

"Enhancing the patient's' right to avoid pain through the EU network of manager of good practices on chronic pain"

Mariano Votta, Director of Active Citizenship Network,

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Good morning everyone. As co-organizer of this initiative, I want to thank you again for your presence here today.

Well, I state that I speak of the Sine Dolore World Park (SDWP) with the privilege of having visited it twice, and I am about to return for the third year. So I hope it will not distract me from being objective.

I can testify how much this initiative has grown up over the years and consequently of how much interest and expectations are growing around it. I will tell the enormous potential and also some limits (mainly related to the costs to reach the island, and the still strong link to a national context) but I'll come back to this shortly.

1. The first point I would like to highlight is the relationship between the small and the large.

It has happened to me several times to hear that it is a beautiful initiative, made in a beautiful place, but in a context that is too small that has no impact.

But I do not believe that an initiative carried out far from the main European capitals and more generally from the buildings of the Institutions can not have an impact on public policies and, ultimately, on the conditions of many citizens.

For years we have been committed to ensuring equal opportunities for access to services for the citizens throughout Europe regardless of where they reside, in order to avoid A-class citizens and B-class citizens. This is why my organization was born in Italy 40 years ago and for this purpose we are still committed today, at local, national and European level. There are many examples of praiseworthy initiatives far from the spotlight but capable of bringing benefit to the community, capable of having a positive impact on the care of common goods because they are oriented towards the general interest. For this to happen, we need a great civic sensitivity by the promoters, but also a support from public and private subjects who believe in it and invest in that specific initiative. This is the case, for example, to remain in the health sector, of the European Health Forum Gastein, hosted by Bad Hofgastein, an Austrian municipality of about 7,000 inhabitants nestled in a fantastic landscape context.

Menorca with its SDWP, on chronic pain, can potentially represent at European level what Bad Hofgastein represents on health policies in general, with his European Health Forum Gastein. It is a challenge and a wish at the same time.

Of course, it depends first of all by the decision of the promoter to continue on it without any auto referential approach, but also it will depend how much public and private bodies want to invest and support it. We have decided to support it not only because it addresses a subject dear to us, the right of patients to avoid pain and suffering, but above all because we have found in Menorca, during the week of the SDWP, a context with a soul, a strong sensitivity and a widespread civic participation - which is in line with our nature and our history of civic association.

The support of the MEP Rosa Estaràs Ferragut is particularly appreciable, for what it is doing at the European level, and for the ability to sensitize its colleagues at the national level. For the same reason I find with disappointment the absence of the European Commission that had also been

invited. In particular, the DG Santè team that manage the EU Health Policy Platform has been invited because, and it is a recent news, this online platform hosts "The Societal Impact of Pain Thematic Network" a commendable initiatives to share best practices and develop policy recommendations of which, I am sure, Sam the Executive Director of EFIC will speak to you later on.

2. And here I come to my second point. What role can the SDWP play in contributing to share best practices and develop policy recommendations? The potential is truly remarkable. Indeed:

2.1 At national level, I think SDWP could represent the perfect context where to promote the Spanish version of the "Societal Impact of Pain" (SIP), it means a multi-stakeholder platform able to provide opportunities for discussion for health care professionals, pain advocacy groups, politicians, healthcare insurance providers, representatives of health authorities, regulators and budget holders. I encourage *Sine Dolore European Pain Foundation* to play an active role on it, in accordance with the promoters of SIP, of course.

2.2 At EU level, we believe that the already mentioned online platform provided by EU Commission, to share best practices, is good but not enough. For this reason, and more in general – with the aim to contribute to make the invisible visible on chronic pain - my organization and the Sine Dolore European Pain Foundation have promoted a joint initiative called "Pain Euro-Mediterranean Coalition", that is neither a new association nor an EU umbrella organisation, but the first civic incubator of best practices against pain across Europe, an informal network composed by manager concretely engaged to carry out good practices across Europe. And the SDWP it will be the context where meet each other, share experiences, promote initiatives in other context.

The idea of this Coalition came out on June 2016 during the event realised at the EU Parliament "[Pain therapy and the degree of patient's pain in the age of cross-border healthcare](#)", and it received the support of the MEPs Interest Group "European Patients' Rights and Cross-border Healthcare" in order to contribute to transfer what we have achieved from the European agenda into the European culture: that is, to raise awareness, fight stigma, improve quality of life for people suffering from acute and severe chronic pain, reduce the socio-economic impact of chronic pain in Europe by ensuring that the right to avoid unnecessary suffering is guaranteed everywhere and to everyone.

In particular, this Coalition, that has the scientific support of the European Multidisciplinary Network in Pain, Research and Education/Efhre International University, aims to be:

- The agora of operators of good practices on pain, encouraging the exchange of experiences among health professionals, healthcare providers, Institutions, civic associations and Patient Advocacy Groups (PAGs);
- An open multi-stakeholder platform mainly addressed to the constituency dealing with pain relief at local and national level across Europe rather than to EU umbrella organisations;
- The fusion of experiences coming from pain and patients' rights constituencies;
- The missing piece necessary to integrate the scientific research on pain with the "civic information" approach on the topic;
- A bridge on pain built in the Mediterranean area but intended to overcome EU borders and reach non-EU countries as well;
- A facilitator for advocacy and policy actions on chronic pain at local, national and European level.

The Coalition was officially presented last year in the framework of the “Sine Dolore World Park”, and the first enthusiastic actors who have decided to join it are advocacy groups & patients organization coming from EU Member States of Portugal, Spain, France, Italy, Croatia, Malta, Bulgaria and – outside EU -, from Kosovo, Albania and Switzerland.

With them, are involved in the Coalition the managers that carry out good practices selected by an international jury of experts in the context of the bi-annual research-project called “[EU Civic Prize on Chronic Pain - Collection of good practices](#)”, the initiative promoted since 2015 by my organization at EU level with the aim to give evidence on existing good practices in terms of struggle against pain. You have received the leaflet, please participate and share with us your ways to work on chronic pain and join our community of managers of good practices! thanks in advance!

Well, the initiative scheduled next 6th of May in Menorca as closing event of the SDWP, already mentioned by Jordi and titled “Making visible the invisible on Chronic Pain: sharing successful experiences from Spain to Europe” is the annual meeting of the informal network of manager of good practices, an occasion to share best practices at EU level and put the premises to develop policy recommendations at national level thanks the great participation of Spanish advocacy groups dealing with the topic.

In general, the diversity of members within the Coalition will strengthen collaborations among all the relevant stakeholders. At the same time, the different perspectives shared will enrich European and national experiences, expertise, data and benchmarking on chronic pain.

We strongly believe that the EU network of manager of good practices on chronic pain could represent a way to reduce the impact of chronic pain in Europe by ensuring that the right to avoid unnecessary suffering and pain ([11th Right in the EU Charter of Patient Rights](#)) could be recognized, guaranteed and respected everywhere and to everyone.

Also for this reason, of course I am glad to invite all you to join us in Menorca in May.

Thank you for your attention.

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