

#VITA

Value and Innovation of Advanced therapies

ATMPs revolution: empowering leaders of EU civic and patients' advocacy groups

EU online training seminar

24 MAY 2022 | 15:00 – 17:00 CEST

For further information, please contact: brussels@activecitizenship.net

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WELCOME

Maddalena D'Urso

Active Citizenship Network/Cittadinanzattiva

Ladies and gentlemen,

Good afternoon and welcome to the EU training seminar *Advanced Therapies Medicinal Products revolution: empowering leaders of EU civic and patients' advocacy groups*.

I'm Maddalena D'Urso, I work as project manager for Active Citizenship Network, the EU branch of the Italian NGO Cittadinanzattiva, deeply involved in the health issue both at the national and at the EU level.

As you know and as the expert will better explain later, when we talk about Advanced Therapies Medicinal Products we refer to all those innovative treatments that contain genetic material or stem cells and offer the possibility of having new treatment opportunities for serious diseases.

Today we have the opportunity to go into the depth of why we are forefront of a revolution as we said in the title of the event.

This training has been developed in the framework of the EU project #VITA: Value and Innovation of Advanced therapies, realized thanks to the commitment of the #VITA consortium coordinated by LS Cube, global law firm.

In particular, #VITA EU project wants to raise awareness about the new frontier of personalized medicine represented by the ATMPs with the final goal to contribute to promote at the European level the importance of access to advanced therapies by the highest possible number of patients.

The training is just the first step of a project that foresees as follow up the realization of a shared document with which we will open a dialogue with European institutions starting with the patients' needs. For instance, yesterday we spoke with the Permanent Representancy of the Czech Republic in Brussels to try to understand the attention toward the issue that they will give during the Czech Presidency's semester that will start in July meanwhile just today the "Working Party on Public Health" of the Council of the European Union that deals with among others issues: patients' rights, blood, tissues, and cells is reunited.

They anticipated that probably the issue will be taken into consideration as a health priority during the Swedish semester to confirm the fact that the issue is on the political agenda and how much is important to be involved in that now.

From our side we have had the opportunity to inform MEPs in particular MEPs from the Interest Group "European Patients' Rights and Cross-border Healthcare" which confirm to us the interest in hosting the public meeting in Brussels in person or online depending on the progress of the pandemic situation, to "push" towards EU public decision-makers to guarantee broader and fairer access on ATMPs.

So to come back to our training, just after the introduction of the ACN Director, Thank you Mariano the training will host 3 key note speeches by three experts that I want to thank in advance:

Of course, after each key speakers' speech, we will have some minutes for Q&A so please write your questions in the dedicated chat and I will read them for you.

I want to let you know that we are recording the seminar and it will be published on our channel on Youtube, we will also publish the documents shared during this training on the website and in the newsletter.

- The first part is dedicated to *ATMPs as a paradigm shift for patients, public decision-makers and healthcare systems*, with Andrea Grignolio - Senior Research Fellow - CNR Interdepartmental Center for Research Ethics and Integrity, Professor of History of Medicine – Vita - Salute San Raffaele University in Milan
- The second part of the training will deal with the *ATMPs as an investment: addressing the public budget and sustainability issues*, with Americo Cicchetti – Professor of Healthcare Management at the Faculty of Economics, Università Cattolica del Sacro Cuore, Rome (Italy) and Director of the Advanced School of Health Economics and Management.
- The third part will give to us the perspective of the Patients Advocacy Groups thanks to the testimony of IPOPI International Patient Organisation for Primary Immunodeficiencies, an expert patients’ umbrella organizations already engaged to advocate on the topic, IPOPI today is represented by Leire Solis – Health Policy and Advocacy Senior Manager. Today they are also involved in London in an international meeting about ATMPs to testify their strong involvement in the issue.