

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
Erasmus MC		The ENCORE expertise center for neurodevelopmental disorders	15q11q13 microduplication syndrome	ORPHA:238446
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Rare Syndromes and Cognitive Disorders	22q11.2 deletion syndrome	ORPHA:567
Radboudumc		Radboudumc Center of Expertise Sex & Gender	46,XX disorder of sex development induced by androgens excess	ORPHA:98078
Radboudumc		Radboudumc Center of Expertise Sex & Gender	46,XY disorder of sex development of endocrine origin	ORPHA:325351
UMC Groningen		UMCG Center of Expertise for Amyloidosis	AA amyloidosis	ORPHA:85445
Leiden UMC		Expert Center for Genetic Cerebral Small Vessel Disease	ABeta amyloidosis, Dutch type	ORPHA:100006
Erasmus MC		Center for Genetic Eye Diseases Rotterdam	Achromatopsia	ORPHA:49382
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 subarachnoid hemorrhage	Acquired aneurysmal subarachnoid hemorrhage	ORPHA:90065
Leiden UMC		Expert Center for Rare Endocrine Conditions	Acquired chronic primary adrenal insufficiency	ORPHA:101963
Leiden UMC		Expert Center for Rare Neuromuscular Diseases	Acquired neuromuscular junction disease	ORPHA:98494
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Neuromuscular Diseases	Acquired peripheral neuropathy	ORPHA:182086
UMC Utrecht	NKI-AvL	UMC Utrecht Expertise Centre for rare endocrine tumors	Acquired pituitary hormone deficiency	ORPHA:95502
UMC Utrecht	NKI-AvL	UMC Utrecht Expertise Centre for rare endocrine tumors	Acquired pituitary hormone deficiency	ORPHA:95502
UMC Utrecht		UMC Utrecht Brain Centre, Neuromuscular Diseases	Acquired skeletal muscle disease	ORPHA:206638
Erasmus MC		Erasmus MC center of expertise for inflammatory disorders of the central nervous system	Acute Disseminated Encephalomyelitis	ORPHA:83597
Erasmus MC		Center of expertise for pregnancy induced diseases	Acute fatty liver of pregnancy	ORPHA:243367
Leiden UMC		Expert Center for Rare Inherited Immunodeficiencies and Stem Cell Transplantation	Acute graft vs host disease	ORPHA:99920
Leiden UMC		Expert Center for Rare Hepatic Disease	Acute liver failure	ORPHA:90062
Leiden UMC		Expert Center for hematopoietic stem cell transplantation and T-cell immunotherapy	Acute lymphoblastic leukemia	ORPHA:513
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 Groningen		UMCG Center of Expertise for Cellular Therapy	Acute myeloid leukemia	ORPHA:519
UMC Utrecht		UMC Utrecht Expertise Centre for malignant hematology	Acute myeloid leukemia	ORPHA:519
Leiden UMC		Expert Center for hematopoietic stem cell transplantation and T-cell immunotherapy	Acute myeloid leukemia	ORPHA:519
Leiden UMC		Expert Center for Rare Bone and Soft Tissue Tumors	Adamantinoma	ORPHA:55881
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
UMC Utrecht	NKI-AvL	UMC Utrecht Expertise Centre for rare endocrine tumors	Adrenal/paraganglial tumor	ORPHA:100091

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
Maxima Medisch Centrum		Center for Adrenal Tumors	Adrenocortical carcinoma	ORPHA:1501
Erasmus MC		Erasmus MC Liver Center of Expertise	Adult hepatocellular carcinoma	ORPHA:210159
Erasmus MC		Hematologic malignancies center of expertise	Aggressive B-cell non-Hodgkin lymphoma	ORPHA:300846
UMC Utrecht		UMC Utrecht Expertise Centre for malignant hematology	AL amyloidosis	ORPHA:85443
UMC Utrecht		UMC Utrecht Expertise Center for rare GI and hepatic diseases	Alagille syndrome	ORPHA:52
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
Leiden UMC	HagaZiekenhuis	Expert Center for Rare Hemoglobinopathies	Alpha- thalassemia and related diseases	ORPHA:275745
Leiden UMC*		Alpha1 International Registry (AIR)	Alpha-1-antitrypsin deficiency	ORPHA:60
UMC Utrecht		UMC Utrecht Expertise Centre for hereditary and congenital nephrologic and urologic disorders	Alport syndrome	ORPHA:63
UMC Utrecht		UMC Utrecht Expertise Centre for congenital orofacial and dental anomalies	Ameloblastoma	ORPHA:314419
Amsterdam UMC		Amsterdam UMC Expertise Center for rare gastrointestinal tumors	Ampulla of Vater carcinoma	ORPHA:300557
UMC Groningen		UMCG Center of Expertise for Amyloidosis	Amyloidosis	ORPHA:69
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
Leiden UMC		Expert Center for Rare Bone and Soft Tissue Tumors	Aneurysmal bone cyst	ORPHA:480553
Erasmus MC		The ENCORE expertise center for neurodevelopmental disorders	Angelman syndrome	ORPHA:72
UMC Groningen		UMCG Center of Expertise ""Unique"" for Rare Genetic Causes of Neurodevelopmental Disorders	Anomaly of Chromosome 6	ORPHA:261712
Amsterdam UMC		Amsterdam UMC expertise centre for gastroenterologic diseases	Anorectal malformation	ORPHA:96346
UMC Groningen		UMCG Center of Expertise for Paediatric Colorectal Malformations	Anorectal Malformation	ORPHA:96346
UMC Utrecht		UMC Utrecht Expertise Centre for congenital esophageal and airway diseases	Anorectal malformation	ORPHA:96346
Erasmus MC		Pediatric Surgical Centre for Anatomical Congenital Malformations	Anorectal Malformations	ORPHA:96346
UMC Utrecht		UMC Utrecht Expertise Centre for uveitis	anterior uveitis	ORPHA:280886
Leiden UMC		Expert Center for Lupus-, Vasculitis- and Complement-mediated Systemic Diseases	Anti-neutrophil cytoplasmic antibody-associated vasculitis	ORPHA:156152
Leiden UMC		Expert Center for Rare Hereditary Bowel Tumors	APC-related attenuated familial adenomatous polyposis	ORPHA:247806
Leiden UMC		Expert Center for Rare Bone Marrow Failure	Aplastic Anemia	ORPHA:182040
Erasmus MC		Center of expertise for inherited cardiovascular diseases	Arrhythmogenic right ventricular cardiomyopathy	ORPHA:247
MUMC+*		Expertise center Cardiogenetics MUMC+	Arrhythmogenic right ventricular dysplasia	ORPHA:247
Amsterdam UMC		Amsterdam UMC Expert Center Fetal Akinesia Deformation Sequence and Arthrogryposis Multiplex Congenita	Arthrogryposis multiplex congenita	ORPHA:1037
NKI-AvL		Expert Center for Hereditary Cancer	Attenuated Familial adenomatous polyposis	ORPHA:220460
UMC Utrecht		UMC Utrecht Brain Centre, Neuromuscular Diseases	ATTRV30M amyloidosis	ORPHA:85447

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UMC Groningen		UMCG Center of Expertise ""Unique"" for Rare Genetic Causes of Neurodevelopmental Disorders	Autism spectrum disorder due to AUTS2 deficiency	ORPHA:352490
UMC Groningen		UMCG Center of Expertise for Blistering Diseases	Auto-immune bullous skin diseases	ORPHA:79669
Erasmus MC		Erasmus MC center of expertise for inflammatory disorders of the central nervous system	Autoimmune encephalopathy with parasomnia and obstructive sleep apnea	ORPHA:420789
Amsterdam UMC		Amsterdam UMC Expert Center for Rare coagulation and red blood cell defects	Autoimmune hemolytic anemia	ORPHA:98375
Leiden UMC		Expert Center for Rare Immune Cytopenias	Autoimmune hemolytic anemia	ORPHA:98375
Amsterdam UMC		Amsterdam UMC Expert Center for immune-mediated and genetic cholestasis syndromes	Autoimmune hepatitis	ORPHA:2137
Erasmus MC		Erasmus MC center of expertise for inflammatory disorders of the central nervous system	Autoimmune neurological channelopathy	ORPHA:98750
Leiden UMC		Expert Center for Rare Immune Cytopenias	Autoimmune thrombocytopenia	ORPHA:71203
Radboudumc		Radboudumc Center of Expertise for Immunodeficiency and autoinflammation	Autoinflammatory syndrome	ORPHA:93665
UMC Groningen		UMCG Center of Expertise for Autoinflammatory Diseases for Adult and Pediatric Patients	Autoinflammatory syndrome	ORPHA:93665
UMC Groningen		UMCG Center of Expertise for Autoinflammatory Diseases for Adult and Pediatric Patients	Autoinflammatory syndrome of childhood	ORPHA:319719
Radboudumc		Radboudumc Center of Expertise for Immunodeficiency and autoinflammation	Autoinflammatory syndrome of children	ORPHA:319719
Radboudumc		Radboudumc Center of Expertise for Immunodeficiency and autoinflammation	Autoinflammatory syndrome with immune deficiency	ORPHA:290839
UMC Groningen		UMCG Center of Expertise ""Unique"" for Rare Genetic Causes of Neurodevelopmental Disorders	Autosomal anomaly	ORPHA:98127
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
Leiden UMC		Expert Center for Rare Hereditary Kidney Disease	Autosomal dominant polycystic kidney disease	ORPHA:730
UMC Groningen		UMCG Expertise Center for Movement Disorders Groningen	Autosomal recessive cerebellar ataxia	ORPHA:1172
Leiden UMC		Expert Center for Familial Melanoma	BAP1-related tumor predisposition syndrome	ORPHA:289539
UMC Utrecht		UMC Utrecht Expertise Centre for hereditary and congenital nephrologic and urologic disorders	Bardet-Biedl syndrome	ORPHA:110
Amsterdam UMC		Amsterdam UMC Expert Center for Hematological Malignancies	B-cell chronic lymphocytic leukemia	ORPHA:67038
UMC Utrecht		UMC Utrecht Expertise Centre for malignant hematology	B-cell chronic lymphocytic leukemia	ORPHA:67038
UMC Utrecht		UMC Utrecht Expertise Centre for malignant hematology	B-cell non-Hodgkin lymphoma	ORPHA:171915
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
Amsterdam UMC		Center for rare movement disorders	Benign adult familial myoclonic epilepsy	ORPHA:86814

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UMC Groningen		UMCG Expertise Center for Movement Disorders Groningen	Benign adult familial myoclonic epilepsy	ORPHA:86814
Amsterdam UMC		Amsterdam UMC Expert Center for immune-mediated and genetic cholestasis syndromes	Benign recurrent intrahepatic cholestasis	ORPHA:65682
UMC Utrecht		UMC Utrecht Expertise Center for rare GI and hepatic diseases	Benign Recurrent Intrahepatic Cholestasis	ORPHA:65682
Leiden UMC	HagaZiekenhuis	Expert Center for Rare Hemoglobinopathies	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	Beta-thalassemia and related diseases	ORPHA:275749
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 hemostasis, Van Creveldkliniek	Blackfan-Diamond anemia	ORPHA:124
Radboudumc		Radboudumc Center of Expertise for Pediatric urology	Bladder exstrophy	ORPHA:93930
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
Erasmus MC		Dutch Craniofacial Center of Expertise	branchial arch or oral-acral syndrome	ORPHA:139036
Amsterdam UMC		Amsterdam UMC expert center for bronchopulmonary dysplasia	Bronchopulmonary dysplasia	ORPHA:70589
MUMC+*		Expertise center Cardiogenetics MUMC+	Brugada syndrome	ORPHA:130
UMC Utrecht		UMC Utrecht Brain Centre, Neuromuscular Diseases	Bulbospinal muscular atrophy	ORPHA:206701
Leiden UMC		Expert Center for Lupus-, Vasculitis- and Complement-mediated Systemic Diseases	C3 glomerulonephritis	ORPHA:329931
Amsterdam UMC		Amsterdam UMC expert center in Rare Bone Disease, including FOP, hereditary OP, FD and Camurati Enge	Camurati-Engelmann disease	ORPHA:1328
Erasmus MC		Erasmus MC Oesophageal and Gastric Cancer center of expertise	Carcinoma of esophagus	ORPHA:70482
NKI-AvL		Center of rare GI tumours	Carcinoma of esophagus, incl. Junction carcinoma	ORPHA70482 2
UMC Groningen		UMCG Center of Expertise for Cholangiocarcinoma	Carcinoma of gallbladder and extrahepatic biliary tract	ORPHA:56044
UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bileduct tumors	Carcinoma of gallbladder and extrahepatic biliary tract	ORPHA:56044
UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bileduct tumors	Carcinoma of gallbladder and extrahepatic biliary tract	ORPHA:56044
UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bileduct tumors	Carcinoma of gallbladder and extrahepatic biliary tract	ORPHA:56044

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bileduct tumors	Carcinoma of gallbladder and extrahepatic biliary tract	ORPHA:56044
UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bileduct tumors	Carcinoma of the ampulla of Vater	ORPHA:300557
UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bileduct tumors	Carcinoma of the ampulla of Vater	ORPHA:300557
UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bileduct tumors	Carcinoma of the ampulla of Vater	ORPHA:300557
UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bileduct tumors	Carcinoma of the ampulla of Vater	ORPHA:300557
UMC Utrecht		Center for inherited cardiovascular disease	Cardiomyopathy	ORPHA:167848
Leiden UMC		Expert Center for Genetic Cerebral Small Vessel Disease	Cathepsin A-related arteriopathy-strokes-leukoencephalopathy	ORPHA:575553
Erasmus MC	Sint Franciscus Vlietland Groep	Mesenteric Ischemia Center Rotterdam	Celiac artery compression syndrome	ORPHA:293208
Erasmus MC	Sint Franciscus Vlietland Groep	Mesenteric Ischemia Center Rotterdam	Celiac artery compression syndrome	ORPHA:293208
Medisch Spectrum Twente		Gastrointestinal ischemia Centre	Celiac trunk compression syndrome	ORPHA:293208
UMC Utrecht	NKI-AvL	UMC Utrecht Expertise Centre for rare endocrine tumors	Central diabetes insipidus	ORPHA:178029
UMC Utrecht	NKI-AvL	UMC Utrecht Expertise Centre for rare endocrine tumors	Central diabetes insipidus	ORPHA:178029
Erasmus MC		The ENCORE expertise center for neurodevelopmental disorders	Central nervous system malformation	ORPHA:98044
Amsterdam UMC	Leiden UMC	Expertise Center for Hereditary Eye Diseases and Central Serous Chorioretinopathy	Central serous chorioretinopathy	ORPHA:443079
Amsterdam UMC	Leiden UMC	Expertise Center for Hereditary Eye Diseases and Central Serous Chorioretinopathy	Central serous chorioretinopathy	ORPHA:443079
Erasmus MC		Dutch Craniofacial Center of Expertise	Cephalocele	ORPHA:268817
Radboudumc		Radboudumc Center of Expertise for CNS and retinal vascular diseases	Cerebral arteriovenous malformation	ORPHA:46724
Leiden UMC		Expert Center for Genetic Cerebral Small Vessel Disease	Cerebral autosomal dominant arteriopathy-subcortical infarcts-leukoencephalopathy	ORPHA:136
Leiden UMC		Expert Center for Genetic Cerebral Small Vessel Disease	Cerebral autosomal recessive arteriopathy-subcortical infarcts-leukoencephalopathy	ORPHA:199354
UMC Utrecht		UMC Utrecht Expertise Centre for rare and complex epilepsies	cerebral cortical dysplasia	ORPHA:268950
UMC Utrecht		UMC Utrecht Expertise Centre for rare and complex epilepsies	cerebral malformations with epilepsy	ORPHA:166478
Radboudumc		Radboudumc Center of Expertise for Hemangiomas and congenital vascular anomalies (HECOVAN)	Cerebrofacial arteriovenous metamerism syndrome	ORPHA:141189
CWZ Nijmegen		Center for Cerebrotendinous xanthomatosis	Cerebrotendinous xanthomatosis	ORPHA:909

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
UMC Groningen		UMCG Center of Expertise ""Unique"" for Rare Genetic Causes of Neurodevelopmental Disorders	CHARGE syndrome	ORPHA:138
UMC Groningen		UMCG Center of Expertise for Cholangiocarcinoma	Cholangiocarcinoma	ORPHA:70567
UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bileduct tumors	Cholangiocarcinoma	ORPHA:70567
UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bileduct tumors	Cholangiocarcinoma	ORPHA:70567
UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bileduct tumors	Cholangiocarcinoma	ORPHA:70567
UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bileduct tumors	Cholangiocarcinoma	ORPHA:70567
UMC Groningen		UMCG Center of Expertise for Congenital Biliary Disorders	Choledochal cyst	ORPHA:480501
Amsterdam UMC		Amsterdam UMC Expert Center for Inborn Errors of Metabolism	Cholesteryl ester storage disease	ORPHA:75234
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	Chordoma	ORPHA:178
Radboudumc	Maastricht UMC+	Radboudumc-Maastricht UMC+ Center of Expertise forÂ Skull base pathology	Chordoma	ORPHA:178
Radboudumc	Maastricht UMC+	Radboudumc-Maastricht UMC+ Center of Expertise forÂ Skull base pathology	Chordoma	ORPHA:178
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
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 intestinal tract	Chronic intestinal failure	ORPHA:294422
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
Amsterdam UMC		Amsterdam UMC Expert Center for Hematological Malignancies	Chronic Myeloid Leukemia (al erkend onder cluster NHL)	ORPHA:521
UMC Utrecht		UMC Utrecht Brain Centre, Neuromuscular Diseases	Chronic polyradiculoneuropathy	ORPHA:208978
Leiden UMC		Expert Center for Rare Endocrine Conditions	Chronic recurrent multifocal osteomyelitis	ORPHA:324964
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
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Inborn Errors of Galactose Metabolism	Classic galactosemia	ORPHA:79239
Erasmus MC		Frontotemporal Dementia center of expertise	classical progressive supranuclear palsy	ORPHA:240071

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
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 disorders	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
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
Radboudumc		Radboudumc Center of Expertise for Cleft lip & palate and orofacial disorders	Cleft palate	ORPHA:2014
UMC Utrecht		UMC Utrecht Expertise Centre for congenital orofacial and dental anomalies	Cleft palate	ORPHA:2014
UMC Utrecht		UMC Utrecht Expertise Centre for congenital orofacial and dental anomalies	Cleft/lip palate	ORPHA:199306
Radboudumc		Radboudumc Center of Expertise for Congenital disorders of dental development	Cleidocranial dysplasia	ORPHA:1452
Radboudumc		Radboudumc Center of Expertise for Pediatric urology	Cloacal exstrophy	ORPHA:93929
Leiden UMC		Expert Center for Rare Ear Diseases	Cochlear nerve deficiency	ORPHA:502318
Leiden UMC		Expert Center for Rare Ear Diseases	Cochleovestibular dysplasia	ORPHA:502305
Erasmus MC		The ENCORE expertise center for neurodevelopmental disorders	Cockayne Syndrome	ORPHA:191
Leiden UMC		Center of expertise Coffin-Siris syndrome	Coffin-Siris syndroom	ORPHA:1465
Oogziekenhuis Rotterdam		Rare Eye Disease Center Rotterdam	Color vision disease	ORPHA:98658
Erasmus MC		Center for Genetic Eye Diseases Rotterdam	Color-vision disease	ORPHA:98658
Leiden UMC		Expert Center for Rare Inherited Immunodeficiencies and Stem Cell Transplantation	Combined T and B cell immunodeficiency	ORPHA:101972
Amsterdam UMC		Amsterdam UMC center of expertise for Vascular Malformations	Complex vascular malformation with associated anomalies	ORPHA:211277
Radboudumc		Radboudumc Center of Expertise for Hemangiomas and congenital vascular anomalies (HECOVAN)	Complex vascular malformation with associated anomalies	ORPHA:211277
Leiden UMC		Expert Center for Rare Inherited Immunodeficiencies and Stem Cell Transplantation	Complications after hematopoietic stem cell transplantation	ORPHA:90053
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
UMC Utrecht	NKI-AvL	UMC Utrecht Expertise Centre for rare endocrine tumors	Congenital adrenal hyperplasia	ORPHA:418
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
Radboudumc		Radboudumc Center of Expertise for Congenital malformations of the intestinal tract	Congenital diaphragmatic hernia	ORPHA:2140

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
Radboudumc		Radboudumc Center of Expertise for Inherited metabolic disorders	Congenital disorder of glycosylation	ORPHA:137
UMC Utrecht		UMC Utrecht Expertise centre for benign hematology, thrombosis and hemostasis, Van Creveldkliniek	Congenital dyserythropoietic anemia	ORPHA:85
UMC Utrecht		UMC Utrecht Expertise Centre for rare otorhinolaryngological diseases	Congenital laryngomalacia	ORPHA:2373
Erasmus MC		Center of rare skin diseases	Congenital lethal erythroderma	ORPHA:1954
Erasmus MC		ErasmusMC Center of expertise for Congenital Hand and Upper Limb Malformations	Congenital limb malformation	ORPHA:68378
Radboudumc		Radboudumc Center of Expertise for neuromuscular disease	Congenital myopathy	ORPHA:97245
Erasmus MC		Center of expertise for congenital lung malformations	Congenital pulmonary airway malformation	ORPHA:2444
UMC Utrecht		UMC Utrecht Expertise Centre for congenital esophageal and airway diseases	Congenital tracheomalacia	ORPHA:95430
Radboudumc		Radboudumc Center of Expertise for Iron disorders	Constitutional anemia due to iron metabolism disorder	ORPHA:98360
Erasmus MC	LUMC	Center for Congenital bone marrow failure and leukemia predisposition syndromes	Constitutional neutropenia	ORPHA:101987
Leiden UMC	Erasmus MC	Center for Congenital bone marrow failure and leukemia predisposition syndromes	Constitutional neutropenia	ORPHA:101987
UMC Utrecht		UMC Utrecht Expertise centre for benign hematology, thrombosis and hemostasis, Van Creveldkliniek	Constitutional neutropenia	ORPHA:101987
UMC Utrecht		UMC Utrecht Expertise Centre for rare and complex epilepsies	continuous spikes and waves during sleep	ORPHA:725
Amsterdam UMC		Amsterdam UMC Expert Center for Developmental Disorders	Cornelia de Lange syndrome	ORPHA:199
Erasmus MC		Frontotemporal Dementia center of expertise	corticobasal syndrome	ORPHA:454887
UMC Utrecht	NKI-AvL	UMC Utrecht Expertise Centre for rare endocrine tumors	Craniopharyngioma	ORPHA:54595
UMC Utrecht	NKI-AvL	UMC Utrecht Expertise Centre for rare endocrine tumors	Craniopharyngioma	ORPHA:54595
Amsterdam UMC		Amsterdam UMC Expert Center for Inborn Errors of Metabolism	Creatine deficiency syndrome	ORPHA:79172
Amsterdam UMC		Amsterdam UMC Expert Center for immune-mediated and genetic cholestasis syndromes	Crigler-Najjar syndrome	ORPHA:205
Erasmus MC		Center for Lysosomal and Metabolic Diseases	Crigler-Najjar syndrome	ORPHA:205
Radboudumc		Radboudumc Center of Expertise for Adrenal diseases	Cushing syndrome	ORPHA:553
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Neuroendocrine Tumors	Cutaneous neuroendocrine carcinoma	ORPHA:79140
UMC Groningen		UMCG Center of Expertise for Neuroendocrine Tumors and Neuroendocrine Carcinomas	Cutaneous neuroendocrine carcinoma	ORPHA:79140
Radboudumc		Radboudumc Center of Expertise for Head and neck and salivary gland tumours	Cutaneous neuro-endocrine carcinoma	ORPHA:79140
Amsterdam UMC		Amsterdam UMC Expert Center for Cystic Fibrosis and Primary Ciliary Dyskinesia	Cystic Fibrosis	ORPHA:586

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
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
Radboudumc		Radboud University Medical Centre CF centre	Cystic fibrosis	ORPHA:586
Amsterdam UMC		Amsterdam UMC expert center for cleft, craniofacial and airway disorders	Cysts and fistulae of the face and oral cavity	ORPHA:155835
Amsterdam UMC		Amsterdam UMC Expertise Center for Systemic Autoimmune diseases	Dermatomyositis	ORPHA:221
Erasmus MC		Center for Genetic Eye Diseases Rotterdam	Developmental defect of the eye	ORPHA:98553
Erasmus MC		Pediatric Surgical Centre for Anatomical Congenital Malformations	Diaphragmatic or abdominal wall malformation	ORPHA:98043
UMC Groningen		UMCG Center of Expertise for Cellular Therapy	Diffuse large B-cell lymphoma	ORPHA:544
Erasmus MC		Center of expertise for inherited cardiovascular diseases	Dilated cardiomyopathy	ORPHA:217604
MUMC+*		Expertise center Cardiogenetics MUMC+	Dilated cardiomyopathy	ORPHA:217604
Erasmus MC		Center for Lysosomal and Metabolic Diseases	disorder of amino acid and other organic acid metabolism	ORPHA:79062
Erasmus MC		Center for Lysosomal and Metabolic Diseases	disorder of branched-chain amino acid metabolism	ORPHA:79197
UMC Utrecht		UMC Utrecht Expertise Centre for inherited metabolic diseases (CIMD-UMCU)	Disorder of carnitine cycle and transport	ORPHA:309130
Amsterdam UMC		Amsterdam UMC Expert Center for Inborn Errors of Metabolism	Disorder of carnitine cycle and carnitine transport	ORPHA:309130
Amsterdam UMC		Amsterdam UMC Expert Center for Inborn Errors of Metabolism	Disorder of fatty acid oxidation and ketone body metabolism	ORPHA:79174
UMC Utrecht		UMC Utrecht Expertise Centre for inherited metabolic diseases (CIMD-UMCU)	Disorder of fatty acid oxidation and ketone body metabolism	ORPHA:79174
UMC Utrecht		UMC Utrecht Expertise Centre for inherited metabolic diseases (CIMD-UMCU)	Disorder of folate metabolism and transport	ORPHA:285657
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Inborn Errors of Fructose Metabolism	Disorder of fructose metabolism	ORPHA:308463
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Inborn Errors of Galactose Metabolism	Disorder of galactose metabolism	ORPHA:308467
Radboudumc		Radboudumc Center of Expertise for Iron disorders	Disorder of iron metabolism and transport	ORPHA:309842
Erasmus MC		Center for Lysosomal and Metabolic Diseases	disorder of lysosomal amino acid transport	ORPHA:79207
UMC Groningen		UMCG Center of Expertise for Defects in Amino Acid and Organic Acid Metabolism	Disorder of phenylalanine metabolism	ORPHA:284814
UMC Utrecht		UMC Utrecht Expertise Centre for inherited metabolic diseases (CIMD-UMCU)	Disorder of purine or pyrimidine metabolism	ORPHA:79224
Amsterdam UMC		Amsterdam UMC Expert Center for Inborn Errors of Metabolism	Disorder of pyridoxine metabolism	ORPHA:79192
Erasmus MC		Center for Lysosomal and Metabolic Diseases	disorder of urea cycle metabolism and ammonia detoxification	ORPHA:79167
Radboudumc		Radboudumc Center of Expertise for Inherited metabolic disorders	Disorders of pyridoxine metabolism	ORPHA:79192
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
UMC Utrecht		UMC Utrecht Expertise Centre for rare and complex epilepsies	Dravet syndrome	ORPHA:33069
Leiden UMC		Expert Center for Rare Neuromuscular Diseases	Duchenne and Becker muscular dystrophy	ORPHA:262

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
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
Radboudumc		Radboudumc Center of Expertise for CNS and retinal vascular diseases	Dural sinus malformation	ORPHA:97339
Radboudumc		Radboudumc Center of Expertise for Congenital neurodevelopmental disorders	DYRK1A-related intellectual disability syndrome	ORPHA:464306
UMC Utrecht		UMC Utrecht Expertise centre for rare genetic dyslipidemia	Dysbetalipoproteinemia	ORPHA:412
UMC Utrecht		UMC Utrecht Expertise Centre for skeletal malformations & Mobility Clinic	Dysostosis	ORPHA:364559
Erasmus MC		Dutch Craniofacial Center of Expertise	Dysostosis with predominant craniofacial involvement	ORPHA:93453
Erasmus MC		Centre of expertise for oligodontia	Ectodermal dysplasia syndrome	ORPHA:79373
Erasmus MC		Center of expertise for Ehlers-Danlos syndromes	Ehlers-Danlos syndrome	ORPHA:98249
Amsterdam UMC		Amsterdam UMC center of expertise for Pulmonary Hypertension	Eisenmenger syndrome	ORPHA:97214
Oogziekenhuis Rotterdam		Rare Eye Disease Center Rotterdam	Endophthalmitis	ORPHA:199323
Amsterdam UMC		Amsterdam UMC Expert Center for Hematological Malignancies	Enteropathy Associated T-cell Lymphoma	ORPHA:86880
Radboudumc		Radboudumc center for systemic autoimmune diseases	Eosinophilic fasciitis	ORPHA:3165
UMC Groningen		UMCG Expertise Center for Movement Disorders Groningen	Epilepsy and/or ataxia with myoclonus as major feature	ORPHA:306756
NKI-AvL		Center of rare GI tumours	Epithelial tumor of anal cancer	ORPHA:424010
Amsterdam UMC		Amsterdam UMC expertise centre for congenital malformations of the oesophagus	Esophageal atresia	ORPHA:1199
Erasmus MC		Pediatric Surgical Centre for Anatomical Congenital Malformations	Esophageal atresia	ORPHA:1199
UMC Utrecht		UMC Utrecht Expertise Centre for congenital esophageal and airway diseases	Esophageal atresia	ORPHA:1199
Oogziekenhuis Rotterdam		Rotterdam Center for Orbital Auto-immune Disorders	Euthyroid Graves orbitopathy	ORPHA:466682
UMC Utrecht		UMC Utrecht Expertise Centre for hereditary and congenital nephrologic and urologic disorders	Exstrophy-epispadias complex	ORPHA:322
UMC Utrecht		Centre of expertise for extracranial carotid artery aneurysms (ECAA)	Extracraniele carotis aneurysma	ORPHA:494424
UMC Utrecht	Prinses Maxima Centrum - PMC	UMC Utrecht Expertise Centre for testicular and extragonadal germ cell tumors	Extragenadal germ cell tumor	ORPHA:363579
UMC Utrecht	Prinses Maxima Centrum - PMC	UMC Utrecht Expertise Centre for testicular and extragonadal germ cell tumors	Extragenadal germ cell tumor	ORPHA:363579
Radboudumc		Radboudumc Center of Expertise for Hemangiomas and congenital vascular anomalies (HECOVAN)	Facial arteriovenous malformation	ORPHA:156230
Erasmus MC		Dutch Craniofacial Center of Expertise	Facial cleft	ORPHA:141229
Radboudumc		Radboudumc Center of Expertise for neuromuscular disease	Facioscapulohumeral dystrophy	ORPHA:269
Leiden UMC		Expert Center for Rare Neuromuscular Diseases	Facioscapulohumeral muscular dystrophy	ORPHA:269

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
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
Leiden UMC		Expert Center for Familial Melanoma	Familial atypical multiple mole melanoma syndrome	ORPHA:404560
UMC Utrecht		UMC Utrecht Expertise Centre for neurovascular malformations and subarachnoid hemorrhage	Familial cerebral saccular aneurysm	ORPHA:231160
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 and urologic disorders	Familial cystic renal disease	ORPHA:93587
Radboudumc		Radboudumc Center of Expertise for Adrenal diseases	Familial hyperaldosteronism	ORPHA:235936
MUMC+*		Expertise center Cardiogenetics MUMC+	Familial long QT syndrome	ORPHA:768
Leiden UMC		Expert Center for Familial Melanoma	Familial melanoma	ORPHA:618
Leiden UMC		Expert Center for Rare Types of Headache	Familial or sporadic hemiplegic migraine	ORPHA:569
UMC Groningen		UMCG Center of Expertise for Familial Breast and Ovarian Cancer	Familial ovarian cancer	ORPHA:213517
Radboudumc	Maastricht UMC+	Radboudumc-Maastricht UMC+ Center of Expertise for Marfan and related disorders	Familial thoracic aortic aneurysm and aortic dissection	ORPHA:91387
Radboudumc	Maastricht UMC+	Radboudumc-Maastricht UMC+ Center of Expertise for Marfan and related disorders	Familial thoracic aortic aneurysm and aortic dissection	ORPHA:91387
Erasmus MC		Center of expertise for inherited cardiovascular diseases	Familial thoracic aortic aneurysms dissections	ORPHA:91387
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Gastrointestinal Motility Disorders	Familial visceral myopathy	ORPHA:2604
Amsterdam UMC		Amsterdam UMC Expert Center Fetal Akinesia Deformation Sequence and Arthrogryposis Multiplex Congenita	Fetal akinesia deformation sequence	ORPHA:994
Leiden UMC		Expert Center for Rare Pregnancy-Related Disorders	Fetal and neonatal alloimmune thrombocytopenia	ORPHA:853
Leiden UMC		Expert Center for Rare Prenatal and Congenital Infections	Fetal cytomegalovirus syndrome	ORPHA:294
Leiden UMC		Expert Center for Rare Pregnancy-Related Disorders	Fetal lower urinary tract obstruction	ORPHA:435365
Leiden UMC		Expert Center for Rare Pregnancy-Related Disorders	Fetal parvovirus syndrome	ORPHA:295
Amsterdam UMC		Amsterdam UMC expert center in Rare Bone Disease, including FOP, hereditary OP, FD and Camurati Enge	Fibrodysplasia Ossificans Progressiva	ORPHA:337
Amsterdam UMC		Amsterdam UMC expert center in Rare Bone Disease, including FOP, hereditary OP, FD and Camurati Enge	Fibrous dysplasia of bone	ORPHA:249

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
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	Fragile X syndrome	ORPHA:908
Erasmus MC		Frontotemporal Dementia center of expertise	Frontotemporal dementia	ORPHA:282
Erasmus MC		Frontotemporal Dementia center of expertise	Frontotemporal dementia with motor neuron disease	ORPHA:275872
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Inborn Errors of Fructose Metabolism	Fructose-1,6-biphosphatasedeficiency	ORPHA:348
Radboudumc		Radboudumc Center of Expertise for Pituitary disease	Functioning pituitary adenoma	ORPHA:314753
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Inborn Errors of Galactose Metabolism	Galactokinase deficiency	ORPHA:79237
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Inborn Errors of Galactose Metabolism	Galactose epimerase deficiency	ORPHA:79238
Amsterdam UMC		Amsterdam UMC Expert Center for Inborn Errors of Metabolism	Galactosemia	ORPHA:352
Radboudumc		Radboudumc Center of Expertise for Sarcomas	Gastrointestinal stromal tumor	ORPHA:44890
Erasmus MC		Erasmus MC Oesophageal and Gastric Cancer center of expertise	Gastric adenocarcinoma and proximal polyposis of the stomach	ORPHA:314022
Erasmus MC		Erasmus MC Oesophageal and Gastric Cancer center of expertise	Gastric linitis plastica	ORPHA:36273
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Neuroendocrine Tumors	Gastroenteropancreatic neuroendocrine neoplasm	ORPHA:100092
NKI-AvL		Sarcoma Expertise Centre Amsterdam	Gastrointestinal stromal tumor	ORPHA:44890
UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bileduct tumors	Gastrointestinal stromal tumor	ORPHA:44890
UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bileduct tumors	Gastrointestinal stromal tumor	ORPHA:44890
UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bileduct tumors	Gastrointestinal stromal tumor	ORPHA:44890
UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bileduct tumors	Gastrointestinal stromal tumor	ORPHA:44890
Leiden UMC		Expert Center for Rare Bone and Soft Tissue Tumors	Gastro-intestinale stromale tumor	ORPHA:44890
Radboudumc		Radboudumc Center of Expertise for Congenital malformations of the intestinal tract	Gastroschisis	ORPHA:2368
Leiden UMC		Expert Center for Rare Hereditary Bowel Tumors	Geattenueerde familiale adenomateuze polyposis	ORPHA:220460
Radboudumc		Radboudumc Center of Expertise Sex & Gender	Gender dysphoria	ORPHA:459690
Amsterdam UMC		Amsterdam UMC Expert Center for rare endocrine conditions	Gender dysphoria	ORPHA:459690
UMC Groningen		UMCG Expertise Center for Movement Disorders Groningen	Generalized isolated dystonia	ORPHA:376724
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

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
UMC Utrecht		Center for inherited cardiovascular disease	Genetic cardiac rhythm disease	ORPHA:101934
Leiden UMC		Expert Center for Genetic Cerebral Small Vessel Disease	Genetic cerebral small vessel disease	ORPHA:477754
Amsterdam UMC		Amsterdam UMC Expert Center for Interstitial Lung Disease	Genetic interstitial lung disease	ORPHA:264992
UMC Groningen		UMCG Center of Expertise for Familial Colorectal Cancer	Genetic intestinal polyposis	ORPHA:363314
UMC Utrecht		UMC Utrecht Expertise Centre for hereditary and congenital nephrologic and urologic disorders	Genetic nephrotic syndrome	ORPHA:564127
Leiden UMC		Expert Center for Rare Neuromuscular Diseases	Genetic neuromuscular junction disease	ORPHA:98495
Erasmus MC	Amsterdam UMC	Expert Center Genetic Obesity	genetic obesity	ORPHA:77828
Erasmus MC	Amsterdam UMC	Expert Center Genetic Obesity	genetic obesity	ORPHA:77828
UMC Utrecht		UMC Utrecht Brain Centre, Neuromuscular Diseases	Genetic peripheral neuropathy	ORPHA:98497
UMC Utrecht		UMC Utrecht Brain Centre, Neuromuscular Diseases	Genetic skeletal muscle disease	ORPHA:206634
UMC Utrecht	Prinses Maxima Centrum - PMC	UMC Utrecht Expertise Centre for testicular and extragonadal germ cell tumors	Germ cell tumor	ORPHA:3399
UMC Utrecht	Prinses Maxima Centrum - PMC	UMC Utrecht Expertise Centre for testicular and extragonadal germ cell tumors	Germ cell tumor	ORPHA:3399
UMC Groningen		UMCG Center of Expertise for Germ Cell Tumors	Germ cell tumor of testis	ORPHA:363504
UMC Utrecht	Prinses Maxima Centrum - PMC	UMC Utrecht Expertise Centre for testicular and extragonadal germ cell tumors	Germ cell tumor of testis	ORPHA:363504
UMC Utrecht	Prinses Maxima Centrum - PMC	UMC Utrecht Expertise Centre for testicular and extragonadal germ cell tumors	Germ cell tumor of testis	ORPHA:363504
Amsterdam UMC	NKI-AvL	Center Gynaecologic Oncology Amsterdam	Gestational trophoblastic disease	ORPHA:254685
Amsterdam UMC	NKI-AvL	Center Gynaecologic Oncology Amsterdam	Gestational trophoblastic disease	ORPHA:254685
Radboudumc*		Radboud Centre for vulvar and cervix cancer and Dutch Mole Registry	Gestational trophoblastic neoplasm; all different subgroups	ORPHA:59305
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
NKI-AvL		Centre for rare nervous system tumor	Glial tumor	ORPHA:182067
UMC Groningen		UMCG Center of Expertise for Brain and Skull Base Tumors	Glial tumor	ORPHA:182067
UMC Utrecht		UMCU Neuro-Oncology Center	Glial tumor	ORPHA:182067
Leiden UMC		Expert Center for Lupus-, Vasculitis- and Complement-mediated Systemic Diseases	Glomerular disease	ORPHA:93548
Radboudumc		Radboudumc Center of Expertise for Rare kidney diseases	Glomerular disease	ORPHA:93548
UMC Utrecht		UMC Utrecht Expertise Centre for soft tissue tumors (OncoMid)	Glomus tumor	ORPHA:391651
UMC Groningen		UMCG Center of Expertise for Carbohydrate, Fatty Acid Oxidation and Ketone Bodies Disorders	Glycogen storage disease	ORPHA:79201
Erasmus MC		Center for Lysosomal and Metabolic Diseases	glycogen storage disease due LAMP2 deficiency	ORPHA:34587
Erasmus MC		Center for Lysosomal and Metabolic Diseases	glycogen storage disease due to acid maltase deficiency	ORPHA:365
UMC Groningen		UMCG Center of Expertise for Carbohydrate, Fatty Acid Oxidation and Ketone Bodies Disorders	Glycogen storage disease due to glucose-6-phosphatase deficiency type Ia	ORPHA:79258
UMC Groningen		UMCG Center of Expertise for Carbohydrate, Fatty Acid Oxidation and Ketone Bodies Disorders	Glycogen storage disease due to glucose-6-phosphatase deficiency type Ib	ORPHA:79259

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
UMC Groningen		UMCG Center of Expertise for Carbohydrate, Fatty Acid Oxidation and Ketone Bodies Disorders	Glycogen storage disease due to glycogen debranching enzyme deficiency	ORPHA:366
Erasmus MC		Center for Lysosomal and Metabolic Diseases	glycoproteinosis	ORPHA:309279
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Genodermatoses	Gorlin syndrome	ORPHA:377
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
Erasmus MC		Expert Center Rare Growth Disorders	Growth hormone insensitivity syndrome	ORPHA:181393
Erasmus MC		Neuromuscular Center Erasmus MC	Guillain-Barré syndrome	ORPHA:2103
Amsterdam UMC		Amsterdam UMC Expert Center for Inborn Errors of Metabolism	Gyrate atrophy of choroid and retina	ORPHA:414
Erasmus MC		Center of expertise for pregnancy induced diseases	HELLP-syndrome	ORPHA:244242
Amsterdam UMC		Amsterdam UMC Expert Center for Rare coagulation and red blood cell defects	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
Leiden UMC	HagaZiekenhuis	Expert Center for Rare Hemoglobinopathies	Hemoglobinopathy	ORPHA:68364
UMC Utrecht		UMC Utrecht Expertise centre for benign hematology, thrombosis and hemostasis, Van Creveldkliniek	Hemoglobinopathy	ORPHA:68364
UMC Utrecht		UMC Utrecht Expertise centre for benign hematology, thrombosis and hemostasis, Van Creveldkliniek	Hemolytic anemia due to red cell pyruvate kinase deficiency	ORPHA:766
Leiden UMC		Expert Center for Rare Pregnancy-Related Disorders	Hemolytic disease due to fetomaternal alloimmunization	ORPHA:275938
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 Transplantation	Hemophagocytic syndrome	ORPHA:158032
Amsterdam UMC		Amsterdam UMC Expert Center for Rare coagulation and red blood cell defects	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 Disorders	Hemophilia	ORPHA:448
Radboudumc		Radboudumc Center of Expertise for Haemophilia and rare coagulation disorders	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 hemostasis, Van Creveldkliniek	Hemophilia	ORPHA:448
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 A	ORPHA:98878

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
Leiden UMC	HagaZiekenhuis	Expert Center for Hemophilia and Related Disorders LUMC-HagaZiekenhuis	Hemophilia B	ORPHA:98879
Leiden UMC	HagaZiekenhuis	Expert Center for Hemophilia and Related Disorders LUMC-HagaZiekenhuis	Hemophilia B	ORPHA:98879
Erasmus MC		Erasmus MC Liver Center of Expertise	Hepatocellular adenoma	ORPHA:54272
Leiden UMC		Expert Center for Rare Hepatic Disease	Hepatocellular carcinoma	ORPHA:88673
UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bileduct tumors	Hepatocellular carcinoma	ORPHA:88673
UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bileduct tumors	Hepatocellular carcinoma	ORPHA:88673
UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bileduct tumors	Hepatocellular carcinoma	ORPHA:88673
UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bileduct tumors	Hepatocellular carcinoma	ORPHA:88673
UMC Groningen		UMCG Center of Expertise for Amyloidosis	Hereditary amyloidosis	ORPHA:444116
Amsterdam UMC		Amsterdam UMC expertise center for primary immunodeficiencies an bone marrow failure syndromes	Hereditary angioedema	ORPHA:91378
UMC Groningen		UMCG Center of Expertise for Amyloidosis	Hereditary ATTR amyloidosis	ORPHA:271861
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
Leiden UMC		Familial and hereditary breast cancer center	Hereditary breast and ovarian cancer syndrome	ORPHA:145
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
Erasmus MC		Academic Breast and Ovarian Cancer Center	Hereditary Breast Cancer	ORPHA:227535
Leiden UMC		Familial and hereditary breast cancer center	Hereditary breast cancer	ORPHA:227535
UMC Groningen		UMCG Center of Expertise for Familial Breast and Ovarian Cancer	Hereditary breast cancer	ORPHA:227535
NKI-AvL		Expert Center for Hereditary Cancer	Hereditary diffuse gastric cancer	ORPHA:26106
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Inborn Errors of Fructose Metabolism	Hereditary fructose intolerance	ORPHA:469
Erasmus MC		Erasmus MC Oesophageal and Gastric Cancer center of expertise	Hereditary gastric cancer	ORPHA:423776
St. Antonius Ziekenhuis		Center for Pulmonary vascular diseases-HHT	Hereditary Hemorrhagic Telangiectasia	ORPHA:774
NKI-AvL		Expert Center for Hereditary Cancer	Hereditary mixed polyposis syndrome	ORPHA:157794
Amsterdam UMC		Amsterdam UMC expertise center for neuromuscular diseases	Hereditary motor and sensory neuropathy	ORPHA:166
Leiden UMC		Expert Center for Rare Hereditary Bowel Tumors	Hereditary nonpolyposis colon cancer	ORPHA:443909
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Genodermatoses	Hereditary palmoplantar keratoderma	ORPHA:79357

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
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
UMC Utrecht	NKI-AvL	UMC Utrecht Expertise Centre for rare endocrine tumors	Hereditary pheochromocytoma-paraganglioma	ORPHA:29072
Radboudumc		Radboudumc Center of Expertise for Rare and genetic movement disorders	Hereditary spastic paraplegia	ORPHA:685
Radboudumc		Radboudumc Center of Expertise for Hereditary cancer	Hereditary gastric cancer	ORPHA:423776
UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bileduct tumors	High-grade dysplasia in patients with Barrett esophagus	ORPHA:231080
UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bileduct tumors	High-grade dysplasia in patients with Barrett esophagus	ORPHA:231080
UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bileduct tumors	High-grade dysplasia in patients with Barrett esophagus	ORPHA:231080
UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bileduct tumors	High-grade dysplasia in patients with Barrett esophagus	ORPHA:231080
Erasmus MC		Erasmus MC Center of Expertise for Rare Kidney and Urinary Tract Disease	Hinman syndrome	ORPHA:84085
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 intestinal tract	Hirschsprung disease	ORPHA:388
UMC Groningen		UMCG Center of Expertise for Neonatal Gastro-Intestinal Diseases	Hirschsprung disease	ORPHA:388
UMC Utrecht		UMC Utrecht Expertise Centre for congenital esophageal and airway diseases	Hirschsprung Disease	ORPHA:388
UMC Groningen		UMCG Center of Expertise for Rare Haematological Diseases	Hodgkin lymphoma	ORPHA:98293
Amsterdam UMC		Amsterdam UMC Expert Center for Hematological Malignancies	Hodgkin Lymphoma (al erkend onder cluster AL&ML)	ORPHA:98293
Leiden UMC		Expert Center for Genetic Cerebral Small Vessel Disease	HTRA1-related autosomal dominant cerebral small vessel disease	ORPHA:482077
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

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
UMC Utrecht		Sylvia Toth Center for Multi-disciplinary follow up of Lysosomal Storage Disorders, University Medical Center Utrecht	Hurler disease	ORPHA:93473
Leiden UMC		Expert Center for Rare Pregnancy-Related Disorders	Hydrops fetalis	ORPHA:1041
UMC Groningen		UMCG Expertise Center for Movement Disorders Groningen	Hyperekplexia	ORPHA:306773
St. Antonius Ziekenhuis		Interstitial Lung Diseases Center of Excellence	Hypersensitivity pneumonitis	ORPHA:31740
Amsterdam UMC		Amsterdam UMC centre of excellence for rare cardiac diseases	Hypertrophic cardiomyopathy	ORPHA:217569
Erasmus MC		Center of expertise for inherited cardiovascular diseases	Hypertrophic cardiomyopathy	ORPHA:217569
UMC Utrecht		UMC Utrecht Expertise Centre for congenital orofacial and dental anomalies	Hypoglossia/aglossia	ORPHA:156212
UMC Utrecht		Center for Neonatal Neurology	Hyoxic ischemic brain injury	ORPHA:137577
Leiden UMC		Expert Center for Rare Inherited Immunodeficiencies and Stem Cell Transplantation	ICF syndrome	ORPHA:2268
Erasmus MC		Center of rare skin diseases	Ichthyosis	ORPHA:79354
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Genodermatoses	Ichthyosis	ORPHA:79354
Leiden UMC		Expert Center for Rare Bone Marrow Failure	Ideopathic aplastic anemia	ORPHA:88
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Balance Disorders	Idiopathic Bilateral Vestibulopathy	ORPHA:171684
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Gastrointestinal Motility Disorders	Idiopathic gastroparesis	ORPHA:558411
Kempenhaeghe, Nederlandse Vereniging van Ziekenhuizen		Center for Sleep Medicine Kempenhaeghe	Idiopathic Hypersomnia	ORPHA:33208
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
OLVG	Amsterdam UMC	Expert Center for idiopathic interstitial pneumonia	Idiopathic interstitial pneumonia	ORPHA:98300
OLVG	Amsterdam UMC	Expert Center for idiopathic interstitial pneumonia	Idiopathic interstitial pneumonia	ORPHA:98300
Amsterdam UMC		Amsterdam UMC expertise center for rare pediatric kidney and urinary tract diseases	Idiopathic nephrotic syndrome	ORPHA:357502
Erasmus MC		Erasmus MC Center of Expertise for Rare Kidney and Urinary Tract Disease	Idiopathic Nephrotic Syndrome	ORPHA:357502
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
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
Radboudumc	Maastricht UMC+	Radboudumc-Maastricht UMC+ Center of Expertise for Marfan and related disorders	Idiopathic spontaneous coronary artery dissection	ORPHA:458718
Radboudumc	Maastricht UMC+	Radboudumc-Maastricht UMC+ Center of Expertise for Marfan and related disorders	Idiopathic spontaneous coronary artery dissection	ORPHA:458718

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
MUMC+*		Expertise center Cardiogenetics MUMC+	Idiopathic ventricular fibrillation - not Brugada type	ORPHA:228140
Erasmus MC		Center of Expertise for Rare Systemic Immune Disease	IgG4-related disease	ORPHA:284264
Erasmus MC		Center of Expertise for Rare Systemic Immune Disease	IgG4-related pachymeningitis	ORPHA:449427
Amsterdam UMC		Amsterdam UMC Expert Center for immune-mediated and genetic cholestasis syndromes	IgG4-related sclerosing cholangitis	ORPHA:447764
UMC Groningen		UMCG Center of Expertise for Benign Hematology	Immune thrombocytopenia	ORPHA:3002
UMC Utrecht		UMC Utrecht Expertise centre for benign hematology, thrombosis and hemostasis, Van Creveldkliniek	Immune thrombocytopenia	ORPHA:3002
Radboudumc		Radboudumc Center of Expertise for Immunodeficiency and autoinflammation	Immunodeficiency due to a complement cascade protein anomaly	ORPHA:101992
Leiden UMC		Expert Center for Lupus-, Vasculitis- and Complement-mediated Systemic Diseases	Immunoglobulin-mediated membranoproliferative glomerulonephritis	ORPHA:329903
Leiden UMC		Expert Center for Rare Neuromuscular Diseases	Inclusion body myositis	ORPHA:611
Erasmus MC		Erasmus MC Expert Center Endocarditis	Infective endocarditis	ORPHA:570762
Erasmus MC		Erasmus MC center of expertise for inflammatory disorders of the central nervous system	Inflammatory and autoimmune disease with epilepsy	ORPHA:166484
Erasmus MC	LUMC	Center for Congenital bone marrow failure and leukemia predisposition syndromes	Inherited acute myeloid leukemia	ORPHA:319465
Leiden UMC	Erasmus MC	Center for Congenital bone marrow failure and leukemia predisposition syndromes	Inherited acute myeloid leukemia	ORPHA:319465
UMC Groningen		UMCG Center of Expertise for Blistering Diseases	Inherited epidermolysis bullosa	ORPHA:79361
UMC Groningen		UMCG Center of Expertise for Genodermatoses	Inherited ichthyosis	ORPHA:183435
Oogziekenhuis Rotterdam		Rare Eye Disease Center Rotterdam	Inherited retinal disorder	ORPHA:71862
Amsterdam UMC	Leiden UMC	Expertise Center for Hereditary Eye Diseases and Central Serous Chorioretinopathy	Inherited retinal disorder/Retinal dystrophy	ORPHA:71862
Amsterdam UMC	Leiden UMC	Expertise Center for Hereditary Eye Diseases and Central Serous Chorioretinopathy	Inherited retinal disorder/Retinal dystrophy	ORPHA:71862
UMC Utrecht		UMC Utrecht Expertise Centre for uveitis	Intermediate uveitis	ORPHA:279914
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
Radboudumc		Radboudumc Center of Expertise for Congenital malformations of the intestinal tract	Intestinal malformation	ORPHA:97945
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	Intractable diarrhea of infancy	ORPHA:73014
UMC Utrecht		UMC Utrecht Expertise Center for rare GI and hepatic diseases	Intractable diarrhea of infancy	ORPHA:73014

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
Radboudumc		Radboudumc Center of Expertise for Congenital malformations of the intestinal tract	Isolated anorectal malformation	ORPHA:557
UMC Groningen		UMCG Center of Expertise for Congenital Biliary Disorders	Isolated biliary atresia	ORPHA:30391
Radboudumc		Radboudumc Center of Expertise for Hereditary blindness	Isolated chorioretinal dystrophy	ORPHA:519300
Radboudumc		Radboudumc Center of Expertise Sex & Gender	Isolated congenital hypogonadotropic hypogonadism	ORPHA:238666
Erasmus MC		Dutch Craniofacial Center of Expertise	Isolated craniosynostosis	ORPHA:139390
Radboudumc		Radboudumc Center of Expertise for Craniofacial disorders	Isolated craniosynostosis	ORPHA:139390
Radboudumc		Radboudumc Center of Expertise for Pediatric urology	Isolated epispadias	ORPHA:93928
Amsterdam UMC		Amsterdam UMC expert center for cleft, craniofacial and airway disorders	Isolated Pierre Robin syndrome	ORPHA:718
Erasmus MC		Cleft Center of expertise Erasmus MC	Isolated Pierre Robin syndrome	ORPHA:718
Radboudumc		Radboudumc Center of Expertise for Liver cysts	Isolated polycystic liver disease	ORPHA:2924
Erasmus MC		Expert Center spinal disraphism Rotterdam	Isolated spina bifida	ORPHA:823
Leiden UMC		Expert Center for Rare Endocrine Conditions	Isolated Sternocostoclavicular Hyperostosis	ORPHA:178311
UMC Utrecht		UMC Utrecht Expertise Centre for congenital esophageal and airway diseases	Isolated tracheoesophageal fistula	ORPHA:454750
UMC Utrecht		UMC Utrecht Expertise Centre for hereditary and congenital nephrologic and urologic disorders	Joubert syndrome and related disorders	ORPHA:140874
Erasmus MC		Centre of expertise for inflammatory myopathies	Juvenile dermatomyositis	ORPHA:93672
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 autoinflammation	Juvenile idiopathic arthritis	ORPHA:92
UMC Utrecht		UMC Utrecht Expertise Centre for systemic autoimmune diseases and primary immune deficiencies	Juvenile idiopathic arthritis	ORPHA:92
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 primary immune deficiencies	Juvenile idiopathic inflammatory myopathy	ORPHA:329888
UMC Groningen		UMCG Center of Expertise for Systemic and Rheumatological Diseases of Childhood	Juvenile Idiopathic arthritis	ORPHA:92
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Rare Syndromes and Cognitive Disorders	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 disorders	KBG syndrome	ORPHA:2332

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
UMC Utrecht		Utrecht Center for Keratoconus and Corneal Dystrophies	Keratoconus	ORPHA:156071
Erasmus MC		Erasmus MC Liver Center of Expertise	Klatskin tumor	ORPHA:99978
Radboudumc		Radboudumc Center of Expertise for Congenital neurodevelopmental disorders	Kleefstra syndrome	ORPHA:261494
Radboudumc		Radboudumc Center of Expertise for Congenital neurodevelopmental disorders	Koolen-de Vries syndrome	ORPHA:96169
Erasmus MC		Center of Expertise for Rare Systemic Immune Disease	Langerhans cell histiocytosis	ORPHA:389
Amsterdam UMC		Center for congenital nevi	Large congenital melanocytic nevus	ORPHA:626
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
UMC Utrecht		UMC Utrecht Expertise Centre for rare otorhinolaryngological diseases	Larynx anomaly	ORPHA:156249
Oogziekenhuis Rotterdam		Rare Eye Disease Center Rotterdam	Leber hereditary optic neuropathy	ORPHA:104
Erasmus MC		Center of expertise for inherited cardiovascular diseases	Left ventricular noncompaction	ORPHA:54260
Erasmus MC	Leiden UMC	Leprosy Center of Expertise	Leprosy	ORPHA:548
Erasmus MC	Leiden UMC	Leprosy Center of Expertise	Leprosy	ORPHA:548
Amsterdam UMC		Amsterdam UMC Leukodystrophy Center	Leukodystrophies	ORPHA:68356
NKI-AvL	Prinses Maxima Centrum - PMC	Expert centre for Li-Fraumeni syndrome	Li-Fraumeni syndrome	ORPHA:524
NKI-AvL	Prinses Maxima Centrum - PMC	Expert centre for Li-Fraumeni syndrome	Li-Fraumeni syndrome	ORPHA:524
Leiden UMC		Expert Center for Rare Neuromuscular Diseases	Limb Girdle Muscular Dystrophy	ORPHA:263
Erasmus MC		Erasmus MC center of expertise for inflammatory disorders of the central nervous system	Limbic encephalitis	ORPHA:163892
Erasmus MC		Erasmus MC center of expertise for inflammatory disorders of the central nervous system	Limbic encephalitis with NMDA receptor antibodies	ORPHA:217253
Amsterdam UMC		Amsterdam UMC expertise center for rare pediatric rheumatologic diseases	Localized scleroderma	ORPHA:90289
Radboudumc		Radboudumc center for systemic autoimmune diseases	Localized scleroderma	ORPHA:90289
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 disorders	Loeys-Dietz syndrome	ORPHA:60030
Radboudumc	Maastricht UMC+	Radboudumc-Maastricht UMC+ Center of Expertise for Marfan and related disorders	Loeys-Dietz syndrome	ORPHA:60030
Amsterdam UMC		Amsterdam UMC Multidisciplinary Lyme Borreliosis Center	Lyme disease	ORPHA:91546
Amsterdam UMC		Amsterdam UMC Expert Center for Hematological Malignancies	Lymphoid hemopathy	ORPHA:171898
Amsterdam UMC		Amsterdam UMC Expert Center for Hematological Malignancies	Lymphoma	ORPHA:223735
Amsterdam UMC		Amsterdam UMC expert center for hereditary cancer	Lynch syndrome	ORPHA:144

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
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
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
NKI-AvL		Expert Center for Hereditary Cancer	Lynch syndroom	ORPHA:144
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 Developmental Disorders	Malan overgrowth syndrome	ORPHA:420179
Radboudumc		Radboudumc Center for male infertility	Male infertility due to gonadal dysgenesis or sperm disorder	ORPHA:399764
Radboudumc		Radboudumc Center for male infertility	Male infertility due to obstructive azoospermia	ORPHA:98343
Erasmus MC		The ENCORE expertise center for neurodevelopmental disorders	Malformation syndrome with hamartosis	ORPHA:98196
Leiden UMC		Expert Center for Rare Endocrine Conditions	Malformation syndrome with short stature	ORPHA:139021
UMC Groningen*		Expertise Center Gyneco-oncology UMCG	Malignant epithelial tumor of ovary; different types adenocarcinoma	ORPHA:398934
Oogziekenhuis Rotterdam	Erasmus MC	Rotterdam centre rare eye cancer	Malignant melanoma of the mucosa	ORPHA:168999
Oogziekenhuis Rotterdam	Erasmus MC	Rotterdam centre rare eye cancer	Malignant melanoma of the mucosa	ORPHA:168999
Erasmus MC		Center of expertise for lung cancer	Malignant peritoneal mesothelioma	ORPHA:168811
NKI-AvL		Expert centre for rare urological diseases	Malignant tumor of penis	ORPHA:398043
Amsterdam UMC		Amsterdam UMC expert centre for Marfan syndrome and related disorders	Marfan and Marfan-related disorders	ORPHA:284993
UMC Groningen		UMCG Center of Expertise 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
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 disorders	Marfan syndrome	ORPHA:558
Radboudumc	Maastricht UMC+	Radboudumc-Maastricht UMC+ Center of Expertise for Marfan and related disorders	Marfan syndrome	ORPHA:558
UMC Groningen		UMCG Center of Expertise for Marfan Syndrome and Related Disorders	Marfan syndrome	ORPHA:558
Amsterdam UMC		Amsterdam UMC Expert Center for Developmental Disorders	Marshall-Smith syndrome	ORPHA:561
Erasmus MC		Center of expertise for rare mast cell related diseases	Mastocytosis	ORPHA:98292
UMC Groningen		UMCG Center of Expertise for Carbohydrate, Fatty Acid Oxidation and Ketone Bodies Disorders	Medium chain acyl-CoA dehydrogenase deficiency	ORPHA:42
UMC Groningen		UMCG Center of Expertise for Brain and Skull Base Tumors	Medulloblastoma	ORPHA:616
Amsterdam UMC		Melioidosis Expertise Center	Melioidosis	ORPHA:31202

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
Leiden UMC		Expert Center for Rare Inherited Immunodeficiencies and Stem Cell Transplantation	Mendelian susceptibility to mycobacterial diseases	ORPHA:748
UMC Groningen		UMCG Center of Expertise for Brain and Skull Base Tumors	Meningioma	ORPHA:2495
Amsterdam UMC		Amsterdam UMC Expert Center for Developmental Disorders	Menke-Hennekam syndrome	ORPHA:592574
NKI-AvL		Rare Skin Cancer Center	Merkel Cell carcinoma	ORPHA:79140
NKI-AvL*		Expert Centre of rare thoracic tumours	Mesotheliom	ORPHA:50251
Radboudumc		Radboudumc Center of Expertise for Immunodeficiency and autoinflammation	Mevalonate kinase deficiency	ORPHA:309025
Amsterdam UMC		Amsterdam UMC expert center for cleft, craniofacial and airway disorders	Microtia	ORPHA:83463
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 Familial Melanoma	MITF-related melanoma and renal cell carcinoma predisposition syndrome	ORPHA:293822
Radboudumc		Radboudumc Center of Expertise for Inherited metabolic disorders	Mitochondrial disease	ORPHA:68380
UMC Groningen		UMCG Center of Expertise for Defects in Amino Acid and Organic Acid Metabolism	Molybdenum cofactor deficientie type A	ORPHA:308386
UMC Utrecht		UMC Utrecht Expertise Centre for rare and complex epilepsies	Monogenetic disease with epilepsy	ORPHA:166472
UMC Groningen		UMCG Center of Expertise ""Unique"" for Rare Genetic Causes of Neurodevelopmental Disorders	Monosomy 22q13.3 (Phelan-McDermid syndrome)	ORPHA:48652
UMC Utrecht		UMC Utrecht Brain Centre, Neuromuscular Diseases	Motor Neuron Disease	ORPHA:98503
Erasmus MC		Center for Lysosomal and Metabolic Diseases	mucopolysaccharidosis	ORPHA:79213
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 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	NKI-AvL	UMC Utrecht Expertise Centre for rare endocrine tumors	Multiple endocrine neoplasia type 2	ORPHA:653
Amsterdam UMC		Amsterdam UMC Expert Center for Hematological Malignancies	Multiple myeloma	ORPHA:29073
Erasmus MC		Hematologic malignancies center of expertise	Multiple myeloma	ORPHA:29073
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Haematological Malignancies	Multiple myeloma	ORPHA:29073

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
UMC Groningen		UMCG Center of Expertise for Cellular Therapy	Multiple myeloma	ORPHA:29073
UMC Utrecht		UMC Utrecht Expertise Centre for malignant hematology	Multiple myeloma	ORPHA:29073
Leiden UMC		Expert Center for Rare Bone and Soft Tissue Tumors	Multiple osteochondromas	ORPHA:321
OLVG		Center for HME-MO (Hereditary multiple exostoses- Multiple osteochondromas)	Multiple osteochondromas	ORPHA:321
Erasmus MC		Erasmus MC center of expertise for inflammatory disorders of the central nervous system	Multiple sclerosis variant	ORPHA:228145
Radboudumc		Radboudumc Center of Expertise for neuromuscular disease	Muscular channelopathy	ORPHA:71864
UMC Utrecht		UMC Utrecht Brain Centre, Neuromuscular Diseases	Muscular dystrophy	ORPHA:98473
Amsterdam UMC		Amsterdam UMC expert center for hereditary cancer	MUTYH-related attenuated familial adenomatous polyposis	ORPHA:247798
Leiden UMC		Expert Center for Rare Hereditary Bowel Tumors	MUTYH-related attenuated familial adenomatous polyposis	ORPHA:247798
Amsterdam UMC		Amsterdam UMC expertise center for neuromuscular diseases	Myasthenia gravis	ORPHA:589
Amsterdam UMC		Amsterdam UMC Expert Center for Hematological Malignancies	Myelodysplastic syndrome	ORPHA:52688
Erasmus MC	LUMC	Center for Congenital bone marrow failure and leukemia predisposition syndromes	Myelodysplastic syndrome	ORPHA:52688
Leiden UMC	Erasmus MC	Center for Congenital bone marrow failure and leukemia predisposition syndromes	Myelodysplastic syndrome	ORPHA:52688
Amsterdam UMC		Amsterdam UMC Expert Center for Hematological Malignancies	Myeloid hemopathy	ORPHA:171895
Erasmus MC		Hematologic malignancies center of expertise	Myeloid hemopathy	ORPHA:171895
UMC Utrecht		UMC Utrecht Expertise Centre for malignant hematology	Myeloproliferative neoplasm	ORPHA:98274
UMC Groningen		UMCG Expertise Center for Movement Disorders Groningen	Myoclonus-dystonia syndrome	ORPHA:36899
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
Kempenhaeghe,Nederlandse Vereniging van Ziekenhuizen		Center for Sleep Medicine Kempenhaeghe	Narcolepsy Type 1	ORPHA:2073
Kempenhaeghe,Nederlandse Vereniging van Ziekenhuizen		Center for Sleep Medicine Kempenhaeghe	Narcolepsy Type 2	ORPHA:83465
NKI-AvL		Center of rare head and neck tumours	Nasopharyngeal carcinoma	ORPHA:150
UMC Utrecht		Head and Neck Working Group Utrecht	Nasopharyngeal carcinoma	ORPHA:150
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

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
UMC Utrecht		UMC Utrecht Expertise Centre for hereditary and congenital nephrologic and urologic disorders	Nephronophthisis	ORPHA:655
Radboudumc		Radboudumc Center of Expertise for Rare kidney diseases	Nephropathy secondary to a storage or other metabolic disease	ORPHA:93593
Amsterdam UMC		Amsterdam UMC expertise center for rare pediatric kidney and urinary tract diseases	Nephrotic Syndrome without extrarenal manifestations	ORPHA:567564
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
Radboudumc		Radboudumc Center of Expertise for neuromuscular disease	Neuralgic amyotrophy	ORPHA:2901
UMC Groningen		UMCG Expertise Center for Movement Disorders Groningen	Neurodegeneration with brain iron accumulation	ORPHA:385
Amsterdam UMC		Amsterdam UMC, Amsterdam Center for Endocrine and Neuroendocrine Tumors (ACCENT)	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
NKI-AvL	UMC Utrecht	Expert Center of Neuroendocrine carcinomas	Neuroendocrine neoplasm	ORPHA:877
UMC Groningen		UMCG Center of Expertise for Neuroendocrine Tumors and Neuroendocrine Carcinomas	Neuroendocrine neoplasm	ORPHA:877
Erasmus MC		The ENCORE expertise center for neurodevelopmental disorders	Neurofibromatosis type 1	ORPHA:636
Radboudumc	Maastricht UMC+	Radboudumc-Maastricht UMC+ Center of Expertise for Skull base pathology	Neurofibromatosis type 2	ORPHA:637
Radboudumc	Maastricht UMC+	Radboudumc-Maastricht UMC+ Center of Expertise for Skull base pathology	Neurofibromatosis type 2	ORPHA:637
UMC Groningen		UMCG Expertise Center for Movement Disorders Groningen	Neurometabolic disease	ORPHA:68385
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
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
Erasmus MC		Erasmus MC center of expertise for inflammatory disorders of the central nervous system	Neuromyelitis optica spectrum disorder	ORPHA:71211
Erasmus MC		Center for Lysosomal and Metabolic Diseases	neuronal ceroid lipofuscinosis	ORPHA:216
Erasmus MC		Frontotemporal Dementia center of expertise	neuronal intranuclear inclusion disease	ORPHA:2289
UMC Utrecht		UMC Utrecht Expertise Centre for neurovascular malformations and subarachnoid hemorrhage	Neurovascular malformation	ORPHA:102006

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
UMC Utrecht		UMC Utrecht Expertise Centre for malignant hematology	Non Hodgkin Lymphoma	ORPHA:547
Erasmus MC		Expert Center Rare Growth Disorders	Non-acquired isolated growth hormone deficiency	ORPHA:631
UMC Utrecht		UMC Utrecht Brain Centre, Neuromuscular Diseases	Non-dystrophic myopathy	ORPHA:206656
Erasmus MC		Center of Expertise for Rare Systemic Immune Disease	Non-Langerhans cell histiocytosis	ORPHA:157987
UMC Groningen		UMCG Center of Expertise for Germ Cell Tumors	Non-seminomatous germ cell tumor of testis	ORPHA:363494
Leiden UMC		Expert Center for Rare Pregnancy-Related Disorders	Non-syndromic central nervous system malformation	ORPHA:108989
UMC Utrecht		UMC Utrecht Expertise Centre for skeletal malformations & Mobility Clinic	Non-syndromic limb reduction defect	ORPHA:93457
UMC Utrecht		UMC Utrecht Expertise Centre for hereditary and congenital nephrologic and urologic disorders	Non-syndromic renal or urinary tract malformation	ORPHA:93546
Amsterdam UMC		Amsterdam UMC expertise center for rare pediatric kidney and urinary tract diseases	Non-syndromic renal or urinary tract malformation; CAKUT	ORPHA:93546
Leiden UMC		Expert Center for Rare Pregnancy-Related Disorders	Non-syndromic respiratory or mediastinal malformation	ORPHA:108993
Radboudumc		Radboudumc Center of Expertise for Pediatric urology	Non-syndromic urogenital tract malformation	ORPHA:165704
UMC Utrecht		UMC Utrecht Expertise Centre for hereditary and congenital nephrologic and urologic disorders	Non-syndromic urogenital tract malformation of male and female	ORPHA:182124
Amsterdam UMC		Amsterdam UMC expert center for cleft, craniofacial and airway disorders	Oculo-auriculo-vertebral spectrum	ORPHA:141132
Bartiméus, Nederlandse Vereniging van Ziekenhuizen		Bartiméus Diagnostic Center for complex visual disorders	Oculocutaneous or ocular albinism	ORPHA:98706
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
UMC Utrecht		UMC Utrecht Expertise Centre for systemic autoimmune diseases and primary immune deficiencies	Oligoarticular juvenile idiopathic arthritis	ORPHA:85410
Erasmus MC		Centre of expertise for oligodontia	Oligodontia	ORPHA:99798
Radboudumc		Radboudumc Center of Expertise for Congenital disorders of dental development	Oligodontia	ORPHA:99798
Leiden UMC		Expert Center for Rare Bone and Soft Tissue Tumors	Ollier disease	ORPHA:296
Radboudumc		Radboudumc Center of Expertise for Congenital malformations of the intestinal tract	Omphalocele	ORPHA:660
Erasmus MC		Center for Lysosomal and Metabolic Diseases	organic aciduria	ORPHA:289899
UMC Utrecht		UMC Utrecht Expertise Centre for skeletal malformations & Mobility Clinic	Osteochondritis dissecans	ORPHA:2764
Amsterdam UMC		Center for Osteochondral Defects of the Talus	Osteochondritis of tarsal/metatarsal bone	ORPHA:2054
Amsterdam UMC		Amsterdam UMC-Isala Zwolle Osteogenesis Imperfecta Expert Center	Osteogenesis imperfecta	ORPHA:666
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

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
UMC Groningen		UMCG Center of Expertise for Bone and Soft Tissue Tumors	Osteosarcoma	ORPHA:668
Radboudumc		Radboudumc Center of Expertise for Cleft lip & palate and orofacial disorders	Otomandibular dysplasia	ORPHA:155896
UMC Utrecht		UMC Utrecht Expertise Centre for congenital orofacial and dental anomalies	Otomandibular dysplasia	ORPHA:155896
Amsterdam UMC	NKI-AvL	Center Gynaecologic Oncology Amsterdam	Ovarian cancer	ORPHA:213500
Amsterdam UMC	NKI-AvL	Center Gynaecologic Oncology Amsterdam	Ovarian cancer	ORPHA:213500
Leiden UMC		Expert Center for Rare Endocrine Conditions	Overgrowth syndrome	ORPHA:93460
UMC Groningen		UMCG Expertise Center for Movement Disorders Groningen	Pantothenate kinase-associated neurodegeneration	ORPHA:157850
UMC Utrecht		UMC Utrecht Expertise Centre for uveitis	panuveitis	ORPHA:280898
Radboudumc		Radboudumc center for facial palsy	Paralytic facial malformation	ORPHA:156224
Erasmus MC		Erasmus MC center of expertise for inflammatory disorders of the central nervous system	Paraneoplastic neurologic syndrome	ORPHA:36388
UMC Groningen		UMCG Expertise Center for Movement Disorders Groningen	Paroxysmal dyskinesia	ORPHA:1431
Radboudumc		Radboudumc Center of Expertise for Paroxysmal nocturnal hemoglobinuria and related aplastic anaemia	Paroxysmal nocturnal hemoglobinuria	ORPHA:447
Leiden UMC		Expert Center for Lupus-, Vasculitis- and Complement-mediated Systemic Diseases	Pauci-immune glomerulonephritis	ORPHA:93126
UMC Utrecht		Center for Neonatal Neurology	Pediatric arterial ischemic stroke	ORPHA:439175
Erasmus MC		Erasmus MC center of expertise for inflammatory disorders of the central nervous system	Pediatric Multiple Sclerosis	ORPHA:477738
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 primary immune deficiencies	Pediatric systemic lupus erythematosus	ORPHA:93552
UMC Utrecht		UMC Utrecht Expertise Centre for systemic autoimmune diseases and primary immune deficiencies	Periodic fever syndromes	ORPHA:101995
Erasmus MC		Center of expertise for inherited cardiovascular diseases	Peripartum cardiomyopathy	ORPHA:563
Amsterdam UMC		Amsterdam UMC expertise center for neuromuscular diseases	Peripheral neuropathy associated with monoclonal gammopathy	ORPHA:209010
UMC Utrecht		UMC Utrecht Brain Centre, Neuromuscular Diseases	Peripheral neuropathy associated with monoclonal gammopathy	ORPHA:209010
UMC Utrecht		Center for Neonatal Neurology	Periventricular leukomalacia	ORPHA:171676
Amsterdam UMC		Amsterdam UMC Expert Center for Inborn Errors of Metabolism	Peroxisomal disease	ORPHA:68373
Amsterdam UMC		Amsterdam UMC expert center for hereditary cancer	Peutz-Jeghers syndrome	ORPHA:2869
Amsterdam UMC		Amsterdam UMC Expert Center for Inborn Errors of Metabolism	Phenylketonuria	ORPHA:716
UMC Groningen		UMCG Center of Expertise for Adrenal Disorders	Pheochromocytoma-paraganglioma	ORPHA:573163

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
Amsterdam UMC		Amsterdam UMC expert center for cleft, craniofacial and airway disorders	Pierre Robin syndrome associated with a chromosomal anomaly	ORPHA:138047
Amsterdam UMC		Amsterdam UMC Expert Center for Developmental Disorders	Pitt-Hopkins syndrome	ORPHA:2896
UMC Utrecht	NKI-AvL	UMC Utrecht Expertise Centre for rare endocrine tumors	Pituitary adenoma	ORPHA:99408
UMC Utrecht	NKI-AvL	UMC Utrecht Expertise Centre for rare endocrine tumors	Pituitary adenoma	ORPHA:99408
Radboudumc		Radboudumc Center of Expertise for Pituitary disease	Pituitary deficiency	ORPHA:101957
UMC Groningen		UMCG Center of Expertise for Pituitary Disorders	Pituitary deficiency	ORPHA:101957
UMC Groningen		UMCG Center of Expertise for Pituitary Disorders	Pituitary tumour	ORPHA:304055
Leiden UMC		Expert Center for hematopoietic stem cell transplantation and T-cell immunotherapy	Plasma cell tumor	ORPHA:98282
UMC Utrecht		UMC Utrecht Expertise Centre for malignant hematology	Plasma cell tumor	ORPHA:98282
Erasmus MC		Center of expertise for lung cancer	Pleural mesothelioma	ORPHA:50251
UMC Utrecht		UMC Utrecht Expertise Centre for systemic autoimmune diseases and primary immune deficiencies	Polyarticular juvenile idiopathic arthritis	ORPHA:404580
Leiden UMC		Expert Center for Rare Endocrine Conditions	Polyendocrinopathy	ORPHA:101956
Erasmus MC		The ENCORE expertise center for neurodevelopmental disorders	Polymalformative genetic syndrome with increased risk of developing cancer	ORPHA:183422
Amsterdam UMC		Amsterdam UMC Expertise Center for Systemic Autoimmune diseases	Polymyositis	ORPHA:732
Erasmus MC		Center for Lysosomal and Metabolic Diseases	Porphyria	ORPHA:738
Radboudumc		Radboudumc Center of Expertise for Pediatric urology	Posterior hypospadias	ORPHA:95706
Radboudumc		Radboudumc Center of Expertise for Pediatric urology	Posterior urethral valve	ORPHA:93110
UMC Utrecht		UMC Utrecht Expertise Centre for uveitis	posterior uveitis	ORPHA:280892
Erasmus MC		Erasmus MC center of expertise for inflammatory disorders of the central nervous system	Postinfectious encephalitis	ORPHA:98253
Amsterdam UMC		Amsterdam UMC expertise center for neuromuscular diseases	Postpoliomyelitis syndrome	ORPHA:2942
Radboudumc		Radboudumc Center of Expertise for Congenital neurodevelopmental disorders	Prader Willi Syndrome	ORPHA:739
Erasmus MC		Expert Center Prader Willi syndrome	Prader-Willi syndrome	ORPHA:739
Erasmus MC		Expert Center Prader Willi syndrome	Prader-Willi-like syndrome	ORPHA:398073
Erasmus MC		Center of expertise for pregnancy induced diseases	Pre-eclampsia (< 34 wks)	ORPHA:275555
Leiden UMC		Expert Center for Rare Bone Marrow Failure	Primary acquired red cell aplasia	ORPHA:98421
Amsterdam UMC		Amsterdam UMC Expert Center for immune-mediated and genetic cholestasis syndromes	Primary Biliary Cholangitis	ORPHA:186
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
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 mineralization	ORPHA:93447

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
Erasmus MC		Erasmus MC Bone Center	Primary bone dysplasia with disorganized development of skeletal components	ORPHA:93450
Leiden UMC		Expert Center for Rare Endocrine Conditions	Primary bone dysplasia with disorganized development of skeletal components	ORPHA:93450
Erasmus MC		Erasmus MC Bone Center	Primary bone dysplasia with increased bone density	ORPHA:93444
Leiden UMC		Expert Center for Rare Endocrine Conditions	Primary bone dysplasia with increased bone density	ORPHA:93444
UMC Utrecht		UMC Utrecht Expertise Centre for malignant hematology	Primary central nervous system lymphoma	ORPHA:46135
Amsterdam UMC		Amsterdam UMC Expert Center for Cystic Fibrosis and Primary Ciliary Dyskinesia	Primary ciliary dyskinesia	ORPHA:244
Amsterdam UMC		Amsterdam UMC expert center for cleft, craniofacial and airway disorders	Primary condylar hyperplasia	ORPHA:477781
Leiden UMC		Expert Center for Rare Cutaneous Lymphoma	Primary cutaneous lymphoma	ORPHA:542
Amsterdam UMC		Amsterdam UMC expertise center for rare pediatric kidney and urinary tract diseases	Primary Hyperoxaluria	ORPHA:416
Amsterdam UMC		Amsterdam UMC expertise center for primary immunodeficiencies an bone marrow failure syndromes	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 Transplantation	Primary immunodeficiency	ORPHA:101997
Radboudumc		Radboudumc Center of Expertise for Immunodeficiency and autoinflammation	Primary immunodeficiency	ORPHA:101997
UMC Utrecht		UMC Utrecht Expertise Centre for systemic autoimmune diseases and primary immune deficiencies	Primary immunodeficiency	ORPHA:101997
UMC Utrecht		UMC Utrecht Expertise Centre for uveitis	primary intraocular lymphoma	ORPHA:279904
Leiden UMC		Expert Center for Rare Endocrine Conditions	Primary lipodystrophy	ORPHA:90970
UMC Groningen		UMCG Center of Expertise for Amyloidosis	Primary localized amyloidosis	ORPHA:314709
UMC Groningen	Nij Smellinghe	Expertise Centre for Lympho-Vascular Medicine	Primary Lymphedema	ORPHA:77240
UMC Groningen	Nij Smellinghe	Expertise Centre for Lympho-Vascular Medicine	Primary Lymphedema	ORPHA:77240
Amsterdam UMC		Amsterdam UMC Expert Center for Hematological Malignancies	Primary Myelofibrosis	ORPHA:824
Amsterdam UMC		Center for rare movement disorders	Primary orthostatic tremor	ORPHA:238606
Erasmus MC		Frontotemporal Dementia center of expertise	Primary progressive aphasia	ORPHA:95432
Erasmus MC		Frontotemporal Dementia center of expertise	primary progressive apraxia of speech	ORPHA:314566
Amsterdam UMC		Amsterdam UMC Expert Center for immune-mediated and genetic cholestasis syndromes	Primary Sclerosing Cholangitis	ORPHA:171
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
UMC Groningen		UMCG Center of Expertise for Amyloidosis	Primary systemic amyloidosis	ORPHA:314701
Erasmus MC		Frontotemporal Dementia center of expertise	PRKAR1B-related neurodegenerative dementia with intermediate filaments	ORPHA:412066
Amsterdam UMC		Amsterdam UMC Expert Center for immune-mediated and genetic cholestasis syndromes	Progressive familial intrahepatic cholestasis	ORPHA:172
UMC Utrecht		UMC Utrecht Expertise Center for rare GI and hepatic diseases	Progressive Familial Intrahepatic Cholestasis	ORPHA:172
Erasmus MC		Dutch Craniofacial Center of Expertise	Progressive hemifacial atrophy	ORPHA:1214
Leiden UMC		Expert Center for Rare Neuromuscular Diseases	Progressive muscular dystrophy	ORPHA:206644

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
UMC Groningen		UMCG Expertise Center for Movement Disorders Groningen	Progressive myoclonic epilepsy type 6	ORPHA:280620
UMC Utrecht	NKI-AvL	UMC Utrecht Expertise Centre for rare endocrine tumors	Prolactinoma	ORPHA:2965
UMC Utrecht	NKI-AvL	UMC Utrecht Expertise Centre for rare endocrine tumors	Prolactinoma	ORPHA:2965
UMC Utrecht		UMC Utrecht Brain Centre, Neuromuscular Diseases	Proximal spinal muscular atrophy	ORPHA:70
Erasmus MC		Erasmus MC Bone Center	Pseudohypoparathyroidism with Albright hereditary osteodystrophy	ORPHA:457059
UMC Utrecht		Dutch National Expertise Center for Pseudoxanthoma elasticum (DNECP)	Pseudoxanthoma elasticum	ORPHA:758
UMC Utrecht		UMC Utrecht Expertise Centre for systemic autoimmune diseases and primary immune deficiencies	Psoriasis-related juvenile idiopathic arthritis	ORPHA:85436
UMC Groningen		UMCG Expertise Center for Movement Disorders Groningen	Psychogenic movement disorders	ORPHA:71519
Radboudumc		Radboudumc Center of Expertise for Hereditary cancer	PTEN hamartoma tumor syndrome	ORPHA:306498
Amsterdam UMC		Amsterdam UMC center of expertise for Pulmonary Hypertension	Pulmonary Arterial Hypertension	ORPHA:182090
Radboudumc		Radboudumc Center of Expertise for Pulmonary hypertension	Pulmonary arterial hypertension associated with congenital heart disease	ORPHA:275803
Radboudumc		Radboudumc Center of Expertise for Pulmonary hypertension	Pulmonary arterial hypertension associated with connective tissue disease	ORPHA:275798
Amsterdam UMC		Amsterdam UMC center of expertise for Pulmonary Hypertension	Pulmonary hypertension owing to lung disease and/or hypoxia	ORPHA:275837
Radboudumc		Radboudumc Center of Expertise for Pulmonary hypertension	Pulmonary hypertension owing to lung disease and/or hypoxia	ORPHA:275837
Amsterdam UMC		Amsterdam UMC center of expertise for Pulmonary Hypertension	Pulmonary hypertension with unclear multifactorial mechanism	ORPHA:275844
Radboudumc		Radboudumc Center of Expertise for Mycobacterial diseases	Pulmonary non-tuberculous mycobacterial infection	ORPHA:411703
Amsterdam UMC		Amsterdam UMC center of expertise for Pulmonary Hypertension	Pulmonary veno-occlusive disease and/or pulmonary capillary haemangiomatosis	ORPHA:431353
Amsterdam UMC		Amsterdam UMC expertise center for primary immunodeficiencies an bone marrow failure syndromes	Quantitative and/or qualitative congenital phagocyte defect	ORPHA:101985
Leiden UMC		Expert Center for Rare Bone Marrow Failure	Rare acquired aplastic anemia	ORPHA:164823
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 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 subarachnoid hemorrhage	Rare arteriovenous malformation	ORPHA:211266

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
Radboudumc		Radboudumc Center of Expertise for Rare and genetic movement disorders	Rare ataxia	ORPHA:102002
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
Amsterdam UMC	NKI-AvL	Center Gynaecologic Oncology Amsterdam	Rare cancer of cervix uteri	ORPHA:213761
Amsterdam UMC	NKI-AvL	Center Gynaecologic Oncology Amsterdam	Rare cancer of cervix uteri	ORPHA:213761
Amsterdam UMC	NKI-AvL	Center Gynaecologic Oncology Amsterdam	Rare cancer of corpus uteri	ORPHA:213569
Amsterdam UMC	NKI-AvL	Center Gynaecologic Oncology Amsterdam	Rare cancer of corpus uteri	ORPHA:213569
UMC Groningen*		Expertise Center Gyneco-oncology UMCG	Rare cancer of the cervix uteri; incl. squamous cell carcinoma	ORPHA:213761
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 anomalies (HECOVAN)	Rare capillary malformation	ORPHA:211247
UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bileduct tumors	Rare carcinoma of small intestine	ORPHA:423957
UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bileduct tumors	Rare carcinoma of small intestine	ORPHA:423957
UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bileduct tumors	Rare carcinoma of small intestine	ORPHA:423957
UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bileduct tumors	Rare carcinoma of small intestine	ORPHA:423957
Amsterdam UMC		Amsterdam UMC centre of excellence for rare cardiac diseases	Rare cardiac diseases	ORPHA:97929
Amsterdam UMC		Amsterdam UMC centre of excellence for rare cardiac diseases	Rare cardiac rhythm diseases	ORPHA:218436
Amsterdam UMC		Amsterdam UMC centre of excellence for rare cardiac diseases	Rare cardiomyopathy	ORPHA:167848
Erasmus MC		Center of expertise for inherited cardiovascular diseases	Rare cardiomyopathy	ORPHA:167848
UMC Groningen		UMCG Center of Expertise for Cardiogenetics	Rare cardiomyopathy	ORPHA:167848
Oogziekenhuis Rotterdam		Rare Eye Disease Center Rotterdam	Rare choroidal disorder	ORPHA:519309
Radboudumc		Radboudumc Center of Expertise for Haemophilia and rare coagulation disorders	Rare coagulation disorder	ORPHA:98429
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
UMC Groningen		UMCG Center of Expertise for Children and Adults with Congenital Heart Diseases	Rare congenital non-syndromic heart malformation	ORPHA:88991
Amsterdam UMC		Amsterdam UMC expertise center for primary immunodeficiencies an bone marrow failure syndromes	Rare constitutional aplastic anemia	ORPHA:68383
Leiden UMC		Expert Center for Rare Bone Marrow Failure	Rare constitutional aplastic anemia	ORPHA:68383

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
UMC Utrecht		UMC Utrecht Expertise centre for benign hematology, thrombosis and hemostasis, Van Creveldkliniek	Rare constitutional hemolytic anemia due to a red cell membrane anomaly	ORPHA:98364
UMC Utrecht		UMC Utrecht Expertise centre for benign hematology, thrombosis and hemostasis, Van Creveldkliniek	Rare constitutional hemolytic anemia due to an enzyme disorder	ORPHA:98369
Leiden UMC		Expert Center for Rare Ear Diseases	Rare deafness	ORPHA:68361
Radboudumc		Radboudumc Center of Expertise Hearing & Genes	Rare deafness	ORPHA:68361
Leiden UMC		Expert Center for Rare Endocrine Conditions	Rare Diabetes Mellitus	ORPHA:101952
Amsterdam UMC		Amsterdam UMC Expertise Center for rare gastrointestinal tumors	Rare digestive tract tumor	ORPHA:98059
Erasmus MC		Cleft Center of expertise Erasmus MC	Rare disease with (Pierre) Robin syndrome	ORPHA:138044
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Gastrointestinal Motility Disorders	Rare diseases involving intestinal motility	ORPHA:104009
Amsterdam UMC		Amsterdam UMC expertise center for rare pediatric kidney and urinary tract diseases	Rare disorder potentially indicated for kidney transplant	ORPHA:506213
UMC Utrecht		UMC Utrecht Expertise Centre for hereditary and congenital nephrologic and urologic disorders	Rare disorder potentially indicated for kidney transplant	ORPHA:506213
Leiden UMC		Expert Center for Rare Pregnancy-Related Disorders	Rare disorder related with pregnancy, childbirth and puerperium	ORPHA:163637
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
Radboudumc		Radboudumc Center of Expertise for Rare and genetic movement disorders	Rare dystonia	ORPHA:68363
Leiden UMC		Expert Center for Rare Endocrine Conditions	Rare Endocrine Growth Disease	ORPHA:90692
Leiden UMC		Expert Center for Ocular Oncology	Rare eye tumor	ORPHA:101950
MUMC+*		Expertise center Cardiogenetics MUMC+	Rare familial disorder with hypertrophic cardiomyopathy	ORPHA:99739
UMC Groningen		UMCG Center of Expertise for Oesophageal and Gastric Carcinoma	Rare gastroesophageal tumor	ORPHA:180821
UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bileduct tumors	Rare gastroesophageal tumor	ORPHA:180821
UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bileduct tumors	Rare gastroesophageal tumor	ORPHA:180821
UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bileduct tumors	Rare gastroesophageal tumor	ORPHA:180821
UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bileduct tumors	Rare gastroesophageal tumor	ORPHA:180821
UMC Utrecht		UMC Utrecht Expertise Centre for hereditary and congenital nephrologic and urologic disorders	Rare genetic renal disease	ORPHA:98056
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Genodermatoses	Rare genetic skin disease	ORPHA:68346
UMC Utrecht		Center for inherited cardiovascular disease	Rare genetic vascular disease	ORPHA:233655

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
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	Medisch Centrum Haaglanden-Bronovo-Nebo	Expert Center for Rare Head and Neck Tumors	Rare head and neck tumor	ORPHA:290849
Leiden UMC	Medisch Centrum Haaglanden-Bronovo-Nebo	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 tumours	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
Leiden UMC		Expert Center for Rare Types of Headache	Rare headache	ORPHA:98022
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 defect	ORPHA:248315
UMC Utrecht		UMC Utrecht Expertise centre for benign hematology, thrombosis and hemostasis, Van Creveldkliniek	Rare hemorrhagic disorder due to a coagulation factors defect	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 hemostasis, Van Creveldkliniek	Rare hemorrhagic disorder due to a platelet anomaly	ORPHA:248326
Leiden UMC	HagaZiekenhuis	Expert Center for Hemophilia and Related Disorders LUMC-HagaZiekenhuis	Rare hemorrhagic disorder due to an acquired coagulation factor defect	ORPHA:166775
Leiden UMC	HagaZiekenhuis	Expert Center for Hemophilia and Related Disorders LUMC-HagaZiekenhuis	Rare hemorrhagic disorder due to an acquired coagulation factor defect	ORPHA:166775
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 Tumors	Rare hepatic and biliary tract tumor	ORPHA:101943
UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bileduct tumors	Rare hepatic and biliary tract tumor	ORPHA:101943
UMC Utrecht	Diakonessenhuis Utrecht, Meander Medical Centre Amersfoort, St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bileduct tumors	Rare hepatic and biliary tract tumor	ORPHA:101943
UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bileduct tumors	Rare hepatic and biliary tract tumor	ORPHA:101943
UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bileduct tumors	Rare hepatic and biliary tract tumor	ORPHA:101943
Radboudumc		Radboudumc Center of Expertise for Iron disorders	Rare hereditary hemochromatosis	ORPHA:220489
UMC Utrecht		UMC Utrecht Expertise centre for rare genetic dyslipidemia	Rare hyperlipidemia	ORPHA:181422
Leiden UMC		Expert Center for Rare Endocrine Conditions	Rare hypothalamic and pituitary disease	ORPHA:181384

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
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
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
UMC Utrecht	NKI-AvL	UMC Utrecht Expertise Centre for rare endocrine tumors	Rare hypothalamic or pituitary disease	ORPHA:181384
Radboudumc		Radboudumc Center for male infertility	Rare idiopathic male infertility	ORPHA:98345
Amsterdam UMC		Amsterdam UMC Expert Center for Inborn Errors of Metabolism	Rare inborn errors of metabolism	ORPHA:68367
Erasmus MC		Center for Lysosomal and Metabolic Diseases	rare inborn errors of metabolism	ORPHA:68367
Erasmus MC		Expertise center for rare IBD and intractable diarrhea	rare inflammatory bowel disease	ORPHA:104012
Radboudumc		Radboudumc Center of Expertise for Congenital neurodevelopmental disorders	Rare intellectual disability	ORPHA:87277
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 anomalies (HECOVAN)	Rare lymphatic malformation	ORPHA:2415
Erasmus MC		Brain Tumor Center of Expertise	Rare nervous system tumor	ORPHA:98062
Erasmus MC		Erasmus MC center of expertise for inflammatory disorders of the central nervous system	Rare neuroinflammatory or neuroimmunological disease	ORPHA:182064
Erasmus MC		The ENCORE expertise center for neurodevelopmental disorders	Rare nonsyndromic intellectual disability	ORPHA:101685
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
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
Leiden UMC		Expert Center for Rare Endocrine Conditions	Rare parathyroid disease and phosphocalcic metabolism anomaly	ORPHA:68415
Radboudumc		Radboudumc Center of Expertise for Rare and genetic movement disorders	Rare parkinsonian disorders	ORPHA:68402
Erasmus MC		Centre of expertise for Children with Autoimmune Diseases	Rare Pediatric Vasculitis	ORPHA:280369
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
Erasmus MC		The ENCORE expertise center for neurodevelopmental disorders	Rare pervasive developmental disorder	ORPHA:168778
Radboudumc		Radboudumc Center of Expertise for Adrenal diseases	Rare primary hyperaldosteronism	ORPHA:181415

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
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 Hypertension	Rare Pulmonary Hypertension	ORPHA:71198
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 and urologic disorders	Rare renal tubular disease	ORPHA:93603
Radboudumc		Radboudumc Center of Expertise for Hereditary blindness	Rare retinal disorder	ORPHA:519315
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
Leiden UMC	Amsterdam UMC	Expert Center for Congenital Heart Defects (CAHAL Children)	Rare Surgical Cardiac Disease	ORPHA:97965
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 for rare endocrine conditions	Rare thyroid disease	ORPHA:101955
Erasmus MC		Erasmus MC Centre of Expertise for Endocrine Disorders	Rare thyroid disease	ORPHA:101955
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
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Neuro-Oncology	Rare tumor of neuroepithelial tissue	ORPHA:251558
Amsterdam UMC		Amsterdam UMC Expertise Center for rare gastrointestinal tumors	Rare tumor of Pancreas	ORPHA:180824
UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bileduct tumors	Rare tumor of pancreas	ORPHA:180824
UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bileduct tumors	Rare tumor of pancreas	ORPHA:180824

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bile duct tumors	Rare tumor of pancreas	ORPHA:180824
UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and bile duct tumors	Rare tumor of pancreas	ORPHA:180824
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 tumours	Rare tumor of salivary glands	ORPHA:276142
Radboudumc		Radboudumc Center of Expertise for Neuro-oncology	Rare tumor of the neuroepithelial tissue	ORPHA:251558
Prinses Maxima Centrum		Princess Máxima Center for rare pediatric tumors	Rare tumor, pediatric	ORPHA:602659
Amsterdam UMC		Amsterdam UMC Expert Center for brain tumors	Rare tumors of neuroepithelial tissue	ORPHA:251558
UMC Utrecht		Head and Neck Working Group Utrecht	Rare tumors of salivary glands	ORPHA:276142
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 upper tract urothelial cancer	Rare urinary tract tumour	ORPHA:98058
Erasmus MC		Erasmus MC Liver Center of Expertise	Rare vascular liver disease	ORPHA:101938
Radboudumc		Radboudumc Center of Expertise for Hemangiomas and congenital vascular anomalies (HECOVAN)	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	Rare venous malformation	ORPHA:211252
Radboudumc		Radboudumc Center of Expertise for Hemangiomas and congenital vascular anomalies (HECOVAN)	Rare venous malformation	ORPHA:211252
Amsterdam UMC	NKI-AvL	Center Gynaecologic Oncology Amsterdam	Rare vulvovaginal tumor	ORPHA:180312
Amsterdam UMC	NKI-AvL	Center Gynaecologic Oncology Amsterdam	Rare vulvovaginal tumor	ORPHA:180312
UMC Groningen*		Expertise Center Gyneco-oncology UMCG	Rare vulvovaginal tumor; squamous cell carcinoma of vulva	ORPHA:494448
Radboudumc		Radboudumc Center of Expertise for Congenital neurodevelopmental disorders	Rasopathies	ORPHA:536391
Erasmus MC		The ENCORE expertise center for neurodevelopmental disorders	RASopathy	ORPHA:536391
Amsterdam UMC		Amsterdam UMC expert center for cleft, craniofacial and airway disorders	Recurrent Respiratory Papillomatosis	ORPHA:60032
Radboudumc		Radboudumc Center of Expertise for Adult urogenital anomalies	Renal cell carcinoma	ORPHA:217071
Amsterdam UMC		Amsterdam UMC expertise center for rare pediatric kidney and urinary tract diseases	Renal or urinary tract malformation	ORPHA:93545
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 and urologic disorders	Renal or urinary tract malformation	ORPHA:93545

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
Erasmus MC		Center of expertise for inherited cardiovascular diseases	Restrictive cardiomyopathy	ORPHA:217632
Erasmus MC		Center for Genetic Eye Diseases Rotterdam	Retinal dystrophy	ORPHA:71862
Leiden UMC		Expert Center for Genetic Cerebral Small Vessel Disease	Retinal vasculopathy with cerebral leukoencephalopathy and systemic manifestations	ORPHA:247691
Erasmus MC		Center for Genetic Eye Diseases Rotterdam	Retinitis pigmentosa	ORPHA:791
Amsterdam UMC		Amsterdam UMC center of excellence for retinoblastoma	Retinoblastoma	ORPHA:790
Leiden UMC*		Expertise Center Pediatric ophthalmology	Retinopathy of prematurity	ORPHA:90050
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Rare Syndromes and Cognitive Disorders	Rett Syndrome	ORPHA:778
Amsterdam UMC		Amsterdam UMC Expert Center for Inborn Errors of Metabolism	Riboflavin transporter deficiency	ORPHA:97229
Amsterdam UMC		Amsterdam UMC Expert Center for Developmental Disorders	Rubinstein-Taybi syndrome	ORPHA:783
Amsterdam UMC		Amsterdam UMC expertise centre for gastroenterologic diseases	Sacrococcyal teratoma	ORPHA:494421
Radboudumc		Radboudumc Center of Expertise for Congenital malformations of the intestinal tract	Sacrococcygeal teratoma	ORPHA:494421
Amsterdam UMC		Amsterdam UMC Expert Center for Interstitial Lung Disease	Sarcoidosis	ORPHA:797
Erasmus MC		Academic center of excellence for sarcoidosis	Sarcoidosis	ORPHA:797
St. Antonius Ziekenhuis		Interstitial Lung Diseases Center of Excellence	Sarcoidosis	ORPHA:797
Radboudumc		Radboudumc Center of Expertise for Immunodeficiency and autoinflammation	Schnitzler syndrome	ORPHA:37748
Radboudumc		Radboudumc Center of Expertise for Congenital disorders of dental development	Schöpf-Schulz-Passarge syndrome	ORPHA:50944
Radboudumc	Maastricht UMC+	Radboudumc-Maastricht UMC+ Center of Expertise for Skull base pathology	Semicircular canal dehiscence syndrome	ORPHA:420402
Radboudumc	Maastricht UMC+	Radboudumc-Maastricht UMC+ Center of Expertise for Skull base pathology	Semicircular canal dehiscence syndrome	ORPHA:420402
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
Leiden UMC		Expert Center for Rare Inherited Immunodeficiencies and Stem Cell Transplantation	Severe combined immunodeficiency	ORPHA:183660
Amsterdam UMC		Amsterdam UMC TPN & Intestinal Failure Clinic	Short bowel syndrome	ORPHA:104008
Erasmus MC		Pediatric Surgical Centre for Anatomical Congenital Malformations	Short bowel syndrome	ORPHA:104008
Radboudumc		Radboudumc Center of Expertise for Congenital malformations of the intestinal tract	Short bowel syndrome	ORPHA:104008
Erasmus MC		Expert Center Rare Growth Disorders	SHOX-related short stature	ORPHA:314795
Amsterdam UMC		Amsterdam UMC expertise center for primary immunodeficiencies and bone marrow failure syndromes	Shwachman-Diamond syndrome	ORPHA:811
UMC Utrecht		UMC Utrecht Expertise centre for benign hematology, thrombosis and hemostasis, Van Creveldkliniek	Sickle cell anemia	ORPHA:232

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
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
Leiden UMC	HagaZiekenhuis	Expert Center for Rare Hemoglobinopathies	Sickle cell disease and related diseases	ORPHA:275752
Radboudumc		Radboudumc Center of Expertise for Iron disorders	Sideroblastic anemia	ORPHA:1047
UMC Utrecht		UMC Utrecht Expertise centre for benign hematology, thrombosis and hemostasis, Van Creveldkliniek	Sideroblastic anemia	ORPHA:1047
Erasmus MC		Expert Center Rare Growth Disorders	Silver-Russell syndrome	ORPHA:813
Amsterdam UMC		Amsterdam UMC center of expertise for Vascular Malformations	Simple vascular malformation	ORPHA:211243
Radboudumc		Radboudumc Center of Expertise for Congenital neurodevelopmental disorders	SIN3A-related intellectual disability syndrome/Witteveen-Kolk syndrome	ORPHA:500163
Leiden UMC		Expert Center for Rare Bone and Soft Tissue Tumors	Skeletal Ewing sarcoma	ORPHA:319
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
Erasmus MC		Center of expertise for lung cancer	Small cell lung cancer	ORPHA:70573
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Neuromuscular Diseases	Sodium channelopathy-related small fiber neuropathy	ORPHA:306577
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
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
Leiden UMC		Expert Center for Rare Bone and Soft Tissue Tumors	Solitary bone cyst	ORPHA:83468
UMC Utrecht		Head and Neck Working Group Utrecht	Squamous cell carcinoma of head and neck	ORPHA:98061
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Head and Neck Oncology	Squamous cell carcinoma of oral cavity and lip	ORPHA:502369
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Head and Neck Oncology	Squamous cell carcinoma of the larynx	ORPHA:494550
UMC Utrecht		Head and Neck Working Group Utrecht	Squamous cell carcinoma of the oral tongue	ORPHA:98061
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Head and Neck Oncology	Squamous cell carcinoma of the oropharynx	ORPHA:500478
UMC Groningen		UMCG Center of Expertise for Blistering Diseases	Stevens-Johnson syndrome/toxic epidermal necrolysis spectrum	ORPHA:95455
Erasmus MC		Erasmus MC center of expertise for inflammatory disorders of the central nervous system	Stiff person spectrum disorder	ORPHA:3198
Erasmus MC		Erasmus MC center of expertise for inflammatory disorders of the central nervous system	Susac syndrome	ORPHA:838
Leiden UMC		Expert Center for Rare Pregnancy-Related Disorders	Syndrome with a central nervous system malformation as a major feature	ORPHA:108991
Erasmus MC		Dutch Craniofacial Center of Expertise	Syndromic craniosynostosis	ORPHA:139393
Radboudumc		Radboudumc Center of Expertise for Craniofacial disorders	Syndromic craniosynostosis	ORPHA:139393

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
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
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
Radboudumc		Radboudumc center for systemic autoimmune diseases	Systemic sclerosis	ORPHA:90291
UMC Groningen		UMCG Center of Expertise for Systemic Autoimmune Diseases	Systemic sclerosis	ORPHA:90291
UMC Utrecht		UMC Utrecht Expertise Centre for systemic autoimmune diseases and primary immune deficiencies	Systemic-onset juvenile idiopathic arthritis	ORPHA:85414
Erasmus MC		Dutch Craniofacial Center of Expertise	Temporomandibular joint anomaly	ORPHA:210581
UMC Groningen		UMCG Center of Expertise for Germ Cell Tumors	Testicular seminomatous germ cell tumor	ORPHA:842
UMC Utrecht		UMC Utrecht Expertise Centre for diagnosis and treatment of thoracic outlet syndrome	Thoracic outlet syndrome	ORPHA:97330
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Vasculitis and Immune-mediated Kidney Disease	Thrombotic microangiopathy	ORPHA:93573
Radboudumc		Radboudumc Center of Expertise for Rare kidney diseases	Thrombotic microangiopathy	ORPHA:93573
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Rare Respiratory Tumors	Thymic tumor	ORPHA:100100
Erasmus MC		Center of expertise for lung cancer	Thymoma	ORPHA:99867
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 Thyroid carcinomas	Thyroid tumor	ORPHA:100087
UMC Groningen		UMCG Center of Expertise for Thyroid Cancer	Thyroid tumor	ORPHA:100087
UMC Utrecht	NKI-AvL	UMC Utrecht Expertise Centre for rare endocrine tumors	Thyroid tumor	ORPHA:100087
UMC Utrecht	NKI-AvL	UMC Utrecht Expertise Centre for rare endocrine tumors	Thyroid tumor	ORPHA:100087
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
UMC Utrecht		UMC Utrecht Expertise Centre for rare otorhinolaryngological diseases	Tracheal anomaly	ORPHA:156252
Erasmus MC		The ENCORE expertise center for neurodevelopmental disorders	Trichothiodystrophy	ORPHA:33364

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
Radboudumc		Radboudumc Center of Expertise for Mycobacterial diseases	Tuberculosis	ORPHA:3389
UMC Groningen		UMCG Center of Expertise for Tuberculosis Beatrixoord	Tuberculosis	ORPHA:3389
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
Erasmus MC		Erasmus MC Centre of Expertise for Endocrine Disorders	Tumor of endocrine glands	ORPHA:182130
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
Radboudumc		Radboudumc Center of Expertise Sex & Gender	Turner syndrome	ORPHA:881
Leiden UMC		Expert Center for Rare Pregnancy-Related Disorders	Twin to twin transfusion syndrome	ORPHA:95431
UMC Groningen		UMCG Center of Expertise for Defects in Amino Acid and Organic Acid Metabolism	Tyrosinemia type 1	ORPHA:882
Radboudumc		Radboudumc Center of Expertise for Pediatric urology	Urogenital tract malformation	ORPHA:83001
UMC Utrecht		UMC Utrecht Expertise Centre for hereditary and congenital nephrologic and urologic disorders	Urogenital tract malformation	ORPHA:83001
Radboudumc		Radboudumc Center of Expertise Hearing & Genes	Usher syndrome	ORPHA:886
Erasmus MC		Rotterdam Ocular Melanoma Center (ROMC)	Uveal melanoma	ORPHA:39044
Leiden UMC		Expert Center for Ocular Oncology	Uveal melanoma	ORPHA:39044
Oogziekenhuis Rotterdam	Erasmus MC	Rotterdam centre rare eye cancer	Uveal melanoma	ORPHA:39044
Oogziekenhuis Rotterdam	Erasmus MC	Rotterdam centre rare eye cancer	Uveal melanoma	ORPHA:39044
Erasmus MC		Centre of Expertise for Uveitis	Uveitis	ORPHA:98715
Erasmus MC		Center of rare skin diseases	Vascular anomaly or angioma	ORPHA:68419
Radboudumc	Maastricht UMC+	Radboudumc-Maastricht UMC+ Center of Expertise for Marfan and related disorders	Vascular Ehlers-Danlos syndrome	ORPHA:286
Radboudumc	Maastricht UMC+	Radboudumc-Maastricht UMC+ Center of Expertise for Marfan and related disorders	Vascular Ehlers-Danlos syndrome	ORPHA:286
Amsterdam UMC		Amsterdam UMC Expertise Center for vasculitis	Vasculitis	ORPHA:52759
Maastricht UMC+		Maastricht UMC+ Center of Expertise for Vasculitis and Immune-mediated Kidney Disease	Vasculitis	ORPHA:52759
UMC Groningen		UMCG Center of Expertise for Systemic Vasculitis	Vasculitis	ORPHA:52759
Radboudumc	Maastricht UMC+	Radboudumc-Maastricht UMC+ Center of Expertise for Skull base pathology	Vestibular schwannoma	ORPHA:252175
Radboudumc	Maastricht UMC+	Radboudumc-Maastricht UMC+ Center of Expertise for Skull base pathology	Vestibular schwannoma	ORPHA:252175
Leiden UMC		Center for vestibular schwannoma and NF2	Vestibular schwannoma	ORPHA:252175
Leiden UMC		Center for Polyomavirus-associated skin infections and cancer (Acronym PASIC)	Virus-associated trichodysplasia spinulosa, usually known as trichodysplasia spinulosa	ORPHA:228379
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

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
UMC Utrecht	NKI-AvL	UMC Utrecht Expertise Centre for rare endocrine tumors	Von Hippel-Lindau disease	ORPHA:892
Amsterdam UMC		Amsterdam UMC Expert Center for Rare coagulation and red blood cell defects	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
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 Disorders	Von Willebrand disease	ORPHA:903
Radboudumc		Radboudumc Center of Expertise for Haemophilia and rare coagulation disorders	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 hemostasis, Van Creveldkliniek	Von Willebrand disease	ORPHA:903
Radboudumc*		Radboud Centre for vulvar and cervix cancer and Dutch Mole Registry	Vulvar intraepithelial neoplasia; rare vulvar cancers and VIN	ORPHA:137583
UMC Utrecht		UMC Utrecht Expertise Centre for malignant hematology	Waldenström macroglobulinemia	ORPHA:33226
Amsterdam UMC		Amsterdam UMC Expert Center for Hematological Malignancies	Waldenstrom macroglobulinemia	ORPHA:33226
UMC Groningen		UMCG Center of Expertise for Amyloidosis	Wild type ATTR amyloidosis	ORPHA:330001
UMC Utrecht		UMC Utrecht Expertise Center for rare GI and hepatic diseases	Wilson disease	ORPHA:905
Erasmus MC		The ENCORE expertise center for neurodevelopmental disorders	Xeroderma Pigmentosum	ORPHA:910
Leiden UMC		Expert Center for Rare Inherited Immunodeficiencies and Stem Cell Transplantation	X-linked agammaglobulinemia	ORPHA:47
UMC Groningen		UMCG Center of Expertise for Hypophosphatemic Rickets	X-linked hypophosphatemia	ORPHA:89936
Amsterdam UMC		Amsterdam UMC expert center in Rare Bone Disease, including FOP, hereditary OP, FD and Camurati Enge	X-linked osteoporosis with fractures	ORPHA:391330