

PROJECT SUMMARY/ABSTRACT – PUBLIC ENGAGEMENT CORE - EPIBIOS4RX

The overarching goal of the Public Engagement Core is to actively engage voluntary organizations with the EpiBioS4Rx CWOW in public outreach and knowledge transfer for the development of effective strategies to successfully design and complete clinical research studies, including future trials of prevention therapy in epilepsy. The scientific premise of EpiBioS4Rx is: Epileptogenesis after traumatic brain injury (TBI) can be prevented with specific treatments; the identification of relevant biomarkers and performance of rigorous preclinical trials will permit the future design and performance of economically feasible full-scale clinical trials of antiepileptogenic therapies.

The Public Engagement Core aims at creating a consortium of consumers and consumer organizations, scientific (professional) societies, health organizations and EpiBioS4Rx investigators to assist with public outreach and facilitate interactions and communication among our partners to effectively promote participatory action research. To achieve a solid grounding between concept, practice and action, we have recruited several constituencies in the planning and decision making processes. A unique feature of our proposed patient engagement program is the preventative nature of this study. We are planning to involve patients who have suffered TBI and are considered to be at risk of developing epilepsy, but do not currently have the condition. Therefore, we are seeking patient involvement in the development of recruitment strategies for clinical trials for epileptogenesis, to which the patients may or may not develop. Subsequently, the *Public Engagement Core* will involve both consumers (actual patients and their caregivers) and consumer groups in identifying effective strategies to design large-scale interventional clinical trials of antiepileptogenic therapies in TBI and committed to effective recruitment and retention.

The ultimate objective of the Core is to create a universal shared resource for epilepsy involving consumers and consumer organizations that could be used to design and execute large-scale intervention studies.