



“THE FEEDING TUBE HAS GIVEN A LOT OF QUALITY OF LIFE TO THE ENTIRE FAMILY.”

FresuCare 
caring at home

NOÉ'S STORY

In the beginning, I was quite unsure and feared that we were interfering in the natural process. I feared also that it could take away Noé's ability to eat. Specialists and another affected mother helped allay these fears of mine and showed that this step can be good for Noé.

First of all, it was a great relief. All of the pressure regarding having to eat and drink is now gone and now the joy of eating is back. Noé is now much healthier and fitter. His nutritional status has also improved. There is much more time left for the entire family. As a result, Noé has also been able to develop better in other areas.



Age of patient
5 years old



Reason for home artificial nutrition
Dravet syndrome



Type of Therapy
Enteral Nutrition



Duration of Treatment
Since October 2019, ongoing

NOÉ'S STORY

BRIEF STORY ABOUT EXPERIENCE ON HOME ARTIFICIAL NUTRITION

Meanwhile, he can eat a little in the form of porridge. Now I can give him what he most likes to eat. If he has days with many epileptic seizures, his food and fluid intake are now ensured and I can also administer the necessary medications to him at any time.

DESCRIBE YOUR DAILY, WEEKLY ROUTINE INCLUDING HOBBIES AND ACTIVITIES:

At mealtimes, Noé receives porridge which he can generally eat well. He gets water and, to some extent, medications via the button. When he can't eat well, he gets Frebini administered via the tube.

Noé is the haven of peace in the family; he can keep himself busy with his red shovel and building blocks and he loves it when other children are around him. Even if he cannot talk, you can tell that he's taking part. Three times per week he goes to a kindergarten which is adapted to his needs and where he is supported. Here and there, he spends a weekend in the Therapieion which is also very good for him and helps him take his own path.



WHAT ADVICE WOULD THE PATIENT GIVE TO NEW PATIENTS?

Don't fear the procedure and don't have a guilty conscience. The feeding tube has given a lot of quality of life to the entire family.

FEEDBACK

I am very satisfied with the HomeCare service. The most important thing for me is that I can count on the reliable deliveries and that I have a contact person.

I also value the personal contact with the field sales staff and the collaboration between the individual institutions. I was pleasantly surprised when someone from HomeCare came for a visit when Noé was in the paediatric intensive care unit.

Also that all of the materials were delivered to our home and that I was once again instructed in everything.

HAS THE PATIENT RECEIVED SUPPORT FROM A PATIENT ASSOCIATION?

I also receive support from Pro Infirmis; they are financing relief service for childcare and are also there otherwise with further services as support.

