## Genetic Information

What mitochondrial disease diagnosis is present? (*Specify*)

Is there a known genetic diagnosis? Yes No

Is this a nuclear or mitochondrial DNA mutation? Nuclear Mitochondrial

Nuclear Mutation (*Specify*):

Mitochondrial DNA mutation (*Specify*):

## Demographic Information

How is person related to the person with mitochondrial disease? The person with mitochondrial disease Mother

Father

Guardian (not a relative) Grandmother Grandfather

Sister Brother Spouse Other, Specify

Weight(*Specify*)

Height (*Specify*)

Mother's Height (*Specify*)

Father's Height (*Specify*)

Have you/ your child had any of the following problems?

Vomiting

GERD, heartburn, mid-line chest pain, esophageal burning

Oral regurgitation Burping

Difficulty or pain with swallowing Feeding difficulties

Abdominal pain

Early satiety (Early fullness) Abdominal bloating or distension

Problems with bowel movements (diarrhea, constipation, straining, pain with bowel movements, blood in the stool)

Poor appetite affecting growth Cyclic vomiting

## Specific questions about how you/your child eats:

How does you/your child eat? Eats by himself (regular diet)

Infant formula (not specialized)

Infant formula (specialized)

Liquid diet (non-infant)

Gastrostomy (G-tube)

Jejunostomy (J-tube)

Gastrojejunostomy (G-J tube)

Nasogastric tube (NG tube)

They do not take any food by mouth or feeding tube TPN (total parenteral nutrition)

What kind of infant formula? (*Specify*)

Why do you/they eat that way? (*Specify*)

What liquid diet do you/they use? (*Specify*)

Are you/your child currently on a restricted diet? Yes

No

What type of specialized diet do you/they eat? Ketogenic diet

Celiac diet /gluten free Vegetarian

Vegan Organic

Food allergen avoidance (shellfish, eggs, nuts, etc.)

Lactose free Sucrose free Fructose Low fat

Low carbohydrate Low protein

High fat

High carbohydrate

High protein

Low Fermentable Oligo-Di-Monosaccharides and Polyols

Other

Specialized diet other (*Specify*)

Why are you/they on a specialized diet? (*Specify*)

Has your/their symptoms changed since the diet started? (*Specify*)

Have you/your child ever been on a restricted diet in the past? Yes

No

What type of specialized diet were you/they on? Ketogenic Diet

Celiac Diet/Gluten Free Vegetarian

Vegan Organic

Food Allergen avoidance (shellfish, eggs, nuts, etc)

Lactose Free Sucrose Free Fructose Free Low Fat

Low Carbohydrate Low Protein

High Fat High Carb High Protein

Low Fermentable Oligo-Di-Monosaccharides and Polyols

Other

Other

Why did you/they stop?

Did the diet affect symptoms?

What other dietary restrictions does you/your child have?

## Vomiting

Does you/your child have vomiting currently or in the Present

past? Past

What was your/your child's age when the problems On the day of birth

began? Less than 2 mo (not on day of birth)

2 mo to 5 mo

6 mo to 12 mo

13 mo to 18 mo

19 mo to 3 y

4 y to 6 y

7 y to 13 y

14 y to 18 y

Greater than 18 y

I don’t know

For the current vomiting episodes, were any of the Right after birth

following triggers present at the time symptoms began? Fever

Upper respiratory infection Surgery

Diarrhea

Prolonged fasting (i.e., not eating well) After starting a medicine

During exercise After a seizure After trauma

I don’t know Other

Present trigger other.

Are the symptoms pretty consistent from day to day? Yes No

Once a day

Multiple times a day

How often does you/your child vomit?

At least once a week, but not daily One to 4 times per month

Less than once a month, more than once a year About once a year

Only once Other

Vomiting Frequency Other

When you/your child has vomiting is it only a single Single episode

episode or do you/they usually vomit repeatedly? Vomits more than once

Vomits repeatedly until there is nothing left

Does the vomiting happen during a specific time of Morning (wake up until 12pm) the day? Afternoon (12pm - 5pm)

Evening (5pm - Bed) Overnight (wakes from sleep) All times of day

Are there particular triggers for vomiting episodes? Yes No

I don’t know

What triggers vomiting episodes?

Do any of the following occur frequently before Fasting more than 12 hours

vomiting starts? Viral illness/Fever

Taking medicine Right after feeding Seizure

Headache/Migraine/Light sensitivity Exercise

Stress

Does you/your child ever have bright green or yellow Yes

vomiting? No

I don’t know

How often has green or yellow vomiting occurred? Only once

Less than half of vomiting episodes Most vomiting episodes

All vomiting episodes

Does you/your child ever vomit blood? Yes No

I don’t know

What color is the blood? Bright red

Dark red Brown Black

I don’t know

Do you ever see blood clots in what you/they vomit? Yes No

I don’t know

Does you/your child have black stool? Note: If they Yes

answer yes, confirm that stool was really black and No

not dark brown or dark green. I don’t know

Does you/your child have abdominal pain before Yes

vomiting? No

I don’t know

Nausea Both

Abdominal pain

Which symptom is most severe with vomiting episodes?

Please provide additional details about current vomiting symptoms.

# Past Vomiting

How old were you/your child when you first started On the day of birth

having issues with vomiting? Less than 2 mo (not on day of birth)

2 mo to 5 mo

6 mo to 12 mo

13 mo to 18 mo

19 mo mo to 3 y

4 y to 6 y

7 y to 13 y

14 y to 18 y

Greater than18 y

I don’t know

How old were you/your child when the vomiting stopped? On the day of birth

Less than 2 mo (not on day of birth)

2 mo to 5 mo

6 mo to 12 mo

13 mo to 18 mo

19 mo to 3 y

4 y to 6 y

7 y to 13 y

14 y to 18 y

Greater than18 y

I don’t know

What stopped the vomiting?

In the past, were the symptoms consistent from day to Yes

Day? No

During that period, how often did you/they vomit? Multiple times a day Once a day

At least once a week, but not daily One to 4 times per month

Less than once a month, more than once a year About once a year

Only once Other

Past Vomiting frequency, Other (*Specify*):

In the past, when you/your child had vomiting, was it Single episode

only a single episode or did you/they usually vomit Vomited more than once

repeatedly? Vomited repeatedly until there was nothing left

Did the vomiting happen during a specific time of the Morning (wake up until 12pm) day? Afternoon (12pm - 5pm)

Evening (5pm - Bed) Overnight (wakes from sleep) All times of day

In the past, were there any particular triggers for Yes

vomiting episodes? No

I don't know

In the past, what had triggered vomiting episodes?

Fasting more than 12 hours

vomiting started? Viral illness/Fever

Did any of the following occur frequently before the

Taking medicine Right after feeding Seizure

Headache/Migraine/ Light sensitivity Exercise

Stress

Did you/your child ever have bright green or yellow Yes

vomiting? No

I don't know

How often did the green or yellow vomiting occur? Only once

Less than half of vomiting episodes Most vomiting episodes

All vomiting episodes

Did you/your child ever vomit blood? Yes No

I don't know

What color was the blood? Bright red

Dark red Brown Black

I don't know

Did you ever see blood clots in what you/they vomited? Yes No

I dont know

Did you/your child ever have black stools? Yes No

I don't know

Did you/your child have abdominal pain before Yes

vomiting? No

I don't know

Which symptom was most severe with past vomiting episodes? Abdominal Pain

Nausea Both

In past episodes of vomiting, was any of the Right after birth

following triggers present at the time symptoms began? Fever

Upper respiratory infection Surgery

Diarrhea

Prolonged fasting (i.e., not eating well) After starting a medicine

During exercise After a seizure After trauma

I dont know Other

Past Triggers Other, *(Specify)*:

Please provide additional details about your/their past vomiting symptoms.

# Cyclic Vomiting

Have you/your child ever been diagnosed with cyclic Yes

vomiting? No

I don't know

Do you/your child have a history of migraines? Yes No

Do you have a family history of migraines? Yes No

Have you/they ever experienced vision changes or Vision Changes

auras? Auras

Both Neither

# GERD, Heartburn, Mid-line Chest Pain, Esophageal Burning

Has you/your child had GERD, heartburn, mid-line Present

chest pain, esophageal burning in the past or Past currently?

For the current GERD, heartburn, mid-line chest pain, On the day of birth

esophageal burning episodes, what was your/their age Less than 2 mo (not on day of birth) when the problems began? 2 mo to 5 mo

6 mo to 12 mo

13 mo to 18 mo

19 mo to 3 y

4 y to 6 y

7 y to 13 y

14 y to 18 y

Greater than 18 y

I don’t know

Are the symptoms pretty consistent from day to day? Yes No

How often do you/they have GERD, heartburn, mid-line Daily

chest pain, esophageal burning? At least once a week, but not daily One to 4 times per month

Less than once a month, more than once a year About once a year

Only once Other

I don’t know

Does GERD, heartburn, mid-line chest pain, esophageal Yes burning disrupt activity? No

Does GERD, heartburn, mid-line chest pain, esophageal Yes burning wake you/your child from sleep? No

Please provide additional details about your/their GERD, heartburn, mid-line chest pain, esophageal burning symptoms.

# Past GERD, Heartburn, Mid-line Chest Pain, Esophageal Burning

For past GERD, heartburn, mid-line chest pain, esophageal On the day of birth

burning episodes, what was your/your child's age Less than 2 mo (not on day of birth) when the problems began? 2 mo to 5 mo

6 mo to 12 mo

13 mo to 18 mo

19 mo to 3 y

4 y to 6 y

7 y to 13 y

14 y to 18 y

Greater than 18 y

I don’t know

How old were you/your child when the symptoms On the day of birth

stopped? Less than 2 mo (not on day of birth)

2 mo to 5 mo

6mo to 12 mo

13 mo to 18 mo

19 mo to 3 y

4 y to 6 y

7 y to 13 y

14 to 18 y

Greater than 18 y

I don’t know

What stopped the GERD, heartburn, mid-line chest pain, and esophageal burning?

In the past, were the symptoms pretty consistent from Yes

day to day? No

How often did you/they have GERD, heartburn, mid-line Daily

chest pain, esophageal burning? At least once a week, but not daily One to 4 times per month

Less than once a month, more than once a year About once a year

Only once Other

I don’t know

Did past GERD, heartburn, mid-line chest pain, esophageal Yes

burning disrupt activity? No

Did past GERD, heartburn, mid-line chest pain, esophageal Yes

burning wake you/your child from sleep? No

Please provide additional details about your/their past GERD, heartburn, mid-line chest pain, esophageal burning symptoms.

# Oral Regurgitation

Do you/your child have oral regurgitation or have Present

they had oral regurgitation in the past? Past

For the current oral regurgitation episodes, what was On the day of birth

your/their age when the problems began? Less than 2 mo (not on day of birth)

2 mo to 5 mo

6 mo to 12 mo

13 mo to 18 mo

19 mo to 3 y

4 y to 6 y

7 y to 13 y

14 y to 18 y

Greater than 18 y

I don’t know

Are the symptoms pretty consistent from day to day? Yes No

How often does the oral regurgitation occur? Daily

At least once a week, but not daily One to 4 times per month

Less than once a month, more than once a year About once a year

Only once Other

I don’t know

Oral Regurgitation Other *(Specify)*

Is the oral regurgitation before, during, or after Before

meals? During

After Variable

Please provide additional details about your/their oral regurgitation symptoms.

# Past Oral Regurgitation

In past oral regurgitation episodes, what was On the day of birth

your/your child's age when the problems began? Less than 2 mo old (not on day of birth)

2 mo to 5 mo

6 mo to 12 mo

13 mo to 18 mo

19 mo to 3 y

4 y to 6 y

7 y to 13 y

14 y to 18 y

Greater than 18 y

I don’t know

How old were you/your child when the symptoms On the day of birth

stopped? Less than 2 mo (not on day of birth)

2 mo to 5 mo

6 mo to 12 mo

13 mo to 18 mo

19 mo to 3 y

4 y to 6 y

7 y to 13 y

14 y to 18 y

Greater than 18 y

I don’t know

What stopped the oral regurgitation?

Were the symptoms pretty consistent from day to day? Yes No

In the past, how often did the oral regurgitation occur? Daily

At least once a week, but not daily

One to 4 times per month

Less than once a month, more than once a year About once a year

Only once

Other

I don’t know

Past Oral Regurgitation Other *(Specify)*

In the past, was the oral regurgitation before, Before

during, or after meals? During

After Variable

Please provide additional details about your/their past oral regurgitation symptoms.

# Burping

Do you/your child have burping or have you/they had Present burping in the past? Past

For the current burping problems, what was your/your child’s age On the day of birth

when the problems began? Less than 2 mo (not on day of birth)

2 mo to 5 mo

6 mo to 12 mo

13 mo to 18 mo

19 mo to 3 y

4 y to 6 y

7 y to 13 y

14 y to 18 y

Greater than 18 y

I don’t know

Is the burping pretty consistent from day to day? Yes No

Does the burping occur with reflux or abdominal Reflux

distension? Abdominal distension

Both

Does the burping occur with any specific drinks or Yes

food? No

What food or drink?

Please provide additional details about your/their burping symptoms

# Past Burping

For the past burping problems, what was your/your child’s age On the day of birth

when the problems began? Less than 2 mo (not on day of birth)

2 mo to 5 mo

6 mo to 12 mo

13 mo to 18 mo

19 mo to 3 y

4 y to 6 y

7 y to 13 y

14 y to 18 y

Greater than 18 y

I don’t know

What was your/their age when the burping problem stopped?

On the day of birth

Less than 2 m (not on day of birth)

2 mo to 5 mo

6 mo to 12 mo

13 mo to 18 mo

19 mo to 3 y

4 y to 6 y

7 y to 13 y

14 y to 18 y

Greater than 18 y

I don’t know

What stopped the burping? (*Specify:*)

Was the burping pretty consistent from day to day? Yes No

Did the burping occur with reflux or abdominal Reflux

distension? Abdominal distension

Both

Did the burping occur with any specific drinks or Yes

food? No

What food or drink? (*Specify*:)

Please provide additional details about your/their past burping symptoms (*Specify*:)

# Difficulty/ Pain with Swallowing

Do you/your child have difficulty or pain with swallowing? Difficulty

Pain

Both

What was your/your child’s age when swallowing On the day of birth

problems began? Less than 2 mo (not on day of birth)

2 to 5 mo

6 to 12 mo

13 to 18 mo

19 mo to 3 y

4 to 6 y

7 to 13 y

14 to 18 y

Greater than 18 y

I don’t know

Are the swallowing problems occurring with liquids or Solids only

solids? Liquids and solids

Liquids only I don’t know

How often do problems with swallowing occur? Daily

At least once a week, but not daily One to 4 times per month

Less than once a month, more than once a year About once a year

Only once Other

I don’t know

Has the difficulty in swallowing changed over time? Yes

No

Please provide additional details about your/their swallowing problems.

How often does pain with swallowing occur? Daily

At least once a week, but not daily One to 4 times per month

Less than once a month, more than once a year About once a year

Only once Other

I don't know

Does pain with swallowing disrupt activity or wake No

child from sleep? Pain wakes child from sleep Pain disrupts activity

Pain wakes child and disrupts activity I don't know

Please add comments about pain with swallowing

Do you/your child feel food gets stuck in your/their Yes

esophagus? No

I don' know

Where do you feel things get stuck? Back of the throat Neck

Upper chest Lower chest

Have you/your child ever had food or a pill removed Yes

from the esophagus? No

How many times?

Have you/your child ever been diagnosed with any of Achalasia

the following: Eosinophilic Esophagitis

Esophageal stricture

# Feeding Difficulties

Can you tell me about your/your child’s feeding difficulties?

# Abdominal Pain

What was your/your child’s age when abdominal pain began? On the day of birth

Less than 2 mo (not on day of birth)

2 mo to 5 mo

6 mo to 12 mo

13 mo to 18 mo

19 mo to 3 y

4y to 6 y

7 y to 13 y

14 y to 18 y

Greater than 18 y

I don’t know

Have you/your child experienced abdominal pain in the Present past or currently? Past

What makes you think they have abdominal pain? The child tells me Holds belly

Holds belly and cries or looks uncomfortable Cries without another obvious cause

Cries all the time Cries with meals Wakes up from sleep Irritability

Other

I don't know

Please provide additional details about your/your child’s abdominal pain.

Where is the abdominal pain located? Choose all that Upper abdomen midline (between umbilicus and apply. bottom of ribs)

Upper abdomen on the right Upper abdomen on the left Entire upper abdomen

Near the belly button

Right lower quadrant (below umbilicus) Left lower quadrant

Lower abdomen midline Entire lower abdomen Entire abdomen Variable locations

I don't know

How often does abdominal pain occur? Daily

At least once a week, but not daily One to 4 times per month

Less than once a month, more than once a year About once a year

Only once Other

I don't know

Abdominal Pain Other (*Specify*)

How long does the abdominal pain last when it occurs? Less than a minute

One minute to 30 minutes 31 minutes to many hours All day

Day and night

Until you/the child falls asleep Until you/the child vomits Until you/the child eats

Until you/the child has a bowel movement Until you/the child urinates

Until you/the child passes gas Variable

None of the above I don't know

Please provide additional comments about the duration of abdominal pain

Fasting more than 12 hours

Do any of the following occur frequently before

abdominal pain starts? Viral illness/Fever

Taking medicine Right after feeding Seizure

Headache/Migraine/Light sensitivity Exercise

Stress Depression Anxiety

Other Psychological Issues Particular Foods

Other

Please provide additional details about abdominal pain triggers.

Does abdominal pain disrupt activity? Yes No

I don't know

Does abdominal pain wake you/your child from sleep? Yes No

I don't know

Is there anything specific that makes the pain better?

Is there anything specific that makes the pain worse?

Please provide additional details about present abdominal pain

# Past Abdominal Pain

What was your/your child’s age when past abdominal pain began? On the day of birth

Less than 2 mo (not on day of birth)

2 mo to 5 mo

6 mo to 12 mo

13 mo to 18 mo

19 mo to 3 y old

4 y to 6 y old

7 y to 13 y old

14 y to 18 y old

Greater than 18 y old

I don’t know

What was your/your child’s age when the abdominal On the day of birth

pain stopped? Less than 2 mo (not on day of birth)

2 mo to 5 mo

6 mo to 12 mo

13 mo to 18 mo

19 mo to 3 y

4 y to 6 y

7y to 13 y

14 y to 18 y old

Greater than 18 y

I don’t know

What stopped the abdominal pain?

The child told me

Held belly

What made you think they had abdominal pain?

Held belly and cried or looked uncomfortable Cried without another obvious cause

Cried all the time Cried with meals Woke up from sleep Irritability

Other

I don't know

Provide additional details if desired about what made you think they had abdominal pain.

Where was the past abdominal pain located? Choose all Upper abdomen midline (between umbilicus and that apply. bottom of ribs)

Right upper abdomen

Left upper abdomen

Entire upper abdomen

Near the belly button

Right lower quadrant (below umbilicus) Left lower quadrant

Lower abdomen midline Entire lower abdomen Entire abdomen Variable locations

I don't know

How often did past abdominal pain occur? Daily

At least once a week, but not daily One to 4 times per month

Less than once a month, more than once a year About once a year

Only once Other

I don't know

Other

How long did the past abdominal pain last when it occurred? Less than a minute

One minute to 30 minutes 31 minutes to many hours All day

Day and night

Until you/the child fell asleep Until you/the child vomited Until you/the child ate

Until you/the child had a bowel movement Until you/the child urinated

Until you/the child passed gas Variable

None of the above I don't know

Please provide additional comments about the duration of past abdominal pain

Fasting more than 12 hours

before abdominal pain started? Viral illness/Fever

Did any of the following triggers occur frequently before

Taking medicine Right after feeding Seizure

Headache/Migraine/Light sensitivity Exercise

Stress

Depression Anxiety

Other psychological Issues Particular Foods

Other

Please provide additional details about past abdominal pain triggers.

Did abdominal pain disrupt activity? Yes No

I don't know

Did abdominal pain wake you/ your child from sleep? Yes No

I don't know

Is there anything specific that made the pain better?

Is there anything specific that made the pain worse?

Please provide additional details about past abdominal pain.

# Early Satiety

Can you tell me about your early fullness?

# Abdominal Bloating and Distension

Do you/your child have bloating or abdominal Present

distension or have they had it in the past? Past

What was your/your child’s age when the abdominal bloating/ On the day of birth

distension problems began? Less than 2 mo (not on day of birth)

2 mo to 5 mo

6 mo to 12 mo

13 mo to 18 mo

19 mo to 3 y

4 y to 6 y

7 y to 13 y

14 y to 18 y

Greater than 18 y

I don’t know

Is the bloating or abdominal distension worse at any Morning (wake up until 12pm) particular time of day? Afternoon (12pm - 5pm)

Evening (5pm - Bed) Overnight (wakes from sleep) All times of the day

I don't know

Air

stool? Stool

Do you think the belly is distended with air or with

Both

I don't know

Are you/your child an air swallower? Yes No

I don't know

Please provide additional details about abdominal bloating and distension

# Past Abdominal Bloating and Distension

What was your/your child’s age when the past abdominal bloating/ On the day of birth

distension problems began? Less than 2 mo (not on day of birth)

2 mo to 5 mo

6 mo to 12 mo

13 mo to 18 mo

19 mo to 3 y

4 y to 6 y

7 y to 13 y

14 yto 18 y

Greater than 18 y

I dont know

What was your/your child’s age when the past abdominal On the day of birth

bloating/distension stopped? Less than 2 mo (not on day of birth)

2 mo to 5 mo

6 mo to 12 mo

13mo to 18 mo

19 mo to 3 y

4 y to 6 y

7 y to 13 y

14 y to 18 y

Greater than 18 y

I don't know

What stopped the past abdominal bloating/distension?

Was the past bloating or abdominal distension worse at any Morning (wake up until 12pm) particular time of day? Afternoon (12pm - 5pm)

Evening (5pm - Bed) Overnight (wakes from sleep) All times of the day

I don't know

Did you think the belly was distended with air or with Air

stool? Stool

Both

I don't know

Please provide additional details about past abdominal bloating and distension

## General Stool Questions:

How often do they have bowel movements? More than once a day Once a day

Every other day

A few times a week Once a week

Less than one a week Only after a suppository

Only after an enema/irrigation/suppository Requires disimpaction with a finger

Uses a cecostomy to induce bowel movements Requires Go lightly by mouth or tube

Other

I don't know

Stool Frequency Other (*Specify*):

What is the consistency of bowel movements? (Bristol Watery

stool scale classification) Mushy

Soft Formed Hard

Hard and large Variable Greasy

Type 1: Separate hard lumps, like nuts (hard to pass)

Type 2: Sausage-shaped, but lumpy

Type 3: Like a sausage but with cracks on its surface

Type 4: Like a sausage or snake, smooth and soft Type 5: Soft blobs with clear cut edges (passed easily)

Type 6: Fluffy pieces with ragged edges, a mushy stool

Type 7: Watery, no solid pieces. Entirely liquid I don't know

Do you/your child use a toilet or a diaper? Toilet Diaper

## Bowel Movement Problems

What was your/your child's age when the bowel movement On the day of birth

problems began? Less than 2 mo (not on day of birth)

2 mo to 5 mo

6 mo to 12 mo

13 mo to 18 mo

19 mo to 3 y

4 y to 6 y

7 y to 13 y

14y to 18 y

Greater than 18 y

I don’t know

Do you/they have to strain to pass bowel movements? Yes No

I don't know

Do you/your child ever have blood in the stool? Yes No

I don't know

What color is the blood in the stool? Bright red

Dark red (maroon) Black

I don't know

What is the largest amount of blood you have seen in Small streaks (i.e., not three dimensional) the stool? Small clumps of clots

Big clots of blood (larger than a dime)

Do you/your child use medicine or other Yes

treatment to help with bowel movements? No

What treatment do you/your child use to help with Glycolax, PEG, Polyethylene Glycol bowel movements? Mineral oil

Kondrumel

Milk of Magnesia Senakot or other Senna

Colace

Dulcolox suppository

Prune juice, apple juice, Kayro syrup Fleets enema

Saline enema

Milk and molasses enema Imodium

Lomotil Peptobismol Other

Defecation Treatment Other:

Have they used any other treatments in the past to help with bowel movements?

Did these treatments help or worsen the bowel movement problem?

Please provide additional details about bowel movement problems.

# Poor appetite affecting growth

Can you tell me more about the poor appetite affecting growth?

# General Medication/ Treatment/Surgery Questions

What other medicines are you/your child taking now? Proton pump inhibitor: Prilosec (omeprazole),

Nexium, Prevacid (lansoprazole), Protonix (pantoprazole) or Aciphex (rabeprazole)

H-2 receptor antagonist: Pepcid (famotidine), Zantac (ranitidine), Tagemet (cimetidine) Carafate

Ondansetron (Zofran)

Tricyclic antidepressant: Amitriptyline, desipramine, imipramine, nortiptyline

SSRI: Citalopram (Celexa), escitalopram (Lexapro), fluoxetine (Prozac), paroxetine (Paxil, Pexeva), sertraline (Zoloft)

Erythromycin Cisapride (Propulsid)

Domperidone (Motilium) Reglan (metaclopramide) Tegaserod (Zelnorm, Zelmac) Linaclotide (Linzess)

CoQ10 (Ubiquinol, Ubiquinone) Riboflavin (vitamin B2)

L-Creatine L-Arginine L-Carnitine

B vitamins (other) Vitamin E Vitamin C

Alpha lipoic acid Folinic acid

Carbamazepine (Tegretol, Carbatrol) Ethosuximide (Zarontin)

Felbatol (Felbamate) Tiagabine (Gabatril) Levetircetam (Keppra) Lamotrigine (Lamictal) Pregabalin (Lyrica) Phenytoin (Dilantin) Topamax (Topiramate) Oxycarbazine (Trileptal) Gabapentin (Neurontin)

Pancreatic enzyme supplements (Creon) Levbid/Levsin/Bentyl

Antibiotics Other

What other medicines do you/your child take?

Have you/ your child taken any medications in the past that you feel helped any of your/your child's GI problems?

Have you/your child taken any medications in the past that you feel have worsened your/your child's GI problems?

Have you/your child tried any "alternative medicine Yes

approaches" to help with any of the problems we No discussed?

What types of alternative medicine have you/your Meditation

child tried? Yoga

Acupuncture Crystal

Faith healer Prayer Massage Exercise

Herbal supplements or medicines Homoepathic medicine Chiropractic care

Colon cleansing Aromatherapy Antioxidants

Supplemental vitamins (not prescribed) Marijuana

Ginger

Over the counter medicine Items bought over the internet Other

What other alternative medicine have you/your child tried?

Did any of these alternative medicine treatments help your/their GI issues?

Did any of these alternative medicine treatments worsen your/your child’s GI problems?

Have you/your child ever had surgery? Yes No

G-tube

J-tube

What type of surgery or procedures have you/they had?

G J - tube (e.g., for venting and feeding)

Colostomy Ileostomy Jejunostomy

Cecostomy (to treat refractory constipation) Hirschsprung (Swenson, Duhamel, Soave) Fundoplication (Nissen, Toupet)

Bowel resection Bowel dilation Botox injection Upper endoscopy Colonoscopy

Esophageal manometry Antroduodenal manometry Colon manometry Anorectal manometry Gastric emptying studies Esophageal pH monitoring

Esophageal impedance monitoring Bladder surgery

Brain surgery Heart surgery Lung surgery

Airway surgery (tracheostomy, laryngomalacia) Kidney surgery

Liver surgery Spleen surgery

Orthopedic surgery (bone or joint) Organ transplant

Muscle Biopsy

Provide additional details about the type of surgery here.

# GI and social issues

How much do the symptoms we discussed affect 1

your/ life? (1 being not at all, 10 being severe 2

interruption) 3

4

5

6

7

8

9

10

If there was a clinical trial regarding GI Yes

issues, would you/they participate in it? No

I don’t know

How long did you/they have GI symptoms before you were diagnosed with mitochondrial disease?

How many GI doctors have you/they seen?

Were these GI symptoms what led to your/ mitochondrial disease diagnosis?

Were your/ GI symptoms recognized as significant before diagnosis of mitochondrial disease?

problems for fear of not being believed about these No

symptoms? I don't know

Have you ever been referred to a psychiatric Yes

professional regarding your/your child's GI symptoms? No

I don't know

Have you ever been concerned about a Munchausen by Yes proxy accusation? No

I don't know

Have you ever had a confrontation with a health care Yes

professional about Munchausen by proxy syndrome? No

I don't know

What setting was this in? ER

Outpatient Clinic Hospital stay Other

Munchausen Setting Other

Is there anything else you want to tell us?