

Williams, Letise

From: Jennifer French <jfrench@neurotechnetwork.org>
Sent: Tuesday, October 23, 2018 12:15 PM
To: Williams, Letise
Subject: Comment for the Patient Engagement Advisory Committee Nov 15

Dear Ms. Letise Williams,

We are submitting comments for the FDA Patient Engagement Advisory Committee meeting on November 15, 2018. I represent the North American Spinal Cord Injury Consortium, (<https://nasciconsortium.org>) which is a unifying organization of individuals with and non-profit organizations representing people living with spinal cord injury. There is much excitement and energy in the Patient Engagement movement, however there still seems to be some gaps in understanding how organizations representing people living with the conditions can be involved with this process. It is not clear how these organizations are chosen as well as a framework for interacting with these organizations.

There are some evolving treatments in the development pipeline for spinal cord injury and we would like to understand how the voice of the consumer can be integrated into this process rather than simply submitting a comment. It is a monumental task to communicate with so many conditions and patient representative organizations; however it is a needed element of the medical review process at the FDA. We would appreciate some advisement of how we can direct our members and organizations to be involved in this process.

Thank you and we look forward to your response as well as the response of the Committee.

Regards,
Jennifer

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