

CH Three-Year Follow-up Study

CH Three Year Follow-up

- Standard of care is to follow-up CH cases until at least age three years (AAP Guidelines)
- Diagnostic verification recommended (permanent vs. transient CH)
 - **Thyroid function trial**
- Rate and outcome of diagnostic verification unknown

CH Three Year Follow-up of 'Borderline' Cases

- 'Borderline' was initially considered as having pre-treatment serum TSH values below the 15th percentile.
 - We expanded our criteria to include all cases.
- Survey developed and pilot tested in collaboration with PEAC endocrinologists
- Medical management data maintained by NBS Follow-up program used to locate cases' physicians.
 - LTFU mitigated by use of MCIR and phone based survey



Demographics of Michigan CH Cases Detected by NBS Classified by Pre-Treatment Serum TSH/FT4 Values, 9/2003-9/2007

Classification	N	%	Mean GA	Mean BW	White (%)	Male (%)	NICU (%)
FT4 < .9, TSH >=40	103	44.78%	37.9	3156	79.1	39.2	19.6
FT4 >=.9, TSH >=40	48	20.87%	38	3254	61.5	33.3	18.2
FT4 < .9, TSH < 40	9	3.91%	34.1	2461	50	66.7	55.6
FT4 >=.9, TSH < 40	70	30.43%	38.5	3001	53.1	58	25.8



Preliminary Findings of the CH Three year follow-up study

- Preliminary findings indicate:
 - Of the 67 returned surveys:
 - 33% (22/67) involved children lost to follow-up (17), moved out of state (4), or deceased (1)
 - 67% (45/67) included medical information

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Preliminary Findings of the CH Three year follow-up study

- Of the 45 returned surveys with medical information:
 - 36% (16/45) had completed diagnostic re-evaluation
 - 81% (13/16) were confirmed with permanent CH
 - 19% (3/16) did not have permanent CH
 - 9% (4/45) had diagnostic re-evaluation in progress
 - 27% (12/45) were confirmed with CH based on increasing treatment dosage
 - 11% (5/45) have not have diagnostic re-evaluation and are still on treatment
 - 18% (8/45) have stopped treatment of their own accord (i.e., without diagnostic re-evaluation); this phenomenon requires further study.
 - One case (family) described miscommunication with health care provider and lack of follow-up as impetus to treatment cessation.
 - All patients who stopped treatment on their own are thought to be transient CH (confirmation of transient CH is pending TSH value receipt- two patients have provided such confirmation to date)

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