Supplement Table 1. Three approaches for estimating prevalence of Duchenne and Becker Muscular Dystrophies among males in Muscular Dystrophy Surveillance, Tracking, and Research network (MD STAR*net*), 1991–2015.

|  |  |
| --- | --- |
| **Method 1** | **Numerator:** Number of cases, 5 to 9 years of age during that year minus number of cases who died/lost-follow-up in that year |
| **Denominator:** Annual population of U.S. male residents within the surveillance region, 5 to 9 years of age |
| **5-year prevalence:** ①Point estimate = Numerator/Denominator; ②Median of the 5 yearly point estimates for that study period\*\*\* |
|  | **Denominator details by states and study year** |
|  | State\* | Study Year |
|  |  | *1991–2004* | *2005* | *2006* | *2007* | *2008* | 2009–2015 |
|  | *AZ, GA* | *5–9 yrs each year, for study year 1991–2010* |
|  | *CO, IA* | *5–9 yrs each year, for study year 1991–2015* |
|  | *wNY* | *12 cty (5–9 yrs)\*\** | *12 cty (5–9 yrs) + 9 cty (5 yrs)*  | *12 cty (5–9 yrs) + 9 cty (5–6 yrs)* | *12 cty (5–9 yrs) + 9 cty (5–7 yrs)* | *12 cty (5–9 yrs) + 9 cty (5–8 yrs)* | *21 cty (5–9 yrs)* |
|  | *NC, SC and UT* | *-* | *5 yrs* | *5–6 yrs* | *5–7 yrs* | *5–8 yrs* | *5–9 yrs* |
| **Method 2** | **Numerator:** Number of cases, who were 5 to 9 years of age for at least one of the five years during that period minus number of cases who died/lost-follow-up before each study period |
| **Denominator:** Population of U.S. male residents within the surveillance region, 5 to 13 years of age, during the final year of each study period only |
| **5-year prevalence:** Numerator/Denominator |
|  | **Denominator details by states and study period** |
|  | State | Study period\*\*\*\* |
|  |  | *P1* | *P2* | *P3* | *P4* | *P5* |  |
|  | *AZ, GA* | *5–13 yrs in1995* | *5–13 yrs in 2000* | *5–13 yrs in 2005* | *5–13 yrs in 2010* | *-* |  |
|  | *CO, IA* | *5–13 yrs in1995* | *5–13 yrs in 2000* | *5–13 yrs in 2005* | *5–13 yrs in 2010* | *5–13 yrs in 2015* |  |
|  | *wNY* | *12 cty (5–13 yrs)* | *12 cty (5–13 yrs)* | *12 cty (5–13 yrs) + 9 cty (5 yrs)* | *12 cty (5–13 yrs) + 9 cty (5–10 yrs)* | *21 cty (5–13 yrs)* |  |
|  | *NC, SC and UT* | *-* | *-* | *5 yrs* | *5–10 yrs* | *5–13 yrs*  |   |
| **Method 3** | **Numerator:** Number of cases, who born in birth cohorts (1986–1990 for PI; 1991–1995 for P2; 1996–2000 for P3; 2001–2005 for P4; and 2006–2010 for P5) minus number of cases who died or lost-follow-up before each study period |
| **Denominator:** Population of U.S. male residents within the surveillance region, 5 to 9 years of age, during the final year of each study period only |
| **5-year prevalence:** Numerator/Denominator |
|  | **Denominator details by states and study period** |
|  | State | Study period\*\*\*\* |
|  |  | *P1* | *P2* | *P3* | *P4* | *P5* |  |
|  | *AZ, GA* | *5–9 yrs in1995* | *5–9 yrs in 2000* | *5–9 yrs in 2005* | *5–9 yrs in 2010* | *-* |  |
|  | *CO, IA* | *5–9 yrs in1995* | *5–9 yrs in 2000* | *5–9 yrs in 2005* | *5–9 yrs in 2010* | *5–9 yrs in 2015* |  |
|  | *wNY* | *12 cty (5–9 yrs)* | *12 cty (5–9 yrs)* | *12 cty (5–9 yrs) +9 cty (5 yrs)* | *21 cty (5–9 yrs)* | *21 cty (5–9 yrs)* |  |
|  | *NC, SC and UT* | *-* | *-* | *5 yrs* | *5-9 yrs* | *5-9 yrs* |  |
| \*AZ = Arizona, CO=Colorado, GA = Georgia, IA = Iowa, NC = North Carolina, wNY = western New York State, SC = South Carolina, UT = Utah\*\* cty = county, yrs=years.\*\*\* Step1: annual point estimates were calculated; Step2: take the median of these point estimates as 5-year prevalence.*\*\*\*\**P1 is 1991–1995; P2 is 1996–2000; P3 is 2001–2005; P4 is 2006–2010; P5 is 2011–2015. |

Supplement Table 2. 5-year period prevalence of Duchenne and Becker muscular dystrophy among males aged 5­­­ to 9 years by race/ethnicity groups, site, and estimating methods, the Muscular Dystrophy Surveillance, Tracking, and Research network (MD STAR*net*).

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|   |   | Non-Hispanic white | Non-Hispanic black | non-Hispanic AIAN/API\* | Hispanic  |
| Study period | State\*\* | Method 1 | Method 2 | Method 3 | Method 1 | Method 2 | Method 3 | Method 1 | Method 2 | Method 3 | Method 1 | Method 2 | Method 3 |
| P1(1991-1995) | AZ | 1.70 (1.59–2.12) | 1.72 (1.20–2.47) | 1.94 (1.22–3.06) | 0.00 (0.00–1.36) | 0.82 (0.04–4.62) | 1.36 (0.07–7.72) | 0.67 (0.61–2.17) | 1.04 (0.28–3.06) | 0.61 (0.03–3.44) | 3.34 (2.74–3.84) | 2.72 (1.83–4.04) | 2.98 (1.81–4.92) |
| CO | 2.05 (1.78–2.41) | 2.05 (1.50–2.81) | 2.41 (1.63–3.56) | 4.47 (2.55–5.69) | 3.05 (1.18–7.83) | 2.55 (0.45–9.29) | 0.00 (0.00–0.00) | 0.00 (0.00–5.05) | 0.00 (0.00–9.37) | 4.38 (3.42–6.10) | 4.33 (2.83–6.61) | 5.81 (3.58–9.43) |
| GA | 1.11 (0.76–1.66) | 1.28 (0.94–1.76) | 1.66 (1.15–2.40) | 0.57 (0.24–0.83) | 0.59 (0.32–1.08) | 0.83 (0.42–1.63) | 0.00 (0.00–0.00) | 0.00 (0.00–4.18) | 0.00 (0.00–7.71) | 1.69 (1.29–2.14) | 1.27 (0.23–4.64) | 2.14 (0.38–7.80) |
| IA | 1.71 (1.59–1.81) | 1.77 (1.25–2.51) | 1.92 (1.21–3.04) | 0.00 (0.00–0.00) | 0.00 (0.00–7.00) | 0.00 (0.00–11.73) | 6.19 (0.00–6.27) | 6.60 (1.17–24.03) | 6.19 (0.32–34.99) | 12.61 (5.11–15.00) | 8.77 (3.41–22.52) | 15.00 (5.84–38.52) |
| wNY | 3.08 (2.32–3.31) | 2.71 (1.98–3.72) | 3.29 (2.24–4.82) | 0.84 (0.00–1.87) | 1.33 (0.36–3.91) | 0.74 (0.04–4.21) | 0.00 (0.00–0.00) | 0.00 (0.00–10.53) | 0.00 (0.00–18.17) | 5.71 (2.64–7.57) | 5.42 (2.11–13.94) | 7.15 (1.95–21.00) |
| P2(1996-2000) | AZ | 1.88 (1.78–2.20) | 2.01 (1.46–2.77) | 2.30 (1.53–3.46) | 1.23 (0.00–1.29) | 0.68 (0.03–3.83) | 0.00 (0.00–4.65) | 0.00 (0.00–0.00) | 0.00 (0.00–1.21) | 0.00 (0.00–2.23) | 3.51 (3.46–4.27) | 3.08 (2.25–4.20) | 3.51 (2.40–5.15) |
| CO | 2.42 (2.20–2.52) | 2.27 (1.70–3.04) | 2.25 (1.51–3.35) | 0.00 (0.00–1.26) | 0.67 (0.03–3.78) | 0.00 (0.00–4.56) | 0.00 (0.00–0.00) | 0.00 (0.00–4.03) | 0.00 (0.00–7.46) | 5.39 (3.69–6.78) | 4.13 (2.84–6.00) | 3.69 (2.20–6.19) |
| GA | 2.24 (1.99–2.39) | 2.00 (1.57–2.56) | 2.12 (1.54–2.93) | 1.17 (0.99–1.53) | 1.25 (0.84–1.84) | 1.53 (0.95–2.44) | 1.52 (1.31–1.85) | 0.73 (0.04–4.15) | 1.31 (0.07–7.39) | 2.67 (1.83–3.48) | 2.17 (1.05–4.47) | 3.03 (1.39–6.60) |
| IA | 2.24 (2.03–2.56) | 1.93 (1.37–2.71) | 2.06 (1.32–3.22) | 5.53 (0.00–7.71) | 4.31 (1.17–12.67) | 7.20 (1.96–21.15) | 5.86 (0.00–6.30) | 2.82 (0.14–15.97) | 0.00 (0.00–19.61) | 4.66 (2.04–10.25) | 4.93 (1.92–12.66) | 2.04 (0.10–11.56) |
| wNY | 2.21 (2.00–2.90) | 2.74 (1.99–3.77) | 2.35 (1.46–3.76) | 0.72 (0.71–1.43) | 0.81 (0.14–2.96) | 0.73 (0.04–4.12) | 0.00 (0.00–0.00) | 0.00 (0.00–10.26) | 0.00 (0.00–18.82) | 4.49 (1.90–6.31) | 3.24 (0.88–9.51) | 1.90 (0.10–10.78) |
| P3(2001-2005 | AZ | 2.18 (1.55–2.35) | 1.89 (1.35–2.64) | 1.55 (0.94–2.56) | 0.00 (0.00–0.00) | 0.00 (0.00–2.22) | 0.00 (0.00–4.21) | 0.62 (0.00–0.63) | 0.33 (0.02–1.85) | 0.62 (0.03–3.52) | 2.03 (1.73–2.20) | 2.05 (1.44–2.91) | 1.77 (1.08–2.93) |
| CO | 1.98 (1.75–2.38) | 2.32 (1.72–3.12) | 2.12 (1.39–3.24) | 0.00 (0.00–0.00) | 0.00 (0.00–2.60) | 0.00 (0.00–4.83) | 0.00 (0.00–1.83) | 0.99 (0.05–5.58) | 1.79 (0.09–10.14) | 2.69 (1.99–2.99) | 2.85 (1.88–4.32) | 2.99 (1.75–5.12) |
| GA | 2.68 (2.10–3.00) | 2.30 (1.82–2.89) | 2.87 (2.16–3.80) | 1.29 (1.00–1.63) | 1.25 (0.85–1.83) | 1.00 (0.56–1.79) | 1.07 (0.00–2.32) | 1.11 (0.20–4.04) | 2.00 (0.36–7.31) | 2.62 (2.30–3.72) | 3.32 (2.07–5.31) | 4.06 (2.32–7.09) |
| IA | 1.88 (1.62–2.15) | 1.89 (1.32–2.69) | 1.88 (1.16–3.05) | 2.34 (2.11–7.17) | 4.75 (1.85–12.22) | 2.11 (0.11–11.94) | 4.74 (0.00–9.60) | 5.19 (0.92–18.89) | 9.24 (1.64–33.62) | 4.49 (1.88–5.35) | 3.45 (1.34–8.86) | 4.49 (1.22–13.19) |
| NC | 2.98 (NA)\*\*\* | 2.98 (1.36–6.49) | 2.98 (1.36–6.49) | 1.22 (NA) | 1.22 (0.06–6.89) | 1.22 (0.06–6.89) | 18.28 (NA) | 18.28 (3.25–66.41) | 18.28 (3.25–66.41) | 2.48 (NA) | 2.48 (0.13–14.05) | 2.48 (0.13–14.05) |
| wNY | 2.27 (2.05–2.42) | 2.23 (1.54–3.22) | 2.20 (1.34–3.64) | 1.66 (0.76–1.73) | 1.32 (0.36–3.88) | 1.67 (0.30–6.10) | 0.00 (0.00–0.00) | 0.00 (0.00–9.57) | 0.00 (0.00–16.91) | 0.00 (0.00–1.88) | 0.97 (0.05–5.50) | 0.00 (0.00–6.55) |
| SC | 2.36 (NA) | 2.36 (0.92–6.08) | 2.36 (0.92–6.08) | 0.00 (NA) | 0.00 (0.00–3.94) | 0.00 (0.00–3.94) | 0.00 (NA) | 0.00 (0.00–80.56) | 0.00 (0.00–80.56) | 0.00 (NA) | 0.00 (0.00–22.88) | 0.00 (0.00–22.88) |
| UT | 1.64 (NA) | 1.64 (0.45–4.82) | 1.64 (0.45–4.82) | 0.00 (NA) | 0.00 (0.00–107.35) | 0.00 (0.00–107.35) | 0.00 (NA) | 0.00 (0.00–42.22) | 0.00 (0.00–42.22) | 0.00 (NA) | 0.00 (0.00–11.27) | 0.00 (0.00–11.27) |
| P4(2006-2010) | AZ | 1.42 (1.00–1.64) | 1.44 (0.98–2.11) | 1.51 (0.91–2.49) | 0.85 (0.00–0.92) | 0.47 (0.02–2.65) | 0.85 (0.04–4.83) | 0.57 (0.54–1.19) | 0.60 (0.11–2.19) | 0.54 (0.03–3.04) | 1.55 (0.79–1.90) | 1.34 (0.90–1.99) | 0.89 (0.47–1.69) |
| CO | 2.12 (1.90–2.47) | 2.16 (1.59–2.93) | 2.17 (1.44–3.25) | 2.25 (0.00–3.38) | 1.85 (0.50–5.43) | 3.34 (0.91–9.80) | 2.88 (1.68–4.80) | 2.41 (0.66–7.08) | 2.80 (0.50–10.19) | 2.87 (2.51–3.26) | 2.70 (1.84–3.95) | 2.51 (1.50–4.22) |
| GA | 1.85 (1.16–2.18) | 1.87 (1.45–2.41) | 1.45 (0.98–2.14) | 0.51 (0.34–0.79) | 0.50 (0.28–0.90) | 0.34 (0.13–0.87) | 2.17 (0.84–2.40) | 1.66 (0.64–4.26) | 2.17 (0.59–6.39) | 3.37 (1.46–3.83) | 2.51 (1.62–3.87) | 1.88 (0.99–3.56) |
| IA | 2.11 (1.41–2.12) | 1.88 (1.31–2.69) | 2.12 (1.34–3.35) | 0.00 (0.00–2.00) | 0.98 (0.05–5.53) | 0.00 (0.00–6.64) | 3.98 (3.68–8.99) | 6.38 (1.74–18.74) | 3.68 (0.19–20.83) | 3.44 (2.61–4.20) | 3.77 (1.73–8.22) | 3.21 (0.87–9.43) |
| NC | 1.91 (1.57–1.97) | 1.78 (1.19–2.67) | 1.59 (0.99–2.55) | 1.12 (0.87–1.75) | 0.89 (0.38–2.09) | 0.87 (0.34–2.24) | 3.47 (0.00–7.96) | 2.19 (0.39–7.99) | 0.00 (0.00–5.02) | 2.10 (1.29–2.34) | 2.26 (1.15–4.46) | 2.34 (1.13–4.82) |
| wNY | 2.32 (2.10–2.77) | 2.26 (1.59–3.21) | 2.32 (1.48–3.62) | 1.41 (0.67–2.22) | 1.21 (0.33–3.54) | 0.69 (0.04–3.89) | 2.93 (0.00–3.47) | 1.75 (0.09–9.90) | 2.86 (0.15–16.21) | 0.00 (0.00–0.00) | 0.00 (0.00–2.85) | 0.00 (0.00–4.71) |
| SC | 1.62 (1.60–1.94) | 1.82 (1.16–2.84) | 1.74 (1.05–2.86) | 1.03 (0.83–1.52) | 0.85 (0.36–1.99) | 1.03 (0.44–2.42) | 0.00 (0.00–0.00) | 0.00 (0.00–10.72) | 0.00 (0.00–12.81) | 3.16 (2.22–4.03) | 3.45 (1.47–8.08) | 4.03 (1.72–9.42) |
| UT | 2.08 (1.89–2.31) | 2.18 (1.49–3.20) | 2.31 (1.54–3.47) | 0.00 (0.00–4.62) | 3.85 (0.20–21.76) | 4.62 (0.24–26.13) | 0.00 (0.00–0.00) | 0.00 (0.00–6.26) | 0.00 (0.00–7.49) | 3.16 (0.00–4.24) | 3.55 (1.87–6.75) | 4.24 (2.23–8.06) |
| P5(2011-2015) | CO | 2.24 (1.41–2.44) | 1.97 (1.43–2.70) | 1.70 (1.07–2.68) | 2.09 (1.00–3.32) | 2.26 (0.88–5.80) | 1.00 (0.05–5.65) | 2.71 (1.34–2.75) | 2.90 (1.13–7.46) | 2.71 (0.48–9.89) | 2.30 (1.70–2.96) | 2.21 (1.47–3.31) | 2.04 (1.17–3.57) |
| IA | 2.61 (2.12–2.95) | 2.57 (1.88–3.51) | 2.61 (1.73–3.96) | 1.41 (0.00–1.53) | 0.83 (0.04–4.70) | 1.41 (0.07–7.97) | 3.33 (0.00–3.59) | 1.73 (0.09–9.82) | 0.00 (0.00–11.88) | 0.94 (0.00–3.07) | 1.59 (0.43–4.68) | 0.00 (0.00–3.50) |
| NC | 1.44 (1.18–2.00) | 1.43 (0.98–2.08) | 1.18 (0.68–2.07) | 0.63 (0.61–0.87) | 0.57 (0.24–1.34) | 0.61 (0.17–1.80) | 0.00 (0.00–0.00) | 0.00 (0.00–2.28) | 0.00 (0.00–3.96) | 2.70 (1.44–3.09) | 1.84 (1.03–3.30) | 1.44 (0.62–3.37) |
| wNY | 1.72 (1.42–2.25) | 2.01 (1.39–2.91) | 1.60 (0.92–2.80) | 0.70 (0.70–1.40) | 0.78 (0.14–2.85) | 0.70 (0.04–3.94) | 0.00 (0.00–0.00) | 0.00 (0.00–5.24) | 0.00 (0.00–9.34) | 4.43 (1.19–5.39) | 3.07 (1.31–7.18) | 5.29 (2.26–12.38) |
| SC | 2.43 (2.07–3.00) | 2.15 (1.54–3.00) | 2.54 (1.67–3.84) | 0.59 (0.39–0.80) | 0.44 (0.17–1.14) | 0.39 (0.07–1.41) | 0.00 (0.00–2.99) | 1.66 (0.09–9.39) | 2.99 (0.15–16.94) | 2.79 (1.32–3.83) | 2.34 (1.07–5.10) | 1.32 (0.23–4.80) |
| UT | 2.22 (1.74–2.38) | 2.07 (1.51–2.84) | 1.84 (1.18–2.87) | 4.30 (0.00–4.53) | 2.32 (0.12–13.15) | 0.00 (0.00–15.96) | 1.82 (0.00–1.84) | 1.00 (0.05–5.66) | 1.82 (0.09–10.30) | 2.65 (1.29–4.16) | 2.96 (1.69–5.17) | 1.29 (0.35–3.78) |
| \*AIAN = American Indian or Alaska Native & Native Hawaiian. API = American Pacific Islander. \*\*AZ = Arizona, CO=Colorado, GA = Georgia, IA = Iowa, NC = North Carolina, wNY = western New York State, SC = South Carolina, UT = Utah.\*\*\* For Method 1, during P3 period, even though only one year of data was available for NC, SC, and UT, we kept using this one-point estimate at year 2005 to estimate the period prevalence. Thus, confidence intervals reported as not applicable (NA).  |