TRIS Survey results

One hundred ninety three Full TRIS Surveys were completed between February 1, 2007 and September 15, 2010. The group represented 69 with a type of trisomy 18, 54 trisomy 13 and 34 trisomy 9. The remaining completions included seven with trisomy 8, five with trisomy 14, five with trisomy 16 and four or less with other "rare rare" trisomy syndromes.

The trisomy 18 group included 48 with full trisomy 18, 11 with mosaic, seven with partial, two with isochromosome and one with tetrasomy. Fifty-four children and young adults (78%) were living at the time of survey completion. Mean age was 83.2 months with a range from 2 to 394 months. The 15 who passed away ranged from two to 258 months. Mean age was 57.7 months.

For individuals with a type of trisomy 13, mean survival age (n = 39, 72%) was 95.8 months (range 2 to 405 months). This group was comprised of 30 with full trisomy 13, 10 with mosaic and 14 with partial. The remaining 15 children lived between two to 290 months with a mean of 60 months.

Fourteen children with trisomy 9 (mosaic, partial, affected p arm only and partial and p arm) were examined. All were living at time of survey completion. The oldest survivor was 293 months old while the youngest was two months of age. Mean age was 78.6 months

Similar analyses were completed for the Modified TRIS Survey (infant survived less than two months). This version of the survey was completed by 142 parents (33 with a type trisomy 18, 103 with trisomy 13, two with trisomy 9, one with trisomy 8, two with trisomy 2 and one with trisomy 1). All with trisomy 18 were diagnosed with the full type (every cell affected). Infants lived up to 62 days with a mean of 7.6 days. All but one (n = 132) with trisomy 13 had the full type. Mean survival was 9.5 days. The one infant with mosaic trisomy 13 lived for 24 days. Finally, one infant with trisomy 9 mosaic and one with partial trisomy 9 were stillborn.

Additional analyses by trisomy type are available in the Results section of the website.

Full TRIS Survey results

Living children by trisomy type	Mean (± SD) and Range
Full trisomy 18 (n = 35)	81.5 months (<u>+</u> 97.61 months) Range: 3 – 394 months
Trisomy 18 mosaic (n = 10)	73.9 months (\pm 88.91 months) Range: 4 – 309 months
Partial trisomy 18 (n = 6)	81.2 months (\pm 82.01 months) Range: 2 – 223 months
Full trisomy 13 (n = 18)	48.4 months (\pm 47.79 months) Range: 2 – 167 months
Trisomy 13 mosaic (n = 9)	115.9 months (<u>+</u> 134.08 months) Range: 9 – 405 months
Partial trisomy 13 (n = 12)	151.8 months (<u>+</u> 120.35 months) Range: 4 – 326 months
Trisomy 9 mosaic (n = 14)	78.6 months (<u>+</u> 89.32 months) Range: 2 – 293 months
Partial trisomy 9 $(n = 7)$	117.7 months (<u>+</u> 109.68 months) Range: 2 – 348 months
Trisomy $9p (n = 8)$	98.5 months (<u>+</u> 153.57 months) Range: 5 – 468 months
Partial trisomy 9p (n = 5)	92.8 months (<u>+</u> 86.03 months) Range: 28 – 219 months

Full TRIS Survey results continued

Deceased children by trisomy type	Mean (± SD) and Range
Full trisomy 18 (n = 13)	42 months (<u>+</u> 73.29 months) Range: 2 – 285 months
Trisomy 18 mosaic (n = 1)	176 months
Partial trisomy 18 (n = 1)	143 months
Full trisomy 13 (n = 12)	40.8 months (<u>+</u> 55.90 months) Range: 2 – 168 months
Trisomy 13 mosaic (n = 1)	7 months
Partial trisomy 13 (n = 2)	202 months (\pm 124.45 months) 114 – 290 months

Modified TRIS Survey results

Trisomy type	Mean (± SD) and Range
Full trisomy 18 (n = 33)	7.6 days (\pm 15.50 days) Range: 0 – 62 days
Full trisomy 13 (n = 102)	9.5 days (\pm 15.50 days) Range: 0 – 60 days
Trisomy 13 mosaic (n = 1)	24 days
Trisomy 9 mosaic (n = 1)	0 days (stillborn)
Partial trisomy 9 $(n = 1)$	0 days (stillborn)