

Overcoming new challenges for advocacy of people with intimate health conditions in Europe

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Welcome speech

Mariano Votta, Responsible for EU Affairs – Cittadinanzattiva-Active Citizenship Network

Good afternoon and welcome to all. It is always a pleasure to meet at these closed meetings, which are necessary to explore topics of special significance to us. I hope you all had a pleasant journey.

Thank you, Pier Raffaele, for introducing me. Today I see familiar faces - associations that have been linked to our network for years - but also new faces, so please let me take a moment to introduce my organization.

My name is Mariano Votta and I work for an NGO very committed to health issues called "Cittadinanzattiva," which was founded in Italy in 1978 when the National Health System was established in my country. Citizens decided to organize themselves to reduce health inequalities. As Italian citizens, on paper, we all have the same rights, but - depending on whether we live in the North or the South of the country - we can face different quality standards, different access to care, different amounts of health workers, hospitals, etc. This is the cornerstone of my organization, which is not focused on a specific disease or health condition, but on the need to strengthen and protect the rights of all citizens, starting with those of patients.

As Cittadinanzattiva's head of EU Affairs and director of our EU branch called "Active Citizenship Network," together with my team-partly based here in Brussels and partly at our headquarters in Rome-we are committed in front of relevant institutions and stakeholders at the EU level to increase the promotion of civic activism and participation in the political arena, and to better protect the rights of citizens and patients, which are the strength and uniqueness of ACN.

Why we are here today

Today's initiative-as you know-is targeted at you as representatives and leaders of Patients Advocacy Groups (PAGs) working locally and nationally to protect patients' rights. It is part of the European project "Overcoming new challenges for advocacy of people with intimate health conditions in Europe" supported by Coloplast and promoted by Cittadinanzattiva-Active Citizenship

Network and F.A.I.S.-Federation of Associations of Incontinents and Ostomates, represented here by its president Pier Raffaele Spena, whom I also thank for his role as moderator today.

As he will tell you in more detail, F.A.I.S. is a non-profit organization that brings together regional voluntary associations for the benefit of incontinent and ostomised people in Italy-with the aim of giving more attention to the sensitive issues related to this topic.

Data from Italy

The numbers say that more than 7 million Italians, aged 18 to 70, suffer from urinary or fecal incontinence. Incontinence is a problem that is still too often felt an embarrassment to address directly. In fact, 57.2 percent of those suffering from urinary incontinence have never discussed the problem with family members and friends; hence a difficulty in providing accurate estimates of the phenomenon¹.

A Hidden Challenge

According to the European Association of Urology, some 55-60 million Europeans suffer from continence problems². This is a pervasive health issue significantly affecting patients and their loved ones, national health systems, the economy, the environment, and society. The debilitating and often chronic consequences of continence problems are felt across gender, age, and socio-economic backgrounds, and can result in a serious negative impact on individuals' quality of life. Physical, psychosocial and economic consequences for patients and their careers are a barrier to full participation in society. Comorbidities are common and diseases such as prostate cancer, bladder cancer and cervical cancer and their treatment can cause continence problems, which increases morbidity significantly.

Focus on ostomy

Today we will focus on an absolutely underestimated health condition. In fact, among the large portion of the European population living with intimate health conditions, more than 700.000 live with a stoma. Despite the large number, they feel that they are invisible to society, mainly due to the lack of:

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https://www.quotidianosanita.it/cronache/articolo.php?articolo_id=89244#:~:text=La%20stomia%20%C3%A8%20un'apertura,malattie%20infiammatorie%20croniche%20o%20tumori.

² https://d56bochluxqnz.cloudfront.net/media/109857_EAU_Urge-To-Act_Manifesto_A5-folder.pdf

- awareness of issues, challenges and opportunities within intimate healthcare by key health decision makers;
- equity in access to healthcare solutions among European Countries;
- patient access to evidence-based innovations in intimate healthcare across Europe;
- a platform for knowledge sharing among people/countries;
- a European HTA opportunity.

These represent new advocacy challenges for people with intimate health conditions in Europe, which Cittadinanzattiva-Active Citizenship Network-along with all of you-wants to help better address.

The idea for this project came from Pier, with whom we are linked by many years of battles in Italy to advocate for the protection of patients' rights, but the merit goes to Coloplast that decided to invest on such a Europe-wide initiative that, as we have already informally anticipated to you in the past weeks, and which my colleague Bianca will better illustrate to you at the end of the event, is not meant to be a spot initiative but the beginning of a journey to help better represent at the European level, to policy makers, relevant stakeholders and the affected people themselves, the health needs of ostomised people.

Thanks to independent experts whom I want to thank in advance, a common set of up-to-date information will be provided today. Experiences will also be shared, building an informal network of specific patient associations, which will be trained to become educators in their communities to improve the adoption of messages aimed at protecting individual and public health, fighting stigma, making the invisible visible, and reducing health inequalities across Europe.

Among you there are associations that are already familiar with the topic, along with others that in a more cross-cutting way are dedicated to protecting patients' rights. We asked some of the "skilled" associations to share their experience. And to all of you we ask that you make the most of this opportunity by interacting and not hesitating to ask questions. We need to feel comfortable this afternoon, and if you have any special needs, please do not hesitate to let us know.

We are eager to learn more because, as always, being well-informed and up-to-date is often the best prerequisite for promoting greater activism, we are also hopeful in the area of intimate health conditions.

Thanks again for the attention. I wish you a fruitful seminar.