PLEASE FILE FOR YOUR INFORMATION

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)

	Yes	No	Result of test +ve	Result of test -ve
Clinical Suspicion	☐	☐		
Rectal Suction Biopsy	☐	☐	☐	☐
Laparotomy	☐	☐	☐	☐
Contrast Study	☐	☐	☐	☐

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 ☐ Date:__ __/__ __/__ __
   - SWENSON ☐
   - OTHER ☐

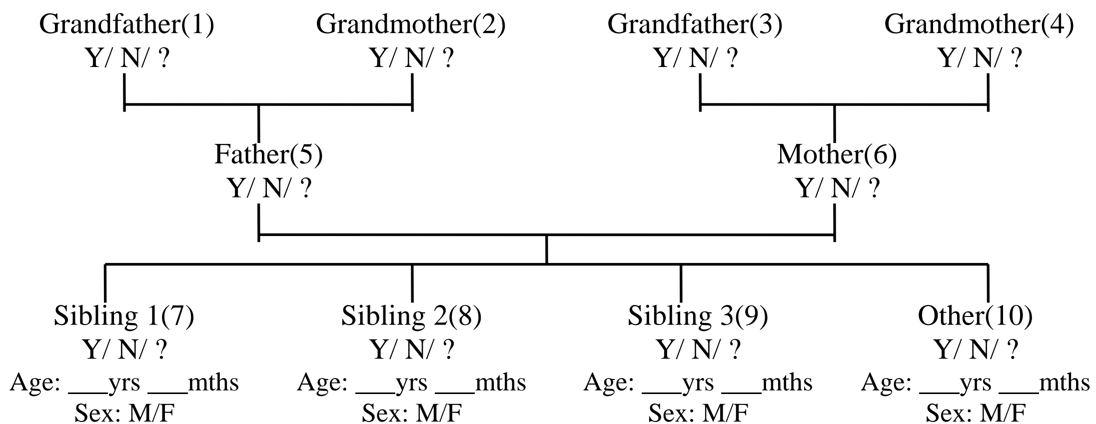
7. Was there any episode of enterocolitis? Y ☐ N ☐ Don't know ☐

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)



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)

	(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)
Skin Depigmentation										
Thyroid Disease										
Crohns Disease										
Constipation										
Neuroblastoma										
Cancer (please specify) ____________										
Other (please specify) ____________										

OTHER COMMENTS

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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.
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