

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

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
NKI-AvL, Nederlandse Vereniging van Ziekenhuizen		Expert Center for Hereditary Cancer	Attenuated Familial adenomatous polyposis	ORPHA:220460
UMC Utrecht		UMC Utrecht Brain Centre, Neuromuscular Diseases	ATTRV30M amyloidosis	ORPHA:85447
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

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
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
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 ☒
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

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UMC Utrecht	Diakonessenhuis Utrecht,Meander Medical Centre Amersfoort,St. Antonius Ziekenhuis	RAKU/Oncomid Expertise Centre for stomach, esophageal, pancreas, liver and biliary 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 biliary 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 biliary 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 biliary 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 biliary 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 biliary 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 biliary 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

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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 metameris syndrome	ORPHA:141189
CWZ Nijmegen		Center for Cerebrotendinous xanthomatosis	Cerebrotendinous xanthomatosis	ORPHA:909
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 for Skull base pathology	Chordoma	ORPHA:178
Radboudumc	Maastricht UMC+	Radboudumc-Maastricht UMC+ Center of Expertise for 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

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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
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
Nederlandse Vereniging van Ziekenhuizen, 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

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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
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

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
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
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
UMC Utrecht		UMC Utrecht Expertise Centre for soft tissue tumors (OncoMid)	Desmoid tumor	ORPHA:873
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

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
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
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
Nederlandse Vereniging van Ziekenhuizen, 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

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
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	Extragonadal germ cell tumor	ORPHA:363579
UMC Utrecht	Prinses Maxima Centrum - PMC	UMC Utrecht Expertise Centre for testicular and extragonadal germ cell tumors	Extragonadal 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
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, Nederlandse Vereniging van Ziekenhuizen		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

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
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
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, Nederlandse Vereniging van Ziekenhuizen**		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 bile duct tumors	Gastrointestinal stromal tumor	ORPHA:44890

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	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 bile duct 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 bile duct 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	Geattenuerde 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
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

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
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
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

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
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
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

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
NKI-AvL, Nederlandse Vereniging van Ziekenhuizen		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, Nederlandse Vereniging van Ziekenhuizen		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, Nederlandse Vereniging van Ziekenhuizen		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
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 biliary 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 biliary 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 biliary tumors	High-grade dysplasia in patients with Barrett esophagus	ORPHA:231080

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	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
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	Hypoxic 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

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
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
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

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
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
Nederlandse Vereniging van Ziekenhuizen, 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
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

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
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
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

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
Nederlandse Vereniging van Ziekenhuizen, 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
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, Nederlandse Vereniging van Ziekenhuizen		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

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
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, Nederlandse Vereniging van Ziekenhuizen		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
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	Mesotheloom	ORPHA:50251
Radboudumc		Radboudumc Center of Expertise for Immunodeficiency and autoinflammation	Mevalonate kinase deficiency	ORPHA:309025

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
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
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

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
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,Nederlandse Vereniging van Ziekenhuizen		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
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

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
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
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

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
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
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

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
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:47738
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
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

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
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
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

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
Amsterdam UMC		Amsterdam UMC expert center for cleft, craniofacial and airway disorders	Primary condylar hyperplasia	ORPHA:47781
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
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

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
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 and 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
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

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
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 bile duct 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 bile duct 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 bile duct 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 bile duct 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
Nederlandse Vereniging van Ziekenhuizen, 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 and 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
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

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
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
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

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
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
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

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
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, Nederlandse Vereniging van Ziekenhuizen		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
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

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
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
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
Amsterdam UMC		Amsterdam UMC Expertise center for Head and Neck tumors	Rare tumor of salivary glands	ORPHA:276142
NKI-AvL, Nederlandse Vereniging van Ziekenhuizen		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
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

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
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, Nederlandse Vereniging van Ziekenhuizen		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, Nederlandse Vereniging van Ziekenhuizen**		Sarcoma Expertise Centre Amsterdam	Soft tissue sarcoma	ORPHA:3394
UMC Groningen		UMCG Center of Expertise for Bone and Soft Tissue Tumors	Soft tissue sarcoma	ORPHA:3394
UMC Utrecht		UMC Utrecht Expertise Centre for soft tissue tumors (OncoMid)	soft tissue sarcoma	ORPHA:3394
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

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
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
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

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
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
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, Nederlandse Vereniging van Ziekenhuizen		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

Ziekenhuis	Partner Organisatie(s)	Naam EC (EN)	Aandoening	Orphacode
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
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