



Chairperson Report 2017

Presented 16 March 2018

During 2017, 7 board meetings were held on, 13th January, 17th February 2017, 10th March, 12th May, 14th July, 9th November and 15 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.

Board

In 2017 the board undergone some changes since during the year Mr Anthony Guillaumier resigned from board in July. An attempt was made to fill up these vacancies from persons who had submitted a nomination at the last general elections in 2015, however one person was not eligible as their organisation were no longer members and other refused. Thus Richmond Foundation nominated Mr Christopher Vella to replace Mr Guillaumier whilst GS1 nominated Dr Godwin Micallef, they both accepted and have been serving on the board since July 2017. Thus for the last months the board was made up by

Gertrude Buttigieg (Chairperson),
Mark Miceli Farrugia (Vice-Chairperson),
Demis Cachia (Treasurer)
Christopher Vella (Secretary),
Moses Azzopardi, Dr Christine Baluci and Dr Ray Galea, (members)

Anthony Guillaumer (Past Chairperson) was given the honorary position of Past-Chairperson.

Thanks to Anthony Guillaumier for faithfully serving MHN as Chairperson for 10 years and he has also promised to keep advising and support when needed. Thanks also to Mr Mark Miceli who served for the past 3 years as Vice-Chairperson and has not submitted his nomination for this time round.

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.

Membership update

During 2017 GSI, Malta Chamber of Pharmacists were accepted as members whilst and Malta Association of Crohn's Disease and Colitis refreshed their membership after they had been inactive for some years. 2 new organisation The Malta Heart Foundation and Nanniet Malta became members whilst another organisation has submitted their membership but still needs to be approved. This makes the total number of MHN members 39.

Update to Statute:

Changes to statute were carried out and these were approved at AGM held in April 2017. Updated version has been submitted to the Commissioner of VOs together with annual returns and we were confirmed compliant for 2017, electronic version is available on website.

Follow-up from AGM 2016 – work in progress in getting MHN registered as a Legal Person. Process is rather cumbersome but we will get there one day.

Activities on Local Level

1. Reaching out to local Policy Makers

A Position paper was prepared and sent to Political parties prior to the Elections.

MHN board met with Hon Dr Deo Debattista, Parliamentary Secretary for Consumer Affairs and Valletta 2018. A meeting with Deputy Prime Minister Hon Chris Fearne is still pending as several dates set were postponed from his office. Other meetings planned with Hon Clifton Grima Parliamentary Secretary for Youth, Sport and Voluntary sector & spokes persons related to sector from the Opposition.

We were invited for an information session on Chemotherapy Standards during consultation process which was being undertaken till January 2018. We voiced our concerns during the session mainly to be more specific on providing a holistic approach to cancer care not just setting standards for administration of Chemotherapy.

Gertrude Buttigieg represented MHN for a Research Priorities for Health Services and Systems project currently being carried out by Health Services. The patient perspective was highlighted at this meeting and well accepted by project co-ordinators.

2. Representation on official bodies

Gertrude Buttigieg represented MHN as patient representative on the Minister's Advisory committee on smoking – this did not meet in 2017 however she was reappointed again for another term starting from 2018. Ms Anne Micallef (Chairperson Europa Donna) has been accepted to represent MHN on the Disciplinary board of the Pharmacy Regulatory Council. Requirements for her input will be ad hoc.

3. Survey among MHN Members

26 organisations out of 39 member organisations replied to the survey carried out. Briefly this indicated that from the response obtained MHN is representing more than 10,000 including professionals, patients, patients' relatives, students and Other. Not including member organisations who failed to fill in the survey and the Malta Blood Donors Association who stated that all blood donors are members so the association could not obtain exact numbers due to reasons of Data Protection. Details of the survey are available on [MHN website](#).

4. Patients' Rights Day 2017

No major events were held this year as MHN resources were very stretched between the different projects and preparations for the SIP Symposium 2017. An attempt had been made with the Superintendence of Public Health to organise a public awareness event on the Patient Charter but they never came back with ideas for collaboration.

5. Participation in Projects

MHN had submitted a proposal for funding through the HSCB Foundation for in-depth research on pain and also submitted a proposal for Civic The Social Impact Awards – mainly the idea was to set-up an information and support helpline dealing with patients' rights – however we did not manage to make it for funding for both projects. We were invited to be partners in a project funded by Horizon 2020 led by a Cypriot entity however this project also did not make it for funding.

6. EUPATI project

The project is officially closed from IMI funding however it has been taken over by EPF and will be carried on. A 3rd call for training was issued and another Breast cancer support group Europa Donna representative (Ms R Caruana) was accepted to take course. MHN will keep working on EUPATI as part of its projects. In fact we have included EUPATI in Maltese on our website launched in 2017. Mary Vella and Anne Micallef have represented EUPATI Malta at the AGM held in Berlin in June 2017. A meeting was afterwards held to plan some activities but not much work was done as we were caught up with other activities.

7. SIS funds

In 2016 MHN benefitted from SIS funds for the project Ref 50/2015 entitled 'Relieving suffering of Chronic Pain Patients', this project was concluded in 2017. The SIS funds are managed by MCVS on behalf of the Ministry for Social Dialogue, Consumer Affairs and Civil Dialogue. The project allowed MHN to put up a new website which was launched in 2017. Initial layout and design was done by a company which was chosen whilst it was mostly built with the work of MHN Secretary supported by Mr David Borg who is a medical student but who has been offering service to MHN under the Youth Volunteer scheme. Thus we would like to thank the Ministry for Social Dialogue, Consumer Affairs and Civil Rights for the availability of such funds and opportunities to have the youth volunteer.

8. Societal Impact of Pain (SIP) Symposium 2017

MHN together with No Pain Foundation Co-hosted SIP Symposium 2017. Dates are 7-9th June this event was held at the Hotel Excelsior and brought to Malta top notch speakers about Pain and development of Policies and health sector. Financial support was also received through the Ministry of Finance and SIP also gave a generous donation to MHN in compensation for work carried out in preparation and during the event. A Pre-symposium focusing on Malta was held on the 7th June during which a Pain Position Paper for Malta was presented, this was followed by conclusion event of the Red Project. A video message by pain patients was done for the occasion, the whole video and shorter videos are available on MHN youtube account. The other 2 days were packed with interesting meetings. It was a pity that none of the Maltese Politicians attended due to the effect of the elections however there was a good participation by 3 Maltese MEPs. A very special occasion the first edition of the European Civic Award for Pain which awards were given by HE Marie Louise Coleiro Preca, President of Malta. For the event she made a very inspiring speech too. More details may be found on the [SIP website](#) including beautiful videos and photos and an impressive publication with proceedings. Thanks to SIP for coming to Malta. Rare diseases and chronic pain were included in the draft conclusions for the Malta Council Presidency.

9. Future of SIP Malta

Meetings for members interested in SIP Malta were held before and after SIP symposium, however so far no results have been achieved in a concrete manner apart from the Consensus paper which was presented during the symposium. Christopher Vella & Gertrude Buttigieg were invited to attend for SIP Symposium follow-up meeting in October 2017, and a decision was taken to support more local initiatives rather than European level. Thus it is important that the SIP Malta remains active to keep up what we have achieved so far.

In order to stimulate the organisations this year instead of organising an event by MHN to promote World Day against pain in October, we offered funding for the members to organise their event to promote the day. Only ARAM took up MHN offered and used funds to organise a morning for members and relatives and this was very well attended.

10. VOPs

In March 2017 contract was signed through the VOPs scheme to carry out project Ref VOPs 25/2017 entitled 'Impact of Pain in Maltese Citizens'. The project was jointly won by MHN & NPF as partners. Through this project data on the degree of pain on Maltese Citizens was carried out after we recruited the services of a project manager, we also had various advisors on board and then a Business Leaders Malta were chosen after a call for tender for data collection was issued. We are in the final stages of the project and a closing conference will be held on 18th April 2018 and project will close by 30th April 2018.

11. Memorandum of Understanding with Malta Medicines Authority

On 1st April 2017, a memorandum of Understanding was signed between MHN and MMA whereby both parts agreed to collaborate through regular communication and support for activities especially events dealing with patient education and empowerment. We thank MMA for this collaboration which is helping MHN organise its events with less financial burden like today.

12. National Cancer Platform

Whilst MHN still supported the NCP during 2017 it was difficult to catch up with this entity too and we have not contributed much directly although we still support and form part of the NCP. A development which happened over the year is that now the Platform is a registered organisation and is set up with its own statute this was consolidated in EGM held in September.

13. MHN 10th Anniversary Celebrations

In 30 November - 1st December 2017, thanks to the possibility of benefitting from Funding through the Training Initiative Scheme through MCVS, MHN managed to organise a 10th anniversary celebration which included also Patient Training event. The Malta Health Network offered introductory training on the European Patient Ambassador Programme ([EPAP](#)) at the Malta Life Sciences Park. The programme provided 35 patients, carers and professionals to represent themselves and others successfully. EPAP's Trainers included Kate Hill and Kjeld Hansen, Council Members of the European Lung Foundation ([ELF](#)), EPAP Patient Advisory Group Members Participants were also addressed by the Hon. Dr Clifton Grima, Parliamentary Secretary for Youth, Sport and Voluntary Organisations.

Participation Certificates were awarded by Prof. Anthony Serracino Inglott, Chairperson of the Malta Medicines Authority, and by the Hon. Dr Deo Debattista, Parliamentary Secretary for Consumer Protection.

This event was reported in the local media, and on the newsletters disseminated by ELF & IAPO.

Activities on a European & International Level

MHN has maintained its membership in European Patients Forum (EPF), European Public Health Alliance (EPHA), Volonteuropa and the International Alliance of Patients' Organisations (IAPO). This is possible and thanks to funding received through the Civil Society Fund managed by the MCVS on behalf of the Parliamentary Secretary for Youth, Sport and Voluntary Organisations.

14. International Alliance of Patients' Organisations IAPO

MHN did not attend for AGM this year however we were notified and invited to attend for the International Alliance of Patients' Organisations (IAPO) 2018 Congress & AGM to be held in Miami, which however board has agreed it is too expensive to send a representative even though there is the possibility of a bursary but it would not cover costs sufficiently.

In 2017 we used the EPAP training and 10th Anniversary Celebrations to promote the Patient Solidarity day which was celebrated on 2nd December.

PR issued by MHN was published in IAPO newsletter and included in events for the day and disseminated to members & promoted on their website.

15. European Patients Forum (EPF)

MHN maintained its affiliation in European Patients Forum (EPF) and was invited to various events and initiatives carried out in 2017.

- I. Matthew Attard from Epilepsy support group applied and was chosen for youth training programme with EPF for 6 months, which he successfully did
- II. Gertrude Buttigieg has represented MHN for EPF AGM held in April. This meeting also included a Leadership Meeting where they gave information on their patient access campaign.
- III. Rachel Portelli (from Malta Diabetes society) was nominated and accepted to be our youth representative on EPF Youth group

16. Active Citizenship Network (ACN)

Gertrude Buttigieg was invited to give a presentation at the Patients' rights day event held on 10th May in Brussels. The presentation was about the possible involvement of patients organisations in regulatory bodies where we shared our experience also linking to the MOU which had just been signed with MMA.

17. European Public Health Alliance (EPHA)

MHN maintained affiliation in European Public Health Alliance (EPHA). Thanks to this communication with EPF and the contacts built with Dr Stefan Buttigieg as participant in EPHA eHealth working group, Gertrude Buttigieg was offered the opportunity of Chairing a session led by EPHA during eHealth Week which was held in May in Malta, it was one of the biggest events which were carried out during the Maltese Presidency. I would like to thank EPHA for the fantastic opportunity.

MHN this year was represented for EPHA AGM by Dr Roberto Debono.

18. Volonteuropa

Maintained affiliation in Volonteuropa we were invited to send representative for annual event and conference looking at youths, MHN was represented by Matthew Attard.

Our members SOS Malta benefitted from our affiliation in Volonteuropa by participating in Training on humanitarian aid – through the EU Aid Volunteers Initiative. An EU AID INFO DAY- An event was organised by MCVS and SOS Malta on the 13th of July 2017. Unfortunately we were only informed about this session at the last minute and nobody from MHN BOA could attend since it was such short notice, this was disappointing but life goes on.

The Future

- I. Finish the Project Ref VOPs 25/2017 entitled 'Impact of Pain in Maltese Citizens'. Research results will be disseminated as widely as possible on a local and European level.
- II. To use these results with policy makers possibly to influence legislation of pain especially in view of the introduction of medical cannabinoids as treatment where we wish to have legislation/policies and practices which are more inclusive and encompassing than just selective.
- III. Hope to manage to meet up with the Deputy Prime Minister and Minister for Health since meetings set so far have all been cancelled from their end.
- IV. Explore options to strengthen awareness on patients rights and implementation of the local patient charter even given its limitations
- V. Look at the matter of Patient Safety and explore the best options to start some work in this area.
- VI. Keep website up to date also with information coming from members.
- VII. Maintain contact with local authorities and our foreign contacts and partners. Hope to be able to strengthen MHN with new members and hopefully staff if a suitable person is found and seconded with MHN – we have also option for youth volunteers should any organisation knows anyone interested.

March 16th 2018.