

Initial Participant Survey

Parent / Guardian Version

This survey is to be filled out by the Parent or legal Guardian of the child age less than 18 years old who has diabetes.

Public reporting burden of this collection of information is estimated to average 10 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC Reports Clearance Officer, 1600 Clifton Road NE, MS D-74, Atlanta, Georgia 30333; ATTN: PRA (0920-0904)



This survey is to be filled out by the **PARENT** or **LEGAL GUARDIAN**. We want to learn more about children and young people who have diabetes. You can help us to do that by filling out these questions. In this survey, we will use the term **CHILD** to refer to **YOUR CHILD** or the child that you are the **LEGAL GUARDIAN** for.

1. What is today's date? _____ / _____ / _____
Month Day Year

For example, if today is May 1, 2011, write in 05/01/2011

2. What is your child's sex? 1 Female 2 Male

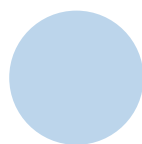
3. Has your doctor or nurse ever told you or your child that your child has diabetes?

1 **YES.** Turn the page and continue on to question 4.

2 **NO. STOP.** Please turn to **page 9** and complete this information.

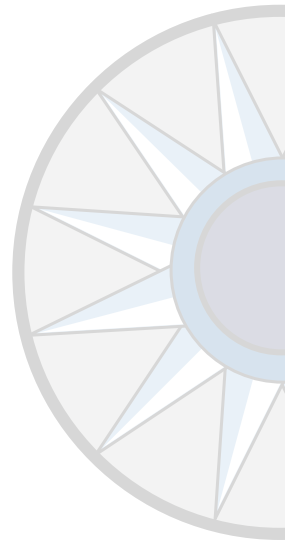
Please mail the survey to us in the stamped envelope.

Thank You
for filling out these questions.



We would like to ask you some questions about your child's birthday, when your child first got diabetes, and how you or your child takes care of his/her diabetes.

Please answer the questions as best as you can. If you do not know the answer to a question, leave it blank.



4. What is your child's birthdate? _____ / _____ / _____
Month Day Year

5. When was your child first told by a doctor or a nurse that he/she had diabetes?
 This means when your child was told about his/her diabetes diagnosis.
 _____ / _____ / _____
Month Day Year

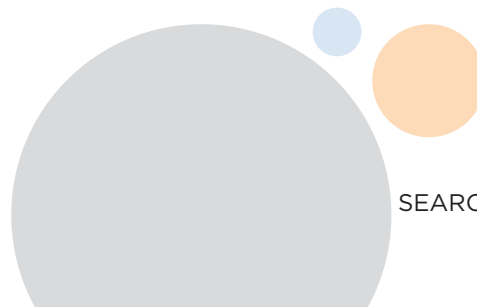
6. How did you first find out that your child had diabetes?
 (Check Yes or No for each question)

Yes 1 <input type="checkbox"/>	No 2 <input type="checkbox"/>	My child was thirsty, had to pee a lot, or got sick very quickly.
Yes 1 <input type="checkbox"/>	No 2 <input type="checkbox"/>	I found out that my child had diabetes when he/she had a school physical or at a regular check-up.
Yes 1 <input type="checkbox"/>	2 No <input type="checkbox"/>	I found out that my child had diabetes when his/her blood sugar was checked at a health fair or at school.
Yes 1 <input type="checkbox"/>	No 2 <input type="checkbox"/>	I found out that my child had diabetes when she was pregnant and the diabetes did not go away after the pregnancy.
Yes 1 <input type="checkbox"/>	No 2 <input type="checkbox"/>	I found out that my child had diabetes when she was pregnant but the diabetes went away after the pregnancy.

If none of the above apply to you, please write on the lines below how you first found out your child had diabetes.

7. What type of diabetes did the doctor or nurse tell you or your child that he/she has?
 (please check one box)

- 1 Type 1 diabetes, IDDM, juvenile diabetes
- 2 Type 2 diabetes, NIDDM
- 3 Maturity onset diabetes of youth (MODY)
- 4 Other type of diabetes, please specify _____
- 5 Don't know



8. Has a doctor or nurse told you or your child that his/her diabetes was caused by:
(please check Yes or No for each question)

8a. cystic fibrosis? 1 Yes 2 No

8b. cancer or medicine to treat cancer? 1 Yes 2 No

8c. another medicine? 1 Yes 2 No

If Yes, what was the medicine?

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

9. Has your child ever taken insulin? 1 Yes 2 No (If No, skip to question 10)

9a. Was he/she taking insulin two weeks after diagnosis? 1 Yes 2 No

9b. Is he/she taking insulin now? 1 Yes 2 No



10. How else does your child take care of his/her diabetes **now**? Does he/she use:
(please check Yes or No for each question)

10a. Diabetes tablets (pills)? 1 Yes 2 No

10b. Diet (meal plans)? 1 Yes 2 No

10c. Exercise? 1 Yes 2 No

10d. Any treatments other than insulin, pills, diet, or exercise: (what?)

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

11. Is your child Spanish/Hispanic/Latino?
(Mark **X** in the "No" box if **not** Spanish/Hispanic/Latino)

No, not Spanish/Hispanic/Latino Yes, Puerto Rican

Yes, Mexican, Mexican Am., Chicano Yes, Cuban

Yes, other Spanish/Hispanic/Latino - Print group: ↓

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

12. What is your child's race? Mark one or more races to indicate what your child considers himself/herself to be.

White

Black, African American

American Indian or Alaska Native; Print name of enrolled or principal tribe:

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

Asian Indian

Japanese

Native Hawaiian

Chinese

Korean

Guamanian or Chamorro

Filipino

Vietnamese

Samoan

Other Asian; Print race:

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

Other Pacific Islander; Print race:

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

13. When your child **first** got diabetes, where did he/she live?

City

State

Zip Code

County

14. When your child **first** got diabetes, was he/she in the Army, Navy, Air Force, Marines or Coast Guard?

1 Yes 2 No 3 Don't know

Now we have some questions about your child's current height and weight.

15. What is your child's **current** weight?

_____ Pounds, or _____ Kilograms Don't know

16. What is your child's **current** height?

_____ Feet _____ Inches or _____ Centimeters Don't know

Now we would like to ask you a few questions about whether or not other people in your child's family have diabetes.

Please provide information about the child's mother, father, brothers, and sisters. This refers to the child's biological or natural parents (not step-parents or adoptive parents) and the child's full or half brothers and sisters, not those who were adopted or step brothers or step sisters.

Please include information for relatives who are living and those who are deceased.

17. Does the child's biological mother have diabetes?

1 Yes 2 No 3 Don't know

17a. If Yes, how old was she when she was diagnosed with diabetes?

_____ years Don't know

18. Did the child's biological mother have any form of diabetes when she was pregnant with the child? This includes Type 1 diabetes, Type 2 diabetes, gestational diabetes, or other types of diabetes.

1 Yes 2 No 3 Don't know

19. Does the child's biological father have diabetes?

1 Yes 2 No 3 Don't know

19a. If Yes, how old was he when he was diagnosed with diabetes?

_____ years Don't know

20. Does the child have any full or half brothers?

1 Yes 2 No 3 Don't know

(If No or Don't know, skip to question 21)

20a. If Yes, how many full or half brothers does your child have?

_____ brothers

20b. If Yes, how many full or half brothers have diabetes?

_____ brothers

21. Does the child have any full or half sisters?

1 Yes 2 No 3 Don't know

(If No or Don't know, skip to question 22)

21a. If Yes, how many full or half sisters does your child have?

_____ sisters

21b. If Yes, how many full or half sisters have diabetes?

_____ sisters



Now we would like to learn a bit about your child's health insurance and health care services.

22. What kind of health insurance plan does your child have **NOW**?
(Answer Yes or No for each question).

22a. Medicaid/Medicare/State-funded/other Federally-funded	Yes 1 <input type="checkbox"/>	No 2 <input type="checkbox"/>
22b. Private insurance, through employer	Yes 1 <input type="checkbox"/>	No 2 <input type="checkbox"/>
22c. Private insurance, purchased on your own	Yes 1 <input type="checkbox"/>	No 2 <input type="checkbox"/>
22d. Military	Yes 1 <input type="checkbox"/>	No 2 <input type="checkbox"/>
22e. School-based insurance	Yes 1 <input type="checkbox"/>	No 2 <input type="checkbox"/>
22f. Tribe/Indian Health Service	Yes 1 <input type="checkbox"/>	No 2 <input type="checkbox"/>
22g. Any other or type unknown	Yes 1 <input type="checkbox"/>	No 2 <input type="checkbox"/>
22h. None	Yes 1 <input type="checkbox"/>	No 2 <input type="checkbox"/>

23. What kind of health insurance plan did your child have when he/she was diagnosed with diabetes?
(Answer Yes or No for each question).

23a. Medicaid/Medicare/State-funded/other Federally-funded	Yes 1 <input type="checkbox"/>	No 2 <input type="checkbox"/>
23b. Private insurance, through employer	Yes 1 <input type="checkbox"/>	No 2 <input type="checkbox"/>
23c. Private insurance, purchased on your own	Yes 1 <input type="checkbox"/>	No 2 <input type="checkbox"/>
23d. Military	Yes 1 <input type="checkbox"/>	No 2 <input type="checkbox"/>
23e. School-based insurance	Yes 1 <input type="checkbox"/>	No 2 <input type="checkbox"/>
23f. Tribe/Indian Health Service	Yes 1 <input type="checkbox"/>	No 2 <input type="checkbox"/>
23g. Any other or type unknown	Yes 1 <input type="checkbox"/>	No 2 <input type="checkbox"/>
23h. None	Yes 1 <input type="checkbox"/>	No 2 <input type="checkbox"/>

24. Who does your child usually go to for most of his/her care related to diabetes?
(Please check only one response).

- 1 Pediatrician
- 2 Family practice or internal medicine physician
- 3 Pediatric endocrinologist/diabetologist (diabetes specialist)
- 4 Adult endocrinologist/diabetologist (diabetes specialist)
- 5 Another type of physician
- 6 Other health care professional (nurse, nurse practitioner, physician assistant, certified diabetes educator, or other)
- 7 Unsure



The next few questions are related to the education and household income of your family.

25. What is the highest degree or level of school that your child's mother/guardian and father/guardian have completed?

	Mother/ guardian	Father/ guardian
25a. Any education less than a high school graduate, no diploma or GED	1 <input type="checkbox"/>	1 <input type="checkbox"/>
25b. High school graduate, (high school diploma) or equivalent (for example, GED)	2 <input type="checkbox"/>	2 <input type="checkbox"/>
25c. Business/technical school, associate degree (AA, AS) or some college	3 <input type="checkbox"/>	3 <input type="checkbox"/>
25d. Bachelor degree (for example, BA, AB, BS) (4-year)	4 <input type="checkbox"/>	4 <input type="checkbox"/>
25e. Master degree (for example MA, MS, MEng, Med., MSW)	5 <input type="checkbox"/>	5 <input type="checkbox"/>
25f. Professional or doctorate degree (for example, MD, DDS, JD, PhD, EdD)	6 <input type="checkbox"/>	6 <input type="checkbox"/>
25g. Don't know	7 <input type="checkbox"/>	7 <input type="checkbox"/>

26. Which of these categories best describes the **total** income of all persons living in the Parent's/Guardian's household for the past 12 months? (check only one category)

- | | |
|--|--|
| 1 <input type="checkbox"/> Less than \$5,000 | 6 <input type="checkbox"/> \$35,000 through \$49,999 |
| 2 <input type="checkbox"/> \$5,000 through \$11,999 | 7 <input type="checkbox"/> \$50,000 through \$74,999 |
| 3 <input type="checkbox"/> \$12,000 through \$15,999 | 8 <input type="checkbox"/> \$75,000 through \$99,999 |
| 4 <input type="checkbox"/> \$16,000 through \$24,999 | 9 <input type="checkbox"/> \$100,000 and greater |
| 5 <input type="checkbox"/> \$25,000 through \$34,999 | 10 <input type="checkbox"/> Don't know |

27. How many people are living in the Parent/Guardian's household?

27a. Total number of people _____

27b. Number of children (less than 18) _____

27c. Number of adults _____

Of the number of adults, how many bring income into the household? _____

Contact Information

We would like to be able to reach you and your child to let you know about other parts of the SEARCH study. To do this, we would like to have the best address and phone number where we can reach you and your child.

A. What is your child's name?

First Name

Middle Name

Last Name

Are there any other names that he / she uses?

Other first names

Other last names

B. What are your child's parent / guardian's names?

First Name

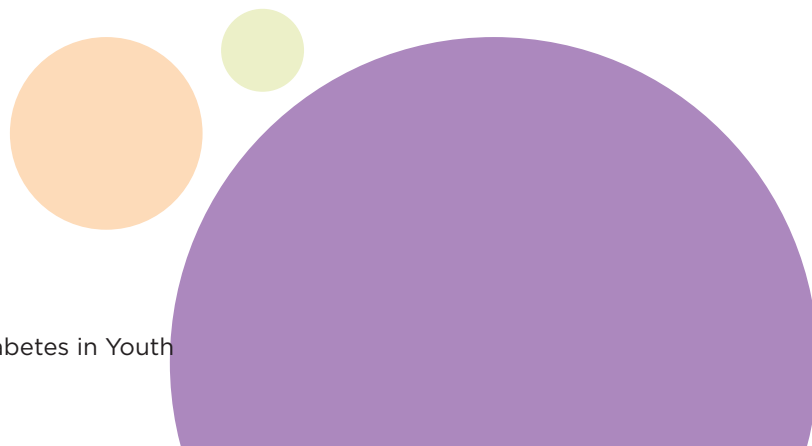
Middle Name

Last Name

First Name

Middle Name

Last Name



C. What is the **best** address, email and phone number to send mail or call?

P.O.Box

Street

Apt#

City

State

Zip

Email address

Phone number (best)

- -

area code

extension

Is this: Home Work Cellular Phone Other

Phone number (other)

- -

area code

extension

Is this: Home Work Cellular Phone Other

Phone number (other)

- -

area code

extension

Is this: Home Work Cellular Phone Other

What is the best time to call? morning afternoon evening

May we contact you over the weekend? Yes No

May we contact you at work? Yes No

Who lives at this address? (check yes or no for each one)

My child does 1 Yes 2 No

Child's Father 1 Yes 2 No

Child's Mother 1 Yes 2 No

Child's Spouse 1 Yes 2 No

Other 1 Yes 2 No

Does your child usually speak:

1 English

2 Spanish

3 Some other language

Specify: _____

Alternate Contact Information

As a part of this study, we may be contacting you in the future. Please provide us with the names, addresses, phone numbers, and email addresses of two people who could contact you if your address or phone number changes.

Contact #1:

First Name

Middle Name

Last Name

Relationship

P.O.Box

Street

Apt#

City

State

Zip Code

Email address

Phone number (best)

area code

extension

Phone number (other)

area code

extension

Phone number (other)

area code

extension



Contact #2:

First Name

Middle Name

Last Name

Relationship

P.O.Box

Street

Apt#

City

State

Zip Code

Email address

Phone number (best)

area code

extension

Phone number (other)

area code

extension

Phone number (other)

area code

extension

Thank You

for filling out this survey.

Please mail it to us in the stamped, pre-addressed envelope. If you have lost the envelope, please send it to the address below.



FOR STUDY USE ONLY

Patient ID Number
Site Sub-site Sequential ID

Date Completed Completed by
Month Day Year

Mode of Administration In Person Telephone Mailed CATI

Date Reviewed Reviewer Code
Month Day Year

Date Entered Data Entry Code
Month Day Year

