EMMA'S STORY

Emma has been feeding on parenteral nutrition (PN) since she was a small baby.

She was diagnosed with malignant neuroblastoma at the age of six months, which was followed by chemotherapy and then major intestinal surgery when she was one year old.

Despite the illness, PN has enabled Emma to live an almost normal life.

Age of patient
4.5 years old

Reason for home artificial nutrition
Malignant neuroblastoma, followed by chemotherapy and major intestinal surgery

Type of therapy
Parenteral Nutrition

Length of time patient was not well before treatment
3.5 years

Country
Switzerland

EMMA'S STORY

BRIEF STORY ABOUT EXPERIENCE ON HOME ARTIFICIAL NUTRITION

Thanks to the parenteral nutrition treatment, Emma is able to live life like any other typical Swiss child. She carries her PN bag and infusion pump in her backpack system to allow for as much freedom as possible. Emma was previously on PN for 21 hours a day which is now reduced to 18 hours a day (overnight and for some of the daytime). She bravely accepts parenteral nutrition as part of her life as the daily routine has long become part of her everyday life.

DESCRIBE YOUR DAILY, WEEKLY ROUTINE INCLUDING HOBBIES AND ACTIVITIES:

Despite the PN the family sits and eats together at the table to enjoy meals and social interaction.

Emma enjoys going for a swim (with the help of a waterproof bandage to protect her Broviac catheter), going on holiday and has started kindergarten this year.

Her parents manage to arrange long journeys and visits to relatives who live far away or visits to holiday destinations.

Emma's mother prepares the infusions at around 7pm in the evening before bed and connects the nutrition to her daughter, she manages the pump and cleaning the catheter as part of her daily ritual. She then disconnects the nutrition when it finishes at 1pm the next day.

Emma and her 8-year-old brother are growing up in a multilingual environment. Since her father is Egyptian, the family mainly speaks English and Arabic at home in addition to Swiss German.

FEEDBACK

Emma's parents are very grateful for her excellent progress after her severe illness left her in need of PN which has allowed her to return to almost normal life.