Form Approved
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(affix label here)

Patient ID Number ☐ Site ☐☐ Sub-site ☐☐☐☐☐ Sequential ID

SEARCH Health Questionnaire – Parent Version

- **The purpose of this questionnaire is to learn more about children and adolescents who have diabetes. This questionnaire is to be completed by the parent or legal guardian of the child (under age 18) who has diabetes.**
- **In the questionnaire, the term "doctor" to refers to the doctor or other health care provider, such as a nurse.**

CO-MORBIDITIES/COMPLICATIONS

1. Has your child ever been tested for any genes related to diabetes?

1❑ Yes →
- 1a. Results: _____
  - 1❑ Don't know
- 1b. When was the test done? ☐☐ Month ☐☐☐☐ Year
- 1c. Where was this test done? _____

2❑ No

3❑ Don't know

2. Has a doctor ever told you or your child that he/she has high cholesterol or an abnormal amount of fat in his/her blood?

1❑ Yes →
- 2a. If yes, has a doctor ever prescribed medicine for high cholesterol or high fat?
  1❑ Yes 2❑ No 3❑ Don't know
- 2b. Is your child now taking prescribed medicine for high cholesterol or high fat?
  1❑ Yes 2❑ No 3❑ Don't know
- 2c. Has a doctor ever recommended changes in your child's diet to lower cholesterol?
  1❑ Yes 2❑ No 3❑ Don't know

2❑ No

3❑ Don't know

3. Has a doctor ever told you or your child that he/she has high blood pressure?

1❑ Yes → 3a. If yes, has a doctor ever prescribed any medicine for high blood pressure?

1❑ Yes 2❑ No 3❑ Don't know

3b. Is your child now taking any medicine for high blood pressure?

1❑ Yes 2❑ No 3❑ Don't know

2❑ No

3❑ Don't know

4. Has a doctor ever told you or your child that he/she had any of the following?

1❑ Yes 2❑ No Addison's Disease

1❑ Yes 2❑ No Asthma

1❑ Yes 2❑ No Celiac disease

1❑ Yes 2❑ No Hyperthyroidism (high thyroid)

1❑ Yes 2❑ No Hypothyroidism (low thyroid)

1❑ Yes 2❑ No Vitiligo (white skin patches)

5. Has a doctor said that diabetes has affected your child's kidneys?

1❑ Yes

2❑ No

3❑ Don't know

6. Has a doctor said that diabetes has damaged the back of your child's eyes, that is, the retina?

1❑ Yes → 6a. If yes, did this require laser treatment of the retina?

1❑ Yes

2❑ No

2❑ No

3❑ Don't know

7. Has your child had any other major illness or medical conditions that we have not asked about?

1❑ Yes → If yes, please describe:

2❑ No

Questions 8 and 9 are for FEMALES only.

8. Has your child already had her first period?

1❑ Yes → 8a. If yes, how old was your child when she had her first period? ☐☐ years old

1❑ Don't know

2❑ No

3❑ Don't know

9. Has a doctor ever told you or your child that your child has polycystic ovaries (PCO, PCOS)?

1❑ Yes

2❑ No

3❑ Don't know

MEDICAL HISTORY

◆ **The next few questions are about emergency room and hospital visits your child may have had.**

10. In the last 6 months, has your child been to the emergency room for any reason?

1❑ Yes → 10a. How many times was your child in the emergency room? ☐☐ # of times

2❑ No

11. In the last 6 months, has your child had one or more night's hospital stay for any reason?

1❑ Yes → 11a. How many times was your child in the hospital for one or more nights? ☐☐ # of times

2❑ No

12. In the past 6 months, has your child had any severe hypoglycemia, that is, very low blood sugar that required him/her to get help?

1❑ Yes →

12a. How many times?	☐☐	# of times
12b. How many times was your child given an injection of glucagon – for hypoglycemia (low blood sugar)?	☐☐	# of times
12c. How many times was "911" or life squad/ paramedics called for hypoglycemia?	☐☐	# of times
12d. How many times did your child go to an emergency room for hypoglycemia?	☐☐	# of times
12e. How many times did your child need to stay overnight at a hospital?	☐☐	# of times

2❑ No

13. In the past 6 months, has your child had ketoacidosis (often called DKA, frequently with high blood sugar, vomiting and shortness of breath)?

1❑ Yes →

13a. How many times?	☐☐	# of times
13b. How many times did this result in an emergency room visit?	☐☐	# of times
13c. How many times did this result in one or more night's hospital stay?	☐☐	# of times

2❑ No

MEDICATION INVENTORY

Insulin Use

14. Was your child ever treated with insulin (shots/pumps) since he/she was diagnosed?

1❑ No *(skip to question 20)*

2❑ Yes

15. If yes, when were insulin shots/pump started?

1❑ At diagnosis

2❑ Less than 1 month after diagnosis

3❑ Within 1-6 months after diagnosis

4❑ Within 6-12 months after diagnosis

5❑ 1 year or more after diagnosis

16. Did your child ever stop taking insulin?

1❑ No *(skip to question 20)*

2❑ Yes

17. If yes, did that happen...

1❑ Less than 1st month after diagnosis

2❑ 1-6 months after diagnosis

3❑ 6-12 months after diagnosis

4❑ 1 year or more after diagnosis

18. How long was your child off insulin?

1❑ Less than 1 month

2❑ 1-6 months

3❑ 6-12 months

4❑ 1 year or more

19. Did your child ever have any episodes of ketoacidosis (DKA) when insulin was stopped?

1❑ Yes

2❑ No

3❑ Don't know

20. How does your child currently treat his/her diabetes? Does your child use: *(check yes or no for each)*

20a. Diabetes tablets (pills)	1❑ Yes	2❑ No
20b. Insulin shots, pump, or pen	1❑ Yes	2❑ No
20c. Diet (meal plan)	1❑ Yes	2❑ No
20d. Exercise	1❑ Yes	2❑ No

20e. Other (what?) →

21. If your child is currently taking insulin, how often does he/she take insulin each day on average? *(if your child is not currently taking insulin, go to question 24)*

1❑ 1 time a day

2❑ 2 times a day

3❑ 3 times a day

4❑ More than 3 times a day

5❑ Insulin pump

22. How does your child take insulin?

1❑ 22a. With a syringe (needle)

2❑ 22b. With an insulin pump

3❑ 22c. With an insulin pen

23. What was the dose of insulin (number of units) that your child took yesterday. *(If your child uses an insulin pump, record the bolus amounts in 23a – 23e, and record the total 24-hour basal dose in 23f. This may require filling out a worksheet of hourly basal rates to determine the total basal dose.)*

Worksheet		
23a.	Breakfast	☐☐☐.☐
23b.	Lunch	☐☐☐.☐
23c.	Dinner	☐☐☐.☐
23d.	Bedtime	☐☐☐.☐
23e.	Other	☐☐☐.☐
23f.	Pump	☐☐☐.☐
Total insulin:		

Is your child under ten years of age? ❑ Yes (*If Yes, continue to Question 24)*
❑ No (*If No, skip to question 26)*

24. How often did your child miss his/her diabetes medicine including insulin?

1❑ Doesn't take diabetes medicine *(skip to question 26)*

2❑ Never *(skip to question 26)*

3❑ 1-3 times a month

4❑ 1-5 times a week

5❑ 1 time a day

6❑ More than 1 time a day

25. Check Yes, No, or Not applicable. When your child misses a diabetes medicine is it because:

25a. 1❑ Yes 2❑ No 3❑ Not applicable Forgot

25b. 1❑ Yes 2❑ No 3❑ Not applicable Thought it would help to lose weight

25c. 1❑ Yes 2❑ No 3❑ Not applicable Worried about low blood sugar

25d. 1❑ Yes 2❑ No 3❑ Not applicable Cannot afford insulin supplies or other medicine

25e. 1❑ Yes 2❑ No 3❑ Not applicable Don't want to give insulin when others are around

25f. 1❑ Yes 2❑ No 3❑ Not applicable Tired of shots

25g. 1❑ Yes 2❑ No 3❑ Not applicable Afraid of needles

25h. 1❑ Yes 2❑ No 3❑ Not applicable Other reason *(specify)*

Prescribed Medications

26. Is your child taking prescribed medication(s) including insulin?

1❑ Yes (*If Yes, document up to 10 medications below. If your child is taking insulin, be certain to include all types or preparations.)*

2❑ No *(if No, skip to question 27)*

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____

Diabetes Education

◆ **The next few questions are about what you have been taught about diabetes.**

27. In the past 12 months have you met with a diabetes nurse or diabetes educator? 1❑ Yes 2❑ No 3❑ Don't know

28. In the past 12 months have you met with a dietician or nutritionist, or talked to someone in detail about your child's diet?

1❑ Yes →

28a. When he/she was staying one or more nights in the hospital	1❑ Yes	2❑ No	3❑ Don't know
28b. As an outpatient	1❑ Yes	2❑ No	3❑ Don't know

2❑ No

29. In the past 12 months, which of the following types of diabetes information have you received from your child's doctor's office or health care plan? *(Check all that apply)*

1❑ Information about diabetes camp

1❑ Information about diabetes support groups

1❑ Written materials about diabetes such as pamphlets or newsletters

1❑ Videos or audio tapes

1❑ Reminder about upcoming appointments

1❑ A copy or explanation of diabetes laboratory or test results

1❑ Diabetes information or advice by telephone

1❑ Diabetes information or advice in person

1❑ How to get diabetes information on the internet

1❑ Information about diabetes research studies other than this study

◆ **Below are some questions about your child's diabetes care and diabetes control. "Doctor", is a doctor or any other health care provider such as a nurse.**

30. How would you rate your child's diabetes care overall: Would you say:

1❑ Excellent
2❑ Good
3❑ Fair
4❑ Poor

31. How would you rate: (*check the appropriate boxes)*

	Excellent	Good	Fair	Poor	Not applicable
Diabetes care from the doctor	1❑	2❑	3❑	4❑	5❑
Getting answers to your diabetes questions	1❑	2❑	3❑	4❑	5❑
Access during emergencies	1❑	2❑	3❑	4❑	5❑
Getting explanation of lab results	1❑	2❑	3❑	4❑	5❑
Courtesy/personal communication style of your doctor	1❑	2❑	3❑	4❑	5❑

32. How would you rate your child's diabetes control: Would you say:

1❑ Excellent
2❑ Good
3❑ Fair
4❑ Needs much work

Home Diabetes Care

◆ **Here are some questions about your child's diabetes care outside of the doctor's office.**

33. Does your child live or stay in more than one home on a regular basis? For example, if the child's parents are separated, this would include spending the weekend with the child's other parent. It would also include other relatives that your child might live or stay with on a regular basis (at least once per month).

1❑ Yes →

33a. If yes, does he/she live in:

1❑ 2 households
2❑ 3 or more households
3❑ Don't know

2❑ No, live in one household

34. How much of your child's diabetes care does your child do for him/herself? Would you say: *(check one)*

1❑ None
2❑ Less than 25%
3❑ 25-75%
4❑ More than 75%
5❑ All *(skip to question 36)*

35. Who helps your child with his/her diabetes care?

35a. Parent/step parent/guardian	1❑ Yes	2❑ No
35b. Grandparent	1❑ Yes	2❑ No
35c. Brother/sister	1❑ Yes	2❑ No
35d. Another person	1❑ Yes	2❑ No

36. Is your child's blood sugar tested at home or any place other than the doctor's office?

1❑ Yes → 36a. How often is your child's blood sugar checked with a glucose meter (glucometer)? *(check one)*

2❑ No *(if no, go to question 37)*

- 1❑ Less than once a week
- 2❑ Less than once a day
- 3❑ 1-2 times a day
- 4❑ 3 times a day
- 5❑ 4-6 times a day
- 6❑ 7 or more times a day
- 7❑ Only when you are sick

36b. Does your child use a continuous glucose monitor (CGM) to measure his/her glucose?

1❑ Yes

2❑ No *(if no go to 36c)*

36b(1). If yes, how does he/she use the CGM?

1❑ He/she has used it through <u>his/her doctor's office</u>

How often has he/she used it? →

- 1❑ 1 time
- 2❑ 2 or more times
- 3❑ Don't know/not sure

2❑ My child has a CGM for use <u>at home</u>

How often does your child use it?

- 1❑ Rarely/never (0-19% of the time)
- 2❑ Occasionally (20-39% of the time)
- 3❑ About half the time (40-59% of the time)
- 4❑ Usually (60-79% of the time)
- 5❑ Most of the time (80-99% of the time)
- 6❑ Always (100% of the time)
- 7❑ Don't know/not sure

36c. What do you usually do when the blood sugar test results are running too high or too low?

36c(1). Make changes to the diabetes treatment (insulin dose or other medications, diet or exercise	1❑ Yes	2❑ No
36c(2). Call his/her diabetes doctor	1❑ Yes	2❑ No
36c(3). Talk to his/her diabetes doctor at the next visit	1❑ Yes	2❑ No

Provider Care

◆ **These questions are about the doctors or health care providers that your child sees.**

37. Who does your child usually see for his/her diabetes care? *(Check only one response)*

1❑ Pediatric endocrinologist/diabetologist (diabetes specialist)
2❑ Pediatrician
3❑ Family practice doctor
4❑ General practice doctor
5❑ Adult endocrinologist/diabetologist (diabetes specialist)
6❑ Internist
7❑ Nurse practitioner/physician's assistant
8❑ Nurse diabetes educator
9❑ Traditional medicine man, healer, or curandero/curandera
10❑ Dietician/Nutritionist
11❑ Other *(specify)* →
12❑ Don't know/unsure of what kind of doctor
13❑ None/no source of medical care

38. Who does your child usually see for his/her medical needs not related to diabetes? *(Check only one response)*

1❑ Pediatric endocrinologist/diabetologist (diabetes specialist)
2❑ Pediatrician
3❑ Family practice doctor
4❑ General practice doctor
5❑ Adult endocrinologist/diabetologist (diabetes specialist)
6❑ Internist
7❑ Nurse practitioner/physician's assistant
8❑ Nurse diabetes educator
9❑ Traditional medicine man, healer, or curandero/curandera
10❑ Dietician/Nutritionist
11❑ Other *(specify)* →
12❑ Don't know/unsure of what kind of doctor
13❑ None/no source of medical care

◆ **Here are questions regarding how often your child sees various medical providers.**

39. Who provides medical care for your child? *(For each provider checked, indicate the number of visits your child had with this provider in the **past 6 months**)*

39a.	1❑ Yes	2❑ No	Pediatric endocrinologist/ diabetologist (diabetes specialist)	☐☐	# of visits in the last 6 months
39b.	1❑ Yes	2❑ No	Pediatrician	☐☐	# of visits in the last 6 months
39c.	1❑ Yes	2❑ No	Family practice doctor	☐☐	# of visits in the last 6 months
39d.	1❑ Yes	2❑ No	General practice doctor	☐☐	# of visits in the last 6 months
39e.	1❑ Yes	2❑ No	Adult endocrinologist/ diabetologist (diabetes specialist)	☐☐	# of visits in the last 6 months
39f.	1❑ Yes	2❑ No	Internist	☐☐	# of visits in the last 6 months
39g.	1❑ Yes	2❑ No	Nurse practitioner/physician's assistant	☐☐	# of visits in the last 6 months
39h.	1❑ Yes	2❑ No	Nurse diabetes educator	☐☐	# of visits in the last 6 months
39i.	1❑ Yes	2❑ No	Traditional medicine man, healer, or curandero/curandera	☐☐	# of visits in the last 6 months
39j.	1❑ Yes	2❑ No	Dietician	☐☐	# of visits in the last 6 months
39k.	1❑ Yes	2❑ No	Eye doctor (optometrist, ophthalmologist)	☐☐	# of visits in the last 6 months
39l.	1❑ Yes	2❑ No	Psychiatrist, psychologist, or mental health counselor	☐☐	# of visits in the last 6 months
39m.	1❑ Yes	2❑ No	Other *(specify)* ☐	☐☐	# of visits in the last 6 months

Insurance and Cost of Diabetes Supplies

40. What kind of health insurance or health care plan does your child have? *(check yes, no or don't know for each one)*

40a. Medicaid/Medicare/State-funded/ other Federally-funded	1❑ Yes	2❑ No
40b. Private insurance, through employer	1❑ Yes	2❑ No
40c. Private insurance, purchased on your own	1❑ Yes	2❑ No
40d. Military	1❑ Yes	2❑ No
40e. School-based insurance	1❑ Yes	2❑ No
40f. Tribe/Indian Health Service	1❑ Yes	2❑ No
40g. Any other or type unknown	1❑ Yes	2❑ No
40h. None *(if none, go to question 42)*	1❑ Yes	2❑ No

41. Does your child's health insurance or health care plan pay for any of his/her… *(check yes, no or don't know for each one)*

41a. Diabetes medicine/insulin	1❑ Yes	2❑ No	3❑ Don't know
41b. Syringes/pens/needles	1❑ Yes	2❑ No	3❑ Don't know
41c. Insulin pump and supplies	1❑ Yes	2❑ No	3❑ Don't know
41d. Home glucose monitor	1❑ Yes	2❑ No	3❑ Don't know
41e. Monitor strips and related supplies	1❑ Yes	2❑ No	3❑ Don't know
41f. Diabetes education	1❑ Yes	2❑ No	3❑ Don't know

41g. ❑ Not applicable

42. About how much do you spend, on average, in a typical month on diabetes medicine and supplies? *(This does not include costs that are covered or later reimbursed by your child's insurance plan).*

1❑ $0 (none)

2❑ $1 - $19

3❑ $20 - $49

4❑ $50 - $99

5❑ $100 - $199

6❑ $200 or more

7❑ Don't know

43. How satisfied are you with your child's current insurance coverage? Would you say:

1❑ Very satisfied

2❑ Satisfied

3❑ Somewhat satisfied

4❑ Not satisfied

44. Has your child's main health insurance plan changed in the last 6 months?

1❑ Yes *(if yes, go to question 44a)*

2❑ No *(if no, go to question 45)*

3❑ Don't know

4❑ Don't want to answer

44a. What were the reasons your child's health insurance plan changed? *(check all that apply)*

1❑ Employer stopped offering this plan

1❑ Doctor left this plan

1❑ Unhappy with benefits/coverage

1❑ Too difficult to get care

1❑ Moved

1❑ Change in jobs

1❑ Other (*specify)* →

1❑ Don't know

1❑ Don't want to answer

45. Has your child's main diabetes provider changed in the last six months?

1❑ Yes *(if yes, go to question 45a)*

2❑ No *(if no, go to question 46)*

3❑ Don't know

4❑ Don't want to answer

45a. What were the reasons your child had a change in diabetes provider? *(check all that apply)*

1❑ No longer covered by health plan

1❑ Too difficult to get care

1❑ Not satisfied with care

1❑ Moved

1❑ Other (*specify)* →

1❑ Don't know

1❑ Don't want to answer

◆ **These questions deal with education and household income. Please remember that your answers are confidential.**

46. What is the highest degree or level of school **you** have COMPLETED?

1❑ No schooling completed

2❑ Nursery school to 4th grade

3❑ 5th grade or 6th grade

4❑ 7th grade or 8th grade

5❑ 9th grade

6❑ 10th grade

7❑ 11th grade

8❑ 12th grade, NO DIPLOMA

9❑ High school graduate (high school diploma) or equivalent (for example: GED)

10❑ Business/technical school

11❑ Some college credit but less than 1 year

12❑ 1 or more years of college, no degree

13❑ Associate degree (for example: AA, AS) (2-year)

14❑ Bachelor's degree (for example: BA, AB, BS) (4-year)

15❑ Master's degree (for example: MA, MS, MEng, MEd, MSW)

16❑ Professional or doctorate degree (for example: MD, DDS, JD, PhD, EdD)

17❑ Don't know

47. What is the highest degree or level of school **your current spouse/partner** has COMPLETED?

1❑ No schooling completed

2❑ Nursery school to 4th grade

3❑ 5th grade or 6th grade

4❑ 7th grade or 8th grade

5❑ 9th grade

6❑ 10th grade

7❑ 11th grade

8❑ 12th grade, NO DIPLOMA

9❑ High school graduate (high school diploma) or equivalent (for example: GED)

10❑ Business/technical school

11❑ Some college credit but less than 1 year

12❑ 1 or more years of college, no degree

13❑ Associate degree (for example: AA, AS) (2-year)

14❑ Bachelor's degree (for example: BA, AB, BS) (4-year)

15❑ Master's degree (for example: MA, MS, MEng, MEd, MSW)

16❑ Professional or doctorate degree (for example: MD, DDS, JD, PhD, EdD)

17❑ Don't know

18❑ Not applicable (no current spouse/partner)

48. Which of these categories best describes the total income of all persons living in your household for the past 12 months? *(Check only one category.)*

1❑ Less than $5,000

2❑ $5,000 through $11,999

3❑ $12,000 through $15,999

4❑ $16,000 through $24,999

5❑ $25,000 through $34,999

6❑ $35,000 through $49,999

7❑ $50,000 through $74,999

8❑ $75,000 through $99,999

9❑ $100,000 and greater

10❑ Don't know

11❑ Prefer not to answer

49. How many people live in your child's main household (including the child and all parents/guardians)?

49a. Total number of people ☐☐

49b. Number of children (less than 18) ☐☐

49c. Number of adults ☐☐

49c(1). Of the number of adults, how many bring income into the household? ☐☐

50. Is your child participating in another research study?

1❑ Yes 50a. If yes, what study? → ☐

2❑ No

◆ As a part of the study, we will be contacting you in the future. It would be helpful to us if you could provide us with the names, addresses, and phone numbers of two people who could contact you even if you move.

Name ☐

Relationship ☐

Address:

☐ P.O. Box ☐ Street ☐ Apt. #

☐ City ☐ State ☐ Zip Code

☐ Email Address

Phone # (best) ☐☐☐ ☐☐☐ ☐☐☐☐ ☐☐☐☐

(area code) ext.

Phone # (other) ☐☐☐ ☐☐☐ ☐☐☐☐ ☐☐☐☐

(area code) ext.

Phone # (other) ☐☐☐ ☐☐☐ ☐☐☐☐ ☐☐☐☐

(area code) ext.

Name

Relationship

Address:

P.O. Box Street Apt. #

City State Zip Code

Email Address

Phone # (best) ☐☐☐ ☐☐☐ ☐☐☐☐ ☐☐☐☐

(area code) ext.

Phone # (other) ☐☐☐ ☐☐☐ ☐☐☐☐ ☐☐☐☐

(area code) ext.

Phone # (other) ☐☐☐ ☐☐☐ ☐☐☐☐ ☐☐☐☐

(area code) ext.

Thank you for completing this questionnaire.

FOR STUDY USE ONLY

Interview Assessment:

1. How much difficulty did the Parent/Guardian have in understanding the questions?

❑ None ❑ Slight ❑ Moderate ❑ A Great Deal ❑ Don't know

2. Were there significant problems with the questionnaire?

❑ Yes ❑ No

If yes describe: →

Date Completed [ ][ ] [ ][ ] [ ][ ][ ][ ] Completed by [ ][ ][ ]
Month Day Year

Mode of Administration 1❑ In-Person 2❑ Telephone

Date Reviewed [ ][ ] [ ][ ] [ ][ ][ ][ ] Reviewer Code [ ][ ][ ]
Month Day Year

Date Entered [ ][ ] [ ][ ] [ ][ ][ ][ ] Data Entry Code [ ][ ][ ]
Month Day Year