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## Georgian Parent's Association for PKU Report

On July 19, the first national conference on phenylketonuria – “A better life with phenylketonuria in Georgia”; was held. The event was organized by the “Georgian Parent's Association for PKU” and with the financial support of the Society for the Study of Congenital Metabolic Diseases “SSIEM”. The conference was attended by parents of children and adolescents with phenylketonuria, as well as geneticists, neurologists, pediatricians and neonatologists.

The speakers of the event spoke about the importance of newborn screening, the needs of children and adolescents with a rare genetic disease - phenylketonuria, as well as the need to expand medical services. CEO of the European Society for the Control of Phenylketonuria.

Tobias Hegedorn took part in an online conference. He spoke about the role of the state in the lives of patients with phenylketonuria and the issues of improving existing services in Georgia. The event was packed with topics and discussion of the problems, which exist in Georgia in this regard.

The conference was joined online by Merve Esji, a volunteer member of the Turkish organization of parents of patients with Phenylketonuria, an expert nutritionist, an advocate for rare diseases, a representative of the fku Parents Association, who shared his experience and practice on the example of Turkey. He noted: “I believe in one thing: it is not diseases that destroy the lives of people, but indifference and ignorance. That is why we are trying to raise awareness about rare diseases and especially about phenylketonuria. Early diagnosis can save many lives. The goal of doctors and nutritionists after early diagnosis of phenylketonuria is to treat and improve the quality of life of affected people. The right to food is the right protected by the Constitution, so we must make every effort to ensure it.”

Tobias Hegedorn, Managing Director of the German organization for the fight against phenylketonuria, also participated and held a question-and-answer discussion. In the very interesting presentation, he talks about the needs of patients diagnosed with phenylketonuria. “Phenylketonuria is a rare genetic disease, which affects both patients and their families. Our shared social responsibility is to ensure that patients and their families have access to the best diagnostic procedures and treatment.” He expressed his support and assistance to us in all matters that will help patients live better.

It was the first and very interesting high-profile conference in Georgia, which we believe will lead to positive changes.

Below are the links from social pages and Media:

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