



**European
Reference
Network**

for rare or low prevalence
complex diseases

Network

Inherited and Congenital
Anomalies (ERNICA)

Name of centre:

Erasmus MC and Erasmus MC Sophia Children's Hospital
Doctor Molewaterplein 40
3015 GD Rotterdam, the Netherlands

Treatment of children/adults:

Children (page 2)

Adults

Treatment of children:

Department of treatment for children: Pediatric intestinal failure team, Department of Pediatric Surgery & Pediatric Gastroenterology

Introductory text:

The multidisciplinary paediatric intestinal failure (IF) team of the Sophia Children's Hospital in Rotterdam takes care of approximately 25 children on long-term home parenteral nutrition (PN). We serve as the referral centre for the southwest region of The Netherlands. We provide home PN training for parents of children newly diagnosed with IF and we monitor children on home PN at our outpatient clinic. The first contact in case of questions/problems is the nurse practitioner.

Lines/repair kits used:	Central venous line used: Broviac® single lumen, Hickman® double lumen, Port-a-Cath Repair kits used: repair kit Broviac® 2.7 Fr, 4.2 Fr and 6.6 Fr
Name and role of relevant team members:	Fleur van der Zee – nurse practitioner Susanna de Vette-van Bekkum – nurse practitioner Emma Koster – dietitian Stefanie Kouwenhoven – dietitian Joanne Olieman – dietitian Bregje Witjes – clinical pharmacist Marja van Schaik – outpatient clinic assistant Marjolein Spoel – paediatrician surgical long-term follow-up Barbara de Koning – paediatric gastroenterologist Hester Langeveld – paediatric surgeon Conny Meeussen – paediatric surgeon René Wijnen – paediatric surgeon
Department/team opening hours and contact details:	Monday – Friday: 8 am – 5 pm darmfalen@erasmusmc.nl +31 (0) 10 7040370
Emergency care opening hours and contact details:	24 hours/day Central phone number: +31 (0) 10 7040704 ask for the paediatric gastroenterologist or paediatric surgeon of the IF team on call