P-014 - EDUCATIONAL PARTICIPATORY AND CULINARY ACTIVITY PROGRAM AIMED AT PATIENTS WITH INBORN METABOLIC DISEASES AND THEIR FAMILIES: 7 YEARS OF IMPLEMENTATION

Lavorgna SL\textsuperscript{1}, Vinuesa MV\textsuperscript{2}, Levy L\textsuperscript{1}, Cresta AS\textsuperscript{1}, Carmona NM\textsuperscript{1}, Blasi SN\textsuperscript{1}

\textsuperscript{(1)} Hospital de Pediatría Juan P. Garrahan. \textsuperscript{(2)} Fundación Garrahan. Buenos Aires-Argentina. slavorgna@yahoo.com

i: Inborn metabolic diseases (IMD) described as disorders of intoxication in most cases require a strict and demanding lifelong dietary treatment. Seven years ago, based on difficulties and barriers detected in a survey and previous experience, we designed a program to anticipate everyday situations and encourage diet compliance. ii: To enhance adherence to nutritional therapy through the implementation of workshops for IMD patients and their families to improve culinary skills and nutritional education. iii: Participatory educational and culinary activities have been designed by metabolic dietitians (2011-2018) aimed at IMD patients (6months-18years) treated with protein/amino-acid restricted diets and their families followed at Garrahan Hospital. Workshops were organized considering age groups and divided into modules developing different topics such as: variety of daily menus; increase of fruit/vegetable intakes; consumption of medical food; calculation of protein intake; management on holidays/social occasions (eating out, parties, camps). iv: 54 workshops were organized from 2011-2018. 76 patients and 71 families participated (Phenylketonuria: 33%; Urea Cycle Disorders: 22%; Organic acidurias: 12%; Maple syrup urine disease: 9%; Tyrosinemia1: 10%; Homocystinuria: 6%; others: 6%). Over 50% of patients began attending the program during the first year of implementation, increasing participation every year. Media: 6.8 patients/year. 50% was the attendance rate, varying from one workshop to another: distance and time (+3hours) to hospital being the first cause of no attendance (37%). The media of patients/workshop was: 5.8(1-23). 30% attended at least 1 workshop and 22% more than 6. Recipes were adapted, trying to match classic/traditional Argentinean foods, using homemade low-protein flour and adding variety of fruits/vegetables to make them healthier, and most of our patients could reproduce them at home frequently. Everyone participated enthusiastically showing interest in both educational and culinary activities. We encouraged teenagers to take a lead role in their diet, promoting self-care and involving them in preparing and calculating their own menus. v: Participation in these workshops presents the opportunity to share ideas, dietary experiences and recipes together with peers to improve conventional instructions for low protein recipes. Further evaluation and more clinical evidence are needed to assess the effectiveness of the program aiming to improve adherence and long-term metabolic control.