

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
715205	H-14-11	Rare neoplastic diseases, Rare neurological diseases	Anterior cutaneous nerve entrapment syndrome	51890	P	296 ACNES Foundation
715366	H-11-52	Rare neoplastic diseases	Rare carcinoma of pancreas	217074	P	87 Alveeskliervereniging
715366	H-11-52	Rare neoplastic diseases	Rare tumor of pancreas	180824	P	87 Alveeskliervereniging
709738	H-7-18	Rare abdominal surgical diseases, Rare neurological diseases	Early-onset autosomal dominant Alzheimers disease	1020	P	2 Alzheimer Nederland
709738	H-7-18	Rare abdominal surgical diseases, Rare neurological diseases	Human Prion Disease	56970	P	2 Alzheimer Nederland
724406	H-9-12	Rare genetic diseases	Bilateral striopallidodentate calcinosis	1980	P	2 Alzheimer Nederland

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
709238	H-11-53	Rare neoplastic diseases	Pleural mesothelioma	50251	P	109 (AVN) Asbestslachtoffers Vereniging Nederland
724687	H-18-11	Rare inborn errors of metabolism	CLN3 disease	228346	P	310 Beat Batten
724687	H-18-11	Rare inborn errors of metabolism	Juvenile neuronal ceroid lipofuscinosis	79264	P	310 Beat Batten
708228	H-14-4	Rare inborn errors of metabolism	Mitochondrial diseases	68380	P	274 LOA/LHON Belangenvereniging
710236	H-6-4	Rare ophthalmic disorders	Leber plus disease	99718	P	274 LOA/LHON Belangenvereniging
716120	H-11-16	Rare endocrine diseases	Non-functioning paraganglioma	94080	P	64 Bijniervereniging NVACP
708145	H-15-7	Rare genetic diseases	Hereditary breast and ovarian cancer syndrome	145	P	89 (BVN) Borstkankervereniging
724346	H-15-9	Rare genetic diseases	Hereditary breast and ovarian cancer syndrome	145	P	89 (BVN) Borstkankervereniging

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
724346	H-15-9	Rare genetic diseases	Hereditary breast cancer	227535	P	Borstkankervereniging 89 (BVN)
708087	H-16-8	Rare cardiac diseases	Brugada syndrome	130	P	337 Brugada Community
708047	H-26-5	Rare circulatory system diseases, Rare gynecologic and obstetric diseases	HELLP syndrome	244242	P	114 Care4Neo
708047	H-26-5	Rare circulatory system diseases, Rare gynecologic and obstetric diseases	Placental insufficiency	439167	P	114 Care4Neo
708047	H-26-5	Rare circulatory system diseases, Rare gynecologic and obstetric diseases	Preeclampsia	275555	P	114 Care4Neo
708047	H-26-5	Rare circulatory system diseases, Rare gynecologic and obstetric diseases	Rare disorders related with pregnancy, childbirth and puerperium	163637	P	114 Care4Neo
710505	H-7-3	Rare gastroenterologic diseases	Omphalocele	660	P	114 Care4Neo
711854	H-8-26	Rare respiratory diseases	Bronchopulmonary Dysplasia	70589	P	114 Care4Neo

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
712061	H-7-16	Rare abdominal surgical diseases, Rare gastroenterologic diseases	Gastroschisis	2368	P	114 Care4Neo
715100	H-26-6	Rare gynecologic and obstetric diseases	Retinopathy of prematurity	90050	P	114 Care4Neo
715304	H-2-15	Rare otorhinolaryngological diseases	Congenital subglottic stenosis	141121	P	114 Care4Neo
716078	H-24-2	Rare circulatory system diseases	Congenital chylothorax	264688	P	114 Care4Neo
724467	H-11-55	Rare neurological diseases	Neonatal hypoxic and ischemic brain injury	137577	P	114 Care4Neo
715100	H-26-6	Rare gynecologic and obstetric diseases	Retinopathy of prematurity	90050	P	322 CHI Support
715100	H-26-6	Rare gynecologic and obstetric diseases	Selective Intrauterine Growth Restriction	617301	P	322 CHI Support
715100	H-26-6	Rare gynecologic and obstetric diseases	Twin Anemia Polycythemia Sequence	617294	P	322 CHI Support

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
715100	H-26-6	Rare gynecologic and obstetric diseases	Twin Reversed Arterial Perfusion sequence 617297	P	322	CHI Support
716098	H-24-6	Rare circulatory system diseases	Aortic malformation 98718	P	147	Contactgroep Marfan Nederland
716098	H-24-6	Rare circulatory system diseases	Ascending aorta anomaly 98725	P	147	Contactgroep Marfan Nederland
716098	H-24-6	Rare circulatory system diseases	Rare disease with thoracic aortic aneurysm and aortic dissection 285014	P	147	Contactgroep Marfan Nederland
724467	H-11-55	Rare neurological diseases	Neonatal hypoxic and ischemic brain injury 137577	P	284	CP Nederland
708169	H-2-10	Rare otorhinolaryngological diseases	Idiopathic Bilateral Vestibulopathy 171684	P	282	De 9e van .....

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
715304	H-2-15	Rare otorhinolaryngological diseases	Cranio-cervical dystonia with laryngeal and upper-limb involvement	420485	P	59 Dystonievereniging
715304	H-2-15	Rare otorhinolaryngological diseases	Congenital laryngeal cyst	141124	P	59 Dystonievereniging
715304	H-2-15	Rare otorhinolaryngological diseases	Laryngeal abductor paralysis	2808	P	59 Dystonievereniging
715304	H-2-15	Rare otorhinolaryngological diseases	Larynx anomaly	156249	P	59 Dystonievereniging
715304	H-2-15	Rare otorhinolaryngological diseases	Congenital subglottic stenosis	141121	P	59 Dystonievereniging
716098	H-24-6	Rare circulatory system diseases	Aortic malformation	98718	P	309 EDS Fonds
716098	H-24-6	Rare circulatory system diseases	Ascending aorta anomaly	98725	P	309 EDS Fonds

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
716098	H-24-6	Rare circulatory system diseases	Rare disease with thoracic aortic aneurysm and aortic dissection	285014	P	309 EDS Fonds
708027	H-4-1	Rare neurological diseases	Cerebral malformation with epilepsy	166478	P	7 Epilepsie NL
708027	H-4-1	Rare neurological diseases	Epilepsy Syndrome	166463	P	7 Epilepsie NL
708027	H-4-1	Rare neurological diseases	Infantile Epilepsy Syndrome	98258	P	7 Epilepsie NL
708027	H-4-1	Rare neurological diseases	Monogenic disease with epilepsy	166472	P	7 Epilepsie NL
708027	H-4-1	Rare neurological diseases	Rare epilepsy	101998	P	7 Epilepsie NL
715205	H-14-11	Rare neoplastic diseases, Rare neurological diseases	Non-recovering obstetric brachial plexus lesion	439202	P	Erbse Parese Vereniging 8 Nederland
724406	H-9-12	Rare genetic diseases	Bilateral striopallidodentate calcinosis	1980	P	Fahr Patiënten 346 Vereniging Nederland

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
709738	H-7-18	Rare abdominal surgical diseases, Rare neurological diseases	Frontotemporal degeneration with dementia	98535	P	9 FTD Lotgenoten
708087	H-16-8	Rare cardiac diseases	Arrhythmogenic right ventricular dysplasia	247	P	58 Harteraad
708087	H-16-8	Rare cardiac diseases	Brugada syndrome	130	P	58 Harteraad
708087	H-16-8	Rare cardiac diseases	Dilated cardiomyopathy	217604	P	58 Harteraad
708087	H-16-8	Rare cardiac diseases	Familial long QT syndrome	768	P	58 Harteraad
708087	H-16-8	Rare cardiac diseases	Idiopathic ventricular fibrillation - not Brugada type	228140	P	58 Harteraad
708087	H-16-8	Rare cardiac diseases	Rare familial disorder with hypertrophic cardiomyopathy	99739	P	58 Harteraad



AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
715332	H-16-12	Rare cardiac diseases	Arrhythmogenic right ventricular cardiomyopathy	247	P	58 Harteraad
715332	H-16-12	Rare cardiac diseases	Dilated cardiomyopathy	217604	P	58 Harteraad
715332	H-16-12	Rare cardiac diseases	Rare cardiomyopathy	167848	P	58 Harteraad
715332	H-16-12	Rare cardiac diseases	Rare hypertrophic cardiomyopathy	217569	P	58 Harteraad
709465	H-9-18	Rare neurological diseases	Genetic cerebral small vessel disease	477754	P	14 HCHWA-D Vereniging

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
708047	H-26-5	Rare circulatory system diseases, Rare gynecologic and obstetric diseases	HELLP syndrome	244242	P	113 HELLP Stichting
708047	H-26-5	Rare circulatory system diseases, Rare gynecologic and obstetric diseases	Preeclampsia	275555	P	113 HELLP Stichting
709091	H-9-19	Rare neurological diseases	Glial tumor	182067	P	91 Hersenletsel.nl
710372	H-9-14	Rare neurological diseases	Glial tumor	182067	P	91 Hersenletsel.nl
715227	H-3-17	Rare endocrine diseases	Meningioma	2495	P	91 Hersenletsel.nl
715366	H-11-52	Rare neoplastic diseases	Glial Tumors	182067	P	91 Hersenletsel.nl
724234	H-15-11	Rare neoplastic diseases	Glial tumor	182067	P	91 Hersenletsel.nl
724234	H-15-11	Rare neoplastic diseases	Meningioma	2495	P	91 Hersenletsel.nl

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
709794	H-22-15	Rare immunological diseases	Systemic lupus erythematosus	536	P	161 Huid Nederland
709794	H-22-15	Rare immunological diseases	Systemic sclerosis	801	P	161 Huid Nederland
710108	H-10-10	Rare skin diseases	Necrotizing soft tissue infection	440368	P	161 Huid Nederland
715007	H-26-7	Rare infectious diseases	Leishmaniasis	507	P	161 Huid Nederland
715061	H-10-4	Rare neoplastic diseases, Rare skin diseases	Neurocutaneous melanocytosis	2481	P	161 Huid Nederland
715061	H-10-4	Rare neoplastic diseases, Rare skin diseases	Pyoderma gangrenosum - acne - hidradenitis suppurativa	289478	P	161 Huid Nederland
716165	H-25-2	Rare infectious diseases	Rare mycoses	163591	P	161 Huid Nederland
720256	H-12-11	Rare hematologic diseases	Dyskeratosis Congenita	1775	P	161 Huid Nederland

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
706222	H-2-16	Rare surgical maxillo-facial diseases	Cleft hard palate	101023	P	17 LaPosa
706222	H-2-16	Rare surgical maxillo-facial diseases	Cleft lip and alveolus	141291	P	17 LaPosa
706222	H-2-16	Rare surgical maxillo-facial diseases	Cleft lip with or without cleft palate	1991	P	17 LaPosa
706222	H-2-16	Rare surgical maxillo-facial diseases	Cleft lip/palate	199306	P	17 LaPosa
706222	H-2-16	Rare surgical maxillo-facial diseases	Cleft palate	2014	P	17 LaPosa
706222	H-2-16	Rare surgical maxillo-facial diseases	Submucosal cleft palate	155878	P	17 LaPosa
715430	H-2-8	Rare developmental anomalies during embryogenesis, Rare neurological diseases Rare otorhinolaryngological diseases Rare surgical maxillo-facial diseases	Paralytic facial malformation	156224	P	17 LaPosa
716058	H-2-2	Rare surgical maxillo-facial diseases	Oculo-auriculo-vertebral spectrum	141132	P	17 LaPosa

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:		P	nr	Patiëntenorganisatie:
724127	H-2-12	Rare surgical maxillo-facial diseases	22q11.2 deletion syndrome	567	P	17	LaPosa
724127	H-2-12	Rare surgical maxillo-facial diseases	22q11.2 duplication syndrome	1727	P	17	LaPosa
724127	H-2-12	Rare surgical maxillo-facial diseases	Isolated Pierre Robin syndrome	718	P	17	LaPosa
724127	H-2-12	Rare surgical maxillo-facial diseases	Rare disease with Pierre Robin syndrome	138044	P	17	LaPosa
716078	H-24-2	Rare circulatory system diseases	Congenital chylothorax	264688	P	200	LGD Alliance
715366	H-11-52	Rare neoplastic diseases	Rare carcinoma of pancreas	217074	P	260	Living with Hope
715366	H-11-52	Rare neoplastic diseases	Rare tumor of pancreas	180824	P	260	Living with Hope

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
715274	H-8-23	Rare hepatic diseases, Rare respiratory diseases	Alpha-1-antitrypsin deficiency	60	P	121 Longfonds
709238	H-11-53	Rare neoplastic diseases	Thymic tumor	100100	P	204 Longkanker Nederland
715145	H-9-11	Rare neurological diseases	Rare autonomic nervous system disorder	423662	P	329 Lotgenoten Lage Bloeddruk Hartpatiënten Nederland
715145	H-9-11	Rare neurological diseases	Pure autonomic failure	441	P	329 Lotgenoten Lage Bloeddruk Hartpatiënten Nederland
710236	H-6-4	Rare ophthalmic disorders	Leber plus disease	99718	P	125 Macula Vereniging
710236	H-6-4	Rare ophthalmic disorders	Uveitis	98715	P	125 Macula Vereniging
710455	H-17-11	Rare genetic diseases	Down syndrome	870	P	146 Marshall Smith Syndroom Research Foundation
710455	H-17-11	Rare genetic diseases	16p11.2p12.2 microdeletion syndrome	261211	P	146 Marshall Smith Syndroom Research Foundation

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
710455	H-17-11	Rare genetic diseases	Distal 16p11.2 microdeletion syndrome	261222	P	146 Marshall Smith Syndroom Research Foundation
710455	H-17-11	Rare genetic diseases	Proximal 16p11.2 microdeletion syndrome	261197	P	146 Marshall Smith Syndroom Research Foundation
710455	H-17-11	Rare genetic diseases	Proximal 16p11.2 microduplication syndrome	370079	P	146 Marshall Smith Syndroom Research Foundation
715386	H-12-18	Rare hematologic diseases	Systemic mastocytosis	2467	P	83 Mastocytose Vereniging Nederland
716145	H-12-3	Rare neoplastic diseases	Myeloproliferative neoplasm	98274	P	78 MPN Stichting
716145	H-12-3	Rare neoplastic diseases	Primary myelofibrosis	824	P	78 MPN Stichting
715121	H-0-4	Rare neurological diseases	Idiopathic hypersomnia	33208	P	210 Narcolepsie Vereniging Nederland
715121	H-0-4	Rare neurological diseases	Narcolepsy type 1	2073	P	210 Narcolepsie Vereniging Nederland
715121	H-0-4	Rare neurological diseases	Narcolepsy type 2	83465	P	210 Narcolepsie Vereniging Nederland

Assessment						
AIMS ID:	Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
715121	H-0-4	Rare neurological diseases	Rare sleep disorder	68354	P	210 Nederland
715080	H-21-6	Rare systemic and rheumatological diseases	Mixed connective tissue disease	809	P	Nationale Vereniging 22 Sjögren Patiënten
709794	H-22-15	Rare immunological diseases	Primary Sjögren syndrome	289390	P	Nationale Vereniging 22 Sjögrenpatiënten (NVSP)
709794	H-22-15	Rare immunological diseases	Systemic lupus erythematosus	536	P	Nationale vereniging voor lupus, aps, sclerodermie en MCTD 128 (NVLE)
709794	H-22-15	Rare immunological diseases	Systemic sclerosis	801	P	Nationale vereniging voor lupus, aps, sclerodermie en MCTD 128 (NVLE)
715080	H-21-6	Rare systemic and rheumatological diseases	Mixed connective tissue disease	809	P	Nationale vereniging voor lupus, aps, sclerodermie en MCTD 128 (NVLE)
712016	H-8-25	Rare respiratory diseases	Cystic Fibrosis	586	P	Nederlandse Cystic Fibrosis Stichting (NCFS) 159



AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
715227	H-3-17	Rare endocrine diseases	Meningioma	2495	P	65 Nederlandse Hypofyse Stichting (NHS)
715254	H-20-8	Rare hepatic diseases	Autoimmune hepatitis	2137	P	19 Nederlandse Leverpatiëntenvereniging (NLV)
715254	H-20-8	Rare hepatic diseases	IgG4-related sclerosing cholangitis	447764	P	19 Nederlandse Leverpatiëntenvereniging (NLV)
715254	H-20-8	Rare hepatic diseases	Primary biliary cholangitis	186	P	19 Nederlandse Leverpatiëntenvereniging (NLV)
715254	H-20-8	Rare hepatic diseases	Primary sclerosing cholangitis	171	P	19 Nederlandse Leverpatiëntenvereniging (NLV)
715366	H-11-52	Rare neoplastic diseases	Rare hepatic and biliary tract tumor	101943	P	19 Nederlandse Leverpatiëntenvereniging (NLV)
715165	H-25-11	Rare infectious diseases	Arboviral fever	344	P	118 Nederlandse Meningitis Stichting

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
708008	H-12-8	Rare hematologic diseases	Rare hemorrhagic disorder due to a qualitative platelet defect	P	275736	74 (NVHP) Nederlandse Vereniging voor Hemofiliepatiënten
716120	H-11-16	Rare endocrine diseases	Non-functioning paraganglioma	P	94080	29 Nederlandse Vereniging voor Mensen met Paragangliomen (NVPG)
710372	H-9-14	Rare neurological diseases	Benign peripheral nerve sheath tumor	P	252131	30 Neurofibromatosevereniging Nederland (NFVN)
715366	H-11-52	Rare neoplastic diseases	Benign peripheral nerve sheath tumor	P	252131	30 Neurofibromatosevereniging Nederland (NFVN)
715366	H-11-52	Rare neoplastic diseases	Malignant peripheral nerve sheath tumor	P	3148	30 Neurofibromatosevereniging Nederland (NFVN)
724234	H-15-11	Rare neoplastic diseases	Benign schwannoma	P	252164	30 Neurofibromatosevereniging Nederland (NFVN)
724234	H-15-11	Rare neoplastic diseases	Vestibular schwannoom	P	252175	30 Neurofibromatosevereniging Nederland (NFVN)

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
715061	H-10-4	Rare neoplastic diseases, Rare skin diseases	Large congenital melanocytic nevus 626	P	141	Nevus Netwerk
715061	H-10-4	Rare neoplastic diseases, Rare skin diseases	Neurocutaneous melanocytosis 2481	P	141	Nevus Netwerk
715486	H-10-9	Rare skin diseases	Large congenital melanocytic nevus 626	P	141	Nevus Netwerk
706031	H-11-15	Rare neoplastic diseases	Vulvar squamous cell carcinoma 494448	P	18	NFK: Patiëntenplatform Zeldzame Kankers
709054	H-11-54	Rare gastroenterologic diseases	Epithelial tumor of anal cancer 424010	P	18	NFK: Patiëntenplatform Zeldzame Kankers
715366	H-11-52	Rare neoplastic diseases	Rare vulvovaginal tumor 180312	P	18	NFK: Patiëntenplatform Zeldzame Kankers
706138	H-5-4	Rare renal diseases	Genetic renal tubular disease 183592	P	31	Nierpatiëntenvereniging Nederland (NVN)
706138	H-5-4	Rare renal diseases	Nephropathy secondary to a storage or other metabolic disease 93593	P	31	Nierpatiëntenvereniging Nederland (NVN)

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
706138	H-5-4	Rare renal diseases	Rare renal tubular disease	93603	P	31 Nierpatiëntenvereniging Nederland (NVN)
709775	H-5-2	Rare inborn errors of metabolism, Rare renal diseases	Glomerular disease	93548	P	31 Nierpatiëntenvereniging Nederland (NVN)
709775	H-5-2	Rare inborn errors of metabolism, Rare renal diseases	Rare renal tubular disease	93603	P	31 Nierpatiëntenvereniging Nederland (NVN)
709775	H-5-2	Rare inborn errors of metabolism, Rare renal diseases	Thrombotic microangiopathy	93573	P	31 Nierpatiëntenvereniging Nederland (NVN)
715227	H-3-17	Rare endocrine diseases	Meningioma	2495	P	64 NVACP
706167	H-14-8	Rare neurological diseases	Rare central nervous system and retinal vascular disease	71281	P	100 Oogvereniging

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
709465	H-9-18	Rare neurological diseases	Rare central nervous system and retinal vascular disease	71281	P	100 Oogvereniging
710024	H-6-6	Rare genetic diseases	Cerebral visual impairment	447788	P	100 Oogvereniging
710024	H-6-6	Rare genetic diseases	Inherited retinal disorder	71862	P	100 Oogvereniging
710236	H-6-4	Rare ophthalmic disorders	Leber plus disease	99718	P	100 Oogvereniging
710236	H-6-4	Rare ophthalmic disorders	Uveitis	98715	P	100 Oogvereniging
715100	H-26-6	Rare gynecologic and obstetric diseases	Retinopathy of prematurity	90050	P	100 Oogvereniging
715227	H-3-17	Rare endocrine diseases	Meningioma	2495	P	34 Osteoporose Vereniging
715227	H-3-17	Rare endocrine diseases	Acquired premature ovarian failure	95709	P	34 Osteoporose Vereniging
724526	H-11-50	Rare neoplastic diseases	Nasopharyngeal carcinoma	150	P	169 Hoofd - Hals Patiëntenvereniging
724526	H-11-50	Rare neoplastic diseases	Rare tumor of salivary glands	276142	P	169 Hoofd - Hals Patiëntenvereniging

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
724526	H-11-50	Rare neoplastic diseases	Squamous cell carcinoma of oral cavity and lip	502369	P	169 Patiëntenvereniging Hoofd - Hals
724526	H-11-50	Rare neoplastic diseases	Squamous cell carcinoma of the hypopharynx	494547	P	169 Patiëntenvereniging Hoofd - Hals
724526	H-11-50	Rare neoplastic diseases	Squamous cell carcinoma of the larynx	494550	P	169 Patiëntenvereniging Hoofd - Hals
724526	H-11-50	Rare neoplastic diseases	Squamous cell carcinoma of the nasal cavity and paranasal sinuses	500464	P	169 Patiëntenvereniging Hoofd - Hals
724526	H-11-50	Rare neoplastic diseases	Squamous cell carcinoma of the oral cavity	502363	P	169 Patiëntenvereniging Hoofd - Hals
724526	H-11-50	Rare neoplastic diseases	Squamous cell carcinoma of the oropharynx	500478	P	169 Patiëntenvereniging Hoofd - Hals
706075	H-11-43	Rare neoplastic diseases, Rare otorhinolaryngological diseases	Nasopharyngeal carcinoma	150	P	169 Patiëntenvereniging Hoofd - Hals

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
715227	H-3-17	Rare endocrine diseases	Acquired premature ovarian failure 95709	P	312	Patiëntenvereniging POI- POF
715450	H-3-18	Rare endocrine diseases, Rare gynecologic and obstetric diseases	Non-acquired premature ovarian failure 95710	P	312	Patiëntenvereniging POI- POF
724526	H-11-50	Rare neoplastic diseases	Rare tumor of salivary glands 276142	P	255	Patiëntenvereniging Speekselklierkanker
720077	H-16-13	Rare cardiac diseases	Aortic malformation 98718	P	127	Patiëntenvereniging voor Aangeboren Hartafwijkingen (PAH)
720077	H-16-13	Rare cardiac diseases	Conotruncal heart malformations 2445	P	127	Patiëntenvereniging voor Aangeboren Hartafwijkingen (PAH)
720077	H-16-13	Rare cardiac diseases	Rare congenital non-syndromic heart malformation 88991	P	127	Patiëntenvereniging voor Aangeboren Hartafwijkingen (PAH)
720077	H-16-13	Rare cardiac diseases	Transposition of the great arteries 216675	P	127	Patiëntenvereniging voor Aangeboren Hartafwijkingen (PAH)

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
720077	H-16-13	Rare cardiac diseases	Univentricular cardiopathy	95483	P	127 Hartafwijkingen (PAH) Patiëntenvereniging voor Aangeboren
710236	H-6-4	Rare ophthalmic disorders	Leber plus disease	99718	P	40 Sarcoïdose Belangenvereniging Nederland
710236	H-6-4	Rare ophthalmic disorders	Uveitis	98715	P	40 Sarcoïdose Belangenvereniging Nederland
709290	H-3-19	Rare endocrine diseases	Thyroid carcinoma	100088	P	60 Schildklier Organisatie Nederland (SON)
709290	H-3-19	Rare endocrine diseases	Thyroid tumor	100087	P	60 Schildklier Organisatie Nederland (SON)
710286	H-6-5	Rare ophthalmic disorders	Necrobiotic xanthogranuloma	158011	P	60 Schildklier Organisatie Nederland (SON)
710286	H-6-5	Rare ophthalmic disorders	IgG4-related ophthalmic disease	449563	P	60 Schildklier Organisatie Nederland (SON)
706222	H-2-16	Rare surgical maxillo-facial diseases	Cleft hard palate	101023	P	287 Schisis Nederland
706222	H-2-16	Rare surgical maxillo-facial diseases	Cleft lip and alveolus	141291	P	287 Schisis Nederland



AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
706222	H-2-16	Rare surgical maxillo-facial diseases	Cleft lip with or without cleft palate	1991	P	287 Schisis Nederland
706222	H-2-16	Rare surgical maxillo-facial diseases	Cleft lip/palate	199306	P	287 Schisis Nederland
706222	H-2-16	Rare surgical maxillo-facial diseases	Cleft palate	2014	P	287 Schisis Nederland
706222	H-2-16	Rare surgical maxillo-facial diseases	Submucosal cleft palate	155878	P	287 Schisis Nederland
724127	H-2-12	Rare surgical maxillo-facial diseases	Isolated Pierre Robin syndrome	718	P	287 Schisis Nederland
724127	H-2-12	Rare surgical maxillo-facial diseases	Rare disease with Pierre Robin syndrome	138044	P	287 Schisis Nederland
715205	H-14-11	Rare neoplastic diseases, Rare neurological diseases	Acquired periheral neuropathy	182086	P	288 SOS Nederland
708228	H-14-4	Rare inborn errors of metabolism	Mitochondrial diseases	68380	P	Spierziekten Nederland 43 (SN)
715205	H-14-11	Rare neoplastic diseases, Rare neurological diseases	Acquired periheral neuropathy	182086	P	Spierziekten Nederland 43 (SN)

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
716037	H-18-1	Rare inborn errors of metabolism	Rare dyslipidemia	101953	P	43 (SN) Spierziekten Nederland
715366	H-11-52	Rare neoplastic diseases	Rare gastroesophageal tumor	180821	P	63 SPKS - Leven met Maag- en Slokdarmkanker
709054	H-11-54	Rare gastroenterologic diseases	Rare gastroesophageal tumor	180821	P	63 of Slokdarmkanker SPKS - Leven met Maag-
715205	H-14-11	Rare neoplastic diseases, Rare neurological diseases	Anterior cutaneous nerve entrapment syndrome	51890	P	295 Stichting ACNES
708228	H-14-4	Rare inborn errors of metabolism	Mitochondrial diseases	68380	P	281 Stichting Cure ADOA Foundation
709839	H-11-19	Rare neoplastic diseases	Adenocarcinoma of the small intestine	104075	P	304 Stichting Darmkanker Nederland
710455	H-17-11	Rare genetic diseases	Down syndrome	870	P	71 Stichting Down Syndroom (SDS)
708027	H-4-1	Rare neurological diseases	Cerebral malformation with epilepsy	166478	P	333 Stichting Dravet Syndroom Nederland / Vlaanderen

Assessment						
AIMS ID:	Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
708027	H-4-1	Rare neurological diseases	Epilepsy Syndrome	166463	P	333 Stichting Dravet Syndroom Nederland / Vlaanderen
708027	H-4-1	Rare neurological diseases	Infantile Epilepsy Syndrome	98258	P	333 Stichting Dravet Syndroom Nederland / Vlaanderen
708027	H-4-1	Rare neurological diseases	Monogenic disease with epilepsy	166472	P	333 Stichting Dravet Syndroom Nederland / Vlaanderen
708027	H-4-1	Rare neurological diseases	Rare epilepsy	101998	P	333 Stichting Dravet Syndroom Nederland / Vlaanderen
708145	H-15-7	Rare genetic diseases	Hereditary breast and ovarian cancer syndrome	145	P	339 Stichting Erfelijke Kanker Nederland (SEKN)
724346	H-15-9	Rare genetic diseases	Hereditary breast and ovarian cancer syndrome	145	P	339 Stichting Erfelijke Kanker Nederland (SEKN)
708208	H-12-7	Rare hematologic diseases, Rare neoplastic diseases	Acute graft versus host disease	99920	P	81 Stichting Hematon
708208	H-12-7	Rare hematologic diseases, Rare neoplastic diseases	B-cell chronic lymphocytic leukemia	67038	P	81 Stichting Hematon

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
708208	H-12-7	Rare hematologic diseases, Rare neoplastic diseases	Chronic graft versus host disease	99921	P	81 Stichting Hematon
708208	H-12-7	Rare hematologic diseases, Rare neoplastic diseases	Graft versus host disease	39812	P	81 Stichting Hematon
710477	H-12-13	Rare hematologic diseases	Chronic Myeloid Leukemia	521	P	81 Stichting Hematon
716145	H-12-3	Rare neoplastic diseases	Acute myeloid leukemia	519	P	81 Stichting Hematon
716145	H-12-3	Rare neoplastic diseases	Chronic myeloid leukemia	521	P	81 Stichting Hematon
716145	H-12-3	Rare neoplastic diseases	Chronic myelomonocytic leukemia	98823	P	81 Stichting Hematon
716145	H-12-3	Rare neoplastic diseases	Myelodysplastic syndrome	52688	P	81 Stichting Hematon
716145	H-12-3	Rare neoplastic diseases	Myeloid hemopathy	171895	P	81 Stichting Hematon

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
716145	H-12-3	Rare neoplastic diseases	Myeloproliferative neoplasm	98274	P	81 Stichting Hematon
716145	H-12-3	Rare neoplastic diseases	Primary myelofibrosis	824	P	81 Stichting Hematon
706167	H-14-8	Rare neurological diseases	Acquired aneurysmal subarachnoid hemorrhage	90065	P	Stichting Hersenaneurysma 315 Patiënten Platform
709465	H-9-18	Rare neurological diseases	Acquired aneurysmal subarachnoid hemorrhage	90065	P	Stichting Hersenaneurysma 315 Patiënten Platform

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
716098	H-24-6	Rare circulatory system diseases	Rare disease with thoracic aortic aneurysm and aortic dissection	285014	P	Stichting Hersenaneurysma 315 Patiënten Platform
708169	H-2-10	Rare otorhinolaryngological diseases	Idiopathic Bilateral Vestibulopathy	171684	P	33 Stichting Hoormij
710372	H-9-14	Rare neurological diseases	Tumor of meninges	252025	P	33 Stichting Hoormij
710372	H-9-14	Rare neurological diseases	Benign peripheral nerve sheath tumor	252131	P	33 Stichting Hoormij
710372	H-9-14	Rare neurological diseases	Glial tumor	182067	P	33 Stichting Hoormij
724234	H-15-11	Rare neoplastic diseases	Benign schwannoma	252164	P	33 Stichting Hoormij
724234	H-15-11	Rare neoplastic diseases	Vestibular schwannoom	252175	P	33 Stichting Hoormij
724234	H-15-11	Rare neoplastic diseases	Glial tumor	182067	P	33 Stichting Hoormij

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
724234	H-15-11	Rare neoplastic diseases	Rare tumor of neuroepithelial tissue	251558	P	33 Stichting Hoormij
724234	H-15-11	Rare neoplastic diseases	Meningioma	2495	P	33 Stichting Hoormij
715332	H-16-12	Rare cardiac diseases	Arrhythmogenic right ventricular cardiomyopathy	247	P	Stichting ICD Dragers 206 Nederland (STIN)
715332	H-16-12	Rare cardiac diseases	Dilated cardiomyopathy	217604	P	Stichting ICD Dragers 206 Nederland (STIN)
715332	H-16-12	Rare cardiac diseases	Rare cardiomyopathy	167848	P	Stichting ICD Dragers 206 Nederland (STIN)

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
715332	H-16-12	Rare cardiac diseases	Rare hypertrophic cardiomyopathy 217569	P		Stichting ICD Dragers 206 Nederland (STIN)
715061	H-10-4	Rare neoplastic diseases, Rare skin diseases	Pyogenic arthritis- pyoderma gangrenosum- acne syndrome 69126	P		135 Stichting KAISZ
715185	H-17-14	Rare developmental anomalies during embryogenesis	Intellectual disability-severe speech delay-mild dysmorphism syndrome 391372	P		342 Stichting Kind Beter
715332	H-16-12	Rare cardiac diseases	Arrhythmogenic right ventricular cardiomyopathy 247	P		338 Stichting LMNA Cardiac



AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
715332	H-16-12	Rare cardiac diseases	Dilated cardiomyopathy	217604	P	338 Stichting LMNA Cardiac
715332	H-16-12	Rare cardiac diseases	Rare cardiomyopathy	167848	P	338 Stichting LMNA Cardiac
715332	H-16-12	Rare cardiac diseases	Rare hypertrophic cardiomyopathy	217569	P	338 Stichting LMNA Cardiac
708145	H-15-7	Rare genetic diseases	Intestinal polyposis syndrome	104010	P	93 Stichting Lynch Polyposis
708145	H-15-7	Rare genetic diseases	Lynch syndrome	144	P	93 Stichting Lynch Polyposis
715366	H-11-52	Rare neoplastic diseases	Malignant melanoma of the mucosa	168999	P	96 Stichting Melanoom

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
708228	H-14-4	Rare inborn errors of metabolism	Mitochondrial diseases	68380	P	199 Stichting Nemo
709008	H-10-11	Rare skin diseases	Merkel Cell carcinoma	79140	P	343 Stichting NETNECKanker
715061	H-10-4	Rare neoplastic diseases, Rare skin diseases	Cutaneous neuroendocrine carcinoma	79140	P	343 Stichting NETNECKanker
708145	H-15-7	Rare genetic diseases	Hereditary breast and ovarian cancer syndrome	145	P	88 Stichting Olijf
715366	H-11-52	Rare neoplastic diseases	Rare gynaecological tumor	98063	P	88 Stichting Olijf
715366	H-11-52	Rare neoplastic diseases	Rare uterine cancer	213564	P	88 Stichting Olijf
715366	H-11-52	Rare neoplastic diseases	Rare vulvovaginal tumor	180312	P	88 Stichting Olijf
715366	H-11-52	Rare neoplastic diseases	Rare ovarian cancer	213500	P	88 Stichting Olijf

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
724182	H-11-32	Rare neoplastic diseases	Vulvar carcinoma	494418	P	88 Stichting Olijf
724182	H-11-32	Rare neoplastic diseases	Ovarian cancer	213500	P	88 Stichting Olijf
724346	H-15-9	Rare genetic diseases	Hereditary breast and ovarian cancer syndrome	145	P	88 Stichting Olijf
724346	H-15-9	Rare genetic diseases	Hereditary site-specific ovarian cancer syndrome	213524	P	88 Stichting Olijf
706031	H-11-15	Rare neoplastic diseases	Malignant epithelial tumor of ovary	398934	P	88 Stichting Olijf
706031	H-11-15	Rare neoplastic diseases	Rare cancer of cervix uteri	213761	P	88 Stichting Olijf
706031	H-11-15	Rare neoplastic diseases	Rare cancer of corpus uteri	213569	P	88 Stichting Olijf
706031	H-11-15	Rare neoplastic diseases	Rare gynecological tumor	98063	P	88 Stichting Olijf
724182	H-11-32	Rare neoplastic diseases	Malignant graniulosacel tumor of ovary	99915	P	88 Stichting Olijf

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
724182	H-11-32	Rare neoplastic diseases	Rare cancer of the cervix uteri	213761	P	88 Stichting Olijf
724182	H-11-32	Rare neoplastic diseases	Rare gynecological tumor	98063	P	88 Stichting Olijf
715145	H-9-11	Rare neurological diseases	Pure autonomic failure	441	P	242 Stichting Orthostatische Tremor
708189	H-11-25	Rare neoplastic diseases	Desmoid tumor	873	P	94 Stichting Patiëntenplatform Sarcomen
708189	H-11-25	Rare neoplastic diseases	Gastrointestinal stromal tumor	44890	P	94 Stichting Patiëntenplatform Sarcomen
709336	H-11-35	Rare neoplastic diseases	Desmoid tumor	873	P	94 Stichting Patiëntenplatform Sarcomen
715026	H-11-19	Rare neoplastic diseases	Desmoid tumor	873	P	94 Stichting Patiëntenplatform Sarcomen
715026	H-11-19	Rare neoplastic diseases	Gastrointestinal stromal tumor	44890	P	94 Stichting Patiëntenplatform Sarcomen

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
715026	H-11-19	Rare neoplastic diseases	Soft tissue sarcoma	3394	P	94 Stichting Patiëntenplatform Sarcomen
715061	H-10-4	Rare neoplastic diseases, Rare skin diseases	Dermatofibrosarcoma protuberans	31112	P	94 Stichting Patiëntenplatform Sarcomen
715366	H-11-52	Rare neoplastic diseases	Malignant peripheral nerve sheath tumor	3148	P	94 Stichting Patiëntenplatform Sarcomen
724576	H-11-41	Rare neoplastic diseases	Desmoid tumor	873	P	94 Stichting Patiëntenplatform Sarcomen
724576	H-11-41	Rare neoplastic diseases	Soft tissue	3394	P	94 Stichting Patiëntenplatform Sarcomen
724628	H-11-31	Rare genetic diseases	Gastro-intestinale stromale tumor	44890	P	94 Stichting Patiëntenplatform Sarcomen
724127	H-2-12	Rare surgical maxillo-facial diseases	Isolated Pierre Robin syndrome	718	P	279 Stichting Pierre Robin Europe

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
724127	H-2-12	Rare surgical maxillo-facial diseases	Rare disease with Pierre Robin syndrome	138044	P	Stichting Pierre Robin 279 Europe
710455	H-17-11	Rare genetic diseases	Down syndrome	870	P	145 Stichting Pitt Hopkins
710455	H-17-11	Rare genetic diseases	16p11.2p12.2 microdeletion syndrome	261211	P	145 Stichting Pitt Hopkins
710455	H-17-11	Rare genetic diseases	Distal 16p11.2 microdeletion syndrome	261222	P	145 Stichting Pitt Hopkins
710455	H-17-11	Rare genetic diseases	Proximal 16p11.2 microdeletion syndrome	261197	P	145 Stichting Pitt Hopkins
710455	H-17-11	Rare genetic diseases	Proximal 16p11.2 microduplication syndrome	370079	P	145 Stichting Pitt Hopkins
708068	H-8-15	Rare respiratory diseases	Pulmonary arterial hypertension	182090	P	Stichting Pulmonale 158 Hypertensie
708068	H-8-15	Rare respiratory diseases	Rare pulmonary hypertension	71198	P	Stichting Pulmonale 158 Hypertensie

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
710455	H-17-11	Rare genetic diseases	Down syndrome	870	P	Stichting Rubinstein-48 Taybi
710455	H-17-11	Rare genetic diseases	16p11.2p12.2 microdeletion syndrome	261211	P	Stichting Rubinstein-48 Taybi
710455	H-17-11	Rare genetic diseases	Distal 16p11.2 microdeletion syndrome	261222	P	Stichting Rubinstein-48 Taybi
710455	H-17-11	Rare genetic diseases	Proximal 16p11.2 microdeletion syndrome	261197	P	Stichting Rubinstein-48 Taybi
710455	H-17-11	Rare genetic diseases	Proximal 16p11.2 microduplication syndrome	370079	P	Stichting Rubinstein-48 Taybi
724127	H-2-12	Rare surgical maxillo-facial diseases	22q11.2 deletion syndrome	567	P	271 Stichting Steun 22q11
724127	H-2-12	Rare surgical maxillo-facial diseases	22q11.2 duplication syndrome	1727	P	271 Stichting Steun 22q11

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
715100	H-26-6	Rare gynecologic and obstetric diseases	Selective Intrauterine Growth Restriction 617301	P	317	Stichting Taps Support
715100	H-26-6	Rare gynecologic and obstetric diseases	Twin Anemia Polycythemia Sequence 617294	P	317	Stichting Taps Support
715100	H-26-6	Rare gynecologic and obstetric diseases	Twin Reversed Arterial Perfusion sequence 617297	P	317	Stichting Taps Support
710236	H-6-4	Rare ophthalmic disorders	Leber plus disease 99718	P	240	Stichting Usher Syndroom
710236	H-6-4	Rare ophthalmic disorders	Uveitis 98715	P	240	Stichting Usher Syndroom
716165	H-25-2	Rare infectious diseases	Rare mycoses 163591	P	72	Stichting voor Afweerstoornissen (SAS)
717024	H-11-51	Rare neoplastic diseases	Germ cell tumor 3399	P	226	Stichting Zaadbalkanker
708008	H-12-8	Rare hematologic diseases	Rare hemorrhagic disorder due to a qualitative platelet defect 275736	P	75	Stichting Zeldzame Bloedziekten (SZB)



AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:		P	nr	Patiëntenorganisatie:
709775	H-5-2	Rare inborn errors of metabolism, Rare renal diseases	Thrombotic microangiopathy	93573	P		Stichting Zeldzame 75 Bloedziekten (SZB)
709794	H-22-15	Rare immunological diseases	Vasculitis	52759	P		51 Vasculitis Stichting
710286	H-6-5	Rare ophthalmic disorders	IgG4-related ophthalmic disease	449563	P		51 Vasculitis Stichting
710505	H-7-3	Rare gastroenterologic diseases	Congenital Chronic Diarrhea with protein- losing enteropathy	329242	P		120 Vereniging Anusatresie
710505	H-7-3	Rare gastroenterologic diseases	Congenital tufting enteropathy	92050	P		120 Vereniging Anusatresie
710505	H-7-3	Rare gastroenterologic diseases	Duodenum atresia	1203	P		120 Vereniging Anusatresie
710505	H-7-3	Rare gastroenterologic diseases	Microvillus inclusion disease	2290	P		120 Vereniging Anusatresie

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
710505	H-7-3	Rare gastroenterologic diseases	Rare diseases involving intestinal motility	104009	P	120 Vereniging Anusatresie
710505	H-7-3	Rare gastroenterologic diseases	Omphalocele	660	P	120 Vereniging Anusatresie
709091	H-9-19	Rare neurological diseases	Glial tumor	182067	P	82 Vereniging Kinderkanker Nederland
710372	H-9-14	Rare neurological diseases	Glial tumor	182067	P	82 Vereniging Kinderkanker Nederland
715366	H-11-52	Rare neoplastic diseases	Glial Tumors	182067	P	82 Vereniging Kinderkanker Nederland
724234	H-15-11	Rare neoplastic diseases	Glial tumor	182067	P	82 Vereniging Kinderkanker Nederland
724234	H-15-11	Rare neoplastic diseases	Rare tumor of neuroepithelial tissue	251558	P	82 Vereniging Kinderkanker Nederland
709885	H-1-9	Rare bone diseases	Osteogenesis imperfecta	666	P	53 Vereniging Osteogenesis Imperfecta (VOI)

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
710545	H-7-2	Rare gastroenterologic diseases	Eosinophilic esophagitis	73247	P	124 (VOKS) Vereniging Ouderen en Kinderen met Slokdarmafsluiting
710545	H-7-2	Rare gastroenterologic diseases	Idiopathic achalasia	930	P	124 (VOKS) Vereniging Ouderen en Kinderen met Slokdarmafsluiting
716098	H-24-6	Rare circulatory system diseases	Aortic malformation	98718	P	148 Vereniging van Ehlers Danlos Patiënten (VED)
716098	H-24-6	Rare circulatory system diseases	Ascending aorta anomaly	98725	P	148 Vereniging van Ehlers Danlos Patiënten (VED)
716098	H-24-6	Rare circulatory system diseases	Rare disease with thoracic aortic aneurysm and aortic dissection	285014	P	148 Vereniging van Ehlers Danlos Patiënten (VED)
710108	H-10-10	Rare skin diseases	Necrotizing soft tissue infection	440368	P	231 Vereniging van Mensen met Brandwonden

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
710545	H-7-2	Rare gastroenterologic diseases	Eosinophilic esophagitis	73247	P	Vereniging voor 182 Allergiepatiënten
710505	H-7-3	Rare gastroenterologic diseases	Rare diseases involving intestinal motility	104009	P	Vereniging Ziekte van 123 Hirschsprung
719220	H-7-15	Rare gastroenterologic diseases, Rare transplant-related disorders, Rare abdominal surgical	Chronic intestinal failure	294422	P	Vereniging Ziekte van 123 Hirschsprung
719220	H-7-15	Rare gastroenterologic diseases	Chronic intestinal pseudoobstruction	2978	P	Vereniging Ziekte van 123 Hirschsprung
719220	H-7-15	Rare gastroenterologic diseases	Secondary short bowel syndrome	95427	P	Vereniging Ziekte van 123 Hirschsprung
706138	H-5-4	Rare renal diseases	Nephropathy secondary to a storage or other metabolic disease	93593	P	Volwassenen Kinderen en Stofwisselingsziekten 56 (VKS)
706138	H-5-4	Rare renal diseases	Rare renal tubular disease	93603	P	Volwassenen Kinderen en Stofwisselingsziekten 56 (VKS)

Assessment						
AIMS ID:	Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
709517	H-9-17	Rare neurological diseases	Pyridoxine Dependent Epilepsy	3006	P	56 (VKS) Volwassenen Kinderen en Stofwisselingsziekten
709775	H-5-2	Rare inborn errors of metabolism, Rare renal diseases	Rare renal tubular disease	93603	P	56 (VKS) Volwassenen Kinderen en Stofwisselingsziekten
716037	H-18-1	Rare inborn errors of metabolism	Rare dyslipidemia	101953	P	56 (VKS) Volwassenen Kinderen en Stofwisselingsziekten
724687	H-18-11	Rare inborn errors of metabolism	Classic organic aciduria	79163	P	56 (VKS) Volwassenen Kinderen en Stofwisselingsziekten
724687	H-18-11	Rare inborn errors of metabolism	CLN3 disease	228346	P	56 (VKS) Volwassenen Kinderen en Stofwisselingsziekten
724687	H-18-11	Rare inborn errors of metabolism	Hurler syndrome	93473	P	56 (VKS) Volwassenen Kinderen en Stofwisselingsziekten
724687	H-18-11	Rare inborn errors of metabolism	Juvenile neuronal ceroid lipofuscinosis	79264	P	56 (VKS) Volwassenen Kinderen en Stofwisselingsziekten

Assessment							
AIMS ID:	Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:	
724687	H-18-11	Rare inborn errors of metabolism	Lysosomal disease	68366	P	56 (VKS)	Volwassenen Kinderen en Stofwisselingsziekten
724687	H-18-11	Rare inborn errors of metabolism	Methylmalonic acidemia with homocystinuria	26	P	56 (VKS)	Volwassenen Kinderen en Stofwisselingsziekten
724687	H-18-11	Rare inborn errors of metabolism	Methylmalonic acidemia without homocystinuria	293355	P	56 (VKS)	Volwassenen Kinderen en Stofwisselingsziekten
724687	H-18-11	Rare inborn errors of metabolism	Neonatal epileptic encephalopathy due to glutaminase deficiency	557064	P	56 (VKS)	Volwassenen Kinderen en Stofwisselingsziekten
724687	H-18-11	Rare inborn errors of metabolism	Neuronal ceroid lipofuscinosis	216	P	56 (VKS)	Volwassenen Kinderen en Stofwisselingsziekten
724687	H-18-11	Rare inborn errors of metabolism	Propionic acidemia	35	P	56 (VKS)	Volwassenen Kinderen en Stofwisselingsziekten

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
724687	H-18-11	Rare inborn errors of metabolism	Rare inborn errors of metabolism	68367	P	56 (VKS) Volwassenen Kinderen en Stofwisselingsziekten
710455	H-17-11	Rare genetic diseases	16p11.2p12.2 microdeletion syndrome	261211	P	290 Zeldsamen
710455	H-17-11	Rare genetic diseases	Distal 16p11.2 microdeletion syndrome	261222	P	290 Zeldsamen
710455	H-17-11	Rare genetic diseases	Proximal 16p11.2 microdeletion syndrome	261197	P	290 Zeldsamen
710455	H-17-11	Rare genetic diseases	Proximal 16p11.2 microduplication syndrome	370079	P	290 Zeldsamen
715185	H-17-14	Rare developmental anomalies during embryogenesis	Coffin-Siris syndrome	1465	P	290 Zeldsamen

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
715185	H-17-14	Rare developmental anomalies during embryogenesis	Intellectual disability-severe speech delay-mild dysmorphism syndrome	391372	P	290 Zeldsamen
715185	H-17-14	Rare developmental anomalies during embryogenesis	Rare intellectual disability	87277	P	290 Zeldsamen
709386	H-7-19	Rare abdominal surgical diseases	Celiac artery compression syndrome	293208	P	Zonder patiëntenorganisatie
709465	H-9-18	Rare neurological diseases	Cerebral sinovenous thrombosis	329217	P	Zonder patiëntenorganisatie
709929	H-22-14	Rare immunological diseases	Exercise-induced malignant hyperthermia	466650	P	Zonder patiëntenorganisatie
709929	H-22-14	Rare immunological diseases	Malignant hyperthermia of anesthesia	423	P	Zonder patiëntenorganisatie



AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
709929	H-22-14	Rare immunological diseases	Rare disease with malignant hyperthermia	466658	P	Zonder patiëntenorganisatie
710077	H-17-16	Rare surgical thoracic diseases	arterial thoracic outlet syndrome	357107	P	Zonder patiëntenorganisatie
710077	H-17-16	Rare surgical thoracic diseases	neurogenic thoracic outlet syndrome	100073	P	Zonder patiëntenorganisatie
710077	H-17-16	Rare surgical thoracic diseases	Thoracic Outlet Syndrome	97330	P	Zonder patiëntenorganisatie
710077	H-17-16	Rare surgical thoracic diseases	venous thoracic outlet syndrome	357131	P	Zonder patiëntenorganisatie
715007	H-26-7	Rare infectious diseases	Arbovirus fever	344	P	Zonder patiëntenorganisatie
715007	H-26-7	Rare infectious diseases	Malaria	673	P	Zonder patiëntenorganisatie
715007	H-26-7	Rare infectious diseases	Rare parasitic disease	163588	P	Zonder patiëntenorganisatie
715007	H-26-7	Rare infectious diseases	Schistosomiasis	1247	P	Zonder patiëntenorganisatie
715121	H-0-4	Rare neurological diseases	Kleine-Levin syndrome	33543	P	Zonder patiëntenorganisatie

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:		P	nr	Patiëntenorganisatie:
715165	H-25-11	Rare infectious diseases	Malaria	673	P		Zonder patiëntenorganisatie
715165	H-25-11	Rare infectious diseases	Middle East respiratory syndrome	576074	P		Zonder patiëntenorganisatie
715165	H-25-11	Rare infectious diseases	Rabies	770	P		Zonder patiëntenorganisatie
715165	H-25-11	Rare infectious diseases	Rare parasitic disease	163588	P		Zonder patiëntenorganisatie
715165	H-25-11	Rare infectious diseases	Schistosomiasis	1247	P		Zonder patiëntenorganisatie
715165	H-25-11	Rare infectious diseases	Severe acute respiratory syndrome	140896	P		Zonder patiëntenorganisatie
715165	H-25-11	Rare infectious diseases	Strongyloidiasis	76	P		Zonder patiëntenorganisatie

AIMS ID:	Assessment Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
715165	H-25-11	Rare infectious diseases	Viral hemorrhagic fever	341	P	Zonder patiëntenorganisatie
715165	H-25-11	Rare infectious diseases	Yellow fever	99829	P	Zonder patiëntenorganisatie
715205	H-14-11	Rare neoplastic diseases, Rare neurological diseases	Neurogenic thoracic outlet syndrome	100073	P	Zonder patiëntenorganisatie
715205	H-14-11	Rare neoplastic diseases, Rare neurological diseases	Pudendal neuralgia	60039	P	Zonder patiëntenorganisatie
719220	H-7-15	Rare gastroenterologic diseases	Parenteral nutrition-associated cholestasis	567983	P	zonder patiëntenorganisatie
719220	H-7-15	Rare gastroenterologic diseases	Microvillus inclusion disease	2290	P	Zonder patiëntenorganisatie
724296	H-9-13	Rare neurological diseases	Moyamoya angiopathy	477768	P	Zonder patiëntenorganisatie
724296	H-9-13	Rare neurological diseases	Moyamoya disease	2573	P	Zonder patiëntenorganisatie

Assessment						
AIMS ID:	Number:	Expertisegebied:	Aandoening:	P	nr	Patiëntenorganisatie:
724467	H-11-55	Rare neurological diseases	Cerebral sinovenous thrombosis	329217	P	Zonder patiëntenorganisatie
724467	H-11-55	Rare neurological diseases	Pediatric arterial ischemic stroke	439175	P	Zonder patiëntenorganisatie