNAZZJONALI TAL-EPILESSIJA LLUM IT-TNEJN L-isport għenha tegħleb l-epilessija

Trudy Kerr: mill-aħħar ta' ħajjitha għall-maratoni

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Christine Mamo

Kienet f'qiegh ta' sodda waslet biex tmut iżda ma qatghetx qalbha, anzi hadet sehem fi 11-il maratona, żewg ultras, u griet madwar 126 kilometru, tant li permezz t'hekk irnexxielha teghleb lepilessija.

Din hi Trudy Kerr li fuq il-pagna personali ta' Facebook esprimiet kif fl-2010 kellha incident kważi fatali tant li sofriet minn emoraģija. Fil-fatt, kollox seħħ wara li marret horse riding fejn minn hemm spiċċat għamlet jumejn mitlufa minn sensiha fi sptar. Iżda kien biss wara erba' xhur li rrealizzat li hemm xi ħaġa iktar serja milli gatt basret. Dan hekk kif bdiet issemmi lin-nanniet tagħha daaslikieku kienu ghadhom hajjin meta dawn kienu ilhom mejtin madwar 20 sena.

Minn hemmhekk, kollox beda sejjer ghall-aghr hekk kif bdiet tesperjenza bhal xokkijet ma' ġisimha kollu, allučinazzjonijiet, u tbati minn episodji ta' nuqqasijiet til-memorja u diffikultajiet meta tkun qed tesprimi lilha nnifisha. Dawn kollha kienu sintomi ta' aččessionijet. Kerr ģieli esperjenzat 60 aččessjoni f'perjodu ta' bejn 24 u 72 siegħa, bit-tobba jgħidulħa li s-sitwazzjoni tista' tibqa' kif inħi jew tmur għallagħar filwaqt li kellħa tieħu tliet pilloli kuljum ħajjitħa kollħa. Iżda dawn il-kundizzjonijiet Kerr qatt ma aččettaħom...

Fl-aghar taghha, Kerr ģieli esperjenzat iktar minn 60 aččessjoni f perjodu ta' bejn 24 u 72 siegha, bit-tobba jghidulha li ssitwazzjoni tista' tibqa' kif inhi jew tmur ghall-aghar filwaqt li kellha tichu tiet pilloli kuljum ghal hajjitha kollha. Iżda dawn ilkundizzjonijiet, Kerr qatt ma aččettathom.

Titet snin wara, Kerr kellha I-opportunità li tichu schem fl-ewwel mrattona taghha li saret fl-Londra, propia f'gheluq I-40 sena taghha. Fl-istess jun, madwar i di-dinja kienu se jsiru tilet girijet, b'Kerr tapplika galalihom kollha biex tittanta xortiha li tigi maghżulha ghal xi wahda minnhom. Iżda mhux talli inghażlet ghal wahda,

talli t-tlieta li huma hatfuha filkelma biex tippartećipa. Dan ghaliex ma kienx komuni li persuna bl-epilessija tichu sehem fil-ĝiri minhabba xniegha u biża' li l-ĝiri kapači jiggrava lkundizzjoni.

Bi preparazzjoni ghall-maratona fLondra, Kerr kienet griet f'maratona li kienet saret f'Malta fl-2013, b'din il-maratona tibqa' marakata f'mohh Kerr hekk kif fl-ahhar taghba kienet esperjenzat - ahhar ačecsijoni f hajjitha. Fil-fatt issa ilha seba' snin ma tesperjenza aččessjoni wahda.

Kerr, li ghal snin shah kienet ta' kuragig ghal hafna, qalet li sabet diversi persumi li tawha s-sapport iżda fuq kollox urew li jemmun fiha biex b'bekk imexxielha taghmel 42 kilometru f'giri. U kien hawnhekk fejn haljet Ker rinqalbet ta' taht fuq tant li l-giri wassalha biex tfiq mill-epilessija minghajr ma hadet ebda tip ta' medičina.



TRUDY KERR: "M'iniex atleta... M'iniex żgħira fl-età. Iżda jien determinata għax jien ikbar mill-iskużi."



Par żarbun wieħed se jwassalha fejn tixtieq!

Kerr tghid li tinsab certa li din is-sena se ĝĝib maghha hafna sfidi izda par żarbun wiehed se jwassalha fejn tixticaj! Par zarbun li mlux talli ghen tilha, izda wkoli lili-ambjent minhabba li hu maghmul minn plastik ričiklat li nstab l'qiegh ta' bahar.

"M'iniex atleta," qalet Kerr. "M'iniex żgħira fl-età. Iżda jien determinata għax jien ikbar mill-iskużi."

