

CoRDS Registry

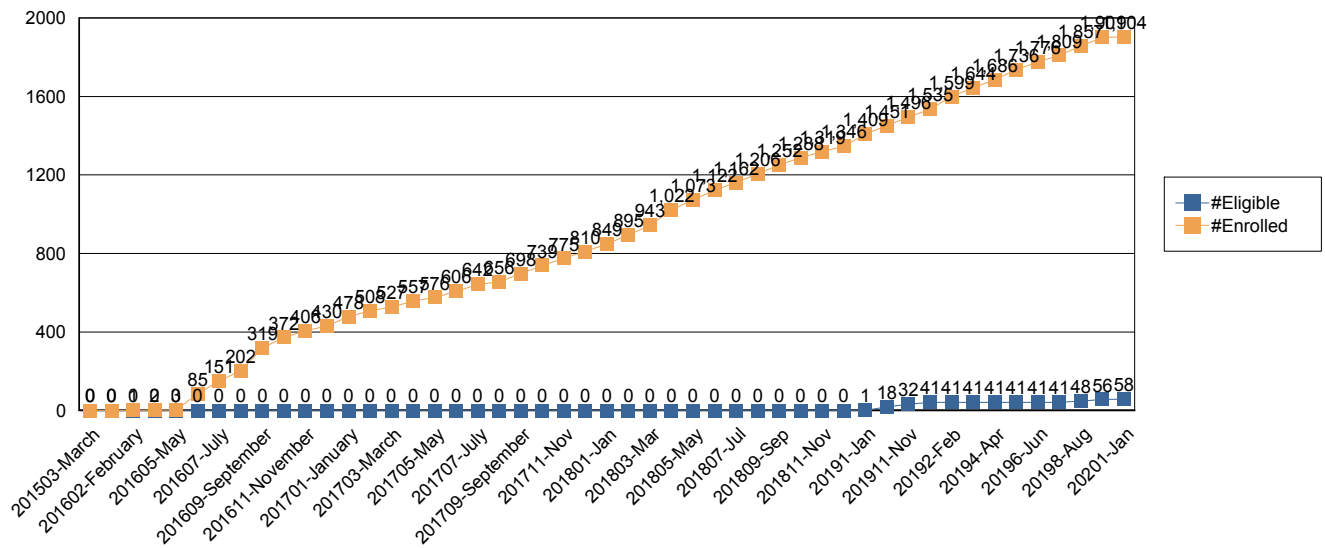
Coordination of Rare Diseases
at Sanford



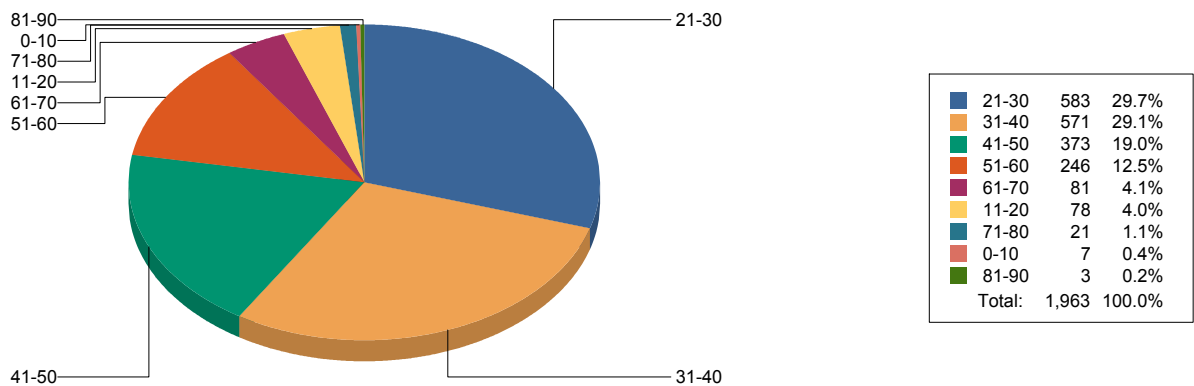
Participant Information

Number of participants currently Eligible:	58
Number of participants currently Enrolled:	1,963
Total Number of Hypersomnia Participants	2,021

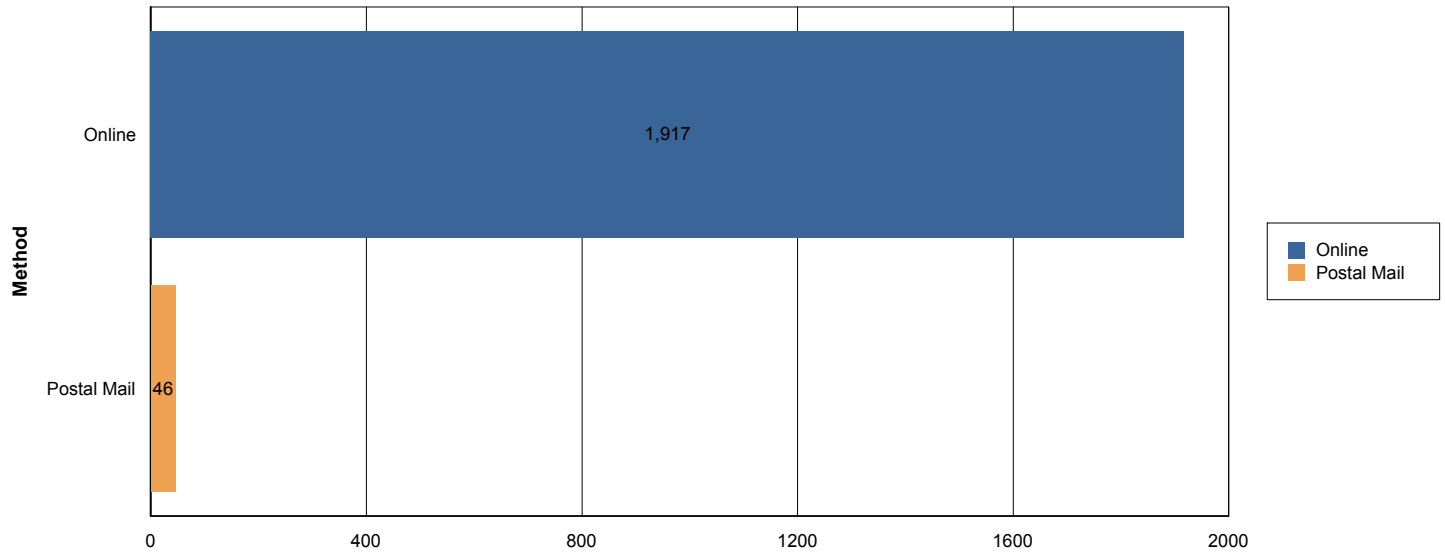
Enrolled and Eligible Participants by Month



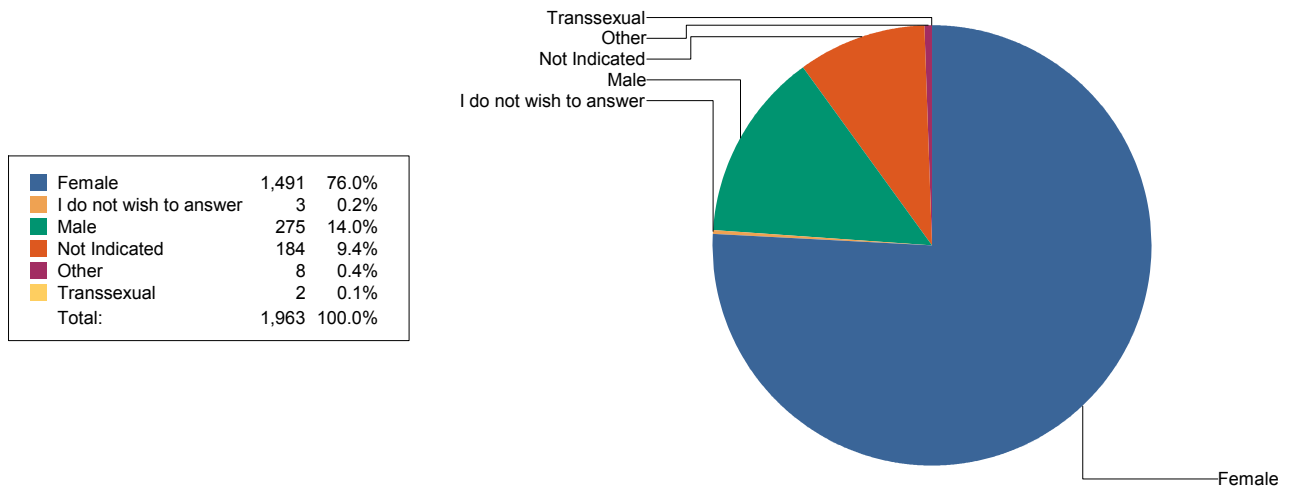
Age of Enrolled Participants



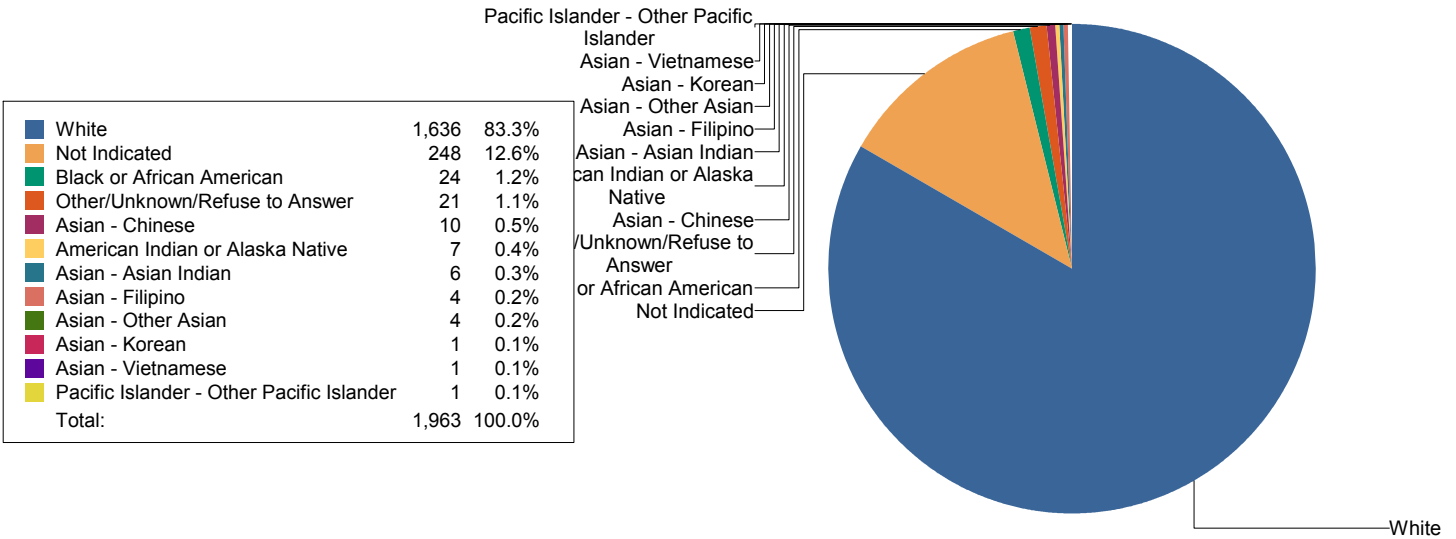
Enrollment Method of Enrolled Participants



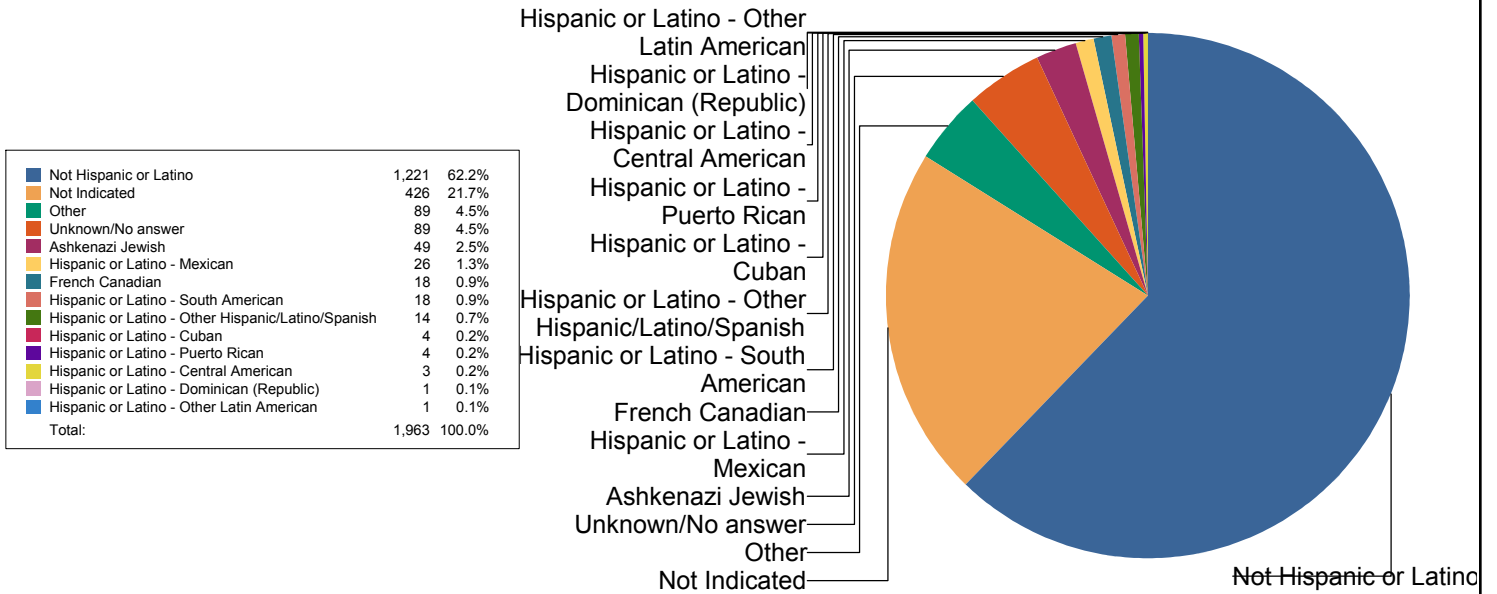
Gender of Enrolled Participants



Race of Enrolled Participant



Ethnicity of Enrolled Participants

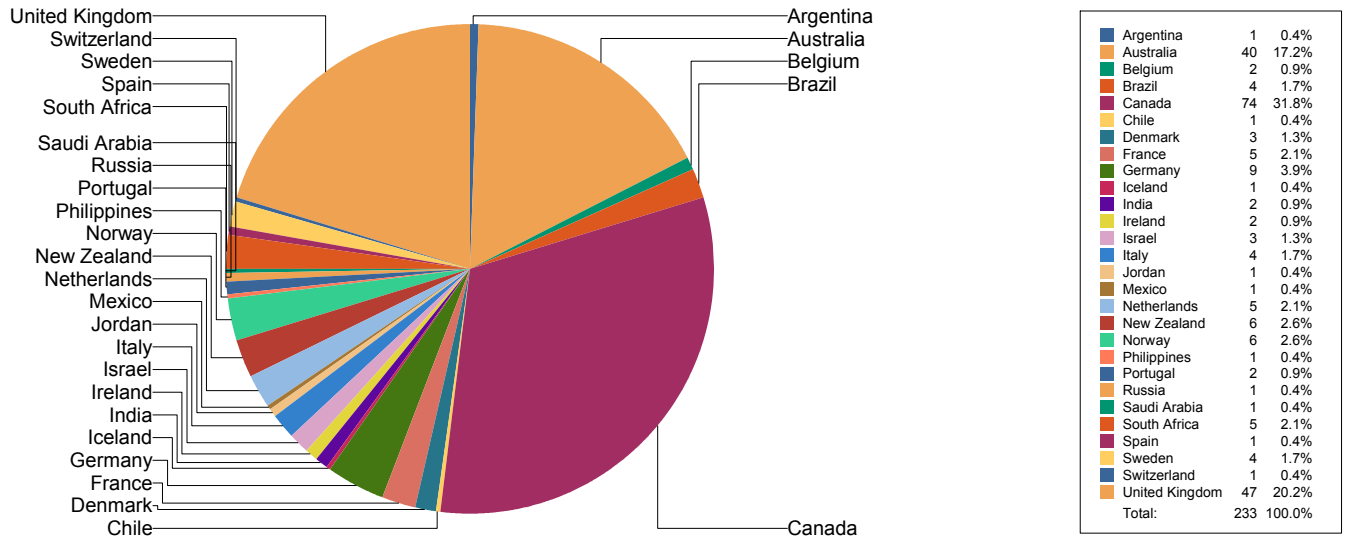


State of Enrolled Participants

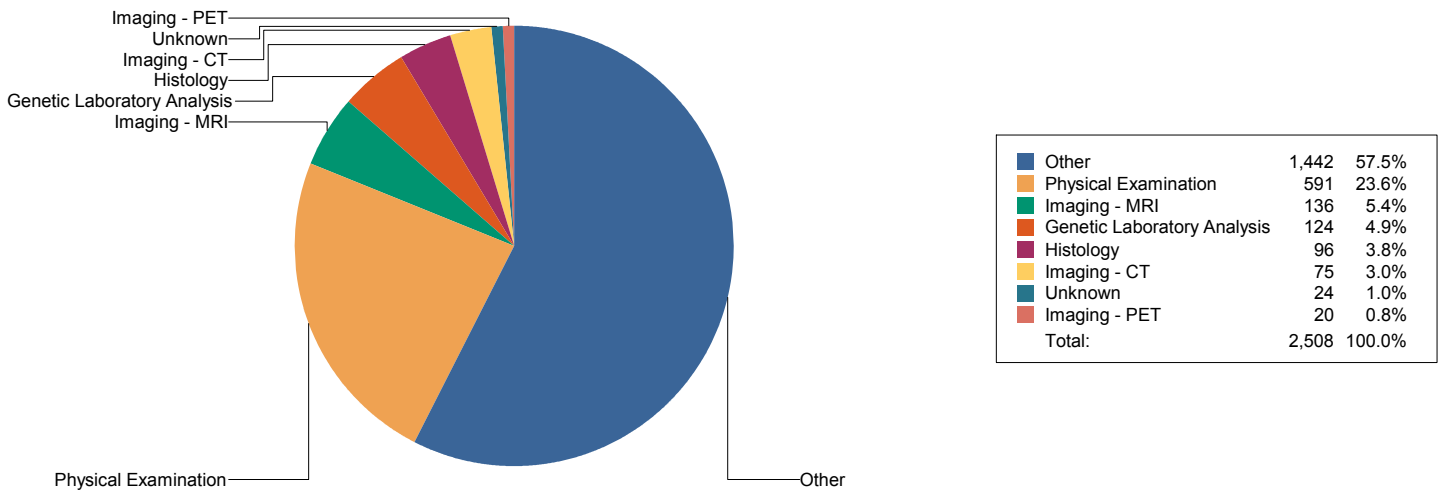
State	Count	Percent
Alabama (AL)	50	2.55
Alaska (AK)	8	0.41
Arizona (AZ)	33	1.68
Arkansas (AR)	7	0.36
California (CA)	97	4.94
Colorado (CO)	44	2.24
Connecticut (CT)	14	0.71
Delaware (DE)	11	0.56
District of Columbia (DC)	8	0.41
Florida (FL)	61	3.11
Georgia (GA)	109	5.55
Hawaii (HI)	2	0.10
Idaho (ID)	7	0.36
Illinois (IL)	70	3.57
Indiana (IN)	42	2.14
Iowa (IA)	33	1.68
Kansas (KS)	24	1.22
Kentucky (KY)	17	0.87
Louisiana (LA)	12	0.61
Maine (ME)	7	0.36
Maryland (MD)	39	1.99
Massachusetts (MA)	38	1.94
Michigan (MI)	56	2.85
Minnesota (MN)	60	3.06
Mississippi (MS)	6	0.31
Missouri (MO)	45	2.29
Montana (MT)	6	0.31
Nebraska (NE)	11	0.56
Nevada (NV)	9	0.46
New Hampshire (NH)	12	0.61
New Jersey (NJ)	28	1.43
New Mexico (NM)	3	0.15
New York (NY)	58	2.95
North Carolina (NC)	54	2.75
North Dakota (ND)	7	0.36
Not In USA (NoUSA)	234	11.92
Ohio (OH)	70	3.57
Oklahoma (OK)	16	0.82
Oregon (OR)	29	1.48
Pennsylvania (PA)	85	4.33
Rhode Island (RI)	7	0.36
South Carolina (SC)	35	1.78
South Dakota (SD)	14	0.71
Tennessee (TN)	43	2.19

Texas (TX)	89	4.53
Utah (UT)	15	0.76
Virginia (VA)	90	4.58
Washington (WA)	70	3.57
West virginia (WV)	12	0.61
Wisconsin (WI)	60	3.06
Wyoming (WY)	6	0.31
Total:	1,963	100%

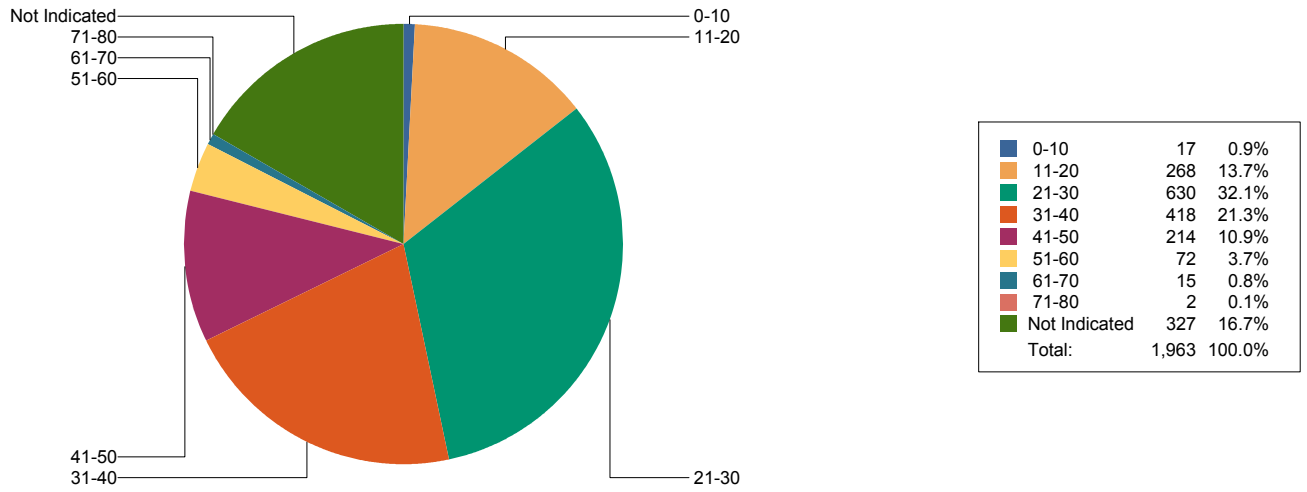
Country of Enrolled Participants (Excluding United States of America=1,730)



Diagnosis Determination of Enrolled Participants (Participants have the option to select multiple diagnosis determination methods.)



Diagnosis Age of Enrolled Participants



Referral Source

- World Orphan Drug Congress
- Wiedemann-Steiner Syndrome Foundation
- USD Center for Disabilities
- University of South Dakota (USD) Sanford School of Medicine
- The Ehlers-Danlos National Foundation (EDNF)
- Stickler Involved People (Stickler Syndrome)
- South Dakota Parent Connection
- Simons Variation In Individuals (VIP) Connect
- Share and Care Network
- Sanford Children's
- National Ataxia Foundation
- LMSarcoma Direct Research Foundation
- Klippel-Feil Syndrome Alliance
- EDSers United Foundation
- CRMO Foundation
- Ben's Friends
- Soft Bones, Inc.
- ResearchMatch
- Klippel-Feil Syndrome Freedom
- Hyperacusis Research Limited, Inc
- 22q Central
- 1p36 Deletion Support and Awareness (1p36 Deletion)
- Global Genes | RARE Project
- Klein-Levin Syndrome Foundation
- Sanford
- 11q Research and Resource Group (11q Syndrome)
- Support Group
- Coordination of Rare Disease at Sanford (CoRDS)
- National Institute of Health (NIH)
- PWN4PWN
- 4p-Support Group
- ClinicalTrials.Gov
- Self-referral (Internet Search / Social Media)
- Other
- Hypersomnia Foundation, Inc.

