

Chairperson Report 2022

28th February 2023

During 2022, 11 board meetings were held on 7 January, 16 February, 11 March, 8 April, 17 May, 10 June, 8 July, 2 September, 7 October, 4 November and 9 December. Some were virtual and others hybrid. 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 2022 January – September was as follows

Gertrude Buttigieg (Chairperson),
Prof Ray Galea (Vice-Chairperson),
Demis Cachia (Treasurer)
Christopher Vella (Secretary)
Marcelline Warrington (member)
Dr Christine Baluci (member)
Godwin Micallef (member)
George Sultana (co-opted member)
Mark Mallia (co-opted member)

However, in September 2022 Prof Ray Galea was appointed as Commissioner for Health in the Office of the Ombudsman and thus he resigned from MHN Board. We would like to thank Prof Galea of 15 years of service to MHN and wish him all the best in the new position which we are certain will also serve in the advancement and safeguarding of patients.

Following this change the board changed as follows:

Gertrude Buttigieg (Chairperson),
Christopher Vella (Vice-Chairperson),
Demis Cachia (Treasurer)
Marcelline Warrington (Secretary)
Dr Christine Baluci (member)
Godwin Micallef (member)
George Sultana (Member)
Mark Mallia (co-opted member)

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.

We are pleased to inform that MHN managed to finalise and obtain Legal Identity status following approval of moving in this direction in the past AGMs. The process was long and bureaucratic but finally we made it.

Funding and Support MHN does not carry out any fund-raising events, our only source of regular income are the annual membership fees. In 2022, 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. For 2022 we received funds for an ERASMUS + project implemented together with the Spanish Platform for Patients Organisations, we also had a generous donation from a donor. We have also managed to be successful in a TIS funded project and VOPs funds – both projects will be implemented in 2023.

Membership update

During 2022, MHN lost 1 member since the organisation was dissolved however we got 2 new members Mental Health Association Malta and Gozo Mental Health Association. Most members have been brought about up to date with membership fees and are engaging more with MHN however there are a couple where we seem to have lost contact. Should any organization experience difficulties with paying membership please approach the board in writing and we will try to help out.

Activities on Local Level

2022 marked the 15th Anniversary of MHN. Being a year where half of it was still dominated with restrictions due to COVID and then things got back to normal involved some thinking on how the best celebrate the year. Thus we worked both on an online presence as shall be explained later but also focused on meeting with Important Stakeholders on a 1-1 basis to bring our voice higher to decision making levels.

On the 18th November we held a special celebration to for the 15th Anniversary. Several representatives from member organisations accepted our invitation and attended for the event together with Minister Julia Farrugia Portelli, Shadow Minister Dr Stephen Spiteri, MCVS CEO Mr Mauro Pace Parascandalo and Past Chairperson of MHN Mr Anthony Guillaumier who also addressed the audience present. He also announced a special award for NGOs in the sector and we are in discussion how this will evolve. Following an overview of work carried out by MHN in the past 15yrs which was presented by Gertrude Buttigieg, Chairperson, the event was also an opportunity to Launch the Patient Empowerment Training course for 2023 which was funded through the Small Initiatives Support fund, funded through Malta Council for the Voluntary sector.

Meeting with Important Stakeholders:

On the 9th February a delegation from MHN met with the Parliament Health Committee. We presented the position paper which had been prepared by MHN following consultation with members and we emphasised on the importance of true representation on Boards and Committees. There was also mention of holding a special parliament session to discuss health however after the general elections the composition of this committee changed and there was no official follow-up. However late in 2022 through another event MHN Chairperson G Buttigieg had a fruitful discussion with Hon Malcolm Paul Agius Galea, the new Chairperson of the

Parliament Health Committee who was as the Med-Tech World Summit in November and he showed an interest in MHN and informed that he will consult with us as needed.

Other official meetings were held with

- Hon Chris Fearne, Deputy Prime Minister & Minister for Health on 10th November
- Hon Julia Farrugia Portelli on 30th September
- Hon Stephen Spiteri, Shadow Minister for Health on 9th November
- We met with Perm Secretary for the Ministry of Health Mr Joseph Chetcuti on 8th November
- Meeting with Officers from MDH unfortunately CEO Ms Cilia Falzon was not available to attend meeting 26th September
- Meeting with Mr Charles Messina, Out-going Commissioner for Health and Newly appointed Commissioner Prof Ray Galea 20th September

A letter of congratulations was sent to Dr Roberta Metsola on her election as President of the European Parliament. Dr Metsola has always supported the work of MHN in the past and also supports various initiatives of our members.

Collaboration with other entities:

The position paper approved at the AGM last year was sent to all political parties prior to the General Elections. Some candidates showed an interest, but we didn't manage to meet up prior to the elections. Once elections were over we sent it again requesting meetings, which meets were held as mentioned earlier and others are still to happen.

MHN kept collaboration with several other entities – this included meeting with member organisations on specific issues but also with other entities these included:

A meeting with Humanists Malta who approached us to support the draft of paper to push forward legislation of Living Wills in Malta – this meeting was followed by several emails and proposal to their original draft. Thanks to the different board members who have contributed very valid feedback throughout this discussion which is still ongoing.

Following the general elections, we tried to follow-up on the matter of 'New Hope' scheme which offers assistance to persons with health issues to access the property market – but feedback was very weak from the Ministerial side.

In May, Gertrude Buttigieg, was invited on behalf of MHN to participate on panel discussion during the **International symposium on patient safety**, organised by the University of Malta. It was an honour to be on such a panel, but it also served as an opportunity to make contacts for further collaboration.

MCAST once again we were invited and participated in Freshers' week in October. We invited members to share our stand at MCAST ARAM, Caritas Epilepsy Support Group, Europa Donna Breast Care Support group and Malta Alliance for Rare Disease joined. Some other organisations had their own stand too. However, following this MCAST approached MHN to promote the MCAST CSR programme which manages the Students' Volunteering scheme. A meeting was held with Mr Camilleri Coordinator of services at MCAST and this was followed by another meeting where member organisations were invited to participate. Response was low.

However, any organisation which is interested they can approach us and we will direct them on how to apply etc.

Med-Tech World Summit 2022: Gertrude Buttigieg represented MHN at the Med-Tech World Summit 2022 Malta 17-18th November in particularly during panel discussion on Digital Health. This was facilitated by Mr Andy Andy Bleaden, Communities Director for ECHAlliance. As MHN we are members of ECHAlliance in fact we are trying again to revive the activities of the ECHAlliance in Malta. Further details will be shared in the coming weeks.

Legal Clinic- Following contacts made by Chris Vella we were approached by Law students who are taking part in the Law Clinic. This is a service provided by the University of Malta whereby Law students take specific cases to evaluate and work on them under the supervision of the Law Clinic supervisor. Following a meeting with 2 students, we offered the services to member organisations and 2 specific organisations mainly Caritas Epilepsy support group and ADHD Malta showed an interest in the service. Any other organisations interested is to approach us and we shall direct accordingly.

Citizens Lab - Meetings were also held, and several email communications followed with SOS Malta. These were about the setting up and how one could participate in the Citizens Lab project as well as benefit from funds for Expert Advice. This information was passed on to members by email – should anyone has queries please get back to us.

An online meeting was held with representatives from ParaOlympics Malta – possible collaboration in the future was explored.

An online meeting with representatives of the Malta Medicines Authority was held in order to re-vamp our MOU and seek better was of collaboration especially in focusing the Patients' Academy of MMA to direct attention on patients' education.

A meeting was held with person responsible on a local level for the European Reference Network in Malta. This office is small and trying to raise more awareness. They regularly send information on webinars and information from other ERNs which information is circulated by email to members.

MHN board members had a meeting with representatives from Servizzi Ewropej Malta who explained services they offer to NGOs including the possibility of use of meeting rooms. Which premises is also available for member organisations.

Following TV interview for Patients' Right day we received email from citizen with a complaint, after we assisted him to get some information from MDH customer care he still wanted to meet up. We met up with him and seems that he was satisfied after that. For other queries we received we have often direct people to specific organisations including member organisations and when they don't come back it is taken that matter has been sorted.

Gertrude Buttigieg was nominated for the election of Malta Council for the Voluntary Sector for the sector of Health and Disability and was elected on council for the next 3yrs.

National Rare Disease Strategy - We were approached by the Office of the Chief Medical Officer at the Ministry for Health to contribute in the consultation process for the National Rare

Disease Strategy which is being prepared by the Ministry. It was a good kick-off meeting followed by some emails and sharing of contacts and linking with the right people. The strategy is at the very initial stages and thus we look forward to further collaboration.

Visibility on the Local level

Whilst we are aware that within the health sector and our members there is an awareness of MHN and what we stand for we have noticed that we are not so well known among the Maltese society as we would like. It is not just for MHN but more important for the values we share and the member organisations which ultimately are MHN. Thus, thanks to a funding opportunity offered by MCVS we submitted and were eligible for funds through the ENISIE. This allowed us the services of a Communications company which helped us develop a marketing strategy but also prepared for us posts for Facebook, boosting of these posts, content writing for some articles to be used in our website. They have assisted also in using the 'branding' for the posts in our posters and we shall also have sponsorship packages worked out to be able to address our funding issues. Thanks to these posts which started toward the end of 2022 we have increase the views of MHN.

In August in view of several industrial actions which were going on and these were perceived as negatively effecting patients MHN issued a press release on the matter. This was given prominence by NET News and the Malta Independent, it also had good following on our Facebook page.

MHN this year was offered a unique opportunity by the Malta Independent where 1 article per month is appearing on the Sunday newspaper – this is also shared electronically. From the response we received we covered 6months in 2022 and have 2023 practically covered. We will approach the organisations who have not take up a month to see if they are interested.

For patient's rights day GB was invited to participate in TVAM where apart from patients' rights we spoke also about the Position paper and ways in which patients can have more voice.

As MHN we kept posting events of member organisations -when we are informed or get to know of these events – on our website and disseminating this information via email. We had 50 posts or newsfeeds on Facebook has also been used regularly and Messenger was also a means of how sometimes public engaged with us. Facebook statistics indicate that almost 14,000 people have visited our page.

Results

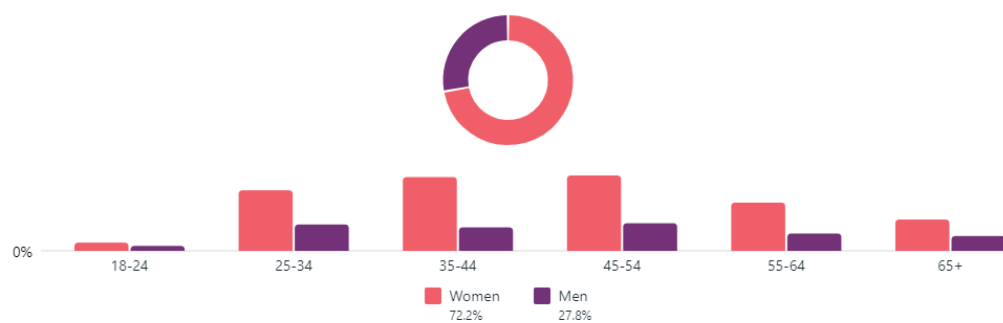
Facebook Page reach ⓘ

13,843 ↑ 62%



Table 1: showing an increase in Facebook reach by 62% in 2022

Age & gender ⓘ



Top towns/cities

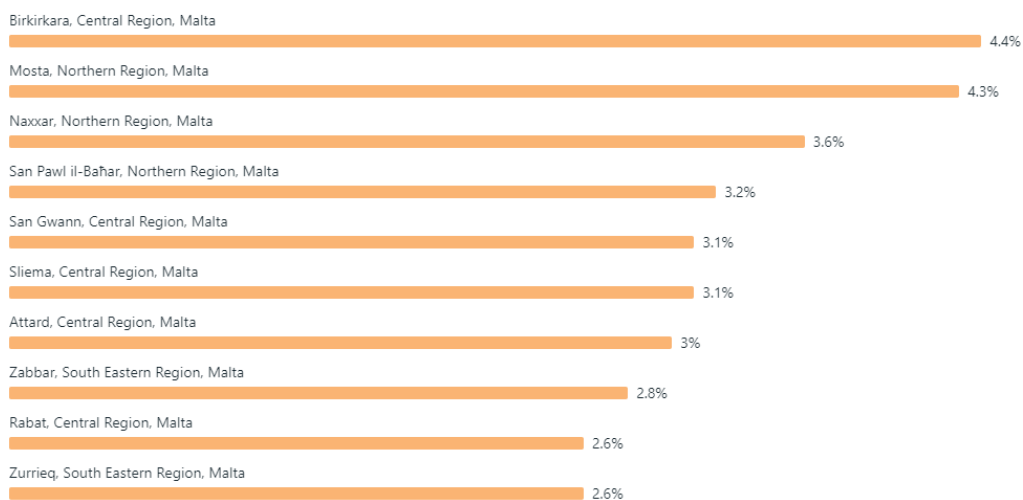


Table 2: Demographic data of people who follow MHN Facebook page by gender and locality

MHN Projects in collaboration with Foreign entities

Erasmus+ project on Managing chronic conditions at the workplace: Following partnership with the Spanish Platform for Patients Organisations in an ERASMUS+ project we fully implemented the project. This involved a focus group with different patients and then guidelines was developed. In beginning 2023 guidelines and videos will be disseminated and project to close in February 2023.

SIP Malta SIP Platform/SIP Malta: As from this year Chirs Vella was delegated the duty of following up meetings and participating in online discussions involving SIP Platform Initiatives. In 2022 meetings were held online almost on a once a month basis. The emphasis of SIP remained on the having Pain included in the ICD-11 and ICF where they also shared papers/articles which were printed in scientific journals speaking about this. Toward the end of the year a document on SIP Digital Health Position Paper was shared to be translated into Maltese for ease of dissemination.

European Patient Academy for Therapeutic Innovation (EUPATI):

MHN has kept its commitment in the EUPATI as one of our projects. This year another person has become a EUPATI Fellow- this is Jane Giudice for ARAM. In April Mary Vella as Patient representative and myself as coordinator for EUPATI Malta were invited for the 10th Anniversary event held in Brussels. It was interesting to see how EUPATI developed in various countries. Especially those where they have strong pharmaceutical research going on. In Malta we are still mostly focusing on getting patients more knowledgeable about their medication and the benefits of proper and safe medication. These trained patients will hopefully be given the adequate opportunity to represent peers at decision making levels.

Horizon 2022: Invited to join as partners in a project: Potential cooperation for EU call "Setting up a European Smart Health Innovation Hub" Funded under Horizon 2022 projects. The scope was to map best practice of digital health initiatives in Europe. We did join as partners, but the project was not selected for funding.

MHN affiliations and collaboration with foreign entities

European Patients Forum (EPF): MHN has kept its membership in EPF thanks to the support received through Civil Society Funds. Through our members MARD MHN was represented for the Annual General Meeting of EP held June in Brussels.

In October Christopher Vella attended for a training bootcamp organised by EPF of Data Saves lives. This is a new concept which is being promoted lately since it is recognised that the safe sharing of data can be useful for research and possible developments in health care and health care services.

The COMPARE EU: was a project of EPF in which MHN has been participating for the past 3 years. This project closed in November 2022 and for the closing conference MHN was represented by Gertrude Buttigieg, Mary Rose Bartolo and Moses Azzopardi as they had actively participated in the Patient Panel during the project. Following research and involvement of professionals and patients the website <https://self-management.eu/> has been developed where one can find material for patient self-management in the conditions of Diabetes, Chronic Obstructive Pulmonary disease, Chronic heart conditions and Diabetes.

Further to this as MHN we regularly disseminate the EPF newsletter which we receive every 2 weeks and practically 24 newsletters were sent out to all members.

Active Citizenship Network (ACN):

During this year MHN renewed a Memorandum of Understanding with ACN to strengthen our collaboration and support to each other.

MHN participated in Patients' Rights day online event organised by ACN in May 2022. For this event we were requested to submit a video with a message about patient's rights. We had a short message by Henry Mamo who is a child with a rare condition. His video message was very touching and was very well accepted on a European level.

ACN held several webinars in 2022 especially on the topics of vaccination. Invitations are regularly sent out to our members and everyone is welcome to join.

ISAL Foundation: This year we only worked on the promotion of World Day Against Pain in September. We had a Facebook post but we also had new material uploaded on our Website. This material was sent by ISAL foundation and was translated by Dr Pietro Piccone who was a volunteer with us during COVID and who has freely accepted to carry out translations and content writing for MHN.

European Public Health Alliance (EPHA):

MHN has kept its membership in EPHA thanks to the support received through Civil Society Funds. Dr Christine Baluci has been delegated the task of following on meetings & activities of EPHA. However MHN is also actively participating in 2 new working groups set up by EPHA – The Digital Cluster which is being followed by Ms Marcelline Warrington and the Politics and Advocacy meetings which are being followed by Mr George Sultana.

As MHN we are still following and contributing to the Anti-Microbial Stakeholder Network in which MHN is a member.

The AMR Patient Group is an initiative by Health First Europe and is comprised of national patient associations from across Europe. Dr Godwin Micallef represents MHN on the AMR Patient Group. The group aims to address the gap in awareness at the patient-level about the danger of antibiotic misuse and the lack of effective infection prevention measures. The AMR Patient Group will empower patients across Europe with the necessary knowledge about antimicrobial resistance so that everyone understands when it is appropriate to take antibiotics and how to take them responsibly. Online meetings are held every quarter and minutes are duly forwarded by myself to MHN. The topics are normally about events by Health First Europe and updates by the 16 member states. Topics are mainly about awareness of AMR.

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.

Volonteuropa we maintained our membership thanks to CVS funds by MCVS. Unfortunately, we could not send a representative for the General Assembly held in June however we participated in the EGM held in December since this was held online. On a regular basis we disseminate information about events and news from Volonteuropa.

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. This year Demis Cachia represented MHN at the first World Patient Congress organised by WPA in Rome in October 2022. There was the possibility also of following the congress online and there were several diverse topic mostly related to Safety and the patient.

Through our affiliation with the different organisations we were informed and invited to attend other events eg the European Oncology Patient Congress in March. We were asked to support a position paper on access to Oncology treatment across Europe, which position paper was sent to all Health Ministers in Europe and we sent it to Minister Fearne.

The Future

1. With funds obtained through the Training Initiative Fund by MCVS between January – March 2023 5 Patient Empowerment sessions will be carried out. These sessions include Access to Medicine, Anti-Microbial Resistance, Patients' Rights, Self-Management and Safe use of Medicines. For these sessions we also have the Support of the Medicines Authority which are sponsoring our venue. These presentations given at sessions are being recorded and will be available on MHN You Tube Channel and website in a section specifically dedicated to this project.
2. MHN also managed to make it for VOPs funding. These are also thanks to MCVS. We shall be producing 4-6 videos with educational messages targeted at patients & public in general. Further information will be given in the coming months.
3. We are re-vamping our contact with ECHAlliance with a webinar to be held in April on Electronic Patients Records.
4. Patients' Rights will remain on our agenda and a seminar is planned for 19th April with the participation of officers from the Ministry of Health who will be speaking about the Treatment abroad options available to Maltese patients. This will include information also on the Cross Border Health Care directive.
5. We will keep meeting with authorities and voicing the importance of having patients truly represented on the boards that matter eg medicines entitlement boards etc.
6. We would like to congratulate all member organisations who were successful in getting funds through VOPs & SIS. We would be willing to support these projects and disseminate the information etc if we are informed. MHN is not the board but it is the members so We would like to have a closer collaboration with member organisations and see how together we can make more difference to patients' life.