



Initial Participant Survey

Parent / Guardian Version

NOTE: All variables in the data have suffix "_parent"

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)

SEARCH 3 Registry Study – Initial Participant Survey (Parent / Guardian Verison) revised 5-14-12



SEARCH for Diabetes in Youth

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.

- What is today's date? _____ / ____ / ____ datecomp
 Month Day Year
 For example, if today is May 1, 2011, write in 05/01/2011
 Multiple in 05/01/2011
 partgend
- 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? hxdmdonu

1 The 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.



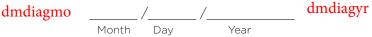


We would like to ask you some questions about your child's birthday, when your child first got diabetes, and how you or your child takes care of his/her diabetes.

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.



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

diagsymp	Yes 1 🗖	No 2 🗖	My child was thirsty, had to pee a lot, or got sick very quickly.
diagphys	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.
diaghefa	Yes 1 🗖	2 No	I found out that my child had diabetes when his/her blood sugar was checked at a health fair or at school.
diagpreg	Yes 1 🗖	No 2 🗖	I found out that my child had diabetes when she was pregnant and the diabetes did not go away after the pregnancy.
diagprwa	Yes 1 🗖	No 2 🗖	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. diagotsp

- 7. What type of diabetes did the doctor or nurse tell you or your child that he/she has? (please check one box)
 diabtype
 - 1 Type 1 diabetes, IDDM, juvenile diabetes
 - 2 🗋 Type 2 diabetes, NIDDM
 - ³ Aturity onset diabetes of youth (MODY)
 - 4 🗋 Other type of diabetes, please specify _____
 - 5 🔲 Don't know



8.		a doctor ase chec			-		-)			diab	etes	was	cause	ed b	y:				
	8a.	cystic fi	brosi	s?	1 🗖 Y	′es	2	No	ł	nxdmc	yst										
	8b.	cancer	or me	edicir	ne to	trea	t cai	ncer?	1	🗋 Yes	2		h	xdmc	atr						
	8c.	another	med	icine	?	1 🔲 \	Yes	2 🔲 N	١o	hxdm	othn	ı									hxdmmesp
			If Yes	s, wh	nat wa	as th	ne m	edicine	э?												Inxuininesp
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9.	Has	your chil	d eve	er tak	en in	sulir	?ו	1 🗖 Ye	es	2 🔲 N	10 (li	f No,	skip	to q	uesti	on 10		nsuev		12	7
	9a.	Was he	/she t	akin	g insi	ulin t	two	weeks	afte	er diag	gnosis	5?	1 🗖	Yes	2 🗋				10	-	ANERT
	9b.	ls he/sh	e tak	ing ir	nsulir	n nov	₩?	1 🗖 Ye	€S	2 🔲 🏻	vo d	mtri	insu		ir	ısdia	ıg2wk	S	1-	~	
10.	(plea 10a. 10b.	else doe ase chec Diabete Diet (m	< Yes s tab eal pl	or N lets (ans)	lo for (pills) ?	· eac)? 1 🔲 Y	ih qu 1 🗖 Kes) 2 🗖 10	I No d	tes n o dmtr mtrd	pill	Does	s he/s	he us	se:				e	
		Exercise		_		2									dn	ntrot	he				
	10d. Any treatments other than insulin, pills, diet, or exercise: (what?)																				
11.	-	our child k X in th	e "Nc	o" bo	x if n	ot S	pani	io? sh/His		ic/Lat											
		No, r								Ye			RICa	1							
		Yes, I								Ye:				parth	niot						
		🗋 Yes, d	otner	Spar	nisn/ i	HISP	anic,	/Latino)-P	rint gi	oup:	•		1							
12.		at is your elf to be		's rac	ce? M	lark	one	or mor	re ra	aces to	o indi	cate	wha	t you	r chil	d cc	onside	rs hir	nself	-/	
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race	paci	🗋 Othe	r Pac	ific Is	and	er; P	rint	race:													racepacidetail

13.	Wh	en y	/our	chi	d fi	rst 🤉	got	diak	pete	s, w	here	e dio	d he	/she	e liv	e?	
• •																	

diagcity															
diagstat	City State	Zip Code	e diagzi	ipc (County	diagco	un								
14.	When your Coast Guar		t got di	abetes	, was h	ne/she in diagarn		vrmy,	Nav	y, Air	Forc	e, Ma	arine	es or	
	1 🗋 Yes 💈	<u>2</u> 🗋 No	3 🗋 Do	n't knc	W	uluguili	15								
Nov	Now we have some questions about your child's current height and weight.														
15.	What is you	ur child's	current	weigh	t?										
		Pour)on't	knov	v w	eigh	tdk		
		weightp				weight	kg								
16.	What is you											- F			
		Feet ightfeet								Lentir eighta					heightd

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?

Yes 2 No 3 Don't know	🗋 Yes	2 🗖 No	3 🗋 Don't know	motherdiab
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17a. If Yes, how old was she when she was diagnosed with diabetes?

mothdiabage _____ years Don't know mothdiabagedk

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

1 Yes 2 No 3 Don't know

fatherdiab

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

_____ years 🔲 Don't know

fathdiabagedk

fathdiabage

20.		s 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 2 If Yes, how many full or half brothers do	fullbrothers		
	20b	brothers If Yes, how many full or half brothers ha brothers	ve diabetes?		
			brotherdiab		
21.	Doe	s 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 2:	fullsisters		
	21a.	If Yes, how many full or half sisters does sisters	s your child have? sistercnt		
	21b.	If Yes, how many full or half sisters have	e diabetes?	N	
		sisters	sisterdiab		
hea	Wha (Ans	would like to learn a bit about your are services. at kind of health insurance plan does your swer Yes or No for each question). a. Medicaid/Medicare/State-funded/othe	r child have NOW ?	Yes	No
spriem		 D. Private insurance, through employer 	i rederany-runded	1 🗖 Yes	2 🗖 No
spripu		c. Private insurance, purchased on your o	wn	1 🗋 Yes 1 🗖	2 🗖 No 2 🗖
smilit	220	d. Military		Yes 1	No 2
sschoo	226	e. School-based insurance		Yes 1 🗖	No 2 🗖

22h. None

22f. Tribe/Indian Health Service

22g. Any other or type unknown

instribe

insothun

insunone

Yes

1 🗖 Yes

1 🗖

Yes

1 🗖

No

2 🗋

No

2 🗖

No

2 🗖

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).

insdiagmedic	23a. Medicaid/Medicare/State-funded/other Federally-funded	Yes 1 🗖	No 2 🗖
insdiagpriem	23b. Private insurance, through employer	Yes 1 🗖	No 2 🗖
insdiagpripu	23c. Private insurance, purchased on your own	Yes 1 🗖	No 2 🗖
insdiagmilit	23d. Military	Yes 1 🗖	No 2 🗖
insdiagschoo	23e. School-based insurance	Yes 1 🗖	No 2 🖵
insdiagtribe	23f. Tribe/Indian Health Service	Yes 1 🗖	No 2 🖵
insdiagothun	23g. Any other or type unknown	Yes 1 🗖	No 2 🖵
insdiagunone	23h. None	Yes 1 🗖	No 2 🗖

24. Who does your child usually go to for most of his/her care related to diabetes? diabcaredr (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?

motheredu	Mother/ guardian	Father/ guardian	fatheredu
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 🗖	

 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?
 partotin

- 1 Less than \$5,000 6 🖸 \$35,000 through \$49,999
- 2 🗋 \$5,000 through \$11,999 7
- 7 🔲 \$50,000 through \$74,999

8 🔲 \$75,000 through \$99,999

- 3 🗋 \$12,000 through \$15,999
- 9 🔲 \$100,000 and greater
- 4 □ \$16,000 through \$24,999 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 _____ parnhous
 - 27b. Number of children (less than 18) _____ parnchil
 - 27c. Number of adults _____ parnadul

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

28.	Was yc	our chi l	ld wit	th diab	etes	s born i	n th	e Ur	nited St	ates	?	bor	nusa						
	1 🗖 Yes	(If Yes	s, go [:]	to que	stior	ר 29)													
	2 🗖 No																		
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borncoun	•																		
arriveusa	20			-	-		d cc	me	to the	Unite	ed State	es to	o live	?		V	Vrite	n year	
	3 🗖 Do	n't kno	w; pr	reter no	ot to	o say													
29.	Was th	ne chil e	d's m	other	oorr	n in the	Unit	ed S	States?	r	nothert	orn	usa						
	1 🗋 Yes	r -		(lf	Yes,	go to	ques	stion	n 30)										
	2 🔲 No																		
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motherarrive	eusa 29										the Unit	ted	State	es?		V	Vrite	n year	:
						ar mot	.nera	irriv	eusauk	-									
	3 🗋 Do	n't kno)w; pr	refer no	ot to	o say													
30.	Was th	e child	l's fat	ther bo	orn ir	h the U	nited	d Sta	ates?	fath	erborn	ısa							
	1 🗖 Yes	ı		(lf	Yes,	go to	next	pag	ge)										
	2 🔲 No																		
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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?

Last Name

Are there any other names that he / she uses?

Oth	ner f	irst	nam	nes										
												·		

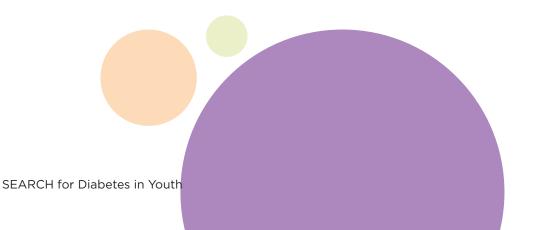
Other last names

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

First	t Na	ame												
Mide	dle	Nan	ne											
Last	: Na	me												

Firs	First Name																			
Mic	Middle Name																			

Last Name

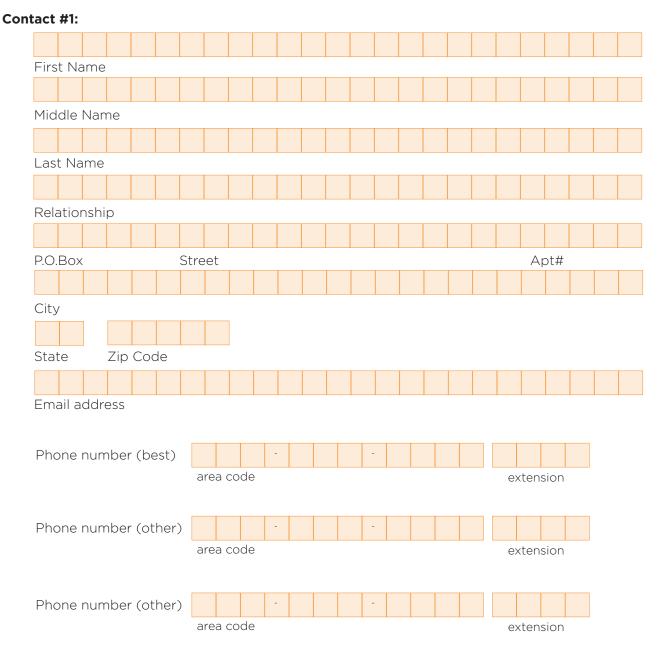


what is the Dest addr									
P.O.Box	Street						Apt#	‡	
City		_11							
State Zip									
Email address									
Phone number (best)	-		-						
	area code					ext	tension		
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May we contact you of May we contact you a Who lives at this addr My child does Child's Father Child's Mother Child's Spouse Other Does your child usual 1 English langeng 2 Spanish langspar 3 Some other langu	e to call? I morning over the weekend? at work? I Yes I ress? (check yes o 1 Yes 2 No 1 Yes 2 No	g aftern Yes No r no for ead livepart livefath livemoth livespou	oon 🖵 e No			Oth	er -		
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C. What is the **best** address, email and phone number to send mail or call?

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 #2:

Firs	st Na	ame																									
Mic	ldle	Nar	ne																								
Las	t Na	ame																									
Rel	atio	nshi	р																								
P.O	.Box	(Stre	et												Apt#								
City	/																										
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Phone number (other))			-				-															
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Pho	one	num	nber	· (ot	her))			-				-														
Phone number (other)							rea (code	e e										ex	tens	ion						

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.



