



When diet is a life-saving therapy: because inclusion grows from awareness

The Italian Glut1 Association illustrates what it means to follow special diets every day in four popular videos with celebrity chef Simone Rugiati

Milan, 15/02/2021 - It might seem like a rare phenomenon, but there are **over 500 metabolic diseases and acquired conditions that require families to manage special diets every day** for real life-saving therapies that 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, the ketogenic diet is the only existing treatment to alleviate some of the symptoms of this syndrome, but following it carefully is not only difficult for these children and their families, but can also lead to **problems with social inclusion and integration**.

This is why the **Italian Glut1 Association** has launched an awareness campaign aimed at families, schools, teachers and more generally to all those who come into contact with people who have to follow **special diets**, thanks to the unconditional support of **VitaFlo - Nestlé Health Science**, during the month when both the International Epilepsy and Rare Disease Days are celebrated. Through four informative videos, the association will try to recount what it really means to have to micromanage the precise content and dosage of one's diet every day, right down to the gram, both from a nutritional point of view and in terms of social consequences. In particular, the first video will be **dedicated to children**, or the "Gluttini" as they are affectionately called by their parents and their school friends. Together with celebrity chef **Simone Rugiati**, TV presenter, author and producer as well as a very popular web influencer, these children show how important it is that social moments such as birthday parties not be precluded to those who, for health reasons, cannot eat certain foods and how **awareness and knowledge of their needs can ensure their inclusion** in all these social occasions which are so important for every child's growth.

"After meeting a mother who told me what the disease consists of and what her little one faces every day - explains chef Rugiati - I enthusiastically accepted to join the project: food is passion, life, bonds, future for me. Knowing that the life and illness of these children strictly depend on a complex diet, and that this diet had to be followed forever and with no margin for error or exceptions, made me wonder how I could help them. And hence my participation in the videos; but above all, a personal bond that was created with the little ones and which continues today".

Here is the link to the video: <https://www.glut1.it/youtube-martinas-party>

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".

"We are a society in which socialization also passes through food and our children, having to follow a strict diet, often find themselves in uncomfortable situations or may even



be socially excluded - underlined Alessandra Camerini, Communication manager of the association. We therefore hope that this project will contribute to making their needs known and improving their integration, without ever forgetting to eliminate labels: because you are a person and not your pathology. 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 **#Insiemeperilglut1** 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:

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