2021 REGISTRY REPORT

A report on birth defects and developmental disabilities in 6271 children reported to the National Birth Defect Registry founded and operated by Birth Defect Research for Children



From the National Birth Defect Registry



Report

National Birth Defect Registry

July 2021

The National Birth Defect Registry was started in 1990 to collect information on all kinds of birth defects, both structural and functional, as well as information on the preconceptual and prenatal health, genetic and exposure histories of both parents. The project was designed and evaluated by an advisory board of seven prominent scientists working in fields ranging from obstetrics and genetics to epidemiology and the effects of toxic exposures on reproduction. The original questionnaire for the project was a 16-page booklet that parents filled out and mailed to Birth Defect Research for Children. Data from the questionnaire were then manually entered into an interrelational data base. Approximately 4,000 case reports were collected in this version of the registry.

In April of 2004, BDRC converted the registry to an on-line project so that parents could fill out the questionnaire at any convenient time of the day or night. The on-line project also allowed for the addition of new sections to the registry questionnaire without the cost of reprinting thousands of questionnaire booklets and mailing them to parents. The quality of data collected is more accurate as well, since the parent enters information directly into the on-line questionnaire and then BDRC staff imports the questionnaire into the main registry taking the completed questionnaire off the internet.

The registry is designed to identify patterns of similar birth defects that may have similar conditions or exposures in common in the pregnancy or pre-conceptual history. This slide presentation made to the National Institute of Environmental Health Sciences explains the operation of the registry and some of the birth defect issues we have worked on using registry data.

http://www.birthdefects.org/NIEHS/3510.html

Parents have completed 5474 online questionnaires with case reports for 6271 children (more than one child in a family can be reported on a questionnaire) in the on-line National Birth Defect Registry. We have reports for 3285 males, 2970 females and 16 cases where the sex was not entered.

Defect	Count
Allergies	1434
Motor Skills Delay	1285
Speech	1108
Reflux	1069
Depression	1021
Frequent Ear Infections	1016
Mood Swings	971

Speech Delay	963
Anger	937
Frequent Headaches	918
Asthma	906
Frequent Upper Respiratory Infections	897
Joint Pain	867
Spelling/Writing	849
Anxiety Disorder	845
Math	842
Muscle Pain/Weakness	788
Chronic Stomach Problems	750
Attention Deficit With Hyperactivity	721
Jaundice At Birth	718
Drug Reaction	717
Comprehension	716
Food Sensitivity	698
Eczema	696
Language Processing	691
Scoliosis	681
Sleep Disorder	670
Memory Problems	649
Heart Murmur	642
Colic As Baby	628
Hay Fever (Allergic Rhinitus)	623
Distractibility	593
Heat/Cold Sensitivity	577
Dyslexia/Reading	561
Attention Deficit Without Hyperactivity	537

Obsessive/Compulsive	532
Menstrual Problems	516
Vision Defect	513
Chronic Fatigue Syndrome (ME/CFS)	505
Abnormal Teeth	501
Seizure Disorder	460
Retardation	458
Acne-Like Rash	436
Light Sensitivity	429
Partial Hearing Loss	422
Unexplained Fevers	410
Frequent Urinary Tract Infections	404
Astigmatism	400
Sensory Integration Dysfunction	390
Hives	358
Anemia	339
Cleft Palate	335
Hypotonia (Floppy Muscles)	335
Gastroschisis	333
Malformed Fingers, Hands Or Arms	329
Auditory Processing Deficit	326
Strawberry Birth Mark	326
Ovarian Cyst	323
Arthritis	322
Amblyopia (Lazy Eye)	294
Muscle (Absent Or Underdeveloped)	290
Apnea	288
Malformed Toes, Feet Or Legs	286

Undescended Testicles	282
Thyroid Defect	276
Malformations Of Vertebrae	275
Clubfoot	270
Latex	267
Hair Loss	267
Frequent Pneumonia	257
High Arched Palate	256
Bi-Polar	251
Postural Orthostatic Tachycardia Syndrome	251
Hydrocephalus	249
Ventricular Septal Defect	246
Visual Memory Deficits	245
Frequent Nose Bleeds	245
Walks On Tiptoes	237
Autoimmune Disorder	232
External Ear Or Ears (Absent of Malformed)	228
Autism	225
Atrial Septal Defect	219
Reduction Deformity Upper Limb	219
Cerebral Palsy	218
Lung (Absent Or Underdeveloped)	217
Facial Asymmetry	213
Breaks Law/Rules Of Society	209
Spina Bifida	205
Chronic Tinnitus (Ringing In Ears)	205
Cleft Lip	205
Strabismus	204

Micrognathia (Small Jaw)	203
Dislocated Hip	200
Oppositional Defiant Disorder	196
Hypertension	193
Infertility	185
Immune Deficiency	185
Low Set Ears	185
Early Puberty	183
Diabetes	176
Psoriasis	174
Rib Abnormality	173
Tethered Spinal Cord	171
Microcephaly	168
Chiari Malformation	167
Cafe Au Lait Birth Mark	166
Vitiligo	162
Endometriosis	161
Diaphragmatic Hernia	160
Changes In Skin Color	159
Umbilical Hernia	156
Syndactyly (Webbed Fingers Or Toes)	155
Borderline Personality Disorder	152
Swollen/Or Bleeding Gums	150
Skin Fungus	149
Tracheoesophageal Fistula	148
Thrush/Chronic Candida	147
Reduction Deformity Lower Limb	143
Neurogenic Bladder	141

Manic Depression	139
Delayed Puberty	138
Hiatal Hernia	136
Internal Ear Or Ears (Absent or Malformed)	134
Early Tooth Eruption	132
Hypoactivity	131
Imperforate Anus	130
Dysmorphic Features	130
Migraines	128
Absence Corpus Callosum	127
Hypoglycemia	126
Contractures Of Elbows/Knees/Joints	124
Cardiac Arrhythmia	122
Chromosome Disorder	121
Deafness	121
Perseveration	120
Malformed Ureter	117
Bony Defect Of Skull	116
Inguinal Hernia	113
Pectus Excavatum	110
Irritable Bowel Syndrome	110
In Utero Growth Retardation	110
Hypospadias	108
Absent Kidney	108
Constitutional Short Stature	108
Facial Bone Deformity	107
Small Sex Organs	107
Malformed Kidney	106

Rheumatoid Arthritis	106
Patent Ductus Arteriosus	106
Nystagmus	100
Hemangioma	99
Craniosynostosis	99
Spina Bifida Occulta	99
Clubfoot With Bone Deformity	98
Malformed Sex Organs	98
PDD (Pervasive Development Disorder)	96
Anencephaly	95
Asperger	95
Ear Tag(S)	95
Vater (Vacterl)	94
Apraxia	94
Goldenhar (Hemifacial Microsomia)	92
Ganglion Cyst	88
Blind	88
Pectoralis (Absent Or Underdeveloped)	87
Growth Hormone Deficiency	86
Chronic Virus	85
Mitral Valve Prolapse	84
Aortic Valve Stenosis/Atresia	82
Sensorineural Hearing Loss	81
Port Wine Stain	78
Liver Function Disorder	76
Pulmonary Valve Stenosis/Atresia	76
Hypoplastic Left Heart Syndrome	74
Cataract	74

Lipoma	74
Brain Cyst	74
Fibromyalgia	74
Neurogenic Bowel	72
Optic Nerve Atrophy	71
Twisted Lower Limb	70
Prune Belly	68
Pigeon Chest	67
Coarctation Of Aorta	67
Pituitary Defect	66
MCS (Multiple Chemical Sensitivity)	64
Poland's	63
Pulmonary Hypertension	63
Tetralogy Of Fallot	63
Down	62
Broncho-pulmonary Dysplasia	59
Transposition Great Arteries	59
Facial Nerve Paralysis	59
Polydactyly (Extra Digits)	58
Schizophrenia	57
Rectal And/Or Intestinal Atresia	57
Anorexia Or Bulimia	57
Pyloric Stenosis	55
Coloboma	55
Amniotic Band	55
Aphasia	52
Cortical Blindness	51
Thin Corpus Callosum	51

Pierre Robin	51
Bicuspid Aortic Valve	51
Mitral Valve Regurgitation	50
Single Umbilical Artery	50
Polycystic Ovarian Syndrome	49
Hydrocele	49
Encephalocele	48
Micropthalmia	48
Hepatomegaly (Enlarged Liver)	47
Hypothyroidism	46
Polycystic Kidney	45
Spondylolisthesis	45
Bradycardia	43
Clubbed Hands	43
Fibroids/Fibroid Tumors	43
Glaucoma	41
Ptosis	41
Hirschsprung's Disease	40
Crohn's Disease	39
Trisomy	39
Holoprosencephaly	39
Bladder Exstrophy	38
Macrocephaly	37
Exotropia	37
Ehlers-Danlos	37
Horseshoe Kidney	37
Absent Gallbladder	37
Syringomyelia	36

Primary Immune Defect	36
Dermoid Cysts	36
Thyroid	35
Arthrogryposis	34
Pulmonary Atresia/Hypoplasia	34
Omphalocele	34
Spinal Stenosis	33
Ataxia	33
Short Bowel	32
Spinal Muscular Atrophy	32
Leukemia	32
Neurofibromatosis	31
Sacral Agenesis	31
Cardiomyopathy	31
Hypertelorism	31
Diabetes Insipidus	30
Pulmonary Artery Anomaly	29
Cystic Hygroma	28
Pilonidal Cyst	28
Dysthymia	28
Dextrocardia	28
Muscular Dystrophy	28
Tourettes'	27
Overgrowth Of Lower Limb	27
Dandy Walker Malformation	27
Septo-Optic Dysplasia	26
Intrauterine Stroke	26
Macroglossia	25

Schizencephaly	25
Splenomegaly (Enlarged Spleen)	25
Double Outlet Right Ventricle	24
Cardiomegaly	24
Tricuspid Valve Stenosis/Atresia	24
Clinodactyly	24
Bicornuate Uterus	23
Spondylosis	21
Absence Of Septum Pellucidum	21
Ambiguous Genitalia	21
Preauricular Pits	21
Lupus	20
Cerebellar Hypoplasia	20
Multiple Sclerosis	20
Hypogammaglobulinemia	20
Twisted Upper Limb	20
Ankyloglossia (Tongue Tied)	20
Choanal Atresia	19
Sarcoma	19
Mitral Valve Stenosis	19
Digeorge	19
Delayed Myelination	19
Overgrowth Of Upper Limb	18
Interstitial Cystitis	18
Hypoplastic Right Heart Syndrome	18
Absent Bladder	17
Lipomyelomeningocele	17
Anophthalmia (Missing Eye)	17

Wolff-Parkinson-White	17
Chondromalacia Patella	17
Hashimoto's Disease	16
Cavernous Hemangioma	16
Cloacal Anomaly	16
Potter	16
Neuroblastoma	16
Endocardial Cushion Defect	16
Pseudotumor Cerebri	16
Epispadias	15
Fibular Hemimelia	15
Biliary Atresia	15
Charge	15
Edwards	15
Lissencephaly	15
Peripheral Pulmonary Stenosis	15
Vascular Ring	14
Turner's	14
Hemihypertrophy	14
Overgrowth (Giant)	14
Celiac's Disease	13
Colpocephaly	13
Osteogenesis Imperfecta	13
Teratomas	13
Static Encephalopathy	13
Klippel-Feil	13
Non-Hodgkins Lymphoma	12
Lymphoma	12

Periventricular Leukomalacia	12
Spastic Paralysis	12
Lymphangioma	12
Caudal Regression	12
Ebstein Anomoly	12
CMV Virus	12
Hydranencephaly	11
Macrostomia	11
Achondroplastic Dwarfism	11
Moebius	11
Lordosis	10
Truncus Arteriosus	10
Psoriatic Arthritis	10
Von Willebrand Disease	10
Graves Disease	10
Hodgkins Disease	10
Hemimegalencephaly	9
Cystic Fibrosis	9
Duane Refraction	8
Treacher Collins	8
Williams	8
Stickler	8
Tuberous Sclerosis	8
Noonan	8
Polysplenia	7
Nail-Patella	7
Hyperpigmentation Of Gums	7
Lamellar Ichthyosis	7

Cloacal Exstrophy	7
Klinefelter	7
Prader-Willi	7
Klippel-Trenaunay-Weber	7
Addison's	7
Cushing	7
Astrocytoma	7
PDD/NOS	7
Beckwith-Wiedemann	7
Tar	6
Crouzon	6
Absent Spleen	6
Marfan	6
Porencephaly	6
Albinism	6
Cornelia De Lange	6
Apert	6
Lennox-Gastaut	6
Angelman	6
Leukodystrophy	5
Brain or CNS	5
Holt-Oram	5
Breast Cancer	5
Fragile X	5
Exophthalmos	5
Absent Uterus/Mayer-Rokitansky-Kuster-Hauser	5

Results by Category

Defect Category	Count
Miscellaneous	2848
Allergies	2526
Learning Disabilities	2194
Gastrointestinal	2163
Immune Response Disorders	1988
Emotional/Behavioral	1915
Developmental Delay	1725
Skin	1607
Central Nervous System	1513
Cranial/Facial	1454
Cardiovascular	1437
Attention Deficit/Activity Disorders	1418
Eye	1377
Limb Defects	1323
Syndromes	1006
Spine	995
Muscle	974
Ear	974
Genitourinary	902
Endocrine	845
Liver/Bile Duct/Spleen	834
Chest	532
Cysts	473
Autistic Spectrum Disorders	337
Tumors-Benign	304
Growth Disorders	299
Cancer	144

Reports Submitted by Location

Chata	Count
State	Count
CA	431
FL	366
TX	350
NY	321
ОН	320
IL	253
MI	250
NJ	243
PA	225
VA	172
NC	157
GA	151
IN	136
MA	135
МО	125
TN	118
WA	112
MD	110
KY	105
WI	103
MN	101
AL	90
AZ	86

СО	81
LA	81
SC	77
ОК	76
KS	76
OR	74
AR	74
IA	71
WV	61
СТ	49
NE	48
UT	47
MT	35
MS	34
ME	34
NV	34
ID	33
NM	30
SD	26
NH	26
AK	24
ND	24
Н	22
RI	20
DE	19
WY	12
VT	12
PR	7

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