

A web-based, patient-driven (by proxy) registry for pediatric epilepsy surgery: the Global Pediatric Epilepsy Surgery Registry

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RATIONALE

Epilepsy surgery in children is no longer considered a last resort to stop drug-resistant seizures; however, there remains a paucity of long-term studies which address the functional impacts of pediatric epilepsy surgery. The objective of this registry is to understand the developmental trajectory in children after epilepsy surgery through patient-reported outcomes by parent proxy. This study is expected to yield important information about delay to surgical evaluation, seizure outcomes, physical functioning, speech, behavioral, and educational outcomes, and quality of life.

METHODS

The registry recruits parents/legal guardians of children with epilepsy who have had epilepsy surgery, are being evaluated for epilepsy surgery, declined surgery, or were not found to be surgical candidates. Parents are recruited via email and social media. Informed consent and baseline surveys in English are completed through the study website using REDCap electronic data capture tools through a series of questionnaires and Patient Reported Outcomes Measurement Information System (PROMIS) short-form parent proxy instruments (Upper Extremity; Cognitive Function; Anger; Mobility; and Peer Relations). The surveys collect information on demographics, seizure onset and characteristics, etiology, surgical evaluation, surgery, seizure outcomes, comorbidities, development, and quality of life. Annually, parents will be asked to update responses to the surveys until the child reaches age 18. The goal of the registry is to have 250 participants by the end of 2020. It has no end date.

RESULTS

The registry was deployed in late February of 2019 with 199 registrants received from eight countries by December 1, 2019. The etiology of epilepsy was related to acquired lesions (stroke) in 27 participants, congenital malformations (hemimegalencephaly 66, cortical dysplasia 68, and other cortical malformations 26) in 160 participants), and progressive conditions (Rasmussen's encephalitis and Sturge-Weber syndrome) in 26 participants, with the remaining etiologies including brain tumor, artery/vein malformation, cytomegalovirus infection, and other conditions. Some participants had multiple conditions.

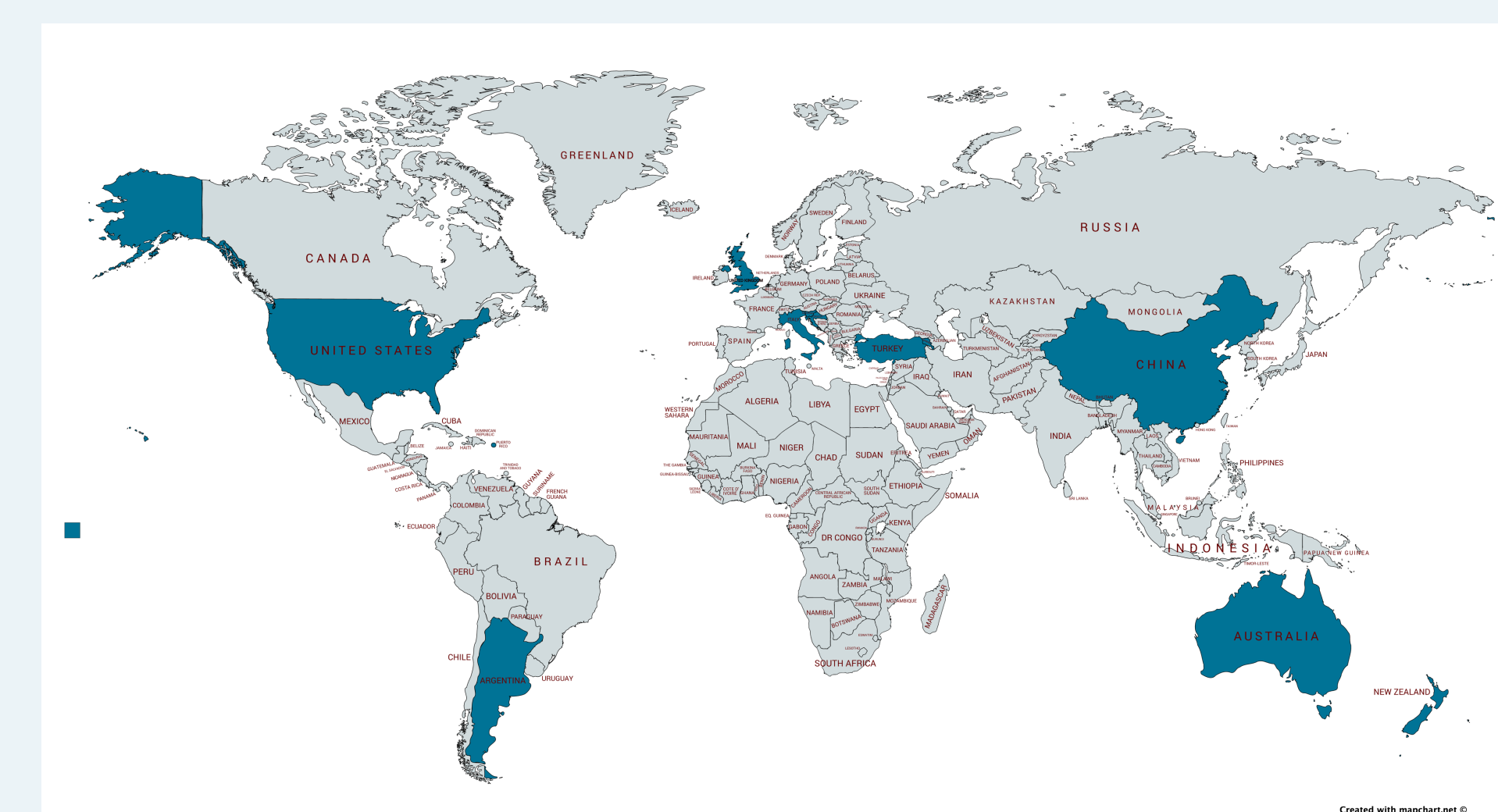
Successful launch of the world's first online registry to track the developmental trajectory after childhood epilepsy surgery



Sex of the children is 46.7% female and 53.5% male. Etiologies of epilepsy were mostly unilateral, with 42% occurring in the left hemisphere of the cerebral cortex, 47% occurring in the right hemisphere of the cerebral cortex, and 9% in both sides.

Various types of hemispherectomy surgeries (e.g. anatomical hemispherectomy, functional hemispherectomy, and hemispherotomies) were performed in 99 children. Other procedures include, but are not limited to, temporal and extra-temporal lobectomies and resections, tuberectomies, and vagus nerve stimulator implantation. Some participants are in the presurgical evaluation phase, declined surgery, or were not found to be surgical candidates.

Future enhancements to the Global Pediatric Epilepsy Surgery Registry will include features such as internationalization, which will expand the availability of the registry to non-English speaking participants.



International participation as of December 1, 2019.

CONCLUSIONS

We have demonstrated the successful deployment of the first patient-driven, by proxy, global registry to understand the developmental trajectory after pediatric epilepsy surgery. The Global Pediatric Epilepsy Surgery Registry is web-based, which allows parents and guardians of children after epilepsy surgery from around the world to register and contribute patient data to the registry in a secure manner. The data generated from the Global Pediatric Epilepsy Surgery Registry will help parents make informed health care decisions for their child when considering epilepsy surgery, including what to expect after epilepsy surgery. It will be crucial in identifying patients suitable for clinical trials and in informing research that will identify interventions to improve functional outcomes and ultimately improve the lives of children after epilepsy surgery.

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