



Chairperson Report 2021

28th February 2022

During 2021, 10 board virtual meetings were held, on 15 January, 18 February, 12 March, 9 April, 14 May, 11 June, 9 July, 10 September, 15 October and 12 November. There was a quorum reached for all of these meetings. In between meetings there was ongoing communication between board members and member organisations via emails and phone calls.

MHN Board for 2021 was newly elected after elections held during AGM on 1st March 2021 and on the first board meeting the following composition was confirmed

Gertrude Buttigieg (Chairperson),
Dr Ray Galea (Vice-Chairperson),
Demis Cachia (Treasurer)
Christopher Vella (Secretary)
Marcelline Warrington (members)
Dr Christine Baluci (members)
Godwin Micallef (members)

George Sultana & Mark Mallia did not make it with the first 7 positions on election, however AGM approved that they can sit on MHN board as members.

We would like to thank the Office of the Prime Minister (OPM) for approving once again the secondment of Ms Melanie Agius Attard to assist MHN in administrative work and upcoming projects.

Following approval in past AGMs, application process to obtain Legal Identity for MHN has been submitted to MBR. They requested various details etc, we submitted all at our end we are now just waiting for finalisation at their end.

Funding and Support MHN does not carry out any fund-raising events, our only source of regular income are the annual membership fees. In 2021, through MCVS we received CSF funds which helped to cover membership fees in our affiliations. We applied and received support through the Voluntary organisations Emergency fund. This helped to sustain certain running costs and a one-time expense to provide masks with MHN logo. These were distributed to member organisations.

Membership update

During 2021, MHN lost 1 member and did not receive any new applications for membership, a couple of other organisations were also experiencing difficulties but so far they are still considered as members. Most members have been brought about up to date with membership

fees. Should any organization experience difficulties with paying membership due to the current situation please approach the board in writing.

Activities on Local Level

Members' concerns:

MHN received concerns about issues with availability of medicines through POYC system from ADHD and Epilepsy Support Group. These queries were discussed separately, and organisations directed accordingly however this led to MHN board to decide to look at the issue deeper. In November 2021 we held a web meeting with members where access to medicine and access to services was discussed. Later a position paper was put together following feedback received. This has been circulated with members and will be up for discussion and approval during AGM.

Meeting with Important Stakeholders:

MHN was represented at Stakeholder Consultation Session in relation to Malta's Sustainable Development strategy 2050 & Action plan 2030. We were also invited to participate in Malta Medicines Authority Stakeholders meeting in preparation of MMA Strategy.

Collaboration with other entities:

MHN kept collaboration with SOS Malta on COVID 19 volunteers. The volunteer pool got smaller, but a fresh call was issued in 2021 for Volunteers to assist with vaccination hubs. Some statistics on volunteers and time given. However, this is not complete as most of the coordination was being done by SOS Malta and at a point we were not receiving anymore the log sheets by volunteers.

Statistics of volunteers for 2021 who worked at the Hubs.

	Name of Hub, place of volunteering	Total hours
1	Vaccination hubs (March- December)	740 hrs
2	Contact Tracing team (Jan-March)	153 hrs
3	Control Master (Jan-March)	490 hrs
4	Ta Qali Hub (Jan-March)	496 hrs
5	Admin Staff (Jan)	124 hrs
6	Case Management (March)	33 hrs
7	St. John Ambulance Staff (March)	12 hrs
	Total in all	2048hrs

Total number of volunteers for 2021

	Volunteers	Amount
1	Active volunteers	92
2	New Applications	49
3	St. John Ambulance Staff	16
	Total in all	157 volunteers

Researchers from MCAST approached MHN for our support for an application for funding through Excellence Programme Fund through ESPLORA. The projects was to develop an Integrated Simulation and Assessment in Donning and Doffing for healthcare professionals (ISADD). MHN supported this and project was successfully executed. Details of the project are available on our website.

Contacts on Cancer matters: MHN representatives has a virtual meeting with MEP Cyrus Engerer following his appointment in EU Parliament on the Cancer Platform, this was a very constructive meeting and he took interest in the ideas we shared.

European Cancer Patient Coalition invited MHN to support and endorse COVID-19 and Cancer joint letter. We have also asked member organisations to endorse this letter which was then sent to the Deputy Prim Minister Hon. Chris Fearne, Shadow Minister Hon. Stephen Spiteri and MEP Cyrus Engerer as policy makers. Further to this on 14 September MHN joined the launch of the Time to Act- COVID 19 campaign in order to raise awareness on the impact of COVID on Cancer patients. MHN was asked by Emanuele Cancer Foundation to participate in this and GB represented MHN and spoke primarily on the rights of the patient.

Erasmus + project on Health Promotion and Prevention: Following participation in Patients' Rights day event organised by ACN online in May 2021, we got in touch with the Spanish platform - Plataforma de organizaciones de pacientes. Later in the year they approached us to be partners in an Erasmus + funded project. The aim of this project is to promote health and disease prevention including immunisation and other more. MHN will be responsible for dissemination of information generated through the project in Malta. Towards the end of 2021 we were informed that the project was selected for funding and we will be working with the Spanish organisation on the project in the coming months. As a result of this we invited the Spanish organisation to submit an abstract for the MAPHM symposium held in November 2021. They did submit and presented a paper about research they carried out about the impact of COVID-19 on Spanish patients.

Air Quality Plan sub-committee: As MHN we were approached by MCVS upon a request from ERA to submit a nominee on behalf of Public Health organisations on the Air Quality Plan sub-committee. We approached our members MAPHM who nominated Dr Roberto Debono to sit on this committee. –

Events by Servizzi Ewropej Malta (SEM) (Meusac) organised events on the European Conference. One such event was on health- Unjoni Ewropea tas-Saħħa- GB participated in this event together with other representatives from the sector. GB mentioned that Health is important and it cannot be left out. GB also mentioned that it is important to think about other pandemics around us such as obesity and mental health. A recording of this session is still available on the SEM Facebook page. The European Conference is now drawing to an end and conclusions and recommendations will be published over the coming months. MHN will be collaborating with SEM to see that health remains on the agenda. Following this event GB was invited to participate for a short interview on programme organised by Malta Employers Association – MEA which was aired on TVM towards the end of 2021.

Cross Border Health Care Directive During this year the EU Commissioner held a Consultation process on Cross Border Health Care Directive- there were various ways of one could give feedback. However MHN was contacted directly to see if MHN has been involved by authorities on the implementation of the directive in Malta. To which it was easy to reply that we

were not involved at all. Late in 2021 we were approached by the staff working on the European reference Network point in Malta. This is mostly beneficial for person who suffer from rare diseases. They gave an overview where they have arrived with the European Reference Network. This has never been used in Malta up till now as they do not even know how it is going to work. MHN will mainly act as a contact point rather than centre of excellence. MHN will act as a bridge to raise awareness and when they have all the information MHN will send email to our members to organise some form of training on how this is going to work.

Contribution to the Smoking and Health Advisory Committee: in 2021 GB was once again nominated as patient representative nominated on committee, however due to the COVID-19 pandemic this committee did not meet at all during 2021.

Life Insurance for chronic patients: The other matter which was on MHN Agenda for 2021 was the issue of Life Insurance for chronic patients. An online meeting was held where all members were invited. A meeting was then held with Ms. Samantha Pace Gasan - Commissioner for the rights of persons with a disability in order to get an update on work which has been carried out, so we don't re-invent the wheel. This matter was also discussed over a virtual meeting with MEP Cyrus Engerer and he assured that by the end of the year a white paper will be issued on the right of insurance but this will mainly apply only to cancer patients. Later MHN requested meetings with Hon. Roderick Galdes and Hon, Julia Farrugia Portelli. The latter never met MHN. However, Hon Roderick Galdes did meet up with MHN representatives. We were presented with a draft operation manual of a scheme which was being prepared by his ministry called 'A New Hope'. MHN agreed to this scheme which will give support to persons who have issues in getting a life-insurance policy to buy a property. It was agreed that MHN will have a representative on the Consultation committee which will be meeting to review the scheme from time to time.

Visibility: We have kept website updated as much as possible. There was a positive response by members to promote their events via Calendar and we are willing to keep doing this and improve. We have also used Facebook page extensively to spread out messages.

Patient rights Day: For Patients' Rights day we organised a webinar on 19th April where we had speakers from EUPATI who spoke about the EUPATI training programmes which are now available for free on the EUPATI Open Classroom. The Fellowship programme is still available but that is at a cost.

World health day 9th April: Following an invitation by Vivian Corporation Malta and Directorate for Health Promotion and Disease, we were included in campaign for World Health Day. The campaign included a billboard set up at Marsa which was followed by videos done to promote healthy lifestyle. These are available on MHN You tube Channel and will be available on MHN website

We were invited to promote World Lung Day- by trying to help persons Setting up Lung Organisation- however we had poor response for this and did not manage to proceed.

COVID Recovery Plan- MCVS subcommittee discussed report and sent to Hon. Dr. Owen Bonnici. Gertrude Buttigieg being the elected representative on MCVS for the sectors of Health & disability – coordinated the aspect of health impact in this report. Recommendations were put forward including those of having hubs in the community so that they can help the clients as Covid 19 not only had an impact on the aspects of culture but also on environment and these

had an impact on our health. Unfortunately, none of the recommendations put forward were included in the government plans.

MHN Chairperson was invited on TVM to give a reaction to the State of the Union Speech on 14th September, considering the impact Health had on Europe in general in the past months. Also during the State of Union several initiatives targeting health were announced including the European Emergency Response Action to have an action plan ready should there be other emergencies in the coming years.

MCAST freshers' week- MHN responded to opportunity offered by MCAST to have a stand during Fresher's week and response was good. 3 MHN members also participated in this Richmond Foundation who attended every day and Caritas Epilepsy, ARAM attended once while ADHD Malta also took part in our stand and they participated twice. It was an opportunity to promote the individual groups and MHN in fact Malta Life Network showed interest in joining MHN, so far have not submitted an application.

MHN Projects

Patient -Doctor Questionnaire

MHN launched a Questionnaire on patient-doctor communication. This was planned as a pilot project for a bigger project possibly funded through VOPS. However, there was very low response by participants that it was not valid to proceed. This was very disappointing despite lots of efforts done to encourage patients to respond.

SIP Malta:

SIP Platform/SIP Malta: GB mostly and at times CV have been participating in online meetings and one to one meetings which are on-going by SIP Platform. Pain is to be included in the meeting cancer plan. MHN has also signed an MOU with SIP committing our ongoing commitment to participate in SIP Europe platform. The right to insurance document has been sent to GB and the document mainly specialises on cancer and by 2025 it is to be placed on legislation at EU level. We co-hosted a webinar on 7th September on raising of awareness on Employment and Pain. This event was supported by EU-OSHA which promoted a newly launched campaign on healthy workplaces Lighten the Load. There are resources available also in Maltese as part of this campaign. Unfortunately, the Maltese version is not too user friendly but we can still make it available on MHN website.

Another webinar was held on the 28 October 2021 and the role of MHN is to disseminate information to participants, and also to disseminate information on social media through the MHN Facebook page and MHN website. This meeting also included the participation of MEP Alex Agius Saliba, who is the Co-Chair of the European Alliance Brain, Mind & Pain, member of the European Parliament Inter group on Disability. We had alerted ourselves this role of the Maltese MEP, and we joined an introductory meeting with him prior to this event. MEP Alex Agius Saliba.

European Patient Academy for Therapeutic Innovation (EUPATI):

MHN has kept it's commitment in the EUPATI as one of our projects. We need to update some content about EUPATI on MHN website and keep promoting EUPATI in Malta. During this year Christine Montague graduated as a EUPATI fellow following successful completion of the training course. We have signed an MOU with EUPATI outlining our terms of affiliation given our limited human and financial resources. Mark Mallia has been appointed as our designated

contact person for EUPATI. We disseminate to members any events or information coming through the project and hope that this is considered useful.

MHN affiliations

European Patients Forum (EPF): MHN has kept its membership in EPF thanks to the support received through Civil Society Funds.

EPF honoured MHN with a certificate of recognition of 10 years membership, we have disseminated this through our website and social media.

In February we joined the extraordinary general meeting 2021 to approve some changes in order to hold the AGM virtually. This was held on 17th April 2021 and we were represented by Demis Cachia.

EPF organised Patient advocate Seminars and GB and Mary Vella of ARAM participated in these interesting seminars. GB and Mary Vella used the item of Life Insurance as the lobbying exercise and it was good practice.

EPF congress was held virtually in October 2021, up to 10 people were allowed to register for free, we were informed that up to 6 people from Malta have registered and participated in the Congress.

Leadership training opportunity by EPF - Mary Vella from ARAM was accepted to participate in this training and she successfully completed the training.

We were invited to join the H2O PROJECT: We identified members for this project 2 from Chron's and Colitis, 1 diabetes, 1 from Lumier Support group & 1 from Breast Care Support group Europa Donna but we do not have any reports on progress on this project.

EPF youth summer camp- we sent invitation to organisations to nominate youths for this opportunity but there was no response from members.

COMPARE EU: this is a project of EPF in which MHN has been participating for the past 2 years. The ultimate objective is to provide web-based material for patient self-management in the conditions of Diabetes, Chronic Obstructive Pulmonary disease, Chronic heart conditions and Diabetes. There are 5 Maltese representatives who regularly attend online meetings and contribute to the project. The last activity in which they were involved was correction of the Maltese translation of documents which will be published for general public. The project should close by end 2022.

Active Citizenship Network (ACN):

MHN participated in Patients' Rights day online event organised by ACN in May 2021. During 2020-2021 we participated also in the ACN Cardiovascular Prevention project which involved online training and this was concluded in 2021. ACN carried out research and information campaign on routine vaccination and the impact of vaccination during COVID.

ISAL Foundation: This year we only worked on the promotion of World Day Against Pain in September.

European Public Health Alliance (EPHA):

MHN has kept its membership in EPHA thanks to the support received through Civil Society Funds. We have supported a letter sent by EPHA to push policy makers for more funding for the

EU Health Programme. A copy of this letter was sent to the Hon Chris Fearn, Minister for Health,

EPHA held a webinar on the paper they published about Digital health.

MHN is an active member of the Anti-Microbial resistance Network and is represented on the AMR Patient Group by Dr Godwin Micallef.

International Alliance for Patients Organisations (IAPO): – we maintained the membership and throughout the year we have sent out the IAPO newsletter to members. This contained several interesting articles and links to webinars held all over the World covering different topics from patient safety to HIV and diabetes. So the topics are very varied and members are encouraged to disseminate the information to join according to their interest.

Volonteurope we maintained our membership thanks to CVS funds by MCVS and MHN represented participated at AGM which was held online also we disseminate newsletters and any invitations to events being organised especially online.

ECH Alliance they consider us a very important contact. We are invited to participate in both the coordinators meetings which are for a selected group of people/entities. But then we are often informed and invited to attend other events where there are interesting presentations especially of best practices from all over the world. Often information about these events is disseminated and we encourage members to participate.

World Patients Alliance: MHN kept its membership in the WPA. We regularly receive invitation for online events which are then disseminated to members.

The Future

1. With hopefully things going back to normality whilst we may retain some online meetings we hope to start some meetings face to face.
2. We would like to have a closer collaboration with member organisations and see how together we can make more difference to patients' life.
3. We would like to tackle the matter of Patients' Rights in more practical ways – more awareness on the rights which actually exist. But also the Charter of Patients 'rights is now 5yrs old and should be up for revision so possibly we will be getting back to you to get your feedback on what you feel should change, improve, work better for patients etc.
4. We would like to work to have better patient representation on the boards that matter eg medicines entitlement boards etc. We may seek to strengthen our collaboration/partnerships with important entities such as the Malta Medicines Authority on their Academy for Patient Centred Excellence and Innovation in Regulatory Services and the Malta Community Chest fund – on access to medicines issues.