

Diet 4 Life

An Initiative to Create an Ecosystem for
Providing Comprehensive Services to
Patients with Inborn Errors of Metabolism



fssai



FOOD SAFETY AND STANDARDS
AUTHORITY OF INDIA

Inspiring Trust, Assuring Safe & Nutritious Food
Ministry of Health and Family Welfare, Government of India



Children born with Inborn Errors of Metabolism (IEM) have special dietary needs, which if unmet, result in cognitive and physical disorders. Without special diets, children with IEM would often not survive infancy. Fortunately, through early identification and initiation of treatment, IEM disorders can be mitigated. IEM is estimated to affect over 30,000 children in India but in the absence of adequate screening facilities for this disorder, 30,000 diagnosed cases most likely represent only the tip of the iceberg.

In May, 2016 Parent Support Group- MERD (Metabolic Errors and Rare Diseases), approached FSSAI to get special diets for IEM imported to India. The initiative include, formulating standards for IEM products while simultaneously permitting import of products in the interim period and reaching out to various stakeholders through workshops and training programmes aimed at building their capacity. This is being called as 'Diet4Life' initiative.

FSSAI has been collaborating with IDA (Indian Dietetic Association), AIIMS (All India Institute of Medical Sciences), ISIEM (Indian Society for Inborn Errors of Metabolism), MERD (Metabolic Errors and Rare Diseases), IAP (Indian Academy of Paediatrics), NNF (National Neonatology Forum), ICMR (Indian Council of Medical Research), ISPGHAN (Indian Society of Paediatric Gastroenterology, Hepatology and Nutrition) and IYNCI (Infant and Young Child Nutrition Council). These stakeholders are part of a Steering Committee which now guides and drives this initiative.

Highlights of the project

- ❖ Standards for 17 IEM conditions (including the hypoallergenic ones) have been approved by the Scientific Panel on Functional Foods, Nutraceuticals, Dietetic products and are under the process of formulation. Meanwhile, imports of all these products have been allowed. Accordingly, the products have started reaching the patients.
- ❖ National-level Training of Trainers (ToT) program on Nutritional Management on Inborn Errors of Metabolism was held on 12th April, 2017 at AIIMS, New Delhi. The workshop was facilitated by Dr. Anita McDonald, International Consultant Dietician in Inherited Metabolic Disorders, Birmingham Children's Hospital, UK. Dr. McDonald sensitized and trained 16 dieticians PAN India on IEM disorder management.
- ❖ First awareness program on IEM was held for Dieticians on 10th January, 2017, Dietetics Day, at AIIMS, New Delhi.
- ❖ Second awareness program was held on 12th -14th February, 2017, in Chennai for doctors, dieticians, parents/patients to build awareness about diets for management of IEM & allergy conditions in children.
- ❖ Third awareness program was held on 16th September, 2017, in Pune for doctors, dieticians, parents/patients to build awareness about diets for management of IEM & allergy conditions in children.
- ❖ A series of awareness programs have been planned throughout the year of 2018.
- ❖ A transactional website on IEM has been developed to share information on metabolic disorders, possible symptoms, diagnostic/treatment centres, diets available etc. with the public. www.diet4life.fssai.gov.in.

In addition to the above, the four large suppliers of imported IEM products viz M/s Nestle India Limited, Abbott Healthcare Pvt. Ltd., Danone Nutricia Pvt. Ltd. and Mead Johnson Nutrition India Pvt. Ltd. have volunteered to provide IEM diets at subsidised rates to an identified number of needy children, since these diets are expensive and cannot be afforded by all.

The project adopts a holistic approach to ensure the availability of diets for patients, training of the relevant medical faculty, awareness generation programs and a portal as a platform for stakeholder interaction and information dissemination.

Way forward, the stakeholders are now working the backward integration to sustain and assist the holistic care and support to IEM patients by strengthening and upgrading existing IEM laboratories.

To know more visit
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