



European Reference Network

for rare or low prevalence
complex diseases

Network

Inherited and Congenital
Anomalies (ERNICA)

Name of centre:

Amsterdam UMC, location AMC
Meibergdreef 9
1105 AZ Amsterdam
Netherlands

Treatment of children/adults:

Children (page 2)

Adults (page 3)

Treatment of children:

Department of treatment for children: TPN&intestinal failure team (multidisciplinary)

Dr. M.M. Tabbers, paediatric gastro enterologist

Introductory text:

In the Netherlands there are 3 expert centers for home TPN and intestinal failure:

1. Amsterdam: Amsterdam UMC / Emma Children's Hospital
2. Rotterdam: Erasmus Medical Center / Sophia Children's hospital
3. Nijmegen: Nijmegen University Medical Center / Amalia Children's hospital

The Amsterdam TPN&IF team takes care for 40-50 children and 200 adults on home TPN and is the largest Dutch center with expertise in short bowel, motility disorders and inborn errors causing intestinal failure and TPN dependency. The centre also provides specialized nutritional care for bridging to complex abdominal surgery.

Tailormade TPN is provided by the hospital pharmacy of the 3 centers.

For standard TPN, pumps and other utensils we work together with the pharmaceutical company APPO Bredaseweg 249, 4705 RN Roosendaal telephone 085 902 3880 website <https://www.appo.nl/>

TPN of Fresenius, Baxter and BBraun.

Lines/repair kits used:	Pediatric lines and repair kits Bard Broviac single lumen catheter with surecuff, size 2.7, 4.2, 6.6 & 9.6 French Bard Hickman dual lumen catheter with surecuff, size 7.0 French Bard Powerline single lumen with surecuff, size 5,0 French Bard Powerline double lumen with surecuff, size 5,0 & 6,0 French Bard Power Hickman single lumen with surecuff, size 8,0 French Bard Power Hickman double lumen with surecuff, size 9,0 French Bard Broviac repair kit, single lumen, size 2.7, 4.2, 6.6 French Brad Hickman repair kit, dual lumen catheter, size 7.0 French only single adapters
Name and role of relevant team members:	Paediatric team: Dr. Merit Tabbers, pediatric gastro-enterologist, head of pediatric home TPN team Dr. Roel Bakx, pediatric surgeon Michiel Lagerweij, Msc. Physician Assistant intervention radiology Benaja de Feijter, nurse specialist Suzanne van Zundert, paediatric dietitian Cora Jonkers, dietitian home PN

Department/team opening hours and contact details:	Home TPN & intestinal failure team paediatrics Monday – Friday +31 (0) 629695144 Email: kinder-teamtpvendarmfalen@amsterdamumc.nl .
Emergency care opening hours and contact details:	In emergency 24/7: Contact - +31 (0) 20 5669111 – Amsterdam UMC and ask for pediatrician or pediatric gastroenterologist on call or the pediatric surgeon on call

Treatment of adults:

Department of treatment for adults:

Prof. dr. M.J.M. Serlie

Dr. E.J. Limonard

Dr. A.C. Simon

HPN and intestinal failure center

Introductory text:

HPN and intestinal failure center has started in 1985. We provide care for around 200 patients depending on HPN. We have transition from paediatrics to adults and our patients are diagnosed with intestinal failure acute and chronic. Our team exists of an endocrinologist, GI surgeon, physician assistants, intervention radiologists, nurse consultants, wound and stoma nurses, dietitians, PHD's, hospital pharmacists and social worker.

For standard TPN, pumps and other utensils we work together with the pharmaceutical company APPO Bredaseweg 249, 4705 RN Roosendaal telephone 085 902 3880 website <https://www.appo.nl/>

TPN of Fresenius, Baxter and BBraun.

Lines/repair kits used:

Adult lines and repair kits
Bard Broviac single lumen catheter with surecuff, size 6.6 & 9.6 French
Bard Hickman dual lumen catheter with surecuff, size 12.0 French
Bard Hickman triple lumen catheter with surecuff, size 12.5 French
Bard Powerline single lumen with surecuff, size 5.0 French
Bard Powerline double lumen with surecuff, size 5.0 & 6.0 French
Bard Power Hickman single lumen with surecuff, size 8.0 French
Bard Power Hickman double lumen with surecuff, size 9.0 French
Bard Broviac repair kit, single lumen, size 6.6 French
Bard Hickman repair kit, dual & triple lumen catheter, size 12.0 & 12.5 French, only single adapters

Name and role of relevant team members:	Prof. Dr. MJM Serlie, Dr. A. Simon, endocrinologists Prof. Dr. MA Boermeester, surgeon Stephanie Kwee, PA Titus Vink, PA Julie Visser, PA Michiel Lagerweij, PA intervention radiology Miriam vd Werf, Natascha van Rijssen, Cora Jonkers: dietitians Charmaine Renfum, nurse consultant Eric Martopawiro, nurse consultant Mariska Starke, team assistant Anne-Loes Gerards, hospital pharmacist
Department/team opening hours and contact details:	Weekdays phone hours 10-12 / 14 – 16 hrs Tel: +31 (0)20 5665120 mail: tpvthuisteam@amc.nl
Emergency care opening hours and contact details:	24/7 020 5669111 Ask for on call internal medicine