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Juggling between the cost and value of new therapies: Does science still serve patient needs? – The Thalassaemia International Federation perspective

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Thalassaemia International Federation (TIF), representing the united voice of people with thalassaemia and their families globally, has been striving for more than three decades to empower research, by academic communities and industry, to focus on developing a safe and effective curative approach for thalassaemia. Such a cure would lead to new lives with equal opportunities and challenges, as for every other person not suffering from a severe chronic disease. A gene therapy product was finally authorised in May 2019 by the European Medicinal Agency, thus marking a milestone in the history of the disease. However, sadly, the product was finally withdrawn from Europe, bringing feelings of great disapointment mainly to patients and their families.

In this presentation, TIF expresses its view reflecting the global patients' perspective on this issue, including some thoughts on why this happened, hoping for more proactive work and actions in the near future acknowledging the great progress and advancements made and other coming up with regards to gene based therapies.

Health policy makers, health insurance authorities and healthcare funders certainly need to consider the competing needs for access to expensive therapies by different patient groups and prioritize resource allocation accordingly while at the same time, further to early and transparent dialogue with every involved stakeholder, the industry has to be proactive in developing sustainable business models.

Finding a compromise among patient needs, public interest and pharmaceutical industry interest is indeed a very challenging equation to solve and what is certain is that all stakeholders to share the same responsibility for working towards ensuring access of patients to advanced therapies, including gene-based ones.

Biography

Dr Androulla Eleftheriou graduated with degrees in Biochemistry, Microbiology and Virology, and Business Administration from London Universities. She completed her postdoctoral fellowship at the Centre for Disease Control in the USA. She is currently the Executive Director of the Thalassaemia International Federation since 2006. She previously served as the Head of the Virus Reference Centre of the Cyprus Ministry of Health, a Director of the Cyprus WHO Collaborating Centre of the Cyprus Ministry of Health, a Board Member of IAPO, EPHA and ESTM and a President of the Cyprus Alliance of Rare Disorders. She has published extensively in peer reviewed journals and is the author of numerous position papers.