

Supplementary Online Content

Barker MM, Beresford B, Bland M, Fraser LK. Prevalence and incidence of anxiety and depression among children, adolescents, and young adults with life-limiting conditions: a systematic review and meta-analysis: a systematic review and meta-analysis. *JAMA Pediatr*. Published online July 8, 2019. doi:10.1001/jamapediatrics.2019.1712

eTable 1. Medline Search Strategy

eTable 2. Risk of Bias Assessment

eTable 3. Anxiety & Depression Assessment Tools

eTable 4. Sub-group analysis of pooled anxiety prevalence

eTable 5. Meta-regression analysis of pooled anxiety prevalence

eTable 6. Sub-group analysis of pooled depression prevalence

eTable 7. Meta-regression analysis of pooled depression prevalence

eFigure 1. Funnel plot for anxiety meta-analysis, with pseudo 95% confidence limits

eFigure 2. Funnel plot for depression meta-analysis, with pseudo 95% confidence limits

This supplementary material has been provided by the authors to give readers additional information about their work.

eTable 1. Medline Search Strategy

Number	Searches	Results
1	exp Child/	1906328
2	exp Infant/	1145037
3	Adolescent/	2013002
4	(child\$ or infant\$ or newborn\$ or new-born\$ or neonat\$ or neo-nat\$ or baby\$ or babies or pediat\$ or paediat\$ or schoolchild\$ or preschool\$).ti,ab,kf.	1864634
5	(adolescen\$ or juvenile\$ or youth\$ or teenage\$ or youngster\$).ti,ab,kf.	354040
6	(young people\$ or young person\$).ti,ab,kf.	24417
7	Anxiety/ or Anxiety Disorders/	102887
8	(anxiety\$ or anxious\$).ti,ab,kf.	155886
9	depression.mp. or Depression/	342148
10	depress*.ti,ab,kf.	391881
11	Depressive Disorder/	73018
12	depressive disorder\$.ti,ab,kf.	28428
13	7 or 8 or 9 or 10 or 11 or 12	560066
14	Creutzfeldt-Jakob Syndrome/	6863
15	(creutzfeldt-jakob\$ or jakob-creutzfeldt\$ or cjd or spongiform encephalopath\$).ti,ab,kf.	10431
16	Subacute Sclerosing Panencephalitis/	2454
17	(subacute sclerosing panencephalit\$ or sub-acute sclerosing panencephalit\$ or sspe or subacute sclerosing leukoencephalit\$ or sub-acute sclerosing leukoencephalit\$ or van bogaert\$ leukoencephalit\$ or measles inclusion body encephalit\$ or mibe).ti,ab,kf.	2444
18	beta-Thalassemia/	8572
19	(beta adj (thalass?emi\$ or thalas?emi\$)).ti,ab,kf.	9706
20	((thalass?emi\$ or thalas?emi\$) adj major).ti,ab,kf.	4070
21	exp Anemia, Aplastic/	17020
22	((hypoplastic or aplastic) adj an?emi\$).ti,ab,kf.	9885
23	(medullary adj3 hypoplas\$).ti,ab,kf.	51
24	exp Neutropenia/	19229
25	((severe or chronic\$) adj3 neutropeni\$).ti,ab,kf.	3376
26	immunologic deficiency syndromes/ or acquired immunodeficiency syndrome/	94764
27	(immun\$ deficiency adj (syndrome\$ or disease\$ or disorder\$)).ti,ab,kf.	6406
28	(immunodeficiency adj (syndrome\$ or disease\$ or disorder\$)).ti,ab,kf.	23881
29	DiGeorge Syndrome/	2083
30	(digeorge\$ or di george\$ or sedlackova\$ or opitz g-bbb or velocardiofacial or velo-cardiofacial or velo-cardio-facial or shprintzen\$ or ctaf).ti,ab,kf.	2473
31	((deletion or vcf or pharyngeal pouch or thymic aplasia or anomaly face) adj (syndrome\$ or disease\$ or disorder\$)).ti,ab,kf.	2393
32	Common Variable Immunodeficiency/	2141
33	((common variable or late onset) adj3 (immunodeficienc\$ or immune deficienc\$ or immunoglobulin deficienc\$ or hypogammaglobulin\$)).ti,ab,kf.	2640
34	acquired hypogammaglobulin\$.ti,ab,kf.	141
35	Cryoglobulinemia/	3310
36	cryoglobulin?em\$.ti,ab,kf.	4269
37	Polyendocrinopathies, Autoimmune/	1255
38	((autoimmune or failure\$) adj3 (polyglandular\$ or polyendocrin\$)).ti,ab,kf.	1371
39	Progeria/	1480
40	(progeria or hutchinson-gilford\$).ti,ab,kf.	1342
41	Tyrosinemias/	432
42	tyrosin?em\$.ti,ab,kf.	1178
43	Maple Syrup Urine Disease/	1234
44	(maple syrup urine or msud).ti,ab,kf.	1173
45	branched chain.ti,ab,kf.	8841
46	(bckd adj5 (deficienc\$ or ketoacid\$ or keto-acid\$)).ti,ab,kf.	83
47	hyperleucine-isoleucin\$.ti,ab,kf.	2

Number	Searches	Results
48	Methylmalonic Acid/	1755
49	(methylmalonic acid?emi\$ or methylmalonic aciduri\$ or methyl malonic acid?emi\$ or methyl malonic aciduri\$).ti,ab,kf.	1291
50	Propionic Acidemia/	167
51	(propionic acid?em\$ or propionic acidur\$ or propionyl-CoA carboxylase deficienc\$ or ketotic glycin?em\$).ti,ab,kf.	722
52	Adrenoleukodystrophy/	1845
53	(adrenoleukodystroph\$ or x-ald or schilder-addison\$ or addison-schilder\$ or adrenomyeloneuropath\$).ti,ab,kf.	2169
54	Carnitine O-Palmitoyltransferase/	2571
55	((carnitine palmitoyltransferase or carnitine palmitoyltransferase or carnitine o-palmitoyltransferase or carnitine o-palmitoyltransferase) adj3 deficienc\$).ti,ab,kf.	289
56	Fanconi Syndrome/	1679
57	(fanconi\$ adj (syndrome\$ or disease\$ or disorder\$)).ti,ab,kf.	1667
58	Cystinosis/	1298
59	(cystinos\$ or cystine storage or cystine diathes\$ or cystine disease\$).ti,ab,kf.	1301
60	Oculocerebrorenal Syndrome/	427
61	((lowe or lowes or oculocerebrorenal or cerebroculorenal or cerebro-oculo-renal) adj3 (syndrome\$ or disease\$ or disorder\$)).ti,ab,kf.	571
62	Metalloproteins/df [Deficiency]	66
63	Molybdenum/df [Deficiency]	72
64	(molybdenum cofactor deficien\$ or molybdenum co-factor deficien\$).ti,ab,kf.	173
65	Oxidoreductases Acting on Sulfur Group Donors/df [Deficiency]	118
66	Sulfite Oxidase/df [Deficiency]	43
67	((sulphite\$ or sulfite\$) adj3 oxidase deficien\$).ti,ab,kf.	149
68	Argininosuccinic Acid/	191
69	(argininosuccinic acidur\$ or argininosuccinic acid?emi\$).ti,ab,kf.	178
70	Citrullinemia/	291
71	(citrullin?emi\$ or citrullinuri\$).ti,ab,kf.	547
72	Amino Acid Metabolism, Inborn Errors/	6544
73	(glutaric acid?emi\$ or glutaric aciduri\$).ti,ab,kf.	772
74	Hyperglycinemia, Nonketotic/	213
75	(glycine encephalopath\$ or non-ketotic hyperglycin?emi\$ or nonketotic hyperglycin?emi\$).ti,ab,kf.	509
76	Hyperargininemia/	216
77	(arginin?emi\$ or arginase deficien\$ or hyperarginin?emi\$).ti,ab,kf.	298
78	Renal Aminoacidurias/	791
79	(aminoaciduri\$ or aminoacid?emi\$).ti,ab,kf.	1159
80	exp glycogen storage disease/	6381
81	(glycogen storage adj (disease\$ or syndrome\$ or disorder\$)).ti,ab,kf.	2766
82	(pompe\$ adj (disease\$ or syndrome\$ or disorder\$)).ti,ab,kf.	1304
83	Galactosemias/	2457
84	galactos?emi\$.ti,ab,kf.	2226
85	Pyruvate Dehydrogenase Complex Deficiency Disease/	455
86	(pyruvate dehydrogenase adj3 deficien\$).ti,ab,kf.	446
87	(oxalosis and (renal or kidney\$)).ti,ab,kf.	445
88	exp Gangliosidoses/	2802
89	gangliosidos\$.ti,ab,kf.	1552
90	(sandhoff\$ adj (disease\$ or syndrome\$ or disorder\$)).ti,ab,kf.	531
91	tay sach\$.ti,ab,kf.	1466
92	Mucopolipidoses/	1120
93	mucopolipidos\$.ti,ab,kf.	918
94	Canavan Disease/	333
95	(canavan\$ leucodystroph\$ or aspartoacylase deficien\$ or aminoacylase 2 deficien\$).ti,ab,kf.	49

Number	Searches	Results
96	((canavan\$ or canavan-van bogaert-bertrand\$) adj (disease\$ or syndrome\$ or disorder\$)).ti,ab,kf.	424
97	Gaucher Disease/	4833
98	(gaucher\$ adj (disease\$ or syndrome\$ or disorder\$)).ti,ab,kf.	4712
99	(glucocerebrosidase deficien\$ or glucosylceramidase deficien\$).ti,ab,kf.	101
100	Leukodystrophy, Metachromatic/	1378
101	(metachromatic leukodystroph\$ or arylsulfatase A deficien\$ or metachromic leukodystroph\$).ti,ab,kf.	1244
102	exp Niemann-Pick Diseases/	2555
103	(niemann-pick\$ or sphingomyelinase deficien\$).ti,ab,kf.	3323
104	Sphingolipidoses/	404
105	sphingolipidos\$.ti,ab,kf.	323
106	Fabry Disease/	3480
107	(fabry\$ adj (disease\$ or syndrome\$ or disorder\$)).ti,ab,kf.	3490
108	(angiokeratoma corporis diffusum or alpha-galactosidase A deficien\$).ti,ab,kf.	390
109	Leukodystrophy, Globoid Cell/	1069
110	(krabbe\$ adj (disease\$ or syndrome\$ or disorder\$)).ti,ab,kf.	885
111	(globoid cell leukodystroph\$ or galactosylceramide lipidos\$ or galactosylcerebrosidase deficien\$ or galactosylceramidase deficien\$).ti,ab,kf.	521
112	Farber Lipogranulomatosis/	42
113	(farber\$ adj (disease\$ or syndrome\$ or disorder\$)).ti,ab,kf.	181
114	(farber\$ lipogranulomatos\$ or ceramidase deficien\$ or fibrocytic dysmucopolysaccharidos\$).ti,ab,kf.	70
115	Pelizaeus-Merzbacher Disease/	338
116	pelizaeus-merzbacher\$.ti,ab,kf.	605
117	Sulfatases/df [Deficiency]	455
118	Multiple Sulfatase Deficiency Disease/	39
119	(sulfatase deficien\$ or sulphatase deficien\$ or mucosulfatidos\$).ti,ab,kf.	507
120	(austin\$ adj (disease\$ or syndrome\$ or disorder\$)).ti,ab,kf.	7
121	sulfatidos\$.ti,ab,kf.	18
122	Sea-Blue Histiocyte Syndrome/	74
123	sea-blue histiocy\$.ti,ab,kf.	233
124	Neuronal Ceroid-Lipofuscinoses/	2056
125	(batten\$ adj (disease\$ or syndrome\$ or disorder\$)).ti,ab,kf.	658
126	(neuronal ceroid lipofuscinos\$ or santavuori-haltia\$ or jansky-bielschowsky\$ or bielschowsky-jansky\$).ti,ab,kf.	1848
127	(kuf\$ adj (disease\$ or syndrome\$ or disorder\$)).ti,ab,kf.	122
128	spielmeyer vogt\$.ti,ab,kf.	120
129	Xanthomatosis, Cerebrotendinous/	339
130	((cerebrotendineous or cerebrotendinous or cerebrotendious or cerebral) adj3 (xanthomatos\$ or cholesteros\$)).ti,ab,kf.	653
131	bogaert-scherer-epstein\$.ti,ab,kf.	5
132	Wolman Disease/	211
133	(wolman\$ adj (disease\$ or syndrome\$ or disorder\$)).ti,ab,kf.	309
134	lysosomal acid lipase deficien\$.ti,ab,kf.	68
135	exp Mucopolysaccharidoses/	6662
136	mucopolysaccharidos\$.ti,ab,kf.	4158
137	(hurler\$ adj2 (syndrome\$ or disease\$ or disorder\$)).ti,ab,kf.	910
138	(hunter\$ adj2 (syndrome\$ or disease\$ or disorder\$)).ti,ab,kf.	884
139	(MPS1 or MPS2 or MPS3 or MPS4 or MPS5 or MPS6 or MPS7 or MPS-1 or MPS-2 or MPS-3 or MPS-4 or MPS-5 or MPS-6 or MPS-7 or MPSI or MPSII or MPSIII or MPSIV or MPSV or MPSVI or MPSVII or MPS-I or MPS-II or MPS-III or MPS-IV or MPS-V or MPS-VI or MPS-VII).ti,ab,kf.	2270
140	(beta glucuronidase deficien\$ or sly syndrome\$ or sly disorder\$ or sly disease\$).ti,ab,kf.	188
141	(maroteaux-lamy\$ or marotaeux-lamy\$ or polydystrophic dwarfism).ti,ab,kf.	329

Number	Searches	Results
142	(morquio\$ or moriquio\$ or beta galactosidase deficien\$).ti,ab,kf.	947
143	(sanfilippo\$ or sanfillipo\$).ti,ab,kf.	627
144	Mucopolidoses/	1120
145	(mucopolidos\$ or pseudo-hurler\$ or pseudohurler\$).ti,ab,kf.	944
146	((inclusion-cell or i-cell) adj (disease\$ or syndrome\$ or disorder\$)).ti,ab,kf.	417
147	Fucosidosis/	168
148	(fucosidos\$ or fucidos\$).ti,ab,kf.	332
149	"Congenital Disorders of Glycosylation"/	643
150	((cdg or ctg) adj (disease\$ or disorder\$ or syndrome\$)).ti,ab,kf.	98
151	(carbohydrate-deficient glycoprotein adj (disease\$ or disorder\$ or syndrome\$)).ti,ab,kf.	259
152	(congenital disorder\$ adj3 glycosylation).ti,ab,kf.	772
153	Lesch-Nyhan Syndrome/	1313
154	((nyhan\$ or kelley-seegmiller\$) adj (syndrome\$ or disorder\$ or disease\$)).ti,ab,kf.	1019
155	juvenile gout.ti,ab,kf.	26
156	Menkes Kinky Hair Syndrome/	1087
157	menkes\$.ti,ab,kf.	1310
158	((copper transport or steely hair or kinky hair) adj (disease\$ or syndrome\$ or disorder\$)).ti,ab,kf.	282
159	alpha 1-Antitrypsin Deficiency/	3417
160	(antitrypsin deficien\$ or A1AD).ti,ab,kf.	2985
161	(AAT deficien\$ or alpha-1 protease deficien\$).ti,ab,kf.	477
162	bisalbumin?emi\$.ti,ab,kf.	192
163	Lipodystrophy, Congenital Generalized/	175
164	(congenital generali?ed lipodystroph\$ or berardinelli\$ or bernardnelli\$).ti,ab,kf.	344
165	Landau-Kleffner Syndrome/	281
166	(landau-kleffner\$ or infantile acquired aphasia\$ or acquired epileptic aphasia\$).ti,ab,kf.	438
167	(aphasia\$ adj5 convulsive).ti,ab,kf.	36
168	Rett Syndrome/	2577
169	(rett\$ adj (syndrome\$ or disease\$ or disorder\$)).ti,ab,kf.	3127
170	cerebroatrophic hyperammon?emi\$.ti,ab,kf.	0
171	Huntington Disease/	12189
172	huntington\$.ti,ab,kf.	15654
173	exp Spinocerebellar Ataxias/	6506
174	(spinocerebellar ataxia\$ or ataxia\$ telangiectasia\$ or louis-bar\$ syndrome\$ or louis-bar\$ disease\$ or louis-bar\$ disorder\$ or machado-joseph\$ or joseph\$ disease\$ or joseph\$ disorder\$ or joseph\$ syndrome\$).ti,ab,kf.	10284
175	Friedreich Ataxia/	2712
176	((friedreich\$ or friedrich\$) adj3 ataxia\$).ti,ab,kf.	2822
177	spinocerebellar degenerat\$.ti,ab,kf.	705
178	"Spinal Muscular Atrophies of Childhood"/	1237
179	(spinal muscular atroph\$ or werdnig hoffman\$).ti,ab,kf.	4515
180	(dubowitz\$ or kugelberg-welander\$).ti,ab,kf.	499
181	Bulbar Palsy, Progressive/	853
182	(fazio-londe\$ or faziolonde\$ or progressive bulbar pals\$).ti,ab,kf.	116
183	Pantothenate Kinase-Associated Neurodegeneration/	517
184	(pantothenate kinase-associated neurodegenerat\$ or PKAN or hallervorden-spatz\$).ti,ab,kf.	604
185	((neurodegeneration adj3 brain iron accumulation) or NBIA\$1).ti,ab,kf.	368
186	Olivopontocerebellar Atrophies/	732
187	(olivopontocerebellar atroph\$ or OPCA or olivopontocerebellar degenerat\$).ti,ab,kf.	820
188	(multiple system atrophy adj5 cerebellar).ti,ab,kf.	164
189	"Diffuse Cerebral Sclerosis of Schilder"/	2622
190	(alper\$ adj (disease\$ or syndrome\$ or disorder\$)).ti,ab,kf.	179
191	(progressive sclerosing poliodystroph\$ or progressive infantile poliodystroph\$).ti,ab,kf.	4
192	(diffuse cerebral sclerosis adj5 schilder\$).ti,ab,kf.	5

Number	Searches	Results
193	Leigh Disease/	1096
194	(leigh\$ adj (syndrome\$ or disease\$ or disorder\$)).ti,ab,kf.	1296
195	(subacute necrotizing encephalomyelopath\$ or subacute necrotising encephalomyelopath\$ or sub-acute necrotizing encephalomyelopath\$ or sub-acute necrotising encephalomyelopath\$ or SNEM).ti,ab,kf.	206
196	(aicardi-gouti?res or aicardia-gouti?res).ti,ab,kf.	348
197	(worster-drought\$ or congenital suprabulbar pares\$).ti,ab,kf.	37
198	multiple sclerosis/ or multiple sclerosis, chronic progressive/ or multiple sclerosis, relapsing-remitting.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	58674
199	(multiple sclerosis or disseminated sclerosis or encephalomyelitis disseminata\$).ti,ab,kf.	65070
200	(demyelinating adj (disease\$ or syndrome\$ or disorder\$)).ti,ab,kf.	6979
201	exp Epilepsies, Myoclonic/	4644
202	myoclonic epileps\$.ti,ab,kf.	2330
203	((lafora\$ or merrf\$ or unverricht-lundborg\$ or janz\$) adj (disease\$ or syndrome\$ or disorder\$)).ti,ab,kf.	745
204	lennox-gastaut\$.ti,ab,kf.	1169
205	(lennox\$ adj (syndrome\$ or disease\$ or disorder\$)).ti,ab,kf.	90
206	Spasms, Infantile/	3478
207	(west\$ adj (syndrome\$ or disease\$ or disorder\$)).ti,ab,kf.	1217
208	Epilepsia Partialis Continua/	238
209	(epilepsia partialis continua or kojevnikov\$ or epilepsia partialis continua or kozhevnikof\$).ti,ab,kf.	473
210	Charcot-Marie-Tooth Disease/	3918
211	(charcot-marie-tooth\$ or peroneal muscular atroph\$).ti,ab,kf.	4168
212	(progressive neuropathic muscular atroph\$ or hereditary peroneal nerve dysfunction\$ or peroneal neuropath\$).ti,ab,kf.	159
213	"Hereditary Sensory and Motor Neuropathy"/	1263
214	(hereditary sensory adj3 motor neuropath\$).ti,ab,kf.	44
215	(hereditary motor adj3 sensory neuropath\$).ti,ab,kf.	888
216	Refsum Disease, Infantile/	11
217	Peroxisomal Disorders/	612
218	(infantile refsum or infantile phytanic acid storage).ti,ab,kf.	154
219	Myasthenic Syndromes, Congenital/	518
220	congenital myasth?eni\$.ti,ab,kf.	788
221	Muscular Dystrophy, Duchenne/	5093
222	(duchenne muscular dystroph\$ or dmd).ti,ab,kf.	10130
223	exp Muscular Dystrophies, Limb-Girdle/	1034
224	(limb-girdle or erb\$ muscular dystroph\$).ti,ab,kf.	2531
225	(sarcoglycanopath\$ or sarcoglycaopath\$).ti,ab,kf.	226
226	Osteochondrodysplasias/	5278
227	(osteochondrodysplas\$ or schwartz-jampel or chondrodystrophi\$ myotoni\$ or myotoni\$ chondrodystrophi\$).ti,ab,kf.	700
228	Myotonia Congenita/	979
229	(congenita\$ myotoni\$ or myotoni\$ congenita\$).ti,ab,kf.	870
230	(thomsen\$ adj (disease\$ or disorder\$ or syndrome\$)).ti,ab,kf.	102
231	((recessive adj3 myotoni\$) or becker\$ myotoni\$).ti,ab,kf.	144
232	Isaacs Syndrome/	260
233	(isaac\$ adj (syndrome\$ or disease\$ or disorder\$)).ti,ab,kf.	150
234	neuromyotoni\$.ti,ab,kf.	465
235	Myotonic Disorders/	298
236	(paramyotoni\$ congenita\$ or congenita\$ paramyotoni\$).ti,ab,kf.	310
237	(eulenburg\$ adj (disease\$ or syndrome\$ or disorder\$)).ti,ab,kf.	1
238	(myotoni\$ adj (disease\$ or disorder\$ or syndrome\$)).ti,ab,kf.	189

Number	Searches	Results
239	pseudomyotoni\$.ti,ab,kf.	89
240	exp Myopathies, Structural, Congenital/	1236
241	(congenital adj3 myopath\$.ti,ab,kf.	1263
242	myopathycongenital.ti,ab,kf.	0
243	((nemaline or rod) adj3 myopath\$.ti,ab,kf.	762
244	((central core or mini-core or minicore or multicore or multi-core) adj (disease\$ or disorder\$ or syndrome\$ or myopath\$)).ti,ab,kf.	542
245	fiber type disproportion.ti,ab,kf.	157
246	fibre type disproportion.ti,ab,kf.	69
247	Muscular Dystrophies/cn [Congenital]	843
248	(congenital\$ adj5 muscular dystroph\$).ti,ab,kf.	1916
249	((centronuclear or myotubular) adj myopath\$).ti,ab,kf.	665
250	exp Mitochondrial Myopathies/	5247
251	(mitochondrial myopath\$ or mitochondrial encephalomyopath\$ or chronic progressive external ophthalmopleg\$).ti,ab,kf.	3479
252	((melas or kearns-sayre\$) adj (syndrome\$ or disease\$ or disorder\$)).ti,ab,kf.	1098
253	Quadriplegia/ and spastic\$.ti,ab,kf.	676
254	(spastic quadriplegi\$ or spastic tetraplegi\$).ti,ab,kf.	674
255	Reye Syndrome/	1734
256	(reye\$ adj (syndrome\$ or disease\$ or disorder\$)).ti,ab,kf.	1804
257	multiple pterygium.ti,ab,kf.	149
258	Hypertension, Pulmonary/ and primary\$.ti,ab,kf.	3712
259	((primary pulmonary or precapillary pulmonary or idiopathic pulmonary) adj (hypertension or ht or arterial hypertension)).ti,ab,kf.	2964
260	((primary bronchopulmonary or precapillary bronchopulmonary or idiopathic bronchopulmonary) adj (hypertension or ht or arterial hypertension)).ti,ab,kf.	0
261	((primary lung or precapillary lung or idiopathic lung) adj (hypertension or ht or arterial hypertension)).ti,ab,kf.	2
262	ipah.ti,ab,kf.	868
263	Cardiomyopathy, Dilated/	16170
264	((congestive or dilated) adj cardiomyopath\$).ti,ab,kf.	16870
265	exp Cardiomyopathy, Hypertrophic/	15053
266	(hypertrophic adj cardiomyopath\$).ti,ab,kf.	12120
267	Cardiomyopathies/cn [Congenital]	177
268	(congenital adj3 cardiomyopath\$).ti,ab,kf.	549
269	Cardiomyopathy, Restrictive/	838
270	(restrictive cardiomyopath\$ or obliterative cardiomyopath\$ or constrictive cardiomyopath\$).ti,ab,kf.	1174
271	exp Pulmonary Fibrosis/	21365
272	(pulmonary fibros\$ or lung fibros\$ or bronchopulmonary fibros\$ or fibrosing alveolit\$ or interstitial pneumonit\$).ti,ab,kf.	19976
273	Respiratory Insufficiency/	31956
274	(respiratory adj (failure\$ or insufficienc\$)).ti,ab,kf.	33679
275	"Cystic Adenomatoid Malformation of Lung, Congenital"/	937
276	((cystic lung or cystic pulmonary or cystic bronchopulmonary) adj (disease\$ or disorder or syndrome\$)).ti,ab,kf.	308
277	(bronchogenic cyst\$ or bronchopulmonary foregut malformation\$).ti,ab,kf.	1618
278	cystic adenomatoid malformation\$.ti,ab,kf.	954
279	lobar emphysem\$.ti,ab,kf.	601
280	(pulmonary sequestration\$ or bronchopulmonary sequestration\$ or lung sequestration\$ or extralobar sequestration\$ or extra-lobar sequestration\$ or intralobar sequestration\$ or intra-lobar sequestration\$).ti,ab,kf.	2064
281	pulmolithias\$.ti,ab,kf.	6
282	exp Liver Failure/	24621
283	((liver\$1 or hepatic) adj3 fail\$).ti,ab,kf.	26355

Number	Searches	Results
284	exp Liver Cirrhosis/	88269
285	(cirrhosis adj3 liver\$1).ti,ab,kf.	37506
286	Hepatic Venous Occlusive Disease/	1297
287	((veno-occlusive or venous occlusive) adj (disease\$ or syndrome\$ or disorder\$)).ti,ab,kf.	2253
288	Exocrine Pancreatic Insufficiency/	2035
289	(swachman-diamond or shwachman-bodian or schwachmann-diamond or shwachmann-bodian).ti,ab,kf.	79
290	Granulomatosis with Polyangiitis/	7185
291	wegener\$ granulomatos\$.ti,ab,kf.	6138
292	(granulomatos\$ adj3 polyangiit\$).ti,ab,kf.	1582
293	Osteolysis, Essential/	835
294	essential osteolys\$.ti,ab,kf.	26
295	((gorham\$ or gorham-stout\$ or vanishing bone or phantom bone) adj (disease\$ or syndrome\$ or disorder\$)).ti,ab,kf.	261
296	((arc or arthrogyrosis renal dysfunction cholestasis) adj (disease\$ or syndrome\$ or disorder\$)).ti,ab,kf.	89
297	Cerebral Hemorrhage/cn [Congenital]	120
298	Cerebral Hemorrhage, Traumatic/	358
299	Cerebral Hemorrhage/ and Birth Injuries.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	222
300	(cerebral h?emorrhage\$ and (birth\$ adj3 injur\$)).ti,ab,kf.	47
301	Asphyxia Neonatorum/	7865
302	asphyxia neonatorum.ti,ab,kf.	1426
303	((perinatal\$ or neonatal\$ or birth\$) adj3 asphyxia\$).ti,ab,kf.	4627
304	Rubella Syndrome, Congenital/	761
305	congenital rubella.ti,ab,kf.	1614
306	exp Cytomegalovirus Infections/cn [Congenital]	1717
307	(congenital adj (cytomegalovirus\$ or cmv)).ti,ab,kf.	1507
308	Chickenpox/cn [Congenital]	262
309	exp Herpes Zoster/cn [Congenital]	37
310	Herpesvirus 3, Human/ and congenital\$.ti,ab,kf.	104
311	((congenital or fetal or foetal) adj3 (varicella\$ or chicken pox\$ or VZV)).ti,ab,kf.	282
312	Toxoplasmosis, Congenital/	2749
313	congenital toxoplasmos\$.ti,ab,kf.	1834
314	exp Hypoxia, Brain/	12700
315	((brain\$ or cerebral) adj3 hypoxi\$).ti,ab,kf.	6546
316	Renal Insufficiency/cn [Congenital]	16
317	Acute Kidney Injury/cn [Congenital]	18
318	Renal Insufficiency, Chronic/cn [Congenital]	7
319	Kidney Failure, Chronic/cn [Congenital]	47
320	(congenital\$ adj3 (kidney failure\$ or renal failure\$ or kidney insufficienc\$ or renal insufficienc\$)).ti,ab,kf.	75
321	(congenital\$ adj3 (kidney disease\$ or renal disease\$)).ti,ab,kf.	243
322	Anencephaly/	3213
323	(anencephal\$ or meroanencephal\$ or craniorachischis\$).ti,ab,kf.	3016
324	(aprosencephal\$ adj3 open cranium).ti,ab,kf.	0
325	Encephalocele/	3791
326	(encephalocele\$ or cranium bifidum).ti,ab,kf.	2217
327	Dandy-Walker Syndrome/	1101
328	dandy-walker\$.ti,ab,kf.	1217
329	Acrocallosal Syndrome/	83
330	(acrocallosal or acro-callosal or acrocolossal or acro colossal).ti,ab,kf.	98
331	Aicardi Syndrome/	81

Number	Searches	Results
332	(aicardi\$ adj (syndrome\$ or disease\$ or disorder\$)).ti,ab,kf.	315
333	Holoprosencephaly/	1175
334	(holoprosencephal\$ or arhinencephal\$ or holosprosencephal\$).ti,ab,kf.	1934
335	Hydranencephaly/	480
336	(hydranencephal\$ or hydrancephal\$ or hydroanencephal\$).ti,ab,kf.	538
337	exp Lissencephaly/	491
338	Microcephaly/	4982
339	(lissencephal\$ or walker-warburg\$ or miller-dieker\$ or norman-robert\$ or microlissencephal\$).ti,ab,kf.	1775
340	((fukuyama\$ or muscle-eye-brain) adj (syndrome\$ or disease\$ or disorder\$)).ti,ab,kf.	195
341	"Malformations of Cortical Development"/	1217
342	(microgyria\$ or microgyrus or micro-gyria\$ or micro-gyrus).ti,ab,kf.	191
343	(pachygyria\$ or pachgyria\$).ti,ab,kf.	457
344	agyria\$.ti,ab,kf.	204
345	Septo-Optic Dysplasia/	193
346	((septo-optic or septooptic) adj dysplas\$).ti,ab,kf.	431
347	de morsier\$.ti,ab,kf.	77
348	(schizencephal\$ or schizencephal\$).ti,ab,kf.	443
349	Arnold-Chiari Malformation/	3535
350	chiari\$ malformation\$.ti,ab,kf.	2102
351	Truncus Arteriosus, Persistent/	892
352	(truncus or common arterial trunk\$).ti,ab,kf.	2357
353	"Transposition of Great Vessels"/	7449
354	((transposition\$ or dextrotransposition\$ or dtransposition\$ or levotransposition\$ or ltransposition\$) adj3 (great arter\$ or main arter\$ or aorta\$ or pulmonary arter\$ or great vessel\$ or main vessel\$)).ti,ab,kf.	6303
355	(dextro-tga or d-tga or levo-tga or l-tga).ti,ab,kf.	261
356	(double inlet adj3 ventricle\$).ti,ab,kf.	329
357	DILV.ti,ab,kf.	33
358	single ventricle\$.ti,ab,kf.	2783
359	Heart Defects, Congenital/ and Atrial Appendage.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	181
360	(isomerism adj3 atrial appendage\$).ti,ab,kf.	29
361	(aspleni\$ or polyspleni\$ or poly-spleni\$).ti,ab,kf.	2005
362	"Tetralogy of Fallot"/	9588
363	(tetralogy adj3 fallot\$).ti,ab,kf.	9066
364	Eisenmenger Complex/	1139
365	(eisenmenger\$ or tardive cyanos\$ or eisenmeyer\$).ti,ab,kf.	1219
366	(pentalogy adj3 fallot\$).ti,ab,kf.	71
367	Pulmonary Atresia/	1412
368	((pulmonary or bronchopulmonary or lung\$) adj3 atresia\$).ti,ab,kf.	3230
369	Tricuspid Atresia/	580
370	((tricuspid or tri) adj3 atresia\$).ti,ab,kf.	1498
371	Ebstein Anomaly/	1997
372	(ebstein\$ adj (anomal\$ or malformation\$)).ti,ab,kf.	1933
373	Hypoplastic Left Heart Syndrome/	2350
374	(hypoplastic left heart adj (syndrome\$ or disease\$ or disorder\$)).ti,ab,kf.	2640
375	((aortic or aorta\$) adj3 atresia\$).ti,ab,kf.	605
376	(mitral adj3 atresia\$).ti,ab,kf.	329
377	((absence\$ or absent\$) adj3 (aorta\$ or aortic)).ti,ab,kf.	507
378	(aplas\$ adj3 (aorta\$ or aortic)).ti,ab,kf.	8
379	exp Aortic Aneurysm/cn [Congenital]	258
380	((((aorta\$ or aortic) adj3 aneurys\$) and congenital\$).ti,ab,kf.	680

Number	Searches	Results
381	(hypoplas\$ adj3 (aorta\$ or aortic)).ti,ab,kf.	955
382	(convulsion\$ adj3 (aorta\$ or aortic)).ti,ab,kf.	2
383	(persistent right adj3 (aorta\$ or aortic)).ti,ab,kf.	76
384	((anomalous pulmonary venous or anamolous pulmonary venous) adj (connection or drainage or return)).ti,ab,kf.	2680
385	((absence\$ or absent\$) adj3 vena\$ cava\$).ti,ab,kf.	308
386	(persistent left adj3 cardinal vein\$).ti,ab,kf.	5
387	Scimitar Syndrome/	754
388	((scimitar\$ or pulmonary venolobar) adj (syndrome\$ or disease\$ or disorder\$)).ti,ab,kf.	573
389	(arteriovenous malformations/ or intracranial arteriovenous malformations/) and bilateral.ti,ab,kf.	432
390	((bilateral AV or bilateral arteriovenous or bilateral arterio-venous) adj3 malform\$).ti,ab,kf.	15
391	((trachea\$ or windpipe\$ or wind-pipe\$) adj3 atresia\$).ti,ab,kf.	122
392	Tracheal Stenosis/	5949
393	((trachea\$ or laryngotrachea\$ or glottic or subglottic or sub-glottic) adj3 stenosis).ti,ab,kf.	4914
394	Bronchopulmonary Dysplasia/	4258
395	((lung\$ or pulmonary or bronchopulmonary) adj3 (hypoplas\$ or dysplas\$)).ti,ab,kf.	9671
396	((absence\$ or absent\$) adj3 (esophag\$ or oesophag\$ or foodpipe or food-pipe\$ or gullet\$)).ti,ab,kf.	481
397	Intestinal Atresia/	2181
398	(duoden\$ adj3 atresia\$).ti,ab,kf.	752
399	((absence\$ or absent\$) adj3 (intestin\$ or gastrointestin\$)).ti,ab,kf.	948
400	((intestin\$ or gastrointestin\$) adj3 atresia\$).ti,ab,kf.	1133
401	((intestin\$ or gastrointestin\$) adj3 stenosis\$).ti,ab,kf.	664
402	(cloaca\$ adj3 (abnor\$ or malform\$ or anomal\$)).ti,ab,kf.	412
403	(cloaca\$ adj3 exophthlmo\$).ti,ab,kf.	0
404	Biliary Atresia/	2992
405	(biliary adj3 atresia\$).ti,ab,kf.	3989
406	(extrahepatic ductopen\$ or extra-hepatic ductopen\$ or progressive obliterative cholangiopath\$).ti,ab,kf.	5
407	(biliary adj3 hypoplas\$).ti,ab,kf.	72
408	(alagille\$ adj3 atresia\$).ti,ab,kf.	32
409	((absence\$ or absent\$) adj3 kidney\$).ti,ab,kf.	880
410	(potter\$ adj (sequence\$ or syndrome\$ or disease\$ or disorder\$)).ti,ab,kf.	316
411	Oligohydramnios/	1294
412	oligohydramn\$.ti,ab,kf.	2451
413	Multicystic Dysplastic Kidney/	513
414	((kidney\$ or renal) adj3 dysplas\$).ti,ab,kf.	3089
415	((meckel\$ or meckelgruber\$ or gruber\$) adj (syndrome\$ or disease\$ or disorder\$)).ti,ab,kf.	475
416	dysencephalia splanchnocystica\$.ti,ab,kf.	8
417	(pena-shokeir\$ or penn-shokeir\$).ti,ab,kf.	104
418	(larsen\$ adj (syndrome\$ or disease\$ or disorder\$)).ti,ab,kf.	256
419	Acrocephalosyndactylia/	1564
420	acrocephalosyndactyl\$.ti,ab,kf.	290
421	(pfeiffer\$ adj (syndrome\$ or disease\$ or syndrome\$)).ti,ab,kf.	352
422	Short Rib-Polydactyly Syndrome/	143
423	short rib\$1.ti,ab,kf.	300
424	(saldino-noonan\$ or majewski\$ or verma-naumoff\$ or beemer-langer\$).ti,ab,kf.	196
425	(jeune\$ adj (syndrome\$ or disease\$ or disorder\$)).ti,ab,kf.	180
426	asphyxiating thoracic dysplas\$.ti,ab,kf.	53
427	exp Chondrodysplasia Punctata/	1082
428	chondrodysplasia punctata\$.ti,ab,kf.	709
429	((conradi\$ or h?nermann\$ or happle\$) adj3 (syndrome\$ or disease\$ or disorder\$)).ti,ab,kf.	197
430	Osteogenesis Imperfecta/	4623

Number	Searches	Results
431	osteogenesis imperfecta.ti,ab,kf.	4407
432	((brittle bone or lobstein\$) adj (disease\$ or disorder\$ or syndrome\$)).ti,ab,kf.	218
433	Osteochondrodysplasias/	5278
434	(spondyloepimetaphyseal or spondyloepiphyseal or spendylo metaphyseal).ti,ab,kf.	683
435	Hernia, Umbilical/	3894
436	(omphalocele\$ or omphalocoele\$ or exomphalos).ti,ab,kf.	2315
437	(hernia\$ adj3 umbilic\$).ti,ab,kf.	2123
438	Gastroschisis/	1245
439	gastroschis\$.ti,ab,kf.	2168
440	Ichthyosis, Lamellar/	758
441	(lamellar\$ adj3 ichthyos\$).ti,ab,kf.	395
442	((harlequin\$ or harloquin\$) adj3 (ichthyos\$ or baby or babies or f?etus\$)).ti,ab,kf.	248
443	(ichthyosis congenita\$ or ichthyosis fetalis or keratosis diffusa fetalis).ti,ab,kf.	82
444	exp Epidermolysis Bullosa/	4916
445	epidermolysis bullosa\$.ti,ab,kf.	4833
446	(johanson-blizzard\$ or johanna-blizzard\$).ti,ab,kf.	96
447	Xeroderma Pigmentosum/	3573
448	xeroderma pigmentosum.ti,ab,kf.	4191
449	Ectodermal Dysplasia/	3398
450	lacrimo-auriculo-dento-digital.ti,ab,kf.	54
451	ectodermal dysplas\$.ti,ab,kf.	2652
452	((ladd or eec) adj (syndrome\$ or disease\$ or disorder\$)).ti,ab,kf.	236
453	Sturge-Weber Syndrome/	1250
454	(sturge-weber or encephalotrigeminal angiomatos\$).ti,ab,kf.	1423
455	Fetal Alcohol Spectrum Disorders/	4029
456	f?etal alcohol.ti,ab,kf.	3685
457	Pierre Robin Syndrome/	1344
458	pierre robin\$.ti,ab,kf.	1095
459	Acrocephalosyndactylia/	1564
460	(acrocephalosyndact\$ or acrocephalopolysyndact\$).ti,ab,kf.	327
461	((apert\$ or crouzon\$ or saethre-chotzen\$ or noack\$ or carpenter\$ or sakati-nyhan-tisdale\$ or goodman\$) adj (syndrome\$ or disorder\$ or disease\$)).ti,ab,kf.	1836
462	Fraser Syndrome/	38
463	(fraser\$ adj (syndrome\$ or disease\$ or disorder\$)).ti,ab,kf.	194
464	cryptophthalmos.ti,ab,kf.	190
465	(cyclopia\$1 or cyclocephal\$ or synophthalmi\$).ti,ab,kf.	596
466	Goldenhar Syndrome/	738
467	(goldenhar\$ or oculo-auriculo-vertebral).ti,ab,kf.	791
468	Mobius Syndrome/	331
469	((m?bius\$ or moebius\$) adj (syndrome\$ or disease\$ or disorder\$)).ti,ab,kf.	542
470	Orofaciodigital Syndromes/	564
471	(orofacioidigital or oro-facial-digital or oral-facial-digital or papillon-league\$ or psaume\$).ti,ab,kf.	457
472	(robin\$ adj (syndrome\$ or disorder\$ or disease\$)).ti,ab,kf.	733
473	(freeman-sheldon\$ or distal arthrogrypos\$ or craniocarpotarsal dysplas\$ or craniocarpotarsal dystroph\$ or canio-carpo-tarsal or windmill-vane-hand\$ or whistling-face).ti,ab,kf.	403
474	De Lange Syndrome/	818
475	((de lange\$ or bushy\$) adj (syndrome\$ or disorder\$ or disease\$)).ti,ab,kf.	875
476	amsterdam dwarfism.ti,ab,kf.	5
477	(aarskog or facioidigitogenital or facio-digito-genital or facial digital genital or shawl scrotum or faciogenital or facio-genital).ti,ab,kf.	191
478	Cockayne Syndrome/	876
479	(cockayne\$ or neill-dingwall\$).ti,ab,kf.	1313
480	(cerebro-oculo-facio-skeletal or cerebro-oculo-facial-skeletal).ti,ab,kf.	67
481	(dubowitz\$ adj (syndrome\$ or disease\$ or disorder\$)).ti,ab,kf.	103

Number	Searches	Results
482	(robinow\$ or robinhow\$).ti,ab,kf.	200
483	(f?etal face or f?etal facies or f?etal faces or acral dysostosis\$ or mesomelic dwarfism or covesdem\$).ti,ab,kf.	243
484	Silver-Russell Syndrome/	210
485	(silver-russell\$ or russell-silver\$).ti,ab,kf.	633
486	(silver\$ adj (syndrome\$ or disease\$ or disorder\$)).ti,ab,kf.	337
487	((seckel\$ or harper\$) adj (syndrome\$ or disease\$ or disorder\$)).ti,ab,kf.	264
488	(microcephalic primordial dwarfism or bird-headed dwarf\$ or virchow-seckel dwarfism).ti,ab,kf.	81
489	Smith-Lemli-Opitz Syndrome/	580
490	(smith-lemli-opitz\$ or dehydrocholesterol reductase deficiency\$).ti,ab,kf.	804
491	Prader-Willi Syndrome/	2916
492	(prader-willie\$ or prader-willie\$).ti,ab,kf.	3200
493	Rubinstein-Taybi Syndrome/	490
494	(rubinstein-taybi\$ or rubenstein-taybi\$ or broad thumb-hallux).ti,ab,kf.	616
495	((rubinstein\$ or rubenstein\$) adj2 (syndrome\$ or disease\$ or disorder\$)).ti,ab,kf.	616
496	Nephritis, Hereditary/	1980
497	(alport\$ adj (syndrome\$ or disease\$ or disorder\$)).ti,ab,kf.	1702
498	(hereditary nephritis or h?emorrhagic familial nephritis).ti,ab,kf.	326
499	(hereditary deafness adj3 nephropath\$).ti,ab,kf.	0
500	(h?ematuria adj3 nephropath\$ adj3 deafness).ti,ab,kf.	4
501	Laurence-Moon Syndrome/	601
502	laurence-moon\$.ti,ab,kf.	489
503	Bardet-Biedl Syndrome/	626
504	(bardet-biedl\$ or biedl-bardet\$).ti,ab,kf.	1050
505	Zellweger Syndrome/	651
506	zellweger\$.ti,ab,kf.	1055
507	((cerebrohepatorenal or cerebro-hepato-renal) adj (syndrome\$ or disease\$ or disorder\$)).ti,ab,kf.	181
508	(edward\$ adj (syndrome\$ or disease\$ or disorder\$)).ti,ab,kf.	297
509	"trisomy 18".ti,ab,kf.	2276
510	(patau\$ adj (syndrome\$ or disease\$ or disorder\$)).ti,ab,kf.	210
511	("trisomy 13" or "trisomy D").ti,ab,kf.	1469
512	"trisomy 22".ti,ab,kf.	293
513	"trisomy 9".ti,ab,kf.	291
514	"trisomy 10".ti,ab,kf.	94
515	duplication syndrome\$.ti,ab,kf.	311
516	(("chromosome 8" or "chr 8") adj5 duplicat\$).ti,ab,kf.	43
517	Chromosome Duplication/	820
518	exp X Chromosome/ab [Abnormalities]	1
519	exp X Chromosome/ and duplicat\$.ti,ab,kf.	954
520	(("chromosome x" or "chr x") and duplicat\$).ti,ab,kf.	84
521	(chromosom\$ abnormality adj5 duplicat\$).ti,ab,kf.	15
522	"tetrasomy 5p".ti,ab,kf.	8
523	(tetrasomy adj3 mosaic\$).ti,ab,kf.	128
524	Chromosomes, Human, Pair 5/ and Mosaicism.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	47
525	Tetrasomy/	67
526	Trisomy/ and (chromosomes, human, pair 9/ or chromosomes, human, pair 10/ or chromosomes, human, pair 13/ or Chromosomes, Human, Pair 18/ or chromosomes, human, pair 22/)	3146
527	Chromosome Deletion/ and Chromosomes, Human, Pair 4/	513
528	(delet\$ adj5 short arm adj5 "chrom\$ 4").ti,ab,kf.	86
529	Wolf-Hirschhorn Syndrome/	135

Number	Searches	Results
530	((wolf-hirschhorn\$ or wolff hirschorn\$ or chromosome deletion dillan\$ or pitt-rogers-dank\$ or pitt\$) adj3 (syndrome\$ or disease\$ or disorder\$)).ti,ab,kf.	693
531	Cri-du-Chat Syndrome/	691
532	((cri du chat\$ or crying cat\$ or 5p or lejeune\$) adj3 (syndrome\$ or disease\$ or disorder\$)).ti,ab,kf.	533
533	Jacobsen Distal 11q Deletion Syndrome/	68
534	((jacobsen\$ or 11q deletion) adj5 (syndrome\$ or disease\$ or disorder\$)).ti,ab,kf.	127
535	exp Monosomy/ and Chromosomes, Human, Pair 9/	774
536	(9p minus or 9p deletion).ti,ab,kf.	111
537	(alfi\$ adj (syndrome\$ or disease\$ or disorder\$)).ti,ab,kf.	3
538	(degouchy\$ or de gouchy\$ or degrouchy\$ or de grouchy\$).ti,ab,kf.	13
539	distal 18q.ti,ab,kf.	17
540	Hypoventilation/cn [Congenital]	223
541	(ondine\$ curse or congenital central hypoventilation or primary alveolar hypoventilation).ti,ab,kf.	684
542	Graft vs Host Disease/ and (Chronic Disease/ or chronic\$.ti,ab,kf.)	7221
543	((graft vs host or graft versus host) adj (disease\$ or syndrome\$ or disorder\$) and chronic\$).ti,ab,kf.	7423
544	exp HIV/	98462
545	exp HIV Infections/	279925
546	(HIV or human immunodeficiency virus\$.ti,ab,kf.	293400
547	(htlv or human t-lymphotropic virus\$ or human t cell lymphotropic virus\$).ti,ab,kf.	13578
548	(acquired immune deficiency syndrome\$ or acquired immunodeficiency syndrome\$).ti,ab,kf.	24909
549	(AIDS adj3 (virus\$ or infection\$)).ti,ab,kf.	8102
550	(AIDS adj (related or associated)).ti,ab,kf.	9356
551	exp Neoplasms/	3290987
552	(cancer\$ or carcin\$ or tumor\$ or tumour\$ or neoplas\$ or adenocarcin\$ or oncol\$ or malignan\$).ti,ab,kf.	2947882
553	Cystic Fibrosis/	34771
554	(cystic fibrosis or fibrocystic or fibro-cystic or mucoviscidosis or cf).ti,ab,kf.	59866
555	Cerebral Palsy/	19638
556	(cerebr\$ adj3 pals\$).ti,ab,kf.	19444
557	Muscle Spasticity/	9059
558	spasticit\$.ti,ab,kf.	9624
559	Quadriplegia/	8151
560	(spastic\$ and (quadripleg\$ or tetrapleg\$)).ti,ab,kf.	1159
561	exp Renal Insufficiency/	166861
562	((kidney\$ or renal) adj3 (failure\$ or insufficienc\$)).ti,ab,kf.	114282
563	(end stage adj3 (kidney or renal)).ti,ab,kf.	35463
564	(("stage 5" or "stage V") adj3 (kidney or renal)).ti,ab,kf.	448
565	(ESRD or ESKD or ESRF or ESKF or CRF or CKF).ti,ab,kf.	28165
566	1 or 2 or 3 or 4 or 5 or 6	3998038
567	or/14-565	5194249
568	13 and 566 and 567	11446
569	568	11446
570	limit 569 to yr="2000 -Current"	7609

eTable 2. Risk of Bias Assessment

Author & Publication Date	External Validity Questions				Internal Validity Questions						Total Score	Risk of Bias	
	1	2	3	4	5	6	7	8	9	10			
Cancer													
Hedström et al. (2005)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	0	Low
Matziou et al. (2008)	✗	✓	✗	✗	✓	✓	✓	✓	✓	✓	✓	3	Low
Kersun et al. (2009)	✗	✗	✓	✗	✓	✓	✓	✓	✓	✓	✓	3	Low
Duruulp & Altay (2012)	✗	✗	✗	✗	✓	✓	✓	✓	✓	✓	✓	4	Moderate
Bemis et al. (2015)	✗	✓	✗	✗	✓	✓	✓	✓	✓	✗	✓	4	Moderate
Rivas-Molina et al. (2015)	✗	✗	✗	✗	✓	✓	✓	✓	✓	✓	✓	4	Moderate
Cystic Fibrosis													
Casier et al. (2008)	✗	✗	✓	✗	✓	✓	✓	✓	✓	✓	✓	3	Low
White et al. (2009)	✗	✓	✗	✗	✓	✓	✓	✓	✗	✓	✓	4	Moderate
Smith et al. (2010)	✗	✗	✓	✗	✓	✓	✓	✓	✓	✓	✓	3	Low
Casier et al. (2011)	✓	✗	✓	✗	✓	✓	✓	✓	✓	✓	✓	2	Low
Modi et al. (2011)	✗	✓	✗	✗	✓	✓	✓	✓	✓	✓	✓	3	Low
Oliver et al. (2014)	✗	✓	✗	✗	✓	✓	✓	✓	✓	✓	✓	3	Low
Quittner et al. (2014)	✓	✓	✗	✗	✓	✓	✓	✗	✓	✓	✓	3	Low
Askew et al. (2017)	✗	✗	✓	✗	✓	✓	✓	✓	✓	✓	✓	3	Low
HIV													
Pao et al. (2000)	✗	✗	✗	✗	✓	✓	✓	✓	✓	NR	✓	5	Moderate
Murphy et al. (2001)	✓	✓	✗	✗	✓	✓	✓	✓	✓	✓	✓	2	Low
Elliott-DeSorbo et al. (2009)	✓	✓	✗	✗	✓	✓	✓	✓	NR	✓	✓	3	Low
Mellins et al. (2009)	✓	✓	✓	✗	✗	✓	✓	✗	✓	✓	✓	3	Low
Elkington et al. (2010)	✓	✓	✓	✗	✓	✓	✓	✓	✓	✓	✓	✓	Low
Andrinopoulos et al. (2011)	✓	✓	✗	✗	✓	✓	✓	✓	✓	✓	✓	2	Low
Martinez et al. (2012)	✓	✓	✗	✗	✓	✓	✓	✓	✓	✓	✓	2	Low
Nachman et al. (2012)	✓	✓	✗	✗	✓	✓	✓	✓	NR	✓	✓	3	Low
Salama et al. (2013)	✗	✓	✗	✗	✓	✓	✓	✓	✓	✓	✓	3	Low
Brown et al. (2015)	✓	✓	✓	✗	✓	✓	✓	✓	✓	✓	✓	1	Low
Thalassemia													
Clemente et al. (2002)	✓	✗	✓	✗	✓	✓	✓	✓	✓	✓	✓	2	Low
Aydinok et al. (2005)	✗	✗	✗	✗	✓	✓	✓	✓	NR	✓	✓	5	Moderate
Cakaloz et al. (2009)	✗	✗	✗	✗	✓	✓	✓	✓	NR	✓	✓	5	Moderate
Adanir et al. (2017)	✗	✗	✗	✗	✓	✓	✓	✓	✓	✓	✓	4	Moderate
Neurological Conditions													
Laufersweiler-Plass et al. (2003)	✓	✓	✗	✗	✗	✓	✓	✓	NR	✓	✓	4	Moderate
Bäckman et al. (2005)	✗	✗	✗	✗	✓	✓	✓	✓	✓	✓	✓	4	Moderate
Amato et al. (2008)	✓	✓	✓	✗	✓	✓	✓	✓	✓	✓	✓	1	Low

Amato et al. (2010)	✓	✗	✓	✗	✓	✓	✓	✓	✓	✓	2	Low
Till et al. (2012)	✗	✗	✗	✗	✗	✓	✓	✓	NR	✓	6	Moderate
Elsenbruch et al. (2013)	✗	✓	✓	✗	✓	✓	✓	✗	NR	✓	4	Moderate
Parrish et al. (2013)	✗	✓	✗	✗	✓	✓	✓	✓	NR	✓	4	Moderate
Chronic Kidney Disease												
Kogon et al. (2013)	✗	✗	✗	✗	✓	✓	✓	✓	✓	✓	4	Moderate
Kogon et al. (2016)	✓	✓	✗	✗	✓	✓	✓	✓	✓	✓	2	Low
Kilicoglu et al. (2016)	✗	✗	✓	✗	✓	✓	✓	✓	✓	✓	3	Low

✓ Yes; ✗ No; NA Not Available

External Validity Questions:

1. Was the study's target population a clear representation of the national population in relation to relevant variables, e.g. age, sex, occupation?
2. Was the sampling frame a true or close representation of the target population?
3. Was some form of random selection used, OR was a census undertaken?
4. Was the likelihood of non-response bias minimal?

Internal Validity Questions:

5. Were data collected directly from the subjects (as opposed to a proxy)?
6. Was an acceptable case definition used in the study?
7. Was the study instrument that measured the parameter of interest (e.g. prevalence) shown to have reliability and validity (if necessary)?
8. Was the same mode of data collection used for all subjects?
9. Was the length of the shortest prevalence period for the parameter of interest appropriate?
10. Were the numerator(s) and denominator(s) for the parameter of interest appropriate?

eTable 3. Anxiety & Depression Assessment Tools

Assessment Tool	Frequency of Use	
	Anxiety Studies	Depression Studies
Self-/Parent-Completed Questionnaires:		
Hospital Anxiety and Depression Scale (HADS)	7	7
The Behavior Assessment Scale for Children (BASC) (self-/parent-completed)	1	3
Brief Symptom Inventory (BSI)	1	1
Beck Youth Inventory (BYI)	1	3
Youth Self Report (YSR)	0	1
The Youth's Inventory-4	1	1
Children's Depression Inventory (CDI)	N.A.	9
The Center for Epidemiological studies Depression Scale (CES-D)	N.A.	4
Depression Inventory for Children and Adolescents (DIKJ)	N.A.	1
Diagnostic Interviews:		
Kiddie Schedule for Affective Disorders and Schizophrenia (K-SADS)	3	2
DSM-based Psychiatric Interview	2	2
Structured Clinical Interview for DSM-IV Axis I Disorders (SCID)	0	1
Computerised Diagnostic Interview Schedule for Children (CDISC)	1	1
Diagnostic Interview Schedule for Children (DISC) (self- and parent-completed)	1	1
Kinder-DIPS (parent-completed)	1	1

eTable 4. Sub-group analysis of pooled anxiety prevalence

Subgroups	Number of Studies	Number of Participants	Pooled Anxiety Prevalence Estimate (95% CI)	I ²	p Value
Diagnostic Group					
Cancer	2	97	10.2% (4.7%-17.2%)	-	-
CF	7	1,589	22.8% (17.1%-29.1%)	64.8%	0.009
HIV	4	2,606	16.9% (5.4%-32.9%)	97.8%	<0.001
Thalassemia	4	120	29.4% (8.8%-55.3%)	87.6%	<0.001
Neurological Conditions	2	135	8.7% (4.4%-14.3%)	-	-
Study Location^a					
Europe	10	430	17.2% (9.9%-26.0%)	78.0%	<0.001
USA	8	2,831	20.8% (11.3%-32.1%)	95.9%	<0.001
Assessment Tool					
Self/parent-completed questionnaire	12	4,072	14.9% (10.9%-19.4%)	87.0%	<0.001
Diagnostic interview	7	475	28.5% (13.2%-46.8%)	93.0%	<0.001
Risk of Bias					
Low	14	4,316	18.2% (12.8%-24.3%)	93.3%	<0.001
Moderate	5	231	23.1% (7.8%-43.0%)	89.2%	<0.001

I² statistic could not be generated for groups containing <=3 studies

^a Excluded: Multi-national studies containing sites in both Europe and the USA, and studies from Mexico excluded due to insufficient numbers

eTable 5. Meta-regression analysis of pooled anxiety prevalence

Covariate	Number of Studies	Beta (95% CI)	p Value	Adj. R ²
Study Location ^a	18	0.05 (-0.12-0.22)	0.53	-4.89%
Assessment Tool	19	0.15 (0.01-0.30)	0.04	43.36%
Risk of Bias	19	0.02 (-0.18-0.21)	0.84	-10.16%
Sample Size	19	-0.00 (-0.00-0.00)	0.60	-11.44%
Mean Age	15	-0.01 (-0.04-0.02)	0.50	-1.09%
% Female	16	0.01 (-0.00-0.02)	0.25	11.01%

^a Excluded: Multi-national studies containing sites in both Europe and the USA, and studies from Mexico excluded due to insufficient numbers

eTable 6. Sub-group analysis of pooled depression prevalence

Subgroups	Number of Studies	Number of Participants	Pooled Anxiety Prevalence Estimate (95% CI)	I ²	p Value
Diagnostic Group					
Cancer	6	268	17.3% (3.8%-36.9%)	92.0%	<0.001
CF	8	1,628	8.4% (4.7%-13.0%)	69.9%	0.002
HIV	9	3,237	24.2% (15.4%-34.2%)	96.0%	<0.001
Thalassemia	4	120	12.8% (7.1%-19.7%)	0.0%	0.43
Neurological Conditions	6	261	7.0% (1.7%-15.0%)	77.2%	0.001
CKD	3	420	16.4% (2.8%-37.3%)	-	-
Study Location^a					
Europe	16	648	9.5% (5.0%-15.1%)	78.0%	<0.001
USA	18	3,971	18.8% (12.6%-25.8%)	95.1%	<0.001
Assessment Tool					
Self/parent-completed questionnaire	28	5,425	15.4% (11.0%-20.4%)	94.0%	<0.001
Diagnostic interview	8	509	10.5% (4.0%-19.3%)	83.9%	<0.001
Risk of Bias					
Low	22	5,432	14.2% (9.7%-19.4%)	94.9%	<0.001
Moderate	14	502	14.8% (6.7%-25.0%)	88.0%	<0.001

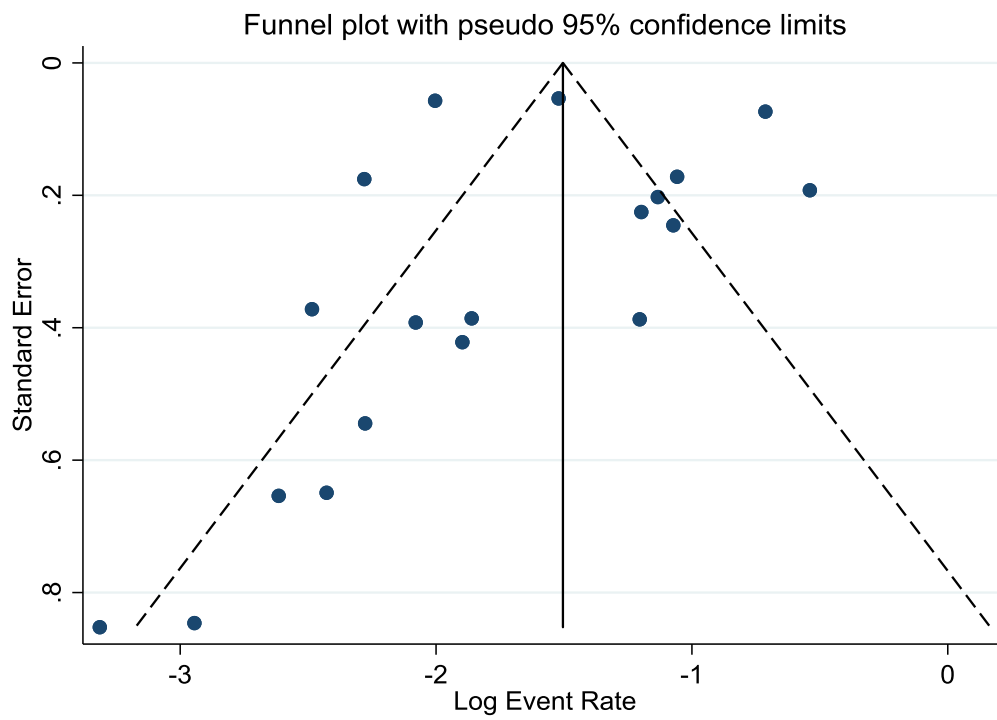
I² statistic could not be generated for groups containing <=3 studies

^a Excluded: Multi-national studies containing sites in both Europe and the USA, and studies from Mexico excluded due to insufficient numbers

eTable 7. Meta-regression analysis of pooled depression prevalence

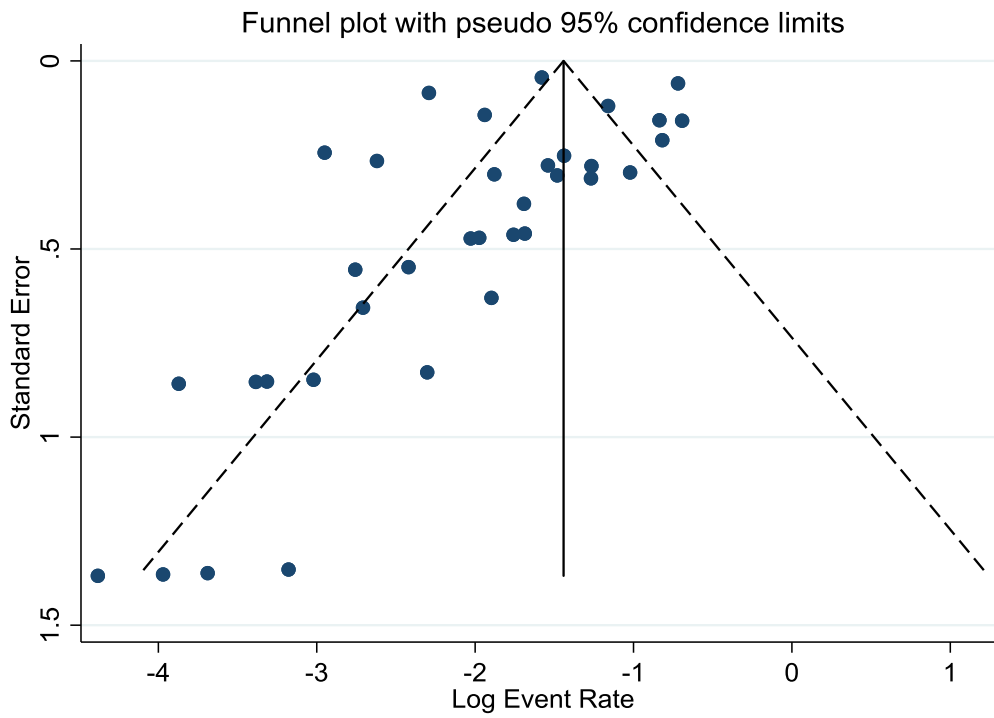
Covariate	Number of Studies	Beta (95% CI)	<i>p</i> Value	Adj. R ²
Study Location ^a	34	0.10 (-0.01-0.22)	0.08	12.35%
Assessment Tool	36	-0.07 (-0.21-0.07)	0.32	3.52%
Risk of Bias	36	0.00 (-0.12-0.12)	0.99	-4.10%
Sample Size	36	0.00 (-0.00-0.00)	0.91	-9.12%
Mean Age	24	0.02 (0.01-0.03)	0.001	100.00%
% Female	32	0.00 (-0.00-0.00)	0.19	-19.8%

^a Excluded: Multi-national studies containing sites in both Europe and the USA, and studies from Mexico and Canada excluded due to insufficient numbers



eFigure 1. Funnel plot for anxiety meta-analysis, with pseudo 95% confidence limits

Legend: Study size is shown on the y-axis and log event rate is shown on the x-axis. Studies included in the meta-analysis are shown by circles. The mean prevalence estimate is shown by the middle vertical line, and the pseudo 95% confidence limits are depicted by the contour lines.



eFigure 2. Funnel plot for depression meta-analysis, with pseudo 95% confidence limits
 Legend: Study size is shown on the y-axis and log event rate is shown on the x-axis. Studies included in the meta-analysis are shown by circles. The mean prevalence estimate is shown by the middle vertical line, and the pseudo 95% confidence limits are depicted by the contour lines.