COVID ADVOCACY EXCHANGE

# Advocacy for Advancements: Patient Insight Influencing Action

www.COVIDAdvocacyExchange.com | **#AdvocacyExchange**

Through perseverance, ingenuity and collaboration, patient advocates have made great strides in supporting their communities despite the unprecedented and unforgiving effects of the pandemic. This session highlights examples of advocacy work to integrate the patient voice in pharmaceutical research and development (R&D), bringing together advocates from across the globe to celebrate moments of success and discuss the meaningful changes they'll continue to advance in 2021.

## Featured Speakers

**Brian Lee, PharmD**
Director, Global Advocacy, CV, Fibrosis, MS and LCM, Bristol Myers Squibb

**Neil Bertelsen**
Health Technology Assessment International (HTAi) Patient and Citizen Involvement Group

**Maria Dutarte**
Coordinator, European Patients' Academy on Therapeutic Innovation (EUPATI)

**Mellanie True Hills, CSP**
Founder and CEO, StopAfib.org

Bristol Myers Squibb™

## Key Points and Resources

- **Sharing resources is an essential part of promoting patient engagement and elevating the patient voice.** The European Patients' Academy on Therapeutic Innovation (EUPATI) works to enhance the capacity of patients who contribute to pharmaceutical R&D. The EUPATI open classroom supports programs like the Expert Patient Training Course, which equips patients with the knowledge and skills to meaningfully contribute across the R&D process, and the EUPATI patient engagement toolbox also offers free, public information about medication R&D, available in 13 languages.
- **Patient insights help prioritize the research agenda and develop therapies that are better aligned with patient needs.** The Bristol Myers Squibb Patient Expert Engagement Resource (PEER) is an initiative to systematically engage with expert patient advocates and gather their input throughout the entire lifecycle of a Bristol Myers Squibb product.
- The PARADIGM Patient Engagement Toolbox is a collection of resources to help prepare patients for engaging in discussions with pharmaceutical companies about early R&D of new therapies.
- **Patients act generously when participating in pharmaceutical R&D.** In return, pharmaceutical developers aim to cultivate reciprocal relationships with their patient participants, consider the effects of respondent fatigue, respect participants' time through thoughtful survey design, and offer appropriate compensation. Many participants also appreciate knowing how their actions made a meaningful contribution to R&D.
- When conducting health technology assessments (HTAs), patient groups may request sensitive information from their patient communities regarding their experiences living with a condition. **Health Technology Assessment Internal (HTAi) developed this resource outlining ethical considerations for advocacy groups when collecting sensitive survey information from their patient communities.**

GRYT HEALTH