



**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, wri	te in 05/01,	/2011

- **2.** What is your child's sex?  $1 \square$  Female  $2 \square$  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.

- **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	Dav	Year	

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

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

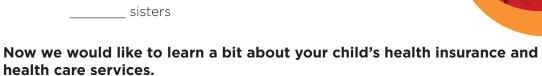


		a doctor or nurse told you or your child that his/her diabetes was caused by: se check Yes or No for each question)
	8a.	cystic fibrosis? 1 Yes 2 No
	8b.	cancer or medicine to treat cancer? 1 \(\begin{align*} \text{Yes} & 2 \(\begin{align*} \text{No} \\ & & \end{align*} \)
	8c.	another medicine? 1 Yes 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.		else does your child take care of his/her diabetes <b>now</b> ? Does he/she use: se 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.	-	ur child Spanish/Hispanic/Latino? k <b>X</b> in the "No" box if <b>not</b> Spanish/Hispanic/Latino)
11.	-	
11.	-	x <b>X</b> in the "No" box if <b>not</b> Spanish/Hispanic/Latino)
11.	-	X in the "No" box if <b>not</b> Spanish/Hispanic/Latino)  No, not Spanish/Hispanic/Latino  Yes, Puerto Rican
11.	-	x X in the "No" box if <b>not</b> Spanish/Hispanic/Latino)  ☐ No, not Spanish/Hispanic/Latino ☐ Yes, Puerto Rican ☐ Yes, Mexican, Mexican Am., Chicano ☐ Yes, Cuban
11.	(Mai	x X in the "No" box if <b>not</b> Spanish/Hispanic/Latino)  ☐ No, not Spanish/Hispanic/Latino ☐ Yes, Puerto Rican ☐ Yes, Mexican, Mexican Am., Chicano ☐ Yes, Cuban
	(Mai	x X in the "No" box if <b>not</b> 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:  ▼ □ In the "No" box if <b>not</b> Spanish/Hispanic/Latino □ Yes, Puerto Rican □ Yes, Cuban □ Yes, other Spanish/Hispanic/Latino - Print group:  ▼ □ In the "No" box if <b>not</b> Spanish/Hispanic/Latino □ Yes, Puerto Rican
	(Mai	x X in the "No" box if <b>not</b> 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:  t is your child's race? Mark one or more races to indicate what your child considers himself/elf to be.
	(Mai	X X in the "No" box if <b>not</b> 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:  □ tis your child's race? Mark one or more races to indicate what your child considers himself/elf to be. □ White □ Black, African American
	(Mai	X X in the "No" box if <b>not</b> 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:  □ tis your child's race? Mark one or more races to indicate what your child considers himself/elf to be. □ White □ Black, African American
	(Mai	X X in the "No" box if <b>not</b> 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:  t is your child's race? Mark one or more races to indicate what your child considers himself/left to be.  White  Black, African American  American Indian or Alaska Native; Print name of enrolled or principal tribe:
	(Mai	X X in the "No" box if <b>not</b> 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:  is your child's race? Mark one or more races to indicate what your child considers himself/ elf to be.  White Black, African American American Indian or Alaska Native; Print name of enrolled or principal tribe:  Asian Indian Japanese Native Hawaiian
	(Mai	X X in the "No" box if <b>not</b> Spanish/Hispanic/Latino

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13.	When your child <b>first</b> got diabetes, where did he/she live?
	City
	State Zip Code County
14.	When your child <b>first</b> got diabetes, was he/she in the Army, Navy, Air Force, Marines or Coast Guard?
	1 ☐ Yes 2 ☐ No 3 ☐ Don't know
Νον	w we have some questions about your child's current height and weight.
15.	What is your child's <b>current</b> weight?
	Pounds, or Kilograms 🗖 Don't know
16.	What is your child's <b>current</b> height?
	Feet Inches or Centimeters \(\bar{\Q}\) Don't know
	w we would like to ask you a few questions about whether or not other people in your ld's family have diabetes.
Dia	and the state of t
	ase provide information about the child's mother, father, brothers, and sisters. This refers to the d's biological or natural parents (not step-parents or adoptive parents) and the child's full or half
	thers and sisters, not those who were adopted or step brothers or step sisters.
Ple	ase include information for relatives who are living and those who are deceased.
17.	
	Does the child's biological mother have diabetes?
	Does the child's biological mother have diabetes?  1  Yes 2 No 3 Don't know
	1 ☐ Yes 2 ☐ No 3 ☐ Don't know
	1 Yes 2 No 3 Don't know  17a. If Yes, how old was she when she was diagnosed with diabetes?
	1 ☐ Yes 2 ☐ No 3 ☐ Don't know
••	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.	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  Did the child's biological mother have any form of diabetes when she was pregnant with the child?
18.	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  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.
18.	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  Did the child's biological mother have any form of diabetes when she was pregnant with the child?
	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  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
18. 19.	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  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  Does the child's biological father 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  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  Does the child's biological father have diabetes?  1 Yes 2 No 3 Don't know
	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  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  Does the child's biological father have diabetes?

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
	<b>20b.</b> 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)
	<b>21a.</b> If Yes, how many full or half sisters does your child have?
	sisters
	<b>21b.</b> If Yes, how many full or half sisters have diabetes?
	sisters



**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 🗖	No 2 <b>1</b>
22b. Private insurance, through employer	Yes 1 🗖	No 2 🗖
22c. Private insurance, purchased on your own	Yes 1 🗖	No 2 <b>1</b>
22d. Military	Yes 1 🗖	No 2 <b>1</b>
22e. School-based insurance	Yes 1 🗖	No 2 <b></b>
22f. Tribe/Indian Health Service	Yes 1 🗖	No 2 🗖
22g. Any other or type unknown	Yes 1 🗖	No 2 <b>1</b>
22h. None	Yes 1 🗖	No 2 <b>_</b>

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**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 🗖	No 2 <b></b>
23b. Private insurance, through employer	Yes 1 🗖	No 2 <b></b>
23c. Private insurance, purchased on your own	Yes 1 🗖	No 2 🗖
23d. Military	Yes 1 🗖	No 2 🗖
23e. School-based insurance	Yes	No 2 <b></b>
23f. Tribe/Indian Health Service	Yes	No 2 🗖
23g. Any other or type unknown	Yes 1□	No 2 🗖
23h. None	Yes 1 🗖	No 2 <b></b>

- **24.** Who does your child usually go to for most of his/her care related to diabetes? (Please check only one response).
  - 1 Pediatrician
  - <sup>2</sup> Family practice or internal medicine physician
  - 3 Pediatric endocrinologist/diabetologist (diabetes specialist)
  - 4 Adult endocrinologist/diabetologist (diabetes specialist)
  - <sup>5</sup> 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 🗖	1 🔲
25b. High school graduate, (high school diploma) or equivalent (for example, GED)	2 🗖	2 🗖
25c. Business/technical school, associate degree (AA, AS) or some college	3 🗖	3 🗖
25d. Bachelor degree (for example, BA, AB, BS) (4-year)	4 🗖	4 🔲
25e. Master degree (for example MA, MS, MEng, Med., MSW)	5 🗖	5 🗖
25f. Professional or doctorate degree (for example, MD, DDS, JD, PhD, EdD)	6 🗖	6 🗖
25g. Don't know	7 🗖	7 🗖

- **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 Less than \$5,000 6 \$35,000 through \$49,999
  - 2 □ \$5,000 through \$11,999 7 □ \$50,000 through \$74,999
  - 3 □ \$12,000 through \$15,999 8 □ \$75,000 through \$99,999
  - 4 \$16,000 through \$24,999 9 \$100,000 and greater
  - 5 \$25,000 through \$34,999 10 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? \_\_\_\_\_

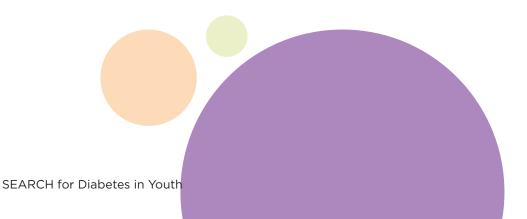
**28.** Was your **child with diabetes** born in the United States?

1 ☐ Yes (If Yes, go to question 29)

#### **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.

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#### **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																							
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City																							
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#### Contact #2:

itact #2:											
First Name											
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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 Numbe		Sub-site S	Sequential ID
Date Completed	Month	Day	Completed by Year
Mode of Adminis	tration	In Person	Telephone Mailed CATI
Date Reviewed	Month	Day	Reviewer Code Year
Date Entered	Month	Day	Data Entry Code Year



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