

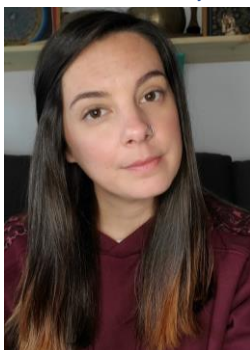
Overcoming new challenges for advocacy of people with intimate health conditions in Europe

17 November 2023 | 14:30 – 18:00

Martin's hotel, Brussels

Participants' list

Inés Aulló Pérez, AEAPAF & FAPOE, Spain



AEAPAF is the Spanish Association for patients Affected by Familial Adenomatous Polyposis. It was established in 2004 due to the lack of information about FAP (Familial Adenomatous Polyposis) both for patients and physicians. FAP is a rare disease, it is an autosomal dominant disease caused by a germline mutation in the APC gene. When diagnosed in time, all patients need to have a prophylactic colorectal surgery to reduce the future risk of colorectal carcinoma (CRC), which is guaranteed to develop without surgical intervention. This, though, is not the only risk, as different manifestations of the disease include congenital hypertrophy of the retinal pigment epithelium (CHRPE), desmoid tumors, extracolonic cancers (thyroid, liver, bile ducts, duodenal, pancreatic, central nervous system), osteomas, liver adenomas, dental alterations, cysts... AEAPAF mission's is to raise awareness about this disease, that can be deadly if not treated, and help patients that find themselves in the same path we did years ago, assisting in finding hospitals and medical teams familiar with FAP around the country, second opinions and also helping them navigate all the ups and downs along the way with the different diagnosis we get.

Patients who undergo the abdominal and pelvic surgeries FAP requires along a patient's life, face diverse intimate problems that sometimes overlap, such as altered daily stool (from 4 to 13 times a day), incontinence (both urinary and stool), decreased fecundity (estimated 50%), sexual disfunctions (e.g: inability to develop or maintain an erection and ejaculation dysfunctions in men, and for women issues with vaginal dryness), libido loss, and/or pelvic floor dysfunctions. Also, most of the patients face the challenge of living with an ileostomy bag, and/or the presence of desmoid tumors that can alter body image.

Bringing all this changes and challenges to light is sometimes difficult to talk about as in our society is not well seen to discuss «such themes» in public, pushing it into the background or under the rug.

FAPOE is the Spanish Federation of Associations of ostomized patients. It is a non-profit organization, constituted on 2021. FAPOE also means all the 28 Associations of ostomized patients from all over the country, being some of them the ones who make up the Board, and all of them united by common objectives, being the main one to achieve the best possible quality of life for ostomized people. In addition, the FAPOE is part of the Spanish Patients Forum(FEP) and has the support of Inclusive Exchangers and the Spanish Society

of Nursing Experts in Stomatopathy, SEDE. The Federation proudly represents and gives voice to a collective of over 210,000 people directly and over one million indirectly, taking into account the family environment.

Inés Aulló Pérez is an AEAPAF Board Member and a FAPOE member.

Almost fourteen years ago she was diagnosed with FAP and it changed her, her life and how she related to the world. Besides having the FAP diagnosis, she had stage 1 cancer, malnutrition, severe anaemia and already had stool incontinence, as her large intestine wasn't working at all. Her family thought she was making it up and that it was impossible to go to the bathroom as many times as she did. After that first fright, her team also had to remove the 25% of her liver due to two small carcinomas caused by a hepatic multiple adenomatosis - another rare expression of the rare disease she has. They're also watching closely her parathyroid gland and after this seminar she'll go straight to the operating room to remove two large sarcomas after 7 months of ineffective chemotherapy - so it's not short of a miracle that she is here today. After overcoming the many challenges of being rare - finding a diagnosis, surviving a colon cancer and the colectomy, incontinenes, keep on fighting day to day with FAP, she started reflecting about her situation and that of many of the patients suffering from her pathology: there were not much information about it, we do not have easy access to the professional teams that help us, and for many months we live in uncertainty, until we find someone with our mutation. There is no definitive treatment either, we are tied to constant vigilance, chemotherapy and surgeries when it's absolutely necessary. All this means that we are always carrying uncertainty in our vital backpack. We have no choice but to be extraordinary and hope for a future that will provide us with some alternative to continuing to fight so that FAP does not beat us to the punch and the ones that comes after us have a better paved path. In the eyes of society, it seems that young people are invincible, that nothing can affect young adults. But cancer, accidents, ostomies, rare (or not) diseases does not understand age, ethnicity, religion or sex. She founded AEAPAF seven years ago, talked to Monica (a friend and President of the Association that couldn't be here today for her own challenges) and started an instagram profile as a patient, sharing how it is, the information she can get to, the things she can discuss with her doctors, the fears she has, talking about everything taboo or not... And all that there is to be young and rare. We need to raise our voices. Alone we are just one, but together we are unstoppable.

Andreas Christodoulou, Cyprus Federation of Patients' Associations (CyFPA), Cyprus



Andreas is the Director of Operations of the Cyprus Federation of Patients' Associations (CyFPA), an EPF member whose mission is to ensure that patients in Cyprus have access to holistic, patient-centered, equitable and social healthcare. As an expert patient advocate and a patient himself, Andreas has been actively involved in the fight to control cancer through the promotion of prevention and early detection of cancer in the general public and the improvement of quality of life of all cancer patients and their relatives. He strongly advocates of the need for a Holistic Patient Care and for a Universal Healthcare Coverage. He has been elected as a Board Member in EPF's Board of Directors in the Annual General Meeting which was held in late April 2023. Since January 2023, he is part of the Expert Scientific Peer committee for the European Network of Youth Cancer Survivors under the EU-CAYAS-NET - co-funded by the European Commission project. On National level, Andreas has served as a Board Member of the Cyprus Federation of Patients' Associations (CyFPA) since early 2017 and from 2020 he was the Treasurer of the Executive Board until January 2023. In November of 2019, he was appointed by the Council of Ministers to serve as a Member at the Board of Directors of the Cyprus' National eHealth Authority (NeHA), which is the national body of Digital Health in Cyprus and the county's national health contact point, as the patients' representative (2019-2024). From late

2020 he serves as a Board and founding member of EUPATI Cyprus, a non-profit foundation that provides education and training to increase the capacity and capability of patients and patient representatives to understand and meaningfully contribute to medicines research and development (R&D). He has also joined the EUPATI Patient Expert Training Programme 2022-2023 as a EUPATI Fellow (6th Cohort). He holds a Bachelor and Master degree in Computer Science and Master in Global Ethics & Human Values from King's College London.

Mónica de Elío, Foro Español de Pacientes, Spain



Mónica de Elío holds a degree in Economics from the Universidad Autónoma de Madrid and has several advanced courses in Marketing and CRM focused on customer knowledge, and an Executive MBA from ESIC. Mónica has extensive experience in the area of customer loyalty and customer service, having worked as head of these areas at British Telecommunication, MercadoLibre and Enron Directo; and in marketing and communication when she worked at WebToGo Mobiles, Argentacomunicación and Tooio Mobile. The diagnosis of type 1 diabetes in a family member led Mónica to become a member, together with her family, of Asociación Diabetes Madrid, and she later became the Head of Communication and Institutional Relations of this association, a position she held for 8 years. Since September 2021 she has been Executive Director of the Spanish Patient Forum. The Spanish Patients' Forum (Foro Español de Pacientes, FEP) is a non-governmental and non-profit organization, founded in 2004 by Dr. Albert Jovell, and the first to be integrated in the European Patients' Forum, being a national and international reference as a valid interlocutor in the defense of the interests of those affected by the disease (patients, families and caregivers) and the general population on health issues through: advocacy, training, prevention, research and the promotion of associationism. The FEP is an umbrella association of more than 80 non-profit entities, made up of Non-Governmental Organizations (NGOs) of different legal nature, such as associations and foundations, as well as legally constituted Autonomous Patient Forums.

Bianca Ferraiolo, Cittadinanzattiva-Active Citizenship Network, Belgium



Bianca Ferraiolo is the Head of the Representative Office to the EU of Cittadinanzattiva - Active Citizenship Network since its opening in March 2015 and works as Senior Manager European Affairs. She is involved in many activities at European level with a special focus on health and patient advocacy issues, liaising with all the relevant stakeholders as umbrella and national patient associations, private companies and the European Institutions and representing Cittadinanzattiva - Active Citizenship Network in several multi-stakeholder initiatives.

She was responsible for the establishment and the secretariat of the Members of the European Parliament Interest Group “European Patients’ Rights & Cross-Border Healthcare” (2015) and of the Inter-Institutional Group “SDGs for well-being and consumers’ protection” (2021).

She is also actively involved in European project management, the organization and realization of important European initiatives as the “European Patients’ Rights Day”.

She is a certified Pharmacist, holds a Masters Degree in Chemistry and a post-graduate Diploma in Marketing and Communications.

Reneta Ilieva, Bulgarian Association for Patients' Defense (BAPD), Bulgaria



She has been in the team of BAPD for 6 years as an associate lawyer and projects' coordinator. She has a number of international participation in health forums and conferences in the EU. Until now she implemented several international projects in a consortium with the European Public Health Alliance (EPHA) on air pollution: "Diesel and Health"; "Clean cities and clean air"; "Clean Transport". Provides legal advice on claiming responsibility from individual providers of medical services related to illegal actions to deprive patients of treatment in medical facilities, drug deprivation, delayed treatment, injuries and infections, medical incidents, refusal to pay for medical services rendered, clinical pathways, services and more. She is fluent in English and Spanish language, with a Masters degree in Law.

Alejandra López Callejón, University Clinic of Valencia, Spain

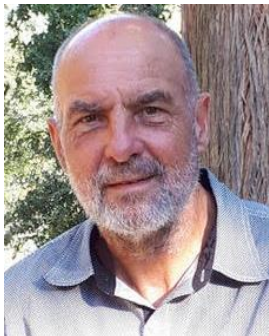


Alejandra López is a stoma therapist at the University Clinic of Valencia. She obtained her nursing diploma in 1996 and her specialisation course in ostomies in 2018. She has worked most of the time in the Emergency and Intensive Care Units of several hospitals.

She has lived and worked in several cities and countries, including the Royal Free Hospital in London for 7 years.

She is very attentive to patients' needs, which is why she has participated in and conducted investigative projects to highlight their needs and provide them with tools to cope with their health conditions. She is in continuous training and participates in patient associations in Spain to share experiences and always try to improve their quality of life.

Jo Maes, EPECS, The Netherlands



EPECS is a non-profit foundation under Dutch law that wants to give a voice to the citizens of the EU. We are convinced that citizens are the basis of the EU and should therefore be and are involved in the EU. By offering tailor-made solutions to these citizens and making their voices heard in various networks and partnerships. EPECS focuses on the health of citizens, the greatest good for all. It is clear that health and economy are connected. The good health of the population promotes the development of a sustainable economy and, conversely, a sustainable economy promotes health. For EPECS, the UN Sustainable Development Goals and corporate social responsibility are conditions sine qua non. For most people, health increasingly depends on a healthy lifestyle. Our global industrial production is out of balance because the 3 Ps – People, Planet, Profit – are not managed in conjunction. As a result, diseases of civilisation such as COPD, diabetes and obesity are developing. These cause the most health problems. Infectious diseases are becoming an ever greater danger worldwide and must be reduced by all possible means. Health care can develop much better in the coming years if it is managed on two tracks: to promote that most people are and remain as healthy as possible, so that they do not have to rely (unnecessarily) on health care; provide the best care for the people who do depend on the healthcare system. On this last point, healthcare in the EU is very advanced and top-notch, although Covid-19 has shown us how fragile our global care is. A healthy lifestyle requires the active participation and responsible behaviour of every citizen. How can this be promoted? Machteld Huber has created worldwide initial support for a new definition of health, namely Positive Health: Health as the ability to adapt and self-manage in the face of life's challenges, social, physical and emotional. Every EU citizen is invited to do this, has the power to do so, and can do so. EPECS does not see health and welfare as ends in themselves, but as tools at the service of the people of the EU. Positive Health promotes equality in health care and enables citizens to take co-responsibility for their own health in a simple way. Having a job, a meaningful life, belonging to loved people, having meaning in life. These are pillars of the Positive Health concept, which strengthen the role of citizens. EPECS has participated in several (EU) projects, organised a lot of citizen summits, is involved in the Cross Border Patient Directive and works together with Euprevent.eu

Jasna Karačić Zanetti, Croatian Association for the Promotion of patient rights, Croatia



Jasna Karačić Zanetti is the president of the Croatian Association for the Promotion of patients' rights. She has a Ph.D. in health diplomacy and she is also the Head of the Health Diplomacy Unit and director of Department of Health Diplomacy and Patient Rights at International chair in bioethics (Former UNESCO chair). She has an active mandate as an ombudsman at the International Council of the Patient Ombudsman. She is an associate lecturer at the diplomatic academy and medical law. She served as a diplomat during the Croatian Presidency of the Council of the European Union 2020, delegated from the Ministry of Health. As a

responsible person for patient rights, she holds consultative status with the United Nations. She got the Rector's Award for Achievements at the UNESCO level for human rights in medicine and the National Geographic Award for Justice in sustainable development goals. She was assigned "Young Leader" for health crisis management in 2021. She is EU Commission expert and associate editor for PLOS ONE journal.

Ana Paula Leon Aguila, Universidad del paciente y la familia, Spain



Ana Paula León Aguila is the Deputy Director of the Universidad del paciente y la familia (Patient and Family University - UPF), which is an innovation academic center that offers accredited education to patients, families, caregivers and volunteers. This is possible only with collaborations from professionals, universities, scientific societies and patient organizations. It's main mission is the empowerment of patients through education, to ensure active participation in decision-making process in health and the improvement of patient experience.

Anastasia Ntanou, Greek Patients' Association, Greece



Anastasia Ntanou is a volunteer at the Greek Patients Association, which is a confederation of more than 70 patients' organizations from all over Greece and across the spectrum of disease. Founded in May 2019, the association is an umbrella (tertiary level) non-profit organization that provides support, advocacy, and capacity building for its members and patients in Greece. With the aim of defending the rights of healthcare recipients, the equal participation of patients in designing and implementing policies concerning them and their contribution to the promotion of public health, the association works to ensure patients' rights are recognized. It also provides assistance in navigating the healthcare system, and advocates for positive changes conducting awareness campaigns and empowering patients to self-advocate. The Greek Patients' Association is recognized by law as an interlocutor of the State for issues concerning health policies.

Anna Obara, East Galway & Midlands Cancer Support, Ireland



Anna Obara is the Centre manager of East Galway & Midlands Cancer Support in Ballinasloe Co. Galway Ireland and she is also a member of Cancer Patients Europe (CPE). She cared for both her aunt who had metastatic breast cancer and her uncle who had prostate cancer. She has spent a lot of time Advocating for them when their voices were not strong enough to do it for themselves.

Working closely with cancer patients and supporting them through their treatment and beyond has made her more aware of how important it is to address the hidden disabilities cancer patients face every day. She is also a Holistic Massage and Reiki Therapist.

Simina Peterfi, European Multiple Sclerosis Platform (EMSP), Belgium



The European Multiple Sclerosis Platform (EMSP), a leading advocacy organization in Europe, dedicated to improving the lives of people affected by Multiple Sclerosis (MS). EMSP focuses on policy advocacy, raising awareness, fostering collaboration, and providing a unified voice for MS patients and stakeholders to enhance access to better treatments, care, and support. Simina Peterfi at EMSP coordinates vital initiatives: Young People's Network, amplifying the voices and needs of young people living with MS, and refines communication strategies for MS Nurse PRO, being in contact with the nursing community and bolstering support for the MS community.

Rosa Piñeiro Fraga, Social-Health Association of Inflammatory Bowel Diseases (ASSEII), Spain



Rosa is a member of the Social-Health Association of Inflammatory Bowel Diseases (ASSEII) since its inception in 2013 and an ostomy patient since 2021. ASSEII is a plural, open and participatory non-profit association, whose greatest concern is the defence of the rights and quality of life of people with Inflammatory Bowel

Diseases (Crohn's and Ulcerative Colitis) and Ostomies, their families and social environment. ASSEII is also a member of FAPOE (Federation of associations of ostomized people of Spain), of the CEDDD (The Spanish Council for the Defense of Disability and Dependency), of the FEP (Spanish Patient Forum), of the Patient Advisory Council in Pontevedra and at the autonomous member of the Segas patient advisory council in the Xunta de Galicia. The association runs several own programs (Settle for psychological support, I need to pass, Sponsor toilet, advice with a lawyer, ostomized toilets...) and collaborates with different programs with other associations of patients with various pathologies. Main aims of ASSEII are to inform, train, advise and make ourselves known to society, breaking the taboo that exists among those affected and their family surroundings about IBD and ostomies. And to achieve a future to talk about them normally, without feeling shame and insecurity. They collaborate with health professionals, health and social administrations at the local, regional and national levels, with official professional associations, for comprehensive support and care of the patient. Thus, acquire the skills and attitudes necessary for the management of the ostomy. Involving their families and caregivers as much as possible, in favour of better social inclusion.

Bárbara Rodríguez Batlle, Spanish Confederation of People with Physical and Organic Disabilities (COCEMFE), Spain



The Spanish Confederation of People with Physical and Organic Disabilities (COCEMFE) is a non-profit association located in Spain. Our mission is to achieve the full inclusion and active participation of people with physical and organic disabilities in all areas of society, through the promotion, defence and claim of the exercise of their rights, as well as coordination, representation and promotion of its Associative Movement thus contributing to the construction of an inclusive and diverse society. COCEMFE is a representative organisation that is socially recognised for its values and its leadership in the exercise of people's rights and in social change, generating a positive impact for the society. Our associative movement is made up of 92 state entities and more than 1600 associations at different administrative levels. COCEMFE and the entities of its associative movement represent more than 2.5 million people with physical and organic disabilities.

Bárbara Rodríguez Batlle is a Project Manager at COCEMFE Central Services. She has been working for the organisation for two years as a Project Manager in all the stages that make up a project. She works in the Department of Projects and Social Innovation supporting the whole project cycle. During these two years, she has participated in research, employment and education proposals following the mission of COCEMFE, which is to promote the inclusion of people with physical and organic disabilities. In the rest of her professional career, she worked in different entities linked to disability as a Consultant and in entities related to International Cooperation.

Irene Schembri, National Patients' Organisation, Malta



The National Patients' Organisation Malta is an NGO managed by patients. The Organisation supports a policy of non-discrimination and encourage all to participate. Most of all, NPO-Malta encourages patients to speak for themselves and take informed decisions. The aims of the National Patients' Organisation are to, advocate and protect the interests of patients/custodians and to empower them so that they can speak for themselves and their family members.

NPO-Malta is continuously raising awareness of the Patients' Charter, providing support and information related to patients' rights, educate patients about their obligations and responsibilities, raise awareness on the cross-border health care directive, educate members on a healthy lifestyle and on the prevention and environmental health among others. The motto for NPO-Malta is "Working **with** not **for** patients".

Irene is the President of NPO-Malta and, in this role, she seeks to listen to patients' problems and advise them on the way forward. She reaches out to many patients through spaces offered in popular national radio phone-in programmes and others. She also writes letters to the Ministry of Health on some general issues, makes herself accessible to patients by inviting them to contact me to give them all the support they may need or advise them on issues that may arise and/or write letters with them to the relevant doctors. She attends meetings held in Malta, online or abroad to keep abreast of different medical and ethical issues.

Agnieszka Siedlarska, STOMAlife fundacja, Poland



The initiator of its creation. Financier, many years of practice in the field of financial management in international corporations. She has accounting qualifications granted by the Ministry of Finance.

She specializes in tax, legal and employment matters in Poland and the EU. While working as a financial director in the Polish branch of a global medical concern, she first encountered issues related to stomas. This experience prompted her to get involved in working for people with a stoma. Her personal sensitivity did not allow her to come to terms with the social exclusion of ostomates and the taboo associated with it. As she says, "the stoma cannot be seen, you can simply live with a stoma, but our ostomates still have to fight for a decent life." The result of these activities was the initiation of the social campaign "STOMAlife. Discover the stoma." She invited social organizations operating in this area to participate. The experience gained during the campaign resulted in the initiative to establish the Foundation. Agnieszka has been very active in the Foundation from the beginning. Her creativity resulted in the creation of many social campaigns, educational programs, training and publications addressed to ostomies, their relatives, but also the medical community and teachers. He co-creates the quarterly "Prostu Żyj", in which ostomates show their everyday lives. Privately, she is a mother of three fantastic children, a lover of dogs and cats.

The STOMAlife Foundation fights against the social exclusion affecting stoma patients. Our aim is to break the taboo associated with stomas and to educate patients and the public about the facts and myths associated with it. The Foundation carry out comprehensive activities for the promotion and protection of health, social welfare and science, higher education and education, especially in the field of action for people affected by diseases of the digestive and urinary tract, including ostomy patients, in particular:

- promoting patients' rights and knowledge of state health policy,
- awakening and stimulating social sensitivity of various communities to the problems of persons with digestive and urinary tract diseases, with particular regard to persons with a stoma and promoting the idea of helping these people in their daily lives;
- undertake activities aimed at the integration and social activation of stoma patients and supporting their families;
- to develop national and international cooperation between those involved in the field of health sector with objectives that are compatible with those of the Foundation;
- to support and activate patient advocacy communities.

Tomáš Skříčka, Czech ILCO, Czech Republic



Tomáš Skříčka is a surgeon, graduated at Brno University of J.E. Purkyne, and specialised in abdominal surgery and onco-surgery. His professional experiences took him in Texas at Baylor University, in Vienna at AKH Hospital, in Milan at Istituto dei Tumori, in London, Moscow, Beograd, Copenhagen, Geneva, Greifswald, Natanya, Lodz, Cairo, Calgary and many other cities and countries.

For many years he has been the head of the Czech coloproctology and president of ESCP (European society of coloproctology), and is co-founder of ECTA (Euroasian Coloproctology Technical Association), continental vice-president of ISUCRS (International Society of University Colorectal Surgeons), president of CEECP (Central and Eastern European Club of Coloproctology). He also is the co-founder of Czech ILCO in 1991 and he's currently the vice-president of the organization.

Together with other colleagues, he organised 22 colorectal congresses (Brno, Piestany, Kaunas, Lodz, Moscow, Debrecen, etc.) and he gave lectures in english, german, italian and russian languages. As an invited specialist he performed surgery in Katmandu, Jakuts, Ulanbator, Cairo, Trnava and several other places.

The Czech ILCO is an umbrella organisation representing all regional ILCO clubs within the Czech Republic. Since 1993, we have been member of IOA and EOA and, over this time, we have cooperated with legal bodies to create new legislation, lobbied the Ministry of Health and represented our organisation's members in dealing with insurance companies, doctors, ostomy pouch producers and other organisations. The aim of the Czech ILCO is to help resolve health issues as well as the social and psychological challenges faced by ostomy patients in an effort to assist their return to life after surgery and to empower them to lead a normal life far beyond. We inform healthcare professionals and laymen both about ostomy patients' needs, raising awareness on what life is like with an ostomy, and keeping them informed of our activities. Our remit is also to actively defend patients' rights wherever we can.

In addition, our organisation prepares and produces training for volunteers wishing to support ostomy patients. With this in place, we have agreements with two hospitals whereby our volunteers can visit new ostomy inpatients and help them overcome the fears and trepidations associated with their surgery. Further, we organise lectures and discussions, take part in other patient organisation meetings and actively contribute

to discussions on stoma-related issues. We place great stress on the need for prevention, encouraging our members to have regular doctor check-ups and we always endeavour to challenge the taboo surrounding ostomy as a health solution. In 2018 Czech ILCO won the Coloplast Merit Award.

Teresa Souto, Movimento Oncológico Ginecológico (MOG), Portugal



MOG is a non-profit association, created in 2019, that is committed to support women with ovarian cancer or other gynecological cancers. Our genesis arises from the urgency of giving voice to the concerns and needs of every woman suffering with this type of cancer. We want to improve their quality of life by raising awareness of the impact of gynecological cancers and collaborating with different entities that help us ensure the proper diagnosis, treatment and follow-up of this community.

In order to achieve its overall mission, MOG has defined a set of objectives, such as:

- to provide support to diagnosed women, as well as their families;
- to raise awareness about the impact of this cancers on the lives of patients and their families;
- to promote health literacy and public education on gynecological cancers and raising awareness of their consequences on everyday activities;
- to help early diagnosis, referral, treatment, control and prevention of this disease as well as motivating access to new therapeutic options.

Teresa Souto is the assessor to MOG's president and in this role she represents the president in several events. She manages the association daily life, which includes contacts with members, other associations and several organizations; manages social media and handles the website update; and also attends training initiatives and conferences, in order to improve the association's knowledge. She also hosts MOG's monthly podcast.

Pier Raffaele Spena, FAIS, Italy



F.A.I.S. (Federazione Associazioni Incontinenti e Stomizzati) is a Non-Profit Voluntary Organisation that groups the Regional Voluntary Associations in favour of incontinent and ostomised people, established in 2002 in Rimini, Italy. Its legal and operational headquarters is located at the National Cancer Institute in Milan.

Some of the Objectives that the Federation pursues are:

- to guarantee rights to all incontinent and ostomised people
- to promote, in each region, the creation of Regional Associations as instruments capable of dialoguing, in an appropriate manner and with appropriate weight, with the various institutions (regional,

provincial and municipal) in order to guarantee adequate and homogeneous assistance to ostomy wearers throughout the country

- promote social campaigns in support of the rights of ostomy wearers and incontinent persons;
- support and promote care projects at regional and national level;
- collaborate with Scientific Societies, Institutions, Associations and Bodies to create a network to support concrete actions in favour of incontinent and ostomised persons.

FAIS has obtained recognition by both the EOA (European Ostomy Association) and the IOA (International Ostomy Association), joining these international organisations as a full member in the name of a consolidated tradition and credibility that, over the years, various Italian Ostomised Associations have gained in the international sphere.

Pier Raffaele Spena is the president of FAIS.

Luminita Valcea, Coalition of Patients Organisation with Chronic Disease, Romania



Luminita Valcea is the executive director of Coalition of Patients Organization with Chronic Disease, being involved in the organization from 2009.

She is a communication expert with 15 years of experience in health communication in general, successively dealing with the communication of healthcare institutions.

She is a trainer in doctor-patient communication, she wrote and implemented European projects.

She collaborated with international organizations like Global Fund to fight AIDS, Tuberculosis and Malaria.

She graduated with a doctorate in Health Communication at the University of Medicine and Pharmacy "Gr.T. Popa" from Iasi.

In 2020, she produced the research report Map of civil society in the field of infectious diseases and vulnerable populations in Romania for the National Committee for the Coordination of HIV and Tuberculosis Control Programs.

Giulia Villa, Università Vita-Salute San Raffaele, Italy



Giulia Villa is Assistant Professor in Nursing Science - Center for Nursing Research and Innovation, Università Vita-Salute San Raffaele, Milan (Italy) since 2021. She got a CNS Clinical Nurse Specialist in Critical Care Nursing, Università Vita-Salute San Raffaele, Milan (IT) in 2010; a MScN Master of Nursing Sciences, Università degli studi di Verona (IT) in 2013; a CIDI Clinical Instruments for Evaluating Health - Development, Evaluation and Implementation, University of Turku, Faculty of Medicine, Department of Nursing Science, Turku (Finland) in 2017 and a Ph.D. in Nursing Sciences and Public Health, Università degli studi di Tor Vergata, Rome (IT) in 2019.

She holds the roles of Board member European Association of Urology Nurses – EAUN, Guidelines and Education (since 2014), Italian Association of Oncology Nurses – AIIAO, vice-president (since 2020), Italian Association of Urology Nurses – AIURO, scientific committee (since 2016). Italian delegate World Council of Enterostomal Therapists – WCET (2019).

Some of her most important national and international professional Honors include:

2021 – Second prize Memorial “Gian Carlo Canese” Revisioni sistematiche della letteratura scientifica. Associazione tecnico scientifica di stomaterapia e incontinenza – AIOSS. Efficacia del programma di prehabilitation per le persone con stomia: revisione sistematica della letteratura.

2019 - Top downloaded paper 2018-2019: Two new tools for self-care in ostomy patients and their informal caregivers: Psychological, clinical, and operative aspects. International Journal of Urological Nursing.

2019 – First prize for best poster presentation, European Association of Urology Nurses – EAUN, 20th International Meeting. Barcelona, Spain.

2016 - First prize for best poster presentation, European Association of Urology Nurses – EAUN, 17th International Meeting. Munich, German.

2015 - Third prize for best poster presentation, European Association of Urology Nurses – EAUN, 16th International Meeting. Madrid, Spain.

2014 - First prize for best poster presentation, European Association of Urology Nurses – EAUN, 15th International Meeting. Stockholm, Sweden.

Mariano Votta, Cittadinanzattiva-Active Citizenship Network, Italy



Mariano Votta is graduated in Political Science at University of Rome. He has a Master in European Public Relations and a Master in Corporate Social Responsibility.

Last July 2013 he was nominated Responsible of EU Affairs at Cittadinanzattiva and Director of Active Citizenship Network, the European interface of the Italian civic organization Cittadinanzattiva, responsible for the international relations with public and private stakeholders such as the European Commission, EU Parliament, EESC, companies.

He is a freelance journalist and programme manager too, with more than 10 years working in the field of citizens' rights, civic information, evaluation of quality standards in services provided by Public Administration and public companies. Between 2011 and 2012 he worked as consultant for the United Nations Development Programme in Colombia, to assert a new governance in the managing of Public Services and Health. In that Country, Cittadinanzattiva opened several Citizen Advisory Centre on Public Services and Health.

In 2015 he took the initiative to encourage and promote the MEPs Interest Group focused on patients' rights called “European Patients' Rights and Cross-border Healthcare” inside the EU Parliament.

Cittadinanzattiva is a non-profit and consumer organization (www.cittadinanzattiva.it). Founded in Italy in 1978, it's independent from political parties, trade unions, private companies and public institutions.

Its main objectives are the promotion of civic participation and the protection of citizens' rights. It considers citizens a fundamental resource for democracy who play an active role in society and should have the opportunity to participate in everyday policy-making.

The headquarters, located in Rome, support the national and European activities.

Active Citizenship Network (ACN) is its branch at European level, created in 2001 and coordinated by Cittadinanzattiva as a flexible network of almost 100 EU civic organizations, based on partnership and on the

participation in common projects, addressed to encourage active participation of citizens in European policy-making. (www.activecitizenship.net). Over the past 10 years, ACN has carried out 30 EU projects together with partners coming from 27 EU Countries.

ACN mirrors Cittadinanzattiva's Italian policies, such as health, corporate social responsibility, transparency, simplification and access in the Public Administration, education and training at the global level.

ACN's mission is to promote and support the construction of the European citizenship as an "active citizenship" which means the exercise of citizens' powers and responsibilities in policy-making.

ACN recognizes the prior role of national and local civic organizations in this process and advocates enrichment of the European Union subsidiarity concept by strengthening the relationship between institutions and citizens, so that institutions favor free initiative of citizens, both individuals and organizations, in carrying out activities directed towards the common good.

ACN partners work in different fields but they all contribute to the Network's mission, i.e. to promote the construction of an active European citizenship. This includes:

- recognizing the primary role of citizens and civic organizations in the care of common goods, and the Public Administration is one of these;
- supporting their participation in policy making at local, national and EU level;
- involving them in the defence of their fundamental rights as citizens, patients, consumers, passengers, users.

In 2007, ACN received the Civil Society Award of the European Economic and Social Committee for its work on citizens' rights.

The initiative is realized by:



With the unconditional support of:

