“Mi PKU” App
Developed in Argentina for PKU patients to improve their quality of life

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HISTORY

An enriching teamwork experience

• CONICET´s Food Safety Network (RSA) motivated by PKU parents, came up with the idea of developing an App for PKU patients

• Together with CITRA (Implementing Unit-CONICET) and QUADION (Tech company), the App was developed

• The three leading Metabolic Teams working with PKU patients in Argentina actively participated in the development: 1) CEDIE- FEI – Hospital de Niños Dr. Ricardo Gutiérrez 2) Hospital de Niños Sor María Ludovica 3) Hospital de Pediatría Juan P. Garrahan

• A group of patients and parents, selected from each Metabolic Team, tested the App before launching it
• Free access Android Spanish tool
• The Database was developed by the metabolic dietitians after a consensus on food, nutrition information, medical food and low protein food used in Argentina (800 records). Macronutrients and Phenylalanine (Phe) content of food was obtained from National and International Food Tables and Food Analyzers

1) Patients record their individual data including personal Phe tolerance and medical food prescribed by their metabolic team

2) The App tracks Phe (mg), protein (gr) or exchanges (20 mg Phe) depending on patient’s choice and dietary approach

3) Displays Phe/protein and medical food daily intake and their distribution throughout the day in real time

4) It is possible to specify in which meal each intake takes place (breakfast, lunch, dinner, snacks)
5) Medical food and other treatments (Sapropterine Dihydrochloride and Neutral Aminoacids) are also tracked.

6) Clear, legible, accurate and complete Food Records in digital format (24-72 hours-monthly) can be shared via email/WhatsApp with the metabolic team.

7) New foods can be suggested by the patients for future updates.

8) It has a calculator which allows to convert mg of Phe into grams of protein.
ADVANTAGES

FOR THE PATIENTS

• Reinforces self-care
• Improves adherence
• Improves independence
• Provides daily education on food contents

FOR THE METABOLIC TEAM

• It simplifies the intake calculation since the digital food records are received with their nutritional information already analyzed (Phe and macronutrients)

• Allows to easily visualize Phe and medical food intake throughout the day and to evaluate individual dietary adjustments to the diet in order to improve adherence

• Optimizes consultation time

• Provides a digital detailed database for academic and research purposes
CONCLUSIONS

➢ Mi PKU reinforces self-care in patients and their families, especially teenagers and adults whose adherence tends to decrease over time.

➢ Also allows the metabolic team to improve and facilitate individual care of PKU patients and provides a detailed database for research and academic work.

➢ Mi PKU App is the result of teamwork and closeness to the patient’s physical, emotional and social needs, which are the key to the success of the treatment.