



Glut1 Deficiency: when food becomes life

The Italian Glut1 Association, with the participation of chef Simone Rugiati, tells what it means to face a disease in which food becomes a life-saver every day

Milan, 11/06/2021 - There are over **500 metabolic diseases and acquired conditions that require the management of special diets every day**, real life-saving therapies that help keep symptoms under control and improve patients' quality of life: among the diseases where food becomes medicine is **Glut1 Deficiency**, a rare genetic syndrome that can lead to epileptic seizures, dystonia, speech difficulties, possible cognitive delay, hypotonia, and sleep disturbances. To date, there is no cure for this disease; but fortunately there is a treatment which can relieve some of the symptoms: the **ketogenic diet**.

Today, on the occasion of the Third European Conference for the disease, **Associazione italiana Glut1**, thanks to the non-conditional support of **VitaFlo - Nestlé Health Science**, has released the third of four videos in the **awareness campaign** aimed at families, schools, teachers, and more generally anyone who is in contact with people affected by Glut1 deficiency syndrome or others who have to follow **special diets**.

The video, titled "**Glut1 Deficiency: when food becomes life**", seeks to illustrate, especially from the point of view of parents and siblings, exactly what it means to **face this disease every day** of one's life: from the more concrete aspects of everyday life, to concerns for the present and the future. The goal is to spread **awareness** about the disease in order to assure **inclusion and support**.

Celebrity chef **Simone Rugiati**, TV presenter, author and producer as well as a very popular web influence, continues his participation.

"Food is passion, life, bonds, future. It's a pleasure that everyone should be able to share – explains chef Rugiati – Yet for people with glut1 deficiency, food could become a poison. Or else the only available treatment! After meeting a mother who told me what the disease consists of and what her little one faces every day, I enthusiastically accepted to join the awareness project. Children with glut1 deficiency didn't choose to have to follow this strict dietary regime, but they don't give up: and for our part we have the duty to support them! I'll keep on doing just that, even now, thanks to the bond I've formed with many of these children".

Here's the link to the video: <https://glut1.it/youtube-when-food-becomes-life>

The four videos were made by **Kemal Comert**, producer and filmmaker specializing in the field of rare diseases who in 2019 won the award for best documentary at the "Uno Sguardo Raro" film festival, and by **Barbara Bernardini**, science popularizer and founder of One Frame "Creative Science Communication", as well as author for the Rai1 program "Superquark".

«Children with glut1 deficiency aren't just children of their own families, they are **all of our children** - Alessandra Camerini, Chair of Communication for the Italian Glut1 Association pointed out. That's why we'll go to great lengths, together, to **make things easier for them and to build a future**. So **nobody gets left behind** and everyone may express their own identity, their own individuality, and their existence, beyond the disease, which cannot and must not determine the value of their lives. We are therefore deeply grateful to all those who enthusiastically participated in this project: chef Simone, Kemal, Barbara, our doctors and splendid children. Thank you for your commitment and for the spectacular result achieved: because #Insiemeperglut1 is more just a hashtag, it's a real inclusive approach to life».



Italian GLUT1 Association

The Italian GLUT1 Association seeks to channel the strengths and hopes of patients suffering from Glut1 deficiency syndrome and their families in order to support scientific research and any initiative aimed at improving knowledge, diagnosis and treatment of the syndrome, protecting the rights of people affected by this disease, promoting their social integration and improving their quality of life. It is made up of parents of children and patients who invest passion and energy day after day, trying to build a future, keeping a careful eye on the present as well as what is to come. For more information, www.glut1.it

For more information:

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