



Chairperson Report 2018

Presented 28th February 2019

During 2018 8 board meetings were held on 19 January, 16 February, 5 April, 15 June, 20 July, 19 September, 23 October & 16 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.

New Board was formed after the AGM

Gertrude Buttigieg (Chairperson),

Dr Ray Galea (Vice-Chairperson),

Demis Cachia (Treasurer)

Christopher Vella (Secretary)

Moses Azzopardi, Dr Christine Baluci and Godwin Micallef (members)

Unfortunately MHN so far has no office and no premises thus we would like to thank the Commissioner for Mental Health for allowing us to hold meeting at their offices when necessary.

Thanks also to the Malta Medicines Authority for covering our expense to host this AGM at Life Sciences Park.

Last but not least thanks OPM for approving the secondment of Ms Melanie Agius Attard to assist MHN in administrative work and upcoming projects.

Membership update

During 2018, MHN received 3 applications for new memberships these were processed and organizations were accepted. These were Maltese Alliance for Rare Diseases (MARD), Beating Hearts Foundation and Karl Vella Foundation. We received another application however this did not match criteria laid out in MHN statute and was refused. This gives a total of 41 organisations, however there are number of organizations who have not paid their membership fees for 2 or 3years despite repeated reminders. There are other organizations where we know they are going through a difficult time. Whilst we understand that these things do happen we might need to take some action during this year to address this situation.

Activities on Local Level

The impact of Pain on Maltese Citizens: This was the highlight project of 2018. This was 80% funded by VOPs which is a fund managed by MCVS on behalf of the Parliamentary Secretary for Youths, Sports and Voluntary Sector (PSYSVS). For the rest of the Funding we were supported by Grunenthal. This project was carried out in partnership with No Pain Foundation. Very interesting results were obtained. These are available in a printed publication which we compiled to bring together the Conference held in April to present the findings and discussion on how these results can be used for policy. A brief leaflet is available and also 2 infographics videos 1 in Maltese and 1 in English can be found on MHN YouTube channel. A page dedicated to the project will be available shortly on MHN website site. Whilst the project is closed we are still awaiting last part of payment from MCVS. Project was presented and very well received on an international level during EUPHA conference held in Ljubljana where project was represented by Prof Julian Mamo. And a very positive response was received from SIP Europe in October when Gertrude Buttigieg presented the findings but also the infographics video where there is a general request to have a 'European Version'.

Professionals involved in the research are now working on a paper which will be published in local or international journal. On the occasion of World Day Against Pain in October there was good coverage in local media.

The project was also submitted as a Best Practice in Pain Award for the initiative by ACN. It will certainly be included in the publication which will bring together all projects submitted, hope to make it for the Award.

Now that this project is closed we wish SIP Malta to be reactivated and see how recommendations from this study can be taken forward.

Patient Safety Campaign: Following events MHN was represented to in 2017 about patient safety, we tried to set things going in Malta however to date we did not manage to cover much ground although this matter remains high on our priorities and agenda.

Collaboration with member organisations. One to One meetings with representatives of Organisations – members and non-members were held. Maltese Alliance for Rare Diseases, Karl Vella Foundation and Beating hearts later joined MHN. Meetings with Dr Klown was not that successful but we are still on good terms. One-to-one meetings were held by Chairperson with Hospice Malta, ABCF, Chron's and Colitis and No Pain Foundation. MHN supported also 'Don't delay connect today' campaign by ARAM. More meetings will be held in 2019.

Visibility Following invitation by Fuq Net on four consecutive days, various members of MHN as well as the MHN itself had the opportunity to introduce their organisation to the general public. MHN representative addressed meeting for Heads of Government as part of the project Social Determinants of Health. This ESF funded project led by the superintendence of public health is currently consulting with different stakeholders to better understand the issue of social determinants of health in the Maltese Islands.

Participation at VO fair December 2018: A joint stall was offered to MHN members whilst others took up a separate stall. Whilst alot of effort was put in this event it was a big let-down for various reasons including place was not central & few people showed interest.

Meeting with Hon.Anthony Agius Decelis, Parlimentary Secretary for Elderly and Disability was held on the 2nd July. MHN was represented by GB, MA and CV. The meeting was overall a very satisfactory meeting, with Hon.Decelis expressing his wish to disseminate the pain toolkit in the institutions for which his office is responsible. This initiative is still work in progress. Possibly also organising 'Train the Trainer' seminar and workshops to have a more complete project.

Public Consultations MHN submitted feedback to Vaccination consultation and feedback for the Mental Health Strategy launched in December is considered too.

Consultation of White Paper for Pain by PPE – local work carried out by MEP Francis Zammit Dimech, MHN presented feedback to the proposed white paper. particularly as regards Chronic pain; the absence of an action plan;the cross border healthcare directive; the importance of the psychological support throughout, starting from day one. Following this, MEP Zammit Dimech also invited a representative of MHN to attend for a conference related to topic – MHN was represented by Prof Ray Galea.

Access to Medicines: MHN has been following the problems reported by the generic medicines for ADHD which are not being as effective as the branded medicine. This matter is still not resolved. However we were very disappointed that when a survey was

sent to members asking if they had any issues with medicines relate to their conditions nobody replied not even to say they were satisfied.

Digital Health MHN has been involved in 2 initiatives

Blockchain / Distributed Ledger Technology for Healthcare – MHN was invited to participate in round table on this topic. This will be followed more in 2019

Digital and Small health Ecosystems following webinars held, MHN was invited to attend the first Digital and Small health Ecosystems meeting held in Malta on the 20th November. Ms Mary Vella did a presentation on behalf of MHN & ARAM. Matter to be followed further in 2019

Activities on a European & International Level

EUPATI – Gertrude Buttigieg as Patient representative and Prof Pierre Mallia attended for EUPATI AGM in Berlin in June 2018. Various things are happening in different countries related to the EUPATI project which is now running under European Patient Forum. During the year several webinars and ‘virtual meetings’ were held and for some of the Ms Mary Vella, EUPATI fellow also participated. We were also considering to have the full EUPATI website translated in Maltese but this works out to be a very big expense +/- €70,000 which sum we do not have and if we did we believe that it could be better used for other projects. However we are still form of EUPATI and hope that we can have more concrete actions locally through the project.

European Patients Forum. MHN was represented for the EPF AGM by Gertrude Buttigieg. This was interesting as there was extensive discussion to formulate the EPF Manifesto for the MEP Elections for 2019 and the themes which emerged are now included in the manifesto. The membership in EPF is supported by partial funding through CSF funds managed by MCVS on behalf of the PSYSVS. Through EPF we circulated various newsletters from them with interesting information, links to surveys and training opportunities including training days for Patient Advocacy Seminar where we were represented by Christine Montague (MS Society). Christopher Vella participated in web-meeting for ‘Universal Access to Healthcare’ working group by EPF. At this stage it was more of an introductory meeting to set the goals and identify core subjects to be tackled in the future working group meetings. Another working group on Digital Health was set up, Maltese representative was not taken up as they has to limit participants and we were already in the other working group.

Maltese participatns were recruited and attended for a session led by EPF as part of the 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. 6 representatives from Malta attended – 4 patients and 2 professionals. First they participated in online questionnaires and then they attended face-to-face workshop in July in Berlin.

Active Citizenship Network: ACN invited MHN for various events during 2018. For Patients Rights day we were represented by Godwin Micallef where initiative on safe use of medicines was introduced. A video message in Maltese was also recorded this is available on MHN facebook & ACN youtube channel. Christine Baluci represented MHN participated also for seminar on the 6 of November 2018 in Brussels about "European active citizens for vaccines promotion mainly on the theme of life-course vaccination. Gertrude Buttigieg attended for patients training days on Value Added Medicine.

European Public Health Alliance EPHA we are still members and have circulated information and surveys initiated by them. However this year we did not attend AGM as the main event were 25th anniversary celebrations and no conference like previous years thus we did not consider it valuable to attend.

International Alliance for Patients Organisations IAPO – congress this year was held in Atlanta – too expensive to attend. We joined through social media the annual campaign for Patient Solidarity Day.

Volonteurope announced their AGM rather late and there was not enough time to organized attendance.

European Association for the Study of Obesity (EASO) we are in touch with them but they have a strange way of working. We will keep contact maybe one day we will understand.

The Future

1. To set meeting with Deputy Prime Minister & Minister for Health Hon Chris Fearne & Shadow Minister for Health Dr Stephen Spiteri.
2. This project will have the aim of improving the patients and Professional collaboration with the common goal of improving health outcome. This will also have an Information campaign with ACN as advisors. Separately or jointly we might consider an education campaign on patient safety.
3. Registering as legal entity & beneficial owners: both processes started but still pending to be finalised
4. Digital and Small health Ecosystems possibly to host a meeting where local stakeholders, especially patient groups will be actively involved to ensure that

local developments are in line with patients' views and needs. Other stakeholders are Ministry for Health, University and professionals.

5. MHN is exploring partnership in EU funded projects – these are still at proposal stage. One will focus the experience of Chronic Pain Patients and the other on setting up an effective structure to deal with patients rights.
6. Members who do not pay their membership – we may consider taking action and remove from members list or consider other possibilities. These will be well considered and present at the next AGM.
7. Better use of website and social media – Site will be updated more regularly and events are being updated and circulated so members are invited to send information about their events in a timely manner to allow for this.
8. Training and empowerment
 - a. As part of the plans for 2019 we had submitted a proposal for SIS funding but we did not make it. Our idea is to have training for patient leaders on how we can be more active and pro-active in the consultation process being carried out for the Health Strategy 2030 eg Mental Health Strategy. Do you think this would be of interest?
 - b. Apart from this a Capacity Building Seminar for patient leaders is being organised by Novartis on 23rd March 2019. Please note – more information will be sent out in the coming weeks.
 - c. We also want to explore ways of reaching more patients and organisations with the EUPATI project.
 - d. Changes to VO Law – a Sectoral meeting is being held on 5th April 2019. This is important since it will specifically focus on the organisations related to the Health Sector. It is relevant too since as a sector we will be called to nominate and vote for a representative from the sector. The sector actually covers health and disability so it will be very competitive.