

Ziekenhuis	Samenwerkingspartner	Naam EC (EN)	(Cluster van) aandoeningen	Orphacode
Leiden UMC		Expert Center for Genetic Cerebral Small Vessel Disease	ABeta amyloidosis, Dutch type	ORPHA:100006
Radboudumc		Radboudumc Center of Expertise for Thyroid carcinomas	Thyroid tumor	ORPHA:100087
UMC Groningen		UMCG Center of Expertise for Thyroid Cancer	Thyroid tumor	ORPHA:100087
Leiden UMC		Expert Center for Rare Endocrine Conditions	Thyroid carcinoma	ORPHA:100088
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Tumors of Endocrine Glands	Thyroid carcinoma	ORPHA:100088
UMC Groningen		UMCG Center of Expertise for Thyroid Cancer	Thyroid carcinoma	ORPHA:100088
Radboudumc		Radboudumc Center of Expertise for Adrenal diseases	Adrenal/paraganglial tumor	ORPHA:100091
UMC Utrecht	NKI-AvL	UMC Utrecht Expertise Centre for rare endocrine tumors	Adrenal/paraganglial tumor	ORPHA:100091
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Neuroendocrine Tumors	Gastroenteropancreatic neuroendocrine neoplasm	ORPHA:100092
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Rare Respiratory Tumors	Thymic tumor	ORPHA:100100
Erasmus MC		The ENCORE expertise center for neurodevelopmental disorders	Rare nonsyndromic intellectual disability	ORPHA:101685
Erasmus MC		Center of expertise for inherited cardiovascular diseases	Genetic cardiac rhythm disease	ORPHA:101934
UMC Groningen		UMCG Center of Expertise for Cardiogenetics	Genetic cardiac rhythm disease	ORPHA:101934
Erasmus MC		Erasmus MC Liver Center of Expertise	Rare vascular liver disease	ORPHA:101938
Erasmus MC		Erasmus MC Liver Center of Expertise	Rare hepatic and biliary tract tumor	ORPHA:101943
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Rare Hepatic and Biliary Tract Tum	Rare hepatic and biliary tract tumor	ORPHA:101943
UMC Utrecht	Diakonessenhuis Utrecht	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver an	Rare hepatic and biliary tract tumor	ORPHA:101943
Leiden UMC		Expert Center for Ocular Oncology	Rare eye tumor	ORPHA:101950
Leiden UMC		Expert Center for Rare Endocrine Conditions	Rare Diabetes Mellitus	ORPHA:101952
Amsterdam UMC		Amsterdam UMC Expert Center for Inborn Errors of Metabolism	Rare dyslipidemia	ORPHA:101953
Erasmus MC		Expertise center Erasmus MC Vascular Genetics	Rare dyslipidemia	ORPHA:101953
Amsterdam UMC		Amsterdam UMC Expert Center for rare endocrine conditions	Rare adrenal disease	ORPHA:101954
Erasmus MC		Erasmus MC Centre of Expertise for Endocrine Disorders	Rare adrenal disease	ORPHA:101954
Leiden UMC		Expert Center for Rare Endocrine Conditions	Rare adrenal disease	ORPHA:101954
Amsterdam UMC		Amsterdam UMC Expert Center for rare endocrine conditions	Rare thyroid disease	ORPHA:101955
Erasmus MC		Erasmus MC Centre of Expertise for Endocrine Disorders	Rare thyroid disease	ORPHA:101955
Leiden UMC		Expert Center for Rare Endocrine Conditions	Polyendocrinopathy	ORPHA:101956
Radboudumc		Radboudumc Center of Expertise for Pituitary disease	Pituitary deficiency	ORPHA:101957
Amsterdam UMC		Amsterdam UMC expertise center for primary immunodeficiencies an bone	Quantitative and/or qualitative congenital phagocyte de	ORPHA:101985
UMC Utrecht		UMC Utrecht Expertise centre for benign hematology, thrombosis and hemo	Constitutional neutropenia	ORPHA:101987
Radboudumc		Radboudumc Center of Expertise for Immunodeficiency and autoinflammat	Immunodeficiency due to a complement cascade protei	ORPHA:101992
UMC Utrecht		UMC Utrecht Expertise Centre for systemic autoimmune diseases and prima	Periodic fever syndromes	ORPHA:101995
Amsterdam UMC		Amsterdam UMC expertise center for primary immunodeficiencies an bone	Primary immunodeficiencies	ORPHA:101997
Erasmus MC		Immunodeficiency center of expertise	Primary Immunodeficiency	ORPHA:101997
Leiden UMC		Expert Center for Rare Inherited Immunodeficiencies and Stem Cell Transpla	Primary immunodeficiency	ORPHA:101997
Radboudumc		Radboudumc Center of Expertise for Immunodeficiency and autoinflammat	Primary immunodeficiency	ORPHA:101997
UMC Utrecht		UMC Utrecht Expertise Centre for systemic autoimmune diseases and prima	Primary immunodeficiency	ORPHA:101997
Radboudumc		Radboudumc Center of Expertise for Rare and genetic movement disorders	Rare ataxia	ORPHA:102002
UMC Utrecht		UMC Utrecht Expertise Centre for neurovascular malformations and subara	Neurovascular malformation	ORPHA:102006
Amsterdam UMC		Amsterdam UMC Expert Center for Developmental Disorders	Rare syndromic intellectual disability	ORPHA:102369
Erasmus MC		The ENCORE expertise center for neurodevelopmental disorders	Rare syndromic intellectual disability	ORPHA:102369
Amsterdam UMC		Amsterdam UMC Expert Center Fetal Akinesia Deformation Sequence and A	Arthrogryposis multiplex congenita	ORPHA:1037
Oogziekenhuis Rotterdam		Rare Eye Disease Center Rotterdam	Leber hereditary optic neuropathy	ORPHA:104
Amsterdam UMC		Amsterdam UMC TPN & Intestinal Failure Clinic	Short bowel syndrome	ORPHA:104008
Radboudumc		Radboudumc Center of Expertise for Congenital malformations of the intest	Short bowel syndrome	ORPHA:104008

Ziekenhuis	Samenwerkingspartner	Naam EC (EN)	(Cluster van) aandoeningen	Orphacode
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Gastrointestinal Motility Disorders	Rare diseases involving intestinal motility	ORPHA:104009
Amsterdam UMC		Amsterdam UMC expert center for hereditary cancer	Intestinal polyposis syndrome	ORPHA:104010
Erasmus MC		Center of Expertise for Familial and Hereditary Tumors	Intestinal polyposis syndrome	ORPHA:104010
Radboudumc		Radboudumc Center of Expertise for Hereditary cancer	Intestinal polyposis syndrome	ORPHA:104010
Erasmus MC		Expertise center for rare IBD and intractable diarrhea	rare inflammatory bowel disease	ORPHA:104012
Leiden UMC		Expert Center for Rare Pregnancy-Related Disorders	Hydrops fetalis	ORPHA:1041
Radboudumc		Radboudumc Center of Expertise for Iron disorders	Sideroblastic anemia	ORPHA:1047
UMC Utrecht		UMC Utrecht Expertise centre for benign hematology, thrombosis and hemo	Sideroblastic anemia	ORPHA:1047
Leiden UMC		Expert Center for Rare Pregnancy-Related Disorders	Non-syndromic central nervous system malformation	ORPHA:108989
Leiden UMC		Expert Center for Rare Pregnancy-Related Disorders	Syndrome with a central nervous system malformation a	ORPHA:108991
Leiden UMC		Expert Center for Rare Pregnancy-Related Disorders	Non-syndromic respiratory or mediastinal malformatio	ORPHA:108993
UMC Utrecht		UMC Utrecht Expertise Centre for hereditary and congenital nephrologic an	Bardet-Biedl syndrome	ORPHA:110
Amsterdam UMC		Amsterdam UMC expert center for cleft, craniofacial and airway disorders	Beckwith Wiedemann syndrome	ORPHA:116
Erasmus MC		Center of Expertise for Rare Systemic Immune Disease	Behcet disease	ORPHA:117
UMC Groningen		UMCG Expertise Center for Movement Disorders Groningen	Autosomal recessive cerebellar ataxia	ORPHA:1172
Amsterdam UMC		Amsterdam UMC expertise centre for congenital malformations of the oeso	Esophageal atresia	ORPHA:1199
Erasmus MC		Pediatric Surgical Centre for Anatomical Congenital Malformations	Esophageal atresia	ORPHA:1199
Erasmus MC		Dutch Craniofacial Center of Expertise	Progressive hemifacial atrophy	ORPHA:1214
Amsterdam UMC		Amsterdam UMC expert center for hereditary cancer	Birt-Hogg-Dubé syndrome	ORPHA:122
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Genodermatoses	Birt-Hogg-Dubé syndrome	ORPHA:122
UMC Utrecht		UMC Utrecht Expertise centre for benign hematology, thrombosis and hemo	Blackfan-Diamond anemia	ORPHA:124
Amsterdam UMC		Amsterdam UMC expert center in Rare Bone Disease, including FOP, heredit	Camurati-Engelmann disease	ORPHA:1328
Leiden UMC		Expert Center for Genetic Cerebral Small Vessel Disease	Cerebral autosomal dominant arteriopathy-subcortical i	ORPHA:136
Radboudumc		Radboudumc Center of Expertise for Inherited metabolic disorders	Congenital disorder of glycosylation	ORPHA:137
Erasmus MC		Cleft Center of expertise Erasmus MC	Rare disease with (Pierre) Robin syndrome	ORPHA:138044
Amsterdam UMC		Amsterdam UMC expert center for cleft, craniofacial and airway disorders	Pierre Robin syndrome associated with a chromosomal a	ORPHA:138047
Leiden UMC		Expert Center for Rare Endocrine Conditions	Malformation syndrome with short stature	ORPHA:139021
Erasmus MC		Dutch Craniofacial Center of Expertise	branchial arch or oral-acral syndrome	ORPHA:139036
Erasmus MC		Dutch Craniofacial Center of Expertise	Isolated craniosynostosis	ORPHA:139390
Radboudumc		Radboudumc Center of Expertise for Craniofacial disorders	Isolated craniosynostosis	ORPHA:139390
Erasmus MC		Dutch Craniofacial Center of Expertise	Syndromic craniosynostosis	ORPHA:139393
Radboudumc		Radboudumc Center of Expertise for Craniofacial disorders	Syndromic craniosynostosis	ORPHA:139393
UMC Utrecht		UMC Utrecht Expertise Centre for hereditary and congenital nephrologic an	Joubert syndrome and related disorders	ORPHA:140874
Amsterdam UMC		Amsterdam UMC expert center for cleft, craniofacial and airway disorders	Oculo-auriculo-vertebral spectrum	ORPHA:141132
Radboudumc		Radboudumc Center of Expertise for Hemangiomas and congenital vascular	Cerebrofacial arteriovenous metameris syndrome	ORPHA:141189
Erasmus MC		Dutch Craniofacial Center of Expertise	Facial cleft	ORPHA:141229
UMC Groningen		UMCG Expertise Center for Movement Disorders Groningen	Paroxysmal dyskinesia	ORPHA:1431
Amsterdam UMC		Amsterdam UMC expert center for hereditary cancer	Lynch syndrome	ORPHA:144
Erasmus MC		Center of Expertise for Familial and Hereditary Tumors	Lynch Syndrome	ORPHA:144
Leiden UMC		Expert Center for Rare Hereditary Bowel Tumors	Lynch syndrome	ORPHA:144
NKI-AVL		Expert Center for Hereditary Cancer	Lynch syndroom	ORPHA:144
Radboudumc		Radboudumc Center of Expertise for Hereditary cancer	Lynch Syndrome	ORPHA:144
UMC Groningen		UMCG Center of Expertise for Familial Colorectal Cancer	Lynch syndrome	ORPHA:144
Amsterdam UMC		Amsterdam UMC expert center for hereditary cancer	Hereditary breast and ovarian cancer syndrome	ORPHA:145
Erasmus MC		Academic Breast and Ovarian Cancer Center	Hereditary breast and ovarian cancer syndrome	ORPHA:145

Ziekenhuis	Samenwerkingspartner	Naam EC (EN)	(Cluster van) aandoeningen	Orphacode
NKI-AVL		Expert Center for Hereditary Cancer	Hereditary breast and ovarian cancer syndrome	ORPHA:145
Radboudumc		Radboudumc Center of Expertise for Hereditary cancer	Hereditary breast and ovarian cancer syndrome	ORPHA:145
UMC Groningen		UMCG Center of Expertise for Familial Breast and Ovarian Cancer	Hereditary breast and ovarian cancer syndrome	ORPHA:145
Radboudumc		Radboudumc Center of Expertise for Congenital disorders of dental develop	Cleidocranial dysplasia	ORPHA:1452
NKI-AVL		Center of rare head and neck tumours	Nasopharyngeal carcinoma	ORPHA:150
Maxima Medisch Centrum		Center for Adrenal Tumors	Adrenocortical carcinoma	ORPHA:1501
Amsterdam UMC		Amsterdam UMC expert center for cleft, craniofacial and airway disorders	Cysts and fistulae of the face and oral cavity	ORPHA:155835
Radboudumc		Radboudumc Center of Expertise for Cleft lip & palate and orofacial disorde	Otomandibular dysplasia	ORPHA:155896
Radboudumc		Radboudumc Center of Expertise for Hemangiomas and congenital vascular	Facial arteriovenous malformation	ORPHA:156230
Amsterdam UMC		Amsterdam UMC expert center for cleft, craniofacial and airway disorders	Larynx anomaly	ORPHA:156249
Erasmus MC		Center of expertise for pediatric laryngotracheal stenosis	Larynx anomaly	ORPHA:156249
Amsterdam UMC		Amsterdam UMC expert center for cleft, craniofacial and airway disorders	Tracheal anomaly	ORPHA:156252
Erasmus MC		Center of expertise for pediatric laryngotracheal stenosis	Tracheal anomaly	ORPHA:156252
NKI-AVL		Expert Center for Hereditary Cancer	Hereditary mixed polyposis syndrome	ORPHA:157794
Amsterdam UMC		Amsterdam UMC expert center for hereditary cancer	Serrated polyposis syndrome	ORPHA:157798
NKI-AVL		Expert Center for Hereditary Cancer	Serrated polyposis syndrome	ORPHA:157798
UMC Groningen		UMCG Expertise Center for Movement Disorders Groningen	Pantothenate kinase-associated neurodegeneration	ORPHA:157850
Erasmus MC		Center of Expertise for Rare Systemic Immune Disease	Non-Langerhans cell histiocytosis	ORPHA:157987
Erasmus MC		Center of Expertise for Rare Systemic Immune Disease	Hemophagocytic syndrome	ORPHA:158032
Leiden UMC		Expert Center for Rare Inherited Immunodeficiencies and Stem Cell Transpla	Hemophagocytic syndrome	ORPHA:158032
Leiden UMC		Expert Center for Rare Pregnancy-Related Disorders	Rare disorder related with pregnancy, childbirth and pue	ORPHA:163637
Erasmus MC		Erasmus MC center of expertise for inflammatory disorders of the central ne	Limbic encephalitis	ORPHA:163892
Amsterdam UMC		Amsterdam UMC expert center for cleft, craniofacial and airway disorders	Rare odontal or periodontal disorder	ORPHA:164001
UMC Utrecht		UMC Utrecht Expertise Centre for congenital orofacial and dental anomalies	Rare odontal or periodontal disorder	ORPHA:164001
Amsterdam UMC		Amsterdam UMC expert center for cleft, craniofacial and airway disorders	Middle ear anomaly	ORPHA:164004
Leiden UMC		Expert Center for Rare Ear Diseases	Middle ear anomaly	ORPHA:164004
UMC Utrecht		UMC Utrecht Expertise Centre for rare otorhinolaryngological diseases	Middle ear anomaly	ORPHA:164004
Leiden UMC		Expert Center for Rare Bone Marrow Failure	Rare acquired aplastic anemia	ORPHA:164823
Radboudumc		Radboudumc Center of Expertise for Pediatric urology	Non-syndromic urogenital tract malformation	ORPHA:165704
Amsterdam UMC		Amsterdam UMC expertise center for neuromuscular diseases	Hereditary motor and sensory neuropathy	ORPHA:166
UMC Utrecht		UMC Utrecht Expertise Centre for rare and complex epilepsies	Monogenetic disease with epilepsy	ORPHA:166472
UMC Utrecht		UMC Utrecht Expertise Centre for rare and complex epilepsies	cerebral malformations with epilepsy	ORPHA:166478
Erasmus MC		Erasmus MC center of expertise for inflammatory disorders of the central ne	Inflammatory and autoimmune disease with epilepsy	ORPHA:166484
Leiden UMC	HagaZiekenhuis	Expert Center for Hemophilia and Related Disorders LUMC-HagaZiekenhuis	Rare hemorrhagic disorder due to an acquired coagulati	ORPHA:166775
Amsterdam UMC		Amsterdam UMC centre of excellence for rare cardiac diseases	Rare cardiomyopathy	ORPHA:167848
UMC Groningen		UMCG Center of Expertise for Cardiogenetics	Rare cardiomyopathy	ORPHA:167848
UMC Groningen		UMCG Center of Expertise for Children and Adults with Congenital Heart Dis	Rare Cardiomyopathy	ORPHA:167848
Erasmus MC		The ENCORE expertise center for neurodevelopmental disorders	Rare pervasive developmental disorder	ORPHA:168778
Erasmus MC		Center of expertise for lung cancer	Malignant peritoneal mesothelioma	ORPHA:168811
Oogziekenhuis Rotterdam	Erasmus MC	Rotterdam centre rare eye cancer	Malignant melanoma of the mucosa	ORPHA:168999
Amsterdam UMC		Amsterdam UMC Expert Center for immune-mediated and genetic cholesta	Primary Sclerosing Cholangitis	ORPHA:171
Erasmus MC		Hematologic malignancies center of expertise	Myeloid hemopathy	ORPHA:171895
UMC Utrecht		UMC Utrecht Expertise Centre for malignant hematology	B-cell non-Hodgkin lymphoma	ORPHA:171915
Amsterdam UMC		Amsterdam UMC Expert Center for immune-mediated and genetic cholesta	Progressive familial intrahepatic cholestasis	ORPHA:172
UMC Utrecht		UMC Utrecht Expertise Center for rare GI and hepatic diseases	Progressive Familial Intrahepatic Cholestasis	ORPHA:172

Ziekenhuis	Samenwerkingspartner	Naam EC (EN)	(Cluster van) aandoeningen	Orphacode
Leiden UMC		Expert Center for Rare Bone and Soft Tissue Tumors	Chordoma	ORPHA:178
Radboudumc	Maastricht UMC+	Radboudumc-Maastricht UMC+ Center of Expertise for Skull base patholog	Chordoma	ORPHA:178
UMC Utrecht	NKI-AvL	UMC Utrecht Expertise Centre for rare endocrine tumors	Central diabetes insipidus	ORPHA:178029
Leiden UMC		Expert Center for Rare Endocrine Conditions	Isolated Sternocostoclavicular Hyperostosis	ORPHA:178311
Amsterdam UMC	NKI-AvL	Center Gynaecologic Oncology Amsterdam	Rare vulvovaginal tumor	ORPHA:180312
UMC Groningen		UMCG Center of Expertise for Oesophageal and Gastric Carcinoma	Rare gastroesophageal tumor	ORPHA:180821
UMC Utrecht	Diakonessenhuis Utrecht	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver an	Rare gastroesophageal tumor	ORPHA:180821
Amsterdam UMC		Amsterdam UMC Expertise Center for rare gastrointestinal tumors	Rare tumor of Pancreas	ORPHA:180824
UMC Utrecht	Diakonessenhuis Utrecht	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver an	Rare tumor of pancreas	ORPHA:180824
Amsterdam UMC		Amsterdam UMC Expert Center for rare endocrine conditions	Rare hypothalamic or pituitary disease	ORPHA:181384
Erasmus MC		Erasmus MC Centre of Expertise for Endocrine Disorders	Rare hypothalamic or pituitary disease	ORPHA:181384
Leiden UMC		Expert Center for Rare Endocrine Conditions	Rare hypothalamic and pituitary disease	ORPHA:181384
Radboudumc		Radboudumc Center of Expertise for Pituitary disease	Rare hypothalamic or pituitary disease	ORPHA:181384
UMC Utrecht	NKI-AvL	UMC Utrecht Expertise Centre for rare endocrine tumors	Rare hypothalamic or pituitary disease	ORPHA:181384
Erasmus MC		Expert Center Rare Growth Disorders	Growth hormone insensitivity syndrome	ORPHA:181393
Radboudumc		Radboudumc Center of Expertise for Adrenal diseases	Rare primary hyperaldosteronism	ORPHA:181415
UMC Utrecht		UMC Utrecht Expertise centre for rare genetic dyslipidemia	Rare hyperlipidemia	ORPHA:181422
Leiden UMC		Expert Center for Rare Bone Marrow Failure	Aplastic Anemia	ORPHA:182040
Erasmus MC		Erasmus MC center of expertise for inflammatory disorders of the central ne	Rare neuroinflammatory or neuroimmunological disease	ORPHA:182064
Leiden UMC		Expert Center for Brain Tumors	Glial Tumor	ORPHA:182067
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Neuro-Oncology	Glial tumor	ORPHA:182067
UMC Groningen		UMCG Center of Expertise for Brain and Skull Base Tumors	Glial tumor	ORPHA:182067
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Neuromuscular Diseases	Acquired peripheral neuropathy	ORPHA:182086
Amsterdam UMC		Amsterdam UMC center of expertise for Pulmonary Hypertension	Pulmonary Arterial Hypertension	ORPHA:182090
Amsterdam UMC		Amsterdam UMC Expert Center for Interstitial Lung Disease	Interstitial Lung Disease	ORPHA:182095
Erasmus MC		Academic center of excellence for Interstitial Lung Disease	Interstitial lung disease	ORPHA:182095
St. Antonius Ziekenhuis		Interstitial Lung Diseases Center of Excellence	Interstitial lung disease	ORPHA:182095
UMC Utrecht		UMC Utrecht Expertise Centre for hereditary and congenital nephrologic an	Non-syndromic urogenital tract malformation of male a	ORPHA:182124
Erasmus MC		Erasmus MC Centre of Expertise for Endocrine Disorders	Tumor of endocrine glands	ORPHA:182130
Erasmus MC		The ENCORE expertise center for neurodevelopmental disorders	Polymalformative genetic syndrome with increased risk	ORPHA:183422
UMC Groningen		UMCG Center of Expertise for Genodermatoses	Inherited ichthyosis	ORPHA:183435
Leiden UMC		Expert Center for Rare Inherited Immunodeficiencies and Stem Cell Transpla	Severe combined immunodeficiency	ORPHA:183660
Amsterdam UMC		Amsterdam UMC Expert Center for immune-mediated and genetic cholesta	Primary Biliary Cholangitis	ORPHA:186
UMC Groningen		UMCG Expertise Center for Movement Disorders Groningen	Focal, segmental or multifocal dystonia	ORPHA:1866
Erasmus MC		The ENCORE expertise center for neurodevelopmental disorders	Cockayne Syndrome	ORPHA:191
Erasmus MC		Center of rare skin diseases	Congenital lethal erythroderma	ORPHA:1954
Amsterdam UMC		Amsterdam UMC Expert Center for Developmental Disorders	Cornelia de Lange syndrome	ORPHA:199
Amsterdam UMC		Amsterdam UMC expert center for cleft, craniofacial and airway disorders	Cleft lip with or without cleft palate	ORPHA:1991
Erasmus MC		Cleft Center of expertise Erasmus MC	Cleft lip with or without cleft palate	ORPHA:1991
Radboudumc		Radboudumc Center of Expertise for Cleft lip & palate and orofacial disorde	Cleft lip with or without cleft palate	ORPHA:1991
UMC Utrecht		UMC Utrecht Expertise Centre for congenital orofacial and dental anomalies	Cleft lip with or without cleft palate	ORPHA:1991
Oogziekenhuis Rotterdam		Rare Eye Disease Center Rotterdam	Endophthalmitis	ORPHA:199323
Leiden UMC		Expert Center for Genetic Cerebral Small Vessel Disease	Cerebral autosomal recessive arteriopathy-subcortical in	ORPHA:199354
Amsterdam UMC		Amsterdam UMC expert center for cleft, craniofacial and airway disorders	Cleft palate	ORPHA:2014
Erasmus MC		Cleft Center of expertise Erasmus MC	Cleft palate	ORPHA:2014

Ziekenhuis	Samenwerkingspartner	Naam EC (EN)	(Cluster van) aandoeningen	Orphacode
Radboudumc		Radboudumc Center of Expertise for Cleft lip & palate and orofacial disorde	Cleft palate	ORPHA:2014
UMC Utrecht		UMC Utrecht Expertise Centre for congenital orofacial and dental anomalies	Cleft palate	ORPHA:2014
Erasmus MC		Academic center of excellence for Interstitial Lung Disease	Idiopathic pulmonary fibrosis	ORPHA:2032
St. Antonius Ziekenhuis		Interstitial Lung Diseases Center of Excellence	Idiopathic pulmonary fibrosis	ORPHA:2032
Amsterdam UMC		Amsterdam UMC Expert Center for immune-mediated and genetic cholesta	Crigler-Najjar syndrome	ORPHA:205
Erasmus MC		Center for Lysosomal and Metabolic Diseases	Crigler-Najjar syndrome	ORPHA:205
UMC Utrecht		UMC Utrecht Brain Centre, Neuromuscular Diseases	Genetic skeletal muscle disease	ORPHA:206634
UMC Utrecht		UMC Utrecht Brain Centre, Neuromuscular Diseases	Acquired skeletal muscle disease	ORPHA:206638
Leiden UMC		Expert Center for Rare Neuromuscular Diseases	Progressive muscular dystrophy	ORPHA:206644
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Neuromuscular Diseases	Myotonic dystrophy	ORPHA:206647
Radboudumc		Radboudumc Center of Expertise for neuromuscular disease	Myotonic dystrophy	ORPHA:206647
UMC Utrecht		UMC Utrecht Brain Centre, Neuromuscular Diseases	Non-dystrophic myopathy	ORPHA:206656
UMC Utrecht		UMC Utrecht Brain Centre, Neuromuscular Diseases	Bulbospinal muscular atrophy	ORPHA:206701
Kempenhaghe,Nederland		Center for Sleep Medicine Kempenhaghe	Narcolepsy Type 1	ORPHA:2073
UMC Utrecht		UMC Utrecht Brain Centre, Neuromuscular Diseases	Chronic polyradiculoneuropathy	ORPHA:208978
Amsterdam UMC		Amsterdam UMC expertise center for neuromuscular diseases	Peripheral neuropathy associated with monoclonal gam	ORPHA:209010
UMC Utrecht		UMC Utrecht Brain Centre, Neuromuscular Diseases	Peripheral neuropathy associated with monoclonal gam	ORPHA:209010
Erasmus MC		Center of expertise for congenital lung malformations	Congenital alveolar capillary dysplasia	ORPHA:210122
Radboudumc		Radboudumc Center of Expertise for Pulmonary hypertension	Congenital alveolar capillary dysplasia	ORPHA:210122
Erasmus MC		Erasmus MC Liver Center of Expertise	Adult hepatocellular carcinoma	ORPHA:210159
Erasmus MC		Neuromuscular Center Erasmus MC	Guillain-Barré syndrome	ORPHA:2103
Erasmus MC		Dutch Craniofacial Center of Expertise	Temporomandibular joint anomaly	ORPHA:210581
Radboudumc		Radboudumc Center of Expertise for Hemangiomas and congenital vascular	Rare vascular tumor	ORPHA:211237
UMC Utrecht		UMC Utrecht Expertise Centre for vascular anomalies	Rare vascular tumor	ORPHA:211237
Amsterdam UMC		Amsterdam UMC center of expertise for Vascular Malformations	Simple vascular malformation	ORPHA:211243
Amsterdam UMC		Amsterdam UMC center of expertise for Vascular Malformations	Rare capillary malformation	ORPHA:211247
Radboudumc		Radboudumc Center of Expertise for Hemangiomas and congenital vascular	Rare capillary malformation	ORPHA:211247
Amsterdam UMC		Amsterdam UMC center of expertise for Vascular Malformations	Rare venous malformation	ORPHA:211252
Radboudumc		Radboudumc Center of Expertise for Hemangiomas and congenital vascular	Rare venous malformation	ORPHA:211252
Amsterdam UMC		Amsterdam UMC center of expertise for Vascular Malformations	Rare arteriovenous malformation	ORPHA:211266
Radboudumc		Radboudumc Center of Expertise for CNS and retinal vascular diseases	Rare arteriovenous malformation	ORPHA:211266
UMC Utrecht		UMC Utrecht Expertise Centre for neurovascular malformations and subara	Rare arteriovenous malformation	ORPHA:211266
Amsterdam UMC		Amsterdam UMC center of expertise for Vascular Malformations	Complex vascular malformation with associated anomal	ORPHA:211277
Radboudumc		Radboudumc Center of Expertise for Hemangiomas and congenital vascular	Complex vascular malformation with associated anomal	ORPHA:211277
Amsterdam UMC	NKI-AvL	Center Gynaecologic Oncology Amsterdam	Ovarian cancer	ORPHA:213500
UMC Groningen		UMCG Center of Expertise for Familial Breast and Ovarian Cancer	Familial ovarian cancer	ORPHA:213517
Amsterdam UMC	NKI-AvL	Center Gynaecologic Oncology Amsterdam	Rare cancer of corpus uteri	ORPHA:213569
Amsterdam UMC		Amsterdam UMC Expert Center for immune-mediated and genetic cholesta	Autoimmune hepatitis	ORPHA:2137
Amsterdam UMC	NKI-AvL	Center Gynaecologic Oncology Amsterdam	Rare cancer of cervix uteri	ORPHA:213761
Radboudumc		Radboudumc Center of Expertise for Congenital malformations of the intest	Congenital diaphragmatic hernia	ORPHA:2140
Erasmus MC		Center for Lysosomal and Metabolic Diseases	neuronal ceroid lipofucsinosis	ORPHA:216
Radboudumc		Radboudumc Center of Expertise for Adult urogenital anomalies	Renal cell carcinoma	ORPHA:217071
Erasmus MC		Erasmus MC center of expertise for inflammatory disorders of the central ne	Limbic encephalitis with NMDA receptor antibodies	ORPHA:217253
Erasmus MC		Center of expertise for inherited cardiovascular diseases	Hypertrophic cardiomyopathy	ORPHA:217569
Erasmus MC		Center of expertise for inherited cardiovascular diseases	Dilated cardiomyopathy	ORPHA:217604

Ziekenhuis	Samenwerkingspartner	Naam EC (EN)	(Cluster van) aandoeningen	Orphacode
Erasmus MC		Center of expertise for inherited cardiovascular diseases	Restrictive cardiomyopathy	ORPHA:217632
Amsterdam UMC		Amsterdam UMC centre of excellence for rare cardiac diseases	Rare cardiac rhythm diseases	ORPHA:218436
Leiden UMC		Expert Center for Rare Hereditary Bowel Tumors	Geattenueerde familiale adenomateuze polyposis	ORPHA:220460
NKI-AVL		Expert Center for Hereditary Cancer	Attenuated Familial adenomatous polyposis	ORPHA:220460
Radboudumc		Radboudumc Center of Expertise for Iron disorders	Rare hereditary hemochromatosis	ORPHA:220489
Amsterdam UMC		Amsterdam UMC Expertise Center for Systemic Autoimmune diseases	Dermatomyositis	ORPHA:221
Amsterdam UMC		Amsterdam UMC Expert Center for Bone and Soft Tissue Sarcomas	Bone Sarcoma	ORPHA:223727
Leiden UMC		Expert Center for Rare Bone and Soft Tissue Tumors	Bone sarcoma	ORPHA:223727
Radboudumc		Radboudumc Center of Expertise for Sarcomas	Bone sarcoma	ORPHA:223727
UMC Groningen		UMCG Center of Expertise for Bone and Soft Tissue Tumors	Bone sarcoma	ORPHA:223727
Amsterdam UMC		Amsterdam UMC Expert Center for Hematological Malignancies	Lymphoma	ORPHA:223735
Leiden UMC		Expert Center for Rare Inherited Immunodeficiencies and Stem Cell Transpla	ICF syndrome	ORPHA:2268
Erasmus MC		Academic Breast and Ovarian Cancer Center	Hereditary Breast Cancer	ORPHA:227535
UMC Groningen		UMCG Center of Expertise for Familial Breast and Ovarian Cancer	Hereditary breast cancer	ORPHA:227535
Erasmus MC		Erasmus MC center of expertise for inflammatory disorders of the central ne	Multiple sclerosis variant	ORPHA:228145
Erasmus MC		Frontotemporal Dementia center of expertise	neuronal intranuclear inclusion disease	ORPHA:2289
UMC Utrecht	Diakonessenhuis Utrecht	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver an	High-grade dysplasia in patients with Barrett esophagus	ORPHA:231080
UMC Utrecht		UMC Utrecht Expertise Centre for neurovascular malformations and subara	Familial cerebral saccular aneurysm	ORPHA:231160
UMC Utrecht		UMC Utrecht Expertise centre for benign hematology, thrombosis and hemo	Sickle cell anemia	ORPHA:232
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Rare Syndromes and Cognitive Dis	Kabuki syndrome	ORPHA:2322
Amsterdam UMC		Amsterdam UMC expertise center for rare pediatric rheumatologic diseases	Kawasaki disease	ORPHA:2331
Radboudumc		Radboudumc Center of Expertise for Congenital neurodevelopmental disord	KBG syndrome	ORPHA:2332
Radboudumc		Radboudumc Center of Expertise for Adrenal diseases	Familial hyperaldosteronism	ORPHA:235936
Radboudumc		Radboudumc Center of Expertise for Congenital malformations of the intest	Gastroschisis	ORPHA:2368
UMC Utrecht		UMC Utrecht Expertise Centre for rare otorhinolaryngological diseases	Congenital laryngomalacia	ORPHA:2373
Erasmus MC		The ENCORE expertise center for neurodevelopmental disorders	15q11q13 microduplication syndrome	ORPHA:238446
Radboudumc		Radboudumc Center of Expertise Sex & Gender	Isolated congenital hypogonadotropic hypogonadism	ORPHA:238666
Erasmus MC		Frontotemporal Dementia center of expertise	classical progressive supranuclear palsy	ORPHA:240071
Amsterdam UMC		Amsterdam UMC center of expertise for Vascular Malformations	Rare lymphatic malformation	ORPHA:2415
Radboudumc		Radboudumc Center of Expertise for Hemangiomas and congenital vascular	Rare lymphatic malformation	ORPHA:2415
Erasmus MC		Center of expertise for pregnancy induced diseases	Acute fatty liver of pregnancy	ORPHA:243367
Amsterdam UMC		Amsterdam UMC Expert Center for Cystic Fibrosis and Primary Ciliary Dyskin	Primary ciliary dyskinesia	ORPHA:244
Erasmus MC		Center of expertise for congenital lung malformations	Congenital pulmonary airway malformation	ORPHA:2444
Erasmus MC		Center of expertise for inherited cardiovascular diseases	Arrhythmogenic right ventricular cardiomyopathy	ORPHA:247
Leiden UMC		Expert Center for Genetic Cerebral Small Vessel Disease	Retinal vasculopathy with cerebral leukoencephalopathy	ORPHA:247691
Amsterdam UMC		Amsterdam UMC expert center for hereditary cancer	MUTYH-related attenuated familial adenomatous polyp	ORPHA:247798
Leiden UMC		Expert Center for Rare Hereditary Bowel Tumors	MUTYH-related attenuated familial adenomatous polyp	ORPHA:247798
Leiden UMC		Expert Center for Rare Hereditary Bowel Tumors	APC-related attenuated familial adenomatous polyposis	ORPHA:247806
UMC Groningen		UMCG Center of Expertise for Benign Hematology	Rare hemorrhagic disorder	ORPHA:248308
Erasmus MC		Expertise Center for Rare Bleeding disorders	Rare hemorrhagic disorder due to a coagulation factors	ORPHA:248315
UMC Utrecht		UMC Utrecht Expertise centre for benign hematology, thrombosis and hemo	Rare hemorrhagic disorder due to a coagulation factors	ORPHA:248315
Erasmus MC		Expertise Center for Rare Bleeding disorders	Rare hemorrhagic disorder due to a platelet anomaly	ORPHA:248326
UMC Utrecht		UMC Utrecht Expertise centre for benign hematology, thrombosis and hemo	Rare hemorrhagic disorder due to a platelet anomaly	ORPHA:248326
Amsterdam UMC		Amsterdam UMC expert center in Rare Bone Disease, including FOP, heredit	Fibrous dysplasia of bone	ORPHA:249
UMC Groningen		UMCG Center of Expertise for Brain and Skull Base Tumors	Meningioma	ORPHA:2495

Ziekenhuis	Samenwerkingspartner	Naam EC (EN)	(Cluster van) aandoeningen	Orphacode
Amsterdam UMC		Amsterdam UMC Expert Center for brain tumors	Rare tumors of neuroepithelial tissue	ORPHA:251558
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Neuro-Oncology	Rare tumor of neuroepithelial tissue	ORPHA:251558
Radboudumc		Radboudumc Center of Expertise for Neuro-oncology	Rare tumor of the neuroepithelial tissue	ORPHA:251558
Radboudumc	Maastricht UMC+	Radboudumc-Maastricht UMC+ Center of Expertise for Skull base patholog	Vestibular schwannoma	ORPHA:252175
Amsterdam UMC	NKI-AvL	Center Gynaecologic Oncology Amsterdam	Gestational trophoblastic disease	ORPHA:254685
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Gastrointestinal Motility Disorders	Familial visceral myopathy	ORPHA:2604
NKI-AVL		Expert Center for Hereditary Cancer	Hereditary diffuse gastric cancer	ORPHA:26106
Radboudumc		Radboudumc Center of Expertise for Congenital neurodevelopmental disord	Kleefstra syndrome	ORPHA:261494
Leiden UMC		Expert Center for Rare Neuromuscular Diseases	Duchenne and Becker muscular dystrophy	ORPHA:262
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Neuromuscular Diseases	Duchenne and Becker muscular dystrophy	ORPHA:262
Radboudumc		Radboudumc Center of Expertise for neuromuscular disease	Duchenne and Becker muscular dystrophy	ORPHA:262
Leiden UMC		Expert Center for Rare Neuromuscular Diseases	Limb Girdle Muscular Dystrophy	ORPHA:263
Amsterdam UMC		Amsterdam UMC Expert Center for Interstitial Lung Disease	Genetic interstitial lung disease	ORPHA:264992
Amsterdam UMC		Amsterdam UMC expert center for spina bifida and spinal cord conditions	Neural tube closure defect	ORPHA:268357
Erasmus MC		Expert Center spinal disraphism Rotterdam	Neural tube closure defect	ORPHA:268357
Erasmus MC		Dutch Craniofacial Center of Expertise	Cephalocele	ORPHA:268817
UMC Utrecht		UMC Utrecht Expertise Centre for rare and complex epilepsies	cerebral cortical dysplasia	ORPHA:268950
Leiden UMC		Expert Center for Rare Neuromuscular Diseases	Facioscapulohumeral muscular dystrophy	ORPHA:269
Radboudumc		Radboudumc Center of Expertise for neuromuscular disease	Facioscapulohumeral dystrophy	ORPHA:269
Leiden UMC		Expert Center for Rare Neuromuscular Diseases	Oculopharyngeal muscular dystrophy	ORPHA:270
Radboudumc		Radboudumc Center of Expertise for neuromuscular disease	Oculopharyngeal muscular dystrophy	ORPHA:270
Erasmus MC		Sickle Cell and Thalassemia Comprehensive Care Center	Alpha thalassemia and related diseases	ORPHA:275745
Leiden UMC	HagaZiekenhuis	Expert Center for Rare Hemoglobinopathies	Alpha- thalassemia and related diseases	ORPHA:275745
Erasmus MC		Sickle Cell and Thalassemia Comprehensive Care Center	Beta-thalassemia and related diseases	ORPHA:275749
Leiden UMC	HagaZiekenhuis	Expert Center for Rare Hemoglobinopathies	Beta- thalassemia and related diseases	ORPHA:275749
Erasmus MC		Sickle Cell and Thalassemia Comprehensive Care Center	Sickle cell disease and related diseases	ORPHA:275752
Leiden UMC	HagaZiekenhuis	Expert Center for Rare Hemoglobinopathies	Sickle cell disease and related diseases	ORPHA:275752
Radboudumc		Radboudumc Center of Expertise for Pulmonary hypertension	Idiopathic pulmonary arterial hypertension	ORPHA:275766
St. Antonius Ziekenhuis		Center for Pulmonary vascular diseases	Idiopathic pulmonary arterial hypertension	ORPHA:275766
Radboudumc		Radboudumc Center of Expertise for Pulmonary hypertension	Pulmonary arterial hypertension associated with connec	ORPHA:275798
Radboudumc		Radboudumc Center of Expertise for Pulmonary hypertension	Pulmonary arterial hypertension associated with congen	ORPHA:275803
Amsterdam UMC		Amsterdam UMC center of expertise for Pulmonary Hypertension	Pulmonary hypertension owing to lung disease and/or h	ORPHA:275837
Radboudumc		Radboudumc Center of Expertise for Pulmonary hypertension	Pulmonary hypertension owing to lung disease and/or h	ORPHA:275837
Amsterdam UMC		Amsterdam UMC center of expertise for Pulmonary Hypertension	Pulmonary hypertension with unclear multifactorial mec	ORPHA:275844
Erasmus MC		Frontotemporal Dementia center of expertise	Frontotemporal dementia with motor neuron disease	ORPHA:275872
Leiden UMC		Expert Center for Rare Pregnancy-Related Disorders	Hemolytic disease due to fetomaternal alloimmunizatio	ORPHA:275938
Amsterdam UMC		Amsterdam UMC Expertise center for Head and Neck tumors	Rare tumor of salivary glands	ORPHA:276142
NKI-AVL		Center of rare head and neck tumours	Rare tumor of salivary glands	ORPHA:276142
Radboudumc		Radboudumc Center of Expertise for Head and neck and salivary gland tumo	Rare tumor of salivary glands	ORPHA:276142
UMC Utrecht		UMC Utrecht Expertise Centre for skeletal malformations & Mobility Clinic	Osteochondritis dissecans	ORPHA:2764
UMC Utrecht		UMC Utrecht Expertise Centre for uveitis	primary intraocular lymphoma	ORPHA:279904
UMC Utrecht		UMC Utrecht Expertise Centre for uveitis	Intermediate uveitis	ORPHA:279914
Erasmus MC		Centre of expertise for Children with Autoimmune Diseases	Rare Pediatric Vasculitis	ORPHA:280369
UMC Groningen		UMCG Expertise Center for Movement Disorders Groningen	Progressive myoclonic epilepsy type 6	ORPHA:280620
UMC Utrecht		UMC Utrecht Expertise Centre for uveitis	anterior uveitis	ORPHA:280886

Ziekenhuis	Samenwerkingspartner	Naam EC (EN)	(Cluster van) aandoeningen	Orphacode
UMC Utrecht		UMC Utrecht Expertise Centre for uveitis	posterior uveitis	ORPHA:280892
UMC Utrecht		UMC Utrecht Expertise Centre for uveitis	panuveitis	ORPHA:280898
Erasmus MC		Frontotemporal Dementia center of expertise	Frontotemporal dementia	ORPHA:282
Erasmus MC		Center of Expertise for Rare Systemic Immune Disease	IgG4-related disease	ORPHA:284264
UMC Groningen		UMCG Center of Expertise for Defects in Amino Acid and Organic Acid Meta	Disorder of phenylalanine metabolism	ORPHA:284814
Amsterdam UMC		Amsterdam UMC expert centre for Marfan syndrome and related disorders	Marfan and Marfan-related disorders	ORPHA:284993
Leiden UMC		Expert Center for Marfan and Related Syndromes	Marfan en Marfan-related disorders	ORPHA:284993
UMC Groningen		UMCG Center of Expertise for Marfan Syndrome and Related Disorders	Marfan and Marfan-related disorders	ORPHA:284993
UMC Utrecht		UMC Utrecht Expertise Centre for inherited metabolic diseases (CIMD-UMC)	Disorder of folate metabolism and transport	ORPHA:285657
Radboudumc	Maastricht UMC+	Radboudumc-Maastricht UMC+ Center of Expertise for Marfan and related d	Vascular Ehlers-Danlos syndrome	ORPHA:286
Amsterdam UMC		Amsterdam UMC expert center for hereditary cancer	Peutz-Jeghers syndrome	ORPHA:2869
Erasmus MC		Center of Expertise for Rare Systemic Immune Disease	Primary Sjögren Syndrome	ORPHA:289390
UMC Groningen		UMCG Center of Expertise for Systemic Autoimmune Diseases	Primary Sjögren syndrome	ORPHA:289390
Leiden UMC		Expert Center for Familial Melanoma	BAP1-related tumor predisposition syndrome	ORPHA:289539
Amsterdam UMC		Amsterdam UMC Expert Center for Developmental Disorders	Pitt-Hopkins syndrome	ORPHA:2896
Erasmus MC		Center for PKU, urea cycle disorders and organic acidurias	organic aciduria	ORPHA:289899
Radboudumc		Radboudumc Center of Expertise for neuromuscular disease	Neuralgic amyotrophy	ORPHA:2901
Amsterdam UMC		Amsterdam UMC Expertise center for Head and Neck tumors	Hereditary pheochromocytoma-paraganglioma	ORPHA:29072
UMC Utrecht	NKI-AvL	UMC Utrecht Expertise Centre for rare endocrine tumors	Hereditary pheochromocytoma-paraganglioma	ORPHA:29072
Amsterdam UMC		Amsterdam UMC Expert Center for Hematological Malignancies	Multiple myeloma	ORPHA:29073
Erasmus MC		Hematologic malignancies center of expertise	Multiple myeloma	ORPHA:29073
UMC Utrecht		UMC Utrecht Expertise Centre for malignant hematology	Multiple myeloma	ORPHA:29073
Radboudumc		Radboudumc Center of Expertise for Immunodeficiency and autoinflammat	Autoinflammatory syndrome with immune deficiency	ORPHA:290839
Amsterdam UMC		Amsterdam UMC Expertise center for Head and Neck tumors	Rare head and neck tumor	ORPHA:290849
Erasmus MC		Expert center for rare head & neck tumors	Rare head and neck tumor	ORPHA:290849
Leiden UMC		Expert Center for Rare Head and Neck Tumors	Rare head and neck tumor	ORPHA:290849
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Head and Neck Oncology	Rare head and neck tumor	ORPHA:290849
Radboudumc		Radboudumc Center of Expertise for Head and neck and salivary gland tumo	Rare head and neck tumor	ORPHA:290849
UMC Groningen		UMCG Center of Expertise for Head and Neck Oncology	Rare head and neck tumor	ORPHA:290849
Radboudumc		Radboudumc Center of Expertise for Liver cysts	Isolated polycystic liver disease	ORPHA:2924
Amsterdam UMC		Amsterdam UMC expertise center for neuromuscular diseases	Chronic inflammatory demyelinating polyneuropathy	ORPHA:2932
Erasmus MC		Neuromuscular Center Erasmus MC	Chronic inflammatory demyelinating polyneuropathy	ORPHA:2932
Erasmus MC	Sint Franciscus Vlietland G	Mesenteric Ischemia Center Rotterdam	Celiac artery compression syndrome	ORPHA:293208
Leiden UMC		Expert Center for Familial Melanoma	MITF-related melanoma and renal cell carcinoma predis	ORPHA:293822
Leiden UMC		Expert Center for Rare Prenatal and Congenital Infections	Fetal cytomegalovirus syndrome	ORPHA:294
Amsterdam UMC		Amsterdam UMC expertise center for neuromuscular diseases	Postpoliomyelitis syndrome	ORPHA:2942
Amsterdam UMC		Amsterdam UMC TPN & Intestinal Failure Clinic	Chronic intestinal failure	ORPHA:294422
Erasmus MC		Pediatric Surgical Centre for Anatomical Congenital Malformations	Chronic intestinal failure	ORPHA:294422
Radboudumc		Radboudumc Center of Expertise for Congenital malformations of the intest	Chronic intestinal failure	ORPHA:294422
Leiden UMC		Expert Center for Rare Pregnancy-Related Disorders	Fetal parvovirus syndrome	ORPHA:295
Leiden UMC		Expert Center for Rare Bone and Soft Tissue Tumors	Ollier disease	ORPHA:296
UMC Utrecht	NKI-AvL	UMC Utrecht Expertise Centre for rare endocrine tumors	Prolactinoma	ORPHA:2965
Amsterdam UMC		Amsterdam UMC expertise centre for gastroenterologic diseases	Chronic intestinal pseudoobstruction	ORPHA:2978
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Gastrointestinal Motility Disorders	Chronic intestinal pseudo-obstruction	ORPHA:2978
UMC Groningen		UMCG Center of Expertise for Benign Hematology	Immune thrombocytopenia	ORPHA:3002

Ziekenhuis	Samenwerkingspartner	Naam EC (EN)	(Cluster van) aandoeningen	Orphacode
UMC Utrecht		UMC Utrecht Expertise centre for benign hematology, thrombosis and hemo	Immune thrombocytopenia	ORPHA:3002
Amsterdam UMC		Amsterdam UMC Expertise Center for rare gastrointestinal tumors	Ampulla of Vater carcinoma	ORPHA:300557
UMC Utrecht	Diakonessenhuis Utrecht	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver an	Carcinoma of the ampulla of Vater	ORPHA:300557
Erasmus MC		Hematologic malignancies center of expertise	Aggressive B-cell non-Hodgkin lymphoma	ORPHA:300846
UMC Groningen		UMCG Center of Expertise for Congenital Biliary Disorders	Isolated biliary atresia	ORPHA:30391
UMC Groningen		UMCG Center of Expertise for Pituitary Disorders	Pituitary tumour	ORPHA:304055
Radboudumc		Radboudumc Center of Expertise for Hereditary cancer	PTEN hamartoma tumor syndrome	ORPHA:306498
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Neuromuscular Diseases	Sodium channelopathy-related small fiber neuropathy	ORPHA:306577
Amsterdam UMC		Amsterdam UMC Expertise Center for rare gastrointestinal tumors	Rare tumor of gallbladder and extrahepatic biliary tract	ORPHA:306633
Radboudumc		Radboudumc Center of Expertise for Gallbladder cancer	Rare tumor of gallbladder and extrahepatic biliary tract	ORPHA:306633
Amsterdam UMC		Amsterdam UMC Expertise Center for rare gastrointestinal tumors	Rare tumor of liver and intrahepatic biliary tract	ORPHA:306636
UMC Groningen		UMCG Expertise Center for Movement Disorders Groningen	Epilepsy and/or ataxia with myoclonus as major feature	ORPHA:306756
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Inborn Errors of Fructose Metaboli	Disorder of fructose metabolism	ORPHA:308463
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Inborn Errors of Galactose Metabo	Disorder of galactose metabolism	ORPHA:308467
Radboudumc		Radboudumc Center of Expertise for Immunodeficiency and autoinflammat	Mevalonate kinase deficiency	ORPHA:309025
Amsterdam UMC		Amsterdam UMC Expert Center for Inborn Errors of Metabolism	Disorder of carnitine cycle and carnitine transport	ORPHA:309130
UMC Utrecht		UMC Utrecht Expertise Centre for inherited metabolic diseases (CIMD-UMC	Disorder of carnitine cycle and transport	ORPHA:309130
Erasmus MC		Center for Lysosomal and Metabolic Diseases	glycoproteinosis	ORPHA:309279
Radboudumc		Radboudumc Center of Expertise for Iron disorders	Disorder of iron metabolism and transport	ORPHA:309842
Erasmus MC		Erasmus MC Oesophageal and Gastric Cancer center of expertise	Gastric adenocarcinoma and proximal polyposis of the s	ORPHA:314022
UMC Utrecht		UMC Utrecht Expertise Centre for congenital orofacial and dental anomalies	Ameloblastoma	ORPHA:314419
Erasmus MC		Frontotemporal Dementia center of expertise	primary progressive apraxia of speech	ORPHA:314566
Radboudumc		Radboudumc Center of Expertise for Pituitary disease	Functioning pituitary adenoma	ORPHA:314753
Erasmus MC		Expert Center Rare Growth Disorders	SHOX-related short stature	ORPHA:314795
St. Antonius Ziekenhuis		Interstitial Lung Diseases Center of Excellence	Hypersensitivity pneumonitis	ORPHA:31740
Leiden UMC		Expert Center for Rare Bone and Soft Tissue Tumors	Skeletal Ewing sarcoma	ORPHA:319
Radboudumc		Radboudumc Center of Expertise for Immunodeficiency and autoinflammat	Autoinflammatory syndrome of children	ORPHA:319719
UMC Groningen		UMCG Center of Expertise for Autoinflammatory Diseases for Adult and Ped	Autoinflammatory syndrome of childhood	ORPHA:319719
Erasmus MC		Erasmus MC center of expertise for inflammatory disorders of the central ne	Stiff person spectrum disorder	ORPHA:3198
Leiden UMC		Expert Center for Rare Bone and Soft Tissue Tumors	Multiple osteochondromas	ORPHA:321
OLVG		Center for HME-MO (Hereditary multiple exostoses-Multiple osteochondrom	Multiple osteochondromas	ORPHA:321
UMC Utrecht		UMC Utrecht Expertise Centre for hereditary and congenital nephrologic an	Exstrophy-epispadias complex	ORPHA:322
Radboudumc		Radboudumc Center of Expertise Sex & Gender	46,XY disorder of sex development of endocrine origin	ORPHA:325351
Amsterdam UMC		Amsterdam UMC expertise center for neuromuscular diseases	Juvenile idiopathic inflammatory myopathy	ORPHA:329888
UMC Utrecht		UMC Utrecht Expertise Centre for systemic autoimmune diseases and prima	Juvenile idiopathic inflammatory myopathy	ORPHA:329888
Leiden UMC		Expert Center for Lupus-, Vasculitis- and Complement-mediated Systemic D	C3 glomerulonephritis	ORPHA:329931
UMC Utrecht		UMC Utrecht Expertise Centre for rare and complex epilepsies	Dravet syndrome	ORPHA:33069
Kempinhaeghe, Nederland		Center for Sleep Medicine Kempinhaeghe	Idiopathic Hypersomnia	ORPHA:33208
UMC Utrecht		UMC Utrecht Expertise Centre for malignant hematology	Waldenström macroglobulinemia	ORPHA:33226
Erasmus MC		The ENCORE expertise center for neurodevelopmental disorders	Trichothiodystrophy	ORPHA:33364
Amsterdam UMC		Amsterdam UMC expert center in Rare Bone Disease, including FOP, heredit	Fibrodysplasia Ossificans Progressiva	ORPHA:337
Radboudumc		Radboudumc Center of Expertise for Mycobacterial diseases	Tuberculosis	ORPHA:3389
UMC Groningen		UMCG Center of Expertise for Tuberculosis Beatrixoord	Tuberculosis	ORPHA:3389
Amsterdam UMC		Amsterdam UMC Expert Center for Bone and Soft Tissue Sarcomas	Soft tissue sarcoma	ORPHA:3394
Leiden UMC		Expert Center for Rare Bone and Soft Tissue Tumors	Soft tissue sarcoma	ORPHA:3394

Ziekenhuis	Samenwerkingspartner	Naam EC (EN)	(Cluster van) aandoeningen	Orphacode
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Soft Tissue Tumors	Soft tissue sarcoma	ORPHA:3394
NKI-AVL		Sarcoma Expertise Centre Amsterdam	Soft tissue sarcoma	ORPHA:3394
UMC Groningen		UMCG Center of Expertise for Bone and Soft Tissue Tumors	Soft tissue sarcoma	ORPHA:3394
UMC Utrecht		UMC Utrecht Expertise Centre for soft tissue tumors (OncoMid)	soft tissue sarcoma	ORPHA:3394
UMC Utrecht	Prinses Maxima Centrum	UMC Utrecht Expertise Centre for testicular and extragonadal germ cell tum	Germ cell tumor	ORPHA:3399
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Inborn Errors of Fructose Metaboli	Fructose-1,6-biphosphatasedeficiency	ORPHA:348
Amsterdam UMC		Amsterdam UMC Expert Center for Inborn Errors of Metabolism	Galactosemia	ORPHA:352
Amsterdam UMC		Amsterdam UMC expertise center for rare pediatric kidney and urinary tract	Idiopathic nephrotic syndrome	ORPHA:357502
Erasmus MC		Erasmus MC Center of Expertise for Rare Kidney and Urinary Tract Disease	Idiopathic Nephrotic Syndrome	ORPHA:357502
Erasmus MC		Erasmus MC Oesophageal and Gastric Cancer center of expertise	Gastric linitis plastica	ORPHA:36273
UMC Groningen		UMCG Center of Expertise for Familial Colorectal Cancer	Genetic intestinal polyposis	ORPHA:363314
Erasmus MC		Center of expertise for rare urinary tract tumors & testicular tumors	Tumor of testis and paratestis	ORPHA:363472
NKI-AVL		Expert centre for rare urological diseases	Tumor of testis and paratestis	ORPHA:363472
UMC Groningen		UMCG Center of Expertise for Germ Cell Tumors	Non-seminomatous germ cell tumor of testis	ORPHA:363494
UMC Groningen		UMCG Center of Expertise for Germ Cell Tumors	Germ cell tumor of testis	ORPHA:363504
UMC Utrecht	Prinses Maxima Centrum	UMC Utrecht Expertise Centre for testicular and extragonadal germ cell tum	Germ cell tumor of testis	ORPHA:363504
UMC Utrecht	Prinses Maxima Centrum	UMC Utrecht Expertise Centre for testicular and extragonadal germ cell tum	Extragonadal germ cell tumor	ORPHA:363579
Erasmus MC		Erasmus MC center of expertise for inflammatory disorders of the central ne	Paraneoplastic neurologic syndrome	ORPHA:36388
Leiden UMC		Expert Center for Rare Endocrine Conditions	Primary Bone Dysplasia	ORPHA:364526
UMC Utrecht		UMC Utrecht Expertise Centre for skeletal malformations & Mobility Clinic	Primary bone dysplasia	ORPHA:364526
UMC Utrecht		UMC Utrecht Expertise Centre for skeletal malformations & Mobility Clinic	Dysostosis	ORPHA:364559
UMC Groningen		UMCG Expertise Center for Movement Disorders Groningen	Myoclonus-dystonia syndrome	ORPHA:36899
UMC Groningen		UMCG Expertise Center for Movement Disorders Groningen	Generalized isolated dystonia	ORPHA:376724
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Genodermatoses	Gorlin syndrome	ORPHA:377
Radboudumc		Radboudumc Center of Expertise for Immunodeficiency and autoinflammat	Schnitzler syndrome	ORPHA:37748
Amsterdam UMC		Amsterdam UMC expertise centre for gastroenterologic diseases	Hirschsprung disease	ORPHA:388
Erasmus MC		Pediatric Surgical Centre for Anatomical Congenital Malformations	Hirschsprung disease	ORPHA:388
Radboudumc		Radboudumc Center of Expertise for Congenital malformations of the intest	Hirschsprung disease	ORPHA:388
UMC Groningen		UMCG Center of Expertise for Neonatal Gastro-Intestinal Diseases	Hirschsprung disease	ORPHA:388
Erasmus MC		Center of Expertise for Rare Systemic Immune Disease	Langerhans cell histiocytosis	ORPHA:389
Leiden UMC		Expert Center for Ocular Oncology	Uveal melanoma	ORPHA:39044
Oogziekenhuis Rotterdam	Erasmus MC	Rotterdam centre rare eye cancer	Uveal melanoma	ORPHA:39044
Amsterdam UMC		Amsterdam UMC expert center in Rare Bone Disease, including FOP, heredit	X-linked osteoporosis with fractures	ORPHA:391330
UMC Utrecht		UMC Utrecht Expertise Centre for soft tissue tumors (OncoMid)	Glomus tumor	ORPHA:391651
Amsterdam UMC		Amsterdam UMC expertise centre for gastroenterologic diseases	Necrotizing enterocolitis	ORPHA:391673
Erasmus MC		Expertise center for rare IBD and intractable diarrhea	Necrotizing enterocolitis	ORPHA:391673
UMC Groningen		UMCG Center of Expertise for Neonatal Gastro-Intestinal Diseases	Necrotizing enterocolitis	ORPHA:391673
NKI-AVL		Expert centre for rare urological diseases	Malignant tumor of penis	ORPHA:398043
Erasmus MC		Expert Center Prader Willi syndrome	Prader-Willi-like syndrome	ORPHA:398073
Amsterdam UMC		Amsterdam UMC Expert Center for Hematological Malignancies	Graft versus host disease	ORPHA:39812
UMC Utrecht		UMC Utrecht Expertise Centre for malignant hematology	Graft versus Host Disease	ORPHA:39812
Leiden UMC		Expert Center for Rare Genetic Neurodegenerative Diseases	Huntington disease	ORPHA:399
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Rare Movement Disorders	Huntington disease	ORPHA:399
UMC Groningen		UMCG Expertise Center for Movement Disorders Groningen	Huntington disease	ORPHA:399
Leiden UMC		Expert Center for Familial Melanoma	Familial atypical multiple mole melanoma syndrome	ORPHA:404560

Ziekenhuis	Samenwerkingspartner	Naam EC (EN)	(Cluster van) aandoeningen	Orphacode
UMC Utrecht		UMC Utrecht Expertise Centre for systemic autoimmune diseases and prima	Polyarticular juvenile idiopathic arthritis	ORPHA:404580
Radboudumc		Radboudumc Center of Expertise for Mycobacterial diseases	Pulmonary non-tuberculous mycobacterial infection	ORPHA:411703
UMC Utrecht		UMC Utrecht Expertise centre for rare genetic dyslipidemia	Dysbetalipoproteinemia	ORPHA:412
Erasmus MC		Frontotemporal Dementia center of expertise	PRKAR1B-related neurodegenerative dementia with inte	ORPHA:412066
Amsterdam UMC		Amsterdam UMC Expert Center for Inborn Errors of Metabolism	Gyrate atrophy of choroid and retina	ORPHA:414
Amsterdam UMC		Amsterdam UMC expertise center for rare pediatric kidney and urinary tract	Primary Hyperoxaluria	ORPHA:416
Radboudumc		Radboudumc Center of Expertise for Adrenal diseases	Congenital adrenal hyperplasia	Orpha:418
UMC Utrecht	NKI-AvL	UMC Utrecht Expertise Centre for rare endocrine tumors	Congenital adrenal hyperplasia	ORPHA:418
Amsterdam UMC		Amsterdam UMC Expert Center for Developmental Disorders	Malan overgrowth syndrome	ORPHA:420179
Radboudumc	Maastricht UMC+	Radboudumc-Maastricht UMC+ Center of Expertise for Skull base patholog	Semicircular canal dehiscence syndrome	ORPHA:420402
Erasmus MC		Erasmus MC center of expertise for inflammatory disorders of the central ne	Autoimmune encephalopathy with parasomnia and obst	ORPHA:420789
Erasmus MC		Erasmus MC Oesophageal and Gastric Cancer center of expertise	Hereditary gastric cancer	ORPHA:423776
Radboudumc		Radboudumc Center of Expertise for Hereditary cancer	Hereditary gastric cancer	ORPHA:423776
UMC Utrecht	Diakonessenhuis Utrecht	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver an	Rare carcinoma of small intestine	ORPHA:423957
Amsterdam UMC		Amsterdam UMC center of expertise for Pulmonary Hypertension	Pulmonary veno-occlusive disease and/or pulmonary ca	ORPHA:431353
Leiden UMC		Expert Center for Rare Pregnancy-Related Disorders	Fetal lower urinary tract obstruction	ORPHA:435365
Amsterdam UMC	Leiden UMC	Expertise Center for Hereditary Eye Diseases and Central Serous Chorioretin	Central serous chorioretinopathy	ORPHA:443079
Leiden UMC		Expert Center for Rare Hereditary Bowel Tumors	Hereditary nonpolyposis colon cancer	ORPHA:443909
Radboudumc		Radboudumc Center of Expertise for Paroxysmal nocturnal hemoglobinuria	Paroxysmal nocturnal hemoglobinuria	ORPHA:447
Amsterdam UMC		Amsterdam UMC Expert Center for immune-mediated and genetic cholesta	IgG4-related sclerosing cholangitis	ORPHA:447764
Amsterdam UMC		Amsterdam UMC Expert Center for Rare coagulation and red blood cell defe	Hemophilia	ORPHA:448
Erasmus MC		Expertise Center for Rare Bleeding disorders	Hemophilia	ORPHA:448
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Hemophilia and Allied Bleeding Di	Hemophilia	ORPHA:448
Radboudumc		Radboudumc Center of Expertise for Haemophilia and rare coagulation diso	Hemophilia	ORPHA:448
UMC Groningen		UMCG Center of Expertise for Benign Hematology	Hemophilia	ORPHA:448
UMC Utrecht		UMC Utrecht Expertise centre for benign hematology, thrombosis and hemo	Hemophilia	ORPHA:448
Leiden UMC		Expert Center for Rare Bone and Soft Tissue Tumors	Gastro-intestinal stromale tumor	ORPHA:44890
NKI-AVL		Sarcoma Expertise Centre Amsterdam	Gastrointestinal stromal tumor	ORPHA:44890
Radboudumc		Radboudumc Center of Expertise for Sarcomas	Gastrointestinal stromal tumor	ORPHA:44890
UMC Utrecht	Diakonessenhuis Utrecht	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver an	Gastrointestinal stromal tumor	ORPHA:44890
Erasmus MC		Center of Expertise for Rare Systemic Immune Disease	IgG4-related pachymeningitis	ORPHA:449427
UMC Utrecht		UMC Utrecht Expertise Centre for congenital esophageal and airway disease	Isolated tracheoesophageal fistula	ORPHA:454750
Erasmus MC		Frontotemporal Dementia center of expertise	corticobasal syndrome	ORPHA:454887
Erasmus MC		Erasmus MC Bone Center	Pseudohypoparathyroidism with Albright hereditary ost	ORPHA:457059
Radboudumc	Maastricht UMC+	Radboudumc-Maastricht UMC+ Center of Expertise for Marfan and related d	Idiopathic spontaneous coronary artery dissection	ORPHA:458718
Radboudumc		Radboudumc Center of Expertise Sex & Gender	Gender dysphoria	ORPHA:459690
UMC Utrecht		UMC Utrecht Expertise Centre for malignant hematology	Primary central nervous system lymphoma	ORPHA:46135
Radboudumc		Radboudumc Center of Expertise for Congenital neurodevelopmental disord	DYRK1A-related intellectual disability syndrome	ORPHA:464306
Oogziekenhuis Rotterdam		Rotterdam Center for Orbital Auto-immune Disorders	Euthyroid Graves orbitopathy	ORPHA:466682
Radboudumc		Radboudumc Center of Expertise for CNS and retinal vascular diseases	Cerebral arteriovenous malformation	ORPHA:46724
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Inborn Errors of Fructose Metaboli	Hereditary fructose intolerance	ORPHA:469
Leiden UMC		Expert Center for Rare Inherited Immunodeficiencies and Stem Cell Transpla	X-linked agammaglobulinemia	ORPHA:47
Erasmus MC		Erasmus MC center of expertise for inflammatory disorders of the central ne	Pediatric Multiple Sclerosis	ORPHA:477738
Leiden UMC		Expert Center for Genetic Cerebral Small Vessel Disease	Genetic cerebral small vessel disease	ORPHA:477754
Amsterdam UMC		Amsterdam UMC expert center for cleft, craniofacial and airway disorders	Primary condylar hyperplasia	ORPHA:477781

Ziekenhuis	Samenwerkingspartner	Naam EC (EN)	(Cluster van) aandoeningen	Orphacode
UMC Groningen		UMCG Center of Expertise for Congenital Biliary Disorders	Choledochal cyst	ORPHA:480501
Leiden UMC		Expert Center for Rare Bone and Soft Tissue Tumors	Aneurysmal bone cyst	ORPHA:480553
Leiden UMC		Expert Center for Genetic Cerebral Small Vessel Disease	HTRA1-related autosomal dominant cerebral small vesse	ORPHA:482077
Amsterdam UMC		Amsterdam UMC expertise centre for gastroenterologic diseases	Sacrococcyceal teratoma	ORPHA:494421
Radboudumc		Radboudumc Center of Expertise for Congenital malformations of the intest	Sacrococcygeal teratoma	ORPHA:494421
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Head and Neck Oncology	Squamous cell carcinoma of the larynx	ORPHA:494550
Radboudumc		Radboudumc Center of Expertise for Congenital neurodevelopmental disord	SIN3A-related intellectual disability syndrome/Wittevee	ORPHA:500163
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Head and Neck Oncology	Squamous cell carcinoma of the oropharynx	ORPHA:500478
Leiden UMC		Expert Center for Rare Ear Diseases	Cochleovestibular dysplasia	ORPHA:502305
Leiden UMC		Expert Center for Rare Ear Diseases	Cochlear nerve deficiency	ORPHA:502318
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Head and Neck Oncology	Squamous cell carcinoma of oral cavity and lip	ORPHA:502369
Erasmus MC		Center of expertise for lung cancer	Pleural mesothelioma	ORPHA:50251
Amsterdam UMC		Amsterdam UMC expertise center for rare pediatric kidney and urinary tract	Rare disorder potentially indicated for kidney transplant	ORPHA:506213
UMC Utrecht		UMC Utrecht Expertise Centre for hereditary and congenital nephrologic an	Rare disorder potentially indicated for kidney transplant	ORPHA:506213
Erasmus MC		Hematologic malignancies center of expertise	Acute lymphoblastic leukemia	ORPHA:513
UMC Utrecht		UMC Utrecht Expertise Centre for malignant hematology	Acute lymphoblastic leukemia	ORPHA:513
Amsterdam UMC		Amsterdam UMC Expert Center for Hematological Malignancies	Acute Myeloid leukemia	ORPHA:519
UMC Utrecht		UMC Utrecht Expertise Centre for malignant hematology	Acute myeloid leukemia	ORPHA:519
Radboudumc		Radboudumc Center of Expertise for Hereditary blindness	Isolated chorioretinal dystrophy	ORPHA:519300
Oogziekenhuis Rotterdam		Rare Eye Disease Center Rotterdam	Rare choroidal disorder	ORPHA:519309
Radboudumc		Radboudumc Center of Expertise for Hereditary blindness	Rare retinal disorder	ORPHA:519315
UMC Utrecht		UMC Utrecht Expertise Center for rare GI and hepatic diseases	Alagille syndrome	ORPHA:52
NKI-AvL	Prinses Maxima Centrum	Expert centre for Li-Fraumeni syndrome	Li-Fraumeni syndrome	ORPHA:524
Amsterdam UMC		Amsterdam UMC Expert Center for Hematological Malignancies	Myelodysplastic syndrome	ORPHA:52688
Amsterdam UMC		Amsterdam UMC Expertise Center for vasculitis	Vasculitis	ORPHA:52759
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Vasculitis and Immune-mediated K	Vasculitis	ORPHA:52759
UMC Groningen		UMCG Center of Expertise for Systemic Vasculitis	Vasculitis	ORPHA:52759
Amsterdam UMC		Amsterdam UMC Expertise Center for Systemic Autoimmune diseases	Systemic lupus erythematosus	ORPHA:536
UMC Groningen		UMCG Center of Expertise for Systemic Autoimmune Diseases	Systemic lupus erythematosus	ORPHA:536
Erasmus MC		The ENCORE expertise center for neurodevelopmental disorders	RASopathy	ORPHA:536391
Radboudumc		Radboudumc Center of Expertise for Congenital neurodevelopmental disord	Rasopathies	ORPHA:536391
Leiden UMC		Expert Center for Rare Cutaneous Lymphoma	Primary cutaneous lymphoma	ORPHA:542
Erasmus MC		Center of expertise for inherited cardiovascular diseases	Left ventricular noncompaction	ORPHA:54260
Erasmus MC		Erasmus MC Liver Center of Expertise	Hepatocellular adenoma	ORPHA:54272
UMC Utrecht	NKI-AvL	UMC Utrecht Expertise Centre for rare endocrine tumors	Craniopharyngioma	ORPHA:54595
UMC Utrecht		UMC Utrecht Expertise Centre for malignant hematology	Non Hodgkin Lymphoma	ORPHA:547
Erasmus MC	Leiden UMC	Leprosy Center of Expertise	Leprosy	ORPHA:548
Radboudumc		Radboudumc Center of Expertise for Adrenal diseases	Cushing syndrome	ORPHA:553
Radboudumc		Radboudumc Center of Expertise for Congenital malformations of the intest	Isolated anorectal malformation	ORPHA:557
Erasmus MC		Center of expertise for inherited cardiovascular diseases	Marfan syndrome	ORPHA:558
Radboudumc	Maastricht UMC+	Radboudumc-Maastricht UMC+ Center of Expertise for Marfan and related d	Marfan syndrome	ORPHA:558
UMC Groningen		UMCG Center of Expertise for Marfan Syndrome and Related Disorders	Marfan syndrome	ORPHA:558
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Gastrointestinal Motility Disorders	Idiopathic gastroparesis	ORPHA:558411
Leiden UMC		Expert Center for Rare Bone and Soft Tissue Tumors	Chondrosarcoma	ORPHA:55880
Leiden UMC		Expert Center for Rare Bone and Soft Tissue Tumors	Adamantinaoma	ORPHA:55881

Ziekenhuis	Samenwerkingspartner	Naam EC (EN)	(Cluster van) aandoeningen	Orphacode
UMC Groningen		UMCG Center of Expertise for Cholangiocarcinoma	Carcinoma of gallbladder and extrahepatic biliary tract	ORPHA:56044
UMC Utrecht	Diakonessenhuis Utrecht	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver an	Carcinoma of gallbladder and extrahepatic biliary tract	ORPHA:56044
Amsterdam UMC		Amsterdam UMC Expert Center for Developmental Disorders	Marshall-Smith syndrome	ORPHA:561
Erasmus MC		Center of expertise for inherited cardiovascular diseases	Peripartum cardiomyopathy	ORPHA:563
UMC Utrecht		UMC Utrecht Expertise Centre for hereditary and congenital nephrologic an	Genetic nephrotic syndrome	ORPHA:564127
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Rare Syndromes and Cognitive Dis	22q11.2 deletion syndrome	ORPHA:567
Amsterdam UMC		Amsterdam UMC expertise center for rare pediatric kidney and urinary tract	Nephrotic Syndrome without extrarenal manifestations	ORPHA:567564
Leiden UMC		Expert Center for Rare Types of Headache	Familial or sporadic hemiplegic migraine	ORPHA:569
Erasmus MC		Erasmus MC Expert Center Endocarditis	Infective endocarditis	ORPHA:570762
Leiden UMC		Expert Center for Genetic Cerebral Small Vessel Disease	Cathepsin A-related arteriopathy-strokes-leukoencepha	ORPHA:575553
Amsterdam UMC		Amsterdam UMC Expert Center for Cystic Fibrosis and Primary Ciliary Dyskin	Cystic Fibrosis	ORPHA:586
Erasmus MC		Cystic Fibrosis center of expertise Rotterdam	Cystic Fibrosis	ORPHA:586
UMC Groningen		UMCG Center of Expertise for Cystic Fibrosis	Cystic fibrosis	ORPHA:586
UMC Utrecht		UMC Utrecht Expertise Centre for cystic fibrosis	Cystic fibrosis	ORPHA:586
Amsterdam UMC		Amsterdam UMC expertise center for neuromuscular diseases	Myasthenia gravis	ORPHA:589
Amsterdam UMC		Amsterdam UMC Expert Center for Developmental Disorders	Menke-Hennekam syndrome	ORPHA:592574
Erasmus MC		Center of expertise for inherited cardiovascular diseases	Loeys Dietz syndrome	ORPHA:60030
Radboudumc	Maastricht UMC+	Radboudumc-Maastricht UMC+ Center of Expertise for Marfan and related d	Loeys-Dietz syndrome	ORPHA:60030
Amsterdam UMC		Amsterdam UMC expert center for cleft, craniofacial and airway disorders	Recurrent Respiratory Papillomatosis	ORPHA:60032
Amsterdam UMC		Amsterdam UMC Expert Center for bronchiectasis	Idiopathic bronchiectasis	ORPHA:60033
Leiden UMC		Expert Center for Rare Neuromuscular Diseases	Inclusion body myositis	ORPHA:611
UMC Groningen		UMCG Center of Expertise for Brain and Skull Base Tumors	Medulloblastoma	ORPHA:616
Leiden UMC		Expert Center for Familial Melanoma	Familial melanoma	ORPHA:618
UMC Utrecht		UMC Utrecht Expertise Centre for hereditary and congenital nephrologic an	Alport syndrome	ORPHA:63
Erasmus MC		Expert Center Rare Growth Disorders	Non-acquired isolated growth hormone deficiency	ORPHA:631
Erasmus MC		The ENCORE expertise center for neurodevelopmental disorders	Neurofibromatosis type 1	ORPHA:636
Radboudumc	Maastricht UMC+	Radboudumc-Maastricht UMC+ Center of Expertise for Å Skull base patholog	Neurofibromatosis type 2	ORPHA:637
UMC Utrecht		UMC Utrecht Brain Centre, Neuromuscular Diseases	Multifocal motor neuropathy	ORPHA:641
Radboudumc		Radboudumc Center of Expertise for Adrenal diseases	Multiple endocrine neoplasia type 1	ORPHA:652
UMC Groningen		UMCG Center of Expertise for Genetic Endocrine Tumour Syndromes	Multiple endocrine neoplasia type 1	ORPHA:652
UMC Utrecht	NKI-AvL	UMC Utrecht Expertise Centre for rare endocrine tumors	Multiple endocrine neoplasia type 1	ORPHA:652
UMC Groningen		UMCG Center of Expertise for Genetic Endocrine Tumour Syndromes	Multiple endocrine neoplasia type 2	ORPHA:653
UMC Utrecht	NKI-AvL	UMC Utrecht Expertise Centre for rare endocrine tumors	Multiple endocrine neoplasia type 2	ORPHA:653
UMC Utrecht		UMC Utrecht Expertise Centre for hereditary and congenital nephrologic an	Nephronophthisis	ORPHA:655
Amsterdam UMC		Amsterdam UMC Expert Center for immune-mediated and genetic cholesta	Benign recurrent intrahepatic cholestasis	ORPHA:65682
UMC Utrecht		UMC Utrecht Expertise Center for rare GI and hepatic diseases	Benign Recurrent Intrahepatic Cholestasis	ORPHA:65682
UMC Utrecht		UMC Utrecht Expertise Centre for skeletal malformations & Mobility Clinic	Osteogenesis imperfecta	ORPHA:666
Leiden UMC		Expert Center for Rare Bone and Soft Tissue Tumors	Osteosarcoma	ORPHA:668
UMC Groningen		UMCG Center of Expertise for Bone and Soft Tissue Tumors	Osteosarcoma	ORPHA:668
UMC Utrecht		UMC Utrecht Expertise Centre for malignant hematology	B-cell chronic lymphocytic leukemia	ORPHA:67038
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Genodermatoses	Rare genetic skin disease	ORPHA:68346
Amsterdam UMC		Amsterdam UMC Leukodystrophy Center	Leukodystrophies	ORPHA:68356
Leiden UMC		Expert Center for Rare Ear Diseases	Rare deafness	ORPHA:68361
Radboudumc		Radboudumc Center of Expertise Hearing & Genes	Rare deafness	ORPHA:68361
Radboudumc		Radboudumc Center of Expertise for Rare and genetic movement disorders	Rare dystonia	ORPHA:68363

Ziekenhuis	Samenwerkingspartner	Naam EC (EN)	(Cluster van) aandoeningen	Orphacode
Amsterdam UMC		Amsterdam UMC Expert Center for Rare coagulation and red blood cell defe	Hemoglobinopathy	ORPHA:68364
Erasmus MC		Sickle Cell and Thalassemia Comprehensive Care Center	Hemoglobinopathy	ORPHA:68364
Leiden UMC	HagaZiekenhuis	Expert Center for Rare Hemoglobinopathies	Hemoglobinopathy	ORPHA:68364
UMC Utrecht		UMC Utrecht Expertise centre for benign hematology, thrombosis and hemo	Hemoglobinopathy	ORPHA:68364
Amsterdam UMC		Amsterdam UMC Expert Center for Inborn Errors of Metabolism	Lysosomal disease	ORPHA:68366
Erasmus MC		Center for Lysosomal and Metabolic Diseases	Lysosomal disease	ORPHA:68366
Amsterdam UMC		Amsterdam UMC Expert Center for Inborn Errors of Metabolism	Rare inborn errors of metabolism	ORPHA:68367
Amsterdam UMC		Amsterdam UMC Expert Center for Inborn Errors of Metabolism	Peroxisomal disease	ORPHA:68373
Erasmus MC		ErasmusMC Center of expertise for Congenital Hand and Upper Limb Malfo	Congenital limb malformation	ORPHA:68378
Radboudumc		Radboudumc Center of Expertise for Inherited metabolic disorders	Mitochondrial disease	ORPHA:68380
Amsterdam UMC		Amsterdam UMC expertise center for neuromuscular diseases	Neuromuscular disease	ORPHA:68381
Erasmus MC		Neuromuscular Center Erasmus MC	Neuromuscular disease	ORPHA:68381
Leiden UMC		Expert Center for Rare Neuromuscular Diseases	Neuromuscular disease	ORPHA:68381
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Neuromuscular Diseases	Neuromuscular disease	ORPHA:68381
Radboudumc		Radboudumc Center of Expertise for neuromuscular disease	Neuromuscular disease	ORPHA:68381
UMC Utrecht		UMC Utrecht Brain Centre, Neuromuscular Diseases	Neuromuscular disease	ORPHA:68381
Amsterdam UMC		Amsterdam UMC expertise center for primary immunodeficiencies an bone	Rare constitutional aplastic anemia	ORPHA:68383
Leiden UMC		Expert Center for Rare Bone Marrow Failure	Rare constitutional aplastic anemia	ORPHA:68383
UMC Groningen		UMCG Expertise Center for Movement Disorders Groningen	Neurometabolic disease	ORPHA:68385
Radboudumc		Radboudumc Center of Expertise for Rare and genetic movement disorders	Rare parkinsonian disorders	ORPHA:68402
Leiden UMC		Expert Center for Rare Bone and Soft Tissue Tumors	Rare bone tumor	ORPHA:68411
Radboudumc		Radboudumc Center of Expertise for Sarcomas	Rare bone tumor	ORPHA:68411
Leiden UMC		Expert Center for Rare Endocrine Conditions	Rare parathyroid disease and phosphocalcic metabolism	ORPHA:68415
Erasmus MC		Center of rare skin diseases	Vascular anomaly or angioma	ORPHA:68419
Radboudumc		Radboudumc Center of Expertise for Rare and genetic movement disorders	Hereditary spastic paraplegia	ORPHA:685
UMC Utrecht		UMC Utrecht Brain Centre, Neuromuscular Diseases	Proximal spinal muscular atrophy	ORPHA:70
Erasmus MC		Erasmus MC Oesophageal and Gastric Cancer center of expertise	Carcinoma of esophagus	ORPHA:70482
UMC Groningen		UMCG Center of Expertise for Cholangiocarcinoma	Cholangiocarcinoma	ORPHA:70567
UMC Utrecht	Diakonessenhuis Utrecht	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver an	Cholangiocarcinoma	ORPHA:70567
Erasmus MC		Center of expertise for lung cancer	Small cell lung cancer	ORPHA:70573
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Rare Respiratory Tumors	Small cell lung cancer	ORPHA:70573
Amsterdam UMC		Amsterdam UMC center of expertise for Pulmonary Hypertension	Chronic thromboembolic pulmonary hypertension	ORPHA:70591
St. Antonius Ziekenhuis		Center for Pulmonary vascular diseases	Chronic thromboembolic pulmonary hypertension	ORPHA:70591
Amsterdam UMC		Amsterdam UMC center of expertise for Pulmonary Hypertension	Rare pulmonary hypertension	ORPHA:71198
Erasmus MC		Center of expertise for Pulmonary hypertension	Rare pulmonary hypertension	ORPHA:71198
Radboudumc		Radboudumc Center of Expertise for Pulmonary hypertension	Rare pulmonary hypertension	ORPHA:71198
UMC Groningen		UMCG Center of Expertise for Children and Adults with Pulmonary Hyperten	Rare Pulmonary Hypertension	ORPHA:71198
Leiden UMC		Expert Center for Rare Immune Cytopenias	Autoimmune thrombocytopenia	ORPHA:71203
Erasmus MC		Soft tissue sarcoma center of expertise	Rare soft tissue tumor	ORPHA:71209
Leiden UMC		Expert Center for Rare Bone and Soft Tissue Tumors	Rare soft tissue tumor	ORPHA:71209
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Soft Tissue Tumors	Rare soft tissue tumor	ORPHA:71209
Radboudumc		Radboudumc Center of Expertise for Sarcomas	Rare soft tissue tumor	ORPHA:71209
Erasmus MC		Erasmus MC center of expertise for inflammatory disorders of the central ne	Neuromyelitis optica spectrum disorder	ORPHA:71211
Amsterdam UMC		Amsterdam UMC Expert Center for Inborn Errors of Metabolism	Phenylketonuria	ORPHA:716
Amsterdam UMC		Amsterdam UMC expert center for cleft, craniofacial and airway disorders	Isolated Pierre Robin syndrome	ORPHA:718

Ziekenhuis	Samenwerkingspartner	Naam EC (EN)	(Cluster van) aandoeningen	Orphacode
Erasmus MC		Cleft Center of expertise Erasmus MC	Isolated Pierre Robin syndrome	ORPHA:718
Amsterdam UMC	Leiden UMC	Expertise Center for Hereditary Eye Diseases and Central Serous Chorioretin	Inherited retinal disorder/Retinal dystrophy	ORPHA:71862
Oogziekenhuis Rotterdam		Rare Eye Disease Center Rotterdam	Inherited retinal disorder	ORPHA:71862
Radboudumc		Radboudumc Center of Expertise for neuromuscular disease	Muscular channelopathy	ORPHA:71864
Erasmus MC		The ENCORE expertise center for neurodevelopmental disorders	Angelman syndrome	ORPHA:72
UMC Utrecht		UMC Utrecht Expertise Centre for rare and complex epilepsies	continuous spikes and waves during sleep	ORPHA:725
Leiden UMC		Expert Center for Rare Hereditary Kidney Disease	Autosomal dominant polycystic kidney disease	ORPHA:730
Erasmus MC		Expertise center for rare IBD and intractable diarrhea	Intractable diarrhea of infancy	ORPHA:73014
UMC Utrecht		UMC Utrecht Expertise Center for rare GI and hepatic diseases	Intractable diarrhea of infancy	ORPHA:73014
Amsterdam UMC		Amsterdam UMC Expertise Center for Systemic Autoimmune diseases	Polymyositis	ORPHA:732
Amsterdam UMC		Amsterdam UMC expert center for hereditary cancer	Familial adenomatous polyposis	ORPHA:733
Leiden UMC		Expert Center for Rare Hereditary Bowel Tumors	Familial adenomatous polyposis	ORPHA:733
NKI-AVL		Expert Center for Hereditary Cancer	Familial adenomatous polyposis	ORPHA:733
Erasmus MC		Porphyria Expertcenter Rotterdam	Porphyria	ORPHA:738
Erasmus MC		Expert Center Prader Willi syndrome	Prader-Willi syndrome	ORPHA:739
Radboudumc		Radboudumc Center of Expertise for Congenital neurodevelopmental disord	Prader Willi Syndrome	ORPHA:739
Leiden UMC		Expert Center for Rare Inherited Immunodeficiencies and Stem Cell Transpla	Mendelian susceptibility to mycobacterial diseases	ORPHA:748
UMC Utrecht		UMC Utrecht Expertise centre for benign hematology, thrombosis and hemo	Hemolytic anemia due to red cell pyruvate kinase deficie	ORPHA:766
UMC Groningen	Nij Smellinghe	Expertise Centre for Lympho-Vascular Medicine	Primary Lymphedema	ORPHA:77240
St. Antonius Ziekenhuis		Center for Pulmonary vascular diseases-HHT	Hereditary Hemorrhagic Telangiectasia	ORPHA:774
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Rare Syndromes and Cognitive Dis	Rett Syndrome	ORPHA:778
Erasmus MC	Amsterdam UMC	Expert Center Genetic Obesity	genetic obesity	ORPHA:77828
Amsterdam UMC		Amsterdam UMC Expert Center for Developmental Disorders	Rubinstein-Taybi syndrome	ORPHA:783
Amsterdam UMC		Amsterdam UMC center of excellence for retinoblastoma	Retinoblastoma	ORPHA:790
Erasmus MC		Center for PKU, urea cycle disorders and organic acidurias Å	disorder of amino acid and other organic acid metabolis	ORPHA:79062
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Neuroendocrine Tumors	Cutaneous neuroendocrine carcinoma	ORPHA:79140
Radboudumc		Radboudumc Center of Expertise for Head and neck and salivary gland tumo	Cutaneous neuro-endocrine carcinoma	ORPHA:79140
UMC Groningen		UMCG Center of Expertise for Neuroendocrine Tumors and Neuroendocrine	Cutaneous neuroendocrine carcinoma	ORPHA:79140
Erasmus MC		Center for PKU, urea cycle disorders and organic acidurias Å	disorder of urea cycle metabolism and ammonia detoxif	ORPHA:79167
Amsterdam UMC		Amsterdam UMC Expert Center for Inborn Errors of Metabolism	Creatine deficiency syndrome	ORPHA:79172
Amsterdam UMC		Amsterdam UMC Expert Center for Inborn Errors of Metabolism	Disorder of fatty acid oxidation and ketone body metabo	ORPHA:79174
UMC Utrecht		UMC Utrecht Expertise Centre for inherited metabolic diseases (CIMD-UMC	Disorder of fatty acid oxidation and ketone body metabo	ORPHA:79174
Amsterdam UMC		Amsterdam UMC Expert Center for Inborn Errors of Metabolism	Disorder of pyridoxine metabolism	ORPHA:79192
Radboudumc		Radboudumc Center of Expertise for Inherited metabolic disorders	Disorders of pyridoxine metabolism	ORPHA:79192
Erasmus MC		Center for PKU, urea cycle disorders and organic acidurias Å	disorder of branched-chain amino acid metabolism	ORPHA:79197
Erasmus MC		Center for Lysosomal and Metabolic Diseases	disorder of lysosomal amino acid transport	ORPHA:79207
Erasmus MC		Center for Lysosomal and Metabolic Diseases	mucopolysaccharidosis	ORPHA:79213
UMC Utrecht		UMC Utrecht Expertise Centre for inherited metabolic diseases (CIMD-UMC	Disorder of purine or pyrimidine metabolism	ORPHA:79224
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Inborn Errors of Galactose Metabo	Galactokinase deficiency	ORPHA:79237
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Inborn Errors of Galactose Metabo	Galactose epimerase deficiency	ORPHA:79238
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Inborn Errors of Galactose Metabo	Classic galactosemia	ORPHA:79239
Erasmus MC		Center of rare skin diseases	Ichthyosis	ORPHA:79354
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Genodermatoses	Ichthyosis	ORPHA:79354
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Genodermatoses	Hereditary palmoplantar keratoderma	ORPHA:79357
UMC Groningen		UMCG Center of Expertise for Blistering Diseases	Inherited epidermolysis bullosa	ORPHA:79361

Ziekenhuis	Samenwerkingspartner	Naam EC (EN)	(Cluster van) aandoeningen	Orphacode
Erasmus MC		Centre of expertise for oligodontia	Ectodermal dysplasia syndrome	ORPHA:79373
UMC Groningen		UMCG Center of Expertise for Blistering Diseases	Auto-immune bullous skin diseases	ORPHA:79669
Erasmus MC		Academic center of excellence for sarcoidosis	Sarcoidosis	ORPHA:797
St. Antonius Ziekenhuis		Interstitial Lung Diseases Center of Excellence	Sarcoidosis	ORPHA:797
Amsterdam UMC		Amsterdam UMC expertise center for neuromuscular diseases	Amyotrophic lateral sclerosis	ORPHA:803
UMC Utrecht		UMC Utrecht Brain Centre, Neuromuscular Diseases	Amyotrophic lateral sclerosis	ORPHA:803
Erasmus MC		The ENCORE expertise center for neurodevelopmental disorders	Tuberous sclerosis complex	ORPHA:805
UMC Utrecht		UMC Utrecht Expertise Centre for tuberous sclerosis	Tuberous sclerosis complex	ORPHA:805
Amsterdam UMC		Amsterdam UMC expertise center for primary immunodeficiencies an bone	Shwachman-Diamond syndrome	ORPHA:811
Erasmus MC		Expert Center Rare Growth Disorders	Silver-Russell syndrome	ORPHA:813
Erasmus MC		Expert Center spinal disraphism Rotterdam	Isolated spina bifida	ORPHA:823
Amsterdam UMC		Amsterdam UMC Expert Center for Hematological Malignancies	Primary Myelofibrosis	ORPHA:824
Radboudumc		Radboudumc Center of Expertise for Pediatric urology	Urogenital tract malformation	ORPHA:83001
UMC Utrecht		UMC Utrecht Expertise Centre for hereditary and congenital nephrologic an	Urogenital tract malformation	ORPHA:83001
Amsterdam UMC		Amsterdam UMC expert center for cleft, craniofacial and airway disorders	Microtia	ORPHA:83463
Kempinhaeghe, Nederland		Center for Sleep Medicine Kempinhaeghe	Narcolepsy Type 2	ORPHA:83465
Leiden UMC		Expert Center for Rare Bone and Soft Tissue Tumors	Solitary bone cyst	ORPHA:83468
Erasmus MC		Erasmus MC center of expertise for inflammatory disorders of the central ne	Acute Disseminated Encephalomyelitis	ORPHA:83597
Erasmus MC		Erasmus MC center of expertise for inflammatory disorders of the central ne	Susac syndrome	ORPHA:838
Erasmus MC		Erasmus MC Center of Expertise for Rare Kidney and Urinary Tract Disease	Hinman syndrome	ORPHA:84085
UMC Groningen		UMCG Center of Expertise for Germ Cell Tumors	Testicular seminomatous germ cell tumor	ORPHA:842
UMC Utrecht		UMC Utrecht Expertise centre for benign hematology, thrombosis and hemo	Congenital dyserythropoietic anemia	ORPHA:85
Leiden UMC		Expert Center for Rare Pregnancy-Related Disorders	Fetal and neonatal alloimmune thrombocytopenia	ORPHA:853
UMC Utrecht		UMC Utrecht Expertise Centre for systemic autoimmune diseases and prima	Oligoarticular juvenile idiopathic arthritis	ORPHA:85410
UMC Utrecht		UMC Utrecht Expertise Centre for systemic autoimmune diseases and prima	Systemic-onset juvenile idiopathic arthritis	ORPHA:85414
UMC Utrecht		UMC Utrecht Expertise Centre for systemic autoimmune diseases and prima	Psoriasis-related juvenile idiopathic arthritis	ORPHA:85436
UMC Utrecht		UMC Utrecht Expertise Centre for malignant hematology	AL amyloidosis	ORPHA:85443
UMC Groningen		UMCG Center of Expertise for Amyloidosis	AA amyloidosis	ORPHA:85445
UMC Utrecht		UMC Utrecht Brain Centre, Neuromuscular Diseases	ATTRV30M amyloidosis	ORPHA:85447
UMC Groningen		UMCG Expertise Center for Movement Disorders Groningen	Benign adult familial myoclonic epilepsy	ORPHA:86814
Radboudumc		Radboudumc Center of Expertise for Congenital neurodevelopmental disord	Rare intellectual disability	ORPHA:87277
UMC Utrecht		UMC Utrecht Expertise Centre for soft tissue tumors (OncoMid)	Desmoid tumor	ORPHA:873
Amsterdam UMC		Amsterdam UMC, Amsterdam Center for Endocrine and Neuroendocrine Tu	Neuroendocrine neoplasm	ORPHA:877
Erasmus MC		Erasmus MC Centre of Expertise for Endocrine Disorders	Neuroendocrine neoplasm	ORPHA:877
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Neuroendocrine Tumors	Neuroendocrine neoplasm	ORPHA:877
NKI-AvL	UMC Utrecht	Expert Center of Neuroendocrine carcinomas	Neuroendocrine neoplasm	ORPHA:877
UMC Groningen		UMCG Center of Expertise for Neuroendocrine Tumors and Neuroendocrine	Neuroendocrine neoplasm	ORPHA:877
Leiden UMC		Expert Center for Rare Bone Marrow Failure	Ideopathic aplastic anemia	ORPHA:88
Radboudumc		Radboudumc Center of Expertise Sex & Gender	Turner syndrome	ORPHA:881
UMC Groningen		UMCG Center of Expertise for Defects in Amino Acid and Organic Acid Meta	Tyrosinemia type 1	ORPHA:882
Radboudumc		Radboudumc Center of Expertise Hearing & Genes	Usher syndrome	ORPHA:886
Leiden UMC		Expert Center for Rare Hepatic Disease	Hepatocellular carcinoma	ORPHA:88673
UMC Utrecht	Diakonessenhuis Utrecht	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver an	Hepatocellular carcinoma	ORPHA:88673
Amsterdam UMC	Leiden UMC	Amsterdam UMC Expertise Center for Congenital Heart Defects (CAHAL)	Rare congenital non-syndromic heart malformation	ORPHA:88991
Erasmus MC		Center of expertise for congenital heart diseases Erasmus MC Rotterdam	Rare congenital non-syndromic heart malformation	ORPHA:88991

Ziekenhuis	Samenwerkingspartner	Naam EC (EN)	(Cluster van) aandoeningen	Orphacode
UMC Groningen		UMCG Center of Expertise for Children and Adults with Congenital Heart Dis	Rare congenital non-syndromic heart malformation	ORPHA:88991
UMC Groningen		UMCG Center of Expertise for Genetic Endocrine Tumour Syndromes	Von Hippel-Lindau disease	ORPHA:892
UMC Utrecht	NKI-AvL	UMC Utrecht Expertise Centre for rare endocrine tumors	Von Hippel-Lindau disease	ORPHA:892
Leiden UMC		Expert Center for Rare Inherited Immunodeficiencies and Stem Cell Transpla	Complications after hematopoietic stem cell transplanta	ORPHA:90053
Leiden UMC		Expert Center for Rare Hepatic Disease	Acute liver failure	ORPHA:90062
Radboudumc		Radboudumc Center of Expertise for CNS and retinal vascular diseases	Acquired aneurysmal subarachnoid hemorrhage	ORPHA:90065
UMC Utrecht		UMC Utrecht Expertise Centre for neurovascular malformations and subara	Acquired aneurysmal subarachnoid hemorrhage	ORPHA:90065
Amsterdam UMC		Amsterdam UMC expertise center for rare pediatric rheumatologic diseases	Localized scleroderma	ORPHA:90289
Amsterdam UMC		Amsterdam UMC Expertise Center for Systemic Autoimmune diseases	Systemic sclerosis	ORPHA:90291
Erasmus MC		Center of Expertise for Rare Systemic Immune Disease	Systemic sclerosis	ORPHA:90291
Leiden UMC		Expert Center for Multidisciplinary Autoimmune Disease Management	Systemic sclerosis	ORPHA:90291
UMC Groningen		UMCG Center of Expertise for Systemic Autoimmune Diseases	Systemic sclerosis	ORPHA:90291
Amsterdam UMC		Amsterdam UMC Expert Center for Rare coagulation and red blood cell defe	Von Willebrand disease	ORPHA:903
Erasmus MC		Expertise Center for Rare Bleeding disorders	Von Willebrand Disease	ORPHA:903
Leiden UMC	HagaZiekenhuis	Expert Center for Hemophilia and Related Disorders LUMC-HagaZiekenhuis	Von Willebrand disease	ORPHA:903
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Hemophilia and Allied Bleeding Di	Von Willebrand disease	ORPHA:903
Radboudumc		Radboudumc Center of Expertise for Haemophilia and rare coagulation diso	Von Willebrand disease	ORPHA:903
UMC Groningen		UMCG Center of Expertise for Benign Hematology	Von Willebrand Disease	ORPHA:903
UMC Utrecht		UMC Utrecht Expertise centre for benign hematology, thrombosis and hemo	Von Willebrand disease	ORPHA:903
UMC Utrecht		UMC Utrecht Expertise Center for rare GI and hepatic diseases	Wilson disease	ORPHA:905
Leiden UMC		Expert Center for Rare Endocrine Conditions	Rare Endocrine Growth Disease	ORPHA:90692
Amsterdam UMC		Amsterdam UMC Expert Center for rare endocrine conditions	Disorders of sex development	ORPHA:90771
Erasmus MC		Center of expertise for DSD	Disorders of sex development	ORPHA:90771
Erasmus MC		The ENCORE expertise center for neurodevelopmental disorders	Fragile X syndrome	ORPHA:908
Leiden UMC		Expert Center for Rare Endocrine Conditions	Primary lipodystrophy	ORPHA:90970
Erasmus MC		The ENCORE expertise center for neurodevelopmental disorders	Xeroderma Pigmentosum	ORPHA:910
Amsterdam UMC		Amsterdam UMC expertise center for primary immunodeficiencies an bone	Hereditary angioedema	ORPHA:91378
Erasmus MC		Center of expertise for inherited cardiovascular diseases	Familial thoracic aortic aneurysms dissections	ORPHA:91387
Radboudumc	Maastricht UMC+	Radboudumc-Maastricht UMC+ Center of Expertise for Marfan and related d	Familial thoracic aortic aneurysm and aortic dissection	ORPHA:91387
Amsterdam UMC		Amsterdam UMC Multidisciplinary Lyme Borreliosis Center	Lyme disease	ORPHA:91546
Amsterdam UMC		Amsterdam UMC expertise center for rare pediatric rheumatologic diseases	Juvenile idiopathic arthritis	ORPHA:92
Erasmus MC		Centre of expertise for Children with Autoimmune Diseases	Juvenile Idiopathic Arthritis	ORPHA:92
Leiden UMC		Expert Center for Multidisciplinary Autoimmune Disease Management	Juvenile Idiopathic Arthritis	ORPHA:92
Radboudumc		Radboudumc Center of Expertise for Immunodeficiency and autoinflammat	Juvenile idiopathic arthritis	ORPHA:92
UMC Groningen		UMCG Center of Expertise for Systemic and Rheumatological Diseases of Ch	Juvenile Idiopathic arthritis	ORPHA:92
UMC Utrecht		UMC Utrecht Expertise Centre for systemic autoimmune diseases and prima	Juvenile idiopathic arthritis	ORPHA:92
Radboudumc		Radboudumc Center of Expertise for Pediatric urology	Posterior urethral valve	ORPHA:93110
Erasmus MC		Erasmus MC Bone Center	Primary bone dysplasia with increased bone density	ORPHA:93444
Erasmus MC		Erasmus MC Bone Center	Primary bone dysplasia with decreased bone density	ORPHA:93446
Erasmus MC		Erasmus MC Bone Center	Primary bone dysplasia with defective bone mineralizati	ORPHA:93447
Erasmus MC		Erasmus MC Bone Center	Primary bone dysplasia with disorganized development	ORPHA:93450
Erasmus MC		Dutch Craniofacial Center of Expertise	Dysostosis with predominant craniofacial involvement	ORPHA:93453
UMC Utrecht		UMC Utrecht Expertise Centre for skeletal malformations & Mobility Clinic	Non-syndromic limb reduction defect	ORPHA:93457
Leiden UMC		Expert Center for Rare Endocrine Conditions	Overgrowth syndrome	ORPHA:93460
Amsterdam UMC		Amsterdam UMC expertise center for rare pediatric kidney and urinary tract	Renal or urinary tract malformation	ORPHA:93545

Ziekenhuis	Samenwerkingspartner	Naam EC (EN)	(Cluster van) aandoeningen	Orphacode
Erasmus MC		Erasmus MC Center of Expertise for Rare Kidney and Urinary Tract Disease	Renal or urinary tract malformation	ORPHA:93545
Radboudumc		Radboudumc Center of Expertise for Rare kidney diseases	Renal or urinary tract malformation	ORPHA:93545
UMC Utrecht		UMC Utrecht Expertise Centre for hereditary and congenital nephrologic an	Renal or urinary tract malformation	ORPHA:93545
UMC Utrecht		UMC Utrecht Expertise Centre for hereditary and congenital nephrologic an	Non-syndromic renal or urinary tract malformation	ORPHA:93546
Leiden UMC		Expert Center for Lupus-, Vasculitis- and Complement-mediated Systemic D	Glomerular disease	ORPHA:93548
Radboudumc		Radboudumc Center of Expertise for Rare kidney diseases	Glomerular disease	ORPHA:93548
Amsterdam UMC		Amsterdam UMC expertise center for rare pediatric rheumatologic diseases	Pediatric systemic lupus erythematosus	ORPHA:93552
Erasmus MC		Centre of expertise for Children with Autoimmune Diseases	Pediatric Systemic Lupus Erythematosus	ORPHA:93552
UMC Utrecht		UMC Utrecht Expertise Centre for systemic autoimmune diseases and prima	Pediatric systemic lupus erythematosus	ORPHA:93552
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Vasculitis and Immune-mediated K	Thrombotic microangiopathy	ORPHA:93573
Radboudumc		Radboudumc Center of Expertise for Rare kidney diseases	Thrombotic microangiopathy	ORPHA:93573
Erasmus MC		Erasmus MC Center of Expertise for Rare Kidney and Urinary Tract Disease	familial cystic renal disease	ORPHA:93587
Radboudumc		Radboudumc Center of Expertise for Rare kidney diseases	Familial cystic renal disease	ORPHA:93587
UMC Groningen		UMCG Center of Expertise for Inherited Kidney Diseases	Familial cystic renal disease	ORPHA:93587
UMC Utrecht		UMC Utrecht Expertise Centre for hereditary and congenital nephrologic an	Familial cystic renal disease	ORPHA:93587
Radboudumc		Radboudumc Center of Expertise for Rare kidney diseases	Nephropathy secondary to a storage or other metabolic	ORPHA:93593
Erasmus MC		Erasmus MC Center of Expertise for Rare Kidney and Urinary Tract Disease	rare renal tubular disease	ORPHA:93603
Radboudumc		Radboudumc Center of Expertise for Rare kidney diseases	Rare renal tubular disease	ORPHA:93603
UMC Utrecht		UMC Utrecht Expertise Centre for hereditary and congenital nephrologic an	Rare renal tubular disease	ORPHA:93603
Radboudumc		Radboudumc Center of Expertise for Immunodeficiency and autoinflammat	Autoinflammatory syndrome	ORPHA:93665
UMC Groningen		UMCG Center of Expertise for Autoinflammatory Diseases for Adult and Ped	Autoinflammatory syndrome	ORPHA:93665
Erasmus MC		Centre of expertise for inflammatory myopathies	Juvenile dermatomyositis	ORPHA:93672
Radboudumc		Radboudumc Center of Expertise for Pediatric urology	Isolated epispadias	ORPHA:93928
Radboudumc		Radboudumc Center of Expertise for Pediatric urology	Cloacal exstrophy	ORPHA:93929
Radboudumc		Radboudumc Center of Expertise for Pediatric urology	Bladder exstrophy	ORPHA:93930
UMC Utrecht		UMC Utrecht Expertise Centre for congenital esophageal and airway disease	Congenital tracheomalacia	ORPHA:95430
Leiden UMC		Expert Center for Rare Pregnancy-Related Disorders	Twin to twin transfusion syndrome	ORPHA:95431
Erasmus MC		Frontotemporal Dementia center of expertise	Primary progressive aphasia	ORPHA:95432
UMC Groningen		UMCG Center of Expertise for Blistering Diseases	Stevens-Johnson syndrome/toxic epidermal necrolysis s	ORPHA:95455
UMC Utrecht	NKI-AvL	UMC Utrecht Expertise Centre for rare endocrine tumors	Acquired pituitary hormone deficiency	ORPHA:95502
Radboudumc		Radboudumc Center of Expertise for Pediatric urology	Posterior hypospadias	ORPHA:95706
Radboudumc		Radboudumc Center of Expertise for Congenital neurodevelopmental disord	Koolen-de Vries syndrome	ORPHA:96169
Amsterdam UMC		Amsterdam UMC expertise centre for gastroenterologic diseases	Anorectal malformation	ORPHA:96346
Erasmus MC		Pediatric Surgical Centre for Anatomical Congenital Malformations	Anorectal Malformations	ORPHA:96346
UMC Groningen		UMCG Center of Expertise for Paediatric Colorectal Malformations	Anorectal Malformations	ORPHA:96346
Amsterdam UMC		Amsterdam UMC center of expertise for Pulmonary Hypertension	Eisenmenger syndrome	ORPHA:97214
Amsterdam UMC		Amsterdam UMC Expert Center for Inborn Errors of Metabolism	Riboflavin transporter deficiency	ORPHA:97229
Radboudumc		Radboudumc Center of Expertise for neuromuscular disease	Congenital myopathy	ORPHA:97245
UMC Utrecht		UMC Utrecht Expertise Centre for diagnosis and treatment of thoracic outle	Thoracic outlet syndrome	ORPHA:97330
Radboudumc		Radboudumc Center of Expertise for CNS and retinal vascular diseases	Dural sinus malformation	ORPHA:97339
Amsterdam UMC		Amsterdam UMC centre of excellence for rare cardiac diseases	Rare cardiac diseases	ORPHA:97929
Leiden UMC	Amsterdam UMC	Expert Center for Congenital Heart Defects (CAHAL Children)	Rare Surgical Cardiac Disease	ORPHA:97965
Leiden UMC		Expert Center for Rare Types of Headache	Rare headache	ORPHA:98022
Erasmus MC		Pediatric Surgical Centre for Anatomical Congenital Malformations	Diaphragmatic or abdominal wall malformation	ORPHA:98043
Erasmus MC		The ENCORE expertise center for neurodevelopmental disorders	Central nervous system malformation	ORPHA:98044

Ziekenhuis	Samenwerkingspartner	Naam EC (EN)	(Cluster van) aandoeningen	Orphacode
UMC Utrecht		UMC Utrecht Expertise Centre for hereditary and congenital nephrologic an	Rare genetic renal disease	ORPHA:98056
Amsterdam UMC		Amsterdam UMC Expertise Center for upper tract urothelial cancer	Rare urinary tract tumour	ORPHA:98058
Erasmus MC		Center of expertise for rare urinary tract tumors & testicular tumors	Rare urinary tract tumor	ORPHA:98058
Amsterdam UMC		Amsterdam UMC Expertise Center for rare gastrointestinal tumors	Rare digestive tract tumor	ORPHA:98059
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Head and Neck Oncology	Rare otorhinolaryngologic tumor	ORPHA:98061
NKI-AVL		Center of rare head and neck tumours	Rare otorhinolaryngologic tumor	ORPHA:98061
Erasmus MC		Brain Tumor Center of Expertise	Rare nervous system tumor	ORPHA:98062
Radboudumc		Radboudumc Center of Expertise Sex & Gender	46,XX disorder of sex development induced by androgen	ORPHA:98078
Erasmus MC		The ENCORE expertise center for neurodevelopmental disorders	Malformation syndrome with hamartosis	ORPHA:98196
Erasmus MC		Center of expertise for Ehlers-Danlos syndromes	Ehlers-Danlos syndrome	ORPHA:98249
Erasmus MC		Erasmus MC center of expertise for inflammatory disorders of the central ne	Postinfectious encephalitis	ORPHA:98253
UMC Utrecht		UMC Utrecht Expertise Centre for malignant hematology	Myeloproliferative neoplasm	ORPHA:98274
UMC Utrecht		UMC Utrecht Expertise Centre for malignant hematology	Plasma cell tumor	ORPHA:98282
Erasmus MC		Center of expertise for rare mast cell related diseases	Mastocytosis	ORPHA:98292
UMC Groningen		UMCG Center of Expertise for Rare Haematological Diseases	Hodgkin lymphoma	ORPHA:98293
OLVG	Amsterdam UMC	Expert Center for idiopathic interstitial pneumonia	Idiopathic interstitial pneumonia	ORPHA:98300
Radboudumc		Radboudumc Center of Expertise for Iron disorders	Constitutional anemia due to iron metabolism disorder	ORPHA:98360
UMC Utrecht		UMC Utrecht Expertise centre for benign hematology, thrombosis and hemo	Rare constitutional hemolytic anemia due to a red cell m	ORPHA:98364
UMC Utrecht		UMC Utrecht Expertise centre for benign hematology, thrombosis and hemo	Rare constitutional hemolytic anemia due to an enzyme	ORPHA:98369
Amsterdam UMC		Amsterdam UMC Expert Center for Rare coagulation and red blood cell defe	Autoimmune hemolytic anemia	ORPHA:98375
Leiden UMC		Expert Center for Rare Immune Cytopenias	Autoimmune hemolytic anemia	ORPHA:98375
Leiden UMC		Expert Center for Rare Bone Marrow Failure	Primary acquired red cell aplasia	ORPHA:98421
Radboudumc		Radboudumc Center of Expertise for Haemophilia and rare coagulation diso	Rare coagulation disorder	ORPHA:98429
Amsterdam UMC		Amsterdam UMC expertise center for neuromuscular diseases	Skeletal muscle disease	ORPHA:98472
Erasmus MC		Neuromuscular Center Erasmus MC	Skeletal muscle disease	ORPHA:98472
Leiden UMC		Expert Center for Rare Neuromuscular Diseases	Skeletal muscle disease	ORPHA:98472
UMC Utrecht		UMC Utrecht Brain Centre, Neuromuscular Diseases	Muscular dystrophy	ORPHA:98473
Amsterdam UMC		Amsterdam UMC expertise center for neuromuscular diseases	Idiopathic inflammatory myopathy	ORPHA:98482
Radboudumc		Radboudumc Center of Expertise for neuromuscular disease	Idiopathic inflammatory myopathy	ORPHA:98482
Leiden UMC		Expert Center for Rare Neuromuscular Diseases	Neuromuscular junction disease	ORPHA:98491
UMC Utrecht		UMC Utrecht Brain Centre, Neuromuscular Diseases	Neuromuscular junction disease	ORPHA:98491
Leiden UMC		Expert Center for Rare Neuromuscular Diseases	Acquired neuromuscular junction disease	ORPHA:98494
Leiden UMC		Expert Center for Rare Neuromuscular Diseases	Genetic neuromuscular junction disease	ORPHA:98495
Amsterdam UMC		Amsterdam UMC expertise center for neuromuscular diseases	Rare Peripheral Neuropathy	ORPHA:98496
Erasmus MC		Neuromuscular Center Erasmus MC	Rare peripheral neuropathy	ORPHA:98496
UMC Utrecht		UMC Utrecht Brain Centre, Neuromuscular Diseases	Genetic peripheral neuropathy	ORPHA:98497
UMC Utrecht		UMC Utrecht Brain Centre, Neuromuscular Diseases	Motor Neuron Disease	ORPHA:98503
Oogziekenhuis Rotterdam		Rare Eye Disease Center Rotterdam	Color vision disease	ORPHA:98658
Bartiméus, Nederlandse Ve		Bartiméus Diagnostic Center for complex visual disorders	Oculocutaneous or ocular albinism	ORPHA:98706
Erasmus MC		Erasmus MC center of expertise for inflammatory disorders of the central ne	Autoimmune neurological channelopathy	ORPHA:98750
Leiden UMC	HagaZiekenhuis	Expert Center for Hemophilia and Related Disorders LUMC-HagaZiekenhuis	Hemophilia A	ORPHA:98878
Leiden UMC	HagaZiekenhuis	Expert Center for Hemophilia and Related Disorders LUMC-HagaZiekenhuis	Hemophilia B	ORPHA:98879
Leiden UMC		Expert Center for Rare Genetic Neurodegenerative Diseases	Autosomal dominant cerebellar ataxia	ORPHA:99
UMC Groningen		UMCG Expertise Center for Movement Disorders Groningen	Autosomal dominant cerebellar ataxia	ORPHA:99
Amsterdam UMC		Amsterdam UMC Expert Center Fetal Akinesia Deformation Sequence and A	Fetal akinesia deformation sequence	ORPHA:994

Ziekenhuis	Samenwerkingspartner	Naam EC (EN)	(Cluster van) aandoeningen	Orphacode
UMC Utrecht	NKI-AvL	UMC Utrecht Expertise Centre for rare endocrine tumors	Pituitary adenoma	ORPHA:99408
Oogziekenhuis Rotterdam		Rare Eye Disease Center Rotterdam	leber plus disease	ORPHA:99718
Erasmus MC		Centre of expertise for oligodontia	Oligodontia	ORPHA:99798
Leiden UMC		Expert Center for Rare Inherited Immunodeficiencies and Stem Cell Transpla	Acute graft vs host disease	ORPHA:99920
Erasmus MC		Erasmus MC Liver Center of Expertise	Klatskin tumor	ORPHA:99978