

AIMS ID:	Expertisegebied:	Aandoening:	Orphacode:	P	nr	Patiëntenorganisatie:
724687	Rare inborn errors of metabolism	Methylmalonic acidemia with homocystinuria	26	P	56	Volwassenen Kinderen en Stofwisselingsziekten (VKS)
724687	Rare inborn errors of metabolism	Propionic acidemia	35	P	56	Volwassenen Kinderen en Stofwisselingsziekten (VKS)
706095	Rare inborn errors of metabolism	Alkaptonuria	56	P	56	Volwassenen Kinderen en Stofwisselingsziekten (VKS)
715274	Rare hepatic diseases, Rare respiratory diseases	Alpha-1-antitrypsin deficiency	60	P	121	Longfonds
715165	Rare infectious diseases	Strongyloidiasis	76	P		Zonder patiëntenorganisatie
708087	Rare cardiac diseases	Brugada syndrome	130	P	58	Harteraad
708087	Rare cardiac diseases	Brugada syndrome	130	P	337	Brugada Community
706009	Rare developmental anomalies during embryogenesis, Rare developmental anomalies during embryogenesis, Rare genetic diseases	CHARGE syndrome	138	P	290	Zeldsamen
708145	Rare genetic diseases	Lynch syndrome	144	P	93	Stichting Lynch Polyposis

AIMS ID:	Expertisegebied:	Aandoening:	Orphacode:	P	nr	Patiëntenorganisatie:
708145	Rare genetic diseases	Hereditary breast and ovarian cancer syndrome	145	P	88	Stichting Olijf
708145	Rare genetic diseases	Hereditary breast and ovarian cancer syndrome	145	P	89 (BVN)	Borstkankervereniging
708145	Rare genetic diseases	Hereditary breast and ovarian cancer syndrome	145	P	339	Stichting Erfelijke Kanker Nederland (SEKN)
724346	Rare genetic diseases	Hereditary breast and ovarian cancer syndrome	145	P	88	Stichting Olijf
724346	Rare genetic diseases	Hereditary breast and ovarian cancer syndrome	145	P	89 (BVN)	Borstkankervereniging
724346	Rare genetic diseases	Hereditary breast and ovarian cancer syndrome	145	P	339	Stichting Erfelijke Kanker Nederland (SEKN)
706075	Rare neoplastic diseases, Rare otorhinolaryngological diseases	Nasopharyngeal carcinoma	150	P	169	Patiëntenvereniging Hoofd - Hals
724526	Rare neoplastic diseases	Nasopharyngeal carcinoma	150	P	169	Patiëntenvereniging Hoofd - Hals
706187	Rare hepatic diseases	Primary sclerosing cholangitis	171	P	19	Nederlandse Leverpatiënten Vereniging (NLV)
715254	Rare hepatic diseases	Primary sclerosing cholangitis	171	P	19 (NLV)	Nederlandse Leverpatiëntenvereniging
715254	Rare hepatic diseases	Primary biliary cholangitis	186	P	19 (NLV)	Nederlandse Leverpatiëntenvereniging

AIMS ID:	Expertisegebied:	Aandoening:	Orphacode:	P	nr	Patiëntenorganisatie:
724687	Rare inborn errors of metabolism	Neuronal ceroid lipofuscinosis	216	P		Volwassenen Kinderen en 56 Stofwisselingsziekten (VKS)
708087	Rare cardiac diseases	Arrhythmogenic right ventricular dysplasia	247	P	58	Harteraad
715332	Rare cardiac diseases	Arrhythmogenic right ventricular cardiomyopathy	247	P	58	Harteraad
715165	Rare infectious diseases	Viral hemorrhagic fever	341	P		Zonder patiëntenorganisatie
715007	Rare infectious diseases	Arbovirus fever	344	P		Zonder patiëntenorganisatie
715165	Rare infectious diseases	Arboviral fever	344	P	118	Nederlandse Meningitis Stichting
706115	Rare inborn errors of metabolism	Glycogen storage disease due to liver glycogen phosphorylase deficiency	369	P		Volwassenen Kinderen en 56 Stofwisselingsziekten (VKS)
709929	Rare immunological diseases	Malignant hyperthermia of anesthesia	423	P		Zonder patiëntenorganisatie
715145	Rare neurological diseases	Pure autonomic failure	441	P	242	Tremor Stichting Orthostatische

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715007	Rare infectious diseases	Leishmaniasis	507	P	161	Huid Nederland
716145	Rare neoplastic diseases	Acute myeloid leukemia	519	P	81	Stichting Hematon
710477	Rare hematologic diseases	Chronic Myeloid Leukemia	521	P	81	Stichting Hematon
716145	Rare neoplastic diseases	Chronic myeloid leukemia	521	P	81	Stichting Hematon
709794	Rare immunological diseases	Systemic lupus erythematosus	536	P	128	Nationale vereniging voor lupus, aps, sclerodermie en MCTD (NVLE)
709794	Rare immunological diseases	Systemic lupus erythematosus	536	P	161	Huid Nederland
724127	Rare surgical maxillo-facial diseases	22q11.2 deletion syndrome	567	P	271	Stichting Steun 22q11
712016	Rare respiratory diseases	Cystic Fibrosis	586	P	159	Nederlandse Cystic Fibrosis Stichting (NCFS)
715061	Rare neoplastic diseases, Rare skin diseases	Large congenital melanocytic nevus	626	P	141	Nevus Netwerk
715486	Rare skin diseases	Large congenital melanocytic nevus	626	P	141	Nevus Netwerk

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710505	Rare gastroenterologic diseases	Omphalocele	660	P	114	Care4Neo
709885	Rare bone diseases	Osteogenesis imperfecta	666	P	53	Vereniging Osteogenesis Imperfecta (VOI)
715007	Rare infectious diseases	Malaria	673	P		Zonder patiëntenorganisatie
715165	Rare infectious diseases	Malaria	673	P		Zonder patiëntenorganisatie
715408	Rare abdominal surgical diseases	Annular pancreas	675	P	87	Alveesklievereniging
724127	Rare surgical maxillo-facial diseases	Isolated Pierre Robin syndrome	718	P	279	Stichting Pierre Robin Europe
724127	Rare surgical maxillo-facial diseases	Isolated Pierre Robin syndrome	718	P	287	Schisis Nederland
708087	Rare cardiac diseases	Familial long QT syndrome	768	P	58	Harteraad
715165	Rare infectious diseases	Rabies	770	P		Zonder patiëntenorganisatie
709794	Rare immunological diseases	Systemic sclerosis	801	P	128	Nationale vereniging voor lupus, aps, sclerodermie en MCTD (NVLE)

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709794	Rare immunological diseases	Systemic sclerosis	801	P	161	Huid Nederland
715080	Rare systemic and rheumatological diseases	Mixed connective tissue disease	809	P	22	Nationale Vereniging Sjögren Patiënten
715080	Rare systemic and rheumatological diseases	Mixed connective tissue disease	809	P	128	Nationale vereniging voor lupus, aps, sclerodermie en MTCD (NVLE)
716145	Rare neoplastic diseases	Primary myelofibrosis	824	P	78	MPN Stichting
716145	Rare neoplastic diseases	Primary myelofibrosis	824	P	81	Stichting Hematon
709618	Rare genetic diseases	Down syndrome	870	P	71	Stichting Down Syndroom (SDS)
710455	Rare genetic diseases	Down syndrome	870	P	71	Stichting Down Syndroom (SDS)
708189	Rare neoplastic diseases	Desmoid tumor	873	P	94	Stichting Patiëntenplatform Sarcomen
709336	Rare neoplastic diseases	Desmoid tumor	873	P	94	Stichting Patiëntenplatform Sarcomen

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715026	Rare neoplastic diseases	Desmoid tumor	873	P 94	Stichting Patiëntenplatform Sarcomen
724576	Rare neoplastic diseases	Desmoid tumor	873	P 94	Stichting Patiëntenplatform Sarcomen
710545	Rare gastroenterologic diseases	Idiopathic achalasia	930	P	Zonder patiëntenorganisatie
709738	Rare abdominal surgical diseases, Rare neurological diseases	Early-onset autosomal dominant Alzheimers disease	1020	P 2	Alzheimer Nederland Care4Neo
710334	Rare neurological diseases	Vein of Galen Aneurysmal Malformation	1053	P 114	Zonder patiëntenorganisatie
710505	Rare gastroenterologic diseases	Duodenum atresia	1203	P	Zonder patiëntenorganisatie
715007	Rare infectious diseases	Schistosomiasis	1247	P	Zonder patiëntenorganisatie
715165	Rare infectious diseases	Schistosomiasis	1247	P	Zonder patiëntenorganisatie
715185	Rare developmental anomalies during embryogenesis	Coffin-Siris syndrome	1465	P 290	Zeldsamen
715227	Rare endocrine diseases	Meningioma	1495	P 65	Nederlandse Hypofyse Stichting (NHS)

AIMS ID:	Expertisegebied:	Aandoening:	Orphacode:	P	nr	Patiëntenorganisatie:
715227	Rare endocrine diseases	Meningioma	1495	P	91	Hersenletsel.nl
708106	Rare immunological diseases	Common variable immunodeficiency	1572	P	72	Stichting voor Afweerstoornissen (SAS)
724127	Rare surgical maxillo-facial diseases	22q11.2 duplication syndrome	1727	P	271	Stichting Steun 22q11
720256	Rare hematologic diseases	Dyskeratosis Congenita	1775	P	161	Huid Nederland
717006	Rare respiratory diseases	Congenital lobar emphysema	1928	P	114	Care4Neo
724406	Rare genetic diseases	Bilateral striopallidodentate calcinosis	1980	P	2	Alzheimer Nederland
706222	Rare surgical maxillo-facial diseases	Cleft lip with or without cleft palate	1991	P	17	LaPosa
706222	Rare surgical maxillo-facial diseases	Cleft lip with or without cleft palate	1991	P	287	Schisis Nederland
706222	Rare surgical maxillo-facial diseases	Cleft palate	2014	P	17	LaPosa
706222	Rare surgical maxillo-facial diseases	Cleft palate	2014	P	287	Schisis Nederland
715121	Rare neurological diseases	Narcolepsy type 1	2073	P	210	Narcolepsie Vereniging Nederland



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715254	Rare hepatic diseases	Autoimmune hepatitis	2137	P	19 (NLV)	Nederlandse Leverpatiëntenvereniging
710505	Rare gastroenterologic diseases	Microvillus inclusion disease	2290	P		Zonder patiëntenorganisatie
719220	Rare gastroenterologic diseases	Microvillus inclusion disease	2290	P		Zonder patiëntenorganisatie
717006	Rare respiratory diseases	Bronchogenic cyst	2357	P		Zonder patiëntenorganisatie
712061	Rare abdominal surgical diseases, Rare gastroenterologic diseases	Gastroschisis	2368	P	114	Care4Neo
717006	Rare respiratory diseases	Congenital pulmonary airway malformation	2444	P	114	Care4Neo
720077	Rare cardiac diseases	Conotruncal heart malformations	2445	P	127	Patiëntenvereniging voor Aangeboren Hartafwijkingen (PAH)
720077	Rare cardiac diseases	Conotruncal heart malformations	2445	P	147	Contactgroep Marfan Nederland
715386	Rare hematologic diseases	Systemic mastocytosis	2467	P	83	Mastocytose Vereniging Nederland
715061	Rare neoplastic diseases, Rare skin diseases	Neurocutaneous melanocytosis	2481	P	141	Nevus Netwerk
715061	Rare neoplastic diseases, Rare skin diseases	Neurocutaneous melanocytosis	2481	P	161	Huid Nederland

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724234	Rare neoplastic diseases	Meningioma	2495	P 91	Hersenletsel.nl
724296	Rare neurological diseases	Moyamoya disease	2573	P 91	Hersenletsel.nl
715304	Rare otorhinolaryngological diseases	Laryngeal abductor paralysis	2808	P	Zonder patiëntenorganisatie
719220	Rare gastroenterologic diseases	Chronic intestinal pseudoobstruction	2978	P 123	Vereniging Ziekte van Hirschsprung
709517	Rare neurological diseases	Pyridoxine Dependent Epilepsy	3006	P 56	Volwassenen Kinderen en Stofwisselingsziekten (VKS)
715366	Rare neoplastic diseases	Malignant peripheral nerve sheath tumor	3148	P 30	Neurofibromatoseverenigin g Nederland (NFVN)
715366	Rare neoplastic diseases	Malignant peripheral nerve sheath tumor	3148	P 94	Stichting Patiëntenplatform Sarcomen
717006	Rare respiratory diseases	Congenital pulmonary sequestration	3161	P 114	Care4Neo
715026	Rare neoplastic diseases	Soft tissue sarcoma	3394	P 94	Stichting Patiëntenplatform Sarcomen

AIMS ID:	Expertisegebied:	Aandoening:	Orphacode:	P	nr	Patiëntenorganisatie:
724576	Rare neoplastic diseases	Soft tissue	3394	P	94	Stichting Patiëntenplatform Sarcomen
717024	Rare neoplastic diseases	Germ cell tumor	3399	P	226	Stichting Zaadbalkanker
706115	Rare inborn errors of metabolism	Multiple acyl-CoA dehydrogenase deficiency	26791	P	56	Volwassenen Kinderen en Stofwisselingsziekten (VKS)
715061	Rare neoplastic diseases, Rare skin diseases	Dermatofibrosarcoma protuberans	31112	P	94	Stichting Patiëntenplatform Sarcomen
715121	Rare neurological diseases	Idiopathic hypersomnia	33208	P	210	Narcolepsie Vereniging Nederland
715121	Rare neurological diseases	Kleine-Levin syndrome	33543	P	91	Hersenletsel.nl
708208	Rare hematologic diseases, Rare neoplastic diseases	Graft versus host disease	39812	P	81	Stichting Hematon
708189	Rare neoplastic diseases	Gastrointestinal stromal tumor	44890	P	94	Stichting Patiëntenplatform Sarcomen
715026	Rare neoplastic diseases	Gastrointestinal stromal tumor	44890	P	94	Stichting Patiëntenplatform Sarcomen
719191	Rare neoplastic diseases	Gastrointestinal stromal tumor	44890	P	94	Stichting Patiëntenplatform Sarcomen

AIMS ID:	Expertisegebied:	Aandoening:	Orphacode:	P	nr	Patiëntenorganisatie:
724628	Rare genetic diseases	Gastro-intestinale stromale tumor	44890	P	94	Stichting Patiëntenplatform Sarcomen
710334	Rare neurological diseases	Cerebral arteriovenous malformation	46724	P	91	Hersenletsel.nl
710334	Rare neurological diseases	Cerebral arteriovenous malformation	46724	P	316	AVM in de hersenen
706009	Rare developmental anomalies during embryogenesis, Rare developmental anomalies during embryogenesis, Rare genetic diseases	Monosomy 22q13.3	48652	P	290	Zeldsamen
709238	Rare neoplastic diseases	Pleural mesothelioma	50251	P	109	Asbestslachtoffers Vereniging Nederland (AVN)
709431	Rare neurological diseases	Anterior cutaneous nerve entrapment syndrome	51890	P	295	Stichting ACNES
709431	Rare neurological diseases	Anterior cutaneous nerve entrapment syndrome	51890	P	296	ACNES Foundation
715205	Rare neoplastic diseases, Rare neurological diseases	Anterior cutaneous nerve entrapment syndrome	51890	P	295	Stichting ACNES
715205	Rare neoplastic diseases, Rare neurological diseases	Anterior cutaneous nerve entrapment syndrome	51890	P	296	ACNES Foundation

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716145	Rare neoplastic diseases	Myelodysplastic syndrome	52688	P 81	Stichting Hematon
709794	Rare immunological diseases	Vasculitis	52759	P 51	Vasculitis Stichting
710334	Rare neurological diseases	Spinal arteriovenous metameric syndrome	53721	P	Zonder patiëntenorganisatie
709738	Rare abdominal surgical diseases, Rare neurological diseases	Human Prion Disease	56970	P 2	Alzheimer Nederland
709738	Rare abdominal surgical diseases, Rare neurological diseases	Human Prion Disease	56970	P 91	Hersenletsel.nl
715205	Rare neoplastic diseases, Rare neurological diseases	Pudendal neuralgia	60039	P	Zonder patiëntenorganisatie
708208	Rare hematologic diseases, Rare neoplastic diseases	B-cell chronic lymphocytic leukemia	67038	P 81	Stichting Hematon
706009	Rare developmental anomalies during embryogenesis, Rare developmental anomalies during embryogenesis, Rare genetic diseases	Rare chromosomal anomaly	68335	P 290	Zeldsamen
715121	Rare neurological diseases	Rare sleep disorder	68354	P 210	Nederland Narcolepsie Vereniging

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724687	Rare inborn errors of metabolism	Lysosomal disease	68366	P	56	Volwassenen Kinderen en Stofwisselingsziekten (VKS)
724687	Rare inborn errors of metabolism	Rare inborn errors of metabolism	68367	P	56	Volwassenen Kinderen en Stofwisselingsziekten (VKS)
708228	Rare inborn errors of metabolism	Mitochondrial diseases	68380	P	43	Spierziekten Nederland (SN)
708228	Rare inborn errors of metabolism	Mitochondrial diseases	68380	P	274	Belangenvereniging LOA/LHON
708228	Rare inborn errors of metabolism	Mitochondrial diseases	68380	P	281	Stichting Cure ADOA Foundation
715061	Rare neoplastic diseases, Rare skin diseases	Pyogenic arthritis-pyoderma gangrenosum-acne syndrome	69126	P	135	Stichting KAISZ
711854	Rare respiratory diseases	Bronchopulmonary Dysplasia	70589	P	114	Care4Neo
717006	Rare respiratory diseases	Bronchopulmonary dysplasia	70589	P	114	Care4Neo
708068	Rare respiratory diseases	Rare pulmonary hypertension	71198	P	158	Stichting Pulmonale Hypertensie

AIMS ID:	Expertisegebied:	Aandoening:	Orphacode:	P nr	Patiëntenorganisatie:
706167	Rare neurological diseases	Rare central nervous system and retinal vascular disease	71281	P 100	Oogvereniging
709465	Rare neurological diseases	Rare central nervous system and retinal vascular disease	71281	P 91	Hersenletsel.nl
709465	Rare neurological diseases	Rare central nervous system and retinal vascular disease	71281	P 100	Oogvereniging
710024	Rare genetic diseases	Inherited retinal disorder	71862	P 100	Oogvereniging
710545	Rare gastroenterologic diseases	Eosinophilic esophagitis	73247	P 182	Vereniging voor Allergiepatiënten
710334	Rare neurological diseases	Foix-Alajouanine syndrome	79093	P	Zonder patiëntenorganisatie

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709008	Rare skin diseases	Merkel Cell carcinoma	79140	P	343	Stichting NETNECKanker
715061	Rare neoplastic diseases, Rare skin diseases	Cutaneous neuroendocrine carcinoma	79140	P	343	Stichting NETNECKanker
724687	Rare inborn errors of metabolism	Classic organic aciduria	79163	P	56	Volwassenen Kinderen en Stofwisselingsziekten (VKS)
706115	Rare inborn errors of metabolism	Disorder of fatty acid oxidation and ketone body metabolism	79174	P	56	Volwassenen Kinderen en Stofwisselingsziekten (VKS)
724687	Rare inborn errors of metabolism	Juvenile neuronal ceroid lipofuscinosis	79264	P	56	Volwassenen Kinderen en Stofwisselingsziekten (VKS)
724687	Rare inborn errors of metabolism	Juvenile neuronal ceroid lipofuscinosis	79264	P	310	Beat Batten
715121	Rare neurological diseases	Narcolepsy type 2	83465	P	210	Narcolepsie Vereniging Nederland
715185	Rare developmental anomalies during embryogenesis	Rare intellectual disability	87277	P	290	Zeldsamen
720077	Rare cardiac diseases	Rare congenital non-syndromic heart malformation	88991	P	127	Patiëntenvereniging voor Aangeboren Hartafwijkingen (PAH)
720077	Rare cardiac diseases	Rare congenital non-syndromic heart malformation	88991	P	147	Contactgroep Marfan Nederland



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715100	Rare gynecologic and obstetric diseases	Retinopathy of prematurity	90050	P	100	Oogvereniging
715100	Rare gynecologic and obstetric diseases	Retinopathy of prematurity	90050	P	114	Care4Neo
706167	Rare neurological diseases	Acquired aneurysmal subarachnoid hemorrhage	90065	P	315	Stichting Hersenaneurysma Patiënten Platform
709465	Rare neurological diseases	Acquired aneurysmal subarachnoid hemorrhage	90065	P	315	Stichting Hersenaneurysma Patiënten Platform
710334	Rare neurological diseases	Acquired aneurysmal subarachnoid hemorrhage	90065	P	315	Stichting Hersenaneurysma Patiënten Platform
717042	Rare skin diseases	Partial deep dermal and full thickness burns	90076	P	231	Vereniging Mensen met Brandwonden

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710505	Rare gastroenterologic diseases	Congenital tufting enteropathy	92050	P		Zonder patiëntenorganisatie
724687	Rare inborn errors of metabolism	Hurler syndrome	93473	P	56	Volwassenen Kinderen en Stofwisselingsziekten (VKS)
709775	Rare inborn errors of metabolism, Rare renal diseases	Glomerular disease	93548	P	31	Nierpatiëntenvereniging Nederland (NVN)
709775	Rare inborn errors of metabolism, Rare renal diseases	Thrombotic microangiopathy	93573	P	31	Nierpatiëntenvereniging Nederland (NVN)
709775	Rare inborn errors of metabolism, Rare renal diseases	Thrombotic microangiopathy	93573	P	75	Stichting Zeldzame Bloedziekten (SZB)
706138	Rare renal diseases	Nephropathy secondary to a storage or other metabolic disease	93593	P	31	Nierpatiëntenvereniging Nederland (NVN)
706138	Rare renal diseases	Nephropathy secondary to a storage or other metabolic disease	93593	P	56	Volwassenen Kinderen en Stofwisselingsziekten (VKS)
706138	Rare renal diseases	Rare renal tubular disease	93603	P	31	Nierpatiëntenvereniging Nederland (NVN)
706138	Rare renal diseases	Rare renal tubular disease	93603	P	56	Volwassenen Kinderen en Stofwisselingsziekten (VKS)

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709775	Rare inborn errors of metabolism, Rare renal diseases	Rare renal tubular disease	93603	P	31	Nierpatiëntenvereniging Nederland (NVN)
709775	Rare inborn errors of metabolism, Rare renal diseases	Rare renal tubular disease	93603	P	56	Volwassenen Kinderen en Stofwisselingsziekten (VKS) Nederlandse Vereniging voor Mensen met
716120	Rare endocrine diseases	Non-functioning paraganglioma	94080	P	29	Paragangliomen (NVPD)
716120	Rare endocrine diseases	Non-functioning paraganglioma	94080	P	64	Bijniervereniging NVACP Vereniging Ziekte van
719220	Rare gastroenterologic diseases	Secondary short bowel syndrome	95427	P	123	Hirschsprung
717042	Rare skin diseases	Stevens-Johnson Syndrome and Toxic epidermal necrolysis Syndrome	95455	P	161	Huid Nederland
717042	Rare skin diseases	Stevens-Johnson Syndrome and Toxic epidermal necrolysis Syndrome	95455	P	231	Vereniging Mensen met Brandwonden Patiëntenvereniging voor Aangeboren
720077	Rare cardiac diseases	Univentricular cardiopathy	95483	P	127	Hartafwijkingen (PAH) Contactgroep Marfan
720077	Rare cardiac diseases	Univentricular cardiopathy	95483	P	147	Nederland

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715227	Rare endocrine diseases	Acquired premature ovarian failure	95709	P	312	Patiëntenvereniging POI-POF
715450	Rare endocrine diseases, Rare gynecologic and obstetric diseases	Non-acquired premature ovarian failure	95710	P	312	Patiëntenvereniging POI-POF
710077	Rare surgical thoracic diseases	Thoracic Outlet Syndrome	97330	P		Zonder patiëntenorganisatie
715408	Rare abdominal surgical diseases	Gastroduodenal malformation	97944	P		Zonder patiëntenorganisatie
715408	Rare abdominal surgical diseases	Intestinal malformation	97945	P	114	Care4Neo
706031	Rare neoplastic diseases	Rare gynecological tumor	98063	P	88	Stichting Olijf
715366	Rare neoplastic diseases	Rare gynaecological tumor	98063	P	88	Stichting Olijf
724182	Rare neoplastic diseases	Rare gynecological tumor	98063	P	88	Stichting Olijf
708027	Rare neurological diseases	Infantile Epilepsy Syndrome	98258	P	7	Epilepsie NL
716145	Rare neoplastic diseases	Myeloproliferative neoplasm	98274	P	78	MPN Stichting

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716145	Rare neoplastic diseases	Myeloproliferative neoplasm	98274	P	81	Stichting Hematon
709738	Rare abdominal surgical diseases, Rare neurological diseases	Frontotemporal degeneration with dementia	98535	P	9	FTD Lotgenoten
710236	Rare ophthalmic disorders	Uveitis	98715	P	100	Oogvereniging
716098	Rare circulatory system diseases	Aortic malformation	98718	P	127	Patiëntenvereniging voor Aangeboren Hartafwijkingen (PAH)
716098	Rare circulatory system diseases	Aortic malformation	98718	P	147	Contactgroep Marfan Nederland
720077	Rare cardiac diseases	Aortic malformation	98718	P	127	Patiëntenvereniging voor Aangeboren Hartafwijkingen (PAH)
720077	Rare cardiac diseases	Aortic malformation	98718	P	147	Contactgroep Marfan Nederland
716098	Rare circulatory system diseases	Ascending aorta anomaly	98725	P	127	Patiëntenvereniging voor Aangeboren Hartafwijkingen (PAH)
716098	Rare circulatory system diseases	Ascending aorta anomaly	98725	P	147	Contactgroep Marfan Nederland

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716145	Rare neoplastic diseases	Chronic myelomonocytic leukemia	98823	P 81	Stichting Hematon
710236	Rare ophthalmic disorders	Leber plus disease	99718	P 100	Oogvereniging Belangenvereniging
710236	Rare ophthalmic disorders	Leber plus disease	99718	P 274	LOA/LHON
708087	Rare cardiac diseases	Rare familial disorder with hypertrophic cardiomyopathy	99739	P 58	Harteraad
715165	Rare infectious diseases	Yellow fever	99829	P	Zonder patiëntenorganisatie
724182	Rare neoplastic diseases	Malignant granulosa cell tumor of ovary	99915	P 88	Stichting Olijf
708208	Rare hematologic diseases, Rare neoplastic diseases	Acute graft versus host disease	99920	P 81	Stichting Hematon
708208	Rare hematologic diseases, Rare neoplastic diseases	Chronic graft versus host disease	99921	P 81	Stichting Hematon
710077	Rare surgical thoracic diseases	neurogenic thoracic outlet syndrome	100073	P	Zonder patiëntenorganisatie
715205	Rare neoplastic diseases, Rare neurological diseases	Neurogenic thoracic outlet syndrome	100073	P	Zonder patiëntenorganisatie
709290	Rare endocrine diseases	Thyroid tumor	100087	P 60	Nederland (SON) Schildklier Organisatie
709290	Rare endocrine diseases	Thyroid carcinoma	100088	P 60	Nederland (SON) Schildklier Organisatie

AIMS ID:	Expertisegebied:	Aandoening:	Orphacode:	P	nr	Patiëntenorganisatie:
709238	Rare neoplastic diseases	Thymic tumor	100100	P	204	Longkanker Nederland
706222	Rare surgical maxillo-facial diseases	Cleft hard palate	101023	P	17	LaPosa
706222	Rare surgical maxillo-facial diseases	Cleft hard palate	101023	P	287	Schisis Nederland
715366	Rare neoplastic diseases	Rare hepatic and biliary tract tumor	101943	P	19	Nederlandse Leverpatiëntenvereniging (NLV)
716037	Rare inborn errors of metabolism	Rare dyslipidemia	101953	P	56	Volwassenen Kinderen en Stofwisselingsziekten (VKS)
708106	Rare immunological diseases	Immunodeficiency predominantly affecting antibody production	101977	P	72	Stichting voor Afweerstoornissen (SAS)
708106	Rare immunological diseases	Primary immunodeficiency	101997	P	72	Stichting voor Afweerstoornissen (SAS)
708027	Rare neurological diseases	Rare epilepsy	101998	P	7	Epilepsie NL
710334	Rare neurological diseases	Neurovascular malformation	102006	P	315	Stichting Hersenaneurysma Patiënten Platform
710505	Rare gastroenterologic diseases	Rare diseases involving intestinal motility	104009	P	123	Vereniging Ziekte van Hirschsprung

AIMS ID:	Expertisegebied:	Aandoening:	Orphacode:	P	nr	Patiëntenorganisatie:
708145	Rare genetic diseases	Intestinal polyposis syndrome	104010	P	93	Stichting Lynch Polyposis
709839	Rare neoplastic diseases	Adenocarcinoma of the small intestine	104075	P	304	Stichting Darmkanker Nederland
717006	Rare respiratory diseases	Non-syndromic respiratory or mediastinal malformation	108993	P	114	Care4Neo
724467	Rare neurological diseases	Neonatal hypoxic and ischemic brain injury	137577	P	91	Hersenletsel.nl
724467	Rare neurological diseases	Neonatal hypoxic and ischemic brain injury	137577	P	114	Care4Neo
724467	Rare neurological diseases	Neonatal hypoxic and ischemic brain injury	137577	P	284	CP Nederland
724127	Rare surgical maxillo-facial diseases	Rare disease with Pierre Robin syndrome	138044	P	279	Stichting Pierre Robin Europe
724127	Rare surgical maxillo-facial diseases	Rare disease with Pierre Robin syndrome	138044	P	287	Schisis Nederland
715165	Rare infectious diseases	Severe acute respiratory syndrome	140896	P		Zonder patiëntenorganisatie
715304	Rare otorhinolaryngological diseases	Congenital subglottic stenosis	141121	P	114	Care4Neo
715304	Rare otorhinolaryngological diseases	Congenital laryngeal cyst	141124	P		Zonder patiëntenorganisatie



AIMS ID:	Expertisegebied:	Aandoening:	Orphacode:	P	nr	Patiëntenorganisatie:
716058	Rare surgical maxillo-facial diseases	Oculo-auriculo-vertebral spectrum	141132	P	17	LaPosa
706222	Rare surgical maxillo-facial diseases	Cleft lip and alveolus	141291	P	17	LaPosa
706222	Rare surgical maxillo-facial diseases	Cleft lip and alveolus	141291	P	287	Schisis Nederland
706222	Rare surgical maxillo-facial diseases	Submucosal cleft palate	155878	P	17	LaPosa
706222	Rare surgical maxillo-facial diseases	Submucosal cleft palate	155878	P	287	Schisis Nederland
715430	Rare developmental anomalies during embryogenesis, Rare neurological diseases Rare otorhinolaryngological diseases Rare surgical maxillo-facial diseases	Paralytic facial malformation	156224	P	17	LaPosa
715304	Rare otorhinolaryngological diseases	Larynx anomaly	156249	P		Zonder patiëntenorganisatie
710286	Rare ophthalmic disorders	Necrobiotic xanthogranuloma	158011	P		Zonder patiëntenorganisatie
715007	Rare infectious diseases	Rare parasitic disease	163588	P		Zonder patiëntenorganisatie
715165	Rare infectious diseases	Rare parasitic disease	163588	P		Zonder patiëntenorganisatie

AIMS ID:	Expertisegebied:	Aandoening:	Orphacode:	P	nr	Patiëntenorganisatie:
716165	Rare infectious diseases	Rare mycoses	163591	P	161	Huid Nederland
708047	Rare circulatory system diseases, Rare gynecologic and obstetric diseases	Rare disorders related with pregnancy, childbirth and puerperium	163637	P	114	Care4Neo
708027	Rare neurological diseases	Epilepsy Syndrome	166463	P	7	Epilepsie NL
708027	Rare neurological diseases	Monogenic disease with epilepsy	166472	P	7	Epilepsie NL
708027	Rare neurological diseases	Cerebral malformation with epilepsy	166478	P	7	Epilepsie NL
715332	Rare cardiac diseases	Rare cardiomyopathy	167848	P	58	Harteraad
715366	Rare neoplastic diseases	Malignant melanoma of the mucosa	168999	P	96	Stichting Melanoom
708169	Rare otorhinolaryngological diseases	Idiopathic Bilateral Vestibulopathy	171684	P	33	Stichting Hoormij
716145	Rare neoplastic diseases	Myeloid hemopathy	171895	P	81	Stichting Hematon

AIMS ID:	Expertisegebied:	Aandoening:	Orphacode:	P	nr	Patiëntenorganisatie:
708106	Rare immunological diseases	Primary immunodeficiency due to a defect in adaptive immunity	179006	P	72	Stichting voor Afweerstoornissen (SAS)
709181	Rare neoplastic diseases	Rare Breast tumor	180250	P	89	Borstkankervereniging (BVN)
709181	Rare neoplastic diseases	Rare Breast tumor	180250	P	94	Stichting Patiëntenplatform Sarcomen
709181	Rare neoplastic diseases	Rare Breast tumor	180250	P	339	Stichting Erfelijke Kanker Nederland (SEKN)
715366	Rare neoplastic diseases	Rare vulvovaginal tumor	180312	P	18	NFK: Patiëntenplatform Zeldzame Kankers
715366	Rare neoplastic diseases	Rare vulvovaginal tumor	180312	P	88	Stichting Olijf
709054	Rare gastroenterologic diseases	Rare gastroesophageal tumor	180821	P	63	SPKS - Leven met Maag- of Slokdarmkanker
715366	Rare neoplastic diseases	Rare gastroesophageal tumor	180821	P	63	SPKS - Leven met Maag- en Slokdarmkanker

AIMS ID:	Expertisegebied:	Aandoening:	Orphacode:	P nr	Patiëntenorganisatie:
715366	Rare neoplastic diseases	Rare tumor of pancreas	180824	P 87	Alvleeskliervereniging
715366	Rare neoplastic diseases	Rare tumor of pancreas	180824	P 260	Living with Hope
715366	Rare neoplastic diseases	Rare tumor of pancreas	180824	P 339	Stichting Erfelijke Kanker Nederland (SEKN)
709091	Rare neurological diseases	Glial tumor	182067	P 82	Vereniging Kinderkanker Nederland
709091	Rare neurological diseases	Glial tumor	182067	P 91	Hersenletsel.nl
710372	Rare neurological diseases	Glial tumor	182067	P 82	Vereniging Kinderkanker Nederland
710372	Rare neurological diseases	Glial tumor	182067	P 91	Hersenletsel.nl
715366	Rare neoplastic diseases	Glial Tumors	182067	P 82	Vereniging Kinderkanker Nederland

AIMS ID:	Expertisegebied:	Aandoening:	Orphacode:	P nr	Patiëntenorganisatie:
715366	Rare neoplastic diseases	Glial Tumors	182067	P 91	Hersenletsel.nl
724234	Rare neoplastic diseases	Glial tumor	182067	P 82	Vereniging Kinderkanker Nederland
724234	Rare neoplastic diseases	Glial tumor	182067	P 91	Hersenletsel.nl
715205	Rare neoplastic diseases, Rare neurological diseases	Acquired periheral neuropathy	182086	P 43	Spierziekten Nederland (SN)
715205	Rare neoplastic diseases, Rare neurological diseases	Acquired periheral neuropathy	182086	P 288	SOS Nederland
708068	Rare respiratory diseases	Pulmonary arterial hypertension	182090	P 158	Hypertensie Stichting Pulmonale
717006	Rare respiratory diseases	Respiratory malformation	182111	P	Zonder patiëntenorganisatie
706138	Rare renal diseases	Genetic renal tubular disease	183592	P 31	Nierpatiëntenvereniging Nederland (NVN)
706222	Rare surgical maxillo-facial diseases	Cleft lip/palate	199306	P 17	LaPosa
706222	Rare surgical maxillo-facial diseases	Cleft lip/palate	199306	P 287	Schisis Nederland
717006	Rare respiratory diseases	Congenital alveolar capillary dysplasia	210122	P 340	Stichting ACD

AIMS ID:	Expertisegebied:	Aandoening:	Orphacode:	P	nr	Patiëntenorganisatie:
715366	Rare neoplastic diseases	Rare ovarian cancer	213500	P	339	Stichting Erfelijke Kanker Nederland (SEKN)
724182	Rare neoplastic diseases	Ovarian cancer	213500	P	339	Stichting Erfelijke Kanker Nederland (SEKN)
724346	Rare genetic diseases	Hereditary site-specific ovarian cancer syndrome	213524	P	88	Stichting Olijf
724346	Rare genetic diseases	Hereditary site-specific ovarian cancer syndrome	213524	P	339	Stichting Erfelijke Kanker Nederland (SEKN)
715366	Rare neoplastic diseases	Rare uterine cancer	213564	P	88	Stichting Olijf
706031	Rare neoplastic diseases	Rare cancer of corpus uteri	213569	P	88	Stichting Olijf
706031	Rare neoplastic diseases	Rare cancer of cervix uteri	213761	P	88	Stichting Olijf
724182	Rare neoplastic diseases	Rare cancer of the cervix uteri	213761	P	88	Stichting Olijf
720077	Rare cardiac diseases	Transposition of the great arteries	216675	P	127	Patiëntenvereniging voor Aangeboren Hartafwijkingen (PAH)
720077	Rare cardiac diseases	Transposition of the great arteries	216675	P	147	Contactgroep Marfan Nederland

AIMS ID:	Expertisegebied:	Aandoening:	Orphacode:	P nr	Patiëntenorganisatie:
715366	Rare neoplastic diseases	Rare carcinoma of pancreas	217074	P 87	Alvleeskliervereniging
715366	Rare neoplastic diseases	Rare carcinoma of pancreas	217074	P 260	Living with Hope
715366	Rare neoplastic diseases	Rare carcinoma of pancreas	217074	P 339	Stichting Erfelijke Kanker Nederland (SEKN)
715332	Rare cardiac diseases	Rare hypertrophic cardiomyopathy	217569	P 58	Harteraad
708087	Rare cardiac diseases	Dilated cardiomyopathy	217604	P 58	Harteraad
715332	Rare cardiac diseases	Dilated cardiomyopathy	217604	P 58	Harteraad

AIMS ID:	Expertisegebied:	Aandoening:	Orphacode:	P	nr	Patiëntenorganisatie:
710334	Rare neurological diseases	Familial cerebral cavernous malformation	221061	P	91	Hersenletsel.nl
710334	Rare neurological diseases	Familial cerebral cavernous malformation	221061	P	316	AVM in de hersenen
724346	Rare genetic diseases	Hereditary breast cancer	227535	P	89	Borstkankervereniging (BVN)
724346	Rare genetic diseases	Hereditary breast cancer	227535	P	339	Stichting Erfelijke Kanker Nederland (SEKN)
711182	Rare abdominal surgical diseases, Rare gastroenterologic diseases, Rare developmental anomalies during embryogenesis	Anal fistula	228113	P	120	Vereniging Anusatresie
711182	Rare abdominal surgical diseases, Rare gastroenterologic diseases, Rare developmental anomalies during embryogenesis	Anal fistula	228113	P	123	Vereniging Ziekte van Hirschsprung
708087	Rare cardiac diseases	Idiopathic ventricular fibrillation - not Brugada type	228140	P	58	Harteraad
724687	Rare inborn errors of metabolism	CLN3 disease	228346	P	56	Volwassenen Kinderen en Stofwisselingsziekten (VKS)
724687	Rare inborn errors of metabolism	CLN3 disease	228346	P	310	Beat Batten



AIMS ID:	Expertisegebied:	Aandoening:	Orphacode:	P	nr	Patiëntenorganisatie:
710334	Rare neurological diseases	Familial cerebral saccular aneurysm	231160	P	315	Stichting Hersenaneurysma Patiënten Platform
708047	Rare circulatory system diseases, Rare gynecologic and obstetric diseases	HELLP syndrome	244242	P	113	HELLP Stichting
708047	Rare circulatory system diseases, Rare gynecologic and obstetric diseases	HELLP syndrome	244242	P	114	Care4Neo
720172	Rare hematologic diseases	Rare hemorrhagic disorder	248308	P	74	Nederlandse Vereniging van Hemofilie-Patiënten (NVHP)
720172	Rare hematologic diseases	Rare hemorrhagic disorder due to a coagulation factors defect	248315	P	74	Nederlandse Vereniging van Hemofilie-Patiënten (NVHP)
720172	Rare hematologic diseases	Rare hemorrhagic disorder due to a platelet anomaly	248326	P	74	Nederlandse Vereniging van Hemofilie-Patiënten (NVHP)
724234	Rare neoplastic diseases	Rare tumor of neuroepithelial tissue	251558	P	82	Vereniging Kinderkanker Nederland
724234	Rare neoplastic diseases	Rare tumor of neuroepithelial tissue	251558	P	91	Hersenletsel.nl

AIMS ID:	Expertisegebied:	Aandoening:	Orphacode:	P	nr	Patiëntenorganisatie:
710372	Rare neurological diseases	Tumor of meninges	252025	P		Zonder patiëntenorganisatie
710372	Rare neurological diseases	Benign peripheral nerve sheath tumor	252131	P	30 g	Nederland (NFVN) Neurofibromatoseverenigin
715366	Rare neoplastic diseases	Benign peripheral nerve sheath tumor	252131	P	30 g	Nederland (NFVN) Neurofibromatoseverenigin
724234	Rare neoplastic diseases	Benign schwannoma	252164	P	30 g	Nederland (NFVN) Neurofibromatoseverenigin
724234	Rare neoplastic diseases	Vestibular schwannoom	252175	P	30 g	Nederland (NFVN) Neurofibromatoseverenigin
710455	Rare genetic diseases	Proximal 16p11.2 microdeletion syndrome	261197	P	290	Zeldsamen
710455	Rare genetic diseases	16p11.2p12.2 microdeletion syndrome	261211	P	290	Zeldsamen
710455	Rare genetic diseases	Distal 16p11.2 microdeletion syndrome	261222	P	290	Zeldsamen

AIMS ID:	Expertisegebied:	Aandoening:	Orphacode:	P	nr	Patiëntenorganisatie:
706009	Rare developmental anomalies during embryogenesis, Rare developmental anomalies during embryogenesis, Rare genetic diseases	Partial deletion of chromosome 6	261791	P	290	Zeldsamen
706115	Rare inborn errors of metabolism	Glycogen storage disease due to liver phosphorylase kinase deficiency	264580	P	56	Volwassenen Kinderen en Stofwisselingsziekten (VKS)
716078	Rare circulatory system diseases	Congenital chylothorax	264688	P	114	Care4Neo
708047	Rare circulatory system diseases, Rare gynecologic and obstetric diseases	Preeclampsia	275555	P	113	HELLP Stichting
708047	Rare circulatory system diseases, Rare gynecologic and obstetric diseases	Preeclampsia	275555	P	114	Care4Neo
708008	Rare hematologic diseases	Rare hemorrhagic disorder due to a qualitative platelet defect	275736	P	75	Stichting Zeldzame Bloedziekten (SZB)
724526	Rare neoplastic diseases	Rare tumor of salivary glands	276142	P	169	Patiëntenvereniging Hoofd - Hals
724526	Rare neoplastic diseases	Rare tumor of salivary glands	276142	P	255	Patiëntenvereniging Speekselklierkanker

AIMS ID:	Expertisegebied:	Aandoening:	Orphacode:	P	nr	Patiëntenorganisatie:
716098	Rare circulatory system diseases	Rare disease with thoracic aortic aneurysm and aortic dissection	285014	P	127	Patientenvereniging voor Aangeboren Hartafwijkingen (PAH)
716098	Rare circulatory system diseases	Rare disease with thoracic aortic aneurysm and aortic dissection	285014	P	315	Stichting Hersenaneurysma Patiënten Platform
716098	Rare circulatory system diseases	Rare disease with thoracic aortic aneurysm and aortic dissection	285014	P	147	Contactgroep Marfan Nederland
709794	Rare immunological diseases	Primary Sjögren syndrome	289390	P	22	Nationale Vereniging Sjögrenpatiënten (NVSP)
715061	Rare neoplastic diseases, Rare skin diseases	Pyoderma gangrenosum - acne - hidradenitis suppurativa	289478	P	161	Huid Nederland
709386	Rare abdominal surgical diseases	Celiac artery compression syndrome	293208	P		Zonder patiëntenorganisatie
724687	Rare inborn errors of metabolism	Methylmalonic acidemia without homocystinuria	293355	P	56	Volwassenen Kinderen en Stofwisselingsziekten (VKS)
719220	Rare gastroenterologic diseases, Rare transplant-related disorders, Rare abdominal surgical	Chronic intestinal failure	294422	P	123	Vereniging Ziekte van Hirschsprung
706095	Rare inborn errors of metabolism	Sulfite oxidase deficiency due to molybdenum cofactor deficiency type A	308386	P	56	Volwassenen Kinderen en Stofwisselingsziekten (VKS)

AIMS ID:	Expertisegebied:	Aandoening:	Orphacode:	P	nr	Patiëntenorganisatie:
709465	Rare neurological diseases	Cerebral sinovenous thrombosis	329217	P	91	Hersenletsel.nl
724467	Rare neurological diseases	Cerebral sinovenous thrombosis	329217	P	91	Hersenletsel.nl
710505	Rare gastroenterologic diseases	Congenital Chronic Diarrhea with protein-losing enteropathy	329242	P		Zonder patiëntenorganisatie
710077	Rare surgical thoracic diseases	arterial thoracic outlet syndrome	357107	P		Zonder patiëntenorganisatie
710077	Rare surgical thoracic diseases	venous thoracic outlet syndrome	357131	P		Zonder patiëntenorganisatie
710455	Rare genetic diseases	Proximal 16p11.2 microduplication syndrome	370079	P	290	Zeldsamen
715185	Rare developmental anomalies during embryogenesis	Intellectual disability-severe speech delay-mild dysmorphism syndrome	391372	P	290	Zeldsamen
715185	Rare developmental anomalies during embryogenesis	Intellectual disability-severe speech delay-mild dysmorphism syndrome	391372	P	342	Stichting Kind Beter
706031	Rare neoplastic diseases	Malignant epithelial tumor of ovary	398934	P	88	Stichting Olijf
706031	Rare neoplastic diseases	Malignant epithelial tumor of ovary	398934	P	339	Stichting Erfelijke Kanker Nederland (SEKN)
715304	Rare otorhinolaryngological diseases	Cranio-cervical dystonia with laryngeal and upper-limb involvement	420485	P	91	Hersenletsel.nl

AIMS ID:	Expertisegebied:	Aandoening:	Orphacode:	P	nr	Patiëntenorganisatie:
715145	Rare neurological diseases	Rare autonomic nervous system disorder	423662	P		Zonder patiëntenorganisatie
709054	Rare gastroenterologic diseases	Epithelial tumor of anal cancer	424010	P	18	NFK: Patiëntenplatform Zeldzame Kankers
708047	Rare circulatory system diseases, Rare gynecologic and obstetric diseases	Placental insufficiency	439167	P	114	Care4Neo
724467	Rare neurological diseases	Pediatric arterial ischemic stroke	439175	P	91	Hersenletsel.nl
715205	Rare neoplastic diseases, Rare neurological diseases	Non-recovering obstetric brachial plexus lesion	439202	P	8	Erbse Parese Vereniging Nederland
710108	Rare skin diseases	Necrotizing soft tissue infection	440368	P	161	Huid Nederland
710108	Rare skin diseases	Necrotizing soft tissue infection	440368	P	231	Vereniging van Mensen met Brandwonden
715254	Rare hepatic diseases	IgG4-related sclerosing cholangitis	447764	P	19	Nederlandse Leverpatiëntenvereniging (NLV)
710024	Rare genetic diseases	Cerebral visual impairment	447788	P	100	Oogvereniging
710286	Rare ophthalmic disorders	IgG4-related ophthalmic disease	449563	P	51	Vasculitis Stichting
709568	Rare circulatory system diseases	Flow Limitation of Iliac Arteries	458837	P		Zonder patiëntenorganisatie

AIMS ID:	Expertisegebied:	Aandoening:	Orphacode:	P	nr	Patiëntenorganisatie:
709929	Rare immunological diseases	Exercise-induced malignant hyperthermia	466650	P		Zonder patiëntenorganisatie
709929	Rare immunological diseases	Rare disease with malignant hyperthermia	466658	P		Zonder patiëntenorganisatie
709465	Rare neurological diseases	Genetic cerebral small vessel disease	477754	P	14	HCHWA-D Vereniging
709465	Rare neurological diseases	Genetic cerebral small vessel disease	477754	P	91	Hersenletsel.nl
724296	Rare neurological diseases	Moyamoya angiopathy	477768	P	91	Hersenletsel.nl
724182	Rare neoplastic diseases	Vulvar carcinoma	494418	P	88	Stichting Olijf
715408	Rare abdominal surgical diseases	Sacrococcygeal teratoma	494421	P	82	Vereniging Kinderkanker Nederland
706031	Rare neoplastic diseases	Vulvar squamous cell carcinoma	494448	P	18	NFK: Patiëntenplatform Zeldzame Kankers
724526	Rare neoplastic diseases	Squamous cell carcinoma of the hypopharynx	494547	P	169	Patiëntenvereniging Hoofd - Hals
724526	Rare neoplastic diseases	Squamous cell carcinoma of the larynx	494550	P	169	Patiëntenvereniging Hoofd - Hals
724526	Rare neoplastic diseases	Squamous cell carcinoma of the nasal cavity and paranasal sinuses	500464	P	169	Patiëntenvereniging Hoofd - Hals
724526	Rare neoplastic diseases	Squamous cell carcinoma of the oropharynx	500478	P	169	Patiëntenvereniging Hoofd - Hals

AIMS ID:	Expertisegebied:	Aandoening:	Orphacode:	P	nr	Patiëntenorganisatie:
724526	Rare neoplastic diseases	Squamous cell carcinoma of the oral cavity	502363	P	169	Patiëntenvereniging Hoofd - Hals
724526	Rare neoplastic diseases	Squamous cell carcinoma of oral cavity and lip	502369	P	169	Patiëntenvereniging Hoofd - Hals
724687	Rare inborn errors of metabolism	Neonatal epileptic encephalopathy due to glutaminase deficiency	557064	P	56	Volwassenen Kinderen en Stofwisselingsziekten (VKS)
719220	Rare gastroenterologic diseases	Parenteral nutrition-associated cholestasis	567983	P	19	Nederlandse Leverpatiëntenvereniging (NLV)
715165	Rare infectious diseases	Middle East respiratory syndrome	576074	P		Zonder patiëntenorganisatie
715100	Rare gynecologic and obstetric diseases	Twin Anemia Polycythemia Sequence	617294	P	317	Stichting Taps Support
715100	Rare gynecologic and obstetric diseases	Twin Reversed Arterial Perfusion sequence	617297	P	317	Stichting Taps Support
715100	Rare gynecologic and obstetric diseases	Selective Intrauterine Growth Restriction	617301	P	317	Stichting Taps Support