



## When a 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: exceptional spokesperson, celebrity chef Simone Rugiati*

**Milan, 07/09/2021** - Although it might seem rare, there are **over 500 metabolic diseases and acquired conditions that require families to manage special diets every day** for real life-saving therapies that improve patients' quality of life. Among the diseases where food becomes "medicine" is **Glut1 Deficiency**, a rare genetic syndrome that may lead to seizures, dystonia, speech difficulties, possible cognitive delays, hypotonia, and sleep disturbances. To date, the ketogenic diet is the only existing treatment to alleviate some of these symptoms. However, following the diet 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, during the back-to-school season, the **Italian Glut1 Association**, thanks to the unconditional support of **VitaFlo - Nestlé Health Science**, is releasing the final video in its **awareness campaign** aimed at teachers, classmates and their parents, schools, families, and more generally all those who come into contact with people who have to follow **special diets**. Together with an exceptional spokesperson, **Simone Rugiati**, celebrity chef, TV presenter, author and producer, as well as a very popular web influencer, the video illustrates what it really means to have to micromanage the content and dosage of one's diet every single day, both from a nutritional point of view and in terms of social consequences. Social occasions such as the school lunch room or birthday parties must not be precluded to those who cannot eat certain foods for health reasons, and **knowledge and awareness** of these people's needs can **ensure their inclusion** in all these social occasions that are so important for growth.

*"Food is passion, life, bonds. It's a pleasure that everyone should be able to appreciate and to share... How would you feel if your child were excluded from all of this for the rest of his life? – explains chef Rugiati – 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 this awareness project. It takes so little to help everyone feel included and I'm pleased to make my contribution: these children's life and disease depend strictly on a complex diet which must be followed precisely, without exceptions, for their entire lives. I stand proudly by their side with these videos and with the friendships that we still maintain".*

Here's a link to the video: <https://youtu.be/THsia9ZYmuk>

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".

«Our society socializes through food, and **our children who follow a strict diet are often in an awkward position or even excluded** - the association explains. We hope this project can help build awareness of their needs and improve their integration, while never forgetting to eliminate labels: because people are people and not their disease. 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»

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### **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](http://www.glut1.it)

### **For more information:**

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