

## Emil

THIS IS A PERSONAL STORY SHARED BY A FAMILY WHOSE CHILD HAS  
ISOVALERIC ACIDEMIA (IVA)

When Emil was born he weighed 2875 k (6.3 lbs), and was 48 cm (19 inches).

On Sept. 14, 1999, when Emil was admitted to "Ryhov Jönköping" hospital in Sweden, he was very sick and cold with other signs of crisis. There is some doubt about "allo-immunization" against neutrofila (neutrofile) and trombocytes. Emil is given trombocyticon and gammagard and CRP 95 several times. He is also treated with benzyl and netilyn. He is very tired and listless but is beginning to open his eyes and becoming more alert.



His weak movements are changing to more lively ones. He has rallied and has clear eyes and fine movement, but very prone to infections as long as neutrofiles are low.

Emil was discharged from the hospital October 4, 1999.

Diagnosis: infection, leucopenia, thrombocytopenic (thrombocytopenia). On October 24, 1999, a lone moron test was performed. Test ok but his immune system low, he was given injections of neupogen from Nov. 3, 1999, to Feb. 23, 2000. He was then pronounced well.

March 2001 - Emil, 19 months. He got sick with an upset stomach and was tired and restless. Examination shows that he has influenza type B and his liver is affected. Diabetes is a concern. Still present, neutropeni, trombocytopeni. Several tests show that Emil has an illness isovaliransyrauri. (Isovaleric Acidemia) IVA. He is given treatments with:

XLEU - MAXAMAID (formula) 30 G daily

GLYCIN (Glycine) caplets 500 mg - 6 caplets daily

MIXT KARNITIN (Carnitine) 100 mg/ml - 6 ml \* 2 daily

Other foods 25g protein daily

At present Emil is feeling well but has to be fed, as he does not eat by himself. He has difficulty chewing foods we, his parents, wish him to eat. He does eat sweets and ice by himself. When Emil is sick with a cold or an upset stomach he refuses to eat or to take his medicine. When this happens we have to take him to the hospital to be fed intravenously. It causes a lot of worry and sleepless nights. It takes a long time for Emil to come back from an infection.

Emil is an active child when feeling well, but is slow in talking. He has not been enrolled in a day-care centre yet, but it is planned to enroll him so he can observe other children, communicate and eat. The food situation is critical. Today he weighs 16.2 kg (36 lbs) and is 99 cm (39 inches) long. His movement has been the following.

7 months rolls around from stomach to back - back to stomach.

10 months sits up from crawling.

12 months 3 weeks - waves.

17 months begins to walk without support. Before he walked around, and held on to furniture and refused to let go.

Emil has one brother nine years and a sister eleven years. They are not affected.

Sincerely,  
Camilla Andersson  
Written April 2003 by Camilla Andersson  
Mother of Emil born September 7, 1999