

# National Epilepsy Surgery Support Activity

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## ABSTRACT

While there are over one million people with drug-resistant epilepsy in India, today, there are only a handful of centers equipped to undertake presurgical evaluation and epilepsy surgery. The only solution to overcome this large surgical treatment gap is to establish comprehensive epilepsy care centers across the country that are capable of evaluating and selecting the patients for epilepsy surgery with the locally available technology and in a cost-effective manner. The National Epilepsy Surgery Support Activity (NESSA) aims to provide proper guidance and support in establishing epilepsy surgery programs across India and in neighboring resource-poor countries, and in sustaining them.

## Key words

Drug resistant epilepsy, epilepsy, epilepsy surgery

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## Rationale

India is the second largest populous country in the world with a current population of 1.2 billion. With a prevalence rate of five per 1,000 person-years and an incidence rate of 50 per 100,000 person-years, it is estimated that at any given time, India has at least 5 million people with active epilepsy, to which nearly 500,000 people are added annually. Considering that one-third of these patients have drug-resistant epilepsy, there are approximately one million people with epilepsy in India at any time, who are potential candidates for presurgical evaluation and epilepsy surgery. As against these large numbers of patients, currently less than 500 epilepsy surgeries are undertaken in India annually, resulting in an enormous surgical treatment gap. This also results in huge health care burden, as 80% of healthcare costs in epilepsy are accounted for by the patients with drug-resistant epilepsy.

Evaluation of the patients with drug-resistant epilepsy requires a multidisciplinary approach within the framework of an organized comprehensive epilepsy surgery program. Currently

there are less than five fully functional comprehensive epilepsy care programs in the country which can cater to a limited number of patients resulting in long waiting lists for the presurgical evaluation and epilepsy surgery in these centers. At the same time, only handful of patients have willingness and resources to travel to these centers which are located far off from their places of living, further discouraging many physicians and patients to approach these centers. The only solution to overcome this problem of large surgical treatment gap and to reduce the waiting lists is to establish comprehensive epilepsy care centers across the country that are capable of evaluating and selecting the patients for epilepsy surgery with the locally available technology and in a cost-effective manner. Such centers do not require elaborate and expensive technologies as majority of patients with well-defined surgically remediable epilepsy syndromes, which forms a large group of patients with drug resistant epilepsy, can be selected noninvasively without the need of additional investigations. However, there is a lack of trained professionals to initiate and maintain the epilepsy surgery programs in India. Even the trained epileptologists face problems in initiating an epilepsy surgery program due to the lack of trained professionals to form a multidisciplinary epilepsy surgery team. Proper guidance and support in the early stages of initiating an epilepsy surgery program can help in overcoming early hurdles in establishing successful epilepsy surgery programs which can subsequently become self-sustained.

## Vision

To establish at least one comprehensive epilepsy surgery program in each state of India by 2020.

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## Objectives

1. To help willing professionals in initiating, establishing, and sustaining comprehensive epilepsy surgery programs across India; and
2. To form a national network of professionals for the management of most difficult cases of epilepsy in India and for continuing epilepsy education.

## Materials and Methods

National Epilepsy Surgery Support Activity (NESSA) is aimed at helping the trained neurologists and neurosurgeons in initiating and establishing epilepsy surgery programs which subsequently can be sustained locally. It will be most helpful for the professionals who have basic short-term training in epilepsy and the basic infrastructure for presurgical evaluation which includes a facility for long-term video electroencephalography (VEEG) and an access to good quality magnetic resonance imaging (MRI). The help will be tailor made as per the local requirements and may take various forms like helping in establishing epilepsy monitoring units, selecting patients for epilepsy surgery and providing expert surgical help in the initial stages. The NESSA team aims to encourage the centers to initially operate on patients who can be selected with minimum investigations and who are likely to have good outcome. Once the program is well-established, then NESSA team will help the centers to select more difficult cases. NESSA also aims to establish a National Epilepsy Network of epilepsy professionals for the management of most difficult cases of epilepsy in India where most difficult cases can be discussed and management plans can be formulated in close group meetings.

## Plan of Action

As per the local requirements, members of the NESSA team will visit the potential centers to help them in establishing

epilepsy surgery programs. The different phases of such visits will be:

1. **To provide first hand advise on initialing and establishing epilepsy monitoring units:** This will usually be the first visit by a team member to provide advice about the basic requirements of epilepsy surgery program and VEEG unit, about the amount and the nature of required equipments, and how to plan and actually run the VEEG monitoring unit, including when and how to start and terminate VEEG monitoring.
2. **To help in selecting patients for epilepsy surgery:** Once the center is functioning and starts undertaking presurgical evaluation, then team members will visit the center for few days during which several cases will be discussed in a multidisciplinary meetings and comprehensive management plan will be formulated.
3. **To help in the initial epilepsy surgeries:** During this phase, the neurosurgeon from the NESSA team will visit the centers and help and train the local neurosurgeons in operating already selected cases.
4. **To establish national epilepsy network:** The NESSA also aims at developing a support system and network for the management of most difficult cases of epilepsy in India. The NESSA team aims to conduct meetings every 3 or 4 months where all the neurologists will be encouraged to bring and discuss difficult cases with epilepsy so that any additional or alternative management strategy can be suggested, if possible.
5. **Website:** NESSA team also plans to develop a website which will provide information about the activities of NESSA and where willing professionals can interact with NESSA team.

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