



## **EUROPEAN PATIENTS' RIGHTS DAY 2021**

### ***The role of civic society and Patients Advocacy Groups for more resilient Health Care Systems. Lessons learned toward a European Health Union***

*5<sup>th</sup> & 6<sup>th</sup> May 2021, from 10:00 to 12:00 CEST*  
Digital Conference

#### **Opening Remarks and Keynote Presentations - 5th May 2021**

**Mariano Votta**  
***Director Active Citizenship Network***

Good morning and greetings from Rome, where the headquarters of Active Citizenship Network is located. Welcome to the European celebration of the fifteen Edition of the European Patients' Rights Day, the second one realized in digital format.

As you probably know, Active Citizenship Network, the European branch of the Italian NGO Cittadinanzattiva, has promoted this multi-stakeholder event since 2007, and as its Director, I am very honored to celebrate its anniversary, especially in this difficult situation that we are all facing.

I believe that each of us remembers the episode, moment, or image that opened our eyes to the fact that our daily activities, our jobs, our lives have been turned upside down.

Upon arrival at the airport in Rome, returning from my usual trip to Brussels, there was the Red Cross waiting for passengers holding thermo scanners. It was February 21, 2020, and in the same evening, we heard the news of the first death in Italy due

to Covid. This is my first personal memory of what would soon turn out to be a global pandemic.

After more than a year, this “nightmare” is not over, although now there seems to be a light at the end of the tunnel. This is especially due to the enormous progress of science (given the speed at which highly effective vaccines have been produced), to the extraordinary abilities of the health care personnel (to whom we will be eternally grateful), to all actors, institutional but not only, who have worked hard to fight the pandemic, and to the high sense of civic duty that the population has shown to have in the vast majority of cases.

However, we still perceive the urgent need to better address the consequences of the Covid-19 pandemic. Evidence collected during the crisis show that COVID-19 has had a significant impact – for instance - on NCDs. Indeed, oncological and chronic patients have been left almost alone for several months.

Rather than recalling the impact of covid, today we want to highlight the actions and reactions that have civic & patients' organizations as protagonists: actions realized despite the pandemic and reactions put in place to mitigate its impact.

In our experience as a civic association, over 30 different types of initiatives have been undertaken in pandemic times by Cittadinanzattiva to contribute to the fight against COVID-19: advocacy activity for chronic patients & therapeutic plans; advocacy activity for cancer & COVID-19 patients; advocacy activity & solidarity for vulnerable target groups; concrete support to the General Practitioners; initiative focused on the citizens' empowerment; civic monitoring; political proposals; local initiatives; updates for our constituency and the public; initiatives to restart; among others.

To enhance the collective learning process induced by the pandemic, in occasion of the annual European Patients' Rights Day, we have decided to start from concrete experiences that have allowed us to think about necessary system changes towards

more resilient health systems, in which it is also necessary to recognize the key role of Patients' Advocacy groups (PAGs), citizens' organizations involved in healthcare issues and, more generally, of all actors that promote health as a common good. From their account of the pandemic, it emerged in particular a story that describes - in a tangible manner - about the great reforming force of civic organizations, capable of responding promptly to new needs by managing services, building alliances, quickly signalling necessary normative or procedural changes, mobilizing resources (both human and economic) and introducing and promoting practices from which it will not be necessary to go back when everything is over.

An activism and involvement – in support of the institutions and for the benefit of local communities - that is not mentioned in the context of the "Proposal for a regulation of the European Parliament and of the Council on serious cross-border threats to health and repealing Decision No 1082/2013/EU"<sup>1</sup>. The proposal reveals a serious lack which proves as completely unjustified in light of the lessons that we should have learnt from the pandemic: in the document (opened for a public consultation until last February) there was no reference to the role and involvement of actors of the civil society and Patient Advocacy Groups (PAGs) which could be engaged in the management of serious cross-border threats to health in support of the institutions and for the benefit of local communities.

We believe that from the today and tomorrow's discussion with the institutions, associations and experts, as well as from the constructive analysis of what has not worked, we can support a concrete multistakeholder engagement – in the shaping of a stronger European Health Union.

*After all, this is an auspicious historical moment: Member States have just sent their National Recovery Plans in which the issue of health is a key element; in a few days the Conference on the Future of Europe will start, and we hope that health-related*

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<sup>1</sup> EU Commission: "Serious cross-border health threats – stronger, more comprehensive rules": <https://ec.europa.eu/info/law/better-regulation/have-your-say/initiatives/12795-Serious-cross-border-health-threats-stronger-more-comprehensive-rules>.

*issues will be placed at the heart of the debate, as it will happen in the next Global Health Summit planned on May 21 in Rome.*

*From the importance that will be given to health-related topics in this European political framework we will understand if "the necessity to create a stronger European Health Union" – as underlined by the European Commission President Ursula von der Leyen in her "State of the Union" statement – is merely a claim or the actual direction taken by the European institutions, and the key element with which we'll evaluate their work.*

We have understood, at both macro and micro level, what must not happen again in the future: among the others, the selfishness and unilateral actions at the expense of solidarity and coordinated actions, as well as the limited access to different health care services. From the point of view of an organization which promotes citizens' activism for the protection of everyone's rights, offering support to people in vulnerable conditions, it is not acceptable to respond to the immediate needs of citizens facing the Covid-19 pandemic simply by closing services. Instead, alternative organizational solutions are needed to guarantee continuity and quality of care.

All panelists who will participate in this year's conference have been invited to share experiences and suggestions, with a specific focus on the resilience of Healthcare Systems.

Well, before I finish my introduction, please let me remind you that today - among other things - we celebrate the "Global Hand Hygiene Day"<sup>2</sup>: there could not be a more exemplifying image for a gesture – cleaning our hands - that we repeat dozens of times a day as a measure of prevention and personal protection. An image that - contrary to what it symbolically represented in the Holy Scriptures - today more than ever means; taking care of our own and other people's health.

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<sup>2</sup> <https://www.who.int/news-room/events/detail/2020/05/05/default-calendar/hand-hygiene-day>.  
[http://www.salute.gov.it/portale/news/p3\\_2\\_1\\_1\\_1.jsp?lingua=italiano&menu=notizie&p=dalministero&id=4680](http://www.salute.gov.it/portale/news/p3_2_1_1_1.jsp?lingua=italiano&menu=notizie&p=dalministero&id=4680)

Finally, let me thank in advance all the panelists invited, in particular MEP Brando Benifei for confirming also this year his interest in this initiative, Pierre Delsaux the Director-General for Health for providing us the EU Commission perspective, and Brian Maguire, a journalist, producer and broadcaster, with great experience on European politics and business, for having agreed to chair the first day of the conference.

Thank you all once again, I wish you a worthwhile and interesting conference.