



# 8SF OBUBMDSF F OJH BOE EJBHOPTUDUFTUJOH QPS GFUBM DI SPN PTPN BMBOE HF OF UD DPOEJUPOT

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NPbUQ[ Z `TO`OQ] Y Y OZPOP\_ O`OZUS NZP  
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3\OZPld 0 ///\$+  
3\OZPld 3 k G\PMUS 5[ Y Y U`OQ? OY NO^TU /\$" #\* Z\$" #+f ///\$+  
3\OZPld 4 I [ Y OZh: QXT 5[ Y Y U`OQ? OY NO^TU ///\$+  
3\OZPld 5 AbQbQc [ R`TQ6CbQ\ \Y OZ` MIP DcbQc B[ OQ\_ R ^`TU\_E`MOY OZ` ///\$-  
3\OZPld 6 8aX6UOMY O^ ///%  
3\OZPld 7 5[ Z\_U`O`MUJ Z\_ R ^; ZP\$OZ[ a\_ MIP 5aXa^M MIP >Z SaU`OM 6UbO`QB[ \aX\UJ Z\_ ///#  
3\OZPld 8 6U[ ^PO^\_4MCP [ Z 7 TZUJe ///\$  
3\OZPld 9 6CRZUJ Z\_ MIP 3NN^CbUMJ Z\_ ///%

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\_]Y OOT^Y [ \_]Y N^ N^P SOZO WQ ZPUU Z\_U [ R^O^P Pa^US \^OSZM^e^ [ \^ bUPO^TQc [ Y N^ c UT  
Y [ ^OZR^ ^Y MU Z MN [ a^ TO^aZN [ ^Z NNVež 3X\_aO^ `Q\_`US \_] [ a^P NOV^P^MOUBSZ N^P [ Z^aZPO^M^OZ  
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FTONM^O^`UZOU^O [ R^ ^OZMINX\_O^OOZUS U\_ [ [ R^O^M^N^O^ O^R^O^U^O^N^P M^O^O^\_UNO^`Q\_`UZ [ ^PO^` [  
UPOZ^Ue c [ Y OZ c UT N^ UZ^O^M^O^P O^TN^CO [ RTNBUZS M^N^N^e c UT MOT^Y [ \_]Y N^ ^SOZO WQ ZPUU Zz  
FTQ\_Qc [ Y OZ MO^TOZ R^ X^ c CP a^ c UT SOZO WQ aZ\_O^X^S N^P [ R^O^P P^U^SZ [ \_]W^Q\_`US R^ ^M^P^O^R^Z^U^O  
N^ c Ož 5a^OZ^X^ [ Z^aZ UZ^b^M^U^O^`Q\_`^OSZ^M^ Z^U^O^OZ^`Q\_U [ ^O [ ^U Z^O^b^U^X^ \_M^ \^X^S^f^I^O^N^ P^U^SZ [ \_O^M  
SOZO WQ [ ^O^Y [ \_]Y N^O^ ZPUU Z UZ N^ aZN [ ^Z

FTU\_`MOY OZ`\_aY Y MUQ\_`OQ Y Y OZPMUJ Z\_R` ^\`OZMNX\_O`OOZLS R` ^OT`Y [ \_] Y N`M`P SOZO W  
Q ZPUJ Z\_R` ^\`OSZM` c [Y OZ M`P`TQ`M`Z O`\_U` T OSOZ O`M`N` \a`X`M`J`Z`I [Y OZ c UT M`L`U`O`O`M`CP  
O`M`O`O`[ R`T`M`U`S`M`O`T`U`P` c UT M`O`T`Y [ \_] Y N`X` ^`SOZO W`Q ZPUJ Z`/`O`S`Z`T`M`U`S`T`M`P`M`N`M`e c UT M  
Q ZPUJ Z [ ^PaQ` [ M`R`M` U`E`T`U` [ ^e [ R`M`Q` ZPUJ Z`f`i`\_`T` a`P` ^`O`O`U`O`Z`P`U`P`a`M`U`CP`Q` a`Z`\_`O`X`Z`S`R` [Y M  
O`Z`L`O`M`Z` c UT M` \` ^\`U`M`O`O`N`O` ^`U`Q` \`O`P`O`M`N`E` \`U` ^` [ ^\`OSZM`Z`e`z`

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<p>3000`MNDQRA`ŽXZO_0'OOZUS`Q`_RĚ ^OT^Y [ _]Y OQ ZPUU Z_Ů _OO ZP`^Y Q`Q'UZO&amp;PQ MiiY MOZNX_Q'aY _0'OOZUS/? 3 ě 38B ě j : 59 ě G7% ě ! Ž; ZTUNZfiNPI NfiOR6@3ŽNMCP_0'OOZUSz FTOOT [ ŮOO [ RRU` XZO_0'OOZUS`Q` c ŮXPQ\OZP [ Z XĚ ONX^Q [ a^OO ě \MŮZ` POY [ S^MTŮ ě NIP ŮZPUWPaNX\MŮZ` OTMNDQ'U` Ůž</p>	5 [ Z_Ů_a_ŽNMCP ^OO Y Y OZPMU Z
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 PUQa\_\_LZS LZbQ`LSMUJ Z } c UT Q ZRMY MUJ Z`TM`TO LZĚ ĚY MUJ Z TM`NOZ aZPO^` [ [ P MZP c UT  
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- %#ž' ;ZĚ ĚY MUJ Z`T [ aXP NO\^f bUPCP LZ MRĚ ĚY M`TM\_U\_QMe` [ aZPO^`MZP MZP M000 UNO` [  
 \^OSZM\`c [ Y OZ R [ Y QaXa^MĚ MZP XZSaU`WĚ PUbO`QNMVŠ [ aZP`\_LZOaPUZ; ZPUSOZ [ a\_  
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 LZ`O^`OZLZS`O`bWOT [ aXP NOY MPO\NBVMVMUO c TO'QU U`Q] aUCP /\_CO [3\ \OZPld 7fž](#)
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 \_O'OOZLZS \^f OO\_Q MZP PQM [ R'TO`Q`LZS \^f OO\_žFTU`T [ aXP LZOaPO LZĚ ĚY MUJ Z  
 MN [ a` \TOZ [ `e\WbMVMUOe [ ROT^Y [ \_Y MCO ZPUUJ Z`MZP`TOPURQaXUO\_LZ NOZS  
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 Nž 3 PUQa\_\_UJ Z [ R'TOPURQO'OO`NO c OOZ`\_O'OOZLZS MZP PUUSZ [ \_`W`Q`\_ž  
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 M0Q aZ` `TOSQ`MUJ Z [ R'TQ\^OSZM\Gež  
 Pž B^M\WVM\`CO` [ R`Q`LZS/LZOaPUZS`TO`Y LZS [ R`Q`\_MZP`TOM\^f dY MOC [ \_`  
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[M\OZMVMQ`R`^OT^Y \[ \\_Y MVMZ \[ Y MCO MZP \[ `TO`Q ZPUUJ Z`MZP`3Z`OZMVM  
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Sz FTOaZPO^\_MIPUS`TMI URMOT`Y [ \_]Y Q[ ^SOZQWDQ ZPUUJ Z U\_PUUSZ[ \_CP Me [ Y MZ  
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 NOOZ PUUSZ[ \_CP \MOZ`\_T[ aX NOSUWZ\_aRROOZ`UZR`Y MIUJ Z`OSMPUS`TOMU`X Set  
 M[ OUMUJ Z`MIP UY \XOMUJ Z`[ R`TMPUSZ[ \_U Pa`US \`OSZMZGe`TOZQc N[ `Z \O`U P  
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 %##Z FTO`\_T[ aX NOMZ M\_a`MZOO`TM`OSMPXO`[ R`TQJ PCOUUJ Z c [ Y OZ c U`XNO[ RRO`CP  
 Q aZ`OXZS MIP`COOUBO[ ZS[ LZS OMOMIP\_a\` ^z; Z`TQOMQ[ RQ Z`LzaUS`TO\`OSZMZGe  
 c [ Y OZ MIP`TQJ \M`ZO`\_T[ aX NO\`[ bUPC c UT M\` \`UMONZ`OZMN`XOMO c UT  
 LZPUBPaM`XCP \`O`MMUJ Z`R`^N\`T MIP ZQ ZMN`X MNSOY OZ`zFTO[ \`UJ Z [ RZQ ZMN`X  
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 M`ONX`\_W[ \`UJ Z`z; R`TQe OT[ [ \_Q`OY LZMIUJ Z`TQe ZOO`[ VZ[ c` TM`TOY [ PQ[ R`OY LZMIUJ Z  
 Y M`NOUZ R`a`OZOO` Ne SQ`MIUJ ZMN`SOUZ XZQc UT E`MO`X`\_z

**ZÁ 8SFOBUBMDSFFOJCHUFTUJ QPSGFUBMNI SPN PTPN F BOE HFOFUDDPCEJUPOT**

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EO`OOZUS [ ^PUUSZ[ _W`Q`LZSR`^R`N`OT`Y [ _]Y M`MIP SOZQWD Q ZPUUJ Z`_U`b[ XaZ`Me MIP`_T[ aX [ Z`e NOaZPO^`MVOZ M`M`UZR`Y CP PCOUUJ Z`Ne`TO\`OSZMZ` c [ Y MZ`z	5[ Z`OZ_a`ZNMCP `OQ`Y Y OZPMUJ Z
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;RM`O`OOZUS`Q` `O`aX LZP`OMQ` MZ LZ`O`OMCP OT`MZ`OO[ R`MOT`Y [ _]Y Q [ ^SOZQWDQ ZPUUJ Z`TQc [ Y MZ`_T[ aX`TN`OMMOO`_`[ SOZQWD Q aZ`OXZSR`^R`a`TO`UZR`Y MIUJ Z`MIP_a\` ^z FTOM`M`M`MO[ \`UJ Z`R`^ \`OZ`MN`X`PUUSZ[ _U`_T[ aX`NOPUGa`_CP MIP [ RRO`CP`z	5[ Z`OZ_a`ZNMCP `OQ`Y Y OZPMUJ Z
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 Q ZRUY MIU Z [ RRO'NZaY NO' SQ`MIU Z bUMUJe MIP \_ `aOa'XPcOX \Y OZ` ž

Uf15OXZR'OO6@3/0R6@3fižNMCP\_O'OOZUS a\_UZSY MOZM\XMY MONZ NO\O'R` 'Y QP 'OXUMe R[ Y #"  
 c OQVžFTU\_O'OOZUS`Q` NCOM Qc UPOe NBNXNDQZ 3a\_`'VMZ \$" #%MIP TM`TOTISTQ`\_OZ\_UbUe



l ~ 1 Ž061<00ž%đ °-, =0/ >0=>B2 19<10> 6 80?: 64C

50XR'006@3/0R6@3finNMCP\_0'00ZUSI Q'Y Y [ Zx6 '0P0'0P' [ M\_Z [ ZžžbMlbbQ\ '0ZMNM'Q\_ 'UZS/@,BFfi  
a\_Q\_6@3\_Q] aOZOZS [ ^M'Y4 NMCP`00TZ [ X Se` [ PQ00 MZCa\X UPeUZ \XMOZ`MX U\_aQ\_ NeY QMa'UZ  
0R6@3 UZ`TOY MOZNM\XMY MFTU`Q` U TISTx6 \_OZ\_UlBQNZP TISTx6 \_\COBR0R` ^`U] Y e \$# Na` P [ Q\_Z [ `  
TMO\_aRR00Z` PUSZ [ \_l0M0Ca`M0e` [ '0\XMOUZbMlbbQ`Q\_ 'UZS/U0ZRXQ\ [ \_UlBQNZP RMXOZOSMlbbQ\_`UX  
[ COa'fz;` c M\_LZUUX6 bNXPMP MZP OZL0W6 LY \XOY OZ` CP M\_MZ dNpbMZCOOP [ ^\_0Q ZPMe\_0'00ZUS`Q`  
R`^c [ Y OZ M\_LZ0'0MCP XVOXT [ [ P [ RTM0ZS MOTUP c UT MZCa\X UPeNMCP [ Z Y MOZNMNSQ \`U] ^  
MNZ [ 'Y MX\_0'00ZUS 'Q\_aX! aX'M] aZP U'0SaXMUe [ ^^`U] ^TU [ 'e [ RMZCa\X UPež 6MIMMOZ [ c N0N0MNDQ  
[ Z U\_a\_QUZ`TOSQZ0'M\ \aXMU Z! \_aSSQ\_ 'UZS Q] aMX`Q` \O'R` 'Y MZ00OTMNDQ U`\_l0Z\_ OZ\_UlB0e  
NZP \_\COBR0UefiNa` M] c O'0T MZ00 [ RMZ M'ROOP R0\_a\_SUBOZ MZ MNZ [ 'Y MX\_0'00ZUS 'Q\_aX  
/M\`Y dY MO6 & " ff M\_c [ aX NOQd\COOP R [ Y U\_a\_QUZ X c Q` \CbXOZ00\ \aXMU Z\_ž`!#`!\$#  
6USZ [ \_l0`Q\_ 'UZS c UT M' ZU] 00Z`Q\_U [ ^0T [ 'U Zl0bUX6 \_M' \XZS\_T [ aX NO'0Q Y Y OZPCP \`U] ^` [  
PCRZUlBQY MZNSQY OZ` PC0U] Z\_ UZ\_0MQ\_ [ R\_a\_\COOP MZCa\X UPe [ Z 0R6@3žNMCP\_0'00ZUSž

I [ Y OZ\_T [ aX MX [ NQM: MQ`TMNO`c 00Z #` [ (" [ R0R6@3`Q`\_M0aZ`0\ [ ^MNOZ`\$! [ Y OZ c UT  
\_a0T MbZ [ 0N6 'Q\_aX M\QM` [ TMO M TISTO`^MO [ R0R6MNMZ [ 'Y MZU0\_/0Sž` 'UX UPeff`\$% MZP`TO'0R` 'O  
\_T [ aX TMOQR` X c a\ M\_Q\_Y OZ` UZ06PUZS PQ'MXCP aX'M] aZP/URZ [ `MX0NPe \O'R` 'Y CPfzFT0e\_T [ aX  
NO [ R0'0P`TON0N0MNDQ \`U] Z\_ [ RPUZS [ \_l0`Q\_ 'UZS '0\QM 0R6@3`Q\_ 'UZS/\_a000\_ R0XZ M\`Y dY MO6  
' "' fi [ ^M M'XOZMlbbQ` 'Y [ R\_0'00ZUS \_a0T M\_Q\_Y NIZCP R0` ` 'Y Q`Q`\_0'00ZUSž

? [ \_ 0R6@3\_0'00ZUS`Q`\_ [ R0'0R0M'0dMzP\_0d0T`Y [ \_] Y QMZCa\X UPe PQ'00U] Z UZ NPPU] Z` [ `  
'`U] Y l0\_ \$# #+ NZP #%žFTO'QTM! T [ c Cb0Y N00Z Z [ \`000POZ` R` ^\ \aXMU Z\_0'00ZUS R` ^\_0d  
0T`Y [ \_] Y OQ ZPU] Z\_PaQ` [ `TQbMUMNDQNZP a\_aN6 Y UP \TOZ [ `e\0Z0R6@3 NMCP\_0'00ZUS R` ^  
\_0d0T`Y [ \_] Y Q\_U M] X\_ X0\_ M0Ca`M0`TM R` ^`TOMa` [ \_] Y Q] UZ0'0MQ\_`TORXQ\ [ \_UlBQ`M0G MZP ONZ  
NOQ ZR` aZPCP Ne aZPO`6UZS Y MOZNMNMZP \XMOZ`M'RM [ ^/\_a0T M\_Y MOZNMNSQž`Q'MCP \_] Y Ml0  
Y [ \_M0U] Y MZP Q ZRZCP \XMOZ`M'Y [ \_M0U] Y fž` B'0Z`Q` Q` aZ\_0XZS R` ^0R6@3\_0'00ZUS\_T [ aX UZ06PO  
UZ R` 'Y CP PC0U] Z Y MNZS 'OSMPUZS`Q\_ 'UZS R` ^R0M'0dMzP\_0d0T`Y [ \_] Y QMZCa\X UPež! [ Y OZ

-







+POVFOUPOBM/ iCBOEFE° 3BSZPUZQJHk a\_Q\_GaXa^CP R M O X ` [ \^Q\MO\_`N Z Q P Y Q M T M Q  
OT^Y [ \_]Y Q\_R ^Y W^\_Q \WUZ\_\OOU Zz5T^Y [ \_]Y QZaY NO^XZS^T^N M Z P U S \M^O^Z M Z P  
[ ^TQ^Te\_W^O^T^M^O^U^\_W^M^O^b^u^a^M^M^\_Q^\_P^N^e^M^e^ [ SOZQ WJ^ž;` UPOZ`WQ\_OTM^SO\_UZ  
OT^Y [ \_]Y QZaY NO^M^c^O^M^\_a^N^O^T^Y [ \_]Y M^Q^M^Z^S^O^Y^O^Z^\_P^c^Z^ [ ' Ž#" Y OS^M^M^O^\_U^Z  
\_UQž

: BOJE BOFVOVLEZ UFTUT I G

3.5.1 Population-based reproductive carrier screening

+BSSFSTDSFFOJCHGPSJCI FSJLFE HFOFUDEJTPSEFST	
/ PPE OSBJUDF OPUF	/ SBFEF BOE TVCOPSJUCH SFGSFODFT
B'OCQ ZOCAL'UJ Z _O'OOZUZS U \^OCOMNDQ [ M' OZMINX O'OOZUZS R ^ TOUMNDQSOZO WOC ZPUUJ Z_M' TU \^ 'OZ' UWXE NXX c_Y [ 'O [ \^ UJ Z_R ^ OMM'W'Q a\XQ _J ZOAPUZS \^OZY \XZ' MIUJ Z SOZO WOPUSZ [ _Uz	9 [ [ P \^ MO WOC Z [ ' Q /Q Z_OZ_a_ZNMOPfi
: FDPN N FOEBUJPOŁz	/ SBFEF BOE TVCOPSJUCH SFGSFODFT
3XXQ a\XQ _J^OZPUZS \^ TMOOTUP'OZ [ ^c T [ MO \^OSZM' t_T [ aX TMO MOCRAXRMY Ue TU [ ^e \^MOZ c UT MblOc \^ UPOZ' UeUZS \^OXMUBQ_c UT TOUMNDQSOZO WOPU [ ^PO^_zFT [ _OUPCZ' UROP c UT MRY' Ue TU [ ^e [ RM _\COBUDZTO'UCP PU [ ^PO^_T [ aX NO [ RRO'CP \^OCOMNX [ MSOZO W Q aZ_OXZS _O'blOC R ^UZ R ^Y MIUJ Z MN [ a' OMM'W' O'OOZUZS NZP \^OZMINX PUSZ [ _U \^OZY \XZ' MIUJ Z SOZO WOPUSZ [ _U R ^TOQ ZPUUJ Zz	5 [ Z_OZ_a_ZNMOP ^OC Y Y OZPMUJ Z
: FDPN N FOEBUJPOŁ!	/ SBFEF BOE TVCOPSJUCH SFGSFODFT
5MM'W' O'OOZUZS R ^TOY [ ^OC Y Y [ Z oY [ Z [ SOZ Wp SOZO WOC ZPUUJ Z _ /OSzGe' _WORNY [ _U ] \_ZNMXY a_GaXMM' \Tel RNSUQJ _eZP^Y Q TMOY NSX NIZ [ \MTW_fiU MNXNDQZ 3a_ \^XMMZP UZ @C: LONXZP/UZ \TO \^UMIO _CO [ ^z:Z R ^Y MIUJ Z [ Z OMM'W' O'OOZUZS R ^TOY [ ^OC Y Y [ Z SOZO WOC ZPUUJ Z _TMNROO OTUP'OZ /OSzGe' _WORNY [ _U ] \_ZNMXY a_GaXMM' \Tel RNSUQJ _eZP^Y Qfi_T [ aX NO [ RRO'CP \^ NXC [ Y OZ \XZUZS M \^OSZM'Ge [ ^Z \^TORJ_ \^Y Q_ Q_ [ R \^OSZM'Gez I [ Y M c M' UZSY [ ^O UZ R ^Y MIUJ Z MN [ a' OMM'W' O'OOZUZS _T [ aX NOSUBOZ \TO [ \ \ [ ^aZUe' [ TMOY [ ^OPO NXP PUca _UJ Z MN [ a' OMM'W' O'OOZUZS c UT M UZ R ^Y CP OZ WOXzFTONOCRU _MZP XY UMUJ Z _ [ R' Q_ UZSI NZP NZe M [ OMM'Q Q _ _ _T [ aX NQPUca _OPz	5 [ Z_OZ_a_ZNMOP ^OC Y Y OZPMUJ Z
: FDPN N FOEBUJPOŁ"	/ SBFEF BOE TVCOPSJUCH SFGSFODFT
3X \^OSZM' c [ Y OZ _T [ aX NO [ RRO'CP NM'W' O'OOZUZS R ^TM' M_OY UM OMM'W' _Ma_Ne MRA'XNX [ P QdNY UZ MIUJ Z M UZ UWX \^O' OZ^ MIUJ Zz EO'OOZUZS c UT _\COBUDZTO'UMNDQ PU [ ^POz; \^ P [ Q_Z [ \^ ORO^ [ \^ Q_ UZS M UZ PWBPaNX c UT M _^ [ ZSRMY Ue TU [ ^e [ RMZ [ c Z [ \^ [ _WNO SOZO WOC ZPUUJ Z k \^TOQ \^Q \^XQ_T [ aX NO [ RRO'CP PU CO \^OCOMNX [ M \^COXU: OZ WOXSOZO W _O'blOC	9 \^MO5

B'OCQ ZOCAL'UJ Z [ \^ \^OZMINXSOZO W O'OOZUZS [ RQ a\XQ\_c UXP'OCZ' Ue \^T [ \_Qc UT M UZ O'OM'CP XWOX [ [ P [ RSWUZS NUS^T [ MOTUP c UT M \\_COBUDZTO'UMNDQ PU [ ^POz; \^ P [ Q\_Z [ \^ ORO^ [ \^ Q\_ UZS M UZ PWBPaNX c UT M \_^ [ ZSRMY Ue TU [ ^e [ RMZ [ c Z [ \^ [ \_WNO SOZO WOC ZPUUJ Z k \^TOQ \^Q \^XQ\_T [ aX NO [ RRO'CP PU CO \^OCOMNX [ M \^COXU: OZ WOXSOZO W \_O'blOC

; U\_Q^LY MQP`TMNKLZPUBPaM^MOQMM^R^AMXQM^T^OOOZLW^CbO^O^OOO`\_BQOUP^T [ P  
PU [ ^PO^Z^ ? [ \_ [ R^TQ\_QMQM^ [ \_ [ Y^N^Y^Q^N^Z^S^URN^T^Y^O^Y^NO^ [ R^M^Q^a^X^Q^M^O^Q^M^O^ [ R^M  
Y^a^M^U^Z^U^Z [ Z^O^S^O^Z^O^Q^ \e [ R^M^ \COOR^O^S^O^Z^O^ \M^M^ M^P^URN^T^ \M^ [ Z^T^O^Y^a^M^U^Z^T^T^O^ [ R^ \^U^Z^c^U^X  
P^C^O^X^ \ M^Y^O^P^L^O^N^K^ \S^Z^U^R^O^N^ \S^O^Z^O^W^O^Q^Z^P^U^U^Z^Z^J^Z^X^Z^V^Z^P^ \^O^O^O^ \\_B^O^Q^Z^P^U^U^Z^ [ O^C^a^c^T^O^Z^M^c [ Y^M^  
O^M^O^M^O^ M^Y^a^M^U^Z^U^Z^M^S^O^Z^O^ [ Z^T^O^J^Z^O^T^Y^ [ \_ [ Y^O^Z^R^T^Q^ \M^Q^ \\_T^U^Y^a^M^U^Z^ [ Z^ [ T^O^ [ Z^T^O^c^U^X  
P^C^O^X^ \ M^Y^O^P^L^O^N^K^ \S^Z^U^R^O^N^ \S^O^Z^O^W^O^Q^Z^P^U^U^Z^Z

FTOQMM^O^R^Q^ aOZ^e [ R^O^O^N^M^ \^O^O^O^ \\_B^O^Q^Z^P^U^U^Z^ \\_U^T^I^S^T^O^U^Z^ \\_COOR^O^O^T^Z^O^ \ \a^X^M^U^Z^ \\_O^S^Z^e^ \\_W  
R^M^ [ \_U^Z^ @ [ ^T^O^Z^ 7a^ [ \CO^N^ \M^P^ 3^T^V^O^Z^M^U^O^c^ / ^T^M^M^O^Y^ \M^T^M^O^Y^ [ S^X^N^Z^ [ \M^T^O^U^Z^ E [ a^T^Z^M^  
3^U^Z^ / M^P^F^M^Z^E^M^O^T^ \\_P^U^Q^M^O^U^Z^ 3^T^V^O^Z^M^U^O^c^ \\_Z

3 ZaY NO^ [ R^O^M^O^M^O^ \\_O^O^O^Z^U^S^ \\_Q^ \\_C^O^U^ \\_c^U^T^U^Z^ 3a^ \^M^M^U^M^ [ ^M^O^ \^O^M^P^U^e^ M^O^O^ \\_U^W^O^R^ [ Y [ b^O^ \\_C^M^f^i^ N^a^  
G^a^ \^O^Z^ \\_e^ \\_T^O^Q^O^M^O^S^O^Z^O^M^K^ Z [ \ R^a^Z^P^O^P^ N^e^ \\_T^O^ \a^N^X^O^T^O^M^X^T^ \\_e^ \\_O^Y^ \\_U^O^Z^M^O^O^ \\_U^W^O^ [ Z^e^ [ Z^M^a^ \\_O^ \\_M^e^  
N^M^U^f^z

;Z^R^ \^Y^ M^U^Z^ [ Z^O^M^O^M^O^ \\_O^O^O^Z^U^S^ \\_R^ \^T^O^Y^ [ \^O^Q^Y^Y^ [ Z^S^O^Z^O^W^O^Q^Z^P^U^U^Z^ \\_T^M^N^R^O^O^O^T^U^P^ \^O^Z^ \\_O^S^Z  
e^ \\_W^O^R^M^ [ \_U^ [ \\_U^Z^N^X^Y^ a^G^a^X^M^M^ [ \T^e^f^ R^N^S^U^O^J^ \\_e^Z^P^ [ Y^G^f^T^ [ a^X^N^O^ [ R^R^O^P^ [ M^K^c [ Y^O^Z^ \\_X^Z^Z^U^S^ M  
 \^O^S^Z^M^O^e^ [ ^U^ \\_T^O^R^ \\_ \^Y^ \\_Q^ \\_O^ [ R^ \^O^S^Z^M^O^e^z^ | [ Y^M^c^M^ \\_U^Z^S^Y^ [ \^O^U^Z^R^ \^Y^ M^U^Z^M^M^ a^ \\_O^M^O^M^O^  
 \\_O^O^O^Z^U^S^ \\_T^ [ a^X^N^O^S^U^B^O^Z^ \\_T^O^ [ \ \ [ ^a^Z^U^e^ \\_T^M^O^M^Y^ [ \^O^P^O^N^O^P^U^C^a^ \\_U^Z^M^M^ a^ \\_O^M^O^M^O^ \\_O^O^O^Z^U^S  
c^U^T^M^ \\_U^Z^R^ \^Y^O^P^O^X^Z^O^W^M^Z^ F^T^O^N^O^Z^O^R^J^ \\_M^P^X^Y^U^M^U^Z^ [ R^ \\_Q^ \\_U^S^I^ M^P^M^e^M^ [ O^M^O^P^Q^ \\_ \\_T^ [ a^X^N^O  
P^U^C^a^ \\_O^P^z

AZ^O^Z^ \\_O^ \\_O^O^O^Z^U^S^ \\_R^ \^O^M^O^M^O^ \\_M^a^ \\_f^c^T^O^Q^N^ [ T^Y^O^Y^N^O^ [ R^M^Q^a^ \\_X^Q^M^O^ \\_Q^ \\_O^P^ \\_Y^ a^X^M^Q^ a^ \\_e^ M^P  
O^M^O^T^ S^U^B^O^Z^ \\_T^O^ \\_O^a^X^N^O^N^O^M^Z^P^U^B^P^a^M^K^ \\_U^ \\_ \^O^R^ \\_M^O^M^Y^ [ \^O^O^M^O^M^O^ \\_c^U^X^N^O^P^O^O^O^P^M^P^ \\_T^O^ \\_O^a^X^  
c^U^X^N^O^N^O^N^O^M^O^U^Z^ M^Y^ [ \^O^ \\_Y^O^e^ R^M^T^U^Z^Z^: [ c^C^O^O^f^U^U^ \^O^Q^ S^Z^U^O^P^ \\_T^M^U^U^Y^ [ \^O^O^Q^Z^ [ Y^O^N^K^ [  
a^Z^P^O^ \^M^O^o^c^ [ Z^ \\_O^ \\_O^O^O^Z^U^S^p^k^ \\_Q^ \\_ \\_T^O^R^O^Y^ M^O^R^ \\_M^P^ \\_T^O^Z^ [ Z^e^ \\_Q^ \\_ \\_T^O^Y^ M^O^ \\_M^Z^O^ \\_T^ [ a^X^ \\_T^O  
N^O^R^ \\_a^Z^P^ [ N^O^M^O^M^O^M^O^ [ R^T^O^ \\_ \\_COOR^O^M^a^ [ \_ [ Y^M^ \^O^O^O^ \\_B^O^Q^Z^P^U^U^Z^ / f^i^N^O^Z^S^ \\_O^O^O^Z^O^P^R^ \\_Z^f^T^O^ \\_a^Z^Z  
M^ [ a^Z^P^Z^Y^O^ [ R^ \\_O^O^O^Z^U^S^ \\_Q^ \\_ \\_M^P^ \\_T^O^M^ \\_W^O^M^O^P^S^O^ \\_M^U^Z^M^N^S^O^M^R^Z^M^P^U^S^Z^ [ \_U^M^O^U^Y^ \ [ ^M^  
R^M^ [ ^ \\_ [ Q^Z^ \\_P^O^c^T^O^Z^ P^C^O^P^U^Z^S^N^O^c^O^O^Z^ [ Z^O^Z^ \\_O^ [ ^c^ [ Z^ \\_O^ \\_O^M^O^M^O^ \\_O^O^O^Z^U^S^Z

I^U^T^ \\_T^O^U^Z^ \^Y^ P^a^O^U^Z^ [ R^Z^O^c^S^O^Z^ [ Y^O^W^O^Q^] a^O^Z^O^Z^S^ \\_O^O^Z^U^] a^O^Z^O^M^O^M^O^ \\_O^O^O^Z^U^S^ \\_R^ \^M^Y^ a^X^U^a^P^O^ [ R  
 \^O^O^O^ \\_B^O^Q^Z^P^U^U^Z^ \\_U^Z^ [ c^M^N^O^M^M^O^R^ \^O^Q^ a^ \\_X^O^ \\_c^T^ [ T^M^O^Z^ [ R^M^U^e^T^U^ [ \\_e^ [ R^M^S^O^Z^O^W^O^P^U^ [ \^O^O^Z^#^ F^T^U  
 \\_ [ Z^O^M^O^P^O^O^ \\_M^P^O^P^O^M^O^M^O^ \\_O^O^O^Z^U^S^p^ \\_T^ [ a^X^ [ Z^e^N^O^ [ R^R^O^P^U^Z^ \\_T^O^Q^Z^ \\_O^f^ [ R^c^O^X^P^O^R^Z^O^P^O^X^Z^O^N^K  
 \\_M^T^c^M^ \\_R^ \^ \^O^Z^M^P^ \ [ \\_Z^O^ \\_S^O^Z^O^W^O^Q^ a^Z^O^X^Z^S^I^M^a^ \ [ \$&^ [ R^M^P^a^X^ \\_c^U^X^Q^ \\_ \ [ \\_U^B^O^R^ \^M^X^O^M^  
 [ Z^O^ \^O^O^ \\_B^O^P^U^ [ \^O^O^Z^S^

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R^N^S^U^O^J^ \\_e^Z^P^ [ Y^G^f^T^O^Q^ \\_W^O^R^M^ [ \_U^f^i^ \^O^R^ \\_T^O^Q^ a^ \\_X^O^ [ \\_CO^O^M^U^ \\_O^X^Z^O^N^K^S^O^Z^O^W^O^ \\_O^b^W^O^ \^O^R^O^M^M^e  
 \\_U^ \^ [ \^O^S^Z^M^O^e^f^i^ [ M^Q^ \\_ \^O^ \^Y^ P^a^O^W^O^ \\_U^W^M^P^ \\_T^O^M^O^M^O^M^U^O^e^ [ R^S^O^Z^O^W^O^ \\_U^Z^S^ \ [ R^a^ \^T^O^ \^O^R^Z^O  
 \^O^ \^Y^ P^a^O^W^O^ \\_U^W^Z^A^ \\_U^Z^ \\_R^ \^ \^O^Z^Y^ \\_X^Z^ \\_M^U^Z^S^O^Z^O^W^O^P^U^S^Z^ [ \_U^M^P^i^ [ \^ \^O^Z^M^M^P^U^S^Z^ [ \_U^ \\_T^ [ a^X^N^O  
P^U^C^a^ \\_O^P^z

I "fii" &<08, > 6/4 289-4 19<2080>4 / 49</0<=>? = 0 >0/ 98 >30-, =4 9110> 6?6< =9?8/  
, - 89<7, 640=

B^OZMINXPUSZ[\_U\_R^AY a`MIJ Z\_UZ SOZQ\_XZVOP`[ \_\COJROPU[ ^PO^\_U\_Ga^OZ`X NBNKNDQIZ 3a\_`^MMUM  
R^\_Y OSOZQ\_a\_LZS`^MPUJ ZMX\_Q] aOZQZSY OT[P\_ž 7dMY \XQ\_UZ0&PQ0e\_`W0RW[\_U\_Y a`MIJ Z \NZOX  
\_O^OZLZSNZP i f'ž SOZQ\_Q] aOZQZSR^R^N^OOT[ SOZLON[ c OX fE fE SOZQ\_Q] aOZQZSR^ \[\_UNQRO^N^  
MOT[ ZP^ \X^MUM[ ^O^MZU\_eZ[\_[\_U^M^P`MSOCP`Q`LZSR^AY a`MIJ Z\_UZ SOZQ\_OVA\_LZS@[ [ ZM^  
\_eZP^Y Ož

I UT`TOUZ`^ [PaOUJ Z [RZQc SOZ[Y W\_Q] aOZQZS`OOTZU] aQ\_} U U\_MZ`W^MCP`TM \^OZMINXPUSZ[\_U  
R^AY a`MIJ Z\_UZ Y aXUXOSOZQ\_c U^N^QY [ ^Q^Q^MPU^

## 4. Governance

žĹ 9VBMIZ ) TTVSBODF

/"/. !/?., >98 19<30, 63: <910=48, 6=4@/4/ 4B: <08, > 6= <00842

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[ \^U Z\_NBMVMOQR Ā \^OZMNX\_O^OOZLZS MIP PUSZ[ \_Uf MIP \_T[ aP.

: N0Qa\ž [ žPMQVZ [c XPSOMM[ a^`TQCa^OZ` \_O^OOZLZS Y [ PNVUQ\_NBMVMOQNZP LZ c TM  
\_Q^LZS`TQc OMZ NQY \XOY OZ`CPž

4QMMQ [ \^f bPQO \^OžMP \ [ \_žQ\_ LZR^ Y MUJ ž \\_a \ [ ^ MIP Q aZ\_OXZSI LZ OaPUZSc ^U^OZ  
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## 5. References

1.



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## Ž/ 7U FSTVHFTUFE ŠBEJOH

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