Please note “You/your child” refers to the participant throughout this worksheet.

## Diagnosis

1. Have you/your child been diagnosed with diabetes? [ ]  Yes [ ]  No [ ]  Unknown

If yes, continue the rest of questions.

1. How old were you/your child at diagnosis?

years months (under 21 years) or years (21 years and older)

1b. Which of these was present at diagnosis (indicate all that apply)?

Clinical symptoms: [ ]  Excessive thirst or urination [ ]  Weight loss (or failure to gain weight in children and adolescents) [ ]  Diabetic ketoacidosis

Laboratory diagnosis: [ ]  Elevated fasting blood sugar [ ]  Elevated random blood sugar

[ ]  Abnormal glucose tolerance testing [ ]  Elevated hemoglobin A1c [ ]  Glucose in the urine

[ ]  Any positive anti-pancreatic auto-antibody laboratory tests

1. Did you/your child receive insulin at the time of diagnosis? [ ]  Yes [ ]  No [ ]  Unknown

### BIRTH HISTORY

1. Were you/your child born at term? [ ]  Yes [ ]  No [ ]  Unknown

If no, answer 3a.

1. How many weeks early were you/your child born?
2. What was you/your child’s birth weight? lbs oz OR kg

### FAMILY HISTORY

1. Do you/your child have any family members (mother, father, sibling, or grandparent only) with history of diabetes? [ ]  Yes [ ]  No [ ]  Unknown

If no, skip to question 6.

If yes, select the relation of the family member and the approximate age of onset.

1. [ ]  Mother [ ]  Father [ ]  Grandparent [ ]  Sibling
	* 1. Age of onset: [ ]  Not known
2. [ ]  Mother [ ]  Father [ ]  Grandparent [ ]  Sibling
	* 1. Age of onset: [ ]  Not known
3. [ ]  Mother [ ]  Father [ ]  Grandparent [ ]  Sibling
	* 1. Age of onset: [ ]  Not known
4. [ ]  Mother [ ]  Father [ ]  Grandparent [ ]  Sibling
	* 1. Age of onset: [ ]  Not known
5. Indicate whether you/your child’s mother or father has a history of the following:
	1. Kidney disease that required dialysis or kidney transplant

[ ]  Mother [ ]  Father [ ]  Both [ ]  Neither [ ]  Unknown

* 1. Heart attacks, heart failure or other heart problems

[ ]  Mother [ ]  Father [ ]  Both [ ]  Neither [ ]  Unknown

* 1. Stroke [ ]  Mother [ ]  Father [ ]  Both [ ]  Neither [ ]  Unknown
	2. High cholesterol [ ]  Mother [ ]  Father [ ]  Both [ ]  Neither [ ]  Unknown
	3. High blood pressure [ ]  Mother [ ]  Father [ ]  Both [ ]  Neither [ ]  Unknown

### SMOKING HISTORY

1. Have you/your child smoked at least 100 cigarettes in his/her life? NOTE: 100 cigarettes = 5 packs

[ ]  Yes [ ]  No [ ]  Unknown

* 1. If YES (you/ your child has smoked at least 100 cigarettes), about how many cigarettes are smoked currently in a typical day?

Please choose only one answer.

[ ]  Less than one cigarette per day

[ ]  1 cigarette per day

[ ]  2 to 5 cigarettes per day

[ ]  6 to 15 cigarettes per day

[ ]  16 to 25 cigarettes per day

[ ]  26 to 35 cigarettes per day

[ ]  More than 35 cigarettes per day

[ ]  Unknown

### EXERCISE INFORMATION

1. In a typical week, how many days do you/your child spend at least 20 minutes doing any physical activities or exercises such as running, working out, aerobics, sports, PE in school, or walking for exercise? [ ]  0 [ ]  1 [ ]  2 [ ]  3 [ ]  4 [ ]  5 [ ]  6 [ ]  7

## Diabetes-Related Treatment History

1. Were you/your child on medicines to lower blood sugar prior to diagnosis of diabetes?

[ ]  Yes [ ]  No [ ]  Unknown

If yes, answer 1a.

1. Select the medication:

[ ]  Metformin

[ ]  Other

### DKA AND SEVERE HYPOGLYCEMIA INFORMATION

1. Since diagnosis have you/your child ever experienced diabetic ketoacidosis (high blood sugar plus ketones, also known as DKA) diagnosed by a doctor for which he/she went to either the hospital, emergency room, or another healthcare facility?

[ ]  Yes [ ]  No

If yes, answer 1a-1b. If no, skip to question 2.

* 1. If yes, # of events
	2. In the past 12 months, have you/your child experienced diabetic ketoacidosis (high blood sugar plus ketones, also known as DKA) diagnosed by a doctor for which he/she went to either the hospital, emergency room, or another healthcare facility?

[ ]  Yes [ ]  No

* + 1. If yes, how many times?
1. Since diagnosis have you/your child ever experienced severe hypoglycemia that resulted in passing out, losing consciousness, or seizure?

[ ]  Yes [ ]  No If yes, answer 2a-2b. If no, skip to question 3.

* + 1. If yes, # of events
		2. In the past 12 months, have you/your child experienced severe hypoglycemia that resulted in passing out, losing consciousness, or seizure?

[ ]  Yes [ ]  No

* + 1. If yes, how many times?

### HOME BLOOD GLUCOSE METER

1. Approximately how many times a day do you/your child check his/her blood sugar? / day

### INSULIN USE

1. Are you currently on insulin? [ ]  Yes [ ]  No

If yes, complete the following:

* 1. What insulin delivery method were you/your child using coming into the visit?

[ ]  Pump

[ ]  Injections (MDI)

[ ]  Injections (fixed dose)

[ ]  Daily long acting only

[ ]  Fixed mix

[ ]  Injections (correction doses only)

[ ]  Injections (daily long acting/ prn corrections)

* 1. Insulin Doses: (enter average if not constant)
		1. Total daily basal insulin (or long acting) in units: [0-200]
		2. Total daily bolus insulin (or short acting) in units: [0-200]
		3. NPH: [ ]  Not used
		4. Premix: [ ]  Not used
	2. Number of missed injections or pump boluses in the past 2 weeks:
	3. If using injections, number of injections per day (enter average if not constant):
		1. Do you/ your child use a Pen? [ ]  Yes [ ]  No [ ]  Unknown

## Diabetes-Related Health Services Utilization

1. In the last 12 months, have you/your child had to use the Emergency Room?

[ ]  Yes [ ]  No [ ]  Don’t know

If yes, complete the following:

1. How many times did you/your child go to the Emergency Room?
2. Number of times you/your child went to the Emergency Room for:
3. Hypoglycemia (low blood sugars)
4. Hyperglycemia (high blood sugars)
5. Other reasons related to diabetes
6. Reasons unrelated to diabetes
7. In the last 12 months, has 911 been called because of your/your child’s diabetes?

[ ]  Yes [ ]  No [ ]  Don’t know

If yes, complete the following:

1. How many times was 911 called?
2. Number of times 911 was called for:
3. Hypoglycemia (low blood sugars)
4. Hyperglycemia (high blood sugars)
5. Other reasons related to diabetes
6. Reasons unrelated to diabetes
7. In the last 12 months, have you/your child had to use an After Hours/Urgent Care Clinic (other than an Emergency Room)? [ ]  Yes [ ]  No [ ]  Don’t know

If yes, complete the following:

* 1. How many times did you/your child go to the After Hours/Urgent Care Clinic?
	2. How many times did you/your child go to the After Hours/Urgent Care Clinic for:
		1. Hypoglycemia (low blood sugars)
		2. Hyperglycemia (high blood sugars)
		3. Other reasons related to diabetes
		4. Reasons unrelated to diabetes
1. In the last 12 months, have you/your child had to be admitted to the Hospital?

[ ]  Yes [ ]  No [ ]  Don’t know

If yes complete the following:

1. How many times were you/your child admitted to the Hospital?
2. How many times were you/your child admitted to the Hospital for:
3. Hypoglycemia (low blood sugars)
	* + 1. # of days for all hypoglycemia admissions:
4. Hyperglycemia (high blood sugars)
	* + 1. # of days for all hyperglycemia admissions:
5. Other reasons related to diabetes
	* + 1. # of days for all other diabetes related admissions:
6. Other reasons unrelated to diabetes
	* + 1. # of days for all non-diabetes related admissions:
7. In the last 12 months, have you/your child seen a health care provider like a physician or nurse practitioner for an office visit? [ ]  Yes [ ]  No [ ]  Don’t know

If yes complete the following:

1. How many times have you/your child seen a health care provider like a physician or nurse practitioner for an office visit for diabetes? [ ]  Unknown
2. How many times have you/your child seen a health care provider like a physician or nurse practitioner for an office visit for other reasons? [ ]  Unknown
3. In the last 12 months, have you/your child seen a dietician?

[ ]  Yes [ ]  No [ ]  Don’t know

If Yes, complete the following:

1. How many times have you/your child seen a dietician? [ ]  Unknown

## General Instructions

This form is intended to obtain additional information regarding the diagnosis, treatment, and health services utilization of individuals with mitochondrial disease who also have diabetes mellitus, which represents a relatively common endocrine complication. (1) This form is based largely on questionnaires utilized by the Pediatric Diabetes Consortium.(2) We consider the data elements of the first section (Diagnosis) to be Supplemental – Highly Recommended for any study focused on diabetes mellitus in mitochondrial disease. The balance of elements are considered Exploratory, based on the purposes of the particular study.

Special note: Laboratory details can be found in the endocrine-related laboratory CRF. Physical activity details can be found in the Exercise Physiology domain. Other elements can be found in the Dietary Supplements CRF. For diabetes related CDEs, please refer to the Medications CRF.

It is noted that that both the pediatric and adult Newcastle Mitochondrial Disease scales include questions related to impaired endocrine function in the context of assessing related to the overall burden of endocrine disease. (3) (4)

Outside of the United States, evaluate the second set of Diabetes-Related Health Services Utilization questions (those referring to 911 calls) with respect to the direct-dial emergency number(s) applicable to the study site.

### CITATIONS

1. Whittaker RG, Schaefer AM, McFarland R, Taylor RW, Walker M, Turnbull DM. Prevalence and progression of diabetes in mitochondrial disease. Diabetologia. 2007;50(10):2085-9. Epub 2007/07/27. doi: 10.1007/s00125-007-0779-9. PubMed PMID: 17653689.
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3. Elson JL, Cadogan M, Apabhai S, Whittaker RG, Phillips A, Trennell MI, et al. Initial development and validation of a mitochondrial disease quality of life scale. Neuromuscular disorders : NMD. 2013;23(4):324-9. Epub 2013/02/26. doi: 10.1016/j.nmd.2012.12.012. PubMed PMID: 23433484; PubMed Central PMCID: PMC3841574.
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