***Estimated Prevalence and Incidence of Amyotrophic Lateral Sclerosis and SOD1 and C9orf72 Genetic Variants***

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# Supplemental Material

**Supplemental Table 1.** Included incidence studies by region and country

|  |  |  |
| --- | --- | --- |
| **Region/country** | **Author and year** | **Incidence per 100,000** |
| China | Fong 2005 [1] | 0.60 |
| China | Zhou 2018 [2] | 0.77 |
| China | Xu 2020 [3] | 1.65 |
| South Korea | Kim 2018 [4] | 1.68 |
| Taiwan | Tsai 2015 [5] | 0.54 |
| *Regional estimate* |  | *0.93* |
| **Europe** |  |  |
| France | Marin 2014 [6] | 3.24 |
| France | Marin 2009 [7] | 3.09 |
| France | Masseret 2013 [8] | 2.53 |
| France | Preux 2000 [9] | 4.90 |
| Germany | Rosenbohm 2017 [10] | 2.40 |
| Germany | Wolf 2014 [11] | 1.80 |
| Germany | Uenal 2014 [12] | 2.60 |
| Ireland | Otoole 2008 [13] | 1.90 |
| Ireland | Traynor 1999 [14] | 2.10 |
| Italy | Chio 2008 [15] | 2.90 |
| Italy | Chio 2017 [16] | 3.50 |
| Italy | Cima 2009 [17] | 1.54 |
| Italy | Georgoulopoulou 2011 [18] | 2.90 |
| Italy | Mandrioli 2014 [19] | 2.68 |
| Italy | Palese 2019 [20] | 2.81 |
| Italy | Piemonte 2001 [21] | 2.50 |
| Italy | Ragonese 2012 [22] | 1.95 |
| Italy | Scialo 2016 [23] | 3.11 |
| Italy | Nicoletti 2016 [24] | 2.00 |
| Italy | Tesauro 2017 [25] | 4.17 |
| Italy | Bandettini di Poggio 2013 [26] | 3.22 |
| Italy | Pugliatti 2013 [27] | 2.50 |
| Italy | Mandrioli 2003 [28] | 2.16 |
| Italy | Logroscino 2005 [29] | 1.60 |
| Italy | Drigo 2013 [30] | 2.72 |
| Italy | Beghi 2007 [32] | 2.20 |
| Italy | Giagheddu 2013 [33]{Giagheddu, 2013 #515} | 1.45 |
| Netherlands | Huisman 2011 [35] | 2.27 |
| Norway | Benjaminsen 2018 [36] | 2.00 |
| Norway | Gundersen 2011 [37] | 2.13 |
| Russia | Brylev 2020 [38] | 1.25 |
| Spain | Pradas 2013 [39] | 1.40 |
| Spain | Aragones 2016 [40] | 2.74 |
| Sweden | Fang 2009 [41] | 3.73 |
| UK | Abhinav 2007 [42] | 1.06 |
| UK | Johnston 2006 [43] | 1.20 |
| UK | Forbes 2007 [44] | 2.44 |
| UK (Ireland) | Logroscino 2010 [45] | 1.97 |
| UK (England and Scotland) | Logroscino 2010 [45] | 2.13 |
| *Regional estimate* |  | *2.31* |
| **North America** |  |  |
| Canada | Golby 2016 [46] | 3.29 |
| Canada | Lareau-Trudel 2013 [47] | 3.01 |
| Canada | Bonaparte 2007 [48] | 2.24 |
| USA | Harper 2015 [49] | 2.20 |
| USA | Wagner 2016 [50] | 1.52 |
| *Regional estimate* |  | *2.35* |
| **Latin America** |  |  |
| Argentina | Bettini 2013 [51] | 3.17 |
| Brazil | Dietrich-Neto 2000 [52] | 0.40 |
| Uruguay | Vazquez 2008 [53] | 1.42 |
| Colombia | Zapata 2019 [54] | 1.40 |
| *Regional estimate* |  | *1.25* |
| Japan | Doi 2014 [55] | 1.76 |
| *Country estimate* |  | 1.76 |

**Supplemental Table 2.** Included prevalence studies by region and country

|  |  |  |
| --- | --- | --- |
| **Region/country** | **Author and year** | **Prevalence per 100,000** |
| China | Fong 2005 [1] | 3.07 |
| China | Xu 2020 [3] | 2.91 |
| South Korea | Kim 2018 [4] | 6.49 |
| Taiwan | Tsai 2015 [5] | 2.09 |
| Taiwan | Hsu 2018 [58] | 2.04 |
|  |  |  |
| *Regional estimate* |  | *3.01* |
| **Region Europe** |  |  |
| Belgium | Roy 2015 [59] | 3.20 |
| Ireland | Lefter 2017 [60] | 7.20 |
| Ireland | Otoole 2008 [13] | 6.40 |
| Ireland | Traynor 1999 [14] | 4.70 |
| Italy | Chio 2017 [16] | 12.26 |
| Italy | Palese 2019 [20] | 7.97 |
| Italy | Scialo 2016 [23] | 7.85 |
| Italy | Pugliatti 2013 [27] | 10.80 |
| Italy | Mandrioli 2003 [28] | 4.63 |
| Italy | Drigo 2013 [30] | 5.27 |
| Italy | Chio 2009 [31] | 7.89 |
| Netherlands | Huisman 2011 [35] | 8.51 |
| Norway | Benjaminsen 2018 [36] | 3.69 |
| Norway | Gundersen 2011 [37] | 4.05 |
| Norway | Nakken 2018 [61] | 7.63 |
| Spain | Pradas 2013 [39] | 5.40 |
| Spain | Aragones 2016 [40] | 8.38 |
| UK | Abhinav 2007 [42] | 3.99 |
| UK | Johnston 2006 [43] | 4.06 |
|  |  |  |
| *Region estimate* |  | *6.23* |
| **Single study** |  |  |
| USA | Mehta 2018 [62] | 5.20 |
| Canada |
| **Region Latin America** |  |  |
| Argentina | Bettini 2013 [51] | 8.86 |
| Brazil | Dietrich-Neto 2000 [52] | 1.20 |
| Brazil | Linden-Junior 2013 [63] | 5.00 |
| Uruguay | Vazquez 2008 [53] | 2.01 |
| Colombia | Zapata 2019 [54] | 4.90 |
|  |  |  |
| *Region estimate* |  | *3.41* |
| **No region assigned** | |  |
| Japan | Doi 2014 [55] | 7.96 |
|  |  |  |

**Supplemental Table 3.** ALS prevalence and incidence by country

**Argentina**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Category** | **2020** | **2021** | **2022** | **2023** | **2024** |
| Total prevalent cases | 1,542 | 1,556 | 1,569 | 1,583 | 1,596 |
| Total incident cases | 564 | 569 | 574 | 579 | 584 |
| Persons living with fALS | 79 | 79 | 80 | 81 | 81 |
| Persons living with sALS | 1,463 | 1,477 | 1,489 | 1,502 | 1,515 |
| Incident cases fALS | 29 | 29 | 29 | 30 | 30 |
| Incident cases sALS | 535 | 540 | 545 | 549 | 554 |
| ALS cases due to SOD1 |  |  |  |  |  |
| Persons living with SOD1 from fALS | 12 | 12 | 12 | 12 | 12 |
| Persons living with SOD1 from sALS | 18 | 18 | 18 | 18 | 18 |
| Incident cases SOD1 from fALS | 4 | 4 | 4 | 4 | 4 |
| Incident cases SOD1 from sALS | 6 | 6 | 7 | 7 | 7 |
| ALS cases due to C9orf72 |  |  |  |  |  |
| Persons living with C9orf72 from fALS | 27 | 27 | 27 | 27 | 27 |
| Persons living with C9orf72 from sALS | 75 | 75 | 76 | 77 | 77 |
| Incident cases C9orf72 from fALS | 10 | 10 | 10 | 10 | 10 |
| Incident cases C9orf72 from sALS | 27 | 28 | 28 | 28 | 28 |

ALS, amyotrophic lateral sclerosis; fALS, familial amyotrophic lateral sclerosis; sALS, sporadic amyotrophic lateral sclerosis; SOD1, superoxide dismutase 1.

**Belgium**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Category** | **2020** | **2021** | **2022** | **2023** | **2024** |
| Total prevalent cases | 716 | 719 | 721 | 723 | 725 |
| Total incident cases | 265 | 266 | 267 | 268 | 268 |
| Persons living with fALS | 37 | 37 | 37 | 37 | 37 |
| Persons living with sALS | 679 | 682 | 684 | 686 | 688 |
| Incident cases fALS | 14 | 14 | 14 | 14 | 14 |
| Incident cases sALS | 251 | 252 | 253 | 254 | 254 |
| ALS cases due to SOD1 |  |  |  |  |  |
| Persons living with SOD1 from fALS | 5 | 5 | 5 | 5 | 5 |
| Persons living with SOD1 from sALS | 8 | 8 | 8 | 8 | 8 |
| Incident cases SOD1 from fALS | 2 | 2 | 2 | 2 | 2 |
| Incident cases SOD1 from sALS | 3 | 3 | 3 | 3 | 3 |
| ALS cases due to C9orf72 |  |  |  |  |  |
| Persons living with C9orf72 from fALS | 12 | 12 | 12 | 12 | 12 |
| Persons living with C9orf72 from sALS | 35 | 35 | 35 | 35 | 35 |
| Incident cases C9orf72 from fALS | 5 | 5 | 5 | 5 | 5 |
| Incident cases C9orf72 from sALS | 13 | 13 | 13 | 13 | 13 |

ALS, amyotrophic lateral sclerosis; fALS, familial amyotrophic lateral sclerosis; sALS, sporadic amyotrophic lateral sclerosis; SOD1, superoxide dismutase 1.

**Brazil**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Category** | **2020** | **2021** | **2022** | **2023** | **2024** |
| Total prevalent cases | 6,589 | 6,634 | 6,676 | 6,716 | 6,754 |
| Total incident cases | 2,653 | 2,671 | 2,688 | 2,704 | 2,719 |
| Persons living with fALS | 336 | 338 | 340 | 343 | 344 |
| Persons living with sALS | 6,253 | 6,296 | 6,336 | 6,373 | 6,410 |
| Incident cases fALS | 135 | 136 | 137 | 138 | 139 |
| Incident cases sALS | 2,518 | 2,535 | 2,551 | 2,566 | 2,580 |
| ALS cases due to SOD1 |  |  |  |  |  |
| Persons living with SOD1 from fALS | 50 | 50 | 50 | 51 | 51 |
| Persons living with SOD1 from sALS | 75 | 76 | 76 | 76 | 77 |
| Incident cases SOD1 from fALS | 20 | 20 | 20 | 20 | 21 |
| Incident cases SOD1 from sALS | 30 | 30 | 31 | 31 | 31 |
| ALS cases due to C9orf72 |  |  |  |  |  |
| Persons living with C9orf72 from fALS | 113 | 114 | 115 | 116 | 116 |
| Persons living with C9orf72 from sALS | 319 | 321 | 323 | 325 | 327 |
| Incident cases C9orf72 from fALS | 45 | 46 | 46 | 47 | 47 |
| Incident cases C9orf72 from sALS | 128 | 129 | 130 | 131 | 132 |

ALS, amyotrophic lateral sclerosis; fALS, familial amyotrophic lateral sclerosis; sALS, sporadic amyotrophic lateral sclerosis; SOD1, superoxide dismutase 1.**Canada**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Category** | **2020** | **2021** | **2022** | **2023** | **2024** |
| Total prevalent cases | 1,969 | 1,991 | 2,012 | 2,033 | 2,054 |
| Total incident cases | 1,165 | 1,178 | 1,191 | 1,203 | 1,216 |
| Persons living with fALS | 100 | 102 | 103 | 104 | 105 |
| Persons living with sALS | 1,869 | 1,889 | 1,909 | 1,929 | 1,949 |
| Incident cases fALS | 59 | 60 | 61 | 61 | 62 |
| Incident cases sALS | 1,106 | 1,118 | 1,130 | 1,142 | 1,154 |
| ALS cases due to SOD1 |  |  |  |  |  |
| Persons living with SOD1 from fALS | 15 | 15 | 15 | 15 | 16 |
| Persons living with SOD1 from sALS | 22 | 23 | 23 | 23 | 23 |
| Incident cases SOD1 from fALS | 9 | 9 | 9 | 9 | 9 |
| Incident cases SOD1 from sALS | 13 | 13 | 14 | 14 | 14 |
| ALS cases due to C9orf72 |  |  |  |  |  |
| Persons living with C9orf72 from fALS | 34 | 34 | 35 | 35 | 35 |
| Persons living with C9orf72 from sALS | 95 | 96 | 97 | 98 | 99 |
| Incident cases C9orf72 from fALS | 20 | 20 | 21 | 21 | 21 |
| Incident cases C9orf72 from sALS | 56 | 57 | 58 | 58 | 59 |

ALS, amyotrophic lateral sclerosis; fALS, familial amyotrophic lateral sclerosis; sALS, sporadic amyotrophic lateral sclerosis; SOD1, superoxide dismutase 1.

**China**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Category** | **2020** | **2021** | **2022** | **2023** | **2024** |
| Total prevalent cases | 43,036 | 43,182 | 43,309 | 43,419 | 43,512 |
| Total incident cases | 13,184 | 13,229 | 13,268 | 13,301 | 13,330 |
| Persons living with fALS | 2,195 | 2,202 | 2,209 | 2,214 | 2,219 |
| Persons living with sALS | 40,841 | 40,980 | 41,100 | 41,205 | 41,293 |
| Incident cases fALS | 672 | 675 | 677 | 678 | 680 |
| Incident cases sALS | 12,512 | 12,554 | 12,591 | 12,623 | 12,650 |
| ALS cases due to SOD1 |  |  |  |  |  |
| Persons living with SOD1 from fALS | 659 | 661 | 663 | 664 | 666 |
| Persons living with SOD1 from sALS | 613 | 615 | 617 | 618 | 619 |
| Incident cases SOD1 from fALS | 202 | 203 | 203 | 203 | 204 |
| Incident cases SOD1 from sALS | 188 | 188 | 189 | 189 | 190 |
| ALS cases due to C9orf72 |  |  |  |  |  |
| Persons living with C9orf72 from fALS | 50 | 51 | 51 | 51 | 51 |
| Persons living with C9orf72 from sALS | 123 | 123 | 123 | 124 | 124 |
| Incident cases C9orf72 from fALS | 15 | 16 | 16 | 16 | 16 |
| Incident cases C9orf72 from sALS | 38 | 38 | 38 | 38 | 38 |

ALS, amyotrophic lateral sclerosis; fALS, familial amyotrophic lateral sclerosis; sALS, sporadic amyotrophic lateral sclerosis; SOD1, superoxide dismutase 1.

**Colombia**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Category** | **2020** | **2021** | **2022** | **2023** | **2024** |
| Total prevalent cases | 1,736 | 1,749 | 1,757 | 1,763 | 1,768 |
| Total incident cases | 635 | 640 | 643 | 645 | 647 |
| Persons living with fALS | 89 | 89 | 90 | 90 | 90 |
| Persons living with sALS | 1,647 | 1,660 | 1,667 | 1,673 | 1,678 |
| Incident cases fALS | 32 | 33 | 33 | 33 | 33 |
| Incident cases sALS | 603 | 607 | 610 | 612 | 614 |
| ALS cases due to SOD1 |  |  |  |  |  |
| Persons living with SOD1 from fALS | 13 | 13 | 13 | 13 | 13 |
| Persons living with SOD1 from sALS | 20 | 20 | 20 | 20 | 20 |
| Incident cases SOD1 from fALS | 5 | 5 | 5 | 5 | 5 |
| Incident cases SOD1 from sALS | 7 | 7 | 7 | 7 | 7 |
| ALS cases due to C9orf72 |  |  |  |  |  |
| Persons living with C9orf72 from fALS | 30 | 30 | 30 | 30 | 30 |
| Persons living with C9orf72 from sALS | 84 | 85 | 85 | 85 | 86 |
| Incident cases C9orf72 from fALS | 11 | 11 | 11 | 11 | 11 |
| Incident cases C9orf72 from sALS | 31 | 31 | 31 | 31 | 31 |

ALS, amyotrophic lateral sclerosis; fALS, familial amyotrophic lateral sclerosis; sALS, sporadic amyotrophic lateral sclerosis; SOD1, superoxide dismutase 1.

**France**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Category** | **2020** | **2021** | **2022** | **2023** | **2024** |
| Total prevalent cases | 4,183 | 4,195 | 4,207 | 4,218 | 4,230 |
| Total incident cases | 2,229 | 2,235 | 2,241 | 2,247 | 2,253 |
| Persons living with fALS | 213 | 214 | 215 | 215 | 216 |
| Persons living with sALS | 3,970 | 3,981 | 3,992 | 4,003 | 4,014 |
| Incident cases fALS | 114 | 114 | 114 | 115 | 115 |
| Incident cases sALS | 2,115 | 2,121 | 2,127 | 2,132 | 2,138 |
| ALS cases due to SOD1 |  |  |  |  |  |
| Persons living with SOD1 from fALS | 32 | 32 | 32 | 32 | 32 |
| Persons living with SOD1 from sALS | 48 | 48 | 48 | 48 | 48 |
| Incident cases SOD1 from fALS | 17 | 17 | 17 | 17 | 17 |
| Incident cases SOD1 from sALS | 25 | 25 | 26 | 26 | 26 |
| ALS cases due to C9orf72 |  |  |  |  |  |
| Persons living with C9orf72 from fALS | 72 | 72 | 72 | 72 | 73 |
| Persons living with C9orf72 from sALS | 202 | 203 | 204 | 204 | 205 |
| Incident cases C9orf72 from fALS | 38 | 38 | 38 | 39 | 39 |
| Incident cases C9orf72 from sALS | 108 | 108 | 108 | 109 | 109 |

ALS, amyotrophic lateral sclerosis; fALS, familial amyotrophic lateral sclerosis; sALS, sporadic amyotrophic lateral sclerosis; SOD1, superoxide dismutase 1.

**Germany**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Category** | **2020** | **2021** | **2022** | **2023** | **2024** |
| Total prevalent cases | 5,177 | 5,185 | 5,192 | 5,197 | 5,202 |
| Total incident cases | 1,881 | 1,884 | 1,887 | 1,889 | 1,890 |
| Persons living with fALS | 264 | 264 | 265 | 265 | 265 |
| Persons living with sALS | 4,913 | 4,921 | 4,927 | 4,932 | 4,937 |
| Incident cases fALS | 96 | 96 | 96 | 96 | 96 |
| Incident cases sALS | 1,785 | 1,788 | 1,791 | 1,793 | 1,794 |
| ALS cases due to SOD1 |  |  |  |  |  |
| Persons living with SOD1 from fALS | 39 | 39 | 39 | 39 | 39 |
| Persons living with SOD1 from sALS | 59 | 59 | 59 | 59 | 59 |
| Incident cases SOD1 from fALS | 14 | 14 | 14 | 14 | 14 |
| Incident cases SOD1 from sALS | 21 | 21 | 21 | 22 | 22 |
| ALS cases due to C9orf72 |  |  |  |  |  |
| Persons living with C9orf72 from fALS | 89 | 89 | 89 | 89 | 89 |
| Persons living with C9orf72 from sALS | 251 | 251 | 251 | 252 | 252 |
| Incident cases C9orf72 from fALS | 32 | 32 | 32 | 32 | 32 |
| Incident cases C9orf72 from sALS | 91 | 91 | 91 | 91 | 91 |

ALS, amyotrophic lateral sclerosis; fALS, familial amyotrophic lateral sclerosis; sALS, sporadic amyotrophic lateral sclerosis; SOD1, superoxide dismutase 1.

**Ireland**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Category** | **2020** | **2021** | **2022** | **2023** | **2024** |
| Total prevalent cases | 299 | 304 | 308 | 311 | 315 |
| Total incident cases | 99 | 100 | 102 | 103 | 104 |
| Persons living with fALS | 15 | 16 | 16 | 16 | 16 |
| Persons living with sALS | 284 | 288 | 292 | 295 | 299 |
| Incident cases fALS | 5 | 5 | 5 | 5 | 5 |
| Incident cases sALS | 94 | 95 | 97 | 98 | 99 |
| ALS cases due to SOD1 |  |  |  |  |  |
| Persons living with SOD1 from fALS | 2 | 2 | 2 | 2 | 2 |
| Persons living with SOD1 from sALS | 3 | 3 | 4 | 4 | 4 |
| Incident cases SOD1 from fALS | 1 | 1 | 1 | 1 | 1 |
| Incident cases SOD1 from sALS | 1 | 1 | 1 | 1 | 1 |
| ALS cases due to C9orf72 |  |  |  |  |  |
| Persons living with C9orf72 from fALS | 5 | 5 | 5 | 5 | 5 |
| Persons living with C9orf72 from sALS | 14 | 15 | 15 | 15 | 15 |
| Incident cases C9orf72 from fALS | 2 | 2 | 2 | 2 | 2 |
| Incident cases C9orf72 from sALS | 5 | 5 | 5 | 5 | 5 |

ALS, amyotrophic lateral sclerosis; fALS, familial amyotrophic lateral sclerosis; sALS, sporadic amyotrophic lateral sclerosis; SOD1, superoxide dismutase 1.

**Italy**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Category** | **2020** | **2021** | **2022** | **2023** | **2024** |
| Total prevalent cases | 4,729 | 4,719 | 4,709 | 4,699 | 4,688 |
| Total incident cases | 1,476 | 1,473 | 1,470 | 1,467 | 1,464 |
| Persons living with fALS | 241 | 241 | 240 | 240 | 239 |
| Persons living with sALS | 4,488 | 4,478 | 4,469 | 4,459 | 4,449 |
| Incident cases fALS | 75 | 75 | 75 | 75 | 75 |
| Incident cases sALS | 1,401 | 1,398 | 1,395 | 1,392 | 1,389 |
| ALS cases due to SOD1 |  |  |  |  |  |
| Persons living with SOD1 from fALS | 36 | 36 | 36 | 36 | 35 |
| Persons living with SOD1 from sALS | 54 | 54 | 54 | 54 | 53 |
| Incident cases SOD1 from fALS | 11 | 11 | 11 | 11 | 11 |
| Incident cases SOD1 from sALS | 17 | 17 | 17 | 17 | 17 |
| ALS cases due to C9orf72 |  |  |  |  |  |
| Persons living with C9orf72 from fALS | 81 | 81 | 81 | 81 | 81 |
| Persons living with C9orf72 from sALS | 229 | 228 | 228 | 227 | 227 |
| Incident cases C9orf72 from fALS | 25 | 25 | 25 | 25 | 25 |
| Incident cases C9orf72 from sALS | 71 | 71 | 71 | 71 | 71 |

ALS, amyotrophic lateral sclerosis; fALS, familial amyotrophic lateral sclerosis; sALS, sporadic amyotrophic lateral sclerosis; SOD1, superoxide dismutase 1.

**Japan**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Category** | **2020** | **2021** | **2022** | **2023** | **2024** |
| Total prevalent cases | 10,071 | 10,037 | 10,000 | 9,960 | 9,917 |
| Total incident cases | 2,227 | 2,220 | 2,212 | 2,203 | 2,193 |
| Persons living with fALS | 514 | 512 | 510 | 508 | 506 |
| Persons living with sALS | 9,557 | 9,525 | 9,490 | 9,452 | 9,411 |
| Incident cases fALS | 114 | 113 | 113 | 112 | 112 |
| Incident cases sALS | 2,113 | 2,107 | 2,099 | 2,091 | 2,081 |
| ALS cases due to SOD1 |  |  |  |  |  |
| Persons living with SOD1 from fALS | 154 | 154 | 153 | 152 | 152 |
| Persons living with SOD1 from sALS | 143 | 143 | 142 | 142 | 141 |
| Incident cases SOD1 from fALS | 34 | 34 | 34 | 34 | 34 |
| Incident cases SOD1 from sALS | 32 | 32 | 31 | 31 | 31 |
| ALS cases due to C9orf72 |  |  |  |  |  |
| Persons living with C9orf72 from fALS | 12 | 12 | 12 | 12 | 12 |
| Persons living with C9orf72 from sALS | 29 | 29 | 28 | 28 | 28 |
| Incident cases C9orf72 from fALS | 3 | 3 | 3 | 3 | 3 |
| Incident cases C9orf72 from sALS | 6 | 6 | 6 | 6 | 6 |

ALS, amyotrophic lateral sclerosis; fALS, familial amyotrophic lateral sclerosis; sALS, sporadic amyotrophic lateral sclerosis; SOD1, superoxide dismutase 1.

**Mexico**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Category** | **2020** | **2021** | **2022** | **2023** | **2024** |
| Total prevalent cases | 4,398 | 4,443 | 4,488 | 4,531 | 4,573 |
| Total incident cases | 1,609 | 1,626 | 1,642 | 1,658 | 1,673 |
| Persons living with fALS | 224 | 227 | 229 | 231 | 233 |
| Persons living with sALS | 4,174 | 4,216 | 4,259 | 4,300 | 4,340 |
| Incident cases fALS | 82 | 83 | 84 | 85 | 85 |
| Incident cases sALS | 1,527 | 1,543 | 1,558 | 1,573 | 1,588 |
| ALS cases due to SOD1 |  |  |  |  |  |
| Persons living with SOD1 from fALS | 33 | 34 | 34 | 34 | 34 |
| Persons living with SOD1 from sALS | 50 | 51 | 51 | 52 | 52 |
| Incident cases SOD1 from fALS | 12 | 12 | 12 | 13 | 13 |
| Incident cases SOD1 from sALS | 18 | 19 | 19 | 19 | 19 |
| ALS cases due to C9orf72 |  |  |  |  |  |
| Persons living with C9orf72 from fALS | 75 | 76 | 77 | 78 | 79 |
| Persons living with C9orf72 from sALS | 213 | 215 | 217 | 219 | 221 |
| Incident cases C9orf72 from fALS | 28 | 28 | 28 | 29 | 29 |
| Incident cases C9orf72 from sALS | 78 | 79 | 79 | 80 | 81 |

ALS, amyotrophic lateral sclerosis; fALS, familial amyotrophic lateral sclerosis; sALS, sporadic amyotrophic lateral sclerosis; SOD1, superoxide dismutase 1.

**Netherlands**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Category** | **2020** | **2021** | **2022** | **2023** | **2024** |
| Total prevalent cases | 1,083 | 1,089 | 1,094 | 1,098 | 1,102 |
| Total incident cases | 401 | 403 | 405 | 407 | 408 |
| Persons living with fALS | 55 | 56 | 56 | 56 | 56 |
| Persons living with sALS | 1,028 | 1,033 | 1,038 | 1,042 | 1,046 |
| Incident cases fALS | 20 | 21 | 21 | 21 | 21 |
| Incident cases sALS | 381 | 382 | 384 | 386 | 387 |
| ALS cases due to SOD1 |  |  |  |  |  |
| Persons living with SOD1 from fALS | 8 | 8 | 8 | 8 | 8 |
| Persons living with SOD1 from sALS | 12 | 12 | 12 | 13 | 13 |
| Incident cases SOD1 from fALS | 3 | 3 | 3 | 3 | 3 |
| Incident cases SOD1 from sALS | 5 | 5 | 5 | 5 | 5 |
| ALS cases due to C9orf72 |  |  |  |  |  |
| Persons living with C9orf72 from fALS | 19 | 19 | 19 | 19 | 19 |
| Persons living with C9orf72 from sALS | 52 | 53 | 53 | 53 | 53 |
| Incident cases C9orf72 from fALS | 7 | 7 | 7 | 7 | 7 |
| Incident cases C9orf72 from sALS | 19 | 19 | 20 | 20 | 20 |

ALS, amyotrophic lateral sclerosis; fALS, familial amyotrophic lateral sclerosis; sALS, sporadic amyotrophic lateral sclerosis; SOD1, superoxide dismutase 1.

**Norway**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Category** | **2020** | **2021** | **2022** | **2023** | **2024** |
| Total prevalent cases | 284 | 286 | 288 | 290 | 292 |
| Total incident cases | 111 | 112 | 112 | 113 | 114 |
| Persons living with fALS | 14 | 15 | 15 | 15 | 15 |
| Persons living with sALS | 270 | 271 | 273 | 275 | 277 |
| Incident cases fALS | 6 | 6 | 6 | 6 | 6 |
| Incident cases sALS | 105 | 106 | 106 | 107 | 108 |
| ALS cases due to SOD1 |  |  |  |  |  |
| Persons living with SOD1 from fALS | 2 | 2 | 2 | 2 | 2 |
| Persons living with SOD1 from sALS | 3 | 3 | 3 | 3 | 3 |
| Incident cases SOD1 from fALS | 1 | 1 | 1 | 1 | 1 |
| Incident cases SOD1 from sALS | 1 | 1 | 1 | 1 | 1 |
| ALS cases due to C9orf72 |  |  |  |  |  |
| Persons living with C9orf72 from fALS | 5 | 5 | 5 | 5 | 5 |
| Persons living with C9orf72 from sALS | 14 | 14 | 14 | 14 | 14 |
| Incident cases C9orf72 from fALS | 2 | 2 | 2 | 2 | 2 |
| Incident cases C9orf72 from sALS | 5 | 5 | 5 | 5 | 6 |

ALS, amyotrophic lateral sclerosis; fALS, familial amyotrophic lateral sclerosis; sALS, sporadic amyotrophic lateral sclerosis; SOD1, superoxide dismutase 1.

**Russia**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Category** | **2020** | **2021** | **2022** | **2023** | **2024** |
| Total prevalent cases | 9,084 | 9,083 | 9,076 | 9,065 | 9,051 |
| Total incident cases | 3,365 | 3,365 | 3,362 | 3,358 | 3,353 |
| Persons living with fALS | 463 | 463 | 463 | 462 | 462 |
| Persons living with sALS | 8,621 | 8,620 | 8,613 | 8,603 | 8,589 |
| Incident cases fALS | 172 | 172 | 171 | 171 | 171 |
| Incident cases sALS | 3,193 | 3,193 | 3,191 | 3,187 | 3,182 |
| ALS cases due to SOD1 |  |  |  |  |  |
| Persons living with SOD1 from fALS | 69 | 69 | 69 | 68 | 68 |
| Persons living with SOD1 from sALS | 103 | 103 | 103 | 103 | 103 |
| Incident cases SOD1 from fALS | 25 | 25 | 25 | 25 | 25 |
| Incident cases SOD1 from sALS | 38 | 38 | 38 | 38 | 38 |
| ALS cases due to C9orf72 |  |  |  |  |  |
| Persons living with C9orf72 from fALS | 156 | 156 | 156 | 156 | 156 |
| Persons living with C9orf72 from sALS | 440 | 440 | 439 | 439 | 438 |
| Incident cases C9orf72 from fALS | 58 | 58 | 58 | 58 | 58 |
| Incident cases C9orf72 from sALS | 163 | 163 | 163 | 163 | 162 |

ALS, amyotrophic lateral sclerosis; fALS, familial amyotrophic lateral sclerosis; sALS, sporadic amyotrophic lateral sclerosis; SOD1, superoxide dismutase 1.

**South Korea**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Category** | **2020** | **2021** | **2022** | **2023** | **2024** |
| Total prevalent cases | 1,544 | 1,545 | 1,546 | 1,546 | 1,547 |
| Total incident cases | 478 | 478 | 478 | 479 | 479 |
| Persons living with fALS | 79 | 79 | 79 | 79 | 79 |
| Persons living with sALS | 1,465 | 1,466 | 1,467 | 1,467 | 1,468 |
| Incident cases fALS | 24 | 24 | 24 | 24 | 24 |
| Incident cases sALS | 454 | 454 | 454 | 455 | 455 |
| ALS cases due to SOD1 |  |  |  |  |  |
| Persons living with SOD1 from fALS | 24 | 24 | 24 | 24 | 24 |
| Persons living with SOD1 from sALS | 22 | 22 | 22 | 22 | 22 |
| Incident cases SOD1 from fALS | 7 | 7 | 7 | 7 | 7 |
| Incident cases SOD1 from sALS | 7 | 7 | 7 | 7 | 7 |
| ALS cases due to C9orf72 |  |  |  |  |  |
| Persons living with C9orf72 from fALS | 2 | 2 | 2 | 2 | 2 |
| Persons living with C9orf72 from sALS | 4 | 4 | 4 | 4 | 4 |
| Incident cases C9orf72 from fALS | 1 | 1 | 1 | 1 | 1 |
| Incident cases C9orf72 from sALS | 1 | 1 | 1 | 1 | 1 |

ALS, amyotrophic lateral sclerosis; fALS, familial amyotrophic lateral sclerosis; sALS, sporadic amyotrophic lateral sclerosis; SOD1, superoxide dismutase 1.

**Spain**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Category** | **2020** | **2021** | **2022** | **2023** | **2024** |
| Total prevalent cases | 3,242 | 3,250 | 3,257 | 3,264 | 3,271 |
| Total incident cases | 974 | 976 | 979 | 981 | 983 |
| Persons living with fALS | 165 | 166 | 166 | 166 | 167 |
| Persons living with sALS | 3,077 | 3,084 | 3,091 | 3,098 | 3,104 |
| Incident cases fALS | 50 | 50 | 50 | 50 | 50 |
| Incident cases sALS | 924 | 926 | 929 | 931 | 933 |
| ALS cases due to SOD1 |  |  |  |  |  |
| Persons living with SOD1 from fALS | 24 | 25 | 25 | 25 | 25 |
| Persons living with SOD1 from sALS | 37 | 37 | 37 | 37 | 37 |
| Incident cases SOD1 from fALS | 7 | 7 | 7 | 7 | 7 |
| Incident cases SOD1 from sALS | 11 | 11 | 11 | 11 | 11 |
| ALS cases due to C9orf72 |  |  |  |  |  |
| Persons living with C9orf72 from fALS | 56 | 56 | 56 | 56 | 56 |
| Persons living with C9orf72 from sALS | 157 | 157 | 158 | 158 | 158 |
| Incident cases C9orf72 from fALS | 17 | 17 | 17 | 17 | 17 |
| Incident cases C9orf72 from sALS | 47 | 47 | 47 | 47 | 48 |

ALS, amyotrophic lateral sclerosis; fALS, familial amyotrophic lateral sclerosis; sALS, sporadic amyotrophic lateral sclerosis; SOD1, superoxide dismutase 1.

**Sweden**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Category** | **2020** | **2021** | **2022** | **2023** | **2024** |
| Total prevalent cases | 643 | 648 | 654 | 659 | 664 |
| Total incident cases | 238 | 240 | 242 | 244 | 246 |
| Persons living with fALS | 33 | 33 | 33 | 34 | 34 |
| Persons living with sALS | 610 | 615 | 621 | 625 | 630 |
| Incident cases fALS | 12 | 12 | 12 | 12 | 13 |
| Incident cases sALS | 226 | 228 | 230 | 232 | 233 |
| ALS cases due to SOD1 |  |  |  |  |  |
| Persons living with SOD1 from fALS | 5 | 5 | 5 | 5 | 5 |
| Persons living with SOD1 from sALS | 7 | 7 | 7 | 8 | 8 |
| Incident cases SOD1 from fALS | 2 | 2 | 2 | 2 | 2 |
| Incident cases SOD1 from sALS | 3 | 3 | 3 | 3 | 3 |
| ALS cases due to C9orf72 |  |  |  |  |  |
| Persons living with C9orf72 from fALS | 11 | 11 | 11 | 11 | 11 |
| Persons living with C9orf72 from sALS | 31 | 31 | 32 | 32 | 32 |
| Incident cases C9orf72 from fALS | 4 | 4 | 4 | 4 | 4 |
| Incident cases C9orf72 from sALS | 12 | 12 | 12 | 12 | 12 |

ALS, amyotrophic lateral sclerosis; fALS, familial amyotrophic lateral sclerosis; sALS, sporadic amyotrophic lateral sclerosis; SOD1, superoxide dismutase 1.

**Taiwan**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Category** | **2020** | **2021** | **2022** | **2023** | **2024** |
| Total prevalent cases | 491 | 492 | 493 | 493 | 494 |
| Total incident cases | 222 | 222 | 223 | 223 | 223 |
| Persons living with fALS | 25 | 25 | 25 | 25 | 25 |
| Persons living with sALS | 466 | 467 | 468 | 468 | 469 |
| Incident cases fALS | 11 | 11 | 11 | 11 | 11 |
| Incident cases sALS | 211 | 211 | 212 | 212 | 212 |
| ALS cases due to SOD1 |  |  |  |  |  |
| Persons living with SOD1 from fALS | 8 | 8 | 8 | 8 | 8 |
| Persons living with SOD1 from sALS | 7 | 7 | 7 | 7 | 7 |
| Incident cases SOD1 from fALS | 3 | 3 | 3 | 3 | 3 |
| Incident cases SOD1 from sALS | 3 | 3 | 3 | 3 | 3 |
| ALS cases due to C9orf72 |  |  |  |  |  |
| Persons living with C9orf72 from fALS | 1 | 1 | 1 | 1 | 1 |
| Persons living with C9orf72 from sALS | 1 | 1 | 1 | 1 | 1 |
| Incident cases C9orf72 from fALS | 0 | 0 | 0 | 0 | 0 |
| Incident cases C9orf72 from sALS | 1 | 1 | 1 | 1 | 1 |

ALS, amyotrophic lateral sclerosis; fALS, familial amyotrophic lateral sclerosis; sALS, sporadic amyotrophic lateral sclerosis; SOD1, superoxide dismutase 1.

**UK**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Category** | **2020** | **2021** | **2022** | **2023** | **2024** |
| Total prevalent cases | 2,683 | 2,700 | 2,718 | 2,736 | 2,754 |
| Total incident cases | 1,080 | 1,087 | 1,094 | 1,101 | 1,109 |
| Persons living with fALS | 137 | 138 | 139 | 140 | 140 |
| Persons living with sALS | 2,546 | 2,562 | 2,579 | 2,596 | 2,614 |
| Incident cases fALS | 55 | 55 | 56 | 56 | 57 |
| Incident cases sALS | 1,025 | 1,032 | 1,038 | 1,045 | 1,052 |
| ALS cases due to SOD1 |  |  |  |  |  |
| Persons living with SOD1 from fALS | 20 | 20 | 21 | 21 | 21 |
| Persons living with SOD1 from sALS | 31 | 31 | 31 | 31 | 31 |
| Incident cases SOD1 from fALS | 8 | 8 | 8 | 8 | 8 |
| Incident cases SOD1 from sALS | 12 | 12 | 12 | 13 | 13 |
| ALS cases due to C9orf72 |  |  |  |  |  |
| Persons living with C9orf72 from fALS | 46 | 47 | 47 | 47 | 47 |
| Persons living with C9orf72 from sALS | 130 | 131 | 132 | 132 | 133 |
| Incident cases C9orf72 from fALS | 19 | 19 | 19 | 19 | 19 |
| Incident cases C9orf72 from sALS | 52 | 53 | 53 | 53 | 54 |

ALS, amyotrophic lateral sclerosis; fALS, familial amyotrophic lateral sclerosis; sALS, sporadic amyotrophic lateral sclerosis; SOD1, superoxide dismutase 1.

**Uruguay**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Category** | **2020** | **2021** | **2022** | **2023** | **2024** |
| Total prevalent cases | 118 | 119 | 119 | 120 | 120 |
| Total incident cases | 43 | 43 | 44 | 44 | 44 |
| Persons living with fALS | 6 | 6 | 6 | 6 | 6 |
| Persons living with sALS | 112 | 113 | 113 | 114 | 114 |
| Incident cases fALS | 2 | 2 | 2 | 2 | 2 |
| Incident cases sALS | 41 | 41 | 42 | 42 | 42 |
| ALS cases due to SOD1 |  |  |  |  |  |
| Persons living with SOD1 from fALS | 1 | 1 | 1 | 1 | 1 |
| Persons living with SOD1 from sALS | 1 | 1 | 1 | 1 | 1 |
| Incident cases SOD1 from fALS | 0 | 0 | 0 | 0 | 0 |
| Incident cases SOD1 from sALS | 0 | 0 | 1 | 1 | 1 |
| ALS cases due to C9orf72 |  |  |  |  |  |
| Persons living with C9orf72 from fALS | 2 | 2 | 2 | 2 | 2 |
| Persons living with C9orf72 from sALS | 6 | 6 | 6 | 6 | 6 |
| Incident cases C9orf72 from fALS | 1 | 1 | 1 | 1 | 1 |
| Incident cases C9orf72 from sALS | 2 | 2 | 2 | 2 | 2 |

ALS, amyotrophic lateral sclerosis; fALS, familial amyotrophic lateral sclerosis; sALS, sporadic amyotrophic lateral sclerosis; SOD1, superoxide dismutase 1.

**USA**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Category** | **2020** | **2021** | **2022** | **2023** | **2024** |
| Total prevalent cases | 17,394 | 17,530 | 17,664 | 17,798 | 17,930 |
| Total incident cases | 6,222 | 6,270 | 6,318 | 6,366 | 6,414 |
| Persons living with fALS | 887 | 894 | 901 | 908 | 914 |
| Persons living with sALS | 16,507 | 16,636 | 16,763 | 16,890 | 17,016 |
| Incident cases fALS | 317 | 320 | 322 | 325 | 327 |
| Incident cases sALS | 5,905 | 5,950 | 5,996 | 6,041 | 6,087 |
| ALS cases due to SOD1 |  |  |  |  |  |
| Persons living with SOD1 from fALS | 131 | 132 | 133 | 134 | 135 |
| Persons living with SOD1 from sALS | 198 | 200 | 201 | 203 | 204 |
| Incident cases SOD1 from fALS | 47 | 47 | 48 | 48 | 48 |
| Incident cases SOD1 from sALS | 71 | 71 | 72 | 72 | 73 |
| ALS cases due to C9orf72 |  |  |  |  |  |
| Persons living with C9orf72 from fALS | 299 | 301 | 304 | 306 | 308 |
| Persons living with C9orf72 from sALS | 842 | 848 | 855 | 861 | 868 |
| Incident cases C9orf72 from fALS | 107 | 108 | 109 | 110 | 110 |
| Incident cases C9orf72 from sALS | 301 | 303 | 306 | 308 | 310 |

ALS, amyotrophic lateral sclerosis; fALS, familial amyotrophic lateral sclerosis; sALS, sporadic amyotrophic lateral sclerosis; SOD1, superoxide dismutase 1.

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