

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

Ob'Dfc[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'

- 6U]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 Yg'Yl cga Yg'U lcd\U cga Yg'UbXdfchYcgU]g]bU]b[`UbX8G!58"
- 9i VUWVbZcfa 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'cfYhYZZMg'UbXa YWU]ga g'cZUá mc]XUb[]cdUhm'UbXVYUW'cZHYVccXVU]b' VUf]Yf']b'8G!58"
- 9l d'cfYhYfc`YcZHYa]WcV]ca Ycb'58 `dUhc`c[m]b'8G"

Develop Model Systems for DS-AD Research

- 7cbX VUWa dYfYbgj YDa]Vg'gi X]Yg'cZU]b[`UbX58]b'Uk]XfU]b[YcZa cXYg'z]bW X]b[`mU]žk cfa žZn'YVU]g'za ci g'žfUžbcbl`i a Ub'df]a UYfB< DžUbX`i a Ub' W`'a cXYg'
- 9l Uá]bYh'ca Yf]WYb[h' UbXfY[i `U]cb]'b'a ci g'Ya cXYgj Yfg g`i a Ub W`'']bYg'
- 8Y]bYU YfYUHXWU] Yg]b'bY fcbg'z [`]UžUbX'YbXchY]U'W`g]'b'a ci g'Y'UbX`i a Ub' a cXYg'
- 8Y]bYhYfc`YcZU YfYUHX`cfa cbU'WU]b[Yg'cb'8G!58 `YbXchm]g'UbXd'Ybchm]g]'b' a ci g'Ya cXYg'
- Gh Xn'h Ycf[]bg'UbXWbg'Yei YbWg'cZU lc]a a i bYWbX]hcbg]'b'Ua ci g'Ya cXY' cZ8G"
- 8Y]bY]b j]c a YWU]ga g]b a cXY' g'ghYa ghUhfYZWVW]b]W`d'Ybchm]g]'b'8Gž dU]h]W'Uf'ndfYBU Xj Ycda YbU' gi X]Yg'h UhVbbchYVWbX VUX]b`i a Ubg'
- 8Y]bYUbXWa dUfY[YbY]W'za YWU]ga g'UbXg[b]ZVbWcZXngY[i `UHX YbXcga Yg' Yl cga Yg'U lcd\U cga Yg'UbXdfchYcgU]g]b'8G]b]a U'a cXYg'
- 7cbX VifYgUfW]b Ua cXY' cZ]bX V]Yg' YbV]b[`cZHYb]fYWfca cga Y&žcf cZ g]W]Z]W YbYg'cb'Wfca cga Y&%''
- 7cb]bi Ylc UbUnmYgnbU]h]WZ bW]cb]b U8G'a ci g'Ya cXYžZcWg]b[`g]W]Z]W`mcb' fYy] Ubh[YbYgUgc `cWUXcb`i a Ub'Wfca cga Y&%'
- 7ca d'YfYWa 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`YfYz`fYz`|bX|b|`g`Zca`8G`fYgMfWk`|` \Uj`Y`|a`d`|W|h`cbg`Zcf`h`Y` \U`h`c`Z`h`Y`cj`YfU` `dcdi` `U`|cb`"

Develop a Cohort(s) for DS Research

- 8Y`Ycd`UW` \cfhcZ`|bX|j`|X`Ugk`|h`8G`UW`cgg`h`Y`|Zgd`Ubz`|bW`X|b|`c`Xf`|bX|j`|X`Ug`fV`cfb`%`+S`!`%`-`Sfz`UbX`h`cgY`Zca`Xj`Yfg`Y`g`V`c`W`b`ca`|WUW`|`fci`bXg`UbX`|`Ye`|`fUd`|W`fY`U`g`Y`bg`f`|b|`f`y`d`f`Y`g`b`h`|`cb`UW`cgg`U` `U`Y`z`g`i`z`UbX`f`U`U`#`h`b`|W`dcdi` `U`|cb`|`fci`dg`"8Y`|b`Y`h`Y`|a`dUW`cZ`f`|gca`m`&%`cb`f`UW`UbX`Y`h`b`|W`h`z`g`d`Y`W`|W`m`U`X`Y`g`|b|`k` \`Y`h`f`8G` \`U`g`U`X`|g`d`f`U`Y`|a`dUW`cb`d`f`h`W`f`f`U`U`c`f`Y`h`b`|W`dcdi` `U`|cbg`" `bW`X`Y`d`f`h`U`f`|gca`m`UbX`a`cg`|W`8G`W` \`c`f`|g`|b`h`Y`g`Y`g`i`X`Y`g`" "
- bW`X`Y`U`g`d`Y`W`|W`g`V`g`i`X`m`c`Z` z`S`S`d`f`h`|W`d`U`b`g`k`|h`8G`|b` `U`f`|`Y`g`i`X`Y`g`g`W`U`g`8G`!`7`cb`b`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`cb`h`|g`|`fci`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`cd`j`U`|X`|`Y`b`c`h`d`Y`g`U`b`X`d`Y`b`c`h`d`Y`g`"
- 7`cb`X`|W`f`Y`g`M`f`W`cb`h`Y` \`U`h` `|a`dUW`cZ` `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`cc`X`z` \`U`f`z`g`U`|j`U`L`Z`ca`d`Y`cd`Y`k`|h`8G`h`f`c`i`|` \`U`Z`X`Y`U`h`cb`c`Z`W`c`f`X`|b`U`h`X`V`c`V`b`_`g`l`c`U`c`k`X`h`U`Y`X`z` `cb`|`|h`i`X`|b`U`W`U`U`M`f`|`n`U`h`cb`f`h`Y`b`c`h`d`|b|`L`c`Z`|b`X`|j`|X`U`g`k`|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`|bW`X|b|`h`c`g`Y`a`U`b`U`|b`Y`X`|b`h`f`b`U`|cb`U`m`i`"

A

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

- 9l`d`U`X`c`b`|`|h`i`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`cb`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`b`|Z`h`Y`c`b`g`Y`h`U`b`X`h`U`Y`M`f`|Y`g`c`Z`W`!`c`W`f`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`M`h`U`|b`h`Y`X`|g`f`|V`i`h`c`b`z`X`a`c`|`f`U`d`|W`g`U`b`X`g`f`j`|j`U`f`U`h`g`c`Z`8G`!`5`8`z`|bW`X|b|`W`a`d`|W`h`cbg`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`|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`m`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`m`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`i`b`X`f`g`U`b`X`h`Y`|a`dUW`cb`W`|`b`|h`cb`U`b`X`V`c`X`m`g`h`Y`a`Z`b`W`|c`b`z`|bW`X|b|`W`X`c`j`U`g`W`U`f` \`U`h`"
- 7`U`f`h`h`Y`h`U`Y`M`f`m`c`Z`g`l`X`Z`f`Y`b`W`g`U`b`X`W`!`c`W`f`f`|b|`W`b`X`|h`c`b`g`c`b`h`Y` \`U`h`c`Z`d`Y`cd`Y`k`|h`8G`c`j`Y`f`h`a`Y`"
- 8Y`Y`cd`X`j`Y`f`g`W` \`c`f`|g`Z`f`|X`b`h`Z`m`|`U`b`X`j`U`|X`h`|b|`d`U`g`a`U`V`c`a`U`f`_`Y`g`"
- bW`X`Y`U`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`|bW`X|b|`Y`l`Y`M`h`j`Y`Z`b`W`|c`b`z`g`Y`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`|bW`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`W` \`U`j`c`f`g`U`b`X`g`W`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)ž]bW X]b[]XbhZ]W]hcb`cZj Ůf]U]hcbgVmfUW#h.b]Wnžgyl žUbXef`
[Yc[fUd\nm`7c`WmXUcb'5 hmb]cb 8 YZ]W# naMŮMj]lm8]gcfXf f5 8 < 8LŮbX
5i hga`GdYmfi a`8]gcfXf f5 G8L/a YbU`YU h`X]gcfXf gžg W'Ug XdfYgg]cbžŮbl]Ynž



- 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`|ZYci hWa YġfYUHXlc`WbWf hYfUdm|b`dYcdYk |h`8Gz Wb|h|bi |b|`h`fci [`g fj lj cfg`|dZlc`|Xbh|Znf|g`ZMcfgZcf`dccbYf`ci hWa YġUbXhUf| Yg Zcf`|b|hj Yb|hcbg`
- 7cbX WfYUFWlc`YġU|g` hYdfy UYbWcZ| i h# U|fc|b|h|j|bU#|j Yf#|XbYn#UXXf WbX|hcbg|b`dYcdYk |h`8G UMcġġhY`|ZġdUb`z|bW X|b|`|Xbh|ZV|hcb`cZj Uf|U|hcbg Vn|U Yz fUW#h|b|V|h|z|g| zcf`| Yc| fUd`n|`7cbX WU`cb| |h X|bU`W`cf|h|g| XmcZ Xngd`U| |U|b`W|`X`Yb`k |h`8G`
- 7cbX WYd|Xa |c`c| |W fYUFWlc`YġU|g` hYdfy UYbWcZg`|b`WbX|hcbg|b`dYcdY k |h`8G UMcġġhY`|ZġdUb`%
- 7cbX WbUhfU`|g|cf|h|g| X|YġcZa i gW`cg`YYU`WbX|hcbg|b`dYcdYk |h`8G UMcġġ hY`|ZġdUb`%
- 7cbX WXXZ|b|hj Yd|Xa |c`c| |W`g|h`X|Yġlc`YġU|g` hYdfy UYbWcZXUWYg|b` dYcdYk |h`8G UMcġġhY`|ZġdUb`z|bW X|b|`|Xbh|ZV|hcb`cZdfchW|hj YUbXf|g` ZMcfgZcf`h`YġY`WbX|hcbg`
- 7ca d|`YXUcb`h`YY|c`c|`m|UbX|h|a |b|`cZa YUvc`|Wk`Y|`|h|g|U|h`g`WUb|`Yg|b`dYcdY k |h`8G UMcġġhY`|ZġdUb`UbXhYdfy UYbWcZgYWbXUfmWbX|hcbg`Ugc`V|U|Xk |h` cVg|h|
- Gh Xn`ck`h`Y|a a i bYng|h`a`a`U|h`fYg|b|bX|j|X`Ug`k |h`8G`Zca`|bZU`W|h`fci [` U|`h`ccXz`UbX`ck`h`Ydfc`Wgga`|`|`h`X|Z|f`Zca`h`Yg`U`a`Ya`U|h`fU|hcb`dfc`Wg|b`h`cgY k |h`ci`h`8G`7cbX W`cb| |h X|bU`g|h`X|Yġlc`a`Ud`h`Y|a a i bYng|h`a`z|bW`f`d`c`f`U|h|`|bZU`a`U`c`f`m`a`U`f`_`Y`f`ġ`g`g`W|h|V|`|h`m|c`|bZV|h`cbg`z`UbX`f`y`g`d`c`b`g`Y`g`lc`j`U`W`b`Y`g`
- Gh Xn`7C`fcbU`=i`g`8|g`U`g`Y`&S`%`f`7`C`J`-8`!`%`L`f|g`_`UbX`a`|h|`U|hcb`g`h`U`M|`|Yg`Zcf`dYcdY k |h`8Gz|bW X|b|`X|Z|f`Y`b|h`U`Y`Z`Z`M`g`c`Z`G`5`F`G`!`7`c`J`!`&|bZV|h`cb`cb`dYcdYk |h`8G UMcġġhY`|ZġdUbz|b|j Uf|ci g`lj |b|`g`h|h|b|`g`7cbX W|U`cf`X`g|h`X|Yġc`Z`Y`Z`Z`M`h`j`Y`X`c`g`b|` UbX|a a i bYfYg`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|hcbgZcf`g|h`Xn`W|`X|bW`XY`U`M`Y`H`W`na`d`c|X`Yi`_`Ya`|U`M`Y`6`!`W`na`d`c|X`Yi`_`Ya`|U`M`Y` a`n`Y`c|X`Yi`_`Ya`|U`W`f`c|b|W`na`d`c`W`h|W`Yi`_`Ya`|U`W`f`c|b|W`na`n`Y`c|X`Yi`_`Ya`|U`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|hcbgZcf`g|h`Xn`W|`X|bW`XY|`U`h`c`Y`g`d`U`YU`f`Y`Z`i`l`z`W`f`c|b|W`b`g`h`d`U`h`c`z`W`f`c|b|W`X`U`f`_`Y`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`|f`f|h`U`V`Y`v`k`Y`g`n`b`X`c`a`Y`z`|bZU`a`U`c`f`m`v`k`Y`X`g`U`g`z`d`Y`d`h`W` i`W`f`z`|`U`g`c`b`y`z`_`Ya`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`g`c`f`k`Y`z`U`b`U`g`h`b`c`g`g`c`f`U`h`Y`g`U`z`Y`g`d`U`YU` 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`g`h`|W`X`ng`d`U`g`h`W`|X`b`Y`n`z`n`X`f`c`b`Y`d`f`c`g`g`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`h`m`|j`Y`f`X`g`U`g`Y`

%7cbX|hcbgZcf`g|h`Xn`W|`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`h`W`a`U`z`V`c`|`g`h`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`c`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'&\$% "' H]gfYgUFW fY [lgfmižg ddcfHXVrh YgYZUj cWNgž
Za]`na Ya Vfgž8G'cf [Ub]nUjcbg'UbXZci bXUjcbgž'UbXB=< =7Cgk]h]b h'Y8G'7cbg'fhi a
fgY5ddYbX] 5LzUa g'hc ZW]HUY]bZcfa Ujcb'g'Uf]b| 'Ua cb| 'dMfgcbgk]h'8GZa]'YgžUbX
fYgUFWYfg'VmW`YMIb| 'Xa c [fUd\]WbX`YUh]bZcfa Ujcb'Uci hdy'cd'Yk]h'8G'h'fci [\ U
gM]Yg'cZcb]bYg' fj Yng` H]g'WbZ'Xb]Užg'W'fYž'UbX'fYg'dcbgj Yk Wg]Yk Ug'Ug' hfUbg'UX
]bhc'GdU]g\]b'&\$% " G]bW&\$% žbYf'm) ž\$S]bXj]X U'gk]h'8G\U YfY [g'fYX"

HY8G!7cbbYMI`dfcZgg]cbU`dcfU`k Ug`U bWYX]b'&\$% `hc`U`ck`U`dfcj YX]bj Yg] [U'cfgž
Wb]W]Ubgž'UbXch Yf'ei U]ZYXdfcZgg]cbUg'hc`UW'gg'h'YXY!]Xb]Z'YXXU'UW`YMIX'h'fci [\ h'Y
fY [lgfmi'a cfYh'Ub(, \$ fYgUFWYfg W'fYbhm`c`XUdfcZgg]cbU UWi bh'HYdfcZgg]cbU`dcfU
cZ'fgh'fY`Yj YgcZUW'gg`%Lj]Yk]b| 'U [fY U'žXY!]Xb]Z'YXXU'Ucf'g' fj Ym'Wb]h'cb'm
&Ld'fZcfa]b| 'Wg'ca]nY'g'UFW'g'cf'g'U'g]W`Yj Ui Ujcb'Zcf'Ub'Ung'gž'di V]W]h'cbž'cf
dfYg'bh'Ujcb/'UbX' LfYMI]h]b| 'dUf]W]Ubg'Zcf fYgUFW'cf Wb]W'g'h'Xm

UbXyl dUbX]b[\WffYbhW]b]W WfY[i]XY]bYgYgU]g\ \XVmhYdfcZygg]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 dYfgf]bW X]b[`Vch W]b]M]Ubg`UbXfYgUfWfYg]cb`8G`lc`XZ]bY
8Gd\Ybchm]YgU]cgg]hY`Z]gdUb i g]b[Uj U`U`VYW]b]W UbX[YbY]W]U` -bZcfa hY
Xj Ycda YbhcZi dX]XW]b]W`[i]XY]bYg]c`]a dfcj YWfYZcf`dYcdYk]h`8G`Vmi
]bWfdcfU]b[X]Ucb WUb[YgfYU]X]c g]U YgcZ`Z]Yf] ["z]bZ]a a U]cb UbX
a Y]Uc`]ga E]UbXcb`U YfUb[Ygk`Yb Ub`]b]fj Yb]cb`a][\hW`a cgh]ZZ]M] Y`"
- =X]b]Z]8Gd\Ybchm]Yg`UbX[Ybchm]d\Ybchm]Y]gg`V]U]cbg]z]bW X]b[`V\Uj]cfU`UbX
Xj Ycda Yb]U a] YgcbYg]c`]bZcfa . i bX]fg]UbX]b[`cZb]h]fU`\]g]cfm]z]V]]bb]b[`
dfYb]U`m]UbX]bW X]b[`di V]fm]UbX]U` h`ccX`h`Y]h]a]b[cZUbX]U]f] YgZcf
]b]fj Yb]cbg]c`]a dfcj YW]b]h]cb`cf`]b]fj YbY]b fY]fYgg]cb/h`Y]Yj c`i h]cb`cZ
W]a a i b]W]h]cb`g.]`g`UbX]d]h`c`c[]Yg]h]U]ZZ]W]Y]f]b[z]V]UbW]z]UbXj]g]cb"
- 9l d`cfYX]ZZ]fYbWg]c`U]g]M]U]b`k`n]g]c]b]U]b]Yci gZ]H`cgg`cW]f]g]cb`n]l]b`g]a Y
W]Yg]cZ]h]g]ca m]g]z]k`Y]h`Y`h`Yd`U]W]b]U]W]b`dfcj]XY]bg]l`]g]cb`h`Yg]Ydf] b]UbW]h]cgg]Yg]z
UbXk`Yb`h`YU]b[`dfcW]gg`V]]bg"

Improve Clinical Research and Therapeutics

- @y YfU YhYi b]ei Ycddcf]i b]h]Yg]h]U]h]W]a YZ]ca `dfYb]U`g]W]Y]b]b[`Zcf`8G`U]g]d]U]h]cZ
fci h]bYdfYb]U`W]f]z]UbX]i bX]fg]UbX]h`Yfc`YcZ]h`Yd`U]W]b]U]b]h`YX]Yj Ycd]b[`Z]h]g`": cf
Y]U]a d`Y]z]X]b]h]Z]b]b[`Z]h]g]Yg]k]h`8G`]b`W]b]h]i]b[`dfY] b]UbW]g]W]U]h]g]h`Ydcgg]V]]h]m]cZ
cZ]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"
- =bW XYdYcdYk]h '8G]b Wb]W]f]UgcZj UW]bYgUbXhYUa Yb]gž]bW X]b] '7CJ =8!% ' j UW]bYgžUg'h YmVWl YU U'UY"
- =bW XYdYcdYk]h '8G'UbXh Yf WfY]j Yfg] ddcf]fghfci [\ci h]h YW]b]W fYgYfW dfcWggžV]]bb]b] 'k]h 'gh XnXYg] bžUbXXj Ycd'gfUM]Yg]c]bW]UgYh YdU]W]U]cb' cZdYcdYk]h '8G'cZ]Z]fYbhU Yžg] žfUW#h b]W]m]bXg]V]cYW]bca]Vg]U]g]b' fYgYfW"
- 7cbg]Xf'Xj Ycd]b] 'di V]Wdf]j UYdU]bYfg\]dgk]h V]chW]bc`c] m] Wl dU]Yg#]Ufa UW]h]W]bX] g]f]m]c]h]g]c]V]Z]W]h YU]Y]h]V]Z]c] dYcdYk]h '8G'""""
- < Ufa cb]nYW]b]W]f]U' dfc]c]W'gžk \Yb'dcgg]V]žk]h]b]Y]b]U]cb]U' YZ]c]f]g]c] Yb]U]Y a Yb]b] Z `X]U]g]U]f]b] ["'8Y Ycd'g] g]U]b]U]Y]X]U] b]c]g]W]d]f]c]c]W'g]U]b]X]U]f]m]b]h]f] Yb]h]cb'

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

- Gh Xmi]a a i bYg`gh`a` X]ZfYbWg]bZ`UbXf]g` ZUMfgUbXdc`h]U` hYUa Yb]g`Zcf`W!
cWff]b]` `a`cgh`Wa a cb]b`dYcd`Yk]h `8G`%`zUbXXZ]bYh`YZ` ``
]a dUMcZU`lc]a a i b]hmc`h`Y` \UH`cZdYcd`Yk]h `8G`" Gh Xnk` \Yh`Y`hYUa YbhcZ
U`lc]a a i bYg`]b`WbX]hcbg`a` UmUXYgg`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]gdcg`g`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`
UXYgg`]h`" Gh Xn`ck` ZU`YXa]h`WcbX]U` Z`bW]cb`UbXfYU`Xcl]XUj` Yg`fYgg]a` dUM
h`YfYU]hcbg` \d`Wk`Yb`bY`fc`c]]W]`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]UW]h]g]bW]U]g`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]UW]h]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`nz`UbX`_`]XbYm`X]g`Ug`Y`"
- Gh Xn]h`Y`cb]`!h`fa` \YU`h` YZ]W]g`cZ` `]b`dYcd`Yk]h `8G`z]bW]X]b]` .`Wb]g`XfU]h`cb`
cZ`g]`z`fUW`Z`h`b]`]h`z`UbX`g`V`c`Wbca]W]U`h`g`k` \U]b]h]j`Yb]hcbg`f]j`W`Ug`X]Yh`UbX
Y`Yf]Ug`La]]`h`U]g]h]b`a`Ub]`Ya`Yb]h`UbXk` \m]d]X`Y`Yg]b`dYcd`Yk]h `8G`k`c`UfY
cV`Y`UfY`cZ`h`k]h]b`Ub`cfa`U`fub]`Y`"
- Gh Xn] ` `]b`dYcd`Yk]h `8G`h`c`i`bX]f]g`UbX`ck` `]j`Yf`
Xng]`bW]cb`a`Um`Wb]f]V]`h`h`c`ch`Yf`W!`cWff]b]` `WbX]hcbg`"
- 7cbX] WfYgUFW`cb`bi`h]Yb]h`Ug`cdf]hcb`UbXa`YfUc`]ga` `]b`dYcd`Yk]h `8G`f]gca`Y]a`Yg`
W`YXh`Y`[i`h`V]b]U`]g]h`c`i`bX]f]g`UbXdf`Y`Yb]j`Y`UbXf]g` ZUMfg`Zcf` `UbX`
fYU`XX]gcf`Xf]g`"
- 7cbX] W]g]h`X]Yg`h`X]Yfa]bYa`cfY`dfW]g`Y`m]h`Y`h`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`h`c`
g]UbX]fX]h`nfc]X` \cfa`cbY`a`Ub]`Ya`Yb]h`
- Gh Xn]X]ZfYb]U`fYg`dcbg`Y`h`c`hnd]Yg`cZ]bZ]W]hcbg`%`z`Ug`k`Y` `Ug]f]g` ZUMfgUbXdc`h]U`
hYUa`Yb]g`z`cf]b]X]j`]X]Ug`k]h `8G`z]bW]X]b]` `Ub]h]V]ch]V]g`z`Ub]h]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`W]h]U`J`]fi`g`G`G]`Q`dbY`a`cb]Uz`
UbXj`UW]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`X]zVi`h`fY`bch]a`]h`X]h`c` hnd]Y%`X]UW]h]g`z`W]UW]X]g`Ug`z`<`Ug]a`c]h`c]h`nfc]X]h]g`z`Ucd`WU`
fYU`Uz`Ucd]W]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`z`]h`]]`cZ`g`c`f]U]g`z`d`g`c`f]U]h]W]h]f]h]g`z`U]h`fcd`h`nz`f`Y`a`Uc]X]U]h]f]h]g`z`Ug`W`]h]g`z` \Ya`c`n]h]W]b]Ya`]Uz`
h`fca`Vc`W]h`c`d]b]W]h]fdi`fUza`n`g]h]g`z`f`Y`g`h]Ygg`Y`]g`nb`X`ca`Y`ff`U`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`Ua`U`cfm`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'ng]hYa 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`
g]a 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"

- I gY`Yggcbg`YfbYXZca Zã |]YgDM dYf]YbWgk]h h`YG5FG!7CJ !&dUbXa]Wc`
Xy Ycd`ghUM]Yg`hU]bW`XYdYcd`Yk]h`8G`]b`d`Ubb]b] `Zcf`Z`h`fy`di`V]W`YU`h`UbX`
X]g`g`Yf`dYd`Uf`Y`b`Y`gg`YZ`cf`g`g`W`U`g`a`U`b`h`U`b]b]` W`FY`]j`Yf`U`W`g`g`c`]b`X]j`]X`U`g`k`]h`8G`
k`c`a`U`h`Y`]g`c`U`X`]b`h`Y`c`g`]h`U`".....

Increase Indusion of People with DS in Research

- HU`Y`]b]c`U`W`i`b`z`k` \`Y`b`X`g`]`b`]b`]`g`d`M`Z`W`Y`g`U`F`W`g`h`X`]`g`z` \`c`k` `d`c`h`b`h`U` `d`U`h`]`M`d`U`b`g`
j`]`Y`k` `h`Y`a` g`Y`j` Y`g`f`]b`W` X`]b]`]`X`y`b`h`]`Y`g`c`Z`f`U`W`Z`]`b`X`Y`z`W`U`g`g`U`b`X`g`M` i`U` `c`f`]`Y`b`h`]`c`b`L`U`b`Z`
c` `h`Y`Y`i` h`b`h`Z`U`g`V`Y`z`f`W`i`]`h`X`]j` Y`g`Y`d`c`d`i` `U`h`c`b`g`c`Z`d`Y`c`d`Y`k`]`h`8G`]`b]c` f`Y`g`U`F`W`g`h`X`]`g`
- 8`y` Y`c`d`f`Y`g`U`F`W`g`h`X`r`i`a` U`h`f`]`U`g`h`U`h`U`Y`U`W`g`]`V`Y`c` `]`b`X`]j`]`X`U`g`k`]`h`8G`z`]`b`W` X`]b]` `.
g`h`X`m`X`Y`g`M`d`h`c`b`g`z`]`b`Z`c`f`a` Y`X`W`b`g`y`b`h`f`g`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`y`b`h`U`]`m`i`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`FY`]j` Y`f`g`]`b`g`h`X`r`i`
X`]`g`]`b`]c` `]`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`g`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`h`f`Y`g`]`b`
d`c`h`b`h`U` `d`U`h`]`M`d`U`b`g`]`U`h`]`M`d`U`Y`]`b`8G`f`Y`U`h`X`c`i` h`Y`U`W`Y`Z`c`f`g`g`U`F`Y`h`Y`U`h`g`h`
]`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`b`X`h`Y`f` W`FY`]j` Y`f`g`]`b`g`h`X`r`i`h`

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

Expand Knowledge on DS, Aging and

- 9l d'cfYdchHh]U dfchWj YZUc'fgZcf U Y'fYUHXa Yb]U]bW X]b['Wa d'Ya YbUfmi UbX]bH] 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]Yfa]bY]Z]hfYi Wgh YWa i 'Uj Y
-

HAY567!8G!fYgUfWfYgk] ``Zc`ck hYw\cfhcZdYcdYk]h`8G!e`WbXi`WlhfYdfc`VMg

- =bj Yg]l UY`ck 8G!58 dUf`YgUbxXjZfZca`gdcfUjW58`k]h]b`Ub`Ua`mc]XZhu`z`bY`fcX]`YbYUjcb`ZUa`Yk`cf`zUbxhc`]Xb]Zria`cX]ZfYg`cZf]g`cZWb] Yfgcb`#ffc]`fyggcb`
- =Xb]Zri]`YbY]Va`cX]ZfYg`cZh`YXj`Ycda`YbhcZ8G!58
- HfUgUY`ci`hWa`Yg!e`UdfW]g]cb`a`YX]WbYZUa`Yk`cf`_`UbXY`dYX]YVW]b]W`hf]Ug

=a dcfUbhinz]h`YbY`h]h]fUjcb`cZ567!8G]bW`Xg`Ub`Ya`d`Uj]g]cb`]bWU]g]b]`h`YX]j`Yfg]hmcZ`]bX]j`]X]Ug]b`h`Yw\cfhcZU`lg`k`]h`8G`HAY58#8G`Ci`hfYUWzF`W]`]la`Yb]z`UbX`9b]`U`Y`a`Yb]7cfYk`]`fU]XmX]ggYa`]bUY]bZcfa`Ujcb`hc`8G`Wa`a`i`b]h]Yg`UbX`Yb]`U`Y`i`bX]fYdfYg]b]XfUWU`Y`h]b]W`fci`dg`"

E. Research Infrastructure and Tools

8]U`bcg]WbXgWYb]b]`a`YUj`fygi`gXZcf`8G`UbXfYU`XWbX]hcbg`Uj`YWb]h]bi`YXhc`Yj`c`j`Y`]b`fYWb]h]m]Ufg`<`ck`Yj`Yfzi`h]`n]Ujcb`cZa`cfYg]f]U]n]YXa`YUj`fygcZZ`bW]cb]b]`UW]cgg`Xca`Ujbg`Wi`XZUW]h]U`a`cfYfY]b]YXd`Ybchm]b]`UbX]Xb]h]Z]W]hcb`cZ]ca`U`_`YfgZcf`a`YX]Wz`W]`b]h]j`Yz`UbXVY`Uj`]cfU`WbX]hcbg`fYU`Xhc`8G`"

=b`h`YbYU`h]fa`zh`Yg]Wb]h]Z]W]Wa`a`i`b]h]mb]YXg!e`Z`fh`Yf]`]a`dfcj`Yhc`g]h]Wb]lei`Ygza`Yh`cXgž`UbXa`YUj`fyg!e`a`cj`Yhc`k`fXUa`]b]a`i`a`g]h]cZ`Wa`a`cb`a`YUj`fygZcf`i`gYUW]cgg]gi`X]Ygž`U`Y`[`fci`dgž`UbX]Yj`Ycda`Yb]U`UbXVY`Uj`]cfU`Xca`Ujbg`HAYZ]YXa`Un]Wb]Z]h]Zca`Ub]U`fY]a`Yb]h`cb`Wa`a`cb`Xca`Ujbg`UbXcb`UW]fYg]h]cZg]UbX]f]n]X]h]gg`UbXa`YUj`fyg]h`U`Wb`VY`Ug]Ygg]X]b]`W]b]W`fyg]UfW`cb`8G!e`U`ck`Zcf`Wa`dUfU]`]h]m]UW]cgg]gi`X]Ygž`bch]b]`h`U]h]Xca`Ujbg`Uddfcdf]UYZcf`cbYg]U`YcZ`]Z]a`Un]bchVYUddfcdf]UYZcf`ch`Yfg`=b`UXX]hcbza`U`]b]`Wa`a`cb`fyg]UfW`fygci`fWg]U`U`VYhc`fyg]UfWfYgž`W`Ug]b]k`a`cXYgZcf`8Gz`fyg]UfW`]b]Z]U]fi`Wi`fYz`UbX]U]U`UbX]h]gg]YfYdcg]hcf]Ygžk`]``U`ck`fyg]UfW`hc`a`cj`YZcfk`fXa`cfYfU]Xni`"

Expand Research Tools

- 8Y`Ycd`UXX]hcbU`bYk`a`cXY`gn]h]a`gZcf`gi`Xn]b]`8G`Uh]h`Yw`i`Ufzcf]`Ub]f]b`UXX]hcb`hc`VU]b]z`UbX]`YbY]WYj`Yg`"
- Gh`Xn]h`YYZZ`W]g`cZd]f]h]f`Ujcb`cZ]b]X]j`]X]U`Wfca`cgca`Y&%]`YbYg]cb`h`Y`X]Z]Z]f]Yb]h]Ujcb`UbXa`U]i`fUjcb`cZb]Y`fcbgž`[`]Uz`UbX`gn]Udg]Y]b`VU]b]cf]`Ubc]Xgž`Ugk`Y`Ug]b]a`cXY`cf]`Ub]ga`gg`W`UgC.`_`UbX8fcgd]`U`"
- 8Y`Ycd`UbXg`ddcfhb]k`Ub]a`U`f]Yza`ci`gžfUzcf`B<`DLa`cXYgZcf`WbXi`W]b]`dfYW]b]W`fyg]UfW`cb`8Gz`]bW`X]b]`h]g]b]`d`Ufa`UW`c]`]W`UbX]`YbY]W]b]h]f]Y`Yb]hcbgž`UbX`WbXi`W]b]`Ub]ca`]W`UbXVY`Uj`]cfU`Ub`Ung]Yg`cZM]U]b`X]j`Ycda`Yb]h]`D]cf]h]n]Y`h`Y`X]j`Ycda`YbhcZa`cXY`gh`U]a`]b]a`]n]Ybcb]Wfca`cgca`Y&%]`YbY]W]W]Ub]`Ygž`UbX]h`cgY`h`U`Wb`fYZ]W]h]Yg]fi`Wi`fU`WUb]`Yg]b]h`Y`i`a`Ub`VU]b`UbX]`a`a`i`bY`gn]h]a`k`]h`ci`h`]b]f]cXi`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|UHX|b|c`bY fcbU`W`hi fyg|c`
g|Xnj Uf|U|cbgVmg| `UbXUbWg|fm|
- I gYVch` UbX a cXY`g|Y`g|c`g|Xm|W|X|c| UgW`Uf`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|h|cbU`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`n|Xj Ycda Yb|c`U`ck`Y`U`i`U|cb`cZ
hY|a dU|cZ

- 8 Yj Ycd:gMYb]b['hcc`g`Zcf`XdfYgg]cbžUbl]YmžUbXch.Yf`W!cWff]b['a YbU`^YUk` WbX]hcbg]b`dYcd`Yk]h`8G""
- 8 Yj Ycd`X]U bcg]WbXgMYb]b['hcc`g`Zcf`^Ya Utc`c[]W]gcfXfg]b`dYcd`Yk]h`8Glc dYfa]hU`cfYXlfYUa Ybñ
- FYZ]bYh`YX]U bcg]WbXgMYb]b['hcc`g`Zcf`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]YgžhUhi gY'Ub[i U YhU]lgYU]m i bXf]g'UbXUVYlc`dYcd'Yk]h '8G'UbXh Yf'Za]`j]Yg'WbgXf'Vch`j]g U'UbXbcb]j]g U a Uhf]Ug'"`Gh Xn'ck ` \YU' WfYdfUW]W'a UmVg]ZcgYf'hYyb[U Ya YbU'X]bX'dYbXbW'cZ'dYcd'Yk]h '8G'"`=Xbh]Znk Ung]lc`Zcg]f'Wa a i b]m]Yb[U YXfYgUfWž W'`U'cfU]b[`k` \YfYdcgg]VYk]h `dYcd'Yk]h '8GžWY]]j Yfg]j ddcf]Ygž'UbXW'a a i b]m] dUfhYfg/i gY'Wa a i b]m]U]j]gcfm'VcUfXg'lc`U [a YbhYh]W'fY]Yk'g'cZfYgUfW'Vm]bg]h]h'cbU'fY]Yk`VcUfXg'"`
- 5i [a Ybh]g]h'a g'Zcf'XU]g'Uf]b[`cZdi V]g'YXW'cf]g'UbXa U`YfYg`]g]U U'UY]bU g]UfWU'YZ'cfa Už]bW'X]b[`Zcg]f]b[]b]m]bU]cbU`XU]g'Uf]b['"`7cbg]Xf'Yg]U]g'U]b[`U di V]W]m]U U'UY'Z'Wb]fU]n]XfYdcg]l'cfm]Zcf 8G'XU]Z]Y]hYf'h'fci [`cf]b'Wb'i b]m]cb` k]h h'Y8G'7cbbYMi`fY]]g]m]z'g`h'UhfYgUfWYfga Um'Wa dUfYh'cgYXU]k]h XU]cb h'Y[YbYU'd'cdi`U]cbž'dYcd'Yk]h]b]Y`YMi`U'UbXXj Ycda Yb]U X]g]U]]h]Yg'ch'Yf'h'U' 8Gžg]V]b[g'cZ'dYcd'Yk]h '8Gž'UbX'dYcd'Yk]h '58'"`8Yj Ycd'f]U]b]b[`UbX'ch'Yf'g' ddcf]h Zcf'8G'W]b]W]g]lc`U'ck`h'Ya`lc`X[]h]n]Yh'Yf'W]b]W'XU]Zcf`g`Va]gg]cb`lc`UWb]fU]n]X fYdcg]l'cfm]XU]m]g]Z'UbX'YbWi`fU`Yh'Yi`gY'cZ[`cW`]Xbh]Z]Yfg]h'U'ck`XU]g'Uf]b[` V]k`Yb'XU]m]g]g'k]h'ci`h'fY`YU]b[`dYf'g'cbU`m]Xbh]Z]UY]b]Z'cfa`U]cb'"`
- H'fci [`h'Y`B7@ 89 8UU7ccfX]b]U]b[`7Yb]m]Z'WMUY'U'Uf] YW'cf]h]g]h'Xm'cZ]b]Xj]X] U'g'k]h '8G'U'W'cg]h'Y`]Z]g]U]b`lc`UWY'fU'Y'fYgUfW]b]lc`W'!cW]ff]b[` Wb]X]h]cbg'"`D'fcj]X]Y'fYgUfWYfg'UbX'h'Y'f'c'U'X'f' 8G'Wa a i b]m]k]h 'UW'g]lc`h'Y'W'cf]h XU]U'UbXXU]U'a]b]b[`UbX'Ub'Ung]g]lc`gž'UbX'Z]W]]h]Y'XU]g'Uf]b[`UbX`]b_ U`Yg'cZ XU]m]g]i`g]b[`i`b]ei`Y]Xbh]Z]Yfg]h'U'nd'fYg]f]Y]b]Xj]X] U'Wb]Z'Xbh]U]m]i'"`
- 9l dUbX'h'Y'fYgUfW]b]Z]U]fi`W'fY'Zcf'8G'Vm]Yg]U]g'U]b[`cf`U [a Ybh]b[`W'`U'cfU]h]cbg Ua`cb[`Y]g]h]b[W]b]W'g]h]g'UbX'fYgUfW`b]Yk`cf`g`Uia`YX]W'#UW]X'a]W]bg]h]h]h]cbg U'W'cg]h'Y'W'i`b]f]m]h'U'Wb]X' W'fYgUfW`fY'U'X'lc`8G'UbX]]g`W'!cW]ff]b[`Wb]X]h]cbg'"` 9b]Wi`fU`Yh`]g'Z'X]fU]cb`cZ]g]h]g]lc`Wb]X' W'U'f[Yg]i`X]Ygž`g`W'U'g'U'cb[]h`X]bU`W'cf]h g]h'Xm'cf`a`i`h]g]h'W]b]W'hf]U'g'`H`Z]W]]h]U'Y'h'Y'f'U'bg'U]cb`cZ]m]g]Wb]X'f'U'bg'U]cbU` fYgUfW`lc`W]b]W`dfU]m]Wž`g`W`g]h]g]g'ci`X`
 - Gi`ddcf]h]b]b]m]X]g]m]d`]b]f]m]h]Ua`cZ'fYgUfWYfg'UbX'W]b]W]U]bgž]b]W'X]b[`h'Y X]j`Ycda`Yb]c`Z`b]k`fYgUfWYfg]b]8Gž`g'ca`YcZk` \ca`'a`Um]Wb]X' W']a`d`Ya`Yb]U]cb`g]m]b]W`dfc`Y'W'g]lc`Y'bg]fY'h'U'h'Y'i`bX]f`n]b[`fYgUfW`fYg]]g` Vb]Z]h]h'Y8G'Wa a i b]m]i'"`
 - :`UW]]h]U'Y'Yb'c` `a`Yb]c`Z`Wb]X]h]cb!`g]m]Z]W]g] V] fci`dgž`U`Yf]U]b[Ygž`cf` `

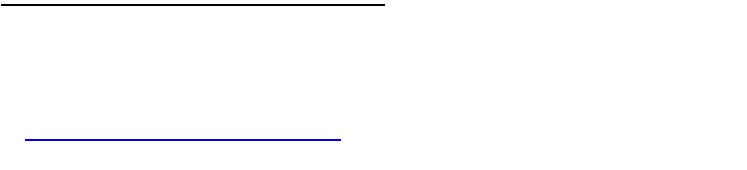
- 9gUW]g\ UZXXfU]cb:cZV]cfYdcg]hcf]Yg]hUk]``dYfa]hV]cVb_]b[:cZW`gžd`Uga Už gfi a žVMfWfcd]bU`Zi]XžUbXVfU]b`UbXchYf`hgg YgZcf`fYgUfW`di fdcgYgž`]bW`X]b[` glā d`YgZca]bXj]X] Ugk]h` WbWf`k]h` 8G``=b]h[fUfV]cfYdcg]hcfm]XUk]h` h`Y8G! 7cbbWf] fYgUfW`fY[]gfm]gZU]gVY` G]hU]X]nYglā d`YW` Y]cb`UbXdfcWgg]b[` a YhcXc`c[]YgUbXdc`]W]gZcf`Wbg]ghbzYei]hU]Yglā d`YX]gf]Vi]hcbžUbX]gU]g\ fYj]k` UbX]gf]Vi]hcb`dfcWggYgZcf`fYgUfWYf`UWgg]h` h`Yglā 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[]h`Y8G`fYdcg]hcfm]k]h` h`YB<` B]Y`fc6]c6Ub_`88`UbXhY]i]g]b[`58` FYgUfW`7Yb]Yg6fU]b`6Ub_g`žg`h`Uh]gg] YZca` dYcd`Yk]h` 8G`Wb`W` Wā`d]fYX]h` h`cgYcV]U]bYXZca`]bXj]X] Ugk]h` 58` UbXchYf`X]gcfX]fg`
- 7c``W]b[]b]Y`fchm]W`Wb]hcf`glā d`Yg`
- 9l`dUbX`ZXXfU`m]Z`bXX`fYgUfW`hU]b]b[`dfc[`fUā`g]h`Ybg`fYUj`]M]b]h]d]dY]b]YcZ` fYgUfWYf]gXc]b[`k`cf_`]b`8GžUbX`cg]h]W]b]Z]Wk`cf_g`cdg]h`U]V]b[`Yā`Yf[]b[`]b]Yg]U] Ucf]g]h[`Yh`Yf`k]h` YgU]g\`YXg]W]b]h]g]b]h`YZ]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``dYfW]h]YcZXi`[`g]UbXXj`]W]g]U]dfc]YXV]h]YI`"G":`ccXUbX8fi`[` 5Xa`]b]g]fU]cb`f]85E`U]YVYb`UYXZcf`dYX]Uf]W`gY`B=7<8`YgU]g\`YXh`YDHB`]b`&S`&S`]h`WbX]W]W]b]W`fYgUfW`UbXW`Y]W]XU]h`Ugg]gh`Y: 85`]b`fY`]g]b[`a`YX]W]cb`UYgZcf` gZf`UbXa`cfYZZ]M]j`Yi`gY]b`W]`X]Yb`"K`cf_]b[`k`]h`fYgUfW`g]h]g]U]fci`bXh`YWi`b]m]ž`h`Y` DHB`g]i`X]Yg]h`YZca`i`U]cbž`Xc]g]b[`žYZZ]W]m]ž`UbXg]Z]hmcZXi`[`gž`Ug`k`Y`Uga`YX]W`Xj`]W]gž` Zcf`i`gY]b`W]`X]Yb`"H`]g]g]fi`W]fYU`ck`g]h`Yb]Yk`cf_`]h`UXX]Ygga`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 hYdUhcđnglc`c[mcZ8G!58ž&`Vi ha cfYfYWbhfWw[b]hcb`cZUk cff]gca Y ÍfY]fyg]cb|`d`YbchmYfYa]bXgi`gcZ`ck`a i WkY`Uj YmYhlc`YufUvci hgca YcZ hYgYW!cWff]b|`bY fc`c[]W`WbX]hcbg`"
- K`|`Y]b hYfYWbhdUgh hYfY`Ug VYb UdU WmcZa YX]W]hcb hf]UghU`cfYXlc dYcd`Y k]h`8Gfk]h`h`Yi Wdhcb`cZgy YFU`Y d`cf]b|`hYcd]ja U`WYa chYfUdmZcf`W]`X`ccX`Y`_`Ya]U]b`8GžUbxgca YZU`YXhf]Ug]lc`ja dfcj YWw[b]hcb`cf`y Yb`dfy YbhXa YbhUz` h]gg]h U]cb]g]a dfcj]b|`ždu]hW`Uf`nk]h`g ddcfhZca hY`B7@ 89 Dfc`Ww

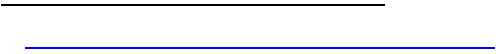
H`Y]a dUwicz hY`B7@ 89 Dfc`WwWbchVYi bXfYg]ja UYXžUg]h`Ug]bZ gXh YZ]YXk]h bYk`Z bX]b|`žvci [`h]bYk`]bj Yg]]Ucfc]b]lc`8GfygUFWžUbxYbwi fu YXbYk`Ubx]ci hcZ h`Y Vcl`Í`UddfcUWYg]lc`h]gk`Y`!`_`bck bWfca cgca U`X]gcfXfzZ bX]a YbU`mWU]]b|`h`YW`h`i`fy cZ8GfygUfW`WbX]`W]XUbxg ddcfhXVriB`="`H`Y`Ya d`Ug]g`cb`g ddcfhcZhf]bYg`Ubx`']b|`cf`ZUW`hm]b|`U]b|`]b`8G!fyUHXfygUFWžh`fci [`]bg]h`hcbU`hf]b|`]`fubhg`dd`Ya Yb]gž`7`]b]W`UbxHfUbg`U]cbU`GVYbW`5k`UfXg]hf]b|`]g`dd`Ya Yb]gž`h`YD<`B`G`Wc`Uf`g`d`c`f`U`a` f`g`Y` [Dfc\] fUa` DcfffUj`](#) EžUbx]bXj]X] U`Z`ck`g`d`UbxWfYf`Xj`Y`cda`YbhUk`UfXgž]g`f`Yg`]b|`]b`nci`b|`Y`g`W]b]g`g`c`b|`b|`h`Y`8G`fygUfW`W`a`a`i`b]m`i`H`Y`U`X]`hcbU`Ya`d`Ug]g`cb`hfUbgZ`fa`Uj`YfygUfW`]g`Ybwi`fu`]b|` bYk`UbxYg]UW`]g`YX`]bj`Yg]]Ucfc]lc`VfcUW`Y`W]b|` bYk`UfYg`cZ]`bei`]fm]b`h`Y`U`g]W`V`W`X`ca`U]b`"5`" cZ h`Y`g`a`U`g`f`Y`g`]b`W`U`g`y`h`Y`d`c`c`cZ`]bj`Yg]]Ucfc]]bj`c`j`YX]b`8G`fygUfW`UbxZ`Z`" h`Y`W`b|`f`Y`g`]`cb`U`a`U`b`U`h`lc`Í`Y`d`U`b`X`h`Y`W`ff`Y`b`h`d`]`d`Y`]`b`Y`c`Z`8G`fygUfW`Í`f`g`Y`5`d`d`Y`X]`9E`"

8Yg]]Y`cb`m`Y]b|`]b`]lg]]bZ`U`W`ž`k`]h`h`Y`Z`f`g`h`g`dd`Ya`Yb]gZ`b`X`X`U`g`c`f`h]`ja`YU`cž`h`Y` ðB7@ 89 Dfc`WwWb`g]`" `V]YU`ja]hXbi`a`Vf`cZgdW]Z`Wci`h`Wa`Yg`U`b`X`X]g`Wj`Yf]Yg]b`h`]g`

g`YbWb|`|b`Ua ci gYa cXY`cZ8G`lc`dfj`Ybh`Là`nìc`|Xd`Uei`YX`dcg|h`cb`|b`h`YV`Uj`b`Ub`Xcbg`hc`Z`
X`Y`a`Ybh`U`gna`dlca`g`k`ci`X`V`Y`U`g`f`|`|b`|`U`W`a`d`|`g`a`Ybh`Ub`X`U`V`Y`U`_`h`f`ci`[`|`|b`h`Y`Z`Y`X`"

Cb`h`Y`W`|b`|W`g`X`Z`|a`dfcj`Y`X`f`Y`U`a`Y`b`g`Z`f`g`a`Y`c`Z`h`Y`a`c`g`h`W`U`Y`b`|`|b`|`U`g`Y`W`g`c`Z`8`G`|`g`U`
k`c`f`h`m`|`c`U`Z`Z`f`k`|`|W`W`a`a`i`b`|`m`|`b`d`i`h`|`g`W`|`h`W`" `D`U`Y`b`g`c`Z`Y`b`f`Y`d`c`f`h`h`U`d`c`c`f`
W`a`a`i`b`|`W`|`c`b`U`b`X`g`Y`W`U`f`|`W`U`|`c`b`Z`U`g`k`Y`U`g`d`c`c`f`g`Y`d`e`i`U`|`m`|`f`|`b`W`X`|`b`|`V`Y`U`h`|`b`|`d`U`g`Y`g`
U`b`X`g`c`f`|`b`|`E`Z`U`Y`g`a`Y`c`Z`h`Y`a`c`g`h`Y`|`|b`|`d`f`c`V`Y`a`g`Z`f`Z`a`|`|`Y`g`V`W`M`g`Y`h`Y`m`W`b`|`U`j`Y`U`a`U`c`f`
|`a`d`U`m`b`c`h`c`b`m`c`b`h`Y`k`Y`!`V`|`b`|`c`Z`h`Y`d`Y`f`g`b`k`|`h`8`G`Z`V`i`h`U`g`c`h`U`c`Z`c`h`Y`f`Z`a`|`m`a`Y`a`V`f`g`"
A`U`b`m`Z`a`|`|`Y`g`U`g`c`Z`U`f`h`Y`d`c`g`g`|`V`|`h`m`c`Z`X`j`Y`c`d`a`Y`b`U`f`Y`f`Y`g`g`|`c`b`|`b`h`Y`f`h`Y`b`g`U`b`X`n`c`i`b`|`
U`X`|`g`k`|`h`8`G`Z`U`b`X`h`Y`c`b`g`Y`h`c`Z`X`Y`a`Y`b`|`U`g`h`Y`f`|`c`j`Y`X`c`b`Y`g`k`|`h`8`G`U`Y`" `H`Y`V`f`c`U`X`f`8`G`
W`a`a`i`b`|`m`|`W`i`X`Y`b`|`U`Y`k`|`h`f`Y`g`U`f`W`f`g`|`c`|`a`dfcj`Y`i`b`X`f`g`|`b`X`|`b`|`c`Z`h`Y`W`g`Y`g`U`b`X`f`b`|`Y`c`Z`
W`|`b`|`W`d`f`Y`g`b`h`|`c`b`g`Z`f`h`Y`g`Y`|`g`g`Y`g`z`k`|`h`h`Y`d`f`|`a`U`f`m`|`c`U`c`Z`X`j`Y`c`d`|`b`|`W`|`b`|`W`|`f`|`U`g`c`Z`h`Y`g`Y`
W`b`X`|`h`c`b`g`g`d`Y`W`Z`W`m`|`b`8`G`" `G`c`a`Y`f`Y`g`U`f`W`f`g`U`f`Y`U`k`m`f`Y`X`j`Y`c`d`|`b`|`U`b`5`8`d`f`Y`Y`b`|`c`b`|`f`|`U`
i`g`|`b`|`U`b`h`|`L`a`n`ìc`|`X`h`Y`f`U`d`n`z`U`b`X`h`Y`g`W`g`g`c`Z`g`W`U`f`|`U`k`ci`X`V`Y`U`g`|`b`|`Z`W`b`h`V`b`Z`h`Z`f`
|`b`X`j`|`X`U`g`U`b`X`Z`a`|`|`Y`g`"

H`Y`i`b`|`e`i`Y`W`U`Y`b`|`Y`g`d`c`g`X`V`m`h`Y`7`C`J`-8`!`%`d`U`b`X`Y`a`|`W`U`g`c`d`f`c`j`|`X`Y`c`d`d`c`f`h`i`b`|`h`Y`g`|`c`
i`b`X`f`g`U`b`X`h`Y`Y`|`|`h`b`Y`X`f`|`g`Z`U`m`f`g`Z`f`a`c`f`Y`g`Y`Y`f`Y`c`i`h`W`a`Y`g`B` 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'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 h'cb'7\]X< YUh UbX< i a Ub'8Yj Ycda Ybh
fB=7< 8L
- BUhcbU =bgjhi h'cb'8YUzYgg'UbXch Yf'7ca a i b]Wjcb'8]gcfXf'gfb=878L
 - BUhcbU =bgjhi h'cZ8Ybh UbX7fUb]cZMU FYgYUFW fB=87FL
 - BUhcbU =bgjhi h'cZ8]UWYg'UbX8][Yghj YUbX?]XbYm8]gYUg'fb=88?L
 - BUhcbU =bgjhi h'cZA YbhU'< YUh fB=A < L
 - BUhcbU =bgjhi h'cZA]bcf]hm< YUh UbX< YUh 8]gUf]h]Yg'fb=A < 8L
 - BUhcbU =bgjhi h'cZBYi fc`c[]W'8]gcfXf'g'UbXGfc_YfB=B8GL
 - BUhcbU`7Ybhf`Zcf`5Xj Ub]b[HFUbg'UhcbU GVMbW'gfb75HGL

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`GnbXca Ylc`5XXYgg`GdVWZV8ck b`GnbXca Y FYgUFWCVYMj Yg
- [BCHC8!%!% .](#) BchWcZ5j U`U`]lmcZ5Xa]blghUj YGi dd`Ya YblgZcfB< ; fUblg : cWgYXcb`8ck b`GnbXca Ylc`5XXYgg`GdVWZV8ck b`GnbXca 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`gnbXca Y`D`UgX5k UfXgZcf =B7@ 89 ff`*%#`' `7`]b]W`HF]UgFYei]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 FYUX]bYggff`&%7`]b]W`HF]U`Bch5`ck YXL
- [BCHC8!%!\\$% \(.](#) BchWcZ7`Uf]Z]W]hcb`cZ5dd`]W]hcb`Gi Va]gg]cb`bZcfa U]cbZcf 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`Ym8UU7ccfX]bU]b] `7Ybhf fl`&7L
- [BCHC8!&\\$!\\$\\$& .](#) BchWcZGdWU`=bMYghfBCG=L` 5Xa]blghUj YGi dd`Ya Yblg`lc BU]cbU`7YbhfZcf`5Xj Ub]b]` HFUg`U]cbU` G]YbWgfb75HGL7`]b]W`UbX HFUg`U]cbU` G]YbW5k UfXgff7HG5LDfc] fUa` ? @&=bg]h] hcbU`7UfYf 8Yj Ycda Ybh

- [BCHIC8!&S!S&.](#) : BCG= 5j U`UW`]hmcZ5Xa]b]ghUj YGi dd`Ya Yb]gZcf hY=B7@ 89 Dfc^WM
- [BCHIC8!&S!S&.](#) : BCG= B< FYgUfW Dfc^WM; fUblgcb'8ck b'GnbXca Yff \$%LZcf hY=B7@ 89 Dfc^WM
- [BCHIC8!&S!S&S.](#) : BCG= `Fi h`@'?]fgWgY]bBU]cbU FYgUfW Gfj]W5k UfX fBFG5E: Y`ck g`]d'5k UfXg'c`Gi ddcfhiHfU]b]b|]b FYgUfW FYUfXlc`8ck b'GnbXca Y UgDufhcZhY=B7@ 89 Dfc^WM
- [BCHIC8!&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; fUblgZcf 5bUngYg'cZ8ck b'GnbXca YfYUfX FYgUfW8UfZcf hY=B7@ 89 Dfc^WMf \$' 7`]b]W Hf]U Bch5`ck YXL
- [F: 5!C8!&S!SS\).](#) : HfUbgZcfa Uj YFYgUfW5k 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 UfXg'Zcf =B7@ 89 ff`*%#'' 7`]b]W Hf]U FYei]fYXL
- [BCHIC8!&S!%&.](#) : BCG=fM UfX]b| `hY5j U`UW`]hmcZI f] Ybh7ca dY]hj YFYj]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

- [BCHIC8!&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 |hYyYbWwifU`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`XngfY`i`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`Ux`UbW|`h`YhfUbgB<`
|b|hU|j`Yh`Y7ca`a`|hYy|bW`XX|b`h`YZgW`nYU`&S%`Uddfcdf|U|cb`"H`Y`WbZfYg`X|fWw
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|`Ucfcg`h`Uk`|`Y`dU`Xh`Y`WffYbhd|dY`|bYcZ`8ck`b`
gnbXca`YfYgMfWzUgkY`Ug`hY|a d`Ya YbU|cb`cZhYbYk`hfUbgB<`|b|hU|jY`-b`UXX|hcbz
h`Y`WbZfYg`YbWwifU`YB<`lc`df|cf|hYnYZ`bX|b|`Zcf`fYgMfW`Zcf`Ya`Yf|`|b|`gY`MbhZ`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`XngfY`i`U|cbz5`n`|Ya`Yffg`XlgMgYzWbWfz
WfXcj`UgW`Uf`XlgMgYzUbXU`hga`"

Fiscal Year 2020 House Report 116 62

Hf|gca m%!!H`Y7ca`a`|hYy`Wa`a`YbXgB<`Zcf`|lg`g`ddcfhcZhY`-bj`Yg|`|U|cb`cZ7c|`
C`Wff|b|`7cbX|hcbg5`Wcgg`h`Y@|ZgdU`b`lc`I`bXf|g|UbX`8ck`b`GnbXca`YfB7@`89L`
-b|hU|jY`H`Y7ca`a`|hYy|bW`Xygbc`Ygg`h`Ub`~*`\$SSSSSS`k`|h`|b`h`YCZ|W`cZh`Y8`|fYm`f`Zcf`
hY`-B7@`89`-b|hU|jY`zUb`|bWUgy`cZ`&SSSSSS`Ucj`Yh`Yi`dYm`XZgW`nYU`&S%`Z`bX|b|`
Y`Y`"H`Y7ca`a`|hYy`dWg`h`Uih`|ga`i`|h`nYfz`hfUbgB<`fYgMfW`|b|hU|jY`Ya`Um`|YX`
gY`MbhZ`W`XgWj`Yf|Yg`h`Uwi`Xg|`b|Z`Wbhm|a`dfcj`YhY`YUH`UbX`ei`U`|hmcZ`|Z`cZ|bXj|`|X`Ug`
k`|h`8ck`b`gnbXca`YUgkY`Uga`|`|cbgcZ`hnd|W`|bXj|`|X`Ug`"

Fiscal Year 2021: House Report 116 450

Hf|gca m%!!H`Y7ca`a`|hYy`Wa`a`YbXgB<`Zcf`|lg`Wb|h|bi`|b|`g`ddcfhcZhY`-Bj`Yg|`|U|b|`
7c|cWff|b|`WbX|hcbgU`Wcgg`h`Y@|ZgdU`b`lc`I`bXf|g|UbX`8ck`b`GnbXca`9`fB7@`89L`
-b|hU|jY`"H`Y7ca`a`|hYy|bW`Xygbc`Ygg`h`Ub`~*)`\$SSSSSS`zUb`|bWUgy`cZ`~)`\$SSSSSS`Ucj`Y`
h`YZgW`nYU`&S`S`Y`Yzk`|h`|b`h`YCZ|W`cZh`Y8`|fYm`f`Zcf`hY`-B7@`89`-b|hU|jY`"H`Y`
7ca`a`|hYy`dWg`h`Uih`|ga`i`|h`nYfz`hfUbgB<`fYgMfW`|b|hU|jY`Ya`Um`Ux`UbW`gY`MbhZ`W`
XgWj`Yf|Yg`h`Uk`|`X`Ua`U|W`m|a`dfcj`YhY`YUH`UbX`ei`U`|hmcZ`|Z`cZ|bXj|`|X`Ugk`|h`8ck`b`
gnbXca`YUgkY`Uga`|`|cbgcZ`hnd|W`|bXj|`|X`Ug`"H`Y7ca`a`|hYy`fYei`Yg`g`h`Y8`|fYm`f`
dfcj`|X`Y`Ud`Ub`k`|h`|b`*`\$`X`hg`cZ`YbU`Ma`YbhcZh`|g5`W`h`U|bW`Xyg`U`|a`Y`|bY`XgW`d|hcb`cZ`
dch`b|h|U`|`fUbc`ddcfh|b|hYg`UbXXUk`|bYg`Zcf`U`Y`dYm`XZ`bX|b|`cddcfh|b|hYg`g`h`Uinc|b|`
|bj`Yg|`Ucfcg`UbX`bYk`fYgMfW`|bg|h|h`hcbg`a`Um`Y`Z`fh`Y`YbWwifU`YX`lc`Y`d`cfY`fYgMfW`|b`h`|g`
gdUW`"H`|gd`Ub`g`ci`X`Ugc`|bW`f`dcf`U`Y`UbX`|bWUgy`d|dY`|bY`fYgMfW`|b|hU|jY`Yg`g`dY`W`Z`Wc`
8ck`b`gnbXca`Y`"

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U fYá YbhYWi fU Yghlgdfc^Wmc WbgXf Wa d'Ya YbfmUbX]bh| fUj Y\YU\ UdfcUWg
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