ISLAMIC REPUBLIC OF IRAN

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Research Affairs

Disease Registry Unit

In the Name of GOD

REGISTRY PROPOSAL: (1-2 PAGES excluding references)

A. Title of Registry

Registry of Refractory Epilepsy in Iranian Children

B. Brief Intro to Registry –Literature Review (1-2 paragraphs)

Epilepsy is one of the common disease of nervous system during childhood, that manifested by recurrent seizures.

Refractory epilepsy also known as Drug-resistant epilepsy (DRE), or pharmaco-resistant epilepsy, is defined as failure of response to adequate trials of two tolerated and appropriately chosen and used antiepileptic drugs.

Refractory epilepsy is commonly diagnosed after several years of uncontrolled seizures; however, in most cases it is evident much earlier. Approximately 30% of people with epilepsy have a refractory form of that.

These patients are exposed to a variety of problems, including the problems and costs of illness and medication and hospitalization, as well as the problems and costs of social limitations. Frequent seizures that interfere with school hours and work in many of these patients lead to social isolation and avoidance of group activities. These children are more likely to experience depression, anxiety, obsessive-compulsive disorder, hopelessness, and self-esteem. One-third of adolescents with epilepsy keep their epilepsy diagnosis and refrains from expressing it in public. Such costs are much higher than the costs of hospitalization and treatment. Some studies refer to these costs as indirect costs. And these costs fall substantially beyond the cost of epilepsy.

For the first time in Iran, we have thought of the national registration of all information on childhood refractory epilepsy. This registry system is supposed to provide a framework for conducting more extensive and accurate research in this field, thereby reducing costs. The system records information about children with refractory epilepsy, using patient records in hospitals, clinics, and health centers around the country. Information about private clinics is also collected in collaboration with specialists, which ultimately contributes to our knowledge of the effective functioning and improvement of treatment outcomes for children with epilepsy.

C. Registry Objectives (what is it you are specifically looking at, trying to reach?)

The data obtained from the registry system may be used in the following ways:

- Determine the causes of refractory epilepsy in children
- Reveal the clinical outcomes of the patients with refractory epilepsy respecting the different etiologies.
- Monitor the patients to prevent complications
- Clinical trials in the treatment of refractory epilepsy in children
- Observing the disease changes during the treatment process
- Help the ministry of health to have a better estimate about the amount of consumption of different antiepileptic in the country and provide it.

D. Registry Design (participants, data collection, statistical analysis plan, etc.)
Participants are all children 1 to 18 years old with refractory epilepsy referred to pediatric neurology clinics or admitted in pediatric neurology departments.
The prevalence of epilepsy in the population is about 3%, and 30% of them are refractory to treatment. Considering there are about 30 millions of people in the country who are under the age of 20, with a rough estimate, there are 300,000 epileptic patients in the country, and about 100,000 of them suffer from refractory epilepsy, which the system will attempt to register them.
The trend will be like this: the data of the patients who fulfill the criteria for refractory epilepsy who present to pediatric neurology clinics and also specialized epilepsy clinics throughout Iran, are entered in the registry system.

E. Timeline for your Registry project (project deadlines set by you and your mentor)
Proposal edition and confirmation takes 1 month.
Registry duration set 5 years and it will be continue more.
Each 5 years data will be evaluated and results use in researchers and articles to improve patient's conditions.

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