Table 2: Demographic characteristics and NDI* match counts of the known decedents (1979–2001) as ascertained in April 2005

		Total	Match	% Match	OR*†	95% CI*†
Sex						
	Female	413	364	88.1	1.00	
	Male	376	345	91.8	1.49	(0.90, 2.48)
Ethnicity						
	Caucasian, non-Hispanic	551	507	92.0	1.00	
	African American	147	131	89.1	0.67	(0.35, 1.25)
	Asian	13	12	92.3	1.19	(0.13, 11.10)
	Hispanic	72	55	76.4	0.30	(0.14, 0.63)
	Unknown/Other	6	4	66.7	0.31	(0.05, 1.99)
SSN						
	Unknown	606	532	87.8	1.00	
	Known	183	177	96.7	4.04	(1.54, 10.58)
Place of birth						
	United States	623	568	91.2	1.00	
	Foreign	23	13	56.5	0.12	(0.04, 0.34)
	Unknown	143	128	89.5	1.02	(0.54, 1.94)
Age at death						
	0–4 years	245	231	90.9	1.00	
	5–9 years	329	291	88.4	0.61	(0.33, 1.10)
	10–19 years	156	141	90.4	0.60	(0.28, 1.32)
	20+ years	50	46	92.0	0.35	(0.09, 1.37)
Total		789	709	89.9		

* NDI, National Death Index; OR, odds ratio; CI confidence interval.
† Odds ratios and 95 percent confidence intervals adjusted for sex, ethnicity, presence of SSN, year of death, location of birth, age at death group, location of treatment institution, institutional compliance and NWTS recorded cause of death.

throughout the study, so those with longer periods of follow-up would have had more opportunity to get an SSN. Parents or adult subjects who report SSNs may also be easier to track for other reasons. Nonetheless, the message is clear that studies with a mortality end-point that anticipate long follow-up periods or a high potential for study drop out should endeavor to collect SSNs both to facilitate tracking and to increase the effectiveness of any future NDI search.

One recent study based on active follow-up of Hispanics over age 65 suggested that NDI linkage rates may under-ascertain deaths in this population [33]. While the results of this study are under review and may have been overstated [34] , our results demonstrate the same phenomenon for young Hispanic subjects. A small portion of the under-ascertainment in adults has been attributed to "salmon bias", the likelihood that foreign born subjects will return home to their country of origin once they become ill [33]. A small portion of the under-ascertainment in our pediatric population was likewise attributable to the low (56.5 percent) match sensitivity observed for subjects known to be foreign born (n = 23), many of whom presumably returned home once treatment was completed.

Dividing 18 by 79.3 gives an expected match rate (22.7 percent) for the presumably deceased subjects that is much lower than the match rate observed for known decedents (89.9 percent). Part of this discrepancy could be due to bias in NWTS rates, for example, the "bad news travels fast" principle such that deaths are reported in preference to the fact that the subject is alive and well. In this case NWTS death rates would be overestimated. Most of the discrepancy, however, is likely due to very substantial under-ascertainment by the NDI of the deaths that pre-

Table 3: Estimated survival at 15 years from diagnosis calculated using follow-up from NWTS* records only†, NWTS records supplemented with NDI* search results and NDI search results only

		NWTS only			NWTS + NDI			NDI only		
	Total	Died	% Alive	95% CI*	Died	% Alive	95% CI	Died	% Alive	95% CI
NWTS-1,2	1,310	317	77.8	(75.4, 79.9)	322	78.1	(75.8, 80.2)	307	79.0	(76.7, 81.1)
NWTS-3,4	4,907	670	85.7	(84.6, 86.7)	683	86.0	(85.0, 87.0)	618	87.4	(86.4, 88.3)

* NWTS, National Wilms Tumor Study; NDI, National Death Index; CI, confidence interval.
† April 2005 ascertainment of January 1, 2002 vital status.