Appendix A – Parental Questionnaire

Phone: 02 9382 1021
Fax: 02 9382 1200

High Street
Randwick NSW 2031
Australia
Phone: 02 9382 1111

Investigation into the Ketogenic Diet for Children with Intractable Epilepsy
at Sydney Children's Hospitals Network (Randwick)

PARENT QUESTIONNAIRE

ID:		Child DOB:	
Consultant:		Date of Interview:	
Your relationship to Child:			

	CLINICAL INFORMATION
1).	Which diet is your child on? (please tick box)
	☐ Classical
	☐ MCT oil
	☐ Modified Atkins
2).	How long has/was your child on the diet?
3).	List the medications your child was/is taking prior to/whilst on the Ketogenic diet. Have medications been reduced due to the Ketogenic Diet? If so how many?
4).	What type(s) and how many seizures was your child having BEFORE commencing the diet?

	Type 1: _____	Type 2: _____	Type 3: _____
	No. ____ per week / month / year (please circle)	No. ____ per week / month / year (please circle)	No. ____ per week / month / year (please circle)
5).	What type(s) and how many seizures was your child having 6 months AFTER commencing the diet?		
	Type 1: _____	Type 2: _____	Type 3: _____
	No. ____ per week / month / year (please circle)	No. ____ per week / month / year (please circle)	No. ____ per week / month / year (please circle)
6).	Have you seen any cognitive improvement in your child from being on the diet? If yes, over what time frame	☐ YES	☐ NO
	If yes – over what time-frame (immediately, 3-6 months, 6-12 months, years)		
	If yes, please specify.		
7).	Have you seen any developmental improvement in your child after commencing the diet?	☐ YES	☐ NO
	If yes – over what time-frame (immediately, 3-6 months, 6-12 months, years)		
	If yes, please specify.		

BEFORE THE KETOGENIC DIET			
8).	How did you learn about the diet?		
9).	Was there anything that worried you about the diet?	☐ YES	☐ NO
	If yes, please specify.		
	Did the worry resolve and how?		
10).	Before commencing the diet did you feel prepared, eg: were you given enough information in preparation for admission to hospital?	☐ YES	☐ NO
	If no, why did you not feel prepared?		
	What would have helped you feel more prepared?		
IN HOSPITAL COMMENCING THE KETOGENIC DIET			

11).	Did you experience any problems in commencing the diet during your hospital admission?	☐ YES	☐ NO
	If yes, please specify.		
	What could have been done better to avoid or resolve the problems?		
12).	Did you feel supported during your hospital admission, eg did you receive adequate supervision and were you given enough information?	☐ YES	☐ NO
	If no, why not?		
	What would have helped you feel more supported?		

13).	Do you have any suggestions on how our service during admission can be improved?

14).	Do you think commencing the diet could be done as an Outpatient (ie, rather than staying in Hospital for the week or more, you would visit the Hospital every day for education)?	☐ YES	☐ NO
	If yes, what would you need to make this work?		
	If no, why not?		

AT HOME WITH THE KETOGENIC DIET			
15).	Did you feel confident continuing the diet at home?	☐ YES	☐ NO
	If yes, what contributed to your confidence?		
	If no, why not?		
	If no, what would have helped you feel more confident?		
16).	What challenges (clinical, financial and personal) have you faced whilst being on the diet? (Please specify)		
17).	Did you receive adequate follow-up after you commenced the diet?	☐ YES	☐ NO
	If yes, what follow-up have you received?		
	If no, why not?		

18).	Do you think a Ketogenic diet Follow-up Clinic would be helpful?	☐ YES	☐ NO
	If yes, who would you like to see at the Clinic?		
	If yes, how often would you like the Clinic?		
	If no, why not?		
19).	Please indicate if your child experienced any of the following side-effects of the Ketogenic Diet.		
	Low blood sugar levels	☐ YES	☐ NO
	High cholesterol	☐ YES	☐ NO
	Kidney stones	☐ YES	☐ NO
	Lethargy	☐ YES	☐ NO
	Vomiting	☐ YES	☐ NO
	Diarrhoea	☐ YES	☐ NO
	Constipation	☐ YES	☐ NO
	Weak bones	☐ YES	☐ NO
	Loss of ketones	☐ YES	☐ NO
	Reflux	☐ YES	☐ NO
	Aspiration	☐ YES	☐ NO

	Weight loss	☐ YES	☐ NO
	Poor growth	☐ YES	☐ NO
	Other (please specify):	☐ YES	☐ NO
	Other (please specify):	☐ YES	☐ NO
	Other (please specify):	☐ YES	☐ NO

20).	Please indicate if you identify with any of the following barriers around the use of the Ketogenic Diet according to the following responses							
	SD = Strongly Disagree	D = Disagree	N = Neutral	A = Agree		SA = Strongly Agree	NA = Not Applicable	
a)	The seizures were a lower priority compared with my child's other problems			SD	D	N	A	SA	NA
b)	Poor efficacy (eg: no or little clinical improvement in seizures)			SD	D	N	A	SA	NA
c)	Cost			SD	D	N	A	SA	NA
d)	No local support available to administer the diet			SD	D	N	A	SA	NA
e)	My personal supports (family) were against the diet			SD	D	N	A	SA	NA
f)	The ketocalculator is/was difficult to understand			SD	D	N	A	SA	NA
g)	My child is too sick to receive the diet			SD	D	N	A	SA	NA
h)	The waiting list is too long			SD	D	N	A	SA	NA
i)	The amount of time involved in preparation was too much for my family			SD	D	N	A	SA	NA
j)	Other (please specify):			SD	D	N	A	SA	NA
k)	Other (please specify):			SD	D	N	A	SA	NA
l)	Other (please specify):			SD	D	N	A	SA	NA

	Comments:

21).	For each of the following items, please indicate whether you believe it would assist with the implementation of the Ketogenic Diet?							
	SD = Strongly Disagree	D = Disagree	N = Neutral	A = Agree		SA = Strongly Agree	NA = Not Applicable	
a)	Better education about the diet to my extended family			SD	D	N	A	SA	NA
b)	Availability of telephone based support			SD	D	N	A	SA	NA
c)	Beginning the diet as an outpatient rather than during an in hospital stay			SD	D	N	A	SA	NA
d)	An outpatient monitoring service			SD	D	N	A	SA	NA
e)	Better kitchen facilities in hospital during the admission			SD	D	N	A	SA	NA
f)	Cookbook			SD	D	N	A	SA	NA
g)	More guidance in understanding the keto-calculator			SD	D	N	A	SA	NA
h)	Menus for home			SD	D	N	A	SA	NA
i)	Other (please specify):			SD	D	N	A	SA	NA
j)	Other (please specify):			SD	D	N	A	SA	NA
k)	Other (please specify):			SD	D	N	A	SA	NA
	Comments:							
22).	Do you have any final comments:							

THANK YOU FOR COMPLETING OUR QUESTIONNARIE