

# NIH Investigation of Co-occurring conditions across the Lifespan to Understand Down syndrome (INCLUDE) Down Syndrome Research Plan

888%

8fUz S&#S#888%

BUcbU' bghh HgcZ< YUk fB=< L  
I "G" 8YdUfa YbhcZ< YUk UbX< i a Ub'GYj jWgfk < GL



# Executive Summary

ObDfc[fYgQ

---

---

---

---

8G ]b Yl ]g]b[ 'UbXZ hi fYW]b]W' hf]Ug' : cf'h ]gfYgMfW d'Ubžh Y]bZcfa U]cb ]g'cf[ Ub]nXX  
Ufc] bXZj YMcUXh Ya Yg'

- 6Ug]WF YgYfW
- 7c\cfh8 Y Ycda Yb#0d]Xa ]c`c[ mi
- 7 ]b]W FYgYfW#7c!cWff]b[ `7cbX]hcbg
- @j ]b[ 'UbX5 [ ]b[ k ]h 8G#Gyf ]WgFYgYfW
- FYgYfW =bZUgfi WifYUbXHcc`g

K ]h]b YUW cZH YgYh Ya Ygžh YfYa UmWYg V\YU]b]g'hc [ fci d'fYUXXcVMMj Yg''9UW h Ya Y  
Ugc \UgUDfc[ fUa DcfffU]hlc \][\`][ \hUb Yl Ua d'YcZUgdWZ]WYgYfW dfc^MMh UhUXfYggYg  
hYh Ya Y'

## Portfolio Analysis

Gb Dfc[ fYggQ





- 8Y Ycd'a cXYgcZHY[ YbY]WUlgza YWU]ga g'UbXg[ b]ZVbWcZXngY[ i `UHX YbXcga YgZl cga YgZU lcd\U cga YgZUbXdfchYcgU]g]bU ]b[ `UbX8G!58"
- 9i VXYWbZcfa U]cb'UbXlcl ]Vá YWU]ga g'cZU [ fY U]b[ `dfch]bg'g WUgVWU Uá mc]XUbXHU žZca `i a Ub]gg Y]b'8G!58"
- 7fYU'UbXWa dUfYa cXYg'lc UggYg'hY]a dUWcZchYf`i a Ub'Wfca cga Y&%[ YbYg cb'U ]b[ `UbX8G!58"
- 8Y]bYX]ZfYbWgUbXga ]'U]h]YgVlk Yb a cXYgcZ8G!58 j Yfg g@UM.Cbg'h58 `UbX Yf'mcbg'h: Uá ]'U'58"
- 9l d'cfYh'YZZMg'UbXa YWU]ga g'cZUá mc]XUb[ ]cdUhm'UbXVYUW'cZHYVccXVU]b' VUf]Yf']b'8G!58"
- 9l d'cfYh'Yfc`YcZHYa ]WcV]ca Ycb'58 `dUhc`c[ m]b'8G"

### Develop Model Systems for DS-AD Research

- 7cbX VWWa dFY Ybgj YDa ]Vg'gi X]Yg'cZU ]b[ `UbX58 ]b'Uk ]XYfUb[ YcZa cXYgZ ]bW X]b[ `mUg'zk cfa žZn'YVU]g'za ci gZfUz'bcbl`i a Ub'df]a UYfB< DIZUbX`i a Ub' W`'a cXYg'
- 9l Uá ]bYh'ca Yf]WYb[ h' UbXfY[ i `U]cb]'b'a ci gYa cXYgj Yfg g`i a Ub W`'' ]bYg'
- 8Y]bYU YfYUHXWU] Yg]b'bY fcbgZ[ `]Uz'UbX'YbXchY]U'W`g]'b'a ci gY'UbX`i a Ub' a cXYg'
- 8Y]bYh'Yfc`YcZU YfYUHX`cfa cbU'WU] Yg'cb'8G!58 `YbXchm]g'UbXd'Ybchm]g]'b' a ci gYa cXYg'
- Gh Xn'h Ycf][ ]bg'UbXWbg'Yei YbWg'cZU lc]a a i bYWbX]hcbg]'b'Ua ci gYa cXY' cZ8G"
- 8Y]bY]bj ]j c a YWU]ga g]b a cXY' gng'hYa ghUhfYZWVW]b]W`d'Ybchm]g]'b'8Gž dU]h]W'Uf'ndfYBU Xj Ycda YbU' gi X]Yg'h UhVbbchYVWbX VIX]b`i a Ubg'
- 8Y]bYUbXWa dUfY[ YbY]Wg'za YWU]ga g'UbXg[ b]ZVbWcZXngY[ i `UHX YbXcga YgZ Yl cga YgZU lcd\U cga YgZUbXdfchYcgU]g]b'8G]b]a U'a cXYg'
- 7cbX VifYgUfW ]b'Ua cXY' cZ]bX V]Yg' YbV]b[ `cZHYb]h]fYWfca cga Y&%cf cZ g]W]Z]W YbYg'cb'Wfca cga Y&%''
- 7cb]bi Ylc UbUnmYgnbUdh]WZ bW]cb ]b'U8G'a ci gYa cXYžZcWg]b[ `g]W]Z]W`mcb' fY]Y Ubh[ YbYgUgc `cWXXcb`i a Ub'Wfca cga Y&%'
- 7ca d'YfY'Wa dUf' GbE `i X]b[ 'U ]b[ `UbX9` ] fYU'cZU`G'a ci gb



---

Ugc`fYWa a cb`|b`dYcd`Yk` \c`Xc`bch`Uj`Y8G`h`YfYzcfYzZ|bX|b| g`Zfca` 8G`fYgMfWk`|` \Uj`Y`  
|a`d`|W|h`cbg`Zcf`h`Y` \U`h`c`Z`h`Y`cj`YfU` `dcdi` `U`h`cb`"

### Develop a Cohort(s) for DS Research

- 8`Yj`Ycd`UW` \cfhc`Z|bX|j` |X| Ugk` |h` 8G`UW`cgg`h`Y` |Zgd`Ubz`|bW`X|b| `c`Xf`|bX|j` |X| Ug`  
f|c`fb`%`+S!`%`-`Sfz`UbX`h`cgY`Zfca` `Xj` Yfg`Y`g`V`c`W`b`ca` |WUW|` fci` bXg`UbX|` Yc|` fUd`|W`  
Uf`Ug`Z`Ybg` f|b|` f`y`d`f`Y`g`b`h`|`cb`UW`cgg`U` `U` Yz`gi` z`UbX`f`U`U`#`h`b|`W`d`cdi` `U`h`cb`|` fci` dg`"  
8`Yz`|b`Y`h`Y`|a` dUW`c`Z`f`|`g`ca` m`&%`cb`f`U`W`Ub`X`Y`h`b|`V`h`z`gd`Y`W`Z`W` m`U`X`Y`g`g`|b|` k` \`Y`h`Y`  
8G` \`U`g`U`X`|`g`d`U`f`U`Y`|a` dUW`c`b` d`U`f`|`W`U`f` f`U`U`U` c`f` Y`h`b|`W`d`cdi` `U`h`cbg`" `b`W`X`Y`d`U`f`|`U`  
h`|`g`ca` m`U`b`X`a` c`g`|`U`W`8G`W` \`c`f`|`g`|b`h`Y`g`Y`g`i` X`Y`g`"
- b`W`X`Y`U`g`d`Y`W`Z`W`g` V`g`i` X`m`c`Z` Z`S`S`d`U`f`|`W`d`U`b`g`k` |h` 8G`|b` `U`f`|` Y`g`i` X`Y`g`z`g` W`U`g`8G`!  
7`c`bb`W`M` .` H`Y`8G`F`Y`|`|`g`f`m`f`g`Y`D`f`c`|` f`U`a` D`c`f`f`U`h`&`L`c`f`B`=` E`g` f`Y`g`M`f`W`  
d`f`c`|` f`U`a` " `7`c` `Y`M` K` 5G`X`U`U`c`b`h`|`g`|` f`ci` d`l`c` d`f`c`j` |X`Y`b`c`i` [ `g`|`U`h`g`|`W` `d`c`k` Y`f`l`c`  
X`j` Y`c`d`j` U`|`X`|` Y`b`c`h`n`l`Y`g`U`b`X`d` Y`b`c`h`n`l`Y`g`"
- 7`c`b`X`|` W`f`Y`g`M`f`W`c`b`h`Y` \`U`h` `|a` dUW`c`Z`c`k` `g`c`V`c`W`b`ca` |W`g`U`h`g`|b`8G`"
- @`|b`\_`h`|`g`W` \`c`f`h`l`c` U`g` Z`|`W`b`h`m`U`f`|` Y`b`i` a` V`f`c`Z`M`c`c`|` |W`g`U`a` d`Y`g`f`Y`|` "Z`V`c`c`X`Z` \`U`f`z`  
g`U`|`j` U`L`Z`f`ca` `d`Y`c`d`Y`k` |h` 8G`h`f`c`i` [ ` \`U`Z`X`Y`U`h`c`b`c`Z`W`c`f`X`|b`U`h`X`V`c`U`b`\_`g`l`c` U`c`k`  
X`h`U`|`Y`Z` `c`b`|` |h` X`|b`U` W`U`U`W`f`|`n`U`h`c`b`f`h` Y`b`c`h`n`l`|b|` E`c`Z`|b`X`|j` |X| Ugk` |h` 8G`" `H`c` U`W`|`Y` Y`  
h`|`g`|` c`U`z`W`b`g`X`f`" `|b`\_`|b|` l`c` Y`|`|`g`|b|` W` \`c`f`|`g`z`|b`W`X|b|` `h`c`g`Y`a` U`b`U`|b`Y`X`|b`h`f`b`U`h`c`b`U`m`i`"

A

### Conduct Longitudinal/Prevalence Studies of Co-Occurring Conditions in DS

- 9l`d`U`X`c`b`|` |h` X`|b`U` `g`i` X`Y`g`c`Z`h`Y`b`U`h` f`U` \`|`g`c`f`m`c`Z`U`|`b|` `U`b`X`5`8`|b`8G`Z`V`M`|`|b`b`|b|`  
Y`f`m`|b` `|Z`" 7`c`b`X`|` W`Y`d`|`X`a`|`c`c`|` |W`g`i` X`Y`g`c`Z`U`X`|` l`g`k` |h` 8G`l`c` |X`Y`h`Z`h`h`Y`c`b`g`Y`h`U`b`X`  
h`U`Y`W`c`f`|`Y`g`c`Z`W`!`c`W`W`f`|b|` `W`b`X`|`h`c`b`g`U`b`X`a` c`f`U`|`h`m`Y`U`h`X`l`c` 5`8`z`U`b`X`U`g`W`h`U`j`b`h`Y`  
X`|`g`f`|`V`i` h`c`b`z`X`a` c`|`f`U`|`W`g`z`U`b`X`g` f`j` |j` U`f`U`h`g`c`Z`8G`!`5`8`z`|b`W`X|b|` `W`a`d`|W`h`c`b`g`c`Z`5`8`  
h`U`h`a` U`h`W`b`f`|`V`i` h`Y`l`c` `a` c`f`U`|`h`m`f`g` W`U`g`d`b`Y`i` a` c`b`|`U`" 9l`U`a` |b`Y`h`Y`|` Y`b`X`Y`z`f`U`W`z`U`b`X`  
Y`h`b|`W`X`Z`f`Y`b`W`g`|b`8G`!`5`8` `c`b`g`Y`h`U`b`X`d`f`c`|` f`Y`g`g`c`b`"
- 9l`U`a` |b`Y`Y`b`j` |f`c`b`a` Y`b`U` U`b`X`V`Y` \`U`j`c`f`U` Z`U`W`c`f`g`f`Y`|` "Z`Y`X` W`h`c`b`z`k` c`f` z` \`c`a` Y`g`M`h`|b|` g`L`U`b`X`  
f`|`g` Z`U`W`c`f`g`f`Y`|` "z`|`Z`g`m`Y`z`X`|`Y`z`Y` Y`f`V`g`y`z`g`Y`d`z`g` V`g`U`b`W`i` g`Y`L`c` `V`h`h`f`i` b`X`f`g`U`b`X`h`Y`  
|a` dUW`c`b`W`|`b|`h`c`b`U`b`X`V`c`X`m`g`h`Y`a` Z`b`W`|`c`b`z`|b`W`X|b|` W`X`c`j` U`g`W`U`f` \`U`h`"
- 7` \`U`f`h`h`Y`h`U`Y`W`c`f`m`c`Z`g`l` X`Z`Z`f`Y`b`W`g`U`b`X`W`!`c`W`W`f`|b|` `W`b`X`|`h`c`b`g`c`b`h`Y` \`U`h` c`Z`  
d`Y`c`d`Y`k` |h` 8G`c`j` Y`f`h`a` Y`"
- 8`Yj`Ycd`Xj` Yfg`Y`W` \`c`f`|`g`Z`f` |X`b`h`Z`n`|b|` `U`b`X`j` U`|`X`h`|b|` `d`U`g`a` U`V`c`a` U`f`\_`Y`g`"
- b`W`X`Y`U`g`g`Y`g`g`a` Y`b`g`c`Z`W`|`b`|`h`j` Y`z`Z`b`W`|`c`b`U` U`b`X`a` c`l`c`f`g`|` `g`f`|b`W`X|b|` `Y`l`Y`M`h`j` Y`  
Z`b`W`|`c`b`z`g`Y`W`#`U`b`|`i` U`Y`U`b`X` \`U`f`|b|` z`U`b`X`V`Y` \`U`j`c`f`g`f`|b`W`X|b|` j` U`|`X`U`X`a` Y`h`c`X`g`l`c`  
a` Y`U`g` f`Y`U`U`h`j` Y`V`Y` \`U`j`c`f`g`U`b`X`g` W`g`g`z` `|b`X`d`l`

Y

X

- 9l Ůa ]bYh.Ydfj UYbWcZbY fc`c[ ]W ŮbXdgnWc`c[ ]W ŮwbX]hcbg]b'dYcd`Yk ]h`8G  
UWcgg h`Y`ZgdUb)z]bW X]b[ ]XbhZVh]cb`cZj Uf]U]cbgVmfUW#h.b]Wnřgyl žUbXef`  
[ Yc[ fUd\nm`7c`WmXUcb'5 hmb]cb 8YZVW# naMUMj ]lm8 ]gcfXf f5 8< 8LŮbX  
5i hga`GdYmfi a`8]gcfXf f5 G8L/a YbU`YUh X]gcfXf gžg W'Ug XdfYgg]cbžUbl ]Ynř



- 7cbX WYd|Xa |c`c| |W fYUFW cb hYdfy UYbWcZMbWfġ|bW X|b| `Yi \_Ya |Uġ|b` dYcdYk |h`8G UMcġġhY`|ZġdUb`UbXdUfh|W Uf m|b`W|`XccX`zUbXhYg fj lj U|`|mi cZh YġYbWfUg Wa dFYXlc`hY| YbYU`dcdi`U|cb``7\ UUMF|nYbYi fcW| b|hj Yz VY U| |cfUzUbXei U|hm|cZ`|ZY ci hWa YġfYUHXlc` WbWf hYfUdm|b`dYcdYk |h`8Gz Wb|h|bi |b|`h`fci |`g fj lj cfg`|dZlc`|Xb|h|Znf|g` ZMcfgZcf`dccbYf`ci hWa YġUbXh|f| Yg Zcf`|b|h|j Yb|h|cbg`
- 7cbX WfYUFWlc`YġU|g` hYdfy UYbWcZ| i h# U|fc|b|h|j|bU#|j Yf# |XbYn#UXXf WbX|h|cbg|b`dYcdYk |h`8G UMcġġhY`|ZġdUb`z|bW X|b|`|Xb|h|Z|W|h|cb`cZj U|U|cbg Vn|U Yz fUW#h|b|V|h|z|g| Zcf`| Yc| fUd`n|`7cbX WU`cb| |h|X|bU`W`cf|h|g|h XmcZ Xngd`U| |U|b`W|`X`Yb`k |h`8G`
- 7cbX WYd|Xa |c`c| |W fYUFWlc`YġU|g` hYdfy UYbWcZg`|b`WbX|h|cbg|b`dYcdY k |h`8G UMcġġhY`|ZġdUb`%
- 7cbX WbUhfU`|g|cf|h|g|h X|YġcZa i gW`cg`YYU`WbX|h|cbg|b`dYcdYk |h`8G UMcġġ hY`|ZġdUb`%
- 7cbX WXXZ|b|h|j Yd|Xa |c`c| |W`g|h|X|Yġlc`YġU|g` hYdfy UYbWcZ|UWYg|b` dYcdYk |h`8G UMcġġhY`|ZġdUb`z|bW X|b|`|Xb|h|Z|W|h|cb`cZdfchW|h|j YUbXf|g` ZMcfgZcf`h`YġY`WbX|h|cbg`
- 7ca d|`YX|U`cb`h`Y`Y|c`c|`m|UbX|h|a |b|`cZa YUvc`|W`k`Y|`|h|g|h|U`g`W|U|b|`Yg|b`dYcdY k |h`8G UMcġġhY`|ZġdUb`UbX`h`Ydfy UYbWcZg`Y`WbX`f`m`WbX|h|cbg`U`g`c`V`U`X`k |h` c`V`g|h`i`
- Gh Xn`ck`h`Y|a a i bY`gn|h`a`a`U`i`f`y`g|b|b`X|j |X`U`g`k |h`8G`Z`ca`|b`Z`U`b`W`h`f`c`i`|` U`k`|`h`cc`X`z`U`X`ck`h`Y`d`f`c`W`g`g`a`|`|`h`X`Z`Z`f`Z`ca`h`Y`g`U`a`Y`a`U`i`f`U`h`c`b`d`f`c`W`g`g|b`h`c`g`Y` k |h`ci`h`8G``7cbX W`cb| |h|X|bU`g|h|X|Yġlc`a`Ud`h`Y|a`a`i`b`Y`gn|h`a`z|b`W`f`d`c`f`U`h|b|` |b`Z`U`a`a`U`c`f`m`a`U`f`\_`Y`f`ġ`g`g`W`d|h`V`|`|h`m`c`|b`Z`W`h|cbg`z`U`b`X`f`y`g`d`c`b`g`Y`g`lc`j`U`W`b`Y`g`
- Gh Xn`7C`f`cb`U`=i`g`8`|g`U`g`Y`&S`%`f`7`C`J`-8`!`%`L`f`|g`\_`U`b`X`a`|h|`U`h`c`b`g`h`U`M`|`Y`g`Z`c`f`d`Y`c`d`Y` k |h`8G`z|bW X|b|`X|Z|f`Y`b|h|U`Y`Z`M`g`c`Z`G`5`F`G`!`7`c`J`!`&|b`Z`W`h|cb`c`b`d`Y`c`d`Y`k |h`8G` UMcġġhY`|ZġdUbz|b|j U|ci g`lj |b|`g`h|h|b|`g``7cbX W|U`cf`X`g`h`X|Y`g`c`Z`Y`Z`W`h|j`Y`X`c`g`b|` UbX|a`a`i`b`Y`f`y`g`d`c`b`g`Y`lc`j`U`W`b`Y`g`lc`d`f`y`Y`b`h`7`C`J`-8`!`%`|b`d`Y`c`d`Y`k |h`8G`

%7cbX|h|cbgZcf`g|h`Xn`W`i`X|bW`XY`U`M`Y`H`W``na`d`c`|X`Y`i`\_`Ya`|U`Z`U`M`Y`6`!`W``na`d`c`|X`Y`i`\_`Ya`|U`Z`U`M`Y` a`n`Y`c`|X`Y`i`\_`Ya`|U`Z`W`f`c`b|W`na`d`c`W`h|W`Y`i`\_`Ya`|U`Z`W`f`c`b|W`a`n`Y`c`|X`Y`i`\_`Ya`|U`Z`H`f`U`b`g`Y`b`h`a`n`Y`c`d`f`c`|Z`f`U`h`j`Y` 8`|g`f`X`f`z`U`b`X`H`f`U`b`g`Y`b`h`5`V`b`c`f`a`U`A`n`Y`c`d`c`|Y`g`g`

%7cbX|h|cbgZcf`g|h`Xn`W`i`X|bW`XY|`U`h`c`Y`g`d`U`Y`U`f`Y`Z`i`l`z`W`f`c`b|W`b`g`h`d`U`h`c`b`z`W`f`c`b|W`X|U`f`\_`U`z`X`ng`d`U`|U`Z` W`|U`W`X|g`U`g`z`<`|f`g`W`g`f`i`b|`X`g`U`g`z`d`m`c`f|W`h`b`c`g`g`z`|f`f`|U`V`Y`V`c`k`Y`g`n`b`X`c`a`Y`z`|b`Z`U`a`a`U`c`f`m`v`c`k`Y`X`g`U`g`z`d`Y`d`h`W` i`W`f`z`|U`g`c`b`y`z`\_`Y`a`c`f`c`|X`g`z`X`j`Y`h`W`|h`g`z`X`c`X`b`U`U`h`Y`g`U`z`g`h`b`c`g`l`c`f`k`Y`z`U`b`U`g`h`b`c`g`l`c`f`U`h`Y`g`U`z`Y`g`d`U`Y`U` U`f`Y`g`U`z`X`ng`f`|U`z`j`c`|X|b|`X`ng`z`b`W`i`c`b`z`\_`|X`b`Y`m`X`g`U`g`z`W`h`g`|W`X`ng`d`U`g`|W`|X`b`Y`n`z`n`X`f`c`b`Y`d`f`c`g`l`z`n`X`f`c`i`f`Y`h`f`z` d`c`g`h`f`c`f`U`h`f`c`f`i`f`Y`h`f`U`j`U`j`Y`g`z`f`b`U`U`Y`b`Y`g`g`z`j`Y`g`W`i`f`Y`h`f`U`f`Y`Z`i`l`z`U`b`X`b`c`b`U`W`c`|W`Z`U`h`m`|j`Y`f`X`g`U`g`Y`

%7cbX|h|cbgZcf`g|h`Xn`W`i`X|bW`XY`U`W`Y`Z`U`c`d`Y`M`U`f`Y`U`z`U`c`d`|W`X`Y`f`a`U`h`h`g`#`W`Y`a`U`z`V`c`|`g`#`|X`U`X`b`|h`g` g`d`d`i`f`h`j`U`z`c`|W`|h`g`z`W`i`|h`g`z`d`g`f`|U`g`g`z` G`H`U`P`G`H` -`

---

## *Program Portrait 2 Cohort Development*

### **DS-Connect®: The Down Syndrome Registry**

Hc`U [ a Yb]lgfYgUFW`cb`8GzB=7< 8 `U bWYX8G!7cbbYMi. `HY8ckb`GnbXfca YFY [lgfmi  
f`hdg #8G7cbbYMi\`"cj L]b`&S% "" H]gfYgUFW fy [lgfmižg ddcfHXVrh YgYZUj cWNgz  
Za ]`na Ya Vfgz8G`cf [ Ub]nUjcbg`UbXZci bXUjcbgž`UbXB< =7Cgk ]h]b`h`Y8G`7cbg`fhi a  
fgY5ddYbX] 5LzUa g`lc`ZUW]HUY]bZcfa Ujcb`g`Uf]b [ `Ua cb [ `dMfgcbgk ]h`8GzZa ]`Ygž`UbX  
fYgUFWYfg`VmW``YMi]b [ `Xa c [ fUd\]WbX`YUh ]bZcfa Ujcb`Uci hdy`cd`Yk ]h`8G`h`fci [ \ `U  
gf]Yg`cZcb`]bYg`fj`Yng`" H]g`WbZ`Xb]Užg`W`fYz`UbX`fyg`dcb`gj`Yk`Wgl]Yk`Ug`Ugc`h`Ubg`U`X  
]b`c`GdU]g` ]b`&S% " G]bW`&S% žbYf`m) ž`S`]bXj ]X`Ugk ]h`8G`U`Y`fY [lgfYX`"

HY8G!7cbbYMi`dfcZgg]cbU`dcfU`k`Ug`U`bWYX]b`&S% `lc`U`ck`U`d`f`c`j`YX]b`j`Yg] [U`c`f`g`z  
W]b]W]b`g`z`UbX`ch`Y`f`ei`U]Z`Y`X`d`f`c`Z`g`g]`c`b`U`g`lc`U`W`g`g`h`Y`X`Y`!`X`b`h`Z`Y`X`X`U`U`W``Y`M`X`h`f`ci` [ `h`Y  
fY [lgfmi`a`c`f`Y`h`U`b`(`,`S`f`Y`g`U`f`W`f`g`W`f`f`b`h`m`c`X`U`d`f`c`Z`g`g]`c`b`U`U`W`i`b`h`H`Y`d`f`c`Z`g`g]`c`b`U`d`c`f`U  
c`Z`f`g`h`f`Y`Y`Y`g`c`Z`U`W`g`g`%`L`j`]`k`]`b` [ `U` [ `f`Y`U`h`z`X`Y`!`X`b`h`Z`Y`X`X`U`U`c`f`g`f`j`Y`m`W`b`h`b`h`c`b`m`  
&L`d`f`Z`c`f`a`]`b` [ `W`g`c`a`]`n`Y`g`U`f`W`Y`g`c`f`g`U`h`g`]`W`Y`j`U`i`U`j`c`b`Z`c`f`U`b`U`ng`g`z`d`i`V`]`W`h`c`b`z`c`f`  
d`f`Y`g`b`h`U`j`c`b`/`U`X`'`L`f`Y`M`i`]`h`b` [ `d`U`h`]`W`d`U`b`g`Z`c`f`f`Y`g`U`f`W`c`f`W`b]W`g`h`X`m`

---

UbXyl dUbX]b[ \WffYbhW]b]W WfY[ i ]XY]bYgYgU]g\ \XVmih YdfcZygg]cbU`a YX]W`UbX  
V\Uj ]cfU`gV]M]YgZcfU`U`U Y[ fci dg`cZdYcdYk ]h`8G"

## Define DS Phenotypes

- 7cbj YbYUdUbY cZYl dYf]g]f]bW`X]b[ `Vch`W]b]M]Ubg`UbXfYgYUfWf]g]Lcb`8G`lc`XZ]bY  
8Gd\Ybchm]YgU]M`cgg`h`Y`]Z]gdUb`i`gb[ Uj`U`U`WYW]b]W`UbX[ YbY]W]U]U`-bZcfa`h`Y  
Xj`Ycda`YbhcZi`dX]U]XW]b]W`[ i ]XY]bYg]lc`]a`dfcj`YWfYZcf`dYcd`Yk`]h`8G`Vm  
]bW]dfcfU]b[ `X]U]cb`W]b[ YgfYU]h`X]lc`g]U`YgcZ`]ZYf]M`["z]bZ]La`a`U]cb`UbX  
a`Y]U]c`]ga`Ez`UbX`cb`U`Yf]b[ Ygk`Yb`Ub`]b]M]j`Yb]h]cb`a`][`h`W]a`cg]h`ZZ]M]j`Y`"
- =>X]b]Z]h`8G`d\Ybchm]Yg`UbX[ Ybchm]M`d\Ybchm]YUgg`V]U]h]cbg]z]b]W`X]b[ `V\Uj`]cfU`UbX  
Xj`Ycda`Yb]U`a`]`Yg]cbYg]z]lc`]bZcfa` . i`bX]Yg]U]b]X]b[ `cZ]b]U]h`fU`\]g]c]f]m]z]V]M`]b]b]b[ `]  
dfYb]U]U`m]UbX]b]W`X]b[ `di`V]f]m]UbX]U]M`h`ccX`h`Y]h]a`]b[ `cZ]UbX]U]f[ YgZcf  
]b]M]j`Yb]h]cb]g]lc`]a`dfcj`YW]b]h]cb]cf`]b]M]j`YbY]b]f]Y]f]Ygg]cb/h`Y]Y]c`i`h]cb]cZ  
W]a`a`i`b]W]h]cb]g`.]`g`UbX`d]U]h`c`c`[ Yg]h`U]h]U]Z]Y]M`Y]f]b[ z]V]U]b]W]z]UbX]j`]g]cb"
- 9l`d`cfYX]Z]Z]f]Yb]W]g`lc`U]g]M]U]b]k`\n]g]d]cb]U]b]Yci`g]Z]H]U`cgg`c]W]f]g]cb`n]i]b]g]a`Y  
W]Yg]c]Z]h]g]ca`m]g]z]k`\Y]h`Y]f`h`Y`d`U]W]b]U]W]b`dfcj`]XY]b]g]l`\]g]cb`h`Yg]Y`df]Y`b]U]b]W]h`cgg]Yg]z  
UbXk`\Yb`h`Y]U`]b[ `dfc]W]gg`V]M`]b]g"

## Improve Clinical Research and Therapeutics

- @y`Yf]U`Yh`Yi`b]ei`Ycddcf]i`b]h]Yg]h`U]h]W]a`Y]Z]ca`dfYb]U]U`g]M]Y]b]b[ `Zcf`8G`U]g]d]U]h]cZ  
fci`h]b]Y`dfYb]U]U`W]f]Z]UbX]i`bX]Y]g]U]b]X]h`Y]fc`YcZ]h`Y`d`U]W]b]U]b]b`h`Y]X]Y`Ycd]b[ `Z]h]g`":`cf  
Y]U]a`d`Y]z]X]b]h]Z]h]b[ `Z]h]g]Yg]k`]h`8G`]b`W]b]h]bi`]b[ `df]Y`b]U]b]W]g]W]Y]U]h]g]h`Y`dcgg]V`]h]m]cZ  
cZ]Z]f]b[

- 7cbXl WlWlWlWlWl fYgYfWlc UgYgg'hYYZlWlWlcZl]bhfj Yb]cbgZcf]a dfcj YXWl b]h]cbž Wl a i b]Wl]cbž\Yf]b] 'UbXVUUbWZUbXj ]g]cb"
- =bWlXl'dYcd'Yk ]h '8G]b WlWlWl h]UgcZj UWl]bYgUbXhYUa Yb]gž]bWlX]b] '7CJ =8!% ' j UWl]bYgžUg'h YmVWl YU U'UY'
- =bWlXl'dYcd'Yk ]h '8G'UbXhYf WfYl ]j Yfg] ddcfYfghfci [ \ci h]hYWl]Wl fYgYfW dfcWggžVl ]bb]b] 'k ]h 'gh XnXg] bžUbXXj Ycd'gfU] ]Yg]c ]bWl]bYg'h YdU]Wl]U]cb' cZdYcd'Yk ]h '8G'cZl]Zl]fYb]U Yžg] žfUW#h]b]Wl]m]bXg]VcYWl]bca ]Vg]U]g]b' fYgYfW"
- 7cbg]Xf'Xj Ycd]b] 'di V]Wdf]j UYdU]bYfg\]dgk ]h 'V]chWl]bc`c] m] Wl dU]Yg#Ufa UWl h]Wl ]bX] g]m]c h]g]g]V]Z]Wl YU]Y h]W]Zcf dYcd'Yk ]h '8G'"""
- < Ufa cb]nYWl]Wl h]U'dfc]cW'gžk \Yb'dcgg]VYžk ]h ]b]Yb]U]cbU'YZc]f]g]c YbUY a Yb]b]Z `XlUg]Uf]b] "'8Y Ycd'g]g]U]bUYX]U]bcg]Wdfc]cW'gUbXYf m]b]hfj Yb]cb'

hY`Uf Ydfcdcfhcb cZW]`XfYb k ]h 8G Vcfb`k ]h `Wb] Yb]U` \YfhWbX]hcbg`h YgY  
ci hWa Yg'a Uhj UfmY`Yb`Ua cb] `W]`XfYb`k ]h `8G`k`c` \Uj Yh YgLa Y`YfhXZYMg UbX  
fYW]j Yh YgLa YfhYUa Yb]g Ug`hnd]W` mXj Ycd]b] `W]`XfYb`

- Gh Xmi]a a i bY`g`h`a` X]ZfYbWg]bZ`UbXf]g` ZUMfgUbXdc]h]U` hYUa Yb]g`Zcf`W!  
cWff]b] ` a`cghWa a cb]b`dYcd`Yk ]h `8G`%`zUbXXZ]bYh`YZ` ``  
]a dUMcZU`lc]a a i b]hmc]b`h`Y` \YU`h`cZdYcd`Yk ]h `8G`" Gh Xnk` \Yh`Y`h`YUa` YbhcZ  
U`lc]a a i bY`g` ]b`WbX]hcbg`a` UmUXMYgg`W!`cWff]b] `U`lc]a a i bY`WbX]hcbg`" 7cbX] W  
fYgUFW`lc` X]Yfa ]bYk` \Yh`Yf`]b`dYcd`Yk ]h `8G`Z` \Uj ]b] `cbYU`lc]a a i bY`X]gcf`Xf`  
dfY]gdcgY`h`Ya` `lc`ch`Y`U`lc]a a i bY`WbX]hcbg`
- 8YgU]VYa`cfYZ` `mi` ]b`8Gz`UbXXj` Ycd`hUf]` YXh`YfUd]Yg`h`c`  
UXMYgg`]h`" Gh Xn`ck` ZU`YXa` ]lc`WcbX]U` Z`bW]cb`UbXfYU`Xcl` ]XUj` Yg`fYgg]a` dUM  
h`YfYU]hcbg` \d`Wk` Yb`bY`fc`c` ]VZ` bW]cbz`W]` b]h]` YXZ]W]g`z`UbX58`"
- 7cbX] WfYgUFW`cb`h`Y`cb]` !h`fa` \YU`h` ]a` dUMcZj` Uf]ci` g`hnd]Yg`cZ` z]bW`X]b]`  
k` \Yh`Y` \Uj ]b] `hnd]Y%`X]UMh]g` ]bW]UgY`h`Y`WUbW`cZ`Xj` Ycd]b]` ch`Yf`U`lc]a a i bY`  
WbX]hcbg`z`UbXk` \Yh`Y` Yf`m`fYUa` YbhcZ`hnd]Y`&`X]UMh]g`Wb`fYX]`W`cb]` Yf]h`fa` \YU`h`  
]gg` Yg`g` W`Ug` \Yfh`X]g`Ug`z`gfc`\_`Yz` ]gcb`dfc`V`Ya` g`z`bY` fcd`h`n`z`UbX`\_`]XbYm`X]g`Ug`Y`"
- Gh Xn]h`Y`cb]` !h`fa` \YU`h` YZ]Mg`cZ` ]b`dYcd`Yk ]h `8Gz` ]bW`X]b]` . `Wb]g`XfU]h`cb`  
cZg]l` z`fUW`Z`h`b]V]h`z`UbX`g`V`c`Wbca` ]Vg`U`h`g`k` \U]b]h]j` Yb]hcbg`f]j` W`Ug`X]Yh`UbX`  
Y`Yf]g`La` ]j` \h`Ug]g]h]b`a` Ub]`Ya` Yb]h`UbXk` \m`]d]X`Y` Yg]b`dYcd`Yk ]h `8G`k`c` UfY`  
cVgY`UfYc`Z`h`k` ]h]b`Ubca`U`fub]`Y`"
- Gh Xni` ]b`dYcd`Yk ]h `8G`lc` i` bX]fg`UbX`ck` `j]` Yf`  
Xng]z` bW]cb`a` Um`Wb]f]V]` h`Y`lc`ch`Y`f`W!`cWff]b]` `WbX]hcbg`"
- 7cbX] WfYgUFW`cb`bi` h]Ybh`Ug`cdf]hcb`UbXa` YfUc`]ga` ]b`dYcd`Yk ]h `8G`f]gca` Y]a` Yg`  
W`YXh`Y`[`i` hV]ub`U` ]g`lc` i` bX]fg`UbXdf`Y` Yb]j` YUbXf]g` ZUMfg`Zcf` UbX`  
fYU`XX]gcf`Xf`g`
- 7cbX] W]g]h`X]Yg`lc` X]Yfa` ]bYa` cfY`dfW]gY`m]h`Yh`nfc`]X]g]a` i` `U]b]` \cfa`cbY`Y` Y`U`h`  
k` \]W` a`Ub]Z]g`g`X]j` Ycd`hYUa` Yb]g`Zcf` ]b`UX]hcb`lc`  
g]UbX]fX]h`nfc`]X`cfa`cbYa`Ub]`Ya`Yb]h`
- Gh Xn]X]ZfYb]U`fYg`dcbgY`lc`hnd]Yg`cZ]bZ]M]cbg`%`z`Ug`k`Y` `Ug]f]g` ZUMfgUbXdc]h]U`  
hYUa` Yb]g`Zcf`]bX]j` ]X]`Ug`k` ]h `8Gz` ]bW`X]b]` `Ub]V]ch]Vg`z`Ub]j` ]fU`a` YX]W]hcbg`z`  
dfY`Yb]U]j` Yg`f]j` W`Ug`dU]j` ]ri`a` UV`Zcf`F`Yg`d]fU`cfm`G`nb`V]h]U`J` ]fi`g`G`G]`Q`dbY`a`cb]Uz`  
UbX]j` UM]bYg`" Gh Xn`ck` `a`Um]bZi`YbW`cj`YfU` \YU`h`z`cb]`Y` ]h`z`UbX`  
ei`U]hmcZ` ]Z`cZdYcd`Yk ]h `8G`"

% H`YgY`WbX]hcbg]bW`XZ`Vi`h`fY`bch`]a` ]h`X]lc` hnd]Y%`X]UMh]g`z`W]UW]X]g`Ug`z`<`Ug]a`ch`c]h`nfc`]X]h]z`Ucd`WU`  
fYU`Uz`Ucd]V]X]fa`U]h]g`W]W]a`Uz`X]fa`U]h]g` \Yf`d]h]Z`fa` ]g`X]fa`Uca`n`g]h]g` \]X]U`X]b]h]g]g`ddi`fU]j`Uz` ]W]Yb`d`Ubi`g`z`  
]W]Yb`g`W]f`c]g]g`z` ]h` ]]`c`z`d`g`c`f]U]g`d`g`c`f]U]h`W]h`f]h]g`z`U]h`f`cd`h`n`z`f`Y`a`Uc`]X]U`h`f]h]g`z`Ug`W` ]h]g`z` \Ya`c`n]m]W]bYa` ]Uz`  
h`fca`Vc`V]h`c`d]b]W]i`fdi`fUza`n`g]h]g`z`f`g`h]Ygg`Y` ]g`n]X]fa`YffU`Y`m]U`lc]a`a`i`bY`z`A`Yb]Y`Y`g`X]g`Ug`z`U`lc]a`a`i`bY`  
YbW`d`U]h]g`z`]bZ]a`a`Ucfm`vck`Y`X]g`Ug`z`#`fc`b`g`X]g`Ug`z`b`f`W`Y`d`g`z`?`Uk`Ug` ]X]g`Ug`z`D`Y`X]U]f]W]5`Zcf`





- 8 Y Ycd dfy Ybhj Ya YUj fYgUbXlfYUa Ybglc UXYgggfi WifU UbXZ bWjcbU  
Ubcfa U]hYg]b'hYU X]lcfm]bXj Yg]M `Uf'gnghYa gcZdYcdYk ]h `8G'cj Y'hY`ZgdUb`  
lc cd]a ]nY
- 8 Y Ycd]bhj Ybhcb]gfUM] ]Ygi gbl `bcb!d\Ufa UW`c[ ]W UddfcUWYg]c`a Ub] Y  
WbWffYbhW!cWff]bl `WbX]hcbg'g W'UddfcUWYgWi `X]bW XYhWbc`c[ ]Yg]c`  
gha i `UYVU]bZ bW]cbž hc a Ub] YhmlY&X]UW]YgUbXga ]`Uf  
WbX]hcbgžUbX , g W UggcV]U Yb[ U Ya Ybžd\ng]W  
UW] ]mžYX] W]cbU ]bW g]cbžlc Yb\UbVW[ b]hcbUbXV\U ]cf" `9j Ui UYbcb!  
d\Ufa UW`c[ ]W UddfcUWYg]b]bXj ]X] Ug'k ]h `8G!58žZcf Vch ]a dfcj ]b[ W[ b]h] Y  
Z bW]cbUbX`ef dfy Ybh]b[ `W[ b]h] YX]m]cfU]cb"

---

---

---

• 8 Yj Ycd'Udd ]WjcbgZcf a cV] YXj ]Wg'UbXWa di hf! VgXh YfUd] Ygic ]bMMUgY  
]bXdYbXbWZcf dYcd Yk ]h '8G' ]b'UMj ]hYgcZXL`m`j ]b[ žYgdWU`mgYZg ddcfh  
hWbc`c[ ]Ygžlc `Wi gX]b`HY`YUhž`ca Y!VgXžUbXgWcc`gM]b] gic`ja dfcj Y  
`Yfb]b[ `UbXWa a i b]Wjcb" "8 Yj Ycd'UbXef`UdhUggghj YXj ]Wgžg WUg; `cU  
Dcg]hcb]b[ Gng]a g'UbXa cV] YXj ]WgZcf hUbgdchUjcbžcf Xj ]WghUh`Yd'lc`  
ZM]hUY ]bM] fUjcb`cZUb`]bXj ]X U k ]h '8G' ]b'lc`hYk cf\_d`UWžfYgXb]U`cf`ca Y  
Ybj ]fcb a YbžUbXWa a i b]h" " "

• 8 Yj Ycd'UbXj U]XUY ]bMj Yb]cbgž]bW`X]b[ `U [ a YbUj YUbXU]fbUj Y  
Wa a i b]Wjcb Xj ]Wg'UbXch Y'lc`gžUa YXU]a dfcj ]b[ `Ub[ i U Yg.]`g'UbX`Yf]b[ .  
WdU] ]hYg]b`dYcd Yk ]h '8Gžg W'UgghU] ]Ygic`cj YWa YX]Z]W]hYg]b gYWW

- I gY`Yggcbg`YfbYXZca Zā ]`YgDM dYf]YbWgk ]h h`YG5FG!7CJ !&dUbXā ]Wc` Xj Ycd`ghUM ]Yg`hU]bW`XYdYcd`Yk ]h`8G`]b`d`Ubb]b] `Zcf`Z`h`fydi`V]WYU`h`UbX X]g`g`Yf`dYdUfYXbYgg`YZcfhg`g`W`Uga`U]bh]b]b]` WfY] ]j`Yf`UW`gg`lc`]bXj ]X`Ugk ]h`8G`k`c`a`UmY]gc`U`X]b`h`Y`cg]hU`".....

## Increase Indusion of People with DS in Research

- HU`Y]b]lc`U`W`i`b]k` \`Yb`X]g] ]b]b] `g`d]M]Z]W]Y]g]U]F]W]g]i`X]Y]g` \`ck` `dch]b]h]U`d]U]h]M]d]U]b]g` j ]Yk` h`Ya`g`Y`j`Y`g`f]b]W`X]b] `]X]b]h]h]Y`g`c`Z`f`U`W`Z` ]b`X]f`z`W`U`g`z`U`b`X`g`M`i`U`cf] ]b]h]U]cb]L`U`b`Z` lc`h`Y`Y] h`b]h]Z]U]g]V]Z`f`W`i` ]h]X]j`Y`f`g`Y`d`c`d`i` `U]h]c]b]g`c`Z`d`Y`c`d`Y`k` ]h`8G`]b]lc`f`Y`g`U]F]W]g]i`X]Y`g`
- 8`y`Y`c`d`f`Y`g`U]F]W]g]i`X`r`i`a`U`h]f] ]U`g`h`U`i`U]F]U`W`g]V]Y]lc` ]b]X]j` ]X`U`g`k` ]h`8G`z`]b]W`X]b] ` `g]i`X`m`X]g]M]d]h]c]b]g`z`]b]Z`c`f`a`Y`X`W`b]g]b]h]f`g]Y`b]h]X`c`W`a`Y`b]g`z`U`b`X] ]b]Z`c`f`a`U]h]c]b`c]b` `W`b]Z`X]b]h]U] ]m]U`b`X`d`f]j`U`w`c`Z`X]U`U` `9]b] ]U`Y`d`Y`c`d`Y`k` ]h`8G`U`b`X`h`Y]f`W`f]Y] ]j`Y`f`g] ]b`g]i`X`r`i` X]g] ]b]lc` ]b]W`Y]g]Y`h`Y`U`d`f`c`d`f] ]U`h]b]Y`g`c`Z`h`Y`g`Y`a`U`h]f] ]U`g`U`b`X`Y`b]g`f`Y`h`U`h`Y`d`f`Y`g]b]h]U]h]c]b` `c`Z`f`Y`g]U]F]W]h`c`d] ]W`U`b`X`f`Y`g` `h`g`X`c`Y`g`b`c`h`i`b] ]b]h]b]h]c]b]U`m]M`g`Y`d`g]n]W`c`c` ]W`g]f`Y`g] ]b` `dch]b]h]U`d]U]h]M]d]U]b]g`d]U]h]M]d]U]Y` ]b`8G`f`Y`U`h`X`c`i`h`Y`U`W`Y`Z`c`f`h`c`g`U`Y`h`Y`U`h]g`

]b]Z`c`f`a`U]h]c]b`U`b`X` \`Y`d` ]b]Z`c`f`a` ]b]X]j` ]X`U`g`k` ]h`8G`U`g]U]F]W`Z`a` ]`Y`g`U`c`i`h`

Z`h`i`g`Y`b`W`i`f`U` ]b] `U`X] ]h]c]b]U`d]U]h]M]d]U]h]c]b] ]b]g]i`X]Y`g`":`c`g]h]f`U`X] ]h]c]b]U`Y`Z`c` `h`c`g`  
 Y`X`i`W`f]Y`f]Y] ]j`Y`f`g`c`Z`d`Y`c`d`Y`k` ]h`8G`U`c`i`h`h`Y`j`

## Expand Knowledge on DS, Aging and

- 9l d'cfYdchHh]U dfchWj YZUc'fgZcf U Y'fYUXXXa Yb]U]bW X]b[ 'Wa d'Ya YbUfmi UbX]bM] fUj Y\YUk UddfcUWYg'Y YV]gZUbXX]Yi'
  - Gh Xmih YgdWZ]W]a dUWcZdcga YbcdU gU \cfa cbYfyd'UWa Ybhih YUdmfk FHLi gYVmi k ca Yb'k ]h '8G'hc X]Mfa ]bY]Z]hfYi Wgh YWa i 'Uj Y
-

HNY567!8G!fYgUfWfYfgk ] ``Zc`ck hYVw\cfhcZdYcdYk ]h`8G!te WbXl WlhfYdfc^Mlg

- =bj Yg]l UY`ck 8G!58 dUfU`YgUbXXjZZfZca`gdcfUjW58`k ]h]b`Ub`Ua mc]XZHu ž bYi fcXl YbYfUjcbZUa Yk cf\_žUbxhc ]Xb]Zria cX]ZYfgcZf]g`cZWb] Yfgcb#tfc[ fYggcb`
- =Xb]Zni YbY]Va cX]ZYfgcZhYXj Ycda YbhcZ8G!58
- HfUbgUYci hWa Yg!te UdfWjgcb a YX]WbYZUa Yk cf\_ UbXYi dYX]YVWb]W`hf]Ug

=a dcfUbnznZhYbYl h]MfUjcb`cZ567!8G]bW XgUb Ya d\Ujgcb]bWUg]b[`hYXj Yfg]mcZ ]bXj ]X] Ug]b hYVw\cfhcZUk`lgk ]h`8G`HNY58#8G!Ci hfYUWZFWW`]la YbzUbX 9b[ U Ya Ybh7cfYk ]`fUd]XmXggYa ]bUY]bZfa Ujcb hc 8G`Wa a i b]h]YgUbXYb[ U Y i bXffYdfYgYbHXfUWU Yhb]W fci dg`"

### E. Research Infrastructure and Tools

8]U bcg]WbXgWYb]b[ a Yuj fYgi gYXZcf 8G`UbXfYUHXWbX]hcbg`Uj YWb]bi YXhc`Yj c`j Y ]b`fYWbhmUfg`< ck Yj Yfzi h`]nUjcb`cZa cfYg]M]U]nYXa Yuj fYgcZZ bW]cb]b[ UMcgg Xca UjbgWi`XZUW]hUYa cfYfY]bYXd`Ybchm]b[ `UbX]Xb]Z]W]hcb`cZ]ca Uf`YfgZcf a YX]Wž W[ b]h] YZUbXVY`Uj ]cfU`WbX]hcbg`fYUHXhc`8G`

=b`hYbYUf`hfa žhYg]Wb]Z]Wwa a i b]mbYXg!te`Z fh`Yf`]a dcfj Ylcc`gžhWb]ei Ygža YhcXgž UbXa Yuj fYg!te`a cj Ylck fXUa ]b]a i a`gYhcZwa a cb`a Yuj fYgZcf`i gYUMcgggi X]YgžU Y [ fci dgžUbXXj Ycda YbU`UbXVY`Uj ]cfU`Xca Ujbg`" HNYZ]YXa UnWb]ZhZca`UbU`fY`Ya Ybh cb`Wa a cb`Xca Ujbg`UbXcb`UWfYgYhcZg]UbXfX]nYXhgg`UbXa Yuj fYgh`UhWb`VYUgYggX]b` W]b]W`fYgUfW`cb`8G!te`U`ck`Zcf`Wa`dUfU]`]mUMcgggi X]Ygžcb]b[`h`UhXca Ujbg Ud]dcdf]UYZcf`cbYgU`YcZ`]Z`a`UrbchVYUd]dcdf]UYZcf`ch`Yfg` =b`UXX]hcbza`U`]b[`Wa`a`cb` fYgUfW`fYgci`fWgU`U`UVYhc`fYgUfWfYgž`W`Ug`bYk`a`cXYg`Zcf`8Gž`fYgUfW`]bZUg]fi`Wi`fYž` UbXX]U`UbX]hgg`YfYdcg]hcf]Ygžk`]``U`ck`fYgUfW`lc`a`cj`YZcfk`fXa`cfYfUd]Xni`

#### Expand Research Tools

- 8Y Ycd`UXX]hcbU`bYk`a`cXY`gnhYa`gZcf`gi`Xn]b[`8G`Uh`h`YW`i`Ufzcf[`Ub`f]b`UXX]hcb` hc`VU]bZ`UbX[`YbY]WYj`Yg`"
- Gh`Xni`h`YYZZ`Mg`cZdYfi`fUjcb`cZ]bXj`]Xi`U`Wfca`cgca`Y&%[`YbYgcb`h`Y` X]ZZ`fYb]Ujcb`UbXa`Ui`fUjcb`cZbYi`fcbgž`[`]Už`UbX`gnb`UdYg]b`VU]b`cf[`Ubc]Xgž`Ugk`Y` Ug]ba`cXY`cf[`Ub]ga`gg`W`UgC.` UbX8fcgd`]`U`
- 8Y Ycd`UbXg`ddcfhbYk`Ub]a`U`f]`Yža`ci`gžf`Užcf`B<`DL`a`cXY`gZcf`WbXl`W]b[` dfYW]b]W`fYgUfW`cb`8Gž`]bW`X]b[`hYg]b[`d`Ufa`UW`c[`]W`UbX[`YbY]W]b]fj`Yb]hcbgž` UbX`WbXl`W]b[`UbUca`]W`UbXVY`Uj`]cfU`Ub`UngYgcZM]b`Xj`Ycda`Yb]`Df]cf]h`nY`h`Y` Xj`Ycda`YbhcZa`cXY`gh`Uha`]b]a`]nYbcb!`Wfca`cgca`Y&%[`YbY]W]W]b[`Ygž`UbX`h`cgY` h`UhWb`fYZ`W]h`Yg]fi`Wi`fU`WUb[`Yg]b`h`Y`a`i`Ub`VU]b`UbX]a`a`i`bY`gnhYa`k`]h`ci`h` ]b]fci`Xi`W]b[`Yi`hfUbYci`g[`YbY]Va`Uhf]U`"...

- 8Yj Ycd'UbXg ddcfhibYk `i a UbW`i `U#ef[ Ubc]XW`hi fygZcf`WbX W|b[ `dfYW|b|W  
fygUfW cb 8G"
- 8Yg| b'bYk `fYUa YbhdUfU| a g'UbXdUk UngZcf`Yg|b| `]b'8G'a ci gYa cXYg  
fg|W|W`nžXcg!fygcbgYUbXlcl |W|mg|X|Yg|"
- 8Yj Ycd'bUbchYWbc`c[ mUbXchYf ga U`!a c`YW`YUdfcUWYg|c`Yb\UbW`Wb|f|g|cZ  
Ua mc|X|a U |b| `fYU YbgZcf ZbYf`fYc`i hcb`g|X|Yg|b`nci b| Y`|bXj |X| Ugk |h 8G"
- 8Yj Ycd`i a Ub'8GW`i `U`a cXYg|f| [ `ž|DG7gX|ZZfYb|U|X|]b|c`bY fcbU`W`hi fyg|c  
g|Xnj Uf|U|cbgVmg| UbXUbW|fm|
- I gYVch` UbX a cXY`g|Y`g|c`g|Xm|W|X|c| UgW`U`Z`bW|cb`UbX`h`YfUdm  
fygcbgY"
- FYZ|bYci hWa Ya YUj fygUfYUxj U|X|hXZcf`g|Xm|b| `dYcd`Yk |h`8GžUbX|ggYa |bU|Y  
hYgYci hWa Ya YUj fyg|c`hYfygUfW`Wa a i b|lm| 9a d`UgnYa YUj fyghU`U`Y  
X|a cbg|U|Y|W|b|W`i |h`|hžg`W`Ug|X|b|Z|b| `WUb| Yg|b`Ub| i U`Y`V`U`j |cfž  
W| b|]hcbžcf`U|U|h|j Yg\_|`g|`6i |`Xcb`h`YB`= `Hcc`Vcl `7c| b|h|j Y6U|f|c`Xj Ycd`cf  
U|U|h|X|]hcbU ci hWa Ya YUj fygZcf`g|Xm|b| `ck`!Z`bW|cb|b| žj Yfnci b| `W|`X|Y|žcf  
Uc`Yg|W|gk |h`8G|`FUW`ci hWa YgX|f|b| `Yf`m|Xj Ycda Yb|c`U`ck`Y`U`i`U|cb`cZ  
hY|a dU|cZ



- 8 Yj Ycd:gMYb]b[ 'hcc`gZcf`XdfYgg]cbžUbl ]YmžUbXch.Yf`W!cWff]b[ 'a YbU`YUH` WbX]hcbg]b'dYcd`Yk ]h`8G''''
- 8 Yj Ycd`X]U bcg]WbXgMYb]b[ 'hcc`gZcf`Ya Ue`c[ ]W]gcfXfg]b'dYcd`Yk ]h`8G`c dYfa ]hU`cfYXlfYUa Yb'i
- FYZ]bYh`YX]U bcg]WbXgMYb]b[ 'hcc`gZcf`j ]gcb!fYU`XWbX]hcbg]b'dYcd`Yk ]h`8G''
-

- K cf\_ k ]h '8G'cf[ Ub]nUjcbg'UbXY dYf]YbWXWb]W'hf]U g]M]U]g]g]lc WMUYUWYgg]VY UbXUddfcdf]UYfYMi ]la Ybha UYf]UgZcf 8G'gh X]YgzhUii gY'Ub[ i U YhU]lgYU]m i bXf]g'UbXUVYlc`dYcd'Yk ]h '8G'UbXh Yf'Za ]`]Yg'WbgXf'Vch`j ]g U'UbXbcb]j ]g U a Uhf]Ug'"`Gh Xn`ck ` \YU`h`WfYdfUW]W`a UmVg]ZcgYf'h`Yyb[ U`Ya`YbhUbX ]bX]dYbXbW'cZdYcd'Yk ]h '8G'"`=Xbh]Znk Ung]lc`Zcg]f`Wa`a`i`b]m]Yb[ U`YXfYg]UfWz W`U'UcfU]b[ `k` \YfYdcgg]VYk ]h`dYcd'Yk ]h '8GzWY] ]j Yfg]j ddcf]Ygž'UbXW`a`a`i`b]m] dUfhYfg/i`gY`Wa`a`i`b]m]U]j ]gcfmVcUfXg'lc`U` [ a`YbhYh]W`fY] ]Yk`g`cZfYg]UfW`Vmi ]bg]h]h]cbU`fY] ]Yk`VcUfXg'"`
- 5i [ a`Ybh]gn]h`a`g`Zcf`XU]U`g`Uf]b[ `cZdi`V]g`YXW`cflg`UbXa`U`YfYg` ]g]U`U`UY]b`U` g]UfWU`YZ`cfa`Uz`]bW`X]b[ `Zcg]f]b[ `]b]m]b]U]cbU`XU]U`g`Uf]b[ '"`7`cbg]Xf`Yg]U]g`]b[ `U` di`V]W]m]U`U`U`W`Y`Z`W`b]f]U`n]X`f`Y`d`c`g]l`c`f`m]Z`f`8G`XU]Z]Y]h`Yf'h`fci` [ `cf]`]b`W`b`i`b]m]cb` k ]h`h`Y`8G`7`cbb]YMi`fY] ]g]f]n]z`g`h`UhfYg]UfWYf`ga`Um`Wa`dUfYh`cgY`XU]U`k ]h`XU]cb` h`Y[ `Yb]fU`d`c`di`U`h]cbz`d`Ycd'Yk ]h`]b]h`Y`YMi`U`Ub`XX]j`Y`c`d`a`Y`b]U`X]g]U]` ]h]Yg`ch`Yf'h`U`b` 8Gz]g]V]b[ ]g`cZ`d`Ycd'Yk ]h`8Gz`Ub`X`d`Ycd'Yk ]h`58'"`8`Yj`Y`cd`h`U]b]b[ `Ub`X`ch`Yf`g`d`dc`f`h` Zcf`8G`W]b]W]g]lc`U`ck`h`Ya`lc`X[ ]h]n]Y`h`Yf`W]b]W`XU]U`Zcf`g`Va`]g]cb`lc`U`W`b]f]U`n]X` fYdc]g]l`c`f`m]U`U]U`g]Z`Ub`X`Y`b]i`f]U`Y`h`Yi`g`Y`c`Z[ `c`W`U`]X`b]h]Z]Yf`g]h`U`i`ck`XU]U`g`Uf]b[ ` V]k`Y`b`XU]U`g]Y`g`k ]h`ci`h`f`Y`U]b[ `dYf`g`c`b`U`m]X`b]h]Z]U`Y]b]Z`cfa`U]cb'"`
- H`fci` [ `h`Y`=B7@ 89`8`U`U`7`ccf]X]b]U]b[ `7`Y`b]h]Z`W`M`U`Y`U`U`f[ `Y`W`c`f`h`g]h`X`m`c`Z` ]b]X]j`]X`U`g`k ]h`8G`U`W`c`g`h`Y`]Z`g]l`U`b`lc`U`W`Y`f`U`Y`f`Y`g]U`f`W`]b]lc`W`!`c`W`f]b[ ` W`b]X]h]cbg'"`D`f`c] ]X]Y`f`Y`g]U`f`W`Y`f`g`U`b`X`h`Y`V`c`U`X`f`8G`W`a`a`i`b]m]k ]h`U`W`g]lc`h`Y`W`c`f`h` XU]U`b`X`XU]U`a`]b]b[ `Ub`X`U`b`U`ng]l`c`c`gž`Ub`X`Z`W]h]Y`XU]U`g`Uf]b[ `Ub`X`]b`U`Y`g`c`Z` XU]U`g]Y`g]i`g]b[ `i`b]e]i`Y]X`b]h]Z]Yf`g]h`U`d`f`Y`g]f]Y]b]X]j`]X`U`W`b]Z`X`b]h]U]m]"`
- 9l`d`Ub`X`h`Y`f`Y`g]U`f`W`]b]Z`U]g]i`W`i`f`Y`Z`f`8G`V`m]Y`g]U]g`]b[ `cf`U` [ a`Y`b]h]b[ `W`U`U`cf`U]h]cbg` U`a`cb[ `Y` ]g]h]b[ `W]b]W`g]h]g`Ub`X`f`Y`g]U`f`W`b`Y`k`cf`\_`g`U`i`a`Y`X]W`#`U`W`X`a` ]W]b]g]h]h]h]cbg` U`W`c`g]h`Y`W`i`b]f]m]h`U`h`W`b]X`i`W`i`f`Y`g]U`f`W`f`Y`U`h`X`lc`8G`Ub`X] ]g`W`!`c`W`f]b[ `W`b]X]h]cbg'"` 9b]W`i`f]U`Y`h`]g`Z`X`f`U]h]cb`c`Z`g]h]g]lc`W`b]X`i`W`i`f`U`f[ `Y`g]i`X]Y`gž`g`W`U`g`U`cb[ ]h`X]b]U`W`c`f`h` g]h`X`m`c`f`a`i`h`g]h]Y`W]b]W`h]f]U`g'`H`c`Z`W]h]U`Y`h`Y`h`f`U`b]g`U]h]cb`c`Z`U`g]W`b]X`h`f`U`b]g`U]h]cbU` f`Y`g]U`f`W`lc`W]b]W`d`f`U`W]Wž`g`W`g]h]g]g`a`ci`X`
  - Gi`d`dc`f`h`U`b`]b]h]f]X]g]M]d`]b]f]m]h]U`a`c`Z`f`Y`g]U`f`W`Y`f`g`U`b`X`W]b]W]U`b]gž`]b]W`X]b[ `h`Y` X]j`Y`c`d`a`Y`b]h]c`Z`b]k`f`Y`g]U`f`W`Y`f`g]b`8Gž`g`a`Y`c`Z`k` \`ca` `a`U`h`i`W`b]X`i`W`i` ]a`d`Y`a`Y`b]h]U]h]cb`g]M]b]W`d`f`c`Y`M]g]lc`Y`b]g]f`Y`h`U`h`Y`i`b`X`f`n]b[ `f`Y`g]U`f`W`f`Y`g] `]g` V`b]Y]Z]h]h`Y`8G`W`a`a`i`b]m]i'"`
  - :`U`W]h]U`Y`Y`b`f`c` `a`Y`b]h]c`Z`W`b]X]h]cb]g]d]W]Z]W]g]V` ]f`ci`d`gž`U`Y`f`U`b[ `Y`gž`c`f` `

- 9gUW]g\ UZXXfU]cb:cZV]cfYdcg]hcf]Yg]hUk ]``dYfa ]hV]cVb\_]b[ :cZW`gřd`Uga Uř gfi a žVMfWfcd]bU`Zi ]XžUbXVfU]b`UbXchYf`hgg YgZcf`fYgUfW`di fdcgYg` ]bW X]b[ ` glā d`YgZca ]bXj ]X Ugk ]h`WbWf`k ]h`8G``=b]f] fUYV]cfYdcg]hcfm]XUk ]h`hY8G! 7cbbWf] fYgUfW`fY] ]gfmUgZUg]VY` G]hU]X]nYglā d`YW`Y]cb`UbXdfcWgg]b[ ` a YhcXc`c[ ]YgUbXdc`]W]gZcf`Wbg]ghbzYei ]hUVYglā d`YX]gf]Vi ]hcbzUbXYgU]g\ fYj ]k`UbXX]gf]Vi ]hcb`dfcWggYgZcf`fYgUfWYf`UWgg]h`hYglā d`Yg]XU` =Xbh]ZnUbX UXXYgg`Uff]YfgUbXa`chj`U]b[ `Z]Wf]g]h`XcbU]cb``7cbg]XfU]cb`g`ci`XUgc`W[ ]j`Yb` h`.
- @]b\_]b[ ]hY8G`fYdcg]hcfm]k ]h`hYB<`BYfc6]c6Ub\_`8s`UbXhYi ]g]b[ `58 FYgUfW`7Yb]Yg6fU]b`6Ub\_g`žg`hUh]gg]YZca`dYcd`Yk ]h`8G`Wb`W` Wā d]fYX]h`h`cgYcVU]bYXZca` ]bXj ]X Ugk ]h`58`UbXchYf`X]gfX]fg
- 7c``W]b[ ]bY`fchm]W`Wb]h`c`glā d`Yg
- 9l`dUbX`ZXXfU`m]Z`bXX`fYgUfW`hU]b]b[ `dfc[`fUā`g]h`Ybg`fYUj`]M]b]h]d]dY]bYcZ` fYgUfWYfgXc]b[ `k`cf\_`]b`8GžUbX`cg]h]W]b]Z]Wk`cf\_g`cdg]hUhV]b[ `Ya`Yf]`b[ ` ]bj`Yg] ]Uc]g]h`[`Yh`Y`k` ]h`YgU]g`YXg]W]b]h]g]b`hYZ]YXZcf`hU]b]b[ `]b`W]b]W`h]Ug`

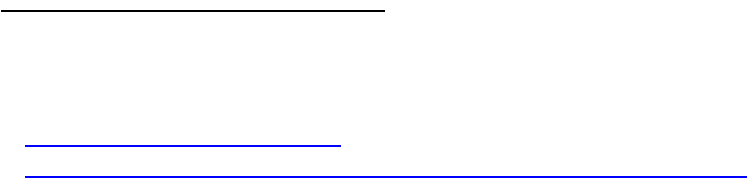
---

***Program Portrait 5 Research Infrastructure and Tools***

**Using the Pediatric Trials Network (PTN) to Test Therapeutics for Children with DS**

Cb`m]Uga U``dYfWb]h]YcZXi [gUbXXj ]WgUd]fcj`YXV]h]YI`"G":`ccXUbX8fi [ ` 5Xa ]b]g]fU]cb`fi`85E`Uj`YVYb`UYXZcf`dYX]Uf]W`gY` B=7<8`YgU]g`YXhYDHB` ]b`&S`\$` h`WbXi`W]b]W`fYgUfW`UbXW`Y]h]XU]h`Ugg]gh`Y: 85 ]b`fY] ]g]b[ `a`YX]W]cb`UYgZcf` gZf`UbXa`cfYZZ]M]j`Yi`gY]b`W]`XfYb`"K`cf\_]b[ `k` ]h`fYgUfW`g]h]g]Ufci`bXh`YWi`b]m]ž`h`Y` DHB`g]i`X]Yg]h`YZca`i`U]cbz`Xc]g]b[`žYZZ]W]m]ž`UbXg`Z]hmcZXi [gžUgk`Y`Uga`YX]W`Xj`]Wgž` Zcf`i`gY]b`W]`XfYb`"H`]g]g]fi`W]fYU`ck`g]h`Yb]k`cf\_`h`UXX]Yga`U]mcZ]h`YWU`Yb[`Y>`f`

h if



---

- ðUX]hcbzXi Ylc`gy YFU`Uf YW`cfhgh X]YgžfYgUFWYfg`Uj YUWihf`i bXfghUbx]b|`cZ hYdUhc d`nglc`c[ mcZ8G!58ž`&`Vi ha cfYfYWbhfWw[ b]hcb`cZUk cff]gca Y ÍfY] fYg]cb|`d`YbchmYfYa ]bXgi`g`cZ`ck`a i Wk Y`Uj YmYhlc`YfbUvci hgca YcZ hYgYw!cWff]b|`bY fc`c[ ]W`WbX]hcbg`"
- K`|`Y]b hYfYwbdUgh hYfY`Ug VYb UdU WmcZa YX]W]hcb hf]UghU]`cfYXlc dYcd`Y k ]h`8Gfk ]h`h`Yi Wdhcb`cZgy YFU`Yi d`cf]b|`hYcd]ja U`WYa ch`YfUdmZcf`W]`X`ccX`Y`\_`Ya ]U]b`8GžUbxgca YZU]`YXhf]Ug]lc`]a dfcj YWw[ b]hcb`cf`y Yb`dfy YbhXá Ybh]Už` h]gg]h U]cb ]g]a dfcj ]b|`ždu]h]W`Uf`nk ]h`g ddcfhZca hY`B7@ 89 Dfc`Ww

H`Y]a dUwicz hY`B7@ 89 Dfc`WwWbchVYi bXfYg]ja UYXžUg]h`Ug]bZ gXh YZ]YXk ]h bYk`Z`bX]b|`žvci [ `h]bYk` ]bj`Ygh] Ucf]g]blc`8GfYgUFWžUbxYbwi fu YXbYk`Ubx]ci hcZ h`Y Vcl`Í`UddfcUWYg]lc`h]gk`Y`!`\_`bck`b`Wfca`cgca`U`X]gcfXfzZ`bX]a`YbU`m`WU]b|`]b|`h`Yw`h`i`fY`cZ8GfYgUFW`WbX]`W]X`Ubx]g`ddcfhXVriB`="`H`Y`Ya`d`Ug]g`cb`g`ddcfhcZhf]U]bYg`Ubx`'1`b]cf`ZUW`hm]Yb|`U`]b|`]b`8GfYUHXfYgUFWžh`fci [ `]bg]h`hcbU`hf]b|b|`[`fubhg`dd`Ya`Yb]gž`7`]b]W`Ubx]hf]Ug]U]cbU`G]WbW5k`UfXg]hf]U]b|b|`g`dd`Ya`Yb]gž`h`YD<`B`G`Wc`Uf]g]dfc[`f]a`fgY`[Dfc\] f\]a`Dcf\]f\]Uj`](#)ÉzUbx]bX]j`]X]U`Z`ck`g`d`Ubx]WfYf`X]j`Ycda`YbhUk`UfXgž]g`fYg`]h]b|`]b`nci`b|`Y`g`W]b]g]g`c]b|b|`h`Y8GfYgUFW`W`a`i`b]m`i`H`YUXX]hcbU`Ya`d`Ug]g`cb`hf]Ug]Z`fa`U]j`YfYgUFW`]g`Ybwi`fu`]b|`bYk`Ubx]Yg]U]g`YX]bj`Ygh] Ucf]g]lc`VfcUW`Yi`W]b|`bYk`UfYg]cZ]bei`]fm]b`h`YUg]Wg]WbW`Xca`U]b`"5`"cZ`h`Yg`a`Ug`fYg]bW]Ug]h`Yd`c`cZ`]bj`Ygh] Ucf]g]bj`c`j`YX]b`8GfYgUFW`Ubx]`Z`"h`Yw`b|`fYg]cbU`a`Ubx]U]lc`Í`Yi`dUbx]h`Y`WffYbhd]dY]bYcZ8GfYgUFWi`fgY`[5`ddYbX\]`9E`"](#)

8Yg]h]Ycb`m]Y]b|`]b`]lg]bZU]Wžk`]h`h`YZ]fghg`dd`Ya`Yb]g]Z`bXXUg`cf]h]ja`YU`cž`h`Y`B7@ 89 Dfc`WwWb`g]`"V]YU`]a`]hX]bi`a`Vf`cZgdW]Z]Wci`h`Wa`Yg`Ubx]X]g]W]j`Y]Yg]b`h`]g`

---



---



---



---

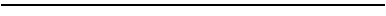


---

g`YbWb|`|bUa ci gYa cXY`cZ8Glc`dfY YbhUa nìc|Xd`Uei YXdcgh|cb|`b`h YVUj`UbXcbgYhcZ  
Xa YbhUgna dIca gk ci `XVYUgf|\_|b|`UWwa d`|g`a YbhUbXUVYU\_hfci [ `|b`h YZYX`

Cb h YW|b|W`g|XZ|a dfcj YXlfYUa YbgZcf`gca YcZha Ya cghWU`Yb|`|b|`UgYWgcZ8G|gU  
k cfhm|`cUzZcf`k`|W`Wa a i b|lm|bdi h|gW|hW" DUFYb|g`cZyb fYdcfhUidccf  
Wa a i b|W|hcb`UbXg|YWW`Ufh|W`U|cbzUg`k Y`Ug`dccb`g`Yd`ei U|lm|fbW`X|b|`VYU|`|b|`dU`gYg  
UbXgbcf|b|`EzUfYgca YcZha Ya cgij Y|`|b|`dfcVYa gZcf`Za`|`YgVWM`gYh`YmWb`Uj`YUa`Ucf`  
|a`dUWbchcb`mcb`hYk`Y`!V|b|`cZha Ydfgcb`k`|h`8GzVi`hUgc`hUhcZch`Yf`Za`|`ma`Ya`Vfg`"  
A`UmZa`|`|YgUgc`ZUf`h`Ydcgg|V|`|hmcZXY`Ycda`YbU`fY`fYgg|cb|`b`h`Y|f`hYbg`UbXnci`b|`  
Uk`lg`k`|h`8GzUbxh`YcbgYhcZXYa`YbhUg`h`Y|f`cj`YXcbYg`k`|h`8G`U`Y`H`YVfcUXf`8G  
Wa a i b|lm|Wi`XYb|`U`Yk`|h`fYgUfWf`g|c`|a`dfcj`Yi`bXfgh`UbX|b|`cZha YW`gYg`UbXfub|`YcZ  
W|b|W`dfYg`b`U|h`cbgZcf`h`YgY`gg`Ygzk`|h`h`Ydf|a`Ufm|`cU`cZXY`Ycd|b|`W|b|W`hf|UgcZha`YgY`  
WbX|h`cbg`gd|W|Z`W`m|b`8G`"Gca`YfYgUfWf`gUfYUk`m`fYXY`Ycd|b|`Ub`58`dfY`Ybhcb`hf|U  
i`gb|`Ub`Ubh|`Ua`nìc|Xh`YfUdnz`UbXh`Yg`Wgg`cZg`WUhf|U`k`ci`XVYUg|`b|Z`Wb`h`Vb`Z|h`Zcf  
|bXj`|X`Ug`UbXZa`|`Yg`"

H`Yi`b|ei`YWU`Yb|`Yg`dcg`XVmh`Y7CJ`-8!%`dUbXa`|WUgc`dfcj`|XY`cddcfh`b|h`Yg|c`  
i`bXfgh`UbXh`Y`Y|`|h`bYXf|g`ZUf`gZcf`a`cfY`gY`YfY`ci`h`Wa`YgB` Yh`



hf]Ug'cZ]bhfj Yb]cbg'bch'i ghZcf'W[ b]hcb'UbXX'a Yb]UhfUa Yb]g'Vi hUgc'Zcf']a a i bY  
X]gcfXf'g'g'Yd'UbYU'Z'YnYX]gcfXf'g'UbX'a Ubmich'Yf'WbX]hcbg'' H\Yg'YZcf]gi bXf'g'Wf'Y'h'Y  
]a dcf]UbW'cZ]j Yfg]h'z'Yei ]h'z'UbX]bW' g]cb']b'ci f'k cf\_Zcf'W'UbX]b'h'Yf'Yg'Uf'W d]f]h]d]Ub]g  
f'W] ]h'X'Zcf'8G'gh'X]Yg'





- E • BUhcbU =bgjhi Ycb'7\]X< YUh UbX< i a Ub'8Yj Ycda Ybh  
fB=7< 8L
- BUhcbU =bgjhi Ycb'8YUzYggUbXch Yf'7ca a i b]Wjcb'8]gcfXfgyfB=878L
  - BUhcbU =bgjhi YcZ8Ybh UbX7fUb]cZMU FYgYUFW fB=87FL
  - BUhcbU =bgjhi YcZ8]UWYgUbX8][ Yghj YUbX? ]XbYm8]gYUgYfB=88?L
  - BUhcbU =bgjhi YcZA YbhU'< YUh fB=A < L
  - BUhcbU =bgjhi YcZA ]bcf]lm< YUh UbX< YUh 8]gUf]hYgYfB=A < 8L
  - BUhcbU =bgjhi YcZBYi fc`c[ ]W'8]gcfXfgyUbXGfc\_YfB=B8GL
  - BUhcbU`7Ybhf`Zcf`5Xj Ub]b[ HFUbgUhcbU GVMbWgYfB75HGL



# Appendix C: Investigation of Co-occurring conditions across the Lifespan to Understand Down syndrome (INCLUDE) Project Funding Opportunity Announcements Since 2018

## Fiscal Year 2018

- [BCHC8!%!% \(.](#) BchWcZ5j U`U` ]lmcZ5Xa ]blghUj YGi dd`Ya YblgZcfB< ; fUblg hUlfYBCH: cWgYXcb`8ck b`GmbXca Ylc`5XXYgg`GdVWZV8ck b`GmbXca Y FYgUFWCVYMj Yg
- [BCHC8!%!% .](#) BchWcZ5j U`U` ]lmcZ5Xa ]blghUj YGi dd`Ya YblgZcfB< ; fUblg : cWgYXcb`8ck b`GmbXca Ylc`5XXYgg`GdVWZV8ck b`GmbXca Y FYgUFWCVYMj Yg

## Fiscal Year 2019

- [BCHC8!%!\\$+% .](#) BchWcZ5j U`U` ]lmcZ7ca dYhUj YGi dd`Ya YblgF`Y ]gcbgZcf hY =B7@ 89 Dfc`Ymff7ca dYhUj YGi dd`Ya YblgF`Y ]gcb 7` ]b]W`HF]U`CdhcbUL
- [F: 5!C8!%!\\$% .](#) 7` ]b]W`HF]Ug8Yj Ycda YbhZcf 7c!CVWff]b] `7cbX]hcbg]b` =bXj ]X Ug`k ]h`8ck b`gmbXca Y`D`UgX5k UfXgZcf =B7@ 89 ff`\*%#`' `7` ]b]W`HF]UgF`Yei ]fYXL
- [F: 5!C8!%!\\$% .](#) HFUgZfa Uj FYgUFW 5k UfXZcf hY =B7@ 89 Dfc`Ymff`\$% 7` ]b]W`HF]U`Bch5` `ck YXL
- [F: 5!C8!%!\\$% .](#) =B7@ 89 7` ]b]W`HF]U`FYU]bYggff`&%7` ]b]W`HF]U`Bch5` `ck YXL
- [BCHC8!%!\\$% \(.](#) BchWcZ7`Uf]Z]W]hcb`cZ5dd`]W]hcb`Gi Va ]gg]cb`bZcfa U]cb`Zcf BCHC8!%!\$+% ÍBchWcZ5j U`U` ]lmcZ7ca dYhUj YGi dd`Ya YblgF`Y ]gcbgZcf hY =B7@ 89 Dfc`Ymff

## Fiscal Year 2020

- [F: 5!C8!&\\$!\\$\\$+ .](#) 8Yj Ycda YbhcZhY =B7@ 89 Dfc`Ymff8UU7ccfX]bU]b] `7Ybhf fi` &7L
- [BCHC8!&\\$!\\$\\$& .](#) BchWcZGdWU` =bYfghfBCG`L. 5Xa ]blghUj YGi dd`Ya Yblg`hc BU]cbU`7Ybhf`Zcf`5Xj Ub]b]` HFUg`U]cbU` G]YbWgfb`75HGL7` ]b]W`UbX HFUg`U]cbU` G]YbW5k UfXgff`HG5LDfc] fUa` ? @&=bg]h] hcbU`7UfYf`8Yj Ycda Ybh

---

---

- [BCHC8!&S!S&.](#) : BCG= 5j U`U`]hmcZ5Xa ]b]ghUj YGi dd`Ya Yb]gZcf hY=B7@ 89 Dfc^Wm
- [BCHC8!&S!S&.](#) : BCG= B< FYgUfW Dfc^Wm; fUbgcb'8ck b'GnbXca Yff \$%LZcf hY=B7@ 89 Dfc^Wm
- [BCHC8!&S!S&S.](#) : BCG= `Fi h`@'? ]fgWgY]bBU]cbU FYgUfW Gfj ]W5k UfX fBFG5E: Y`ck g`]d'5k UfXg`c`Gi ddcfhHfU]b]b] ]b FYgUfW FYUfXlc`8ck b'GnbXca Y UgDufhcZhY=B7@ 89 Dfc^Wm
- [BCHC8!&S!S&%.](#) : BCG= `A Yb]cfYX7UfYf 8Yj Ycda Ybh5k UfXg`c : cgMf hY7UfYfg cZ=bj Yg] ] Ucf]Di fg ]b] FYgUfW FYUfXlc`8ck b'gnbXca YUgDufhcZhY=B7@ 89 Dfc^Wm
- [F: 5!C8!&S!SS\\*.](#) : Ga U` FYgUfW; fUbgZcf 5bUngYg`cZ8ck b'GnbXca YfYUfX FYgUfW8UfZcf hY=B7@ 89 Dfc^WmF \$` 7`]b]W Hf]U Bch5`ck YXL
- [F: 5!C8!&S!SS\).](#) : HfUbgZcf a Uj YF YgUfW 5k UfXZcf hY=B7@ 89 Dfc^WmF \$% 7`]b]W Hf]U Bch5`ck YXL
- [F: 5!C8!&S!SS\(.](#) : =B7@ 89 7`]b]W Hf]U FYU]bYggfF &%7`]b]W Hf]U Bch5`ck YXL
- [F: 5!C8!&S!SS.](#) : 7`]b]W Hf]Ug8Yj Ycda YbhZcf 7c!CVWff]b] 7cbX]hcbg]b` =bXj ]X Ug`k ]h`8ck b'GnbXca Y`D`UgYX5k UfXgZcf =B7@ 89 ff`\*%#`' `7`]b]W Hf]U FYei ]fYXL
- [BCHC8!&S!%&.](#) : BCG=fM UfX]b] `hY5j U`U`]hmcZI f] Ybh7ca dY]hj YF Yj ]g]cbg`UbX 5Xa ]b]ghUj YGi dd`Ya Yb]gZcf FYgUfW`cb`7cfcbU ]fi g8]gUgY&S%`f7CJ`8!%L]b` =bXj ]X Ug`k ]h`8ck b'GnbXca YZcf hY=B7@ 89 Dfc^Wm

## Fiscal Year 2021

- [BCHC8!&S!SS%](#) : BCG= `5Xa ]b]ghUj YGi dd`Ya Yb]g`c B75HG`7HG5 Dfc[ fUa `? @& =bg]h]hcbU`7UfYf` 7`]b]W [ fUa F



# **Appendix E: Congressional Directives**

fYgMfWzUgkY`Ug`hY|a d`Ya YbU|cb`cZhYbYk`hfUbgB<`|b|hU|jY`-b`UXX|hcbzhY  
7ca a |hHY`YbWi fU`YgB<`lc`df|cf|hYnYZ`bX|b|`Zcf`fYgMfW`lc`|a`dfcj`YhY`YUH`UbX  
bYi`fcXj`Ycda`YbhcZ|bXj|`|X`Ugk`|h`8ck`b`gnbXca`YUbXhnd|W`|bXj|`|X`Ug`Uhf|g`Zcf`  
|a`a`i`bY`gnghA`XngfYi`U|cbz5`n`|Ya`Yffg`XlgMgYzWbWfzWfXcj`UgW`Uf`XlgMgYzUbXU`hga`"

### **Fiscal Year 2019 Conference (House) Report 115 952**

.....Hf|gca m%!!H`Y`WbZfYg`Udd`U`Xh`YB<`Zcf`g|`b|Z`Wbhm|bWUg|b|`|lg|bj`Yga`Yb|h|b  
8ck`b`gnbXca`YfYgMfW`UbX`Zcf`h`YB<`8`|fYm`ffg`YUXfg`|d`|b`Uj`UbW|`h`YhfUbgB<`  
|b|hU|j`Yh`Y7ca`a`|hHY`|bW`XX|b`h`YZgW`nYU`&S%`Uddfcdf|U|cb`"H`Y`WbZfYg`X|fWm  
B<`lc`Wb|h|bi`Yhc`a`U`Y`|bj`Yga`Yb|g|b`8ck`b`gnbXca`YfYgMfW`h`Udf|cf|hYnYZ`bX|b|`Zcf`Vch`  
fYgMfW`|`fUbg`UbXYUf`mg|U`Y`|bj`Yg|`|Uc`fg`h`Uk`|`Y`dU`bX`h`Y`W`ff`Y`b`hd|dY`|bY`cZ`8ck`b`  
gnbXca`YfYgMfWzUgkY`Ug`hY|a d`Ya YbU|cb`cZhYbYk`hfUbgB<`|b|hU|jY`-b`UXX|hcbz  
h`Y`WbZfYg`YbWi`fU`YB<`lc`df|cf|hYnYZ`bX|b|`Zcf`fYgMfW`Zcf`Ya`Yf|`|b|`gY`M`b`h`Z`W  
cddcfh|b|hYg`lc`|a`dfcj`YhY`YUH`UbX`bYi`fcXj`Ycda`YbhcZ|bXj|`|X`Ugk`|h`8ck`b`gnbXca`Y  
UbXhnd|W`|bXj|`|X`Ug`Uhf|g`Zcf`|a`a`i`bY`gnghA`XngfYi`U|cbz5`n`|Ya`Yffg`XlgMgYzWbWfz  
WfXcj`UgW`Uf`XlgMgYzUbXU`hga`"

### **Fiscal Year 2020 House Report 116 62**

Hf|gca m%!!H`Y7ca`a`|hHY`Wa`a`YbXgB<`Zcf`|lg`g`ddcfhcZhY`-bj`Yg|`|U|cb`cZ7c|`  
C`W`ff|b|`7cbX|hcbg5`Wcgg`h`Y`@|Z`gdU`b`lc`I`bX`fg`U`bX`8ck`b`GnbXca`Y`fB7@`89L`  
-b|hU|jY`H`Y7ca`a`|hHY`|bW`Xygc`~`Ygg`h`U`~`\*)`z`S`S`S`S`S`S`k`|h`|b`h`Y`C`Z`|`W`c`Z`h`Y`8`|fYm`f`Zcf`  
hY`-B7@`89`-b|hU|jY`z`U`b`|bW`U`g`y`c`Z`~`&`z`S`S`S`S`S`S`U`c`j`Y`h`Y`i`d`Y`M`X`Z`g`W`n`U`f`&S%`Z`bX|b|`  
~`Y`Y`"H`Y7ca`a`|hHY`Y`d`W`g`h`U`h`|`g`a`i`|`h`n`U`f`z`h`f`U`b`g`B<`fYgMfW`|b|hU|jY`Ya`U`m`|`Y`X`  
gY`M`b`h`Z`W`X`g`W`j`Y`|`Y`g`h`U`h`W`i`X`g`|`b|Z`W`b`h`m`|`a`d`f`c`j`Y`h`Y`Y`U`h`U`b`X`e`i`U`|`h`m`c`Z`|`Z`y`c`Z`|`b`X`j`|`X`U`g`  
k`|h`8ck`b`gnbXca`Y`U`g`k`Y`~`U`g`a`|`~`|`c`b`g`c`Z`h`nd|W`|bXj|`|X`Ug`"

### **Fiscal Year 2021: House Report 116 450**

Hf|gca m%!!H`Y7ca`a`|hHY`Wa`a`YbXgB<`Zcf`|lg`Wb|h|bi`|b|`g`ddcfhcZhY`-Bj`Yg|`|U|b|`  
7c|c`W`ff|b|`W`b`X|h`c`b`g`U`W`c`g`g`h`Y`@|Z`gdU`b`lc`I`bX`fg`U`bX`8ck`b`gnbXca`9`fB7@`89L`  
-b|hU|jY`H`Y7ca`a`|hHY`|bW`Xygc`~`Ygg`h`U`~`\*)`z`S`S`S`S`S`S`U`b`|bW`U`g`y`c`Z`~`z`S`S`S`S`S`S`U`c`j`Y`  
h`Y`Z`g`W`n`U`f`&S`S`~`Y`Y`z`k`|h`|b`h`Y`C`Z`|`W`c`Z`h`Y`8`|fYm`f`Zcf`hY`-B7@`89`-b|hU|jY`H`Y`  
7ca`a`|hHY`Y`d`W`g`h`U`h`|`g`a`i`|`h`n`U`f`z`h`f`U`b`g`B<`fYgMfW`|b|hU|jY`Ya`U`m`U`j`U`b`W`g`Y`M`b`h`Z`W`  
X`g`W`j`Y`|`Y`g`h`U`h`k`|`~`X`U`a`U`j`W`~`m`|a`d`f`c`j`Y`h`Y`Y`U`h`U`b`X`e`i`U`|`h`m`c`Z`|`Z`y`c`Z`|`b`X`j`|`X`U`g`k`|h`8ck`b`  
gnbXca`Y`U`g`k`Y`~`U`g`a`|`~`|`c`b`g`c`Z`h`nd|W`|bXj|`|X`Ug`"H`Y7ca`a`|hHY`f`Y`e`i`Y`g`g`h`Y`8`|fYm`f`  
d`f`c`j`|`X`Y`U`d`U`b`k`|h`|b`\*`\$`X`h`g`c`Z`Y`b`U`M`a`Y`b`h`c`Z`h`|`g`5`W`h`U`h`|`b`W`X`y`g`U`h`a`Y`|`b`Y`X`y`g`W`d`h`c`b`c`Z`  
d`c`h`b`h`U`|`f`U`b`h`c`d`d`c`f`h`|`b|hYg`U`b`X`X`U`X`|`b`Y`g`Zcf`U`~`Y`i`d`Y`M`X`Z`bX|b|`cddcfh|b|hYg`g`h`U`h`n`c`i`b|`  
|bj`Yg|`|Uc`fg`U`b`X`b`Y`k`fYgMfW`|bg|h|h`c`b`g`a`U`h`Y`Z`f`h`Y`Y`b`W`i`fU`Y`X`h`Y`i`d`c`f`Y`fYgMfW`|b`h`|g`  
gdUW`"H`|g`d`U`b`g`c`i`X`U`g`c`|b`W`f`d`c`f`U`Y`U`b`X`|b`W`U`g`y`d`j`d`Y`|b`Y`fYgMfW`|b|hU|jY`Y`g`g`d`Y`Z`W`c`  
8ck`b`gnbXca`Y`"

### **Fiscal Year 2021: Conference Report 116RCP68.JES-Division H**

U fYá YbhYWi fU Yghlgdfc^Wmc WbgXf Wa d'Ya YbUmUbX]bM fUj Y\YU\ UdffcUWg  
lc UXYggW!cWff1 f gh 'LX' 1  
7\1 gYa 1 1 1 jY dab f U f 1 6YU  
5` ] ? 1 jY dab [



# Appendix F: Selected Research Accomplishments/Bibliography

Gb Dfc[ fYgQ