

Thursday, July 23, 2020

## The Patient Voice & Patient-Focused Drug Development

### Resources

Read more about patient Oriana's journey from her native Portugal where she battled a rare and aggressive form of ovarian cancer: [Oriana Sousa's Story](#)

Visit the **Dealing with Cancer** website to see a video from Oriana and learn more about psychological support for oncologic patients, survivors, caregivers, family members and friends while reducing the negative impact of the disease. and more: [Dealing with Cancer](#)

Share4Rare funded by a Horizon2020 grant from the European Commission, is building a community to gather patients, clinicians and researchers to make a difference in rare diseases. It is a patient centered platform focused in the research that matters most to patients: [Visit Share4Rare](#)

The Lupus and Allied Diseases Association, Inc provides education, support and outreach. Visit <https://www.ladainc.org/> to access additional information.

Three leading voices in the US—the Lupus and Allied Diseases Association, the Lupus Foundation of America and the Lupus Research Alliance joined together to host the Lupus Patient-Focused Drug Development (PFDD) meeting. To learn more about this effort click here: [http://lupuspfdd.org/lupus\\_pfdd\\_initiative.aspx](http://lupuspfdd.org/lupus_pfdd_initiative.aspx)

**Overview:** This session brought together patients, physicians, and advocates to discuss how patient-focused drug development impacts the way researchers and pharmaceutical companies design clinical trials and how the entire health care ecosystem is becoming more responsive to patients.

[www.COVIDAdvocacyExchange.com](http://www.COVIDAdvocacyExchange.com) | [#AdvocacyExchange](https://twitter.com/AdvocacyExchange)

The European Patients' Academy is a pan-European [innovative medicines initiative](#) project implemented as a public-private partnership funding health research and innovation: [European Patients' Academy on Therapeutic Intervention](#)

### Featured Speakers

*Click on panelists name for LinkedIn profile if available*



[Samit Hirawat M.D.](#)  
Panel Moderator, CMO  
Global Drug Development  
Bristol Myers Squibb



[Tamás Bereczky MA, Ph.D.](#)  
Courses and Contents  
Coordinator  
[EUPATI](#)



[Begonya Nafria](#)  
Coordinator, Share4Rare &  
Patient Engagement in Research  
Coordinator, Sant Joan de Déu  
Children's Hospital



[Kathleen A. Arntsen](#)  
National Patient Advocate  
President & CEO  
Lupus and Allied Diseases  
Association, Inc



[Oriana Sousa](#)  
SCOCHT Survivor  
Founder/Psychologist,  
Dealing with Cancer,  
Patient Advocate, Rare 2030,  
EUPATI Student



[Danielle Halstrom](#)  
Vice President and Head, R&D,  
Commercial and GPS  
Communications, Global Advocacy  
Bristol Myers Squibb