**Appendix Table C35. Outcome assessment: Treatment, retinoblastoma**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Study (Investigator, country, year)** | **Re-cord Num-ber** | **Group (N)** | **Primary Outcomes** | **Secondary Outcomes** | **F/U Frequency/Duration** | **Comment** |
| Cozza, Italy, 2009 | 70 | HSCT (3) | Survival | NR | 66% alive at median FU of 61.5 months33% dead at 16 months |   |
| Dai, Canada, 2008 | 1410 | HSCT (1) | Survival | NR | death at 32 months follow-up | she had CNS involvement |
| Dunkel, USA, 2000 | 14610 | HSCT (4) | Survival | No major harms reported | 100% of patients were alive at a median FU of 57 months (46-80) |   |
| Hertzberg et al, Germany, 2001 | 13810 | 1 | Survival | Harms | Alive 4 years+ post transplant |   |
| Jubran, USA, 2004 | 9480 | HSCT (4) | Survival | No major harms reported | 100% dead at median of 25 months FU |   |
| Kremens, Germany, 2003 | 10860 | HSCT (5) | Survival | No major harms reported | 100% alive median 57 months (8-107) |   |
| Matsubara, Japan, 2005 | 7580 | HSCT (5) | Survival | harms | 60% alive at a median of 107 months FU40% died at a median of 26 months FU | the two patients who died developed CNS involvementthe three others remained non CNS |
| Moshfeghi et al, USA, 2002 | 12230 | 1 | Survival | NR | 16 months | dead at 16 months |
| Namouni, France, 1997 | 18090 | cut end of optic nerve/ocular globe (6)Isolated orbital (7)Various metastasis (8)CNS/spinal axis (4) | Overall Survival | Harms | Cut end/globe-83% (NED) at median 33 (8-55) 20% (DOD) 9 months Isolated orbital-86% (NED) at median 51.5 (25-74), 14% (PD) 5 bone or bone marrow-63% (NED) at median 37 (11-70), 37% (DOD) 13(10-20)CNS-75% (DOD) at median 10 (7-26), 25% (NED) 63 | all numbers are monthsthe 37% DOD with bone mets developed CNS after transplant |
| Rodriguez-Galindo, USA, 2003 | 10420 | HSCT (4) | Survival | Harms | 50% alive at median FU of 6.5 years (6-7)50% dead at median FU of 66 months (44-88) | 2 who are deceased developed CNS involvement |
| Taguchi, Japan, 2005 | 7430 | HSCT (1) | Survival | NR | 19 months | Dead at 19 months after transplant Non CNS group |
| Dimaras, Canada, 2009 | 2137 | HSCT (1) | Survival | Harms | 8.3 years post transplant |  |
| **Study (Investigator, country, year)** | **Record Num-ber** | **Group (N)** | **Primary Out-comes** | **Secondary Outcomes** | **F/U Frequency/Duration** | **Comment** |
| Dunkel, USA, 2010 | 2148 | HSCT (8) | Survival | Event free survival, harms |  |  |
| Dunkel, USA, 2010 | 2149 | HSCT (15) | survival | harms, retinoblastoma free |  | 13 of the 15 actually received transplant |