

Chairperson Report 2020

Presented 1st March 2021

During 2020 9 board meetings were held, 2 face-to-face on 10 January & 7 February, 2 partly face-to-face and partly virtual on 10 July & 9 October and 5 virtual meetings held on 7 April, 29 May, 11 September, 13 November & 11 December. 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 2020 remained unchanged from previous year and was formed by Gertrude Buttigieg (Chairperson),
Dr Ray Galea (Vice-Chairperson),
Demis Cachia (Treasurer)
Christopher Vella (Secretary)
Moses Azzopardi, Dr Christine Baluci and Godwin Micallef (members)

In view of the fact that this was the 3rd year of the current board, thanks go to all officers who have served the full term. Special thanks go to Mr. Moses Azzopardi who has served on MHN board for the past 6 years and has decided not to submit his nomination for elections. Many thanks Moses. All other members have submitted their nomination for the elections, and we wish them the best of luck whilst thanking them for their past service and thanks in advance for their willingness to keep serving.

As you all know Malta Health Network (MHN) so far has no office and no premises thus we would like to thank the Commissioner for Mental Health and the Meeting Place for allowing us to hold meetings at their offices when necessary including 2 training sessions which were part of our Patient Empowerment training programme carried out over 2019-2020. Due to exigencies of this year MHN board activity moved to online platform like other organisations. However, this did not hinder the efficiency in which MHN business was carried out.

Thanks goes also to the Malta Medicines Authority for covering our expense to host our last AGM at Life Sciences Park which was also the concluding event for our Patient Empowerment training programme funded through the Training Initiative Scheme (TIS) by the Malta Council for the Voluntary Sector (MCVS).

Last but not least thanks to 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.

Membership update & Survey

During 2020, MHN received 1 application for new memberships this was processed, and Genetic & Genomic Counselling Association of Malta was accepted. Unfortunately, 1 organisation has been dissolved and another organization decided not to remain members anymore. 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.

Between July-September we had 2 students who did their volunteering placement with MHN, these helped to carry out a survey among members. From this survey it resulted that MHN members represent almost 12,000 people. These include patients, family members, patient representatives, professionals, and volunteers. Half of the members are patients themselves whilst between the different organisations there are over 1,200 professionals. These include medical doctors, Chiropractors, Physiotherapists, Occupational Therapists, Speech Language Pathologists, educators, and other professionals who are part of advisory boards, administrative staff as well as trained teachers and other university graduates.

Whilst the number of patients is around 6,000 there are organisations who have a wider reach through social media where they have over 5,000 members in their Facebook page. When these organisations were asked how many patients'/ relatives/cases make part of their organisations they answered that around 2,300 form part and this apart from the fact that some organisations support around 400 vulnerable families and 250 family caregivers.

Regarding students who form part of these organisations one will find that there are around 100 students among the different organisations but then the MMSA alone has around 650 medical students that also form part and give their contribution. General public there are around 456 persons who give a helping hand to these associations and some are committee members. While some of these members pay a nominal fee.

To align MHN work with the areas considered as priorities by the members, these were asked which areas they considered more important:

- 1. Patients' Rights
- 2. Health Policy
- 3. Patient Empowerment
- 4. Patient Safety
- 5. Self-Management
- 6. Access to Innovative Medicines
- 7. Chronic Pain issues
- 8. Access to medicines in schools
- 9. Safe use of antibiotics

Activities on Local Level

Meeting with Important Stakeholders:

In January 2020 MHN representatives met Prof Anthony Serracino Inglott, obo Malta Medicines Authority with the aim of strengthening our relations between both entities. MMA were interested in concrete collaboration on the Patient Academy project and interested in hosting the EUPATI training and possible accreditation. Further to this meeting MHN to participate in the MMA stakeholder strategy meeting held online in November 2020.

TIS funded Training Programme: Empowering patients and Health related NGOs to influence Health Policy at National and International levels

Following 2 successful training sessions held in 2019 both held at San Anton Palace, thanks to the courtesy of the Office of the President of Malta and the last 2 sessions and Certificate Award Ceremony were held in 2020

Session 3 Patients' Empowerment

Session 4 The Patient and Legislation

Tth February 2020

Session 5 Certificates Award Ceremony

28th February 2020

Feedback was very positive and will serve as guidance for future events. Presentations for which we had permission to share are available on MHN websites.

MHN Application as legal identity: This was voted for at the last AGM and we are working on it, we hope to conclude this process this year including the changes to the statute which were requested by MBR in order for our application to be accepted.

Collaboration with other entities:

Collaboration with the COVID-19 Response team in helping with volunteers. In March 2020 as the pandemic hit Malta, MHN board agreed to contribute to the national emergency by mobilizing an initiative to rope in Volunteers to help with various duties embarked upon by Public Health Department. A call was launched and within 3 weeks we had close to 500 volunteers registered. These were deployed in various tasks including administrative work with Environmental health, contact tracing, helping with POYC and administrative help at the swabbing hubs. We recruited people from all walks of life, and everyone was gladly giving his utmost. At the same time, we collaborated with Malta Medical students' association who were assisting also in the Covid-19 helpline. Between March-April we totalled 10,000hrs of volunteering. SOS Malta was also helping in the logistic coordination and in May 2020 we launched an online volunteers' recruitment portal which is still active till today. Between May till end 2020 we kept helping with volunteers as things changed. It is estimated that we gave more than 12,000hrs of volunteering between May-December and the volunteers involved over this period was around 400 people. There were times when we also helped the Malta Trust Foundation which was distributing food aid and we had

volunteers helping with other ad-hoc duties such as doing shopping, getting medicines or dog walking for families in quarantine. This effort was recognized by the Superintendent of Public Health, Dr Charmaine Gauci who signed the nomination of MHN for the Voluntary Organisation Award 2020. Unfortunately, we did not win the award but being nominated was already an honour.

Contribution to the Smoking and Health Advisory Committee: in 2020 GB was once again nominated as patient representative nominated on committee, however due to the COVID-19 pandemic this committee met only twice and then stopped altogether.

During AGM we committed to put on MHN agenda the matter of accessibility of medicines to school children, unfortunately nothing was done on this subject – maybe the new board would take it up again.

The other matter which was discussed was the issue of Life Insurance for chronic patients. An online meeting was held where all members were invited. Work on this topic has started and we plan to work more on it during this term.

Collaboration with MEUSAC – during consultation on the Europe Beating Cancer Plan – MHN submitted online feedback during the consultation which was carried out by the EU Commission. MHN made were also presented to MEUSAC which was carrying out exercise to get opinion of Maltese entities on EU Pharmaceuticals Strategy. GB was also invited to participate in EU day online seminar by MEUSAC held on 6th May. The virtual meeting was very positive were attended minister and unions. MHN was chosen to participate.

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. We were invited by NET TV to invite members to participate in TV programme, various organizations accepted. Also we supported an initiative by MCVS to participate in program on Volunteering which was aired during summer on TVM.

MHN Projects

Societal Impact of Pain (SIP) Malta – we have kept this project going through having a dedicated session in January where participants were invited to indicate the priorities for the coming year. Unfortunately, due to Covid we did not proceed further however in we held and online meeting and issued an expression of interest to see how participants were interested in contributing. Since special attention was on training of patients and professionals this will be given a priority this year. In fact, GB & CV have represented SIP Malta on various online meetings held by SIP Platform and we have submitted our request for support for these initiatives. We look forward to work on this throughout the year.

European Patient Academy for Therapeutic Innovation (EUPATI): We have kept our participation alive. Throughout the year there was a change in the Maltese representative for Pharma who is now Mr Mark Mallia, who has taken a very keen interest in the project and thus we hope to organize some events to raise more awareness on this project and it's benefits for the patient population. Ms Christine Montague was also accepted to do the EUPATI fellow training and is currently undergoing the training. This has now changed to an online programme and we hope to open up the opportunity to more Maltese participants to take up the training. We are still emphasizing on EUPATI that the course needs to be accredited by a recognized institution e.g. a University so it will attract more interest. In the meantime, the website has been revamped and links are available through MHN website where some of the content is also available in Maltese.

European Patients Forum (EPF): MHN has kept its membership in EPF thanks to the support received through Civil Society Funds. This year all EPF events were online and MHN representatives participated in EGM and AGM. Thanks to EPF we could also offer leadership training programme for which various patients submitted an application, but Ms Mary Vella was selected and did the programme. Another opportunity was for the Youth Summer Camp for which 2 representatives from MARD were selected and again the training was carried online. EPF has also offered various webinars during this year most of which were also recorded and are available on EPF social media channels

We are still contributing to the EPF led project COMPAR-EU project. This is a Horizon 2020 project. EPF is leading the package Eliciting patients' priorities and preferences. This project is looking at chronic conditions primarily Type 2 Diabetes, Obesity, Chronic Obstructive Pulmonary disease and heart failure. We have 4 Maltese participants in the project. All meetings related to this project have moved online and the plan is that this project will be concluded by end of this year.

Active Citizenship Network (ACN): Like other events the events organized by ACN moved to online webinars. In 2020 we were invited to nominate persons to participate in the Understanding for Cardiovascular Prevention Initiative. This is a 2-year project which will involve training and then dissemination of information on a local level. 2 nurses who work in the field of Cardiovascular education and rehabilitation participated in part of the training. This project is still ongoing and MHN participation is still active.

ISAL Foundation: Following MOU signed in 2019 we were partners in a project proposal on Chronic pain – called Sentinels of Pain which was submitted through the Europe for Citizens fund 2020, unfortunately project did not make it for funding for by a very slim margin. Other opportunities will come!

European Public Health Alliance (EPHA): we are still members, thanks again for support for membership through CSF. This year we managed to participate in AGM which was held online. Thanks to our active participation in 2019 in the Roadmap for action on antimicrobial resistance

(AMR) published in November 2019 we have now joined the Stakeholder Network on Antimicrobial Resistance (AMR) and we are being represented by Dr Godwin Micallef for the Antimicrobial resistance patient Group. This groups meets for regular workshops and is looking at ways of how to raise awareness on anti-microbial resistance.

International Alliance for Patients Organisations (IAPO): – we maintained the membership and an abstract submitted for IAPO congress planned to be held in April 2020 in Scotland was accepted. Unfortunately, due to the pandemic the Congress was postponed on an online event held in September and since agenda changed more to focus on Covid our paper was not presented.

Volonteurope we maintained our membership and MHN represented participated at AGM which was held online.

Collaboration with **ECH Alliance** was kept even though local events were interrupted. They invited MHN to participate in Pop-up EcoSystem in July on Digital health system where we shared how digital tools helped in recruiting volunteers to help in the Covid-19 response team. This was followed up with an online meeting with their staff on ways of how digital tools could be used to help home-bound patients but so far we have not had any further news from their end.

World Patients Alliance, MHN board agree that we join as full members. We applied and were accepted. Membership if free and we joined as they share common positions as MHN by focusing on patient empowerment and they target patient education. Invitations to their events will be sent to all members.

MHN has also registered on the EU Transparency register.

The Future

- 1. Now obviously the new board will seek to plan the work for the coming 3 years, however work which already started is to be continued.
- 2. We are going to seek collaboration with CRPD on the topic of Life Insurances for Chronic Patients since we are informed that they have already started working on this issue and joining forces seems a possible way forward.
- 3. We would like to have a closer collaboration with member organisations and see how together we can make more difference to patients' life.
- 4. As a follow-up to our partnership in ACN & EPHA on Anti-microbial resistance we shall be seeking ways of collaboration with local Health Authorities in view of the local Anti-microbial resistance strategy, given the pandemic allows this
- As already mentioned, we shall seek ways of collaborating more with the Malta Medicines Authority on their Academy for Patient Centred Excellence and Innovation in Regulatory Services.