

Nr EC	Aandoening	Orphacode	Patiëntenorganisatie	Vragenlijst ingediend?	P - PNR
G-24-12	ABeta amyloidosis, Dutch type	ORPHA:100006	Vereniging HCHWA-D	Nee	P 14
G-8-7	Tubular duplication of the esophagus	ORPHA:100048	Vereniging voor Ouderen en Kinderen met Slokdarmafsluiting (VOKS)	Ja	P 124
G-17-10	Neurogenic thoracic outlet syndrome	ORPHA:100073	RSI-vereniging	Nee	P 305
G-11-43	Laryngeal neuroendocrine tumor	ORPHA:100083	St NET-Groep	Ja	P 62
G-11-43	Middle ear neuroendocrine tumor	ORPHA:100084	St NET-Groep	Ja	P 62
G-11-1	Thyroid tumor	ORPHA:100087	Schildklier Organisatie NL (SON)	Ja	P 60
G-11-13	Thyroid tumor	ORPHA:100087	Schildklier Organisatie NL (SON)	Ja	P 60
G-11-35	Thyroid Tumor	ORPHA:100087	Schildklier Organisatie NL (SON)	Ja	P 60
G-11-13	Thyroid carcinoma	ORPHA:100088	Schildklier Organisatie NL (SON)	Ja	P 60
G-11-35	Thyroid carcinoma	ORPHA:100088	Schildklier Organisatie NL (SON)	Ja	P 60
G-3-11	Thyroid carcinoma	ORPHA:100088	Schildklier Organisatie NL (SON)	Ja	P 60
G-3-17	Thyroid carcinoma	ORPHA:100088	Schildklier Organisatie NL (SON)	Ja	P 60
G-3-13	Adrenal/paraganglial tumor	ORPHA:100091	Nlse Vereniging voor patiënten met Paragangliomen (NVPG)	Ja	P 29
G-3-13	Adrenal/paraganglial tumor	ORPHA:100091	Bijniervereniging (NVACP)	Nee	P 64
G-3-2	Adrenal/paraganglial tumor	ORPHA:100091	Nlse Vereniging voor Patiënten met Paragangliomen (NVPG)	Ja	P 29
G-3-2	Adrenal/paraganglial tumor	ORPHA:100091	Bijniervereniging (NVACP)	Nee	P 64
G-11-29	Gastroenteropancreatic neuroendocrine neoplasm	ORPHA:100092	St NET-Groep	Ja	P 62
G-11-27	Thymic tumor	ORPHA:100100	Longkankervereniging	Ja	P 204
G-11-39	Thymic tumor	ORPHA:100100	Longkankervereniging	Ja	P 204
G-17-14	Rare non-syndromic intellectual disability	ORPHA:101685	EMB NL	Nee	P 285
G-17-14	Rare non-syndromic intellectual disability	ORPHA:101685	St Complex Care United	Nee	P 306
G-17-5	Rare non-syndromic intellectual disability	ORPHA:101685	EMB NL	Nee	P 285
G-17-5	Rare non-syndromic intellectual disability	ORPHA:101685	St Complex Care United	Nee	P 306
G-17-5	Rare non-syndromic intellectual disability	ORPHA:101685	St Grin Syndroom	Ja	P 313
G-16-3	Genetic cardiac rhythm disease	ORPHA:101934	Harteraad	Ja	P 58
G-16-3	Genetic cardiac rhythm disease	ORPHA:101934	St ICD dragers NL (STIN)	Nee	P 206
G-16-7	Genetic cardiac rhythm disease	ORPHA:101934	Harteraad	Ja	P 58
G-16-7	Genetic cardiac rhythm disease	ORPHA:101934	St ICD dragers NL (STIN)	Nee	P 206
G-7-7	Rare pancreatic disease	ORPHA:101937	Alvleeskliervereniging (AVKV)	Nee	P 87
G-20-4	Rare vascular liver disease	ORPHA:101938	NLse Leverpatiënten Vereniging (NLV)	Ja	P 19
G-11-22	Rare hepatic and biliary tract tumor	ORPHA:101943	NLse Leverpatiënten Vereniging (NLV)	Ja	P 19
G-11-31	Rare hepatic and biliary tract tumor	ORPHA:101943	NLse Leverpatiënten Vereniging (NLV)	Ja	P 19
G-20-4	Rare hepatic and biliary tract tumor	ORPHA:101943	NLse Leverpatiënten Vereniging (NLV)	Ja	P 19
G-8-14	Rare pulmonary disease	ORPHA:101944	Zonder patiëntenorganisatie	Nvt	P nvt
G-11-47	Rare eye tumor	ORPHA:101950	NFK-Patiëntenplatform zeldzame kankers	Ja	P 18
G-3-17	Rare Diabetes Mellitus	ORPHA:101952	Diabetes Vereniging NL (DVN)	Nee	P 103
G-18-12	Rare dyslipidemia	ORPHA:101953	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Nee	P 56
G-18-12	Rare dyslipidemia	ORPHA:101953	Harteraad	Nee	P 58
G-18-2	Rare dyslipidemia	ORPHA:101953	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-18-2	Rare dyslipidemia	ORPHA:101953	Harteraad	Nee	P 58

G-18-5	Rare dyslipidemia	ORPHA:101953	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Nee	P 56
G-18-5	Rare dyslipidemia	ORPHA:101953	Harteraad	Ja	P 58
G-3-17	Rare adrenal disease	ORPHA:101954	Nlse Vereniging voor Patiënten met Paragangliomen (NVPG)	Ja	P 29
G-3-17	Rare adrenal disease	ORPHA:101954	Bijniervereniging (NVACP)	Nee	P 64
G-3-4	Rare adrenal disease	ORPHA:101954	Nlse Vereniging voor Patiënten met Paragangliomen (NVPG)	Ja	P 29
G-3-4	Rare adrenal disease	ORPHA:101954	Bijniervereniging (NVACP)	Nee	P 64
G-3-9	Rare adrenal disease	ORPHA:101954	Nlse Vereniging voor Patiënten met Paragangliomen (NVPG)	Ja	P 29
G-3-9	Rare adrenal disease	ORPHA:101954	Bijniervereniging (NVACP)	Nee	P 64
G-3-4	Rare thyroid disease	ORPHA:101955	Schildklier Organisatie NL (SON)	Ja	P 60
G-3-9	Rare thyroid disease	ORPHA:101955	Schildklier Organisatie NL (SON)	Ja	P 60
G-3-17	Polyendocrinopathy	ORPHA:101956	Nlse Vereniging voor Patiënten met Paragangliomen (NVPG)	Ja	P 29
G-3-17	Polyendocrinopathy	ORPHA:101956	Belangenvereniging Von Hippel-Lindau	Nee	P 66
G-3-1	Pituitary deficiency	ORPHA:101957	NLse Hypofyse St (NHS)	Ja	P 65
G-3-6	Pituitary deficiency	ORPHA:101957	NLse Hypofyse St (NHS)	Ja	P 65
G-3-2	Primary adrenal insufficiency	ORPHA:101958	Bijniervereniging (NVACP)	Nee	P 64
G-22-12	Quantitative and/or qualitative congenital phagocyte defect	ORPHA:101985	St voor Afweerstoornissen (SAS)	Ja	P 72
G-22-12	Quantitative and/or qualitative congenital phagocyte defect	ORPHA:101985	Shwachman Syndroom Support Holland (SSSH)	Nee	P 76
G-12-11	Constitutional neutropenia	ORPHA:101987	St voor Afweerstoornissen (SAS)	Ja	P 72
G-12-11	Constitutional neutropenia	ORPHA:101987	St Hematon	Ja	P 81
G-22-1	Immunodeficiency due to a complement cascade protein anomaly	ORPHA:101992	St voor Afweerstoornissen (SAS)	Ja	P 72
G-22-11	Periodic fever syndromes	ORPHA:101995	St KAISZ	Ja	P 135
G-22-1	Primary immunodeficiency	ORPHA:101997	St voor Afweerstoornissen (SAS)	Ja	P 72
G-22-11	Primary immunodeficiency	ORPHA:101997	St voor Afweerstoornissen (SAS)	Ja	P 72
G-22-12	Primary immunodeficiency	ORPHA:101997	St voor Afweerstoornissen (SAS)	Ja	P 72
G-22-13	Primary immunodeficiency	ORPHA:101997	St voor Afweerstoornissen (SAS)	Ja	P 72
G-22-8	Primary Immunodeficiency	ORPHA:101997	St voor Afweerstoornissen (SAS)	Ja	P 72
G-4-1	Rare epilepsy	ORPHA:101998	Epilepsiefonds	Nee	P 7
G-9-1	Rare ataxia	ORPHA:102002	ADCA/Ataxie Vereniging NL	Nee	P 1
G-9-1	Rare ataxia	ORPHA:102002	Spierziekten NL	Ja	P 43
G-9-6	Rare ataxia	ORPHA:102002	ADCA/Ataxie Vereniging NL	Nee	P 1
G-9-6	Rare ataxia	ORPHA:102002	Spierziekten NL	Ja	P 43
G-24-7	Neurovascular malformation	ORPHA:102006	Hersenletsel.nl	Nee	P 91
G-24-7	Neurovascular malformation	ORPHA:102006	Hersenaneurysma Patiëntenplatform (HPP)	Nee	P 315
G-24-9	Neurovascular malformation	ORPHA:102006	Hersenletsel.nl	Nee	P 91
G-24-9	Neurovascular malformation	ORPHA:102006	Hersenaneurysma Patiëntenplatform (HPP)	Nee	P 315
G-25-6	Rickettsial disease	ORPHA:102021	Zonder patiëntenorganisatie	Nvt	P nvt
G-17-14	Multiple congenital anomalies/dysmorphic syndrome-intellectual disability	ORPHA:102283	Zeldsamen	Ja	P 290
G-17-14	Multiple congenital anomalies/dysmorphic syndrome-variable intellectual disability	ORPHA:102284	Zeldsamen	Ja	P 290
G-17-14	Multiple congenital anomalies/dysmorphic syndrome without intellectual disability	ORPHA:102285	EMB NL	Nee	P 285
G-17-14	Multiple congenital anomalies/dysmorphic syndrome without intellectual disability	ORPHA:102285	St Complex Care United	Nee	P 306
G-17-11	Rare syndromic intellectual disability	ORPHA:102369	St Pitt Hopkins Syndroom	Ja	P 145
G-17-11	Rare syndromic intellectual disability	ORPHA:102369	Zeldsamen	Nee	P 290

G-17-5	Rare syndromic intellectual disability	ORPHA:102369	EMB NL	Nee	P 285
G-17-5	Rare syndromic intellectual disability	ORPHA:102369	Zeldsamen	Ja	P 290
G-17-5	Rare syndromic intellectual disability	ORPHA:102369	St Complex Care United	Nee	P 306
G-14-2	Arthrogryposis multiplex congenita	ORPHA:1037	Handvereniging	Nee	P 13
G-14-2	Arthrogryposis multiplex congenita	ORPHA:1037	Spierziekten NL	Ja	P 43
G-20-6	Autoimmune pancreatitis	ORPHA:103919	Alvleeskliervereniging (AVKV)	Nee	P 87
G-6-4	Leber hereditary optic neuropathy	ORPHA:104	Belangenvereniging LOA/LHON	Ja	P 274
G-7-1	Short bowel syndrome	ORPHA:104008	Crohn & Colitis NL	Nee	P 119
G-7-4	Short bowel syndrome	ORPHA:104008	Crohn & Colitis NL	Ja	P 119
G-7-6	Short bowel Syndrome	ORPHA:104008	Crohn & Colitis NL	Ja	P 119
G-7-3	Rare disease involving intestinal motility	ORPHA:104009	Vereniging Ziekte van Hirschsprung	Ja	P 123
G-7-9	Rare disease involving intestinal motility	ORPHA:104009	Vereniging Ziekte van Hirschsprung	Ja	P 123
G-15-1	Intestinal polyposis syndrome	ORPHA:104010	St Lynch Polyposis	Ja	P 93
G-15-2	Intestinal polyposis syndrome	ORPHA:104010	St Lynch Polyposis	Ja	P 93
G-15-4	Intestinal polyposis syndrome	ORPHA:104010	St Lynch Polyposis	Ja	P 93
G-15-7	Intestinal polyposis syndrome	ORPHA:104010	St Lynch Polyposis	Ja	P 93
G-7-3	Rare inflammatory bowel disease	ORPHA:104012	Crohn & Colitis NL	Ja	P 119
G-7-5	Rare inflammatory bowel disease	ORPHA:104012	Crohn & Colitis NL	Ja	P 119
G-11-23	Adenocarcinoma of the small intestine	ORPHA:104075	St Darmkanker	Nee	P 304
G-7-9	Myopathic intestinal pseudoobstruction	ORPHA:104077	Vereniging Ziekte van Hirschsprung	Ja	P 123
G-7-9	Unclassified intestinal pseudoobstruction	ORPHA:104078	Vereniging Ziekte van Hirschsprung	Ja	P 123
G-26-6	Hydrops fetalis	ORPHA:1041	OSCAR Nederland	Ja	P 73
G-26-6	Hydrops fetalis	ORPHA:1041	Care4Neo	Ja	P 114
G-12-11	Sideroblastic anemia	ORPHA:1047	St Zeldzame Bloedziekten	Nee	P 75
G-12-2	Sideroblastic anemia	ORPHA:1047	St Zeldzame Bloedziekten	Nee	P 75
G-7-6	Non-syndromic intestinal malformation	ORPHA:108967	Maag Lever Darm St	Nee	P 105
G-26-6	Non-syndromic central nervous system malformation	ORPHA:108989	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Nee	P 56
G-26-6	Non-syndromic central nervous system malformation	ORPHA:108989	Syringomyelie Patiënten Vereniging (SPV)	Nee	P 177
G-26-6	Non-syndromic central nervous system malformation	ORPHA:108989	CP NL	Nee	P 284
G-26-6	Non-syndromic central nervous system malformation	ORPHA:108989	EMB NL	Nee	P 285
G-26-6	Non-syndromic central nervous system malformation	ORPHA:108989	SBH NL	Nee	P 286
G-26-6	Syndrome with a central nervous system malformation as a major feature	ORPHA:108991	Care4Neo	Ja	P 114
G-26-6	Syndrome with a central nervous system malformation as a major feature	ORPHA:108991	CP NL	Nee	P 284
G-26-6	Syndrome with a central nervous system malformation as a major feature	ORPHA:108991	EMB NL	Nee	P 285
G-26-6	Syndrome with a central nervous system malformation as a major feature	ORPHA:108991	SBH NL	Nee	P 286
G-26-6	Non-syndromic respiratory or mediastinal malformation	ORPHA:108993	Care4Neo	Ja	P 114
G-0-1	Rare disorder due to toxic effects	ORPHA:108999	St OPS	Ja	P 220
G-17-2	Non-syndromic limb malformation	ORPHA:109011	Handvereniging	Nee	P 13
G-13-3	Bardet-Biedl syndrome	ORPHA:110	Bardet Biedl syndroom St	Nee	P 273
G-2-8	Aplasia cutis congenita	ORPHA:1114	LaPosa	Ja	P 17
G-2-13	Beckwith Wiedemann syndrome	ORPHA:116	LaPosa	Ja	P 17
G-25-2	Aspergillosis	ORPHA:1163	St voor Afweerstoornissen (SAS)	Ja	P 72

G-25-2	Aspergillosis	ORPHA:1163	Huid NL	Ja	P 161
G-25-2	Allergic bronchopulmonary aspergillosis	ORPHA:1164	St voor Afweerstoornissen (SAS)	Ja	P 72
G-21-5	Behcet disease	ORPHA:117	Vasculitits St	Ja	P 51
G-21-5	Behcet disease	ORPHA:117	St KAISZ	Nee	P 135
G-9-9	Autosomal recessive cerebellar ataxia	ORPHA:1172	ADCA/Ataxie Vereniging NL	Nee	P 1
G-9-9	Autosomal recessive cerebellar ataxia	ORPHA:1172	Spierziekten NL	Ja	P 43
G-7-10	Rare intestinal disease	ORPHA:117569	St Lynch Polyposis	Ja	P 93
G-7-10	Rare intestinal disease	ORPHA:117569	Crohn & Colitis NL	Nee	P 119
G-7-10	Rare intestinal disease	ORPHA:117569	Vereniging Ziekte van Hirschsprung	Ja	P 123
G-7-11	Esophageal atresia	ORPHA:1199	Vereniging voor Ouderen en Kinderen met Slokdarmafsluiting (VOKS)	Ja	P 124
G-7-2	Esophageal atresia	ORPHA:1199	Vereniging voor Ouderen en Kinderen met Slokdarmafsluiting (VOKS)	Ja	P 124
G-7-6	Esophageal atresia	ORPHA:1199	Vereniging voor Ouderen en Kinderen met Slokdarmafsluiting (VOKS)	Ja	P 124
G-2-8	Progressive hemifacial atrophy	ORPHA:1214	LaPosa	Ja	P 17
G-2-8	Progressive hemifacial atrophy	ORPHA:1214	HEVAS	Nee	P 131
G-2-8	Progressive hemifacial atrophy	ORPHA:1214	St Eigen Gezicht	Nee	P 247
G-10-7	Birt-Hogg-Dubé syndrome	ORPHA:122	Zonder patiëntenorganisatie	Nvt	P nvt
G-15-2	Birt-Hogg-Dubé syndrome	ORPHA:122	Zonder patiëntenorganisatie	Nvt	P nvt
G-12-11	Blackfan-Diamond anemia	ORPHA:124	St Zeldzame Bloedziekten - BDA Contactgroep	Nee	P 75
G-12-11	Blackfan-Diamond anemia	ORPHA:124	Vereniging Kinderkanker NL	Nee	P 82
G-12-26	Blackfan-Diamond anemia	ORPHA:124	St Zeldzame Bloedziekten - BDA Contactgroep	Nee	P 75
G-12-26	Blackfan-Diamond anemia	ORPHA:124	Vereniging Kinderkanker NL	Nee	P 82
G-25-11	Schistosomiasis	ORPHA:1247	Zonder patiëntenorganisatie	Nvt	P nvt
G-25-6	Schistosomiasis	ORPHA:1247	Zonder patiëntenorganisatie	Nvt	P nvt
G-16-8	Brugada syndrome	ORPHA:130	Harteraad	Ja	P 58
G-16-8	Brugada syndrome	ORPHA:130	Patiëntenvereniging Aangeboren Hartafwijkingen	Nee	P 127
G-1-2	Camurati-Engelmann disease	ORPHA:1328	FOP St NL	Ja	P 162
G-25-2	Chronic mucocutaneous candidiasis	ORPHA:1334	St voor Afweerstoornissen (SAS)	Ja	P 72
G-25-2	Chronic mucocutaneous candidiasis	ORPHA:1334	Huid NL	Ja	P 161
G-24-12	Cerebral autosomal dominant arteriopathy-subcortical infarcts-leukoencephalopathy	ORPHA:136	Alzheimer NL	Ja	P 2
G-18-1	Congenital disorder of glycosylation	ORPHA:137	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-9-3	Neonatal hypoxic and ischemic brain injury	ORPHA:137577	Hersenletsel.nl	Nee	P 91
G-11-32	Vulvar intraepithelial neoplasia	ORPHA:137583	St Olijf	Nee	P 88
G-11-48	Vulvar intraepithelial neoplasia	ORPHA:137583	St Olijf	Nee	P 88
G-2-11	Choanal atresia	ORPHA:137914	Zonder patiëntenorganisatie	Nvt	P nvt
G-17-4	CHARGE syndrome	ORPHA:138	Zeldsamen	Nee	P 290
G-2-2	Rare disease with Pierre Robin Syndrome	ORPHA:138044	St Pierre Robin Europe	Nee	P 279
G-2-2	Rare disease with Pierre Robin Syndrome	ORPHA:138044	Schisis NL	Nee	P 287
G-2-7	Rare disease with Pierre Robin Syndrome	ORPHA:138044	St Pierre Robin Europe	Nee	P 279
G-2-7	Rare disease with Pierre Robin Syndrome	ORPHA:138044	Schisis NL	Nee	P 287
G-2-13	Pierre Robin syndrome associated with a chromosomal anomaly	ORPHA:138047	St Pierre Robin Europe	Nee	P 279
G-3-17	Malformation syndrome with short stature	ORPHA:139021	Belangenvereniging van Kleine Mensen (BVKM)	Nee	P 4
G-3-17	Malformation syndrome with short stature	ORPHA:139021	Nlse hypofyse St (NHS)	Ja	P 65

G-2-8	Branchial arch or oral-acral syndrome	ORPHA:139036	LaPosa	Ja	P 17
G-2-4	Isolated craniosynostosis	ORPHA:139390	LaPosa	Ja	P 17
G-2-8	Isolated craniosynostosis	ORPHA:139390	LaPosa	Ja	P 17
G-2-4	Syndromic craniosynostosis	ORPHA:139393	LaPosa	Ja	P 17
G-2-8	Syndromic craniosynostosis	ORPHA:139393	LaPosa	Ja	P 17
G-13-3	Joubert syndrome and related disorders	ORPHA:140874	EMB NL	Nee	P 285
G-25-11	Severe acute respiratory syndrome	ORPHA:140896	Zonder patiëntenorganisatie	Nvt	P nvt
G-2-11	Nasolacrimal duct cyst	ORPHA:141083	Zonder patiëntenorganisatie	Nvt	P nvt
G-2-11	Nasal dermoid cyste	ORPHA:141103	Zonder patiëntenorganisatie	Nvt	P nvt
G-2-11	Nasal encephalocele	ORPHA:141118	LaPosa	Ja	P 17
G-2-11	Congenital subglottic stenosis	ORPHA:141121	Zonder patiëntenorganisatie	Nvt	P nvt
G-2-13	Oculo-auriculo-vertebral spectrum	ORPHA:141132	LaPosa	Ja	P 17
G-2-2	Oculo-auriculo-vertebral spectrum	ORPHA:141132	LaPosa	Ja	P 17
G-24-2	Cerebrofacial arteriovenous metamerie syndrome	ORPHA:141189	CTMC-OVM	Ja	P 92
G-24-2	Cerebrofacial arteriovenous metamerie syndrome	ORPHA:141189	HEVAS	Ja	P 131
G-2-11	Nasal dorsum fistulae	ORPHA:141219	Zonder patiëntenorganisatie	Nvt	P nvt
G-2-8	Facial cleft	ORPHA:141229	LaPosa	Ja	P 17
G-9-9	Paroxysmal dyskinesia	ORPHA:1431	Dystonie Vereniging	Nee	P 59
G-15-1	Lynch syndrome	ORPHA:144	St Lynch Polyposis	Ja	P 93
G-15-12	Lynch syndrome	ORPHA:144	St Lynch Polyposis	Ja	P 93
G-15-2	Lynch syndrome	ORPHA:144	St Lynch Polyposis	Ja	P 93
G-15-3	Lynch syndrome	ORPHA:144	St Lynch Polyposis	Ja	P 93
G-15-4	Lynch syndrome	ORPHA:144	St Lynch Polyposis	Ja	P 93
G-15-6	Lynch syndrome	ORPHA:144	St Lynch Polyposis	Ja	P 93
G-15-1	Hereditary breast and ovarian cancer syndrome	ORPHA:145	St Olijf	Nee	P 88
G-15-1	Hereditary breast and ovarian cancer syndrome	ORPHA:145	Borstkankervereniging NL (BVN)	Ja	P 89
G-15-10	Hereditary breast and ovarian cancer syndrome	ORPHA:145	St Olijf	Nee	P 88
G-15-10	Hereditary breast and ovarian cancer syndrome	ORPHA:145	Borstkankervereniging NL (BVN)	Ja	P 89
G-15-2	Hereditary breast and ovarian cancer syndrome	ORPHA:145	St Olijf	Nee	P 88
G-15-2	Hereditary breast and ovarian cancer syndrome	ORPHA:145	Borstkankervereniging NL (BVN)	Ja	P 89
G-15-5	Hereditary breast and ovarian cancer syndrome	ORPHA:145	St Olijf	Nee	P 88
G-15-5	Hereditary breast and ovarian cancer syndrome	ORPHA:145	Borstkankervereniging NL (BVN)	Ja	P 89
G-15-6	Hereditary breast and ovarian cancer syndrome	ORPHA:145	St Olijf	Nee	P 88
G-15-6	Hereditary breast and ovarian cancer syndrome	ORPHA:145	Borstkankervereniging NL (BVN)	Ja	P 89
G-15-7	Hereditary breast and ovarian cancer syndrome	ORPHA:145	St Olijf	Nee	P 88
G-15-7	Hereditary breast and ovarian cancer syndrome	ORPHA:145	Borstkankervereniging NL (BVN)	Ja	P 89
G-15-9	Hereditary breast and ovarian cancer syndrome	ORPHA:145	St Olijf	Nee	P 88
G-15-9	Hereditary breast and ovarian cancer syndrome	ORPHA:145	Borstkankervereniging NL (BVN)	Ja	P 89
G-2-3	Cleidocranial dysplasia	ORPHA:1452	LaPosa	Ja	P 17
G-2-3	Cleidocranial dysplasia	ORPHA:1452	St Eigen Gezicht	Nee	P 247
G-11-36	Nasopharyngeal carcinoma	ORPHA:150	Patiëntenvereniging Hoofd-Hals	Ja	P 169
G-11-43	Nasopharyngeal carcinoma	ORPHA:150	Patiëntenvereniging Hoofd-Hals	Ja	P 169

G-3-12	Adrenocortical carcinoma	ORPHA:1501	Bijniervereniging (NVACP)	Nee	P 64
G-3-2	Adrenocortical carcinoma	ORPHA:1501	Bijniervereniging (NVACP)	Nee	P 64
G-3-7	Adrenocortical carcinoma	ORPHA:1501	Bijniervereniging (NVACP)	Nee	P 64
G-2-13	Cysts and fistulae of the face and oral cavity	ORPHA:155835	LaPosa	Ja	P 17
G-2-13	Cysts and fistulae of the face and oral cavity	ORPHA:155835	St Eigen Gezicht	Nee	P 247
G-2-12	Otomandibular dysplasia	ORPHA:155896	LaPosa	Ja	P 17
G-2-2	Otomandibular dysplasia	ORPHA:155896	LaPosa	Ja	P 17
G-2-2	Otomandibular dysplasia	ORPHA:155896	St Eigen Gezicht	Nee	P 247
G-21-8	Predominantly large-vessel vasculitis	ORPHA:156140	Vasculitits St	Ja	P 51
G-21-8	Predominantly medium-vessel vasculitis	ORPHA:156143	Vasculitits St	Ja	P 51
G-21-8	Predominantly small-vessel vasculitis	ORPHA:156146	Vasculitits St	Ja	P 51
G-21-8	Anti-neutrophil cytoplasmic antibody-associated vasculitis	ORPHA:156152	Vasculitits St	Ja	P 51
G-2-12	Hypoglossia/aglossia	ORPHA:156212	LaPosa	Ja	P 17
G-2-12	Hypoglossia/aglossia	ORPHA:156212	St Eigen Gezicht	Nee	P 247
G-2-12	Hypoglossia/aglossia	ORPHA:156212	Schisis NL	Nee	P 287
G-2-8	Paralytic facial malformation	ORPHA:156224	LaPosa	Ja	P 17
G-2-8	Paralytic facial malformation	ORPHA:156224	St Eigen Gezicht	Nee	P 247
G-24-2	Facial arteriovenous malformation	ORPHA:156230	CTMC-OVM	Ja	P 92
G-24-2	Facial arteriovenous malformation	ORPHA:156230	HEVAS	Ja	P 131
G-2-12	Syndrome or malformation associated with head and neck malformations	ORPHA:156237	LaPosa	Ja	P 17
G-2-12	Syndrome or malformation associated with head and neck malformations	ORPHA:156237	St Eigen Gezicht	Nee	P 247
G-2-2	Syndrome or malformation associated with head and neck malformations	ORPHA:156237	LaPosa	Ja	P 17
G-2-2	Syndrome or malformation associated with head and neck malformations	ORPHA:156237	St Eigen Gezicht	Nee	P 247
G-2-11	Pinnae and external auditory canal anomaly	ORPHA:156243	St Hoormij	Nee	P 33
G-2-11	Nose & Cavum anomaly	ORPHA:156246	Zonder patiëntenorganisatie	Nvt	P nvt
G-2-11	Larynx anomaly	ORPHA:156249	Zonder patiëntenorganisatie	Nvt	P nvt
G-2-13	Larynx anomaly	ORPHA:156249	Zonder patiëntenorganisatie	Nvt	P nvt
G-2-5	Larynx anomaly	ORPHA:156249	Zonder patiëntenorganisatie	Nvt	P nvt
G-2-11	Tracheal anomaly	ORPHA:156252	Vereniging voor Ouderen en Kinderen met Slokdarmafsluiting (VOKS)	Ja	P 124
G-2-13	Tracheal anomaly	ORPHA:156252	Vereniging voor Ouderen en Kinderen met Slokdarmafsluiting (VOKS)	Ja	P 124
G-2-5	Tracheal anomaly	ORPHA:156252	Vereniging voor Ouderen en Kinderen met Slokdarmafsluiting (VOKS)	Ja	P 124
G-16-10	Rare syndrome with cardiac malformations	ORPHA:156532	Patiëntenvereniging Aangeboren Hartafwijkingen	Ja	P 127
G-8-14	Rare genetic respiratory disease	ORPHA:156610	NLse Cystic Fibrosis St (NCFS)	Ja	P 159
G-8-14	Rare genetic respiratory disease	ORPHA:156610	St LAM NL	Nee	P 160
G-15-6	Hereditary mixed polyposis syndrome	ORPHA:157794	St Lynch Polyposis	Ja	P 93
G-15-2	Serrated polyposis syndrome	ORPHA:157798	St Lynch Polyposis	Ja	P 93
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G-9-5	Paroxysmal Hemicrania	ORPHA:157835	Hoofdpijnnet	Ja	P 32
G-9-5	Trigeminal autonomic cephalgia	ORPHA:157843	Hoofdpijnnet	Ja	P 32
G-9-9	Pantothenate kinase-associated neurodegeneration	ORPHA:157850	Alzheimer NL	Ja	P 2
G-9-9	Pantothenate kinase-associated neurodegeneration	ORPHA:157850	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-9-9	Pantothenate kinase-associated neurodegeneration	ORPHA:157850	St IJzersterk	Ja	P 189

G-9-9	Pantothenate kinase-associated neurodegeneration	ORPHA:157850	Kans voor PKAN-kinderen	Nee	P 289
G-21-5	Non-Langerhans cell histiocytosis	ORPHA:157987	Histiocytose NL	Nee	P 46
G-6-5	Necrobiotic xanthogranuloma	ORPHA:158011	Huid NL	Ja	P 161
G-21-5	Hemophagocytic syndrome	ORPHA:158032	Histiocytose NL	Nee	P 46
G-21-5	Hemophagocytic syndrome	ORPHA:158032	St Zeldzame Bloedziekten	Nee	P 75
G-22-13	Hemophagocytic syndrome	ORPHA:158032	Histiocytose NL	Nee	P 46
G-22-13	Hemophagocytic syndrome	ORPHA:158032	St Zeldzame Bloedziekten	Nee	P 75
G-2-11	Isolated congenital nasal pyriform aperture stenosis	ORPHA:162516	Zonder patiëntenorganisatie	Nvt	P nvt
G-12-2	Hereditary hyperferritinemia-cataract syndrome	ORPHA:163	Oogvereniging	Nee	P 100
G-25-11	Rare parasitic disease	ORPHA:163588	Zonder patiëntenorganisatie	Nvt	P nvt
G-25-6	Rare parasitic disease	ORPHA:163588	Zonder patiëntenorganisatie	Nvt	P nvt
G-25-2	Rare mycosis	ORPHA:163591	St voor Afweerstoornissen (SAS)	Ja	P 72
G-25-2	Rare mycosis	ORPHA:163591	Huid NL	Ja	P 161
G-26-5	Rare disorder related with pregnancy, childbirth and puerperium	ORPHA:163637	Hellp St	Nee	P 113
G-26-5	Rare disorder related with pregnancy, childbirth and puerperium	ORPHA:163637	Care4Neo	Ja	P 114
G-26-5	Rare disorder related with pregnancy, childbirth and puerperium	ORPHA:163637	C.H.I. Support	Nee	P 322
G-26-6	Rare disorder related with pregnancy, childbirth and puerperium	ORPHA:163637	Hellp St	Nee	P 113
G-26-6	Rare disorder related with pregnancy, childbirth and puerperium	ORPHA:163637	Care4Neo	Ja	P 114
G-26-6	Rare disorder related with pregnancy, childbirth and puerperium	ORPHA:163637	C.H.I. Support	Nee	P 322
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G-2-12	Rare odontal or periodontal disorder	ORPHA:164001	St Eigen Gezicht	Nee	P 247
G-2-12	Rare odontal or periodontal disorder	ORPHA:164001	Schisis NL	Nee	P 287
G-2-13	Rare odontal or periodontal disorder	ORPHA:164001	LaPosa	Ja	P 17
G-2-13	Rare odontal or periodontal disorder	ORPHA:164001	St Eigen Gezicht	Nee	P 247
G-2-13	Rare odontal or periodontal disorder	ORPHA:164001	Schisis NL	Nee	P 287
G-2-11	Middle ear anomaly	ORPHA:164004	St Hoormij	Nee	P 33
G-2-13	Middle ear anomaly	ORPHA:164004	St Hoormij	Nee	P 33
G-2-14	Middle ear anomaly	ORPHA:164004	St Hoormij	Nee	P 33
G-12-26	Rare acquired aplastic anemia	ORPHA:164823	St AA & PNH	Nee	P 104
G-13-2	Non-syndromic urogenital tract malformation	ORPHA:165704	St MRK Vrouwen	Ja	P 112
G-14-7	Hereditary motor and sensory neuropathy	ORPHA:166	Spierziekten NL	Ja	P 43
G-4-1	Epilepsy syndrome	ORPHA:166463	Epilepsiefonds	Nee	P 7
G-4-1	Monogenic disease with epilepsy	ORPHA:166472	Epilepsiefonds	Nee	P 7
G-4-2	Monogenic disease with epilepsy	ORPHA:166472	Epilepsiefonds	Nee	P 7
G-4-1	Cerebral malformation with epilepsy	ORPHA:166478	Epilepsiefonds	Nee	P 7
G-4-2	Cerebral malformation with epilepsy	ORPHA:166478	Epilepsiefonds	Nee	P 7
G-22-9	Inflammatory and autoimmune disease with epilepsy	ORPHA:166484	Epilepsiefonds	Nee	P 7
G-12-24	Rare hemorrhagic disorder due to an acquired coagulation factor defect	ORPHA:166775	Zonder patiëntenorganisatie	Nvt	P nvt
G-16-1	Rare cardiomyopathy	ORPHA:167848	Harteraad	Ja	P 58
G-16-3	Rare cardiomyopathy	ORPHA:167848	Harteraad	Ja	P 58
G-16-7	Rare cardiomyopathy	ORPHA:167848	Harteraad	Ja	P 58

G-17-5	Rare pervasive developmental disorder	ORPHA:168778	NLse Vereniging voor Autisme	Nee	P 26
G-8-10	Malignant peritoneal mesothelioma	ORPHA:168811	Asbestslachtoffers Vereniging NL (AVN)	Ja	P 109
G-11-20	Malignant melanoma of the mucosa	ORPHA:168999	St Melanoom	Nee	P 96
G-11-34	Malignant melanoma of the mucosa	ORPHA:168999	St Melanoom	Nee	P 96
G-20-4	Primary sclerosing cholangitis	ORPHA:171	NLse Leverpatiënten Vereniging (NLV)	Ja	P 19
G-20-6	Primary sclerosing cholangitis	ORPHA:171	NLse Leverpatiënten Vereniging (NLV)	Ja	P 19
G-9-3	Periventricular leukomalacia	ORPHA:171676	Zonder patiëntenorganisatie	Nvt	P nvt
G-2-10	Idiopathic Bilateral Vestibulopathy	ORPHA:171684	St Hoormij	Nee	P 33
G-12-19	Myeloid hemopathy	ORPHA:171895	St Hematon	Ja	P 81
G-12-3	Myeloid hemopathy	ORPHA:171895	St Hematon	Ja	P 81
G-12-10	B-cell non-Hodgkin lymphoma	ORPHA:171915	St Hematon	Ja	P 81
G-20-5	Progressive familial intrahepatic cholestasis	ORPHA:172	NLse Leverpatiënten Vereniging (NLV)	Ja	P 19
G-20-6	Progressive familial intrahepatic cholestasis	ORPHA:172	NLse Leverpatiënten Vereniging (NLV)	Ja	P 19
G-12-11	Dyskeratosis congenita	ORPHA:1775	St Hematon	Ja	P 81
G-12-26	Dyskeratosis congenita	ORPHA:1775	St Hematon	Ja	P 81
G-11-16	Chordoma	ORPHA:178	St Patiëntenplatform Sarcomen	Ja	P 94
G-11-44	Chordoma	ORPHA:178	St Patiëntenplatform Sarcomen	Ja	P 94
G-1-8	Chordoma	ORPHA:178	St Patiëntenplatform Sarcomen	Ja	P 94
G-3-13	Central diabetes insipidus	ORPHA:178029	NLse Hypofyse St (NHS)	Ja	P 65
G-3-17	Isolated Sternocostoclavicular Hyperostosis	ORPHA:178311	NLse vereniging van patiënten met sternocosto clavculaire hyperostosis	Ja	P 42
G-22-13	Primary immunodeficiency due to a defect in adaptive immunity	ORPHA:179006	St voor Afweerstoornissen (SAS)	Ja	P 72
G-13-2	Absence of uterine body	ORPHA:180142	Zonder patiëntenorganisatie	Nvt	P nvt
G-11-26	Rare uterine adnexal tumor	ORPHA:180220	St Olijf	Nee	P 88
G-11-6	Malignant tumor of fallopian tubes	ORPHA:180242	St Olijf	Nee	P 88
G-15-10	Rare malignant breaSt tumor	ORPHA:180257	Borstkankervereniging NL (BVN)	Ja	P 89
G-11-48	Rare vulvovaginal tumor	ORPHA:180312	St Olijf	Nee	P 88
G-11-6	Rare vulvovaginal tumor	ORPHA:180312	St Olijf	Nee	P 88
G-11-31	Rare gastroesophageal tumor	ORPHA:180821	SPKS - Leven met maag- of slokdarmkanker	Nee	P 63
G-11-45	Rare gastroesophageal tumor	ORPHA:180821	SPKS - Leven met maag- of slokdarmkanker	Nee	P 63
G-11-23	Rare tumor of pancreas	ORPHA:180824	Alvleeskliervereniging (AVKV)	Nee	P 87
G-11-23	Rare tumor of pancreas	ORPHA:180824	Living with Hope	Nee	P 260
G-11-31	Rare tumor of pancreas	ORPHA:180824	Alvleeskliervereniging (AVKV)	Nee	P 87
G-11-31	Rare tumor of pancreas	ORPHA:180824	Living with Hope	Nee	P 260
G-11-9	Rare tumor of pancreas	ORPHA:180824	Alvleeskliervereniging (AVKV)	Nee	P 87
G-11-9	Rare tumor of pancreas	ORPHA:180824	Living with Hope	Nee	P 260
G-3-1	Rare hypothalamic or pituitary disease	ORPHA:181384	NLse Hypofyse St (NHS)	Ja	P 65
G-3-13	Rare hypothalamic or pituitary disease	ORPHA:181384	NLse Hypofyse St (NHS)	Ja	P 65
G-3-17	Rare hypothalamic or pituitary disease	ORPHA:181384	NLse Hypofyse St (NHS)	Ja	P 65
G-3-4	Rare hypothalamic or pituitary disease	ORPHA:181384	NLse Hypofyse St (NHS)	Ja	P 65
G-3-9	Rare hypothalamic or pituitary disease	ORPHA:181384	NLse Hypofyse St (NHS)	Ja	P 65
G-3-15	Growth hormone insensitivity syndrome	ORPHA:181393	Belangenvereniging van Kleine Mensen (BVKM)	Nee	P 4
G-3-15	Growth hormone insensitivity syndrome	ORPHA:181393	NLse Hypofyse St (NHS) iom NVGG	Ja	P 65

G-3-15	Growth hormone insensitivity syndrome	ORPHA:181393	NVGG - Nlse vereniging voor groeihoormoondeficiëntie en	Nee	P 194
G-3-11	Rare hyperparathyroidism	ORPHA:181408	Zonder patiëntenorganisatie	Nvt	P nvt
G-3-2	Adrenogenital syndrome	ORPHA:181412	Bijniervereniging (NVACP)	Nee	P 64
G-3-2	Rare primary hyperaldosteronism	ORPHA:181415	Bijniervereniging (NVACP)	Nee	P 64
G-3-7	Rare primary hyperaldosteronism	ORPHA:181415	Bijniervereniging (NVACP)	Nee	P 64
G-18-12	Rare hyperlipidemia	ORPHA:181422	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Nee	P 56
G-12-26	Aplastic Anemia	ORPHA:182040	St AA & PNH	Nee	P 104
G-12-21	Rare thrombotic disease of hematologic origin	ORPHA:182054	St Zeldzame Bloedziekten - TTP Contactgroep	Nee	P 75
G-22-9	Rare neuroinflammatory or neuroimmunological disease	ORPHA:182064	MS Vereniging NL	Nee	P 21
G-22-9	Rare neuroinflammatory or neuroimmunological disease	ORPHA:182064	Spierziekten NL	Ja	P 43
G-22-9	Rare neuroinflammatory or neuroimmunological disease	ORPHA:182064	Oogvereniging	Nee	P 100
G-11-24	Glial tumor	ORPHA:182067	Vereniging Kinderkanker NL	Nee	P 82
G-11-24	Glial tumor	ORPHA:182067	Hersenletsel.nl	Nee	P 91
G-11-44	Glial tumor	ORPHA:182067	Vereniging Kinderkanker NL	Nee	P 82
G-11-44	Glial tumor	ORPHA:182067	Hersenletsel.nl	Nee	P 91
G-11-49	Glial Tumor	ORPHA:182067	Vereniging Kinderkanker NL	Nee	P 82
G-11-49	Glial Tumor	ORPHA:182067	Hersenletsel.nl	Nee	P 91
G-14-5	Acquired peripheral neuropathy	ORPHA:182086	Spierziekten NL	Ja	P 43
G-8-4	Pulmonary Arterial Hypertension	ORPHA:182090	St Pulmonale Hypertensie	Ja	P 158
G-8-12	Interstitial lung disease	ORPHA:182095	Sarcoïdose NL	Ja	P 40
G-8-12	Interstitial lung disease	ORPHA:182095	Nationale vereniging voor lupus, APS, sclerodermie en MCTD (NVLE)	Nee	P 128
G-8-12	Interstitial lung disease	ORPHA:182095	Belangenvereniging Longfibrosepatiënten NL	Ja	P 152
G-8-12	Interstitial lung disease	ORPHA:182095	St LAM NL	Nee	P 160
G-8-12	Interstitial lung disease	ORPHA:182095	LGD Alliance NL	Nee	P 200
G-8-14	Interstitial lung disease	ORPHA:182095	Sarcoïdose NL	Ja	P 40
G-8-14	Interstitial lung disease	ORPHA:182095	Nationale vereniging voor lupus, APS, sclerodermie en MCTD (NVLE)	Nee	P 128
G-8-14	Interstitial lung disease	ORPHA:182095	Belangenvereniging Longfibrosepatiënten NL	Nee	P 152
G-8-14	Interstitial lung disease	ORPHA:182095	St LAM NL	Nee	P 160
G-8-14	Interstitial lung disease	ORPHA:182095	LGD Alliance NL	Nee	P 200
G-8-2	Interstitial lung disease	ORPHA:182095	Sarcoïdose NL	Ja	P 40
G-8-2	Interstitial lung disease	ORPHA:182095	Nationale vereniging voor lupus, APS, sclerodermie en MCTD (NVLE)	Nee	P 128
G-8-2	Interstitial lung disease	ORPHA:182095	Belangenvereniging Longfibrosepatiënten NL	Ja	P 152
G-8-2	Interstitial lung disease	ORPHA:182095	St LAM NL	Nee	P 160
G-8-2	Interstitial lung disease	ORPHA:182095	LGD Alliance NL	Nee	P 200
G-8-22	Interstitial lung disease	ORPHA:182095	Sarcoïdose NL	Ja	P 40
G-8-22	Interstitial lung disease	ORPHA:182095	Nationale vereniging voor lupus, APS, sclerodermie en MCTD (NVLE)	Nee	P 128
G-8-22	Interstitial lung disease	ORPHA:182095	Belangenvereniging Longfibrosepatiënten NL	Ja	P 152
G-8-22	Interstitial lung disease	ORPHA:182095	St LAM NL	Nee	P 160
G-8-22	Interstitial lung disease	ORPHA:182095	LGD Alliance NL	Nee	P 200
G-8-14	Respiratory malformation	ORPHA:182111	Zonder patiëntenorganisatie	Nvt	P nvt
G-13-3	Non-syndromic urogenital tract malformation of male and female	ORPHA:182124	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-3-9	Tumor of endocrine glands	ORPHA:182130	Nlse Vereniging voor Patiënten met Paragangliomen (NVPG)	Ja	P 29

G-3-9	Tumor of endocrine glands	ORPHA:182130	St NET-Groep	Ja	P 62
G-21-6	Systemic autoimmune disease	ORPHA:182228	Vasculitits St	Nee	P 51
G-21-6	Systemic autoimmune disease	ORPHA:182228	Nationale vereniging voor lupus, APS, sclerodermie en MCTD (NVLE)	Ja	P 128
G-21-8	Eosinophilic granulomatosis and polyangiitis	ORPHA:183	Vasculitits St	Ja	P 51
G-17-5	Polymalformative genetic syndrome with increased risk of developing cancer	ORPHA:183422	Neurofibromatosevereniging NL (NFVN)	Ja	P 30
G-17-5	Polymalformative genetic syndrome with increased risk of developing cancer	ORPHA:183422	Vereniging Kinderkanker NL	Nee	P 82
G-10-3	Inherited ichthyosis	ORPHA:183435	Vereniging voor Ichthyosisnetwerken	Ja	P 237
G-10-3	Genetic epidermal appendage anomaly	ORPHA:183447	Huid NL	Ja	P 161
G-10-3	Genetic pigmentation anomaly of the skin	ORPHA:183463	Neurofibromatosevereniging NL (NFVN)	Ja	P 30
G-10-3	Genetic dermis disorder	ORPHA:183472	Huid NL	Ja	P 161
G-9-10	Genetic Neurodegenerative Diseases	ORPHA:183500	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Nee	P 56
G-9-5	Rare Genetic Headache	ORPHA:183509	Hoofdpijnnet	Ja	P 32
G-22-13	Severe combined immunodeficiency	ORPHA:183660	St voor Afweerstoornissen (SAS)	Ja	P 72
G-20-4	Primary biliary cholangitis	ORPHA:186	NLse Leverpatiënten Vereniging (NLV)	Ja	P 19
G-20-6	Primary Biliary Cholangitis	ORPHA:186	NLse Leverpatiënten Vereniging (NLV)	Ja	P 19
G-9-9	Focal, segmental or multifocal dystonia	ORPHA:1866	Dystonie Vereniging	Nee	P 59
G-17-5	Cockayne Syndrome	ORPHA:191	St Hoormij	Nee	P 33
G-17-5	Cockayne Syndrome	ORPHA:191	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Nee	P 56
G-17-5	Cockayne Syndrome	ORPHA:191	St Amy and Friends	Nee	P 319
G-8-7	Congenital lobar emphysema	ORPHA:1928	Zonder patiëntenorganisatie	Nvt	P nvt
G-10-4	Congenital lethal erythroderma	ORPHA:1954	Huid NL	Ja	P 161
G-10-4	Congenital lethal erythroderma	ORPHA:1954	Vereniging voor Ichthyosisnetwerken	Ja	P 237
G-11-20	Esthesioneuroblastoma	ORPHA:1957	Hersenletsel.nl	Nee	P 91
G-11-44	Esthesioneuroblastoma	ORPHA:1957	Hersenletsel.nl	Nee	P 91
G-17-11	Cornelia de Lange syndrome	ORPHA:199	Vereniging Cornelia de Lange Syndroom	Ja	P 144
G-2-12	Cleft lip with or without cleft palate	ORPHA:1991	Schisis NL	Nee	P 287
G-2-13	Cleft lip with or without cleft palate	ORPHA:1991	Schisis NL	Nee	P 287
G-2-2	Cleft lip with or without cleft palate	ORPHA:1991	Schisis NL	Nee	P 287
G-2-7	Cleft lip with or without cleft palate	ORPHA:1991	Schisis NL	Nee	P 287
G-6-4	Endophthalmitis	ORPHA:199323	Oogvereniging	Nee	P 100
G-24-12	Cerebral autosomal recessive arteriopathy-subcortical infarcts-leukoencephalopathy	ORPHA:199354	Alzheimer NL	Ja	P 2
G-2-12	Cleft palate	ORPHA:2014	Schisis NL	Nee	P 287
G-2-13	Cleft palate	ORPHA:2014	Schisis NL	Nee	P 287
G-2-2	Cleft palate	ORPHA:2014	Schisis NL	Nee	P 287
G-2-7	Cleft palate	ORPHA:2014	Schisis NL	Nee	P 287
G-8-12	Idiopathic pulmonary fibrosis	ORPHA:2032	Belangenvereniging Longfibrosepatiënten NL	Ja	P 152
G-8-22	Idiopathic pulmonary fibrosis	ORPHA:2032	Belangenvereniging Longfibrosepatiënten NL	Ja	P 152
G-18-15	Crigler-Najjar syndrome	ORPHA:205	NLse Leverpatiënten Vereniging (NLV)	Nee	P 19
G-18-15	Crigler-Najjar syndrome	ORPHA:205	Crigler-Najjar St	Nee	P 176
G-20-6	Crigler-Najjar syndrome	ORPHA:205	NLse Leverpatiënten Vereniging (NLV)	Ja	P 19
G-20-6	Crigler-Najjar syndrome	ORPHA:205	Crigler-Najjar St	Nee	P 176
G-18-9	Essential fructosuria	ORPHA:2056	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56

G-11-32	Borderline epithelial tumor of ovary	ORPHA:206473	St Olijf	Nee	P 88
G-14-6	Genetic skeletal muscle disease	ORPHA:206634	Spierziekten NL	Ja	P 43
G-14-6	Acquired skeletal muscle disease	ORPHA:206638	Spierziekten NL	Ja	P 43
G-14-10	Progressive muscular dystrophy	ORPHA:206644	Spierziekten NL	Ja	P 43
G-14-1	Myotonic dystrophy	ORPHA:206647	Spierziekten NL	Ja	P 43
G-14-5	Myotonic dystrophy	ORPHA:206647	Spierziekten NL	Ja	P 43
G-14-6	Non-dystrophic myopathy	ORPHA:206656	Spierziekten NL	Ja	P 43
G-14-6	Bulbospinal muscular atrophy	ORPHA:206701	Spierziekten NL	Ja	P 43
G-0-3	Narcolepsy type 1	ORPHA:2073	Narcolepsie Vereniging NL (NVN)	Nee	P 210
G-0-4	Narcolepsy type 1	ORPHA:2073	Narcolepsie Vereniging NL (NVN)	Nee	P 210
G-14-6	Chronic polyradiculoneuropathy	ORPHA:208978	Spierziekten NL	Ja	P 43
G-14-6	Peripheral neuropathy associated with monoclonal gammopathy	ORPHA:209010	Spierziekten NL	Ja	P 43
G-14-7	Peripheral neuropathy associated with monoclonal gammopathy	ORPHA:209010	Spierziekten NL	Ja	P 43
G-7-10	Solitary rectal ulcer syndrome	ORPHA:209964	Vereniging Anusatresie	Nee	P 120
G-7-10	Solitary rectal ulcer syndrome	ORPHA:209964	Vereniging Ziekte van Hirschsprung	Ja	P 123
G-8-1	Congenital alveolar capillary dysplasia	ORPHA:210122	Zonder patiëntenorganisatie	Nvt	P nvt
G-8-7	Congenital alveolar capillary dysplasia	ORPHA:210122	Zonder patiëntenorganisatie	Nvt	P nvt
G-20-4	Adult hepatocellular carcinoma	ORPHA:210159	NLse Leverpatiënten Vereniging (NLV)	Ja	P 19
G-14-3	Guillain-Barré syndrome	ORPHA:2103	Spierziekten NL	Ja	P 43
G-2-8	Temporomandibular joint anomaly	ORPHA:210581	LaPosa	Ja	P 17
G-24-2	Rare vascular tumor	ORPHA:211237	CTMC-OVM	Ja	P 92
G-24-2	Rare vascular tumor	ORPHA:211237	HEVAS	Ja	P 131
G-24-2	Rare vascular tumor	ORPHA:211237	LGD Alliance NL	Nee	P 200
G-24-8	Rare vascular tumor	ORPHA:211237	CTMC-OVM	Ja	P 92
G-24-8	Rare vascular tumor	ORPHA:211237	HEVAS	Ja	P 131
G-24-8	Rare vascular tumor	ORPHA:211237	LGD Alliance NL	Nee	P 200
G-24-3	Simple vascular malformation	ORPHA:211243	CTMC-OVM	Ja	P 92
G-24-3	Simple vascular malformation	ORPHA:211243	HEVAS	Ja	P 131
G-24-2	Rare capillary malformation	ORPHA:211247	CTMC-OVM	Ja	P 92
G-24-2	Rare capillary malformation	ORPHA:211247	HEVAS	Ja	P 131
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G-24-3	Rare capillary malformation	ORPHA:211247	HEVAS	Ja	P 131
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G-11-32	Rare cancer of cervix uteri	ORPHA:213761	St Olijf	Nee	P 88
G-11-48	Rare cancer of cervix uteri	ORPHA:213761	St Olijf	Nee	P 88
G-11-6	Rare cancer of cervix uteri	ORPHA:213761	St Olijf	Nee	P 88
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G-22-9	Limbic encephalitis with NMDA receptor antibodies	ORPHA:217253	Nlse Meningitis St	Nee	P 118
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G-16-8	Dilated cardiomyopathy	ORPHA:217604	St Genetische Hartspierziekte PLN	Nee	P 249
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G-16-1	Rare cardiac rhythm disease	ORPHA:218436	St ICD dragers NL (STIN)	Nee	P 206
G-16-11	Non-genetic cardiac rhythm disease	ORPHA:218439	Patiëntenvereniging Aangeboren Hartafwijkingen	Nee	P 127
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G-21-2	Diffuse cutaneous systemic sclerosis	ORPHA:220393	Nationale vereniging voor lupus, APS, sclerodermie en MCTD (NVLE)	Ja	P 128
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G-21-2	Limited systemic sclerosis	ORPHA:220407	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-21-2	Limited systemic sclerosis	ORPHA:220407	Nationale vereniging voor lupus, APS, sclerodermie en MCTD (NVLE)	Ja	P 128
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G-22-13	ICF syndrome	ORPHA:2268	St voor Afweerstoornissen (SAS)	Ja	P 72
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G-7-1	Anal fistula	ORPHA:228113	Vereniging Anusatresie	Nee	P 120
G-7-10	Anal fistula	ORPHA:228113	Crohn & Colitis NL	Nee	P 119
G-7-10	Anal fistula	ORPHA:228113	Vereniging Anusatresie	Nee	P 120
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G-7-8	Anal fistula	ORPHA:228113	Vereniging Anusatresie	Nee	P 120
G-16-8	Idiopathic ventricular fibrillation - not Brugada type	ORPHA:228140	Harteraad	Ja	P 58
G-16-8	Idiopathic ventricular fibrillation - not Brugada type	ORPHA:228140	St ICD dragers NL (STIN)	Nee	P 206
G-22-9	Multiple sclerosis variant	ORPHA:228145	MS Vereniging NL	Nee	P 21
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G-18-11	CLN3-ziekte	ORPHA:228346	Beat Batten	Nee	P 310
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G-11-31	High-grade dysplasia in patients with Barrett esophagus	ORPHA:231080	Zonder patiëntenorganisatie	Nvt	P nvt
G-24-7	Familial cerebral saccular aneurysm	ORPHA:231160	Hersenaneurysma Patiëntenplatform (HPP)	Nee	P 315
G-24-7	Familial cerebral saccular aneurysm	ORPHA:231160	Hersenaneurysma Patiëntenplatform (HPP)	Nee	P 315
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G-7-10	Ileal pouch anal anastomosis related faecal incontinence	ORPHA:238621	Vereniging Ziekte van Hirschsprung	Ja	P 123
G-3-3	Isolated congenital hypogonadotropic hypogonadism	ORPHA:238666	NLse Hypofyse St (NHS)	Ja	P 65
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G-24-3	Rare lymphatic malformation	ORPHA:2415	HEVAS	Ja	P 131
G-24-3	Rare lymphatic malformation	ORPHA:2415	LGD Alliance NL	Nee	P 200
G-24-8	Rare lymphatic malformation	ORPHA:2415	CTMC-OVM	Ja	P 92

G-24-8	Rare lymphatic malformation	ORPHA:2415	HEVAS	Ja	P 131
G-24-8	Rare lymphatic malformation	ORPHA:2415	LGD Alliance NL	Nee	P 200
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G-24-10	Congenital primary lymphedema without systemic or visceral involvement	ORPHA:2416	HEVAS	Nee	P 131
G-24-10	Congenital primary lymphedema without systemic or visceral involvement	ORPHA:2416	NL Net	Ja	P 142
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G-26-5	HELLP syndrome	ORPHA:244242	Care4Neo	Ja	P 114
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G-24-12	Retinal vasculopathy with cerebral leukoencephalopathy and systemic manifestations	ORPHA:247691	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Nee	P 56
G-24-12	Retinal vasculopathy with cerebral leukoencephalopathy and systemic manifestations	ORPHA:247691	Oogvereniging	Nee	P 100
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G-15-12	MUTYH-related attenuated familial adenomatous polyposis	ORPHA:247798	St Lynch Polyposis	Ja	P 93
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G-12-8	Rare hemorrhagic disorder	ORPHA:248308	NLse Vereniging van Hemofilie-Patiënten (NVHP)	Nee	P 74
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G-12-12	Rare hemorrhagic disorder due to a coagulation factors defect	ORPHA:248315	NLse Vereniging van Hemofilie-Patiënten (NVHP)	Nee	P 74
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G-12-8	Rare hemorrhagic disorder due to a coagulation factors defect	ORPHA:248315	NLse Vereniging van Hemofilie-Patiënten (NVHP)	Nee	P 74
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G-12-11	Rare hemorrhagic disorder due to a platelet anomaly	ORPHA:248326	NLse Vereniging van Hemofilie-Patiënten (NVHP)	Nee	P 74
G-12-12	Rare hemorrhagic disorder due to a platelet anomaly	ORPHA:248326	NLse Vereniging van Hemofilie-Patiënten (NVHP)	Nee	P 74
G-12-6	Rare hemorrhagic disorder due to a platelet anomaly	ORPHA:248326	NLse Vereniging van Hemofilie-Patiënten (NVHP)	Nee	P 74
G-12-8	Rare hemorrhagic disorder due to an acquired platelet anomaly	ORPHA:248347	ITP vereniging	Ja	P 79
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G-15-11	Meningioma	ORPHA:2495	Hersenletsel.nl	Nee	P 91
G-3-17	Meningioma	ORPHA:2495	NLse Hypofyse St (NHS)	Ja	P 65
G-3-17	Meningioma	ORPHA:2495	Hersenletsel.nl	Nee	P 91
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G-21-6	Overlapping connective tissue disease	ORPHA:251312	Nationale vereniging voor lupus, APS, sclerodermie en MCTD (NVLE)	Ja	P 128
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G-11-24	Rare tumor of neuroepithelial tissue	ORPHA:251558	Hersenletsel.nl	Nee	P 91
G-11-3	Rare tumor of neuroepithelial tissue	ORPHA:251558	Vereniging Kinderkanker NL	Nee	P 82

G-11-3	Rare tumor of neuroepithelial tissue	ORPHA:251558	Hersenletsel.nl	Nee	P 91
G-11-7	Rare tumor of neuroepithelial tissue	ORPHA:251558	Vereniging Kinderkanker NL	Nee	P 82
G-11-7	Rare tumor of neuroepithelial tissue	ORPHA:251558	Hersenletsel.nl	Nee	P 91
G-11-16	Tumor of cranial and spinal nerves	ORPHA:252057	St Hoormij	Nee	P 33
G-11-16	Tumor of cranial and spinal nerves	ORPHA:252057	St Hoormij	Nee	P 33
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G-11-16	Benign schwannoma	ORPHA:252164	Neurofibromatosevereniging NL (NFVN)	Ja	P 30
G-11-16	Benign schwannoma	ORPHA:252164	St Hoormij	Nee	P 33
G-11-16	Vestibular schwannoma	ORPHA:252175	Neurofibromatosevereniging NL (NFVN)	Ja	P 30
G-11-16	Vestibular schwannoma	ORPHA:252175	St Hoormij	Nee	P 33
G-11-44	Vestibular schwannoma	ORPHA:252175	Neurofibromatosevereniging NL (NFVN)	Ja	P 30
G-11-44	Vestibular schwannoma	ORPHA:252175	St Hoormij	Nee	P 33
G-15-13	Melanoma and neural system tumor syndrome	ORPHA:252206	St Melanoom	Nee	P 96
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G-11-32	Gestational trophoblastic disease	ORPHA:254685	St Olijf	Nee	P 88
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G-9-7	Moyamoya disease	ORPHA:2573	Hersenletsel.nl	Nee	P 91
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G-7-9	Familial visceral myopathy	ORPHA:2604	Maag Lever Darm St	Nee	P 105
G-15-6	Hereditary diffuse gastric cancer	ORPHA:26106	Zonder patiëntenorganisatie	Nvt	P nvt
G-17-1	Kleefstra syndrome	ORPHA:261494	Zeldsamen	Ja	P 290
G-17-4	Anomaly of Chromosome 6	ORPHA:261712	Zeldsamen	Nee	P 290
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G-14-10	Duchenne and Becker muscular dystrophy	ORPHA:262	Duchenne Parent Project	Nee	P 6
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G-14-5	Duchenne and Becker muscular dystrophy	ORPHA:262	Spierziekten NL	Ja	P 43
G-14-10	Limb Girdle Muscular Dystrophy	ORPHA:263	Spierziekten NL	Ja	P 43
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G-21-6	Interstitial lung disease specific to adulthood	ORPHA:264735	Belangenvereniging Longfibrosepatiënten NL	Ja	P 152
G-21-6	Interstitial lung disease specific to adulthood	ORPHA:264735	St LAM NL	Nee	P 160
G-21-6	Secondary interstitial lung disease specific to adulthood associated with a systemic	ORPHA:264745	Sarcoïdose NL	Ja	P 40
G-21-6	Secondary interstitial lung disease specific to adulthood associated with a systemic	ORPHA:264745	Nationale vereniging voor lupus, APS, sclerodermie en MCTD (NVLE)	Ja	P 128
G-21-6	Interstitial lung disease in childhood and adulthood	ORPHA:264757	Zonder patiëntenorganisatie	Nvt	P nvt
G-21-6	Secondary interstitial lung disease in childhood and adulthood associated with a	ORPHA:264949	Zonder patiëntenorganisatie	Nvt	P nvt
G-21-6	Exposure-related interstitial lung disease	ORPHA:264984	Belangenvereniging Longfibrosepatiënten NL	Ja	P 152
G-8-12	Genetic interstitial lung disease	ORPHA:264992	LGD Alliance NL	Nee	P 200
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G-17-3	Neural tube closure defect	ORPHA:268357	Syringomyelie Patiënten Vereniging (SPV)	Nee	P 177

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G-17-6	Neural tube closure defect	ORPHA:268357	SBH NL	Nee	P 286
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G-17-9	Malformation of the neurenteric canal, spinal cord and column	ORPHA:268843	SBH NL	Nee	P 286
G-4-2	Cerebral cortical dysplasia	ORPHA:268950	Epilepsiefonds	Nee	P 7
G-14-1	Facioscapulohumeral muscular dystrophy	ORPHA:269	Spierziekten NL	Ja	P 43
G-14-10	Facioscapulohumeral muscular dystrophy	ORPHA:269	Spierziekten NL	Ja	P 43
G-14-1	Oculopharyngeal muscular dystrophy	ORPHA:270	Spierziekten NL	Ja	P 43
G-14-10	Oculopharyngeal muscular dystrophy	ORPHA:270	Spierziekten NL	Ja	P 43
G-12-15	Hereditary ATTR amyloidosis	ORPHA:271861	St Amyloïdose NL	Ja	P 138
G-26-5	Preeclampsia	ORPHA:275555	Hellp St	Nee	P 113
G-26-5	Preeclampsia	ORPHA:275555	Care4Neo	Ja	P 114
G-12-20	Alpha-thalassemia and related diseases	ORPHA:275745	OSCAR Nederland	Ja	P 73
G-12-25	Alpha-thalassemia and related diseases	ORPHA:275745	OSCAR Nederland	Ja	P 73
G-12-20	Beta-thalassemia and related diseases	ORPHA:275749	OSCAR Nederland	Ja	P 73
G-12-25	Beta-thalassemia and related diseases	ORPHA:275749	OSCAR Nederland	Ja	P 73
G-12-20	Sickle cell disease and related diseases	ORPHA:275752	OSCAR Nederland	Ja	P 73
G-12-25	Sickle cell disease and related diseases	ORPHA:275752	OSCAR Nederland	Ja	P 73
G-8-1	Idiopathic pulmonary arterial hypertension	ORPHA:275766	St Pulmonale Hypertensie	Ja	P 158
G-8-21	Idiopathic pulmonary arterial hypertension	ORPHA:275766	St Pulmonale Hypertensie	Ja	P 158
G-8-15	Pulmonary arterial hypertension associated with another disease	ORPHA:275791	St Pulmonale Hypertensie	Nee	P 158
G-21-6	Pulmonary arterial hypertension associated with connective tissue disease	ORPHA:275798	Nationale vereniging voor lupus, APS, sclerodermie en MCTD (NVLE)	Ja	P 128
G-21-6	Pulmonary arterial hypertension associated with connective tissue disease	ORPHA:275798	St Pulmonale Hypertensie	Ja	P 158
G-8-1	Pulmonary arterial hypertension associated with connective tissue disease	ORPHA:275798	Nationale vereniging voor lupus, APS, sclerodermie en MCTD (NVLE)	Nee	P 128
G-8-1	Pulmonary arterial hypertension associated with connective tissue disease	ORPHA:275798	St Pulmonale Hypertensie	Ja	P 158
G-8-15	Pulmonary arterial hypertension associated with connective tissue disease	ORPHA:275798	Nationale vereniging voor lupus, APS, sclerodermie en MCTD (NVLE)	Nee	P 128
G-8-15	Pulmonary arterial hypertension associated with connective tissue disease	ORPHA:275798	St Pulmonale Hypertensie	Nee	P 158
G-8-1	Pulmonary arterial hypertension associated with congenital heart disease	ORPHA:275803	St Pulmonale Hypertensie	Ja	P 158
G-8-15	Pulmonary arterial hypertension associated with congenital heart disease	ORPHA:275803	St Pulmonale Hypertensie	Nee	P 158
G-8-15	Pulmonary arterial hypertension associated with portal hypertension	ORPHA:275813	St Pulmonale Hypertensie	Nee	P 158
G-8-1	Pulmonary hypertension owing to lung disease and/or hypoxia	ORPHA:275837	St Pulmonale Hypertensie	Ja	P 158
G-8-4	Pulmonary hypertension owing to lung disease and/or hypoxia	ORPHA:275837	St Pulmonale Hypertensie	Ja	P 158
G-8-4	Pulmonary hypertension with unclear multifactorial mechanism	ORPHA:275844	St Pulmonale Hypertensie	Ja	P 158
G-9-4	Frontotemporal dementia with motor neuron disease	ORPHA:275872	Alzheimer NL	Ja	P 2
G-9-4	Frontotemporal dementia with motor neuron disease	ORPHA:275872	FTD Lotgenoten	Ja	P 9
G-26-6	Hemolytic disease due to fetomaternal alloimmunization	ORPHA:275938	Care4Neo	Ja	P 114
G-11-28	Rare tumor of salivary glands	ORPHA:276142	Patiëntenvereniging Hoofd-Hals	Ja	P 169
G-11-28	Rare tumor of salivary glands	ORPHA:276142	Patiëntenvereniging Speekselklierkanker	Ja	P 255
G-11-36	Rare tumor of salivary glands	ORPHA:276142	Patiëntenvereniging Hoofd-Hals	Ja	P 169
G-11-36	Rare tumor of salivary glands	ORPHA:276142	Patiëntenvereniging Speekselklierkanker	Ja	P 255
G-11-4	Rare tumor of salivary glands	ORPHA:276142	Patiëntenvereniging Hoofd-Hals	Ja	P 169

G-11-4	Rare tumor of salivary glands	ORPHA:276142	Patiëntenvereniging Speekselklierkanker	Ja	P 255
G-11-42	Rare tumor of salivary glands	ORPHA:276142	Patiëntenvereniging Hoofd-Hals	Ja	P 169
G-11-42	Rare tumor of salivary glands	ORPHA:276142	Patiëntenvereniging Speekselklierkanker	Ja	P 255
G-11-43	Rare tumor of salivary glands	ORPHA:276142	Patiëntenvereniging Hoofd-Hals	Ja	P 169
G-11-43	Rare tumor of salivary glands	ORPHA:276142	Patiëntenvereniging Speekselklierkanker	Ja	P 255
G-1-5	Osteochondritis dissecans	ORPHA:2764	Zonder patiëntenorganisatie	Nvt	P nvt
G-9-5	Hypnic headache	ORPHA:276429	Hoofdpijnnet	Ja	P 32
G-3-7	Sporadic pheochromocytoma/secretory paraganglioma	ORPHA:276621	Nlse Vereniging voor Patiënten met Paragangliomen (NVPG)	Ja	P 29
G-3-7	Sporadic pheochromocytoma/secretory paraganglioma	ORPHA:276621	Bijniervereniging (NVACP)	Nee	P 64
G-6-7	Primary intraocular lymphoma	ORPHA:279904	NFK-Patiëntenplatform zeldzame kankers	Ja	P 18
G-6-7	Primary intraocular lymphoma	ORPHA:279904	St Hematon	Ja	P 81
G-6-7	Intermediate uveitis	ORPHA:279914	Oogvereniging	Ja	P 100
G-11-6	Extramammary Paget disease	ORPHA:2800	Borstkankervereniging NL (BVN)	Ja	P 89
G-22-11	Rare systemic or rheumatologic diseases of childhood	ORPHA:280342	Jeugdreuma Vereniging NL	Nee	P 134
G-22-11	Rare systemic or rheumatologic diseases of childhood	ORPHA:280342	St.KAISZ	Ja	P 135
G-22-3	Rare systemic or rheumatologic diseases of childhood	ORPHA:280342	Jeugdreuma Vereniging NL	Nee	P 134
G-22-5	Rare pediatric vasculitis	ORPHA:280369	Vasculitits St	Ja	P 51
G-22-7	Rare Pediatric Vasculitis	ORPHA:280369	Vasculitits St	Ja	P 51
G-9-9	Progressive myoclonic epilepsy type 6	ORPHA:280620	Epilepsiefonds	Nee	P 7
G-6-7	Anterior uveitis	ORPHA:280886	Oogvereniging	Ja	P 100
G-6-7	Posterior uveitis	ORPHA:280892	Oogvereniging	Ja	P 100
G-6-7	Panuveitis	ORPHA:280898	Oogvereniging	Ja	P 100
G-9-4	Frontotemporal dementia	ORPHA:282	Alzheimer NL	Ja	P 2
G-9-4	Frontotemporal dementia	ORPHA:282	FTD Lotgenoten	Ja	P 9
G-10-3	Familial benign chronic pemphigus (Hailey-Hailey disease)	ORPHA:2841	Hailey Hailey	Nee	P 302
G-10-7	Familial benign chronic pemphigus (Hailey-Hailey disease)	ORPHA:2841	Hailey Hailey	Nee	P 302
G-21-5	IgG4-related diseases	ORPHA:284264	St voor Afweerstoornissen (SAS)	Ja	P 72
G-21-7	IgG4-related diseases	ORPHA:284264	St voor Afweerstoornissen (SAS)	Ja	P 72
G-22-9	CLIPPERS	ORPHA:284448	ADCA/Ataxie Vereniging NL	Nee	P 1
G-22-9	CLIPPERS	ORPHA:284448	Epilepsiefonds	Nee	P 7
G-18-4	Disorder of phenylalanine metabolism	ORPHA:284814	PKU Vereniging NL	Ja	P 37
G-18-4	Disorder of phenylalanine metabolism	ORPHA:284814	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-24-13	Marfan and Marfan-related disorders	ORPHA:284993	Contactgroep Marfan NL	Ja	P 147
G-24-4	Marfan and Marfan-related disorders	ORPHA:284993	Contactgroep Marfan NL	Ja	P 147
G-24-5	Marfan and Marfan-related disorders	ORPHA:284993	Contactgroep Marfan NL	Ja	P 147
G-18-13	Disorder of folate metabolism and transport	ORPHA:285657	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-24-6	Vascular Ehlers-Danlos syndrome	ORPHA:286	Vereniging van Ehlers Danlos Patiënten (VED)	Ja	P 148
G-24-6	Vascular Ehlers-Danlos syndrome	ORPHA:286	EDS Fonds	Ja	P 309
G-15-2	Peutz-Jeghers syndrome	ORPHA:2869	St Lynch Polyposis	Ja	P 93
G-12-5	Hereditary elliptocytosis	ORPHA:288	St Zeldzame Bloedziekten	Nee	P 75
G-21-2	Primary Sjögren syndrome	ORPHA:289390	Nationale Vereniging Sjögrenpatiënten (NVSP)	Ja	P 22
G-21-5	Primary Sjögren Syndrome	ORPHA:289390	Nationale Vereniging Sjögrenpatiënten (NVSP)	Ja	P 22

G-15-13	BAP1-related tumor predisposition syndrome	ORPHA:289539	St Melanoom	Nee	P 96
G-11-16	Juvenile nasopharyngeal angiofibroma	ORPHA:289596	Zonder patiëntenorganisatie	Nvt	P nvt
G-11-44	Juvenile nasopharyngeal angiofibroma	ORPHA:289596	Zonder patiëntenorganisatie	Nvt	P nvt
G-17-11	Pitt-Hopkins syndrome	ORPHA:2896	St Pitt Hopkins Syndroom	Ja	P 145
G-24-10	Late-onset primary lymphedema without systemic or visceral involvement	ORPHA:289825	CMTC-OVM	Ja	P 92
G-24-10	Late-onset primary lymphedema without systemic or visceral involvement	ORPHA:289825	HEVAS	Nee	P 131
G-24-10	Late-onset primary lymphedema without systemic or visceral involvement	ORPHA:289825	NL Net	Ja	P 142
G-18-8	Organic aciduria	ORPHA:289899	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-14-1	Neuralgic amyotrophy	ORPHA:2901	Spierziekten NL	Ja	P 43
G-11-42	Hereditary pheochromocytoma-paraganglioma	ORPHA:29072	Nlse Vereniging voor Patiënten met Paragangliomen (NVPG)	Ja	P 29
G-11-42	Hereditary pheochromocytoma-paraganglioma	ORPHA:29072	Bijniervereniging (NVACP)	Nee	P 64
G-3-13	Hereditary pheochromocytoma-paraganglioma	ORPHA:29072	Nlse Vereniging voor Patiënten met Paragangliomen (NVPG)	Ja	P 29
G-3-13	Hereditary pheochromocytoma-paraganglioma	ORPHA:29072	Bijniervereniging (NVACP)	Nee	P 64
G-3-14	Hereditary pheochromocytoma-paraganglioma	ORPHA:29072	Nlse Vereniging voor Patiënten met Paragangliomen (NVPG)	Ja	P 29
G-3-14	Hereditary pheochromocytoma-paraganglioma	ORPHA:29072	Bijniervereniging (NVACP)	Nee	P 64
G-12-10	Multiple myeloma	ORPHA:29073	St Hematon	Ja	P 81
G-12-13	Multiple myeloma	ORPHA:29073	St Hematon	Ja	P 81
G-12-17	Multiple myeloma	ORPHA:29073	St Hematon	Ja	P 81
G-12-19	Multiple myeloma	ORPHA:29073	St Hematon	Ja	P 81
G-12-7	Multiple myeloma	ORPHA:29073	St Hematon	Ja	P 81
G-10-4	Systemic disease with skin involvement	ORPHA:290836	CMTC-OVM	Ja	P 92
G-10-4	Systemic disease with skin involvement	ORPHA:290836	Huid NL	Ja	P 161
G-22-1	Autoinflammatory syndrome with immune deficiency	ORPHA:290839	St voor Afweerstoornissen (SAS)	Ja	P 72
G-22-1	Autoinflammatory syndrome with immune deficiency	ORPHA:290839	St KAISZ	Nee	P 135
G-11-20	Rare head and neck tumor	ORPHA:290849	St Hoormij	Nee	P 33
G-11-20	Rare head and neck tumor	ORPHA:290849	Patiëntenvereniging Hoofd-Hals	Ja	P 169
G-11-28	Rare head and neck tumor	ORPHA:290849	St Hoormij	Nee	P 33
G-11-28	Rare head and neck tumor	ORPHA:290849	Patiëntenvereniging Hoofd-Hals	Ja	P 169
G-11-4	Rare head and neck tumor	ORPHA:290849	St Hoormij	Nee	P 33
G-11-4	Rare head and neck tumor	ORPHA:290849	Patiëntenvereniging Hoofd-Hals	Ja	P 169
G-11-42	Rare head and neck tumor	ORPHA:290849	St Hoormij	Nee	P 33
G-11-42	Rare head and neck tumor	ORPHA:290849	Patiëntenvereniging Hoofd-Hals	Ja	P 169
G-11-43	Rare head and neck tumor	ORPHA:290849	St Hoormij	Nee	P 33
G-11-43	Rare head and neck tumor	ORPHA:290849	Patiëntenvereniging Hoofd-Hals	Ja	P 169
G-11-46	Rare head and neck tumor	ORPHA:290849	St Hoormij	Nee	P 33
G-11-46	Rare head and neck tumor	ORPHA:290849	Patiëntenvereniging Hoofd-Hals	Ja	P 169
G-20-1	Isolated polycystic liver disease	ORPHA:2924	NLse Leverpatiënten Vereniging (NLV)	Ja	P 19
G-14-3	Chronic inflammatory demyelinating polyneuropathy	ORPHA:2932	Spierziekten NL	Ja	P 43
G-14-7	Chronic inflammatory demyelinating polyneuropathy	ORPHA:2932	Spierziekten NL	Ja	P 43
G-7-14	Celiac artery compression syndrome	ORPHA:293208	Maag Lever Darm St	Nee	P 105
G-15-13	MITF-related melanoma and renal cell carcinoma predisposition syndrome	ORPHA:293822	St Melanoom	Nee	P 96
G-17-15	Fetal cytomegalovirus syndrome	ORPHA:294	Care4Neo	Ja	P 114

G-17-15	Fetal cytomegalovirus syndrome	ORPHA:294	St CMV	Nee	P 320
G-10-3	Rare nevus	ORPHA:294057	Nevus Netwerk	Nee	P 141
G-14-7	Postpoliomyelitis syndrome	ORPHA:2942	Spierziekten NL	Ja	P 43
G-7-1	Chronic intestinal failure	ORPHA:294422	Crohn & Colitis NL	Nee	P 119
G-7-10	Chronic intestinal failure	ORPHA:294422	Crohn & Colitis NL	Nee	P 119
G-7-10	Chronic intestinal failure	ORPHA:294422	Vereniging Ziekte van Hirschsprung	Ja	P 123
G-7-4	Chronic intestinal failure	ORPHA:294422	Maag Lever Darm St	Nee	P 105
G-7-4	Chronic intestinal failure	ORPHA:294422	Crohn & Colitis NL	Ja	P 119
G-7-6	Chronic intestinal failure	ORPHA:294422	Crohn & Colitis NL	Ja	P 119
G-17-2	Syndrome with limb reduction defects	ORPHA:294955	Handvereniging	Nee	P 13
G-26-6	Fetal parvovirus syndrome	ORPHA:295	Care4Neo	Ja	P 114
G-1-8	Ollier disease	ORPHA:296	HME-MO Vereniging NL	Ja	P 15
G-1-8	Ollier disease	ORPHA:296	Vereniging Kinderkanker NL	Nee	P 82
G-3-13	Prolactinoma	ORPHA:2965	NLse Hypofyse St (NHS)	Ja	P 65
G-7-1	Chronic intestinal pseudoobstruction	ORPHA:2978	Vereniging Ziekte van Hirschsprung	Ja	P 123
G-7-3	Chronic intestinal pseudoobstruction	ORPHA:2978	Vereniging Ziekte van Hirschsprung	Ja	P 123
G-7-9	Chronic intestinal pseudoobstruction	ORPHA:2978	Vereniging Ziekte van Hirschsprung	Ja	P 123
G-12-11	Immune thrombocytopenia	ORPHA:3002	St voor Afweerstoornissen (SAS)	Ja	P 72
G-12-11	Immune thrombocytopenia	ORPHA:3002	ITP vereniging	Ja	P 79
G-12-14	Immune thrombocytopenia	ORPHA:3002	ITP vereniging	Ja	P 79
G-11-23	Carcinoma of the ampulla of Vater	ORPHA:300557	Alvleeskliervereniging (AVKV)	Nee	P 87
G-11-23	Carcinoma of the ampulla of Vater	ORPHA:300557	Living with Hope	Nee	P 260
G-11-31	Carcinoma of the ampulla of Vater	ORPHA:300557	Alvleeskliervereniging (AVKV)	Nee	P 87
G-11-31	Carcinoma of the ampulla of Vater	ORPHA:300557	Living with Hope	Nee	P 260
G-11-9	Ampulla of Vater carcinoma	ORPHA:300557	Alvleeskliervereniging (AVKV)	Nee	P 87
G-11-9	Carcinoma of the ampulla of Vater	ORPHA:300557	Living with Hope	Nee	P 260
G-12-19	Aggressive B-cell non-Hodgkin lymphoma	ORPHA:300846	St Hematon	Ja	P 81
G-7-1	Caudal regression sequence	ORPHA:3027	Maag Lever Darm St	Nee	P 105
G-20-7	Isolated biliary atresia	ORPHA:30391	NLse Leverpatiënten Vereniging (NLV)	Ja	P 19
G-3-6	Pituitary tumour	ORPHA:304055	NLse Hypofyse St (NHS)	Ja	P 65
G-15-1	PTEN hamartoma tumor syndrome	ORPHA:306498	St PTEN België-NL	Nee	P 95
G-14-5	Sodium channelopathy-related small fiber neuropathy	ORPHA:306577	Spierziekten NL	Ja	P 43
G-11-5	Rare tumor of gallbladder and extrahepatic biliary tract	ORPHA:306633	NFK-Patiëntenplatform zeldzame kankers	Ja	P 18
G-11-5	Rare tumor of gallbladder and extrahepatic biliary tract	ORPHA:306633	NLse Leverpatiënten Vereniging (NLV)	Ja	P 19
G-11-9	Rare tumor of gallbladder and extrahepatic biliary tract	ORPHA:306633	NFK-Patiëntenplatform zeldzame kankers	Ja	P 18
G-11-9	Rare tumor of gallbladder and extrahepatic biliary tract	ORPHA:306633	NLse Leverpatiënten Vereniging (NLV)	Ja	P 19
G-11-9	Rare tumor of liver and intrahepatic biliary tract	ORPHA:306636	NFK-Patiëntenplatform zeldzame kankers	Ja	P 18
G-11-9	Rare tumor of liver and intrahepatic biliary tract	ORPHA:306636	NLse Leverpatiënten Vereniging (NLV)	Ja	P 19
G-23-1	Complication after organ transplantation	ORPHA:306644	Huid NL	Ja	P 161
G-0-1	Rare parkinsonian syndrome due to intoxication	ORPHA:306679	St OPS	Ja	P 220
G-0-1	Manganese poisoning	ORPHA:306682	St OPS	Ja	P 220
G-9-8	Rare tremor disorder	ORPHA:306712	Contactgroep Orthostatische tremor	Nee	P 242

G-9-6	Rare choreic movement disorder	ORPHA:306715	Dystonie Vereniging	Nee	P 59
G-9-9	Epilepsy and/or ataxia with myoclonus as major feature	ORPHA:306756	ADCA/Ataxie Vereniging NL	Nee	P 1
G-9-9	Epilepsy and/or ataxia with myoclonus as major feature	ORPHA:306756	Epilepsiefonds	Nee	P 7
G-9-9	Hyperekplexia	ORPHA:306773	Dystonie Vereniging	Nee	P 59
G-18-4	Sulfite oxidase deficiency due to molybdenum cofactor deficiency type A	ORPHA:308386	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-18-9	Disorder of fructose metabolism	ORPHA:308463	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-18-10	Disorder of galactose metabolism	ORPHA:308467	Galactosemievereniging	Nee	P 12
G-22-1	Mevalonate kinase deficiency	ORPHA:309025	St KAISZ	Nee	P 135
G-18-13	Disorder of carnitine cycle and carnitine transport	ORPHA:309130	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-18-2	Disorder of carnitine cycle and carnitine transport	ORPHA:309130	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-18-15	Glycoproteinosis	ORPHA:309279	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-12-2	Disorder of iron metabolism and transport	ORPHA:309842	Hemochromatose Vereniging NL (HVN)	Ja	P 107
G-11-18	Gastric adenocarcinoma and proximal polyposis of the stomach	ORPHA:314022	Zonder patiëntenorganisatie	Nvt	P nvt
G-2-12	Ameloblastoma	ORPHA:314419	Patiëntenvereniging Hoofd-Hals	Ja	P 169
G-9-4	Primary progressive apraxia of speech	ORPHA:314566	Alzheimer NL	Ja	P 2
G-9-4	Primary progressive apraxia of speech	ORPHA:314566	FTD Lotgenoten	Ja	P 9
G-12-15	Primary systemic amyloidosis	ORPHA:314701	St Amyloïdose NL	Ja	P 138
G-12-15	Primary localized amyloidosis	ORPHA:314709	St Amyloïdose NL	Ja	P 138
G-3-1	Functioning pituitary adenoma	ORPHA:314753	NLse Hypofyse St (NHS)	Ja	P 65
G-3-15	SHOX-related short stature	ORPHA:314795	Belangenvereniging van Kleine Mensen (BVKM)	Nee	P 4
G-3-15	SHOX-related short stature	ORPHA:314795	NLse Hypofyse St (NHS) iom NVGG	Ja	P 65
G-14-11	Malignant peripheral nerve sheath tumor	ORPHA:3148	St Patiëntenplatform Sarcomen	Nee	P 94
G-8-7	Congenital pulmonary sequestration	ORPHA:3161	Zonder patiëntenorganisatie	Nvt	P nvt
G-8-22	Hypersensitivity pneumonitis	ORPHA:31740	Belangenvereniging Longfibrosepatiënten NL	Ja	P 152
G-1-8	Skeletal Ewing sarcoma	ORPHA:319	Vereniging Kinderkanker NL	Nee	P 82
G-1-8	Skeletal Ewing sarcoma	ORPHA:319	St Patiëntenplatform Sarcomen	Ja	P 94
G-22-1	Autoinflammatory syndrome of childhood	ORPHA:319719	St voor Afweerstoornissen (SAS)	Ja	P 72
G-22-1	Autoinflammatory syndrome of childhood	ORPHA:319719	St KAISZ	Nee	P 135
G-22-6	Autoinflammatory syndrome of childhood	ORPHA:319719	St KAISZ	Ja	P 135
G-22-9	Stiff person spectrum disorder	ORPHA:3198	NLse Meningitis St	Nee	P 118
G-1-4	Multiple osteochondromas	ORPHA:321	HME-MO Vereniging NL	Ja	P 15
G-1-4	Multiple osteochondromas	ORPHA:321	Vereniging Kinderkanker NL	Nee	P 82
G-1-8	Multiple osteochondromas	ORPHA:321	HME-MO Vereniging NL	Ja	P 15
G-1-8	Multiple osteochondromas	ORPHA:321	Vereniging Kinderkanker NL	Nee	P 82
G-13-3	Exstrophy-epispadias complex	ORPHA:322	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-11-16	Multiple paragangliomas associated with polycythemia	ORPHA:324299	NLse Vereniging voor Patiënten met Paragangliomen (NVPG)	Ja	P 29
G-11-16	Multiple paragangliomas associated with polycythemia	ORPHA:324299	Bijniervenvereniging (NVACP)	Nee	P 64
G-22-11	Chronic nonbacterial osteomyelitis/Chronic recurrent multifocal osteomyelitis	ORPHA:324964	St KAISZ	Ja	P 135
G-3-3	46,XY disorder of sex development of endocrine origin	ORPHA:325351	DSD NL	Ja	P 70
G-14-7	Juvenile idiopathic inflammatory myopathy	ORPHA:329888	Spierziekten NL	Ja	P 43
G-22-11	Juvenile idiopathic inflammatory myopathy	ORPHA:329888	Spierziekten NL	Ja	P 43
G-5-7	C3 glomerulonephritis	ORPHA:329931	Nierpatiënten Vereniging NL (NVN)	Ja	P 31

G-5-7	C3 glomerulonephritis	ORPHA:329931	Nationale vereniging voor lupus, APS, sclerodermie en MCTD (NVLE)	Ja	P 128
G-12-15	Wild type ATTR amyloidosis	ORPHA:330001	St Amyloïdose NL	Ja	P 138
G-0-1	Lead poisoning	ORPHA:330015	St OPS	Ja	P 220
G-0-1	Mercury poisoning	ORPHA:330021	St OPS	Ja	P 220
G-4-2	Dravet syndrome	ORPHA:33069	Epilepsiefonds	Nee	P 7
G-12-26	Congenital amegakaryocytic thrombocytopenia	ORPHA:3319	NLse Vereniging van Hemofilie-Patiënten (NVHP)	Nee	P 74
G-0-3	Idiopathic Hypersomnia	ORPHA:33208	Narcolepsie Vereniging NL (NVN)	Nee	P 210
G-0-4	Idiopathic hypersomnia	ORPHA:33208	Narcolepsie Vereniging NL (NVN)	Nee	P 210
G-12-10	Waldenström macroglobulinemia	ORPHA:33226	St Hematon	Ja	P 81
G-17-5	Trichothiodystrophy	ORPHA:33364	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Nee	P 56
G-17-5	Trichothiodystrophy	ORPHA:33364	St Amy and Friends	Nee	P 319
G-8-7	Tracheal agenesis	ORPHA:3346	Zonder patiëntenorganisatie	Nvt	P nvt
G-0-4	Kleine-Levin syndrome	ORPHA:33543	Zonder patiëntenorganisatie	Nvt	P nvt
G-1-2	Fibrodysplasia Ossificans Progressiva	ORPHA:337	FOP St NL	Ja	P 162
G-17-9	Neural tube defect	ORPHA:3388	Syringomyelie Patiënten Vereniging (SPV)	Nee	P 177
G-25-1	Tuberculosis	ORPHA:3389	Zonder patiëntenorganisatie	Nvt	P nvt
G-25-5	Tuberculosis	ORPHA:3389	Zonder patiëntenorganisatie	Nvt	P nvt
G-11-11	Soft tissue sarcoma	ORPHA:3394	Vereniging Kinderkanker NL	Nee	P 82
G-11-11	Soft tissue sarcoma	ORPHA:3394	St Patiëntenplatform Sarcomen	Ja	P 94
G-11-25	Soft tissue sarcoma	ORPHA:3394	Vereniging Kinderkanker NL	Nee	P 82
G-11-25	Soft tissue sarcoma	ORPHA:3394	St Patiëntenplatform Sarcomen	Ja	P 94
G-11-40	Soft tissue sarcoma	ORPHA:3394	Vereniging Kinderkanker NL	Nee	P 82
G-11-40	Soft tissue sarcoma	ORPHA:3394	St Patiëntenplatform Sarcomen	Ja	P 94
G-11-41	soft tissue sarcoma	ORPHA:3394	Vereniging Kinderkanker NL	Nee	P 82
G-11-41	soft tissue sarcoma	ORPHA:3394	St Patiëntenplatform Sarcomen	Ja	P 94
G-1-6	Soft tissue sarcoma	ORPHA:3394	Vereniging Kinderkanker NL	Nee	P 82
G-1-6	Soft tissue sarcoma	ORPHA:3394	St Patiëntenplatform Sarcomen	Ja	P 94
G-1-8	Soft tissue sarcoma	ORPHA:3394	Vereniging Kinderkanker NL	Nee	P 82
G-1-8	Soft tissue sarcoma	ORPHA:3394	St Patiëntenplatform Sarcomen	Ja	P 94
G-11-33	Germ cell tumor	ORPHA:3399	Vereniging Kinderkanker NL	Nee	P 82
G-11-33	Germ cell tumor	ORPHA:3399	St Zaadbalkanker	Ja	P 226
G-25-11	Viral hemorrhagic fever	ORPHA:341	Zonder patiëntenorganisatie	Nvt	P nvt
G-25-6	Viral hemorrhagic fever	ORPHA:341	Zonder patiëntenorganisatie	Nvt	P nvt
G-5-8	Autosomal dominant tubulointerstitial kidney disease	ORPHA:34149	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-25-11	Arbovirus fever	ORPHA:344	NLse Meningitis St	Nee	P 118
G-25-6	Arbovirus fever	ORPHA:344	NLse Meningitis St	Nee	P 118
G-18-7	glycogen storage disease due LAMP2 deficiency	ORPHA:34587	Spierziekten NL	Ja	P 43
G-18-7	glycogen storage disease due LAMP2 deficiency	ORPHA:34587	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-18-9	Fructose-1,6-biphosphatasedeficiency	ORPHA:348	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-18-2	Galactosemia	ORPHA:352	Galactosemievereniging	Nee	P 12
G-17-4	Autism spectrum disorder due to AUTS2 deficiency	ORPHA:352490	NLse Vereniging voor Autisme	Nee	P 26
G-17-10	Arterial thoracic outlet syndrome	ORPHA:357107	Harteraad	Ja	P 58

G-17-10	Arterial thoracic outlet syndrome	ORPHA:357107	RSI-vereniging	Nee	P 305
G-17-10	Venous thoracic outlet syndrome	ORPHA:357131	Harteraad	Ja	P 58
G-17-10	Venous thoracic outlet syndrome	ORPHA:357131	RSI-vereniging	Nee	P 305
G-5-2	Idiopathic nephrotic syndrome	ORPHA:357502	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-5-5	Idiopathic Nephrotic Syndrome	ORPHA:357502	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-11-18	Gastric linitis plastica	ORPHA:36273	Zonder patiëntenorganisatie	Nvt	P nvt
G-15-3	Genetic intestinal polyposis	ORPHA:363314	St Lynch Polyposis	Ja	P 93
G-11-17	Tumor of testis and paratestis	ORPHA:363472	St Zaadbalkanker	Ja	P 226
G-11-37	Tumor of testis and paratestis	ORPHA:363472	St Zaadbalkanker	Ja	P 226
G-11-12	Non-seminomatous germ cell tumor of testis	ORPHA:363494	Vereniging Kinderkanker NL	Nee	P 82
G-11-12	Non-seminomatous germ cell tumor of testis	ORPHA:363494	St Zaadbalkanker	Ja	P 226
G-11-12	Germ cell tumor of testis	ORPHA:363504	Vereniging Kinderkanker NL	Nee	P 82
G-11-12	Germ cell tumor of testis	ORPHA:363504	St Zaadbalkanker	Ja	P 226
G-11-33	Germ cell tumor of testis	ORPHA:363504	Vereniging Kinderkanker NL	Nee	P 82
G-11-33	Germ cell tumor of testis	ORPHA:363504	St Zaadbalkanker	Ja	P 226
G-11-33	Extragenitaal germ cell tumor	ORPHA:363579	Vereniging Kinderkanker NL	Nee	P 82
G-11-33	Extragenitaal germ cell tumor	ORPHA:363579	St Zaadbalkanker	Ja	P 226
G-22-9	Paraneoplastic neurologic syndrome	ORPHA:36388	NLse Meningitis St	Nee	P 118
G-1-5	Primary bone dysplasia	ORPHA:364526	Belangenvereniging van Kleine Mensen (BVKM)	Nee	P 4
G-1-5	Primary bone dysplasia	ORPHA:364526	Vereniging Osteogenesis Imperfecta (VOI)	Ja	P 53
G-1-5	Primary bone dysplasia	ORPHA:364526	Vereniging MED-SED	Ja	P 154
G-1-5	Primary bone dysplasia	ORPHA:364526	NLse Vereniging van Rugpatiënten 'de Wervelkolom' (NVRN)	Nee	P 172
G-1-5	Primary bone dysplasia	ORPHA:364526	Patiëntenvereniging Fibreuze Dysplasie	Ja	P 246
G-1-5	Primary bone dysplasia	ORPHA:364526	Klub Lange Mensen	Nee	P 269
G-3-17	Primary bone dysplasia	ORPHA:364526	Belangenvereniging van Kleine Mensen (BVKM)	Nee	P 4
G-3-17	Primary bone dysplasia	ORPHA:364526	Vereniging Osteogenesis Imperfecta (VOI)	Ja	P 53
G-3-17	Primary bone dysplasia	ORPHA:364526	Vereniging MED-SED	Nee	P 154
G-3-17	Primary bone dysplasia	ORPHA:364526	NLse Vereniging van Rugpatiënten 'de Wervelkolom' (NVRN)	Nee	P 172
G-3-17	Primary bone dysplasia	ORPHA:364526	Patiëntenvereniging Fibreuze Dysplasie	Ja	P 246
G-3-17	Primary bone dysplasia	ORPHA:364526	Klub Lange Mensen	Nee	P 269
G-1-5	Dysostosis	ORPHA:364559	LaPosa	Ja	P 17
G-1-5	Dysostosis	ORPHA:364559	Vereniging Kinderkanker NL	Nee	P 82
G-18-7	Glycogen storage disease due to acid maltase deficiency	ORPHA:365	Spierziekten NL	Ja	P 43
G-18-7	Glycogen storage disease due to acid maltase deficiency	ORPHA:365	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-18-3	Glycogen storage disease due to glycogen debranching enzyme deficiency	ORPHA:366	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-18-3	Glycogen storage disease due to glycogen branching enzyme deficiency	ORPHA:367	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-9-9	Myoclonus-dystonia syndrome	ORPHA:36899	Dystonie Vereniging	Nee	P 59
G-18-3	GSD due to liver glycogen phosphorylase deficiency	ORPHA:369	NLse Leverpatiënten Vereniging (NLV)	Nee	P 19
G-13-1	Interstitial cystitis	ORPHA:37202	Interstitiële Cystitis Patiëntenvereniging (ICP)	Ja	P 173
G-21-8	Anti-glomerular basement membrane disease	ORPHA:375	Vasculitis St	Ja	P 51
G-9-9	Generalized isolated dystonia	ORPHA:376724	Dystonie Vereniging	Nee	P 59
G-10-7	Gorlin syndrome	ORPHA:377	Vereniging voor Ectodermale Dysplasie (VVED)	Nee	P 55

G-22-1	Schnitzler syndrome	ORPHA:37748	St KAISZ	Nee	P 135
G-9-9	Neurodegeneration with brain iron accumulation	ORPHA:385	Alzheimer NL	Ja	P 2
G-9-9	Neurodegeneration with brain iron accumulation	ORPHA:385	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-9-9	Neurodegeneration with brain iron accumulation	ORPHA:385	St IJzersterk	Ja	P 189
G-9-9	Neurodegeneration with brain iron accumulation	ORPHA:385	Kans voor PKAN-kinderen	Nee	P 289
G-7-1	Hirschsprung disease	ORPHA:388	Vereniging Ziekte van Hirschsprung	Ja	P 123
G-7-12	Hirschsprung disease	ORPHA:388	Vereniging Ziekte van Hirschsprung	Ja	P 123
G-7-3	Hirschsprung disease	ORPHA:388	Vereniging Ziekte van Hirschsprung	Ja	P 123
G-7-6	Hirschsprung disease	ORPHA:388	Vereniging Ziekte van Hirschsprung	Ja	P 123
G-21-5	Langerhans cell histiocytosis	ORPHA:389	Histiocytose NL	Nee	P 46
G-25-6	Histoplasmosis	ORPHA:390	Huid NL	Ja	P 161
G-11-34	Uveal melanoma	ORPHA:39044	St Melanoom	Nee	P 96
G-11-47	Uveal melanoma	ORPHA:39044	St Melanoom	Nee	P 96
G-1-2	X-linked osteoporosis with fractures	ORPHA:391330	NLse Vereniging van Rugpatiënten 'de Wervelkolom' (NVRN)	Nee	P 172
G-11-41	Glomus tumor	ORPHA:391651	Zonder patiëntenorganisatie	Nvt	P nvt
G-9-8	Off-periods in Parkinson disease not responding to oral treatment	ORPHA:391655	Parkinson Vereniging NL	Ja	P 35
G-7-12	Necrotizing enterocolitis	ORPHA:391673	Care4neo	Ja	P 114
G-7-12	Necrotizing enterocolitis	ORPHA:391673	Vereniging Ziekte van Hirschsprung	Ja	P 123
G-7-3	Necrotizing enterocolitis	ORPHA:391673	Care4neo	Nee	P 114
G-7-5	Necrotizing enterocolitis	ORPHA:391673	Care4neo	Ja	P 114
G-13-2	Classic homocystinuria	ORPHA:394	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Nee	P 56
G-11-37	Malignant tumor of penis	ORPHA:398043	NFK-Patiëntenplatform zeldzame kankers	Ja	P 18
G-3-16	Prader-Willi-like syndrome	ORPHA:398073	Prader-Willi St	Ja	P 236
G-12-10	Graft versus hoSt disease	ORPHA:39812	St Hematon	Ja	P 81
G-12-13	Graft versus hoSt disease	ORPHA:39812	St Hematon	Ja	P 81
G-11-15	Malignant epithelial tumor of ovary	ORPHA:398934	St Olijf	Nee	P 88
G-11-32	Malignant epithelial tumor of ovary	ORPHA:398934	St Olijf	Nee	P 88
G-11-32	Malignant non-epithelial tumor of ovary	ORPHA:398940	St Olijf	Nee	P 88
G-9-10	Huntington disease	ORPHA:399	Vereniging van Huntington	Nee	P 16
G-9-6	Huntington disease	ORPHA:399	Vereniging van Huntington	Nee	P 16
G-9-9	Huntington disease	ORPHA:399	Vereniging van Huntington	Nee	P 16
G-3-10	Rare genetic male infertility	ORPHA:399980	Freja	Nee	P 110
G-3-10	Rare genetic male infertility	ORPHA:399980	NLse Klinefelter Vereniging	Nee	P 117
G-15-13	Familial atypical multiple mole melanoma syndrome	ORPHA:404560	St Melanoom	Nee	P 96
G-22-11	Polyarticular juvenile idiopathic arthritis	ORPHA:404580	Jeugdreuma Vereniging NL	Nee	P 134
G-25-1	Pulmonary non-tuberculous mycobacterial infection	ORPHA:411703	Zonder patiëntenorganisatie	Nvt	P nvt
G-18-12	Dysbetalipoproteinemia	ORPHA:412	Harteraad	Nee	P 58
G-9-4	PRKAR1B-related neurodegenerative dementia with intermediate filaments	ORPHA:412066	Alzheimer NL	Ja	P 2
G-18-1	Gyrate atrophy of choroid and retina	ORPHA:414	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-18-2	Gyrate atrophy of choroid and retina	ORPHA:414	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-9-3	Bilirubin encephalopathy	ORPHA:415286	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Nee	P 56
G-5-2	Primary Hyperoxaluria	ORPHA:416	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Nee	P 56

G-3-13	Congenital adrenal hyperplasia	ORPHA:418	Bijniervereniging (NVACP)	Nee	P 64
G-3-2	Congenital adrenal hyperplasia	Orpha:418	Bijniervereniging (NVACP)	Nee	P 64
G-18-3	Medium chain acyl-CoA dehydrogenase deficiency	ORPHA:42	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-17-11	Malan overgrowth syndrome	ORPHA:420179	Zeldsamen	Nee	P 290
G-11-16	Semicircular canal dehiscence syndrome	ORPHA:420402	Zonder patiëntenorganisatie	Nvt	P nvt
G-2-11	Semicircular canal dehiscence syndrome	ORPHA:420402	Zonder patiëntenorganisatie	Nvt	P nvt
G-9-5	Visual Snow syndrome	ORPHA:420556	Hoofdpijnnet	Ja	P 32
G-22-9	Autoimmune encephalopathy with parasomnia and obstructive sleep apnea	ORPHA:420789	Apneuvereniging	Nee	P 68
G-22-9	Autoimmune encephalopathy with parasomnia and obstructive sleep apnea	ORPHA:420789	Nlse Meningitis St	Nee	P 118
G-9-11	Rare autonomic nervous system disorder	ORPHA:423662	Zonder patiëntenorganisatie	Nvt	P nvt
G-11-18	Hereditary gastric cancer	ORPHA:423776	Zonder patiëntenorganisatie	Nvt	P nvt
G-15-1	Hereditary gastric cancer	ORPHA:423776	Zonder patiëntenorganisatie	Nvt	P nvt
G-11-31	Rare carcinoma of small intestine	ORPHA:423957	St Darmkanker	Nee	P 304
G-15-7	Inherited digestive cancer-predisposing syndrome	ORPHA:425003	Maag Lever Darm St	Nee	P 105
G-8-4	Pulmonary veno-occlusive disease and/or pulmonary capillary haemangiomatosis	ORPHA:431353	St Pulmonale Hypertensie	Ja	P 158
G-26-6	Fetal lower urinary tract obstruction	ORPHA:435365	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-1-7	Hypophosphatemic Rickets	ORPHA:437	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Nee	P 56
G-26-5	Placental insufficiency	ORPHA:439167	Hellp St	Nee	P 113
G-26-5	Placental insufficiency	ORPHA:439167	Care4Neo	Ja	P 114
G-9-3	Pediatric arterial ischemic stroke	ORPHA:439175	Hersenletsel.nl	Nee	P 91
G-14-11	Non-recovering obstetric brachial plexus lesion	ORPHA:439202	Erbse Parese Vereniging NL	Nee	P 8
G-15-3	Familial colorectal cancer type X	ORPHA:440437	St Lynch Polyposis	Ja	P 93
G-9-11	Pure autonomic failure	ORPHA:441	Zonder patiëntenorganisatie	Nvt	P nvt
G-9-5	Hemicrania continua	ORPHA:443070	Hoofdpijnnet	Ja	P 32
G-6-3	Central serous chorioretinopathy	ORPHA:443079	Oogvereniging	Nee	P 100
G-26-3	Postpartum Psychose	ORPHA:443173	Me Mam	Ja	P 215
G-15-12	Hereditary nonpolyposis colon cancer	ORPHA:443909	St Lynch Polyposis	Ja	P 93
G-12-15	Hereditary amyloidosis	ORPHA:444116	St Amyloïdose NL	Ja	P 138
G-12-4	Paroxysmal nocturnal hemoglobinuria	ORPHA:447	St AA & PNH	Nee	P 104
G-20-6	IgG4-related sclerosing cholangitis	ORPHA:447764	NLse Leverpatiënten Vereniging (NLV)	Ja	P 19
G-6-6	Cerebral visual impairment	ORPHA:447788	Oogvereniging	Nee	P 100
G-12-1	Hemophilia	ORPHA:448	NLse Vereniging van Hemofilie-Patiënten (NVHP)	Nee	P 74
G-12-11	Hemophilia	ORPHA:448	NLse Vereniging van Hemofilie-Patiënten (NVHP)	Nee	P 74
G-12-12	Hemophilia	ORPHA:448	NLse Vereniging van Hemofilie-Patiënten (NVHP)	Nee	P 74
G-12-14	Hemophilia	ORPHA:448	NLse Vereniging van Hemofilie-Patiënten (NVHP)	Nee	P 74
G-12-6	Hemophilia	ORPHA:448	NLse Vereniging van Hemofilie-Patiënten (NVHP)	Nee	P 74
G-12-8	Hemophilia	ORPHA:448	NLse Vereniging van Hemofilie-Patiënten (NVHP)	Nee	P 74
G-11-2	Gastrointestinal stromal tumor	ORPHA:44890	St Patiëntenplatform Sarcomen	Ja	P 94
G-11-31	Gastrointestinal stromal tumor	ORPHA:44890	St Patiëntenplatform Sarcomen	Ja	P 94
G-11-40	Gastrointestinal stromal tumor	ORPHA:44890	St Patiëntenplatform Sarcomen	Ja	P 94
G-1-8	Gastrointestinal stromal tumor	ORPHA:44890	St Patiëntenplatform Sarcomen	Ja	P 94
G-8-14	Pleural empyema	ORPHA:449266	Zonder patiëntenorganisatie	Nvt	P nvt

G-21-5	IgG4-related pachymeningitis	ORPHA:449427	St voor Afweerstoornissen (SAS)	Ja	P 72
G-21-5	IgG4-related pachymeningitis	ORPHA:449427	Nlse Meningitis St	Nee	P 118
G-6-5	IgG4-related ophthalmic disease	ORPHA:449563	Oogvereniging	Nee	P 100
G-12-17	Plasma cell leukemia	ORPHA:454714	St Hematon	Ja	P 81
G-7-11	Isolated tracheoesophageal fistula	ORPHA:454750	Vereniging voor Ouderen en Kinderen met Slokdarmafsluiting (VOKS)	Ja	P 124
G-9-4	Corticobasal syndrome	ORPHA:454887	Alzheimer NL	Ja	P 2
G-9-4	Corticobasal syndrome	ORPHA:454887	Parkinson Vereniging NL	Ja	P 35
G-1-3	Pseudohypoparathyroidism with Albright hereditary osteodystrophy	ORPHA:457059	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-24-6	Idiopathic spontaneous coronary artery dissection	ORPHA:458718	Contactgroep Marfan NL	Ja	P 147
G-3-3	Gender dysphoria	ORPHA:459690	DSD NL	Ja	P 70
G-12-10	Primary central nervous system lymphoma	ORPHA:46135	St Hematon	Ja	P 81
G-17-1	DYRK1A-related intellectual disability syndrome	ORPHA:464306	Zeldsamen	Ja	P 290
G-6-5	Euthyroid Graves orbitopathy	ORPHA:466682	Schildklier Organisatie NL (SON)	Ja	P 60
G-6-5	Euthyroid Graves orbitopathy	ORPHA:466682	Oogvereniging	Nee	P 100
G-24-1	Cerebral arteriovenous malformation	ORPHA:46724	CMTC-OVM	Ja	P 92
G-24-1	Cerebral arteriovenous malformation	ORPHA:46724	HEVAS	Nee	P 131
G-24-9	Cerebral arteriovenous malformation	ORPHA:46724	CMTC-OVM	Ja	P 92
G-24-9	Cerebral arteriovenous malformation	ORPHA:46724	HEVAS	Nee	P 131
G-18-9	Hereditary fructose intolerance	ORPHA:469	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-22-13	X-linked agammaglobulinemia	ORPHA:47	St voor Afweerstoornissen (SAS)	Ja	P 72
G-22-9	Pediatric Multiple Sclerosis	ORPHA:477738	MS Vereniging NL	Nee	P 21
G-24-12	Genetic cerebral small vessel disease	ORPHA:477754	Vereniging HCHWA-D	Nee	P 14
G-9-7	Moyamoya angiopathy	ORPHA:477768	Hersenletsel.nl	Nee	P 91
G-9-7	Rare disorder with a moyamoya angiopathy	ORPHA:477771	Hersenletsel.nl	Nee	P 91
G-2-13	Primary condylar hyperplasia	ORPHA:477781	LaPosa	Ja	P 17
G-20-7	Choledochal cyst	ORPHA:480501	Nlse Leverpatiënten Vereniging (NLV)	Ja	P 19
G-1-8	Aneurysmal bone cyst	ORPHA:480553	Vereniging Kinderkanker NL	Nee	P 82
G-24-12	HTRA1-related autosomal dominant cerebral small vessel disease	ORPHA:482077	Alzheimer NL	Ja	P 2
G-26-4	Genetic non-acquired premature ovarian failure	ORPHA:485382	Freya	Nee	P 110
G-26-4	Genetic non-acquired premature ovarian failure	ORPHA:485382	St POI-POF	Ja	P 312
G-17-4	Monosomy 22q13.3 (Phelan-McDermid syndrome)	ORPHA:48652	Zeldsamen	Nee	P 290
G-21-7	IgG4-related retroperitoneal fibrosis	ORPHA:49041	St RPF NL	Ja	P 280
G-11-32	Vulvar carcinoma	ORPHA:494418	St Olijf	Nee	P 88
G-11-48	Vulvar carcinoma	ORPHA:494418	St Olijf	Nee	P 88
G-7-1	Sacrococcygeal teratoma	ORPHA:494421	Vereniging Kinderkanker NL	Nee	P 82
G-7-3	Sacrococcygeal teratoma	ORPHA:494421	Vereniging Kinderkanker NL	Nee	P 82
G-7-6	Sacrococcygeal teratoma	ORPHA:494421	Vereniging Kinderkanker NL	Nee	P 82
G-11-15	Vulvar squamous cell carcinoma	ORPHA:494448	St Olijf	Nee	P 88
G-11-32	Vulvar squamous cell carcinoma	ORPHA:494448	St Olijf	Nee	P 88
G-9-6	Rare hyperkinetic movement disorder	ORPHA:494457	Zonder patiëntenorganisatie	Nvt	P nvt
G-11-43	Squamous cell carcinoma of the hypopharynx	ORPHA:494547	Patiëntenvereniging Hoofd-Hals	Ja	P 169
G-11-28	Squamous cell carcinoma of the larynx	ORPHA:494550	Patiëntenvereniging Hoofd-Hals	Ja	P 169

G-11-43	Squamous cell carcinoma of the larynx	ORPHA:494550	Patiëntenvereniging Hoofd-Hals	Ja	P 169
G-17-1	SIN3A-related intellectual disability syndrome/Witteveen-Kolk syndrome	ORPHA:500163	Zeldsamen	Ja	P 290
G-11-43	Squamous cell carcinoma of the nasal cavity and paranasal sinuses	ORPHA:500464	Patiëntenvereniging Hoofd-Hals	Ja	P 169
G-11-28	Squamous cell carcinoma of the oropharynx	ORPHA:500478	Patiëntenvereniging Hoofd-Hals	Ja	P 169
G-11-43	Squamous cell carcinoma of the oropharynx	ORPHA:500478	Patiëntenvereniging Hoofd-Hals	Ja	P 169
G-2-14	Cochleovestibular dysplasia	ORPHA:502305	St Hoormij	Nee	P 33
G-2-14	Cochlear nerve deficiency	ORPHA:502318	St Hoormij	Nee	P 33
G-11-28	Squamous cell carcinoma of oral cavity and lip	ORPHA:502369	Patiëntenvereniging Hoofd-Hals	Ja	P 169
G-11-43	Squamous cell carcinoma of oral cavity and lip	ORPHA:502369	Patiëntenvereniging Hoofd-Hals	Ja	P 169
G-11-39	Pleural mesothelioma	ORPHA:50251	Asbestslachtoffers Vereniging NL (AVN)	Ja	P 109
G-8-10	Pleural mesothelioma	ORPHA:50251	Asbestslachtoffers Vereniging NL (AVN)	Ja	P 109
G-3-17	Neuroendocrine neoplasms of the pancreas	ORPHA:506052	St NET-groep	Ja	P 62
G-3-17	Neuroendocrine neoplasms of the pancreas	ORPHA:506052	Alvleeskliervereniging (AVKV)	Nee	P 87
G-3-17	Neuroendocrine neoplasms of the pancreas	ORPHA:506052	Living with hope	Nee	P 260
G-13-3	Rare disorder potentially indicated for kidney transplant	ORPHA:506213	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-5-2	Rare disorder potentially indicated for kidney transplant	ORPHA:506213	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-8-5	Rare disorder potentially indicated for lung transplant	ORPHA:506222	St Pulmonale Hypertensie	Ja	P 158
G-25-6	Leishmaniasis	ORPHA:507	Huid NL	Ja	P 161
G-25-6	Leptospirosis	ORPHA:509	Nlse Meningitis St	Nee	P 118
G-12-10	Acute lymphoblastic leukemia	ORPHA:513	St Hematon	Ja	P 81
G-12-17	Acute lymphoblastic leukemia	ORPHA:513	St Hematon	Ja	P 81
G-12-19	Acute lymphoblastic leukemia	ORPHA:513	St Hematon	Ja	P 81
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G-14-11	Anterior cutaneous nerve entrapment syndrome	ORPHA:51890	ACNES Foundation	Nee	P 296
G-14-9	Anterior cutaneous nerve entrapment syndrome	ORPHA:51890	St ACNES	Nee	P 295
G-14-9	Anterior cutaneous nerve entrapment syndrome	ORPHA:51890	ACNES Foundation	Nee	P 296
G-12-10	Acute myeloid leukemia	ORPHA:519	St Hematon	Ja	P 81
G-12-13	Acute myeloid leukemia	ORPHA:519	St Hematon	Ja	P 81
G-12-3	Acute myeloid leukemia	ORPHA:519	St Hematon	Ja	P 81
G-6-4	Infective keratitis	ORPHA:519278	Oogvereniging	Nee	P 100
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G-6-4	Rare choroidal disorder	ORPHA:519309	Oogvereniging	Nee	P 100
G-6-1	Rare retinal disorder	ORPHA:519315	Oogvereniging - Patiëntengroep Retina	Nee	P 100
G-6-1	Rare retinal disorder	ORPHA:519315	Macula Vereniging (MD)	Nee	P 125
G-6-4	Rare retinal disorder	ORPHA:519315	Oogvereniging - Patiëntengroep Retina	Nee	P 100
G-6-4	Rare retinal disorder	ORPHA:519315	Macula Vereniging (MD)	Nee	P 125
G-20-5	Alagille syndrome	ORPHA:52	NLse Leverpatiënten Vereniging (NLV)	Ja	P 19
G-12-3	Chronic myeloid leukemia	ORPHA:521	St Hematon	Ja	P 81
G-12-9	Chronic myeloid leukemia	ORPHA:521	St Hematon	Ja	P 81
G-15-8	Li-Fraumeni syndrome	ORPHA:524	St Diagnose Kanker (SDK)	Nee	P 183
G-21-2	MALT lymphoma	ORPHA:52417	St Hematon	Ja	P 81
G-21-2	MALT lymphoma	ORPHA:52417	Vereniging Kinderkanker NL	Nee	P 82

G-0-2	Prepubertal anorexia nervosa	ORPHA:525738	Weet: St rond eetstoornissen	Nee	P 221
G-12-13	Myelodysplastic syndrome	ORPHA:52688	St Hematon	Ja	P 81
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G-21-8	Vasculitis	ORPHA:52759	Vasculitits St	Ja	P 51
G-22-11	Vasculitis	ORPHA:52759	Vasculitits St	Ja	P 51
G-22-2	Vasculitis	ORPHA:52759	Vasculitits St	Ja	P 51
G-22-5	Vasculitis	ORPHA:52759	Vasculitits St	Ja	P 51
G-21-2	Systemic lupus erythematosus	ORPHA:536	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-21-2	Systemic lupus erythematosus	ORPHA:536	Nationale vereniging voor lupus, APS, sclerodermie en MCTD (NVLE)	Ja	P 128
G-21-6	Systemic lupus erythematosus	ORPHA:536	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-21-6	Systemic lupus erythematosus	ORPHA:536	Nationale vereniging voor lupus, APS, sclerodermie en MCTD (NVLE)	Ja	P 128
G-21-9	Systemic lupus erythematosus	ORPHA:536	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-21-9	Systemic lupus erythematosus	ORPHA:536	Nationale vereniging voor lupus, APS, sclerodermie en MCTD (NVLE)	Ja	P 128
G-21-9	Systemic lupus erythematosus	ORPHA:536	Huid NL	Ja	P 161
G-17-1	Rasopathies	ORPHA:536391	Neurofibromatosevereniging NL (NFVN)	Ja	P 30
G-17-1	Rasopathies	ORPHA:536391	St Noonan Syndroom	Ja	P 47
G-17-5	Rasopathies	ORPHA:536391	Neurofibromatosevereniging NL (NFVN)	Ja	P 30
G-17-5	Rasopathies	ORPHA:536391	St Noonan Syndroom	Ja	P 47
G-12-23	Primary cutaneous lymphoma	ORPHA:542	NFK-Patiëntenplatform zeldzame kankers	Ja	P 18
G-12-23	Primary cutaneous lymphoma	ORPHA:542	St Hematon	Ja	P 81
G-12-23	Primary cutaneous lymphoma	ORPHA:542	St Huidlymfoom	Ja	P 311
G-12-17	CAR T cell therapy-associated cytokine release syndrome	ORPHA:542323	St Hematon	Ja	P 81
G-16-7	Left ventricular noncompaction	ORPHA:54260	Harteraad	Ja	P 58
G-20-4	Hepatocellular adenoma	ORPHA:54272	NLse Leverpatiënten Vereniging (NLV)	Ja	P 19
G-12-17	Diffuse large B-cell lymphoma	ORPHA:544	St Hematon	Ja	P 81
G-21-8	Hemolytic uremic syndrome	ORPHA:544458	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-3-13	Craniopharyngioma	ORPHA:54595	NLse Hypofyse St (NHS)	Ja	P 65
G-3-13	Craniopharyngioma	ORPHA:54595	Vereniging Kinderkanker NL	Nee	P 82
G-12-10	Non Hodgkin Lymphoma	ORPHA:547	St Hematon	Ja	P 81
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G-20-6	Lymphoplasmacytic inflammatory pseudotumor of the liver	ORPHA:555437	NLse Leverpatiënten Vereniging (NLV)	Ja	P 19
G-7-1	Isolated anorectal malformation	ORPHA:557	Vereniging Anusatresie	Nee	P 120
G-16-7	Marfan syndrome	ORPHA:558	Contactgroep Marfan NL	Ja	P 147
G-24-5	Marfan syndrome	ORPHA:558	Contactgroep Marfan NL	Ja	P 147
G-24-6	Marfan syndrome	ORPHA:558	Contactgroep Marfan NL	Ja	P 147
G-7-9	Idiopathic gastroparesis	ORPHA:558411	Maag Lever Darm St	Nee	P 105
G-7-9	Idiopathic gastroparesis	ORPHA:558411	Vereniging Ziekte van Hirschsprung	Ja	P 123
G-1-8	Chondrosarcoma	ORPHA:55880	Vereniging Kinderkanker NL	Nee	P 82
G-1-8	Chondrosarcoma	ORPHA:55880	St Patiëntenplatform Sarcomen	Ja	P 94
G-1-8	Adamantinoma	ORPHA:55881	Vereniging Kinderkanker NL	Nee	P 82
G-1-8	Adamantinoma	ORPHA:55881	St Patiëntenplatform Sarcomen	Ja	P 94

G-11-31	Carcinoma of gallbladder and extrahepatic biliary tract	ORPHA:56044	NLse Leverpatiënten Vereniging (NLV)	Ja	P 19
G-20-2	Carcinoma of gallbladder and extrahepatic biliary tract	ORPHA:56044	NFK-Patiëntenplatform zeldzame kankers	Ja	P 18
G-20-2	Carcinoma of gallbladder and extrahepatic biliary tract	ORPHA:56044	NLse Leverpatiënten Vereniging (NLV)	Ja	P 19
G-17-11	Marshall-Smith syndrome	ORPHA:561	Marshall Smith Syndroom Research Foundation	Ja	P 146
G-20-6	Primary biliary cholangitis/primary sclerosing cholangitis and autoimmune hepatitis	ORPHA:562639	NLse Leverpatiënten Vereniging (NLV)	Ja	P 19
G-16-7	Peripartum cardiomyopathy	ORPHA:563	Harteraad	Ja	P 58
G-13-3	Genetic nephrotic syndrome	ORPHA:564127	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-17-8	22q11.2 deletion syndrome	ORPHA:567	St Steun 22q11	Nee	P 271
G-5-2	Disorder with multisystemic involvement and glomerulopathy	ORPHA:567562	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-5-2	Nephrotic Syndrome without extrarenal manifestations	ORPHA:567564	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-24-10	Primary lymphedema without systemic or visceral involvement	ORPHA:568041	CMTC-OVM	Ja	P 92
G-24-10	Primary lymphedema without systemic or visceral involvement	ORPHA:568041	HEVAS	Nee	P 131
G-24-10	Primary lymphedema without systemic or visceral involvement	ORPHA:568041	NL Net	Ja	P 142
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G-24-10	Disorder with multisystemic involvement and primary lymphedema	ORPHA:568047	NL Net	Ja	P 142
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G-18-10	Galactose mutarotase deficiency	ORPHA:570422	Galactosemievereniging	Nee	P 12
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G-3-7	Pheochromocytoma-paraganglioma	ORPHA:573163	Bijniervereniging (NVACP)	Nee	P 64
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G-25-11	Middle EaSt respiratory syndrome	ORPHA:576074	Zonder patiëntenorganisatie	Nvt	P nvt
G-25-6	Middle EaSt respiratory syndrome	ORPHA:576074	Zonder patiëntenorganisatie	Nvt	P nvt
G-8-14	Cystic fibrosis	ORPHA:586	NLse Cystic Fibrosis St (NCFS)	Ja	P 159
G-8-17	Cystic fibrosis	ORPHA:586	NLse Cystic Fibrosis St (NCFS)	Ja	P 159
G-8-20	Cystic fibrosis	ORPHA:586	NLse Cystic Fibrosis St (NCFS)	Ja	P 159
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G-17-11	Menke-Hennekam syndrome	ORPHA:592574	Zeldsamen	Nee	P 290
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G-2-13	Recurrent Respiratory Papillomatosis	ORPHA:60032	Zonder patiëntenorganisatie	Nvt	P nvt
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G-13-3	Alport syndrome	ORPHA:63	Nierpatiënten Vereniging NL (NVN)	Ja	P 31

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G-3-15	Non-acquired isolated growth hormone deficiency	ORPHA:631	NVGG - Nlse vereniging voor groeihoormoondeficiëntie en	Nee	P 194
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G-17-5	Neurofibromatosis type 1	ORPHA:636	Neurofibromatosevereniging NL (NFVN)	Ja	P 30
G-11-16	Neurofibromatosis type 2	ORPHA:637	Neurofibromatosevereniging NL (NFVN)	Ja	P 30
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G-1-1	Osteogenesis imperfecta	ORPHA:666	Vereniging Osteogenesis Imperfecta (VOI)	Ja	P 53
G-1-5	Osteogenesis imperfecta	ORPHA:666	Vereniging Osteogenesis Imperfecta (VOI)	Ja	P 53
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G-1-8	Osteosarcoma	ORPHA:668	Vereniging Kinderkanker NL	Nee	P 82
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G-12-10	B-cell chronic lymphocytic leukemia	ORPHA:67038	St Hematon	Ja	P 81
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G-25-11	Malaria	ORPHA:673	Zonder patiëntenorganisatie	Nvt	P nvt
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G-17-14	Rare chromosomal anomaly	ORPHA:68335	XXX-Contactgroep Triple-X Syndroom	Nee	P 178
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G-10-3	Rare genetic skin disease	ORPHA:68346	Vereniging voor Ichthyosisnetwerken	Ja	P 237
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G-10-7	Rare genetic skin disease	ORPHA:68346	Vereniging voor Ichthyosisnetwerken	Ja	P 237
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G-2-1	Rare deafness	ORPHA:68361	Federatie van ouders van dove kinderen (FODOK)	Nee	P 209

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G-2-1	Rare deafness	ORPHA:68361	NLse Federatie van Ouders van Slechthorende kinderen en van kinderen met	Nee	P 321
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G-2-14	Rare deafness	ORPHA:68361	Federatie van ouders van dove kinderen (FODOK)	Nee	P 209
G-2-14	Rare deafness	ORPHA:68361	NLse Federatie van Ouders van Slechthorende kinderen en van kinderen met	Nee	P 321
G-2-6	Rare deafness	ORPHA:68361	St Hoornmij	Nee	P 33
G-2-6	Rare deafness	ORPHA:68361	Federatie van ouders van dove kinderen (FODOK)	Nee	P 209
G-2-6	Rare deafness	ORPHA:68361	NLse Federatie van Ouders van Slechthorende kinderen en van kinderen met	Nee	P 321
G-9-1	Rare dystonia	ORPHA:68363	Dystonie Vereniging	Nee	P 59
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G-12-11	Hemoglobinopathy	ORPHA:68364	OSCAR Nederland	Ja	P 73
G-12-12	Hemoglobinopathy	ORPHA:68364	OSCAR Nederland	Ja	P 73
G-12-20	Hemoglobinopathy	ORPHA:68364	OSCAR Nederland	Ja	P 73
G-12-25	Hemoglobinopathy	ORPHA:68364	OSCAR Nederland	Ja	P 73
G-18-11	Lysosomal disease	ORPHA:68366	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-18-15	Lysosomal disease	ORPHA:68366	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-18-2	Lysosomal disease	ORPHA:68366	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-18-13	Rare inborn errors of metabolism	ORPHA:68367	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-18-15	Rare inborn errors of metabolism	ORPHA:68367	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-18-2	Rare inborn errors of metabolism	ORPHA:68367	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-18-2	Peroxisomal disease	ORPHA:68373	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
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G-14-4	Mitochondrial disease	ORPHA:68380	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-14-4	Mitochondrial disease	ORPHA:68380	St Nemo	Ja	P 199
G-14-4	Mitochondrial disease	ORPHA:68380	Belangenvereniging LOA/LHON	Ja	P 274
G-14-4	Mitochondrial disease	ORPHA:68380	Cure ADOA Foundation	Ja	P 281
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G-9-9	Neurometabolic disease	ORPHA:68385	Spierziekten NL	Ja	P 43
G-9-9	Neurometabolic disease	ORPHA:68385	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-9-9	Neurometabolic disease	ORPHA:68385	St IJzersterk	Ja	P 189
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G-11-2	Rare bone tumor	ORPHA:68411	Vereniging Kinderkanker NL	Nee	P 82
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G-1-8	Rare bone tumor	ORPHA:68411	HME-MO Vereniging NL	Ja	P 15
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G-3-17	Rare parathyroid disease and phosphocalcic metabolism anomaly	ORPHA:68415	Zonder patiëntenorganisatie	Nvt	P nvt
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G-7-10	Radiation proctitis	ORPHA:70475	Vereniging Ziekte van Hirschsprung	Ja	P 123
G-7-10	Radiation proctitis	ORPHA:70475	St Darmkanker	Nee	P 304
G-11-18	Carcinoma of esophagus	ORPHA:70482	Zonder patiëntenorganisatie	Nvt	P nvt
G-11-31	Cholangiocarcinoma	ORPHA:70567	NFK-Patiëntenplatform zeldzame kankers	Ja	P 18
G-11-31	Cholangiocarcinoma	ORPHA:70567	NLse Leverpatiënten Vereniging (NLV)	Ja	P 19
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G-20-2	Cholangiocarcinoma	ORPHA:70567	NLse Leverpatiënten Vereniging (NLV)	Ja	P 19
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G-8-18	Bronchopulmonary dysplasia	ORPHA:70589	Care4Neo	Nee	P 114
G-8-9	Bronchopulmonary dysplasia	ORPHA:70589	Care4Neo	Nee	P 114
G-8-21	Chronic thromboembolic pulmonary hypertension	ORPHA:70591	St Pulmonale Hypertensie	Ja	P 158
G-8-4	Chronic thromboembolic pulmonary hypertension	ORPHA:70591	St Pulmonale Hypertensie	Ja	P 158
G-8-1	Rare pulmonary hypertension	ORPHA:71198	St Pulmonale Hypertensie	Ja	P 158
G-8-13	Rare pulmonary hypertension	ORPHA:71198	St Pulmonale Hypertensie	Ja	P 158
G-8-4	Rare pulmonary hypertension	ORPHA:71198	St Pulmonale Hypertensie	Ja	P 158
G-8-5	Rare pulmonary hypertension	ORPHA:71198	St Pulmonale Hypertensie	Ja	P 158
G-12-8	Rare hemorrhagic disorder due to a constitutional platelet anomaly	ORPHA:71202	NLse Vereniging van Hemofilie-Patiënten (NVHP)	Nee	P 74
G-12-22	Autoimmune thrombocytopenia	ORPHA:71203	ITP vereniging	Ja	P 79

G-11-19	Rare soft tissue tumor	ORPHA:71209	Vereniging Kinderkanker NL	Nee	P 82
G-11-19	Rare soft tissue tumor	ORPHA:71209	St Patiëntenplatform Sarcomen	Ja	P 94
G-11-2	Rare soft tissue tumor	ORPHA:71209	Vereniging Kinderkanker NL	Nee	P 82
G-11-2	Rare soft tissue tumor	ORPHA:71209	St Patiëntenplatform Sarcomen	Ja	P 94
G-11-25	Rare soft tissue tumor	ORPHA:71209	Vereniging Kinderkanker NL	Nee	P 82
G-11-25	Rare soft tissue tumor	ORPHA:71209	St Patiëntenplatform Sarcomen	Ja	P 94
G-1-8	Rare soft tissue tumor	ORPHA:71209	Vereniging Kinderkanker NL	Nee	P 82
G-1-8	Rare soft tissue tumor	ORPHA:71209	St Patiëntenplatform Sarcomen	Ja	P 94
G-22-9	Neuromyelitis optica spectrum disorder	ORPHA:71211	MS Vereniging NL	Nee	P 21
G-22-9	Neuromyelitis optica spectrum disorder	ORPHA:71211	Oogvereniging	Nee	P 100
G-18-1	Classic glucose transporter type 1 deficiency syndrome	ORPHA:71277	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-9-9	Psychogenic movement disorders	ORPHA:71519	Dystonie Vereniging	Nee	P 59
G-18-2	Phenylketonuria	ORPHA:716	PKU Vereniging NL	Ja	P 37
G-18-8	Phenylketonuria	ORPHA:716	PKU Vereniging NL	Ja	P 37
G-2-13	Isolated Pierre Robin syndrome	ORPHA:718	St Pierre Robin Europe	Nee	P 279
G-2-2	Isolated Pierre Robin Syndrome	ORPHA:718	St Pierre Robin Europe	Nee	P 279
G-2-7	Isolated Pierre Robin syndrome	ORPHA:718	St Pierre Robin Europe	Nee	P 279
G-6-3	Inherited retinal disorder	ORPHA:71862	Oogvereniging	Nee	P 100
G-6-3	Inherited retinal disorder	ORPHA:71862	Macula Vereniging (MD)	Nee	P 125
G-6-4	Inherited retinal disorder	ORPHA:71862	Oogvereniging	Nee	P 100
G-6-4	Inherited retinal disorder	ORPHA:71862	Macula Vereniging (MD)	Nee	P 125
G-6-6	Inherited retinal disorder	ORPHA:71862	Oogvereniging	Nee	P 100
G-6-6	Inherited retinal disorder	ORPHA:71862	Macula Vereniging (MD)	Nee	P 125
G-14-1	Muscular channelopathy	ORPHA:71864	Spierziekten NL	Ja	P 43
G-17-5	Angelman syndrome	ORPHA:72	Vereniging Angelman Syndroom NL	Ja	P 3
G-4-2	Continuous spikes and waves during sleep	ORPHA:725	Epilepsiefonds	Nee	P 7
G-21-8	Microscopic polyangiitis	ORPHA:727	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-21-8	Microscopic polyangiitis	ORPHA:727	Vasculitits St	Ja	P 51
G-5-8	Autosomal dominant polycystic kidney disease	ORPHA:730	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-20-5	Intractable diarrhea of infancy	ORPHA:73014	Maag Lever Darm St	Nee	P 105
G-7-5	Intractable diarrhea of infancy	ORPHA:73014	Maag Lever Darm St	Nee	P 105
G-5-8	Autosomal recessive polycystic kidney disease	ORPHA:731	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-21-9	Polymyositis	ORPHA:732	Spierziekten NL	Ja	P 43
G-15-12	Familial adenomatous polyposis	ORPHA:733	St Lynch Polyposis	Ja	P 93
G-15-2	Familial adenomatous polyposis	ORPHA:733	St Lynch Polyposis	Ja	P 93
G-15-6	Familial adenomatous polyposis	ORPHA:733	St Lynch Polyposis	Ja	P 93
G-15-7	Familial adenomatous polyposis	ORPHA:733	St Lynch Polyposis	Ja	P 93
G-18-6	Porphyria	ORPHA:738	NLse Leverpatiënten Vereniging (NLV)	Ja	P 19
G-18-6	Porphyria	ORPHA:738	Patiëntenvereniging Acute Porfyrie	Ja	P 300
G-17-1	Prader-Willi syndrome	ORPHA:739	Prader-Willi St	Ja	P 236
G-3-16	Prader-Willi syndrome	ORPHA:739	Prader-Willi St	Ja	P 236
G-22-13	Mendelian susceptibility to mycobacterial diseases	ORPHA:748	St voor Afweerstoornissen (SAS)	Ja	P 72

G-25-11	Strongyloidiasis	ORPHA:76	Zonder patiëntenorganisatie	Nvt	P nvt
G-12-11	Hemolytic anemia due to red cell pyruvate kinase deficiency	ORPHA:766	St Zeldzame Bloedziekten - PKD Contactgroep	Nee	P 75
G-16-8	Familial long QT syndrome	ORPHA:768	Harteraad	Ja	P 58
G-25-11	Rabies	ORPHA:770	Zonder patiëntenorganisatie	Nvt	P nvt
G-25-6	Rabies	ORPHA:770	Zonder patiëntenorganisatie	Nvt	P nvt
G-24-10	Primary Lymphedema	ORPHA:77240	NL Net	Ja	P 142
G-24-11	Hereditary Hemorrhagic Telangiectasia	ORPHA:774	Harteraad	Ja	P 58
G-17-8	Rett Syndrome	ORPHA:778	Nederlandse Rett Syndroom Vereniging	Ja	P 166
G-3-5	genetic obesity	ORPHA:77828	NL Net	Nee	P 142
G-3-5	genetic obesity	ORPHA:77828	Nederlandse St Over Gewicht	Nee	P 265
G-17-11	Rubinstein-Taybi syndrome	ORPHA:783	St Rubinstein-Taybi Syndroom	Nee	P 48
G-19-1	Retinoblastoma	ORPHA:790	Oogvereniging	Nee	P 100
G-18-8	Disorder of amino acid and other organic acid metabolism	ORPHA:79062	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-11-14	Cutaneous neuroendocrine carcinoma	ORPHA:79140	St NET-Groep	Ja	P 62
G-11-29	Cutaneous neuroendocrine carcinoma	ORPHA:79140	St NET-Groep	Ja	P 62
G-11-4	Cutaneous neuro-endocrine carcinoma	ORPHA:79140	St NET-Groep	Ja	P 62
G-18-8	Disorder of urea cycle metabolism and ammonia detoxification	ORPHA:79167	PKU Vereniging NL	Ja	P 37
G-18-8	Disorder of urea cycle metabolism and ammonia detoxification	ORPHA:79167	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-18-1	Disorders of Neurotransmitter metabolism and transport	ORPHA:79169	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-18-2	Creatine deficiency syndrome	ORPHA:79172	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-18-13	Disorder of fatty acid oxidation and ketone body metabolism	ORPHA:79174	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-18-2	Disorder of fatty acid oxidation and ketone body metabolism	ORPHA:79174	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-18-3	Disorder of fatty acid oxidation and ketone body metabolism	ORPHA:79174	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-18-1	Disorders of pyridoxine metabolism	ORPHA:79192	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-18-2	Disorders of pyridoxine metabolism	ORPHA:79192	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-18-8	Disorder of branched-chain amino acid metabolism	ORPHA:79197	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-14-4	Disorder of energy metabolism	ORPHA:79200	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-14-4	Disorder of energy metabolism	ORPHA:79200	St Nemo	Ja	P 199
G-14-4	Disorder of energy metabolism	ORPHA:79200	Cure ADOA Foundation	Ja	P 281
G-18-3	Glycogen storage disease	ORPHA:79201	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-18-7	Glycogen storage disease	ORPHA:79201	Spierziekten NL	Ja	P 43
G-18-7	Glycogen storage disease	ORPHA:79201	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-18-15	Disorder of lysosomal amino acid transport	ORPHA:79207	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-18-15	Mucopolysaccharidosis	ORPHA:79213	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-18-13	Disorder of purine or pyrimidine metabolism	ORPHA:79224	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-18-15	Sphingolipidosis	ORPHA:79225	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-18-10	Galactokinase deficiency	ORPHA:79237	Galactosemievereniging	Nee	P 12
G-18-10	Galactose epimerase deficiency	ORPHA:79238	Galactosemievereniging	Nee	P 12
G-18-10	Classic galactosemia	ORPHA:79239	Galactosemievereniging	Nee	P 12
G-18-3	Glycogen storage disease due to glucose-6-phosphatase deficiency type Ia	ORPHA:79258	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-18-3	Glycogen storage disease due to glucose-6-phosphatase deficiency type Ib	ORPHA:79259	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-18-11	Juvenile neuronal ceroid lipofuscinosis	ORPHA:79264	Alzheimer NL	Ja	P 2

G-18-11	Juvenile neuronal ceroid lipofuscinosis	ORPHA:79264	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-10-4	Ichthyosis	ORPHA:79354	Vereniging voor Ichthyosisnetwerken	Ja	P 237
G-10-7	Ichthyosis	ORPHA:79354	Vereniging voor Ichthyosisnetwerken	Ja	P 237
G-10-7	Erythrokeratoderma	ORPHA:79355	Huid NL	Ja	P 161
G-10-3	Hereditary palmoplantar keratoderma	ORPHA:79357	Huid NL	Ja	P 161
G-10-7	Hereditary palmoplantar keratoderma	ORPHA:79357	Huid NL	Ja	P 161
G-10-2	Inherited epidermolysis bullosa	ORPHA:79361	Debra NL	Ja	P 132
G-10-7	Ectodermal dysplasia syndrome	ORPHA:79373	Vereniging voor Ectodermale Dysplasie (VVED)	Nee	P 55
G-2-9	Ectodermal dysplasia syndrome	ORPHA:79373	Vereniging voor Ectodermale Dysplasie (VVED)	Nee	P 55
G-10-6	Rare urticaria	ORPHA:79384	PP Urticaria	Ja	P 57
G-10-5	Rare skin tumor or hamartoma	ORPHA:79386	Neurofibromatosevereniging NL (NFVN)	Ja	P 30
G-10-5	Rare skin tumor or hamartoma	ORPHA:79386	STSN	Ja	P 49
G-10-5	Rare skin tumor or hamartoma	ORPHA:79386	St PTEN België-NL	Nee	P 95
G-10-5	Rare skin tumor or hamartoma	ORPHA:79386	St Melanoom	Nee	P 96
G-10-5	Rare skin tumor or hamartoma	ORPHA:79386	Nevus Netwerk	Ja	P 141
G-10-5	Rare skin tumor or hamartoma	ORPHA:79386	Huidkanker St (HUKAS)	Nee	P 318
G-12-18	Diffuse cutaneous mastocytosis	ORPHA:79456	Mastocytosevereniging NL	Ja	P 83
G-25-6	Rare form of salmonellosis	ORPHA:795	Zonder patiëntenorganisatie	Nvt	P nvt
G-10-2	Auto-immune bullous skin diseases	ORPHA:79669	Netwerk voor blaarziekten	Nee	P 133
G-21-6	Sarcoidosis	ORPHA:797	Sarcoïdose NL	Ja	P 40
G-8-11	Sarcoidosis	ORPHA:797	Sarcoïdose NL	Ja	P 40
G-8-22	Sarcoidosis	ORPHA:797	Sarcoïdose NL	Ja	P 40
G-14-6	Amyotrophic lateral sclerosis	ORPHA:803	Spierziekten NL	Ja	P 43
G-14-6	Amyotrophic lateral sclerosis	ORPHA:803	ALS Patients Connected	Nee	P 268
G-14-7	Amyotrophic lateral sclerosis	ORPHA:803	Spierziekten NL	Ja	P 43
G-14-7	Amyotrophic lateral sclerosis	ORPHA:803	ALS Patients Connected	Nee	P 268
G-17-5	Tuberous sclerosis complex	ORPHA:805	STSN	Ja	P 49
G-5-6	Tuberous sclerosis complex	ORPHA:805	STSN	Ja	P 49
G-21-9	Anti-synthetase syndrome	ORPHA:81	Spierziekten NL	Ja	P 43
G-12-26	Shwachman-Diamond syndrome	ORPHA:811	Shwachman Syndroom Support Holland (SSSH)	Nee	P 76
G-22-12	Shwachman-Diamond syndrome	ORPHA:811	Shwachman Syndroom Support Holland (SSSH)	Nee	P 76
G-3-15	Silver-Russell syndrome	ORPHA:813	Belangenvereniging van Kleine Mensen (BVKM)	Nee	P 4
G-3-15	Silver-Russell syndrome	ORPHA:813	Nlse Hypofyse St (NHS)	Ja	P 65
G-3-15	Silver-Russell syndrome	ORPHA:813	SGA Platform	Ja	P 193
G-18-1	Sjögren-Larsson syndrome	ORPHA:816	Nationale Vereniging Sjögrenpatiënten (NVSP)	Ja	P 22
G-12-5	Hereditary spherocytosis	ORPHA:822	St Zeldzame Bloedziekten - Sferocytose Contactgroep	Nee	P 75
G-17-6	Isolated spina bifida	ORPHA:823	SBH NL	Nee	P 286
G-17-9	Isolated spina bifida	ORPHA:823	SBH NL	Nee	P 286
G-12-13	Primary myelofibrosis	ORPHA:824	MPN St	Ja	P 78
G-12-13	Primary myelofibrosis	ORPHA:824	St Hematon	Ja	P 81
G-12-3	Primary myelofibrosis	ORPHA:824	MPN St	Ja	P 78
G-12-3	Primary myelofibrosis	ORPHA:824	St Hematon	Ja	P 81

G-13-2	Urogenital tract malformation	ORPHA:83001	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-13-2	Urogenital tract malformation	ORPHA:83001	St MRK Vrouwen	Ja	P 112
G-13-2	Urogenital tract malformation	ORPHA:83001	NLse Klinefelter Vereniging	Nee	P 117
G-13-3	Urogenital tract malformation	ORPHA:83001	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-13-3	Urogenital tract malformation	ORPHA:83001	St MRK Vrouwen	Ja	P 112
G-13-3	Urogenital tract malformation	ORPHA:83001	NLse Klinefelter Vereniging	Nee	P 117
G-25-6	Scrub typhus	ORPHA:83317	Huid NL	Ja	P 161
G-2-13	Microtia	ORPHA:83463	LaPosa	Ja	P 17
G-2-13	Microtia	ORPHA:83463	St Eigen Gezicht	Nee	P 247
G-2-2	Microtia	ORPHA:83463	LaPosa	Ja	P 17
G-2-2	Microtia	ORPHA:83463	St Eigen Gezicht	Nee	P 247
G-0-3	Narcolepsy Type 2	ORPHA:83465	Narcolepsie Vereniging NL (NVN)	Nee	P 210
G-0-4	Narcolepsy type 2	ORPHA:83465	Narcolepsie Vereniging NL (NVN)	Nee	P 210
G-1-8	Solitary bone cyst	ORPHA:83468	Vereniging Kinderkanker NL	Nee	P 82
G-22-9	Acute Disseminated Encephalomyelitis	ORPHA:83597	MS Vereniging NL	Nee	P 21
G-22-9	Acute Disseminated Encephalomyelitis	ORPHA:83597	Hersenletsel.nl	Nee	P 91
G-22-9	Acute Disseminated Encephalomyelitis	ORPHA:83597	Oogvereniging	Nee	P 100
G-22-9	Susac syndrome	ORPHA:838	Oogvereniging	Nee	P 100
G-22-9	Susac syndrome	ORPHA:838	Nlse Meningitis St	Nee	P 118
G-13-2	Hinman syndrome	ORPHA:84085	Zonder patiëntenorganisatie	Nvt	P nvt
G-5-5	Hinman syndrome	ORPHA:84085	Zonder patiëntenorganisatie	Nvt	P nvt
G-11-12	Testicular seminomatous germ cell tumor	ORPHA:842	Vereniging Kinderkanker NL	Nee	P 82
G-11-12	Testicular seminomatous germ cell tumor	ORPHA:842	St Zaadbalkanker	Ja	P 226
G-12-11	Congenital dyserythropoietic anemia	ORPHA:85	St Zeldzame Bloedziekten - CDA contactgroep	Nee	P 75
G-12-11	Congenital dyserythropoietic anemia	ORPHA:85	St AA & PNH	Nee	P 104
G-26-6	Fetal and neonatal alloimmune thrombocytopenia	ORPHA:853	Care4Neo	Ja	P 114
G-22-11	Oligoarticular juvenile idiopathic arthritis	ORPHA:85410	Jeugdreuma Vereniging NL	Nee	P 134
G-22-11	Systemic-onset juvenile idiopathic arthritis	ORPHA:85414	Jeugdreuma Vereniging NL	Nee	P 134
G-22-11	Psoriasis-related juvenile idiopathic arthritis	ORPHA:85436	Jeugdreuma Vereniging NL	Nee	P 134
	Psoriasis-related juvenile idiopathic arthritis	ORPHA:85436	Psoriasispatiënten NL	Nee	P 307
G-12-10	AL amyloidosis	ORPHA:85443	St Amyloidose NL	Ja	P 138
G-12-15	AA amyloidosis	ORPHA:85445	St Amyloidose NL	Ja	P 138
G-14-6	ATTRV30M amyloidosis	ORPHA:85447	St Amyloidose NL	Ja	P 138
G-9-9	Benign adult familial myoclonic epilepsy	ORPHA:86814	Epilepsiefonds	Nee	P 7
G-17-12	Down syndrome	ORPHA:870	St Down Syndroom (SDS)	Nee	P 71
G-17-1	Rare intellectual disability	ORPHA:87277	Zeldsamen	Ja	P 290
G-11-25	Desmoid tumor	ORPHA:873	St Patiëntenplatform Sarcomen	Ja	P 94
G-11-41	Desmoid tumor	ORPHA:873	St Patiëntenplatform Sarcomen	Ja	P 94
G-11-14	Neuroendocrine neoplasm	ORPHA:877	St NET-Groep	Ja	P 62
G-11-29	Neuroendocrine neoplasm	ORPHA:877	St NET-Groep	Ja	P 62
G-11-38	Neuroendocrine neoplasm	ORPHA:877	St NET-Groep	Ja	P 62
G-11-8	Neuroendocrine neoplasm	ORPHA:877	St NET-Groep	Ja	P 62

G-3-9	Neuroendocrine neoplasm	ORPHA:877	St NET-Groep	Ja	P 62
G-12-26	Ideopathic aplastic anemia	ORPHA:88	St AA & PNH	Nee	P 104
G-3-3	Turner syndrome	ORPHA:881	Turner Contact NL	Ja	P 50
G-18-4	Tyrosinemia type 1	ORPHA:882	NLse Leverpatiënten Vereniging (NLV)	Nee	P 19
G-2-1	Usher syndrome	ORPHA:886	Oogvereniging	Nee	P 100
G-2-1	Usher syndrome	ORPHA:886	St Ushersyndroom	Ja	P 240
G-11-31	Hepatocellular carcinoma	ORPHA:88673	NLse Leverpatiënten Vereniging (NLV)	Ja	P 19
G-20-8	Hepatocellular carcinoma	ORPHA:88673	NLse Leverpatiënten Vereniging (NLV)	Ja	P 19
G-7-1	VACTERL/VATER associatie	ORPHA:887	Vereniging Anusatresie	Nee	P 120
G-7-1	VACTERL/VATER associatie	ORPHA:887	Vereniging voor Ouderen en Kinderen met Slokdarmafsluiting (VOKS)	Ja	P 124
G-16-10	Rare congenital non-syndromic heart malformation	ORPHA:88991	Patiëntenvereniging Aangeboren Hartafwijkingen	Ja	P 127
G-16-2	Rare congenital non-syndromic heart malformation	ORPHA:88991	Patiëntenvereniging Aangeboren Hartafwijkingen	Ja	P 127
G-16-6	Rare congenital non-syndromic heart malformation	ORPHA:88991	Patiëntenvereniging Aangeboren Hartafwijkingen	Ja	P 127
G-3-13	Von Hippel-Lindau disease	ORPHA:892	Belangenvereniging Von Hippel-Lindau	Nee	P 66
G-3-14	Von Hippel-Lindau disease	ORPHA:892	Belangenvereniging Von Hippel-Lindau	Nee	P 66
G-6-4	Von Hippel-Lindau disease	ORPHA:892	Belangenvereniging Von Hippel-Lindau	Nee	P 66
G-1-7	X-linked hypophosphatemia	ORPHA:89936	Patiëntenvereniging voor XLH	Nee	P 293
G-21-8	Granulomatosis with polyangiitis	ORPHA:900	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-21-8	Granulomatosis with polyangiitis	ORPHA:900	Vasculitits St	Ja	P 51
G-21-2	Undifferentiated connective tissue syndrome	ORPHA:90002	Nationale vereniging voor lupus, APS, sclerodermie en MCTD (NVLE)	Ja	P 128
G-6-8	Retinopathy of prematurity	ORPHA:90050	Oogvereniging	Nee	P 100
G-25-7	Sepsis in premature infants	ORPHA:90051	Care4Neo	Nee	P 114
G-22-13	Complications after hematopoietic stem cell transplantation	ORPHA:90053	St voor Afweerstoornissen (SAS)	Ja	P 72
G-22-13	Complications after hematopoietic stem cell transplantation	ORPHA:90053	St Hematon	Ja	P 81
G-20-8	Acute liver failure	ORPHA:90062	NLse Leverpatiënten Vereniging (NLV)	Ja	P 19
G-24-1	Acquired aneurysmal subarachnoid hemorrhage	ORPHA:90065	Hersenaneurysma Patiëntenplatform (HPP)	Nee	P 315
G-24-7	Acquired aneurysmal subarachnoid hemorrhage	ORPHA:90065	Hersenaneurysma Patiëntenplatform (HPP)	Nee	P 315
G-24-9	Acquired aneurysmal subarachnoid hemorrhage	ORPHA:90065	Hersenaneurysma Patiëntenplatform (HPP)	Nee	P 315
G-22-3	Localized scleroderma	ORPHA:90289	Nationale vereniging voor lupus, APS, sclerodermie en MCTD (NVLE)	Ja	P 128
G-21-2	Systemic sclerosis	ORPHA:90291	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-21-2	Systemic sclerosis	ORPHA:90291	Nationale vereniging voor lupus, APS, sclerodermie en MCTD (NVLE)	Ja	P 128
G-21-5	Systemic sclerosis	ORPHA:90291	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-21-5	Systemic sclerosis	ORPHA:90291	Nationale vereniging voor lupus, APS, sclerodermie en MCTD (NVLE)	Ja	P 128
G-21-6	Systemic sclerosis	ORPHA:90291	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-21-6	Systemic sclerosis	ORPHA:90291	Nationale vereniging voor lupus, APS, sclerodermie en MCTD (NVLE)	Ja	P 128
G-21-9	Systemic sclerosis	ORPHA:90291	Nationale vereniging voor lupus, APS, sclerodermie en MCTD (NVLE)	Ja	P 128
G-12-1	Von Willebrand disease	ORPHA:903	NLse Vereniging van Hemofilie-Patiënten (NVHP)	Nee	P 74
G-12-11	Von Willebrand disease	ORPHA:903	NLse Vereniging van Hemofilie-Patiënten (NVHP)	Nee	P 74
G-12-12	Von Willebrand disease	ORPHA:903	NLse Vereniging van Hemofilie-Patiënten (NVHP)	Nee	P 74
G-12-14	Von Willebrand Disease	ORPHA:903	NLse Vereniging van Hemofilie-Patiënten (NVHP)	Nee	P 74
G-12-24	Von Willebrand disease	ORPHA:903	NLse Vereniging van Hemofilie-Patiënten (NVHP)	Nee	P 74
G-12-6	Von Willebrand Disease	ORPHA:903	NLse Vereniging van Hemofilie-Patiënten (NVHP)	Nee	P 74

G-12-8	Von Willebrand disease	ORPHA:903	NLse Vereniging van Hemofilie-Patiënten (NVHP)	Nee	P 74
G-20-5	Wilson disease	ORPHA:905	NLse Leverpatiënten Vereniging (NLV)	Ja	P 19
G-20-5	Wilson disease	ORPHA:905	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Nee	P 56
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G-3-17	Rare Endocrine Growth Disease	ORPHA:90692	NLse Hypofyse St (NHS)	Ja	P 65
G-3-17	Rare Endocrine Growth Disease	ORPHA:90692	Prader-Willi St	Ja	P 236
G-3-17	Rare Endocrine Growth Disease	ORPHA:90692	Klub Lange Mensen	Nee	P 269
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G-3-4	Disorders of sex development	ORPHA:90771	NLse Klinefelter Vereniging	Nee	P 117
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G-3-8	Disorders of sex development	ORPHA:90771	DSD NL	Ja	P 70
G-3-8	Disorders of sex development	ORPHA:90771	NLse Klinefelter Vereniging	Nee	P 117
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G-3-17	Primary lipodystrophy	ORPHA:90970	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Nee	P 56
G-17-5	Xeroderma Pigmentosum	ORPHA:910	Huid NL	Ja	P 161
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G-22-12	Hereditary angioedema	ORPHA:91378	Vereniging voor angio oedeem	Nee	P 84
G-16-7	Familial thoracic aortic aneurysm and aortic dissection	ORPHA:91387	Harteraad	Ja	P 58
G-16-7	Familial thoracic aortic aneurysm and aortic dissection	ORPHA:91387	Contactgroep Marfan NL	Ja	P 147
G-24-6	Familial thoracic aortic aneurysm and aortic dissection	ORPHA:91387	Contactgroep Marfan NL	Ja	P 147
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G-21-6	Juvenile idiopathic arthritis	ORPHA:92	Jeugdreuma Vereniging NL	Nee	P 134
G-22-1	Juvenile idiopathic arthritis	ORPHA:92	Jeugdreuma Vereniging NL	Nee	P 134
G-22-11	Juvenile idiopathic arthritis	ORPHA:92	Jeugdreuma Vereniging NL	Nee	P 134
G-22-3	Juvenile idiopathic arthritis	ORPHA:92	Jeugdreuma Vereniging NL	Nee	P 134
G-22-4	Juvenile idiopathic arthritis	ORPHA:92	Jeugdreuma Vereniging NL	Nee	P 134
G-22-7	Juvenile idiopathic arthritis	ORPHA:92	Jeugdreuma Vereniging NL	Nee	P 134
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G-1-3	Primary bone dysplasia with decreased bone density	ORPHA:93446	Vereniging Osteogenesis Imperfecta (VOI)	Ja	P 53
G-1-3	Primary bone dysplasia with decreased bone density	ORPHA:93446	NLse Vereniging van Rugpatiënten 'de Wervelkolom' (NVR)	Nee	P 172
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G-1-3	Primary bone dysplasia with disorganized development of skeletal components	ORPHA:93450	LGD Alliance NL	Nee	P 200
G-1-3	Primary bone dysplasia with disorganized development of skeletal components	ORPHA:93450	Patiëntenvereniging Fibreuze Dysplasie	Ja	P 246
G-2-9	Cleidocranial dysplasia and isolated cranial ossification defect	ORPHA:93451	LaPosa	Ja	P 17
G-2-9	Cleidocranial dysplasia and isolated cranial ossification defect	ORPHA:93451	St Eigen Gezicht	Nee	P 247
G-2-8	Dysostosis with predominant craniofacial involvement	ORPHA:93453	LaPosa	Ja	P 17
G-2-8	Dysostosis with predominant craniofacial involvement	ORPHA:93453	St Eigen Gezicht	Nee	P 247
G-1-5	Non-syndromic limb reduction defect	ORPHA:93457	Handvereniging	Nee	P 13

G-3-17	Overgrowth syndrome	ORPHA:93460	LaPosa	Ja	P 17
G-3-17	Overgrowth syndrome	ORPHA:93460	NLse Hypofyse St (NHS)	Ja	P 65
G-3-17	Overgrowth syndrome	ORPHA:93460	Marshall Smith Syndroom Research Foundation	Nee	P 146
G-3-17	Overgrowth syndrome	ORPHA:93460	Klub Lange Mensen	Nee	P 269
G-13-3	Renal or urinary tract malformation	ORPHA:93545	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-5-1	Renal or urinary tract malformation	ORPHA:93545	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
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G-5-5	Renal or urinary tract malformation	ORPHA:93545	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-13-3	Non-syndromic renal or urinary tract malformation	ORPHA:93546	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-5-1	Glomerular disease	ORPHA:93548	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-5-1	Glomerular disease	ORPHA:93548	Nationale vereniging voor lupus, APS, sclerodermie en MCTD (NVLE)	Nee	P 128
G-5-7	Glomerular disease	ORPHA:93548	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-5-7	Glomerular disease	ORPHA:93548	Nationale vereniging voor lupus, APS, sclerodermie en MCTD (NVLE)	Ja	P 128
G-21-2	Pediatric systemic lupus erythematosus	ORPHA:93552	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-21-2	Pediatric systemic lupus erythematosus	ORPHA:93552	Nationale vereniging voor lupus, APS, sclerodermie en MCTD (NVLE)	Ja	P 128
G-22-11	Pediatric systemic lupus erythematosus	ORPHA:93552	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-22-11	Pediatric systemic lupus erythematosus	ORPHA:93552	Nationale vereniging voor lupus, APS, sclerodermie en MCTD (NVLE)	Ja	P 128
G-22-3	Pediatric systemic lupus erythematosus	ORPHA:93552	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-22-3	Pediatric systemic lupus erythematosus	ORPHA:93552	Nationale vereniging voor lupus, APS, sclerodermie en MCTD (NVLE)	Ja	P 128
G-22-7	Pediatric systemic lupus erythematosus	ORPHA:93552	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-22-7	Pediatric systemic lupus erythematosus	ORPHA:93552	Nationale vereniging voor lupus, APS, sclerodermie en MCTD (NVLE)	Ja	P 128
G-21-8	Thrombotic microangiopathy	ORPHA:93573	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-21-8	Thrombotic microangiopathy	ORPHA:93573	St Zeldzame Bloedziekten - TTP Contactgroep	Nee	P 75
G-5-1	Thrombotic microangiopathy	ORPHA:93573	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-5-1	Thrombotic microangiopathy	ORPHA:93573	St Zeldzame Bloedziekten - TTP Contactgroep	Nee	P 75
G-13-3	Familial cystic renal disease	ORPHA:93587	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
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G-5-4	Familial cystic renal disease	ORPHA:93587	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-5-5	Familial cystic renal disease	ORPHA:93587	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-5-1	Nephropathy secondary to a storage or other metabolic disease	ORPHA:93593	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-5-1	Nephropathy secondary to a storage or other metabolic disease	ORPHA:93593	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-13-3	Rare renal tubular disease	ORPHA:93603	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-13-3	Rare renal tubular disease	ORPHA:93603	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Nee	P 56
G-5-1	Rare renal tubular disease	ORPHA:93603	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-5-1	Rare renal tubular disease	ORPHA:93603	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-5-4	Rare renal tubular disease	ORPHA:93603	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-5-4	Rare renal tubular disease	ORPHA:93603	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Ja	P 56
G-5-5	Rare renal tubular disease	ORPHA:93603	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-5-5	Rare renal tubular disease	ORPHA:93603	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Nee	P 56
G-22-1	Autoinflammatory syndrome	ORPHA:93665	St voor Afweerstoornissen (SAS)	Ja	P 72
G-22-1	Autoinflammatory syndrome	ORPHA:93665	St KAISZ	Nee	P 135
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G-21-3	Juvenile dermatomyositis	ORPHA:93672	Spierziekten NL	Ja	P 43
G-22-4	Juvenile dermatomyositis	ORPHA:93672	Spierziekten NL	Ja	P 43
G-15-11	Schwannomatoses	ORPHA:93921	Neurofibromatosevereniging NL (NFVN)	Ja	P 30
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G-13-2	Cloacal exstrophy	ORPHA:93929	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
G-13-2	Bladder exstrophy	ORPHA:93930	Blaasextrophie NL (BEN)	Nee	P 108
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G-11-16	Non-functioning paraganglioma	ORPHA:94080	Bijniervereniging (NVACP)	Nee	P 64
G-3-7	Non-functioning paraganglioma	ORPHA:94080	Nlse Vereniging voor Patiënten met Paragangliomen (NVPG)	Ja	P 29
G-3-7	Non-functioning paraganglioma	ORPHA:94080	Bijniervereniging (NVACP)	Nee	P 64
G-2-8	Acalvaria	ORPHA:945	LaPosa	Ja	P 17
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G-7-10	Secondary short bowel syndrome	ORPHA:95427	Vereniging Ziekte van Hirschsprung	Ja	P 123
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G-8-7	Congenital tracheomalacia	ORPHA:95430	Zonder patiëntenorganisatie	Nvt	P nvt
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G-9-4	Primary progressive aphasia	ORPHA:95432	FTD Lotgenoten	Ja	P 9
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G-3-13	Acquired pituitary hormone deficiency	ORPHA:95502	NLse Hypofyse St (NHS)	Ja	P 65
G-13-2	Posterior hypospadias	ORPHA:95706	DSD NL	Ja	P 70
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G-26-4	Acquired premature ovarian failure	ORPHA:95709	St POI-POF	Ja	P 312
G-26-4	Non acquired premature ovarian failure	ORPHA:95710	Freya	Nee	P 110
G-26-4	Non acquired premature ovarian failure	ORPHA:95710	St POI-POF	Ja	P 312
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G-2-11	Rare otorhinolaryngological malformation	ORPHA:96333	LaPosa	Ja	P 17
G-2-11	Rare otorhinolaryngological malformation	ORPHA:96333	St Hoormij	Nee	P 33
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G-7-6	Anorectal Malformations	ORPHA:96346	Vereniging Anusatresie	Nee	P 120
G-8-4	Eisenmenger syndrome	ORPHA:97214	Patiëntenvereniging Aangeboren Hartafwijkingen	Ja	P 127
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G-14-1	Congenital myopathy	ORPHA:97245	Spierziekten NL	Ja	P 43
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G-24-1	Dural sinus malformation	ORPHA:97339	CMTC-OVM	Ja	P 92
G-24-1	Dural sinus malformation	ORPHA:97339	HEVAS	Nee	P 131
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G-24-9	Dural sinus malformation	ORPHA:97339	HEVAS	Nee	P 131
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G-16-1	Rare cardiac diseases	ORPHA:97929	St Noonan Syndroom	Ja	P 47
G-16-1	Rare cardiac diseases	ORPHA:97929	Harteraad	Ja	P 58
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G-16-11	Rare Surgical Cardiac Disease	ORPHA:97965	Patiëntenvereniging Aangeboren Hartafwijkingen	Ja	P 127
G-3-4	Rare endocrine disease	ORPHA:97978	Nlse Vereniging voor Patiënten met Paragangliomen (NVPG)	Ja	P 29
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G-3-4	Rare endocrine disease	ORPHA:97978	NLse Hypofyse St (NHS)	Ja	P 65
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G-17-5	Central nervous system malformation	ORPHA:98044	Syringomyelie Patiënten Vereniging (SPV)	Nee	P 177
G-9-3	Central nervous system malformation	ORPHA:98044	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Nee	P 56
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G-3-10	Rare male infertility	ORPHA:98048	NLse Klinefelter Vereniging	Nee	P 117
G-8-14	Rare allergic respiratory disease	ORPHA:98052	Zonder patiëntenorganisatie	Nvt	P nvt
G-13-3	Rare genetic renal disease	ORPHA:98056	Nierpatiënten Vereniging NL (NVN)	Ja	P 31
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G-11-28	Rare otorhinolaryngologic tumor	ORPHA:98061	St Hoornmij	Nee	P 33
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G-11-15	Rare gynecological tumor	ORPHA:98063	St Olijf	Nee	P 88
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G-3-3	46,XX disorder of sex development induced by androgens excess	ORPHA:98078	DSD NL	Ja	P 70
G-17-4	Autosomal anomaly	ORPHA:98127	Zeldsamen	Nee	P 290
G-17-5	Malformation syndrome with hamartosis	ORPHA:98196	St PTEN België-NL	Nee	P 95
G-9-6	Category Combined dystonia	ORPHA:98203	Dystonie Vereniging	Nee	P 59
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G-21-4	Ehlers-Danlos syndrome	ORPHA:98249	EDS Fonds	Ja	P 309

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G-12-10	Myeloproliferative neoplasm	ORPHA:98274	St Hematon	Ja	P 81
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G-12-10	Plasma cell tumor	ORPHA:98282	St Hematon	Ja	P 81
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G-12-16	Hodgkin lymphoma	ORPHA:98293	St Hematon	Ja	P 81
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G-8-16	Idiopathic interstitial pneumonia	ORPHA:98300	Belangenvereniging Longfibrosepatiënten NL	Ja	P 152
G-12-2	Constitutional anemia due to iron metabolism disorder	ORPHA:98360	Volwassenen, Kinderen en Stofwisselingsziekten (VKS)	Nee	P 56
G-12-11	Rare constitutional hemolytic anemia due to a red cell membrane anomaly	ORPHA:98364	St Zeldzame Bloedziekten	Nee	P 75
G-12-5	Rare constitutional hemolytic anemia due to a red cell membrane anomaly	ORPHA:98364	St Zeldzame Bloedziekten	Nee	P 75
G-12-5	Hereditary stomatocytosis	ORPHA:98365	St Zeldzame Bloedziekten	Nee	P 75
G-12-11	Rare constitutional hemolytic anemia due to an enzyme disorder	ORPHA:98369	St Zeldzame Bloedziekten - PKD Contactgroep	Nee	P 75
G-12-12	Autoimmune hemolytic anemia	ORPHA:98375	St Zeldzame Bloedziekten - AIHA Contactgroep	Nee	P 75
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G-8-7	Pulmonary agenesis	ORPHA:984	Zonder patiëntenorganisatie	Nvt	P nvt
G-12-26	Primary acquired red cell aplasia	ORPHA:98421	St AA & PNH	Nee	P 104
G-12-1	Rare coagulation disorder	ORPHA:98429	NLse Vereniging van Hemofilie-Patiënten (NVHP)	Nee	P 74
G-12-8	Rare coagulation disorder	ORPHA:98429	NLse Vereniging van Hemofilie-Patiënten (NVHP)	Nee	P 74
G-14-10	Skeletal muscle disease	ORPHA:98472	Spierziekten NL	Ja	P 43
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G-14-6	Muscular dystrophy	ORPHA:98473	Spierziekten NL	Ja	P 43
G-14-1	Idiopathic inflammatory myopathy	ORPHA:98482	Spierziekten NL	Ja	P 43
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G-14-10	Neuromuscular junction disease	ORPHA:98491	Spierziekten NL	Ja	P 43
G-14-6	Neuromuscular junction disease	ORPHA:98491	Spierziekten NL	Ja	P 43
G-14-10	Acquired neuromuscular junction disease	ORPHA:98494	Spierziekten NL	Ja	P 43
G-14-10	Genetic neuromuscular junction disease	ORPHA:98495	Spierziekten NL	Ja	P 43
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G-14-7	Rare Peripheral Neuropathy	ORPHA:98496	Spierziekten NL	Ja	P 43
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G-14-6	Motor Neuron Disease	ORPHA:98503	Spierziekten NL	Ja	P 43
G-6-8	Rare lens disease	ORPHA:98639	Oogvereniging	Nee	P 100
G-6-4	Color vision disease	ORPHA:98658	Oogvereniging	Nee	P 100
G-6-6	Oculocutaneous or ocular albinism	ORPHA:98706	Oogvereniging	Nee	P 100

G-6-4	Uveitis	ORPHA:98715	Oogvereniging	Nee	P 100
G-22-9	Autoimmune neurological channelopathy	ORPHA:98750	Nlse Meningitis St	Nee	P 118
G-12-3	Chronic myelomonocytic leukemia	ORPHA:98823	St Hematon	Ja	P 81
G-12-18	Indolent systemic mastocytosis	ORPHA:98848	Mastocytosevereniging NL	Ja	P 83
G-12-18	Systemic mastocytosis with associated hematologic neoplasm	ORPHA:98849	St Hematon	Ja	P 81
G-12-18	Systemic mastocytosis with associated hematologic neoplasm	ORPHA:98849	Mastocytosevereniging NL	Ja	P 83
G-12-18	Aggressive systemic mastocytosis	ORPHA:98850	Mastocytosevereniging NL	Ja	P 83
G-12-18	MaSt cell leukemia	ORPHA:98851	St Hematon	Ja	P 81
G-12-18	MaSt cell leukemia	ORPHA:98851	Mastocytosevereniging NL	Ja	P 83
G-12-24	Hemophilia A	ORPHA:98878	NLse Vereniging van Hemofilie-Patiënten (NVHP)	Nee	P 74
G-12-24	Hemophilia B	ORPHA:98879	NLse Vereniging van Hemofilie-Patiënten (NVHP)	Nee	P 74
G-9-10	Autosomal dominant cerebellar ataxia	ORPHA:99	ADCA/Ataxie Vereniging NL	Nee	P 1
G-9-9	Autosomal dominant cerebellar ataxia	ORPHA:99	ADCA/Ataxie Vereniging NL	Nee	P 1
G-14-2	Fetal akinesia deformation sequence	ORPHA:994	Spierziekten NL	Ja	P 43
G-3-13	Pituitary adenoma	ORPHA:99408	NLse Hypofyse St (NHS)	Ja	P 65
G-6-4	leber plus disease	ORPHA:99718	Belangenvereniging LOA/LHON	Ja	P 274
G-16-8	Rare familial disorder with hypertrophic cardiomyopathy	ORPHA:99739	Harteraad	Ja	P 58
G-2-9	Oligodontia	ORPHA:99798	Vereniging voor Ectodermale Dysplasie (VVED)	Nee	P 55
G-2-9	Oligodontia	ORPHA:99798	St Eigen Gezicht	Nee	P 247
G-7-9	Neuronal intestinal pseudoobstruction	ORPHA:99811	Vereniging Ziekte van Hirschsprung	Ja	P 123
G-25-11	Yellow fever	ORPHA:99829	Zonder patiëntenorganisatie	Nvt	P nvt
G-8-10	Thymoma	ORPHA:99867	Longkankervereniging	Ja	P 204
G-11-32	Malignant Granulosaceltumor of ovary	ORPHA:99915	St Olijf	Nee	P 88
G-12-17	Acute graft versus hoSt disease	ORPHA:99920	St Hematon	Ja	P 81
G-22-13	Acute graft versus hoSt disease	ORPHA:99920	St Hematon	Ja	P 81
G-20-4	Klatskin tumor	ORPHA:99978	NLse Leverpatiënten Vereniging (NLV)	Ja	P 19
G-25-10	Implant-Related Infections	Pending	Zonder patiëntenorganisatie	Nvt	P nvt
G-26-6	Selective IUGR	Pending	Care4Neo	Ja	P 114
G-26-6	Twin anemia polycythemia sequence	Pending	Care4Neo	Ja	P 114
G-26-6	Twin reversed arterial perfusion sequence	Pending	Care4Neo	Ja	P 114
G-26-6	Selective IUGR	Pending	Taps Support	Ja	P 317
G-26-6	Twin anemia polycythemia sequence	Pending	Taps Support	Ja	P 317
G-26-6	Twin reversed arterial perfusion sequence	Pending	Taps Support	Ja	P 317