Spina Bifida Questionnaire

Child and Family Characteristics (Primary = adult who is with child most often at home; Secondary = adult who is with the child next most often at home)

Child: _____male _____female Age:_______ Height:_________ Weight:__________

Primary caregiver: ___male___female Age:______ Height:______ Weight:_______Relationship:______

Secondary caregiver:___male___female Age:_____ Height:______ Weight:______Relationship:______

Type of Spina Bifida

Which diagnosis does your child have? _____meningomyelocele _____meningocele ____occulta

_____lipomeningocele _____lipomeningomyelocele

What is the level of your child's lesion? _____T12 or higher _____L1-L3 _____L4 – L5 _____Sacral

Health Information

Have you ever been told by a health professional that your child has any of the following conditions? If yes, mark the box in front of the condition.

Yes	Condition	Yes	Condition	Yes	
	Hydrocephalus		ADHD or attention problems		Food Allergies
	Clubfoot or joint deformities		Learning Disability		Failure to Thrive
	Latex allergy		Anxiety or Obsessive Compulsive Disorder		Lactose Intolerance
	Bladder Dysfunction		Cerebral Palsy		Gastroesophageal Reflux
	Seizure Disorder		Depression or Bipolar Disorder		Delayed gastric emptying
	Mental Retardation		Asthma or chronic lung problems		Other GI disease
	Scoliosis or spinal curvature		Autism, PDD, or Asperger's		Metabolic disorder
	Arnold Chiari malformation		Blindness or severe vision problems		Liver Disease
	Kidney disease		Hearing problem or Deafness		Sinus Problems
	Pressure sores		Diabetes		
	Tethered spinal cord or syringomylia		Seasonal Allergies		Other:________________

Assessment of Physical Disability

Last week how hard was it for your child to…	**Not hard at all**	**A little hard**	**Moderately hard**	**Very hard**	**My child can't do it**	**Not applicable**
Walk						
Walk without a body brace						
Keep up with friends when walking						
Wheel his or her wheelchair						
Keep up with friends in his or her wheelchair						
Move to and from the tub (or shower) from wheelchair						
Move to and from the toilet from wheelchair						
Put on braces by himself or herself						
Put on shoes and sock without help						
Put on pants without help						
Get clothes to fit him or her						
Do enema by himself or herself						
Insert the catheter by himself or herself						
Take a bath or shower without help						
Go from sitting to standing						
Go up and down stairs						
Play wheelchair basketball						

Mobility

Does your child? Walk without assistance Wear braces on feet or legs Use a cane or walker
Use a wheelchair Use a motorized wheelchair Uses crutches

How much does your child's weight adversely affect his/her mobility?
No effect Minimal effects Moderate effects Severely effects

Feeding or eating issues

Does your child have any of the following problems? Please include when (age) each problem started.

____Does your child refuse to eat all or most food, resulting in problems with growth or dependency on tube feedings? If yes, when did this problem start? _________
____Does your child have problems eating certain food textures or does your child eat textures that are not developmentally appropriate? If yes, when did this problem start? ____

____Does your child eat only a narrow variety of foods? If yes, when did this problem start?__________

____Does your child have problems with lip closure, chewing, tongue lateralization, or other oral motor delays? If yes, how long has this been a problem?__________

____Does your child have any problems with swallowing, documented with a swallow study or other study showing aspiration? If yes, how long has this been a problem?_______

____ Does your child refuse food if not a certain temperature or brand or does your child require certain dinnerware (cups, plates, spoons, etc) at meals? When did this start?

____Does your child currently receive nasogastric or gastrostomy tube feedings? If yes, how many ounces per day______________________

Drinking Preference Inventory (circle or fill-in the blank; 1 cup = 8 ounces)

Does your child drink a supplement (e.g. Pediasure, Boost, etc.)? Yes No

If yes, which one?___________________________________ How much/ day?__________________

What kind of milk does your child usually drink? Whole 2% 1% Skim Soy Rice

How much/day? ___________

Is your child's milk usually flavored? Yes No

If yes, what is used? Chocolate/strawberry syrup Flavored powder Instant Breakfast Ovaltine Other__________

Does your child drink? Hot chocolate Milkshake Drinkable yogurt

How many ounces of these drinks does your child drink per day? _______ ounces

How much 100% juice does your child drink per day? _______ ounces

How much other fruit drinks (Hi-C, Kool Aid, etc.) does your child drink per day? ______ounces

How much soda or iced tea does your child drink per day? _______ ounces

Does it usually have caffeine? Yes No What type is it usually? Regular Diet

How much water does your child drink per day? _______ounces

Food Preference Inventory

Circle about how often your child eats at least a *portion* of this food (the portion is listed after the food); **No =** a *portion* of this food is never eaten; **Week** = at least once per week; **Day** = once per day, **Many =** more than once per day. If the child eats other foods not included here, write them in the blanks below.

Food	**How often is food eaten by your child?**	Is this food eaten by the family?	Food	**How often is food eaten by your child?**	Is this food eaten by the family?
Apple	No Week Day Many	Yes	Crackers	No Week Day Many	Yes
Apple Juice	No Week Day Many	Yes	Fruit Roll-up/Snacks	No Week Day Many	Yes
Applesauce	No Week Day Many	Yes	Other Candy	No Week Day Many	Yes
Apricots	No Week Day Many	Yes	Pie	No Week Day Many	Yes
Avocado	No Week Day Many	Yes	Potato Chips	No Week Day Many	Yes
Banana	No Week Day Many	Yes	Pretzels	No Week Day Many	Yes
Banana Chips	No Week Day Many	Yes	Bacon	No Week Day Many	Yes
Berries	No Week Day Many	Yes	Baked Beans	No Week Day Many	Yes
Cantaloupe	No Week Day Many	Yes	Chicken	No Week Day Many	Yes
Cherries	No Week Day Many	Yes	Chicken Nugget	No Week Day Many	Yes
Cranberry Sauce	No Week Day Many	Yes	Chicken salad	No Week Day Many	Yes
Cranberry Juice	No Week Day Many	Yes	Clams/oysters	No Week Day Many	Yes
Fruit Cocktail	No Week Day Many	Yes	Crab/lobster	No Week Day Many	Yes
Grapefruit	No Week Day Many	Yes	Eggs	No Week Day Many	Yes
Grapefruit Juice	No Week Day Many	Yes	Fish	No Week Day Many	Yes
Grapes	No Week Day Many	Yes	Fish Stick	No Week Day Many	Yes
Grape Juice	No Week Day Many	Yes	Ham	No Week Day Many	Yes
Honeydew	No Week Day Many	Yes	Ham salad	No Week Day Many	Yes
Kiwi	No Week Day Many	Yes	Hamburger	No Week Day Many	Yes
Lemonade	No Week Day Many	Yes	Hot Dog	No Week Day Many	Yes
Mango	No Week Day Many	Yes	Lamb	No Week Day Many	Yes
Nectarine	No Week Day Many	Yes	Lentils	No Week Day Many	Yes
Oranges	No Week Day Many	Yes	Liver	No Week Day Many	Yes
Orange Juice	No Week Day Many	Yes	Lunchmeat	No Week Day Many	Yes
Peaches	No Week Day Many	Yes	Meatloaf	No Week Day Many	Yes
Pear	No Week Day Many	Yes	Other Beans	No Week Day Many	Yes
Pineapple	No Week Day Many	Yes	Other nuts/seeds	No Week Day Many	Yes
Plums	No Week Day Many	Yes	Peanut Butter	No Week Day Many	Yes
Prunes	No Week Day Many	Yes	Peanuts	No Week Day Many	Yes
Prune Juice	No Week Day Many	Yes	Popcorn	No Week Day Many	Yes
Strawberry	No Week Day Many	Yes	Pork	No Week Day Many	Yes
Raisins	No Week Day Many	Yes	Roast Beef	No Week Day Many	Yes
Watermelon	No Week Day Many	Yes	Sausage	No Week Day Many	Yes
American Cheese	No Week Day Many	Yes	Shrimp	No Week Day Many	Yes
Cheese Spread	No Week Day Many	Yes	Steak	No Week Day Many	Yes
Chocolate Milk	No Week Day Many	Yes	Tuna salad	No Week Day Many	Yes
Cottage Cheese	No Week Day Many	Yes	Turkey	No Week Day Many	Yes
Cream Cheese	No Week Day Many	Yes	Veal	No Week Day Many	Yes
Hot Chocolate	No Week Day Many	Yes	Venison	No Week Day Many	Yes
Ice Cream	No Week Day Many	Yes	Chili	No Week Day Many	Yes
Milk	No Week Day Many	Yes	Pot Pie	No Week Day Many	Yes
Milk Shake	No Week Day Many	Yes	Soup	No Week Day Many	Yes
Other Cheese(s)	No Week Day Many	Yes	Stew	No Week Day Many	Yes
Pudding	No Week Day Many	Yes	Stuffing	No Week Day Many	Yes
Sherbet	No Week Day Many	Yes	Bagel	No Week Day Many	Yes
Sour Cream	No Week Day Many	Yes	Breakfast Bars	No Week Day Many	Yes
Tofu	No Week Day Many	Yes	Cereal (cold)	No Week Day Many	Yes
Yogurt	No Week Day Many	Yes	Corn Bread	No Week Day Many	Yes
Asparagus	No Week Day Many	Yes	Cream of Wheat	No Week Day Many	Yes
Beets	No Week Day Many	Yes	Donut/pastry	No Week Day Many	Yes
Broccoli	No Week Day Many	Yes	Egg Noodles	No Week Day Many	Yes
Cabbage	No Week Day Many	Yes	Farina	No Week Day Many	Yes
Carrots	No Week Day Many	Yes	French Fries	No Week Day Many	Yes
Cauliflower	No Week Day Many	Yes	French Toast	No Week Day Many	Yes
Coleslaw	No Week Day Many	Yes	Grits	No Week Day Many	Yes
Celery	No Week Day Many	Yes	Lasagna/ravioli	No Week Day Many	Yes
Corn	No Week Day Many	Yes	Macaroni	No Week Day Many	Yes

Creamed Corn	No Week Day Many	Yes	Muffins/rolls	No Week Day Many	Yes
Cucumbers	No Week Day Many	Yes	Noodles	No Week Day Many	Yes
Greens	No Week Day Many	Yes	Oatmeal	No Week Day Many	Yes
Green or Wax Beans	No Week Day Many	Yes	Pancake	No Week Day Many	Yes
Lettuce (salad)	No Week Day Many	Yes	Pita	No Week Day Many	Yes
Lima beans	No Week Day Many	Yes	Pizza	No Week Day Many	Yes
Onion	No Week Day Many	Yes	Poptart	No Week Day Many	Yes
Peas	No Week Day Many	Yes	Potato(mashed/baked)	No Week Day Many	Yes
Green Pepper	No Week Day Many	Yes	Potato salad	No Week Day Many	Yes
Pickles	No Week Day Many	Yes	Ramen Noodles	No Week Day Many	Yes
Radish	No Week Day Many	Yes	Rice	No Week Day Many	Yes
Sauerkraut	No Week Day Many	Yes	Spaghetti	No Week Day Many	Yes
Spinach	No Week Day Many	Yes	Spaghettios	No Week Day Many	Yes
Squash	No Week Day Many	Yes	Stuffing/filling	No Week Day Many	Yes
Sweet Potato	No Week Day Many	Yes	Taco/burrito	No Week Day Many	Yes
Tomato	No Week Day Many	Yes	Waffle	No Week Day Many	Yes
Turnip	No Week Day Many	Yes	Wheat/grain Bread	No Week Day Many	Yes
Cake (any type)	No Week Day Many	Yes	White Bread	No Week Day Many	Yes
Cheese Puffs/Curls	No Week Day Many	Yes		No Week Day Many	Yes
Chocolate Candy	No Week Day Many	Yes		No Week Day Many	Yes
Cookies	No Week Day Many	Yes		No Week Day Many	Yes
Corn/tortilla Chips	No Week Day Many	Yes		No Week Day Many	Yes

Mealtimes

How many times in the last week did any of the following events occur?

How many meals did your child eat without an adult?
Never 1-2 meals 3-4 meals 5 or more meals

How many meals did your child eat with the T.V. on?
None 1-2 meals 3-4 meals 5 or more meals

How often did you make your child a separate meal because he/she would not eat the family meal?
Never 1-2 meals 3-4 meals 5 or more meals

How many meals eaten at home were with peers or siblings?
None 1-2 meals 3-4 meals 5 or more meals

How often did your child request food other than at scheduled meal or snack time?
None 1-2 times 3-4 times 5 or more times

How many meals did your child ***not*** eat at the kitchen or dining room table?
None 1-2 times 3-4 times 5 or more times

How many meals were eaten at "fast food" restaurants?
None 1-2 times 3-4 times 5 or more times

How often do the following *typically* occur? (circle only one answer)
Do you allow your child to eat whenever they request food between meals?
Always Usually Sometimes Seldom Never

Do you make mealtimes fun or entertaining?
Always Usually Sometimes Seldom Never

Do you insist your child try 'one bite' of a new food?
Always Usually Sometimes Seldom Never

Do you insist your child take a bite of each food before they can leave the table?
Always Usually Sometimes Seldom Never

Do you physically put food into your child's mouth?
Always Usually Sometimes Seldom Never

Do you allow your child to choose favorite plates or utensils to eat with?
Always Usually Sometimes Seldom Never

Do you punish your child for not eating (spanking or time-out)?
Always Usually Sometimes Seldom Never

Do you insist your child 'clean his/her plate' before they leave the table?
Always Usually Sometimes Seldom Never

Do you praise your child for eating?
Always Usually Sometimes Seldom Never

Do you offer activities as a reward for eating?
Always Usually Sometimes Seldom Never

Do you give your child the option of eating foods other than those served?
Always Usually Sometimes Seldom Never

Do you send your child away from the table if he/she is not eating?
Always Usually Sometimes Seldom Never

Do you allow your child to flavor foods however he or she wants?
Always Usually Sometimes Seldom Never

Do you make your child stay at the table until all or a certain amount of food has been eaten?
Always Usually Sometimes Seldom Never

Do you restrict your child from eating certain foods without your permission?
Always Usually Sometimes Seldom Never

Do you give your child dessert for eating certain foods?
Always Usually Sometimes Seldom Never

Do you encourage your child to eat fruits and vegetables every day?
Always Usually Sometimes Seldom Never

Growth

Does your child receive growth hormone? Yes No

Has your child entered puberty? Yes No If yes, how old was your child?____________

Activity Information

Please indicate how many hours per week/day, your child participates in the following activities.

Activity	Amount of Time			
Watches television or videos (hours per day)	Never	Less than 1	1-3 hours	more than 3 hours
Plays videotapes or computer games (hours per day)	Never	Less than 1	1-3 hours	more than 3 hours
Time spent on the Internet (hours per day)	Never	Less than 1	1-3 hours	more than 3 hours
Rides a bicycle or scooter (hours per week)	Never	Less than 1	1-3 hours	more than 3 hours
Plays team sports (hours per week)	Never	Less than 1	1-3 hours	more than 3 hours
Swims or jogs (hours per week)	Never	Less than 1	1-3 hours	more than 3 hours
Reads or plays board games (hours per week)	Never	Less than 1	1-3 hours	more than 3 hours
Draws, paints, or works on crafts (hours per week)	Never	Less than 1	1-3 hours	more than 3 hours
Takes a walk (hours per week)	Never	Less than 1	1-3 hours	more than 3 hours
Dances or plays outside (hours per week)	Never	Less than 1	1-3 hours	more than 3 hours
Lifts weights or exercises (hours per week)	Never	Less than 1	1-3 hours	more than 3 hours
Plays any individual sports (hours per week)	Never	Less than 1	1-3 hours	more than 3 hours

Toileting (Circle all that apply.)

Does your child use any of the following: diaper pull up training pants/plastic pants

Does your child wet during the day? Never Sometimes 1-2 times/day Always

Does your child wet during the night? Never Sometimes 1-2 times/day Always

What would best describe your child's most typical bowel movement?
Soft, well-formed stool loose, watery stool hard, dry stool small, round pebbles

How often does your child have a bowel movement?
2 or more/day once/day 3-4 times/week 1-2 times/week once/week or less

Approximately what percentage of your child's bowel movements are in the toilet?
None Some Most All

How many bowel accidents does your child have per week?

How often does your child use the following?

Medication/treatment	How often?	Medication/treatment	How often?
Miralax or glycolax	Never Monthly Weekly Daily	Milk of Magnesia	Never Monthly Weekly Daily
Lactulose or Kristulose	Never Monthly Weekly Daily	Mineral Oil	Never Monthly Weekly Daily
Enema	Never Monthly Weekly Daily	High fiber diet	Never Monthly Weekly Daily
Magnesium citrate	Never Monthly Weekly Daily	Colace	Never Monthly Weekly Daily
Malt supex	Never Monthly Weekly Daily	Citracel	Never Monthly Weekly Daily
Metamucil or psyllium	Never Monthly Weekly Daily	Benafiber or unifiber	Never Monthly Weekly Daily
Glycerin suppositories	Never Monthly Weekly Daily	Oral biscodyl	Never Monthly Weekly Daily
Sennekot or senna	Never Monthly Weekly Daily	Sodium phosphate	Never Monthly Weekly Daily
Ducolax tabs	Never Monthly Weekly Daily	Other:	Never Monthly Weekly Daily

Mealtime Behavior

How often does this happen?	Never 1	Seldom 2	Sometimes 3	Often 4	Always 5	Is this a problem for you? Yes	No
My child chews food as expected for his/her age.	1	2	3	4	5	Yes	No
My child enjoys eating	1	2	3	4	5	Yes	No
My child asks for food which he/she shouldn't have	1	2	3	4	5	Yes	No
My child gags at mealtimes	1	2	3	4	5	Yes	No
I feel confident my child eats enough	1	2	3	4	5	Yes	No
My child vomits at mealtimes	1	2	3	4	5	Yes	No
My child makes food for him/her self when not allowed	1	2	3	4	5	Yes	No
I get upset when my child doesn't eat	1	2	3	4	5	Yes	No
At home my child eats food he/she shouldn't have	1	2	3	4	5	Yes	No
My child uses cutlery as expected for his/her age	1	2	3	4	5	Yes	No
At friends' homes my child eats food he/she shouldn't have	1	2	3	4	5	Yes	No
My child asks for food between meals	1	2	3	4	5	Yes	No

If you are a single parent, skip the next three (3) questions.							
My child's behavior at meals upsets my spouse	1	2	3	4	5	Yes	No
My child interrupts conversations with my spouse at meals	1	2	3	4	5	Yes	No
I get upset with my spouse at meals	1	2	3	4	5	Yes	No
If you have only one child, skip the following question.							
My child's behavior at meals upsets our other children	1	2	3	4	5	Yes	No

Child's Foods in the Past 24 Hours

List all foods and beverages your child actually consumed in the past 24 hours. Include both meals and snacks.

TIME OF DAY	FOOD OR BEVERAGE	AMOUNT
Early morning:		
Mid-morning:		
Noon:		
Afternoon:		
Evening or nighttime:		

Was this typical for the child? (1 = no, 2 = yes) ________________

If no, how different from usual?
____