HIRSCHSPRUNG’S DISEASE (HSCR) QUESTIONNAIRE
Australian Paediatric Surveillance Unit

DOCTOR’S INFORMATION
Name: _________________________________________  Code: _______ Rept code: ____/____
Contact phone no.: ____________________________

PATIENT’S INFORMATION
Surname:(first 2 letters) |___|___| First name:(first 2 letters) |___|___|  Sex:  M / F
Date of Birth: __ __/__ __/ __ __    Post code of residence:|___|___|___|___|
Birth weight:________gms  Gestation:________weeks
Country of origin: (e.g. father/mother was born in Australia but the ancestral line was originated from Europe then
the country of origin is Europe)
Father: _____________________________  Mother:______________________________
Country of Birth:
Father: _____________________________  Mother:______________________________

CLINICAL FEATURES
1. Date of first HSCR symptoms: __ __/ __ __/ __ __
Were there any of the following symptoms during the neonatal period?(please tick, can be more
than one)
Vomiting□ Delayed passage of meconium□ Abdominal distention□ Enterocolitis□
Other□ please specify________________________________________
If the diagnosis was made after the neonatal period what were the presenting problems? (please tick,
can be more than one)
Constipation□ Vomiting□ Abdominal distention□ Enterocolitis□
Other□ please specify ________________________________________
2. Date of definitive diagnosis:  __ __/__ __/ __ __
3. How was HSCR diagnosed: (please tick, can be more than one method)

<table>
<thead>
<tr>
<th>Method</th>
<th>Yes</th>
<th>No</th>
<th>Result of test</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical Suspicion</td>
<td></td>
<td></td>
<td>+ve -ve</td>
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<tr>
<td>Rectal Suction Biopsy</td>
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<td>Laparotomy</td>
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<td>Contrast Study</td>
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4. Region where aganglionosis begins: (please tick)
   Ultra short □ Transverse colon □
   Rectal □ Ascending colon □
   Sigmoid □ Caecal □
   Descending colon □ Ileal □
   Splenic flxure □ Prox. small bowel □
   Complete aganglionosis □

5. The initial surgical procedure: (please tick)
   Colostomy □ Date: __ __/__ __/ __ __
   Primary Repair □
6. The definitive surgical procedure:(please tick)
   NOT YET DONE ☐
   SOAVE ☐
   DUHAMEL ☐
   SWENSON ☐
   OTHER ☐

   Date: __ __/ __/ __

7. Was there any episode of enterocolitis?  Y  N  Don’t know

8. Presence of associated anomalies:
   Down’s syndrome ☐
   Extra digits ☐
   Isolated cardiac anomalies ☐
   Depigmentation ☐
   Developmental delayed ☐
   Others, (please specify) ☐

9. Current status:  Alive ☐  Dead ☐

   If dead, date: __ __/ __/ __

FAMILY HISTORY

10. Presence of positive HSCR (please indicate by circling, Y=yes, N=No, ?=don’t know)

   Grandfather(1) Y/ N/ ?
   Grandmother(2) Y/ N/ ?
   Grandfather(3) Y/ N/ ?
   Grandmother(4) Y/ N/ ?
   Father(5) Y/ N/ ?
   Mother(6) Y/ N/ ?
   Sibling 1(7) Y/ N/ ?
   Age: ___ yrs ___ mths
   Sex: M/F
   Sibling 2(8) Y/ N/ ?
   Age: ___ yrs ___ mths
   Sex: M/F
   Sibling 3(9) Y/ N/ ?
   Age: ___ yrs ___ mths
   Sex: M/F
   Other(10) Y/ N/ ?
   Age: ___ yrs ___ mths
   Sex: M/F

   Other relatives, please specify: ____________________________

11. Other family history of disease: (please indicate Y =yes, N=no or ?=don’t know, number corresponds to the number in the family tree)

   Skin Depigmentation (1) (2) (3) (4) (5) (6) (7) (8) (9) (10)
   Thyroid Disease
   Crohn’s Disease
   Constipation
   Neuroblastoma
   Cancer (please specify)

   Other (please specify)

OTHER COMMENTS
________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________

Thank you for completing this questionnaire. A short follow-up questionnaire will be sent in the future for follow-up information.

Please return to:
Danny Cass, Surgical Research Department
The New Children’s Hospital, POBox 3515, Parramatta NSW 2124.
Telephone: (02) 9845-3059  Fax: (02) 9845-3082