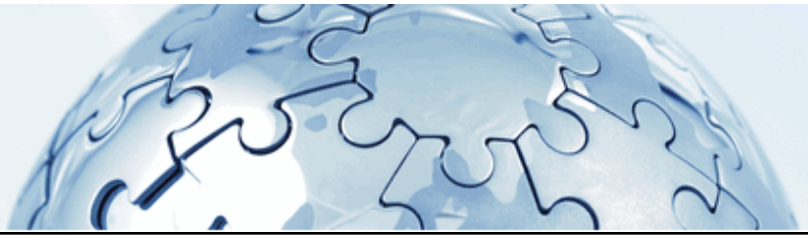


# CoRDS Registry

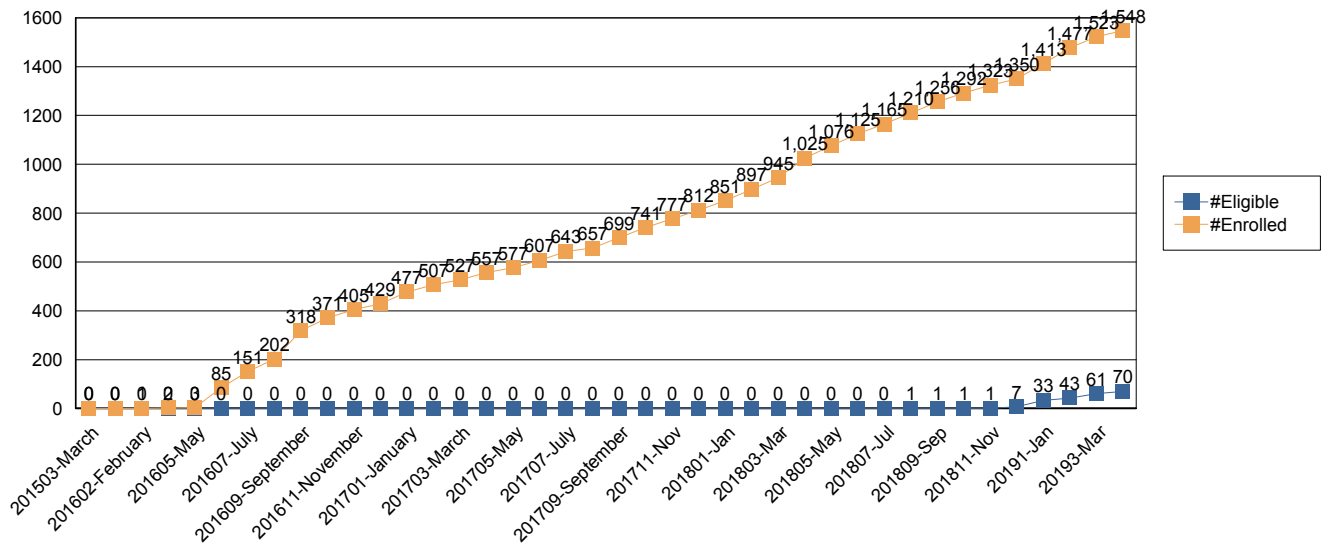
Coordination of Rare Diseases  
at Sanford



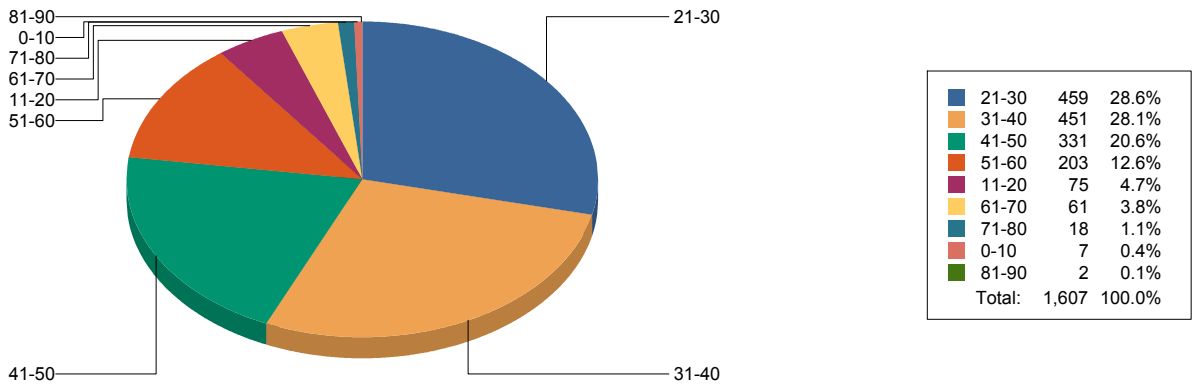
## Participant Information

Number of participants currently Eligible:	70
Number of participants currently Enrolled:	1,607
<b>Total Number of Hypersomnia Participants</b>	<b>1,677</b>

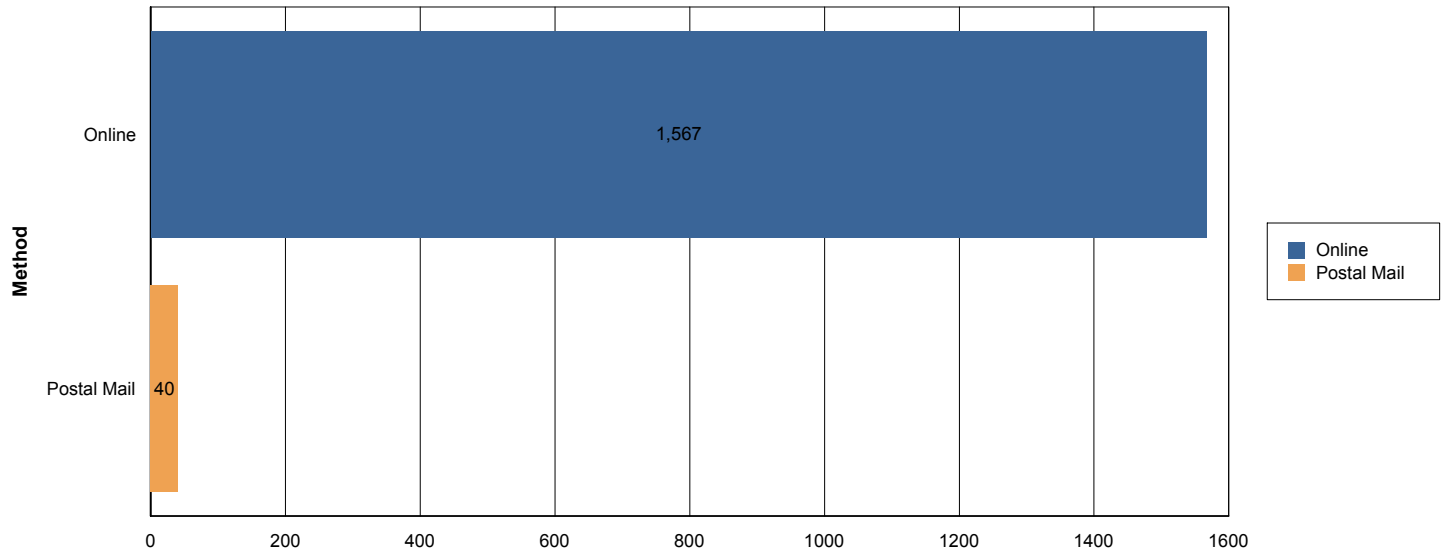
## Enrolled and Eligible Participants by Month



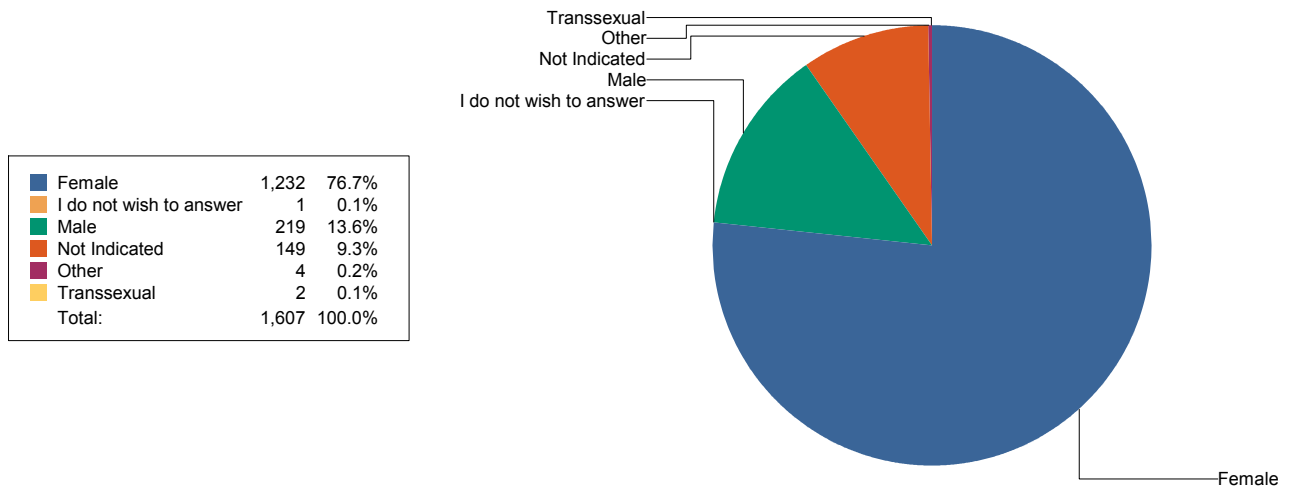
## Age of Enrolled Participants



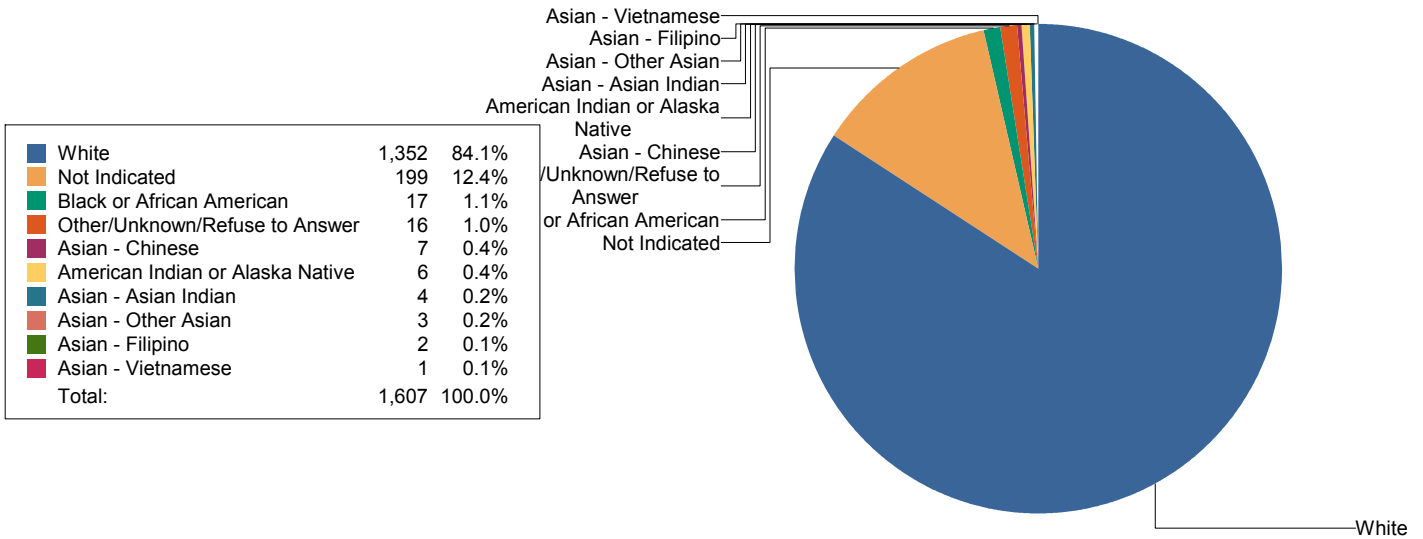
## Enrollment Method of Enrolled Participants



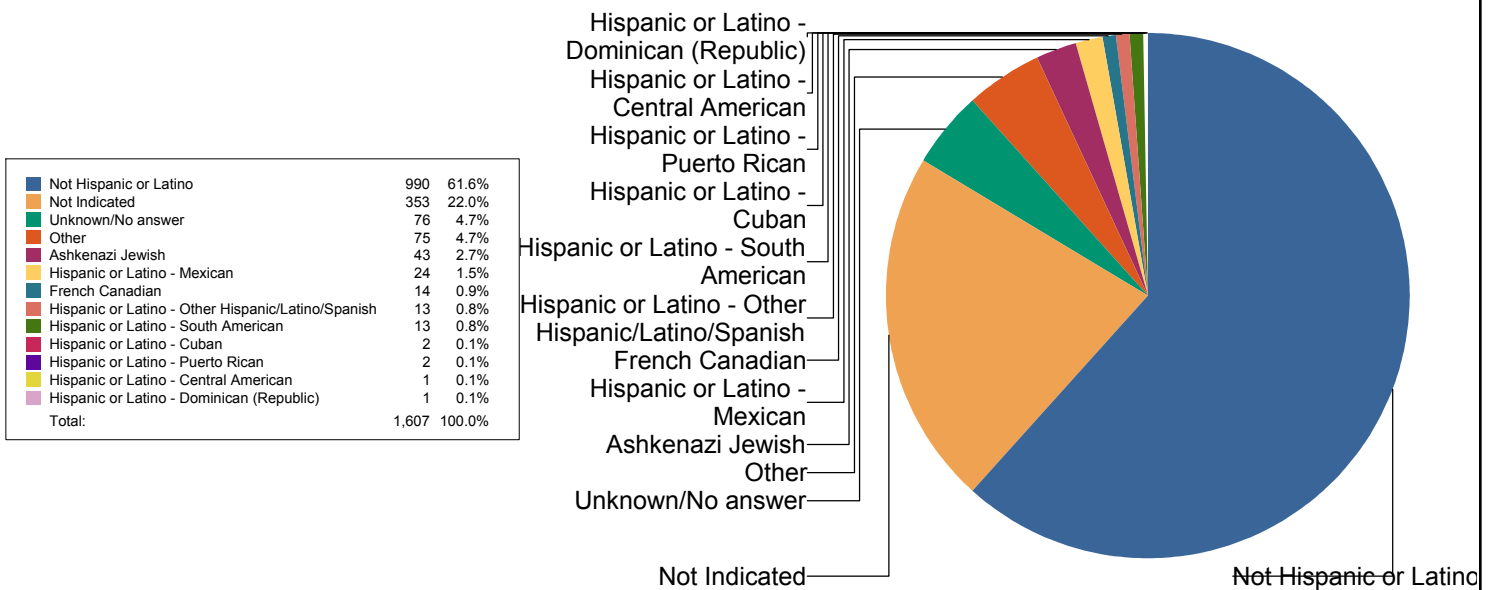
## Gender of Enrolled Participants



## Race of Enrolled Participant



## Ethnicity of Enrolled Participants

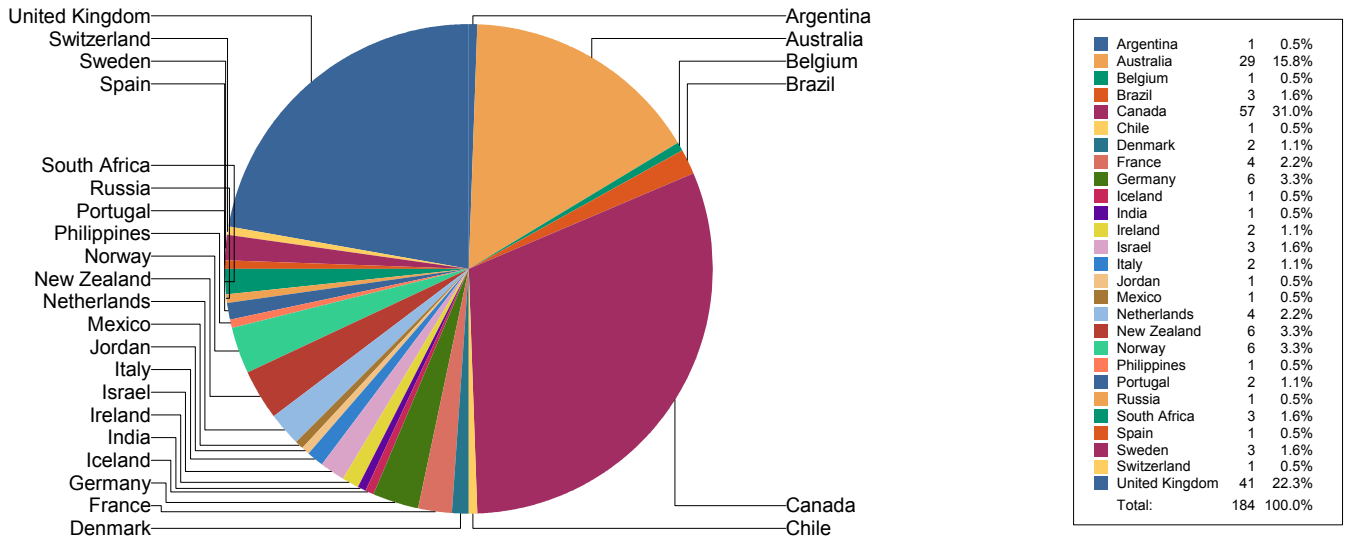


## State of Enrolled Participants

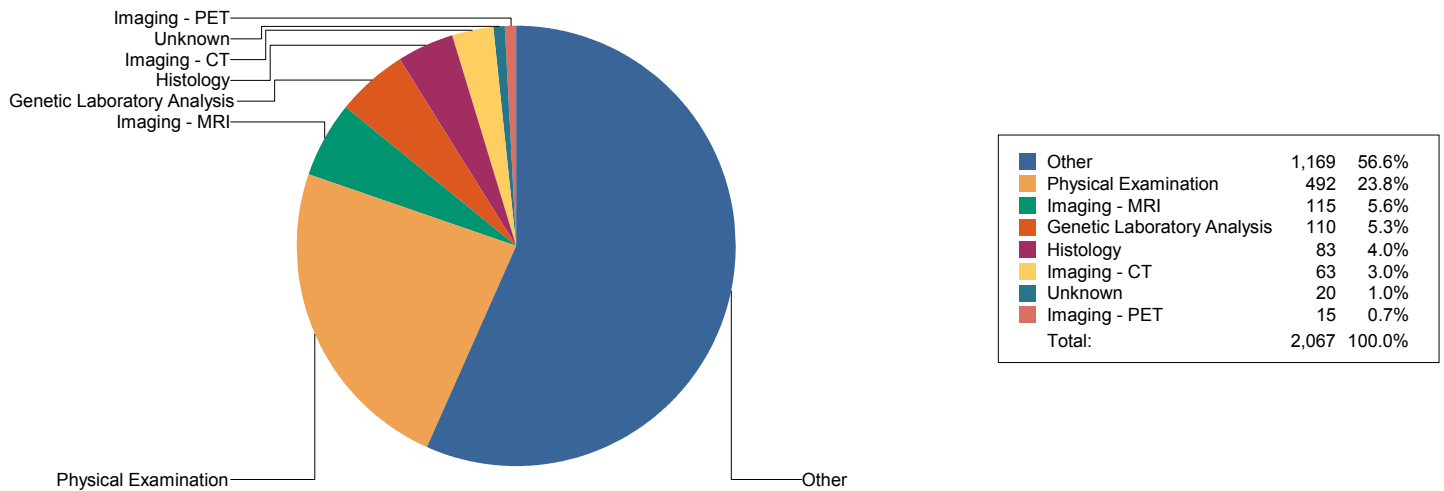
<b>State</b>	<b>Count</b>	<b>Percent</b>
Alabama (AL)	41	2.55
Alaska (AK)	8	0.50
Arizona (AZ)	27	1.68
Arkansas (AR)	4	0.25
California (CA)	73	4.54
Colorado (CO)	39	2.43
Connecticut (CT)	10	0.62
Delaware (DE)	11	0.68
District of Columbia (DC)	4	0.25
Florida (FL)	56	3.48
Georgia (GA)	98	6.10
Hawaii (HI)	2	0.12
Idaho (ID)	8	0.50
Illinois (IL)	48	2.99
Indiana (IN)	35	2.18
Iowa (IA)	27	1.68
Kansas (KS)	15	0.93
Kentucky (KY)	14	0.87
Louisiana (LA)	10	0.62
Maine (ME)	6	0.37
Maryland (MD)	32	1.99
Massachusetts (MA)	33	2.05
Michigan (MI)	50	3.11
Minnesota (MN)	52	3.24
Mississippi (MS)	6	0.37
Missouri (MO)	32	1.99
Montana (MT)	5	0.31
Nebraska (NE)	10	0.62
Nevada (NV)	9	0.56
New Hampshire (NH)	9	0.56
New Jersey (NJ)	22	1.37
New Mexico (NM)	2	0.12
New York (NY)	48	2.99
North Carolina (NC)	46	2.86
North Dakota (ND)	4	0.25
Not In USA (NoUSA)	185	11.51
Ohio (OH)	58	3.61
Oklahoma (OK)	11	0.68
Oregon (OR)	25	1.56
Pennsylvania (PA)	70	4.36
Rhode Island (RI)	5	0.31
South Carolina (SC)	29	1.80
South Dakota (SD)	13	0.81
Tennessee (TN)	36	2.24

Texas (TX)	69	4.29
Utah (UT)	14	0.87
Virginia (VA)	78	4.85
Washington (WA)	55	3.42
West virginia (WV)	12	0.75
Wisconsin (WI)	46	2.86
Wyoming (WY)	5	0.31
<b>Total:</b>	<b>1,607</b>	<b>100%</b>

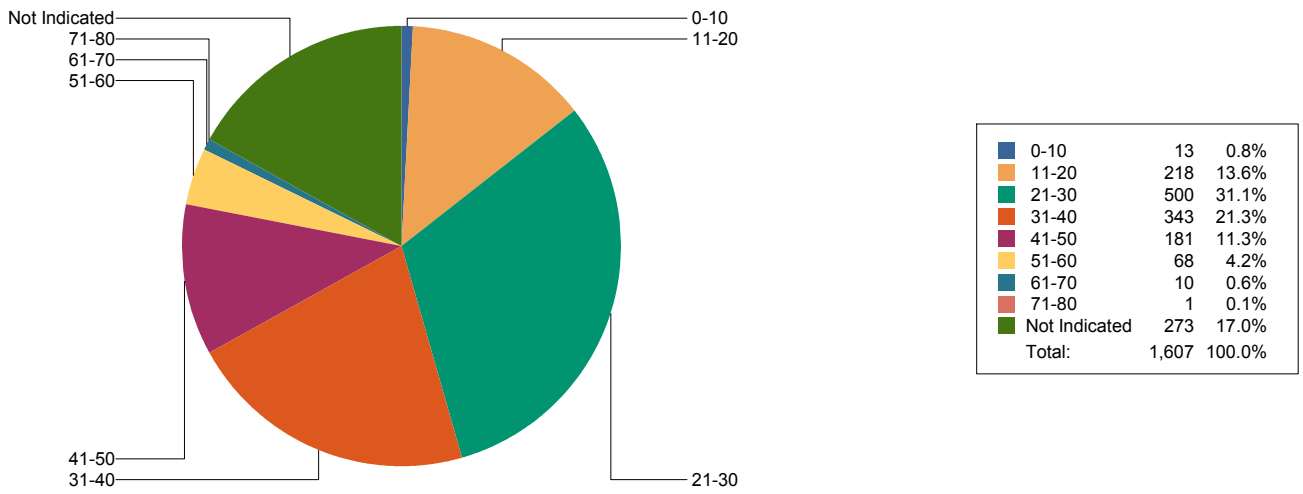
**Country of Enrolled Participants (Excluding United States of America=1,423)**



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



## Diagnosis Age of Enrolled Participants



## Referral Source

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
Soft Bones, Inc.	Simons Variation In Individuals (VIP) Connect	Sanford Children's Connect
National Ataxia Foundation	LMSarcoma Direct Research Foundation	Klippel-Feil Syndrome Freedom
Klippel-Feil Syndrome Alliance	EDSers United Foundation	Ben's Friends
22q Central	ResearchMatch	Hyperacusis Research Limited, Inc
1p36 Deletion Support and Awareness (1p36 Deletion)	Global Genes   RARE Project	Sanford
Klein-Levin Syndrome Foundation	11q Research and Resource Group (11q Syndrome)	National Institute of Health (NIH)
Support Group	Coordination of Rare Disease at Sanford (CoRDS)	PWN4PWN
4p-Support Group	ClinicalTrials.gov	Self-referral (Internet Search / Social Media)
Other	Hypersomnia Foundation, Inc.	

