

CoRDS

Rare Disease Registry



Summary Report as on (16-August-2022 09:55)

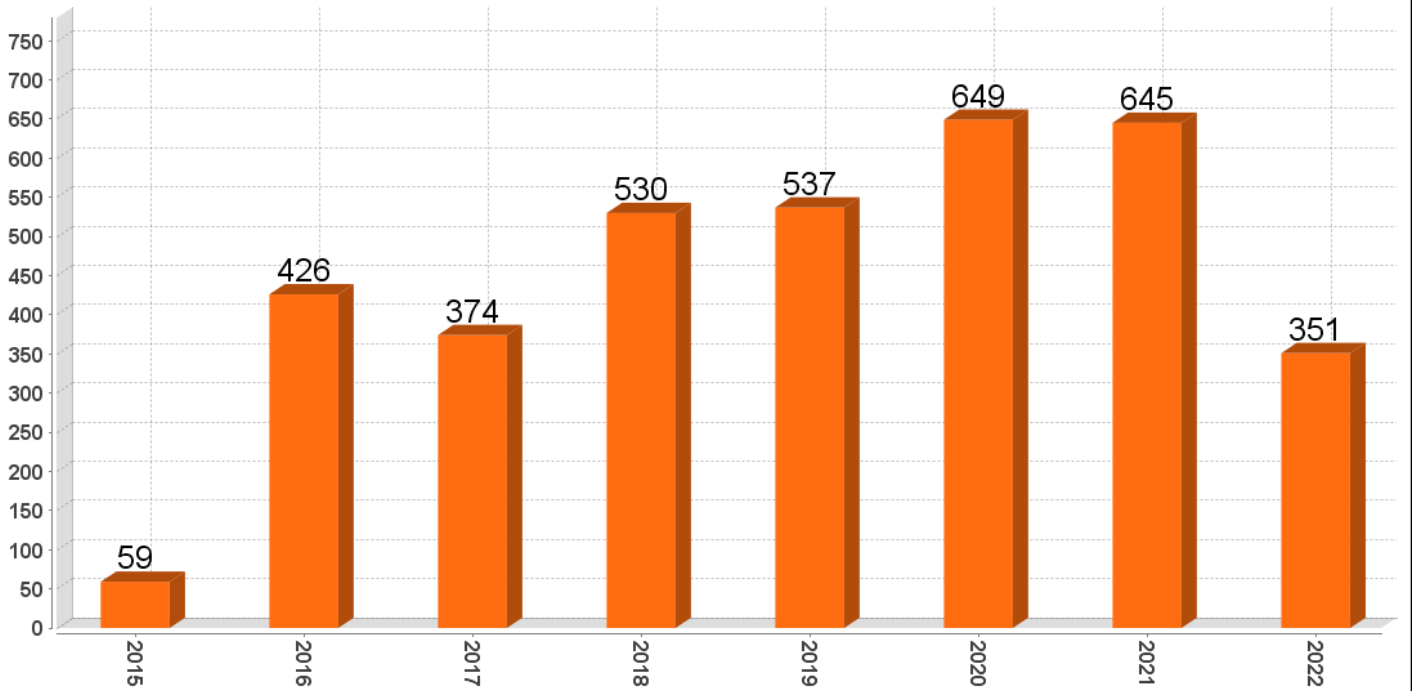
Participant Information

Number Of Participants Currently Enrolled

3571

Enrolled Participants By Year

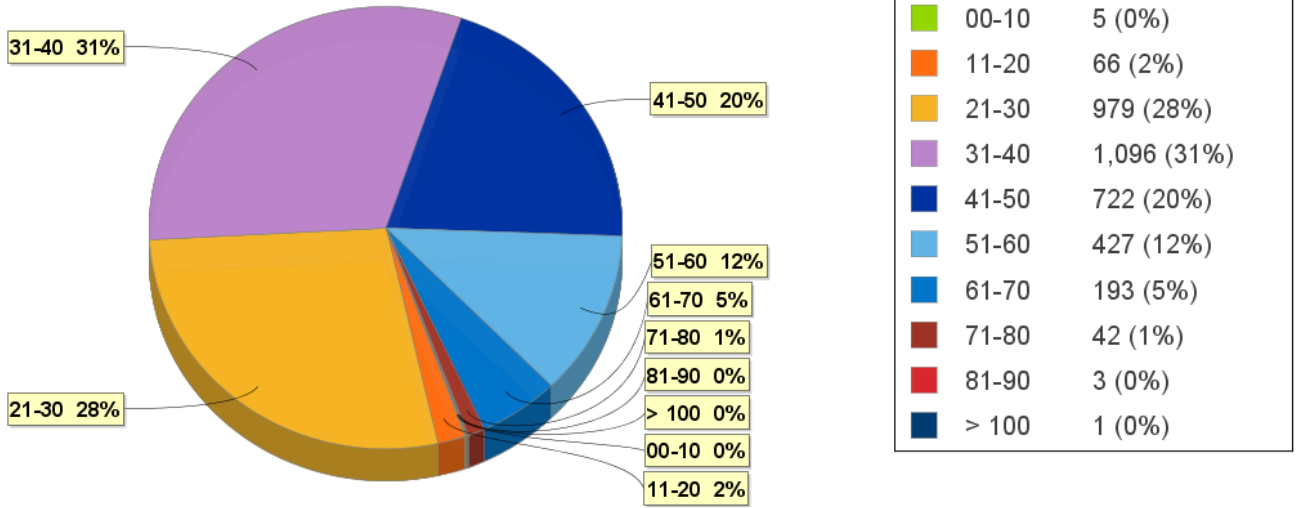
Enrolled Participants
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Age of Enrolled Participants

Age of Enrolled Participants

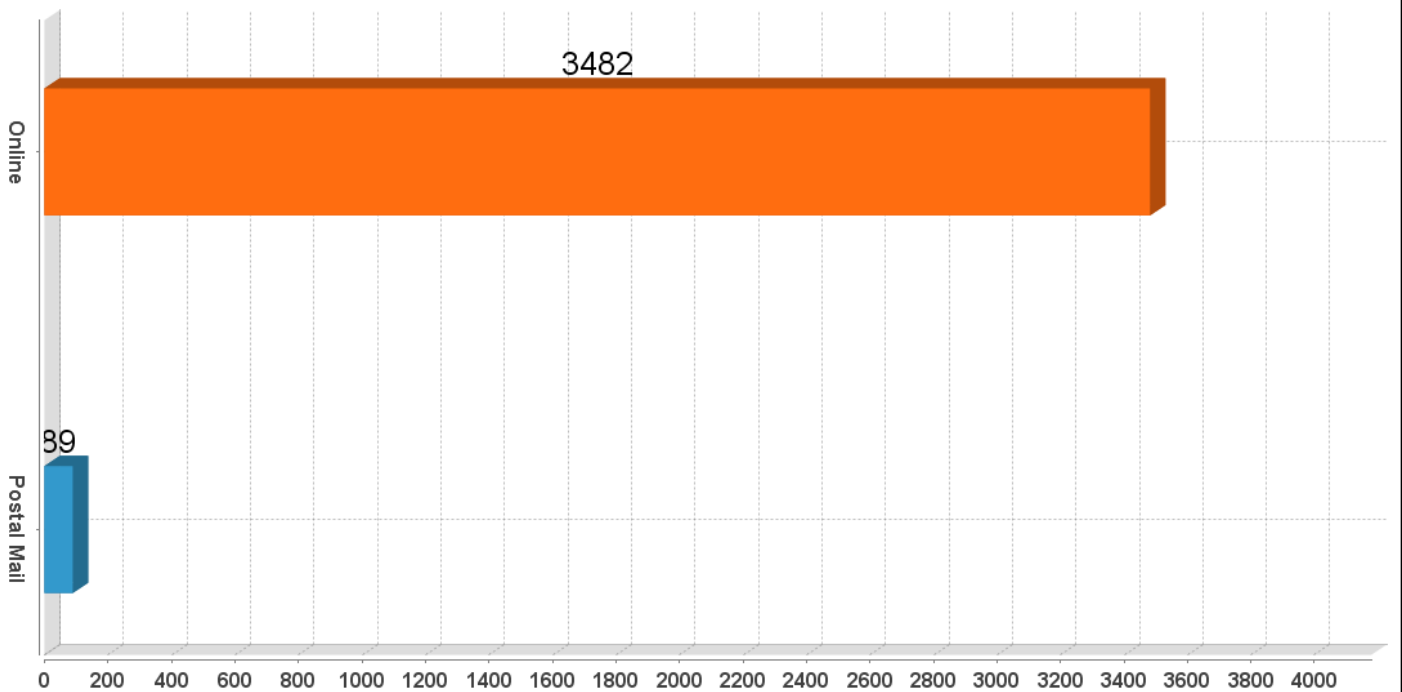
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Enrolled Method Of Enrolled Participants

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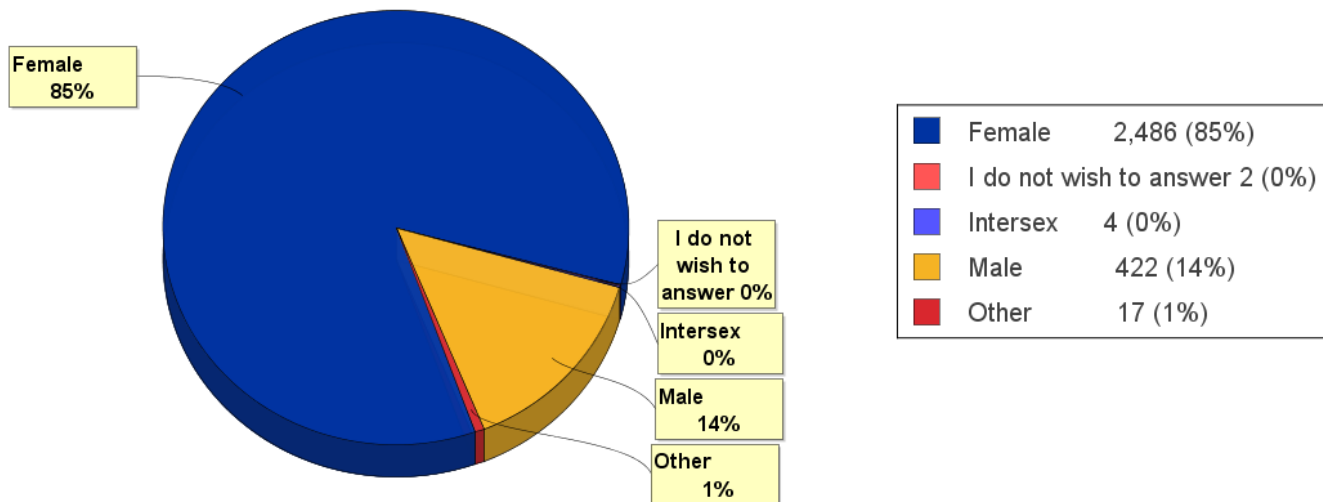
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Enrolled Gender Of Participants

Sex

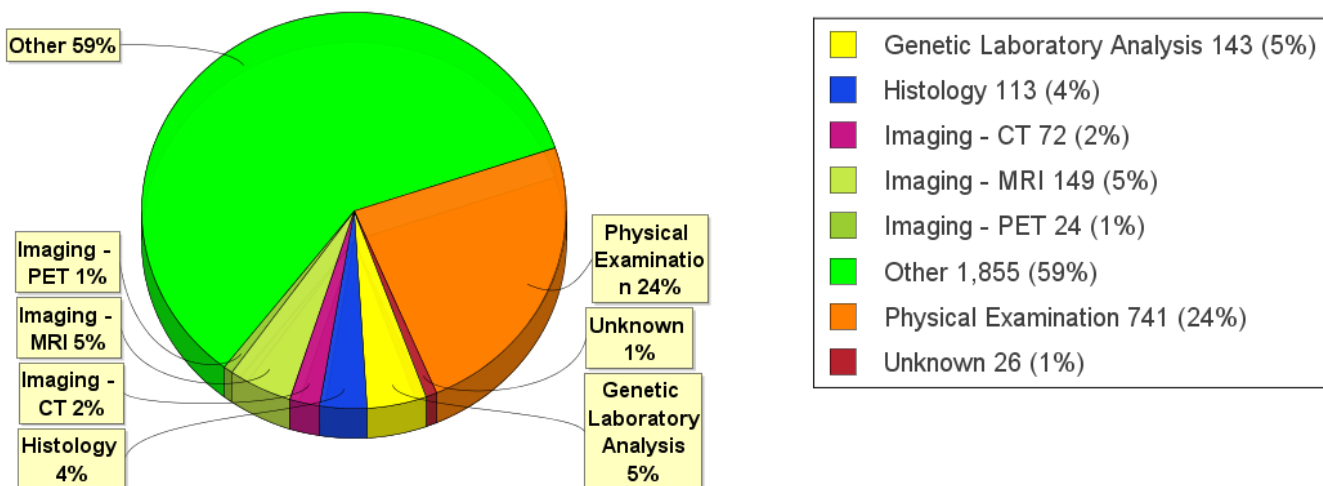
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Diagnosis Determination Of Enrolled Participants

How was the diagnosis determined?

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State Of Enrolled Participants

State	Count	Percentage
Alabama (AL)	79	2.29%
Alaska (AK)	11	0.32%
Arizona (AZ)	55	1.59%
Arkansas (AR)	19	0.55%
California (CA)	147	4.26%
Colorado (CO)	66	1.91%
Connecticut (CT)	27	0.78%
Delaware (DE)	13	0.38%
District of Columbia (DC)	11	0.32%
Florida (FL)	99	2.87%
Georgia (GA)	149	4.32%
Hawaii (HI)	5	0.14%
Idaho (ID)	16	0.46%
Illinois (IL)	115	3.33%
Indiana (IN)	68	1.97%
Iowa (IA)	48	1.39%
Kansas (KS)	32	0.93%
Kentucky (KY)	37	1.07%
Louisiana (LA)	16	0.46%
Maine (ME)	13	0.38%
Maryland (MD)	59	1.71%
Massachusetts (MA)	64	1.85%
Michigan (MI)	86	2.49%
Minnesota (MN)	108	3.13%
Mississippi (MS)	14	0.41%
Missouri (MO)	71	2.06%
Montana (MT)	9	0.26%
Nebraska (NE)	20	0.58%
Nevada (NV)	13	0.38%
New Hampshire (NH)	22	0.64%
New Jersey (NJ)	48	1.39%
New Mexico (NM)	5	0.14%
New York (NY)	103	2.98%
North Carolina (NC)	91	2.64%

State	Count	Percentage
North Dakota (ND)	10	0.29%
Not In USA (NoUSA)	430	12.46%
Not Indicated	231	6.69%
Ohio (OH)	122	3.54%
Oklahoma (OK)	22	0.64%
Oregon (OR)	50	1.45%
Pennsylvania (PA)	136	3.94%
Rhode Island (RI)	9	0.26%
South Carolina (SC)	49	1.42%
South Dakota (SD)	23	0.67%
Tennessee (TN)	71	2.06%
Texas (TX)	154	4.46%
Utah (UT)	31	0.90%
Vermont (VT)	5	0.14%
Virginia (VA)	136	3.94%
Washington (WA)	110	3.19%
West virginia (WV)	18	0.52%
Wisconsin (WI)	98	2.84%
Wyoming (WY)	7	0.20%
Total:	3451	100.00%

Country Of Enrolled Participants

Country	Count	Percentage
Antigua and Barbuda	1	0.03%
Argentina	2	0.06%
Australia	86	2.49%
Austria	1	0.03%
Belgium	2	0.06%
Brazil	9	0.26%
Canada	137	3.97%
Chile	1	0.03%
Denmark	5	0.14%
France	8	0.23%
Germany	19	0.55%
Greece	2	0.06%
Iceland	2	0.06%
India	3	0.09%
Iran	1	0.03%
Ireland	3	0.09%
Israel	3	0.09%
Italy	6	0.17%
Japan	2	0.06%
Jordan	1	0.03%
Luxembourg	1	0.03%
Mexico	3	0.09%
Netherlands	10	0.29%
New Zealand	8	0.23%
Norway	11	0.32%
Not Indicated	233	6.75%
Peru	1	0.03%
Philippines	1	0.03%
Portugal	2	0.06%
Puerto Rico	3	0.09%
Russia	2	0.06%
Saudi Arabia	1	0.03%
Singapore	1	0.03%
South Africa	5	0.14%

Country	Count	Percentage
Spain	3	0.09%
Sweden	5	0.14%
Switzerland	5	0.14%
United Kingdom	77	2.23%
United States of America (USA)	2785	80.70%
Total:	3451	100.00%

Race Of Enrolled Participants

Race	Count	Percentage
American Indian or Alaska Native	48	2.24%
Asian - Chinese	22	1.03%
Asian - Filipino	8	0.37%
Asian - Indian	10	0.47%
Asian - Japanese	11	0.51%
Asian - Korean	3	0.14%
Asian - Other	8	0.37%
Asian - Vietnamese	3	0.14%
Black or African American	48	2.24%
Other/Unknown/Refuse to Answer	27	1.26%
Pacific Islander - Other	4	0.19%
White	1954	91.05%
Total:	2146	100.00%

Ethnicity Of Enrolled Participants

Ethnicity	Count	Percentage
Ashkenazi Jewish	80	4.08%
French Canadian	27	1.38%
Hispanic/Latino - Central American	4	0.20%
Hispanic/Latino - Cuban	4	0.20%
Hispanic/Latino - Dominican	2	0.10%
Hispanic/Latino - Mexican	23	1.17%
Hispanic/Latino - Puerto Rican	9	0.46%
Hispanic/Latino - South American	30	1.53%
Not Hispanic or Latino	1549	78.91%
Other	99	5.04%
Other Hispanic/Latino/Spanish	20	1.02%
Other Latin American	4	0.20%
Unknown/No answer	112	5.71%
Total:	1963	100.00%

Age of Diagnosis

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