ISLAMIC REPUBLIC OF IRAN

Shahid Beheshti
University of Medical Sciences

Research Affairs

Disease Registry Unit

In the Name of GOD

Registry of ketogenic diets

Ketogenic diet is the first step of treatment for some disease like Pyruvate Dehydrogenase Deficiency and GLUT-1 Deficiency, also it can be used as a reliable treatment method for some other disorders like: Epileptic Spasm, Dravet Syndrome, Doose Syndrome and Refractory seizure.

The efficacy of Fasting and Ketogenic Diet (KD) was clarified in the early 1920s for epileptic patients and after that in 1976 it used for Pyruvate Dehydrogenase Deficiency.

First it was a high fat, low carbohydrate diet administered after 48 hours of fasting by the gradual introduction of calories (Ketogenic meals) over 3 days but now there are different methods of KD diet; all have high fat and low carbohydrate components with variable design and administration to make the diet more tolerable. These methods include:

- **Classic Ketogenic Diet (KD); inpatient, outpatient and for infants.**
- **Medium-chain Triglyceride KD (MCT-KD)**
- **Modified Atkins Diet (MAD)**
- **Low Glycaemic Index Diet (LGID)**

Now, the Ketogenic diet is considered as an effective, acceptable, non-pharmacological treatment all over the world, for Pyruvate Dehydrogenase Deficiency, GLUT-1 Deficiency, Refractory seizures and many other conditions such as Alzheimer's disease or ALS.

It should mention that The KD is an effective treatment but it is not entirely benign. It must be prescribed thoughtfully, implemented carefully, and monitored closely. Side effects are divided into early (Such as Acidosis, Constipation, Fatigue, Food refusal, Vomiting and Hypoglycemia) and late complications (Such as Dyslipidemia, Bone fractures, Poor linear growth, Vitamin D deficiency, Kidney stones).

So register patients and follow-up them is really important in KD.

Objectives:

- **Obtain the exact number of patients that are treating with ketogenic diet to plan for following-up and monitoring them.**
- **Follow-up of patients for early action for complications.**
- **To plan for financial problem during treatment.**
- **Check disease changes during diet therapy.**

Registry design

Participants are all children 1 to 18 years of age that refer to pediatric neurology departments and can be cure with the Ketogenic diet.

Estimated number of patients is about 1500 members each year in the country.

Patient's registry process is according to certain way; in specific centers neuroscientists after confirming Ketogenic diet treatment refer patients to dietitians for consultation and initiation of the diet.

Data sources are Records, Examination and patient's history, Lab data and calculated diet data that collect with neuroscientists and dietitians.

Timeline registry

Proposal edition and confirmation takes 1 month.

Registry duration set 10 years and it will be continue more.

Each 10 years data will be evaluated and results use in researchers and articles to improve patient's conditions.

Pediatric Neurology Research Center

Mofid Children's Hospital

Dr. Parvaneh Karimzadeh