

**Interview-Based Patient- and Caregiver-Reported Experiences of Hunger and Improved
Quality of Life With Setmelanotide Treatment in Bardet-Biedl Syndrome**

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Supplementary Material:

Interview Guides

PATIENT INTERVIEW GUIDE

I. Introduction

[Interviewer introduces herself and notetaker and briefly reiterates the purpose and format of the interview.]

- First, thank you again for participating in an interview with us.
- During the interview today, we will ask you about your hunger before starting the (first) clinical trial and any changes you have experienced since you started taking the study medication (setmelanotide).
- The information gathered during these interviews will supplement the clinical trial results and contribute to knowledge about hunger in the context of BBS.
- As a reminder, your participation is completely voluntary, and you may end the discussion at any time. Of course, you should also feel free to ask us any questions you have or request a break in the interview at any time.
- We expect today's interview to last 50-60 minutes. We have a series of topics we wish to cover with you but also intend for these interviews to be conversational. As such, we encourage you to describe experiences related to your hunger and the study medication as they come to mind.
- With your permission, we will audio record today's interview to make sure we do not miss any important information and to help us create a transcript of the interview. All information you provide to us will be kept confidential. While they will be provided to the study sponsor, all names and any other identifying information will first be removed from the interview transcripts.
- Please keep in mind that there are no wrong answers to our questions. Hunger is a completely internal state, and it is important that we better understand your experience with hunger. We appreciate the opportunity to learn from your experiences and are truly grateful for your time.
- Before we begin, do you have any questions?
- Okay, I'm going to go ahead and turn on my recorder.

START RECORDING

I am now audio recording. Do I have your permission to continue with the audio-recorded interview?

- Yes → **CONTINUE**
- No → **STOP INTERVIEW**

II. Experiences Before Clinical Trial

We'd first like to hear about your experiences before you started the (first) clinical trial of setmelanotide in which you participated.

- About how long ago did you start that (first) trial?
- As best you can remember, please tell us about your hunger or appetite before you started that trial.
 - How did you feel when you woke up in the morning?
 - How would you describe any changes in your hunger throughout the day?
 - How you describe your hunger at night?
 - How often did you wake up feeling hungry during the night?
- How did you feel when you were the most hungry?
 - On a scale of 0-to-10 where 0 is not hungry at all and 10 is the hungriest possible, how would you rate the highest level of hunger you experienced before the (first) clinical trial?
 - When you were at a [0-to-10 answer], how did you feel physically? What did you feel in your body?
- Would you ever describe the way you felt at a [0-to-10 answer] as “painful”? Please tell us more about that.
 - When you were at a [0-to-10 answer], how did you feel mentally or emotionally? What sorts of things were you saying to yourself?
- When during the day did you feel the most hungry?
 - How much of the day did you feel this way?
- Were there times you didn't feel hungry at all, like a 0 on that 0-to-10 scale?
 - [If yes] How much of the time, during a typical day, did you not feel hungry at all?
- What did that feel like? How did this differ from when you felt hungry?

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- When would you not feel hungry? What time of day or under what circumstances?
 - How long would that last?
 - *[If no]* On our same 0-to-10 scale where 0 is not hungry at all and 10 is the hungriest possible, what's the lowest level of hunger you experienced before the (first) clinical trial?
 - How would you describe a *[0-to-10 answer]*? What did that feel like?
 - When would you feel this lowest level of hunger?
 - How long would that last?
 - Before the (first) clinical trial, how did you feel after eating a meal?
 - Did you ever feel full or satisfied?
 - *[If yes]* How often did you feel full or satisfied after eating?
 - How long did this feeling last?
 - *[If no]* On our same 0-to-10 scale where 0 is not hungry at all and 10 is the hungriest possible, how did you typically feel after eating a meal before the (first) clinical trial?
 - How long did this feeling last?
 - How did your hunger affect how much and what you ate throughout the day?
 - How did your hunger affect how often you ate?
 - How often did you typically eat throughout the day?
 - How did your hunger affect what you ate?
 - Were there any foods you tended to eat only when you were very hungry?
 - Did you ever eat things that others would find inedible or distasteful to satisfy your hunger? Please tell us about that. *[If needed: for example, condiments, food that others have left on their plates, food from the trash]*
 - How would you describe your ability to control how much and what you ate before the (first) clinical trial?
 - Did you ever have difficulty obtaining food when you were very hungry?
 - *[If yes]* What kinds of things did you do to get food?
 - How did your hunger affect your life? [If patient spontaneously uses the word “hyperphagia,” use this term for the next set of questions.]
 - Did your hunger/hyperphagia affect your mood or emotions? How?
 - Did your hunger/hyperphagia ever make you feel anxious or depressed? Please tell us more about that.

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- Did your hunger/hyperphagia affect your sleep? How?
 - Was it difficult to get to sleep? Did you wake up during the night because you were hungry? Please tell us more about that.
 - Did your hunger/hyperphagia affect you at work/school? How?
 - How often, if ever, did you find it difficult to get things done because you were hungry? What made it more difficult?
 - How often, if ever, did you have trouble concentrating because you were hungry?
 - How often, if ever, did you need to take breaks to find something to eat?
 - Did your hunger/hyperphagia affect your social life? How?
 - Did your hunger/hyperphagia affect your leisure or recreational activities? How?
 - How often, if ever, did you need to stop what you were doing to find something to eat?
 - Did your hunger/hyperphagia affect your interactions or relationships with your family? How? [*Probe parents, siblings, as needed*]
 - What about interactions or relationships with your friends?
 - What bothered you most about your hunger/hyperphagia before the (first) clinical trial?
 - What did you do to cope or deal with your hunger/hyperphagia before the (first) clinical trial?
 - What was the most difficult thing about dealing with your hunger/hyperphagia before the (first) clinical trial?

III. Experiences During and After Clinical Trial

Next, we'd like to hear about your experiences during the clinical trial(s) and how you feel today.

- How has your hunger changed, if at all, since you started the (first) clinical trial of setmelanotide?
 - Do you feel more or less hungry during the day than you used to? What about at night? Please tell me more about that.
 - Does your hunger feel different than it used to? How?
 - Did it take time to notice the change? When did you first notice the change?

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- On that scale of 0-to-10 where 0 is not hungry at all and 10 is the hungriest possible, how would you rate the highest level of hunger you experience now?
 - Do you feel that highest level of hunger more or less of the time now? Please tell me more about that.
 - Are there times you don't feel hungry at all, like a 0 on that 0-to-10 scale?
 - *[If yes]* How much of the time, during a typical day, do you not feel hungry at all?
 - When or under what circumstances do you not feel hungry?
 - *[If no]* On our same 0-to-10 scale where 0 is not hungry at all and 10 is the hungriest possible, what's the lowest level of hunger you experience now?
 - How do you feel now after eating a meal?
 - Do you ever feel full or satisfied?
 - *[If yes]* How often do you feel full or satisfied after eating?
 - Does it take less food for you to feel full or satisfied? Please tell us more about that.
 - How long does this feeling last?
 - *[If no]* On our same 0-to-10 scale where 0 is not hungry at all and 10 is the hungriest possible, how do you typically feel after eating a meal now?
 - Does it take less food for you to get down to that *[0-to-10 answer]* on the hunger scale? Please tell us more about that.
 - How long does this feeling last?
 - How do you feel these changes in your hunger? Are they meaningful or important to you? Why?
 - How have the changes in your hunger affected how much you eat?
 - How have the changes in your hunger affected what you eat?
 - Are there types of foods you eat less often now? Please tell us about that.
 - Do you ever eat things that others would find inedible or distasteful to satisfy your hunger now? Please tell us about that.
 - How would you describe your ability to control how much and what you eat now? Do you feel like you have more control over your eating now? Please tell us more about that.

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- Have you lost weight since you started the (first) clinical trial?
 - *[If yes]* Approximately how much weight have you lost?
 - If you remember, when did you first start to notice you were losing weight?
 - How have the changes in your hunger affected how you feel?
 - Do you feel different physically? How?
 - Do you feel different mentally or emotionally? How?
 - How have the changes in your hunger affected the way you think about and obtain food?
 - Do you spend more or less time thinking about food? Please tell me more about that.
 - Do you spend more or less time getting or looking for food? Please tell me more about that.
 - How have the changes in your hunger affected your life?
 - Have the changes in your hunger affected your mood or emotions? How?
 - Does your hunger ever make you feel anxious or depressed now? Please tell us more about that.
 - Have the changes in your hunger affected your sleep? How?
 - Is it easier to get to sleep? Do you wake up less often during the night? Please tell us more about that.
 - Have the changes in your hunger affected your work/school? How?
 - Is it easier to get things done at work/school? How?
 - How often, if ever, do you have trouble concentrating because you are hungry?
 - How often, if ever, do you need to take breaks to find something to eat?
 - Have the changes in your hunger affected your social life? How?
 - Have the changes in your hunger affected your leisure or recreational activities? How?
 - How often, if ever, do you need to stop what you are doing to find something to eat?
 - Have the changes in your hunger affected your interactions or relationships with your family? How? *[Probe parents, siblings, as needed]*
 - What about interactions and relationships with your friends?
 - What are the most important changes in your life that you associate with the changes in your hunger?

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- I know it's been a while, but how quickly did you start to notice the changes in your hunger?
 - What did you notice first? How did you know there was a change?
 - What did you notice after that? Did the changes become more noticeable, or did your hunger sort of stay the same after that?

IV. Treatment Satisfaction and Overall Impact

- Overall, how satisfied are you with the effect of the study medication (setmelanotide) on your hunger? Not at all satisfied, a little satisfied, or very satisfied? What makes you say you're *[participant's answer]*?
 - *[If not very satisfied]* In what other way would you like a medication to change your hunger? Why is this important to you?
- Thinking about your experiences overall, how has taking the study medication (setmelanotide) changed your life?
 - Do you feel better now? In what ways?
 - Are you more active?
 - Is it easier to make healthy food choices?
 - Has it changed how you feel about the future? How?
 - How do you feel about these changes? Are they important to you? Why?
- Has taking the study medication (setmelanotide) changed the way your BBS is managed? How?
- How would you feel about it if you were told you had to stop taking the study medication (setmelanotide)? Why?

V. Closing

Is there anything else about your experiences or any feedback related to the studies you've been participating in that you would like to share with us?

The sponsor of the study asked us to thank you, on their behalf, for sharing your valuable thoughts and experiences with us. Thank you so much!

CAREGIVER INTERVIEW GUIDE

I. Introduction

[Interviewer introduces herself and notetaker and briefly reiterates the purpose and format of the interview.]

- First, thank you again for participating in an interview with us.
- During the interview today, we will ask to describe what you've observed in relation to your son's/daughter's hunger before starting the (first) clinical trial and any changes you have noticed since he/she started taking setmelanotide.
- The information gathered during these interviews will supplement the clinical trial results and contribute to knowledge about hyperphagia (extreme, unrelenting hunger) in the context of BBS.
- As a reminder, your participation is completely voluntary, and you may end the discussion at any time. Of course, you should also feel free to ask us any questions you have or request a break in the interview at any time.
- We expect today's interview to last 50 to 60 minutes. We have a series of topics we wish to cover with you but also intend for these interviews to be conversational. As such, we encourage you to describe observations related to your son's/daughter's hunger and the study medication as they come to mind.
- With your permission, we will audio record today's interview to make sure we do not miss any important information and to help us create a transcript of the interview. All information you provide to us will be kept confidential. While they will be provided to the study sponsor, all names and any other identifying information will first be removed from the transcripts of the interviews.
- Please keep in mind that there are no wrong answers to our questions. We appreciate the opportunity to learn from your experiences and are truly grateful for your time.
- Before we begin, do you have any questions?
- Okay, I'm going to go ahead and turn on my recorder.

START RECORDING

I am now audio recording. Do I have your permission to continue with the audio-recorded interview?

- Yes → **CONTINUE**
- No → **STOP INTERVIEW**

II. Experiences Before Clinical Trial

We'd first like to hear about your observations before your son/daughter started the (first) clinical trial of setmelanotide in which he/she participated.

- About how long ago did your son/daughter start that (first) trial?
- As best you can, please tell us about your son's/daughter's hunger or appetite before that first trial.
 - How often did he/she seem to feel hungry during the day?
 - How often did your he/she wake up feeling hungry during the night?
- What did you observe when he/she was the most hungry?
 - How did he/she behave?
 - What sorts of things did he/she say?
 - What sorts of things did he/she do?
 - When during the day did he/she seem to feel the most hungry?
 - How much of the day did he/she seem to feel this way?
- How did your son/daughter try to obtain food when he/she was very hungry and food was not easily accessible (i.e., it wasn't time for a normal meal or snack)?
 - What else did he/she do to obtain food? *[Try to obtain as much information about food-seeking behaviors before asking more specific probes below.]*
 - Did he/she try to bargain with you for more food?
 - Did he/she sneak food during the day? What about during the night?
 - Did he/she try to get other people to give him/her food?
 - Did he/she ever take food off others' plates? Out of the trash?
 - Please tell us about an occasion when your son/daughter was especially clever or persistent in order to obtain food.
- How did your son/daughter react if he/she was very hungry and unable to obtain food?
 - Did he/she get upset? Cry? Throw temper tantrums?

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- How difficult was it for you to redirect him/her to thinking about something other than food?
 - Were there times your son/daughter didn't seem to feel hungry at all?
 - *[If yes]* How much of the time, during a typical day, did he/she not seem hungry at all?
 - How could you tell he/she wasn't hungry?
 - Under what circumstances would he/she not feel hungry?
 - How long would that last?
 - *[If no]* How would you describe the lowest level of hunger your son/daughter experienced before the (first) clinical trial?
 - How could you tell he/she wasn't very hungry?
 - Under what circumstances would you notice this lowest level of hunger?
 - How long would that last?
 - Before the (first) clinical trial, how do you think your son/daughter felt after eating a meal?
 - Did he/she ever seem to feel full or satisfied?
 - *[If yes]* How could you tell he/she felt full or satisfied?
 - How often did he/she seem to feel full or satisfied after eating?
 - How long do you think this feeling lasted?
 - How did your son's/daughter's hunger affect what and how much he/she ate?
 - Did your son/daughter ask for specific types of foods before the (first) clinical trial?
 - *[If yes]* What kind of foods did he/she ask for most frequently?
 - Did your son/daughter ever eat things that others would find inedible or distasteful to satisfy his/her hunger? Please tell us about that. *[If needed: for example, condiments, food that others have left on their plates, food from the trash]*
 - How often did he/she typically eat throughout the day?
 - To what extent did he/she have control over how much he/she ate before the (first) clinical trial?
 - How did your son's/daughter's hyperphagia affect his/her life?
 - Did your son's/daughter's hyperphagia affect his/her mood or emotions? How?

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- Do you think your son's/daughter's hyperphagia ever made him/her feel anxious or depressed? Please tell us more about that.
 - Did your son's/daughter's hyperphagia affect his/her sleep? How?
 - To the best of your knowledge, did your son's/daughter's hyperphagia affect him/her at work/school? How?
 - Do you think he/she had difficulty getting things done because he/she was hungry?
 - Did he/she have trouble concentrating when he/she was hungry?
 - Did he/she need to take breaks to find something to eat?
 - Did your son's/daughter's hyperphagia affect his/her social life? How?
 - Did your son's/daughter's hyperphagia affect his/her leisure or recreational activities? How?
 - Did your son's/daughter's hyperphagia affect his/her interactions or relationships within your family? How?
 - Did it affect his/her interactions or relationship with you? How?
 - What about interactions or relationships with his/her siblings?
 - What about interactions or relationships with his/her friends?
 - How did your son's/daughter's hyperphagia affect *your* life?
 - Did your son's/daughter's hyperphagia affect your mood or emotions? How?
 - Did your son's/daughter's hyperphagia affect your sleep? How?
 - Did your son's/daughter's hyperphagia affect your productivity? How?
 - Did you miss time at work? How often?
 - Did you have difficulty getting things done? Why?
 - Did your son's/daughter's hyperphagia affect your social life? How?
 - Did your son's/daughter's hyperphagia affect your leisure or recreational activities? How?
 - Did your son's/daughter's hyperphagia affect your relationships with other family or friends? How?
 - What bothered you most about your son's/daughter's hyperphagia before starting the (first) clinical trial?
 - What types of strategies did you try to cope or deal with your son's/daughter's hyperphagia before starting the (first) clinical trial?
 - What was the biggest challenge you faced in dealing with your son's/daughter's hyperphagia before starting the (first) clinical trial?

III. Experiences During and After Clinical Trial

Next, we'd like to hear about your observations since your son/daughter started treatment with setmelanotide.

- How has your son's/daughter's hunger changed, if at all, since he/she started the (first) clinical trial of setmelanotide?
 - Does he/she seem to feel more or less hungry during the day? What about at night? Please tell me more about that.
 - Does he/she seem to feel really hungry more or less of the time? Please tell me more about that.
 - Are there times he/she doesn't seem to feel hungry at all?
 - *[If yes]* How much of the time, during a typical day, does he/she not seem hungry at all?
 - How can you tell when he/she isn't hungry? What does he/she say or do?
 - Under what circumstances does he/she not feel hungry?
 - How long does that last?
 - *[If no]* How would you describe the lowest level of hunger your son/daughter experiences now?
 - How can you tell when he/she isn't very hungry? What does he/she say or do?
 - Under what circumstances do you notice this lowest level of hunger?
 - How long does that last?
- How do you think your son/daughter feels now after eating a meal?
 - Does he/she ever feel full or satisfied?
 - *[If yes]* How can you tell he/she feels full or satisfied?
 - How often does he/she seem to feel full or satisfied after eating?
 - Does it take less food for him/her to feel full or satisfied? Please tell us more about that.
 - How long do you think this feeling typically lasts?
- How meaningful or important do you think these changes in your son's/daughter's hunger are to him/her? Why?
- How meaningful or important are these changes in your son's/daughter's hunger to you? Why?

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- How have the changes in your son's/daughter's hunger affected how much he/she eats?
 - Have you changed how often or how much food you provide? How?
 - Do you allow him/her more freedom when it comes to choosing and accessing food? Please tell us more about that.
 - To what extent can he/she control how much he/she eats now? Please tell us more about that.
 - How have the changes in your son's/daughter's hunger affected what he/she eats?
 - Have you changed what you provide in terms of meals and snacks? How?
 - Does he/she ask for different types of foods now? Please tell us more about that.
 - Does he/she ever eat things that others would find inedible or distasteful to satisfy your son's/daughter's hunger now? *[If yes]* Please tell us about that.
 - Did he/she lose weight since he/she started the (first) clinical trial?
 - *[If yes]* Approximately how much weight has he/she lost?
 - If you remember, when did you first start to notice he/she was losing weight?
 - Has he/she gotten taller since starting the (first) clinical trial? How much has he/she grown?
 - How have the changes in your son's/daughter's hunger affected the way he/she behaves?
 - Do you think he/she spends more or less time thinking about food?
 - *[If yes]* How can you tell he/she is thinking about food less often?
 - Does he/she spend more or less time talking about food? Please tell me more about that.
 - Does he/she spend more or less time working to obtain food? Please tell me more about that.
 - How does your son/daughter react now if he/she is denied food?
 - How have the changes in your son's/daughter's hunger affected his/her life?
 - Have the changes in your son's/daughter's hunger affected his/her mood or emotions? How?
 - Do you think your son/daughter feels more or less anxious or depressed now? Please tell us more about that.

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- Have the changes in your son's/daughter's hunger affected his/her sleep? How?
 - Do you think it's easier for him/her to get things done at work/school? What makes it easier?
 - Have the changes in your son's/daughter's hunger affected his/her social life? How?
 - Have the changes in your son's/daughter's hunger affected his/her leisure or recreational activities? How?
 - Have the changes in your son's/daughter's hunger affected his/her interactions or relationships within your family (parents, siblings)? How?
 - Has his/her interactions or relationship with you changed? How?
 - What about interactions or relationships with his/her siblings?
 - What about interactions or relationships with his/her friends?
 - How have the changes in your son's/daughter's hunger affected *your* life?
 - Have the changes in your son's/daughter's hunger affected your mood or emotions?
 - Have the changes in your son's/daughter's hunger affected your sleep? How?
 - Have the changes in your son's/daughter's hunger affected your productivity? How?
 - Have the changes in your son's/daughter's hunger affected your social life? How?
 - Have the changes in your son's/daughter's hunger affected your leisure or recreational activities? How?
 - Have the changes in your son's/daughter's hunger affected your relationships with other family or friends? How?
 - What are the most important changes in your son's/daughter's life that you associate with the changes in his/her hunger?
 - What are the most important changes in your life that you associate with the changes in your son's/daughter's hunger?
 - I know it's been a while, but how quickly did you start to notice the changes in your son's/daughter's hunger?
 - What did you notice first? How did you know there was a change?
 - What did you notice after that? Did the changes become more noticeable, or did your son's/daughter's hunger sort of stay the same after that?

IV. Treatment Satisfaction and Overall Impact

- Overall, how satisfied are you with the effect of the study medication (setmelanotide) on your son's/daughter's hunger? Not at all satisfied, a little satisfied, or very satisfied? What makes you say you're *[participant's answer]*?
 - *[If not very satisfied]* In what other way would you like a medication to change your son's/daughter's hunger? Why is this important to you?
- Thinking about your son's/daughter's experiences overall, how has taking the study medication (setmelanotide) changed his/her life?
 - Does he/she seem to feel better now? In what ways?
 - Is he/she more active?
 - Is it easier to follow his/her diet?
 - How do you feel about these changes? How important are they to you? Why?
- How has your son's/daughter's treatment with setmelanotide changed your life?
 - Do you feel better now? In what ways?
 - Has it changed how you feel about the future? How?
 - How important are these changes to you? Why?
- Has treatment with setmelanotide changed the way your son's/daughter's BBS is managed? How?
- How would you feel about it if you were told that your son/daughter had to stop taking setmelanotide? Why?

V. Closing

Is there anything else about your son's/daughter's experiences or any feedback related to the studies he/she has been participating in that you would like to share with us?

The sponsor of the study asked us to thank you, on their behalf, for sharing your valuable thoughts and experiences with us. Thank you so much!

MODIFIED (FINAL) CAREGIVER INTERVIEW GUIDE

I. Introduction

[Interviewer introduces herself and notetaker and briefly reiterates the purpose and format of the interview.]

- First, thank you again for participating in an interview with us.
- During the interview today, we will ask to describe what you've observed in relation to your son's/daughter's hunger before starting the (first) clinical trial and any changes you have noticed since he/she started taking setmelanotide.
- The information gathered during these interviews will supplement the clinical trial results and contribute to knowledge about hyperphagia (extreme, unrelenting hunger) in the context of BBS.
- As a reminder, your participation is completely voluntary, and you may end the discussion at any time. Of course, you should also feel free to ask us any questions you have or request a break in the interview at any time.
- We expect today's interview to last 50 to 60 minutes. We have a series of topics we wish to cover with you but also intend for these interviews to be conversational. As such, we encourage you to describe observations related to your son's/daughter's hunger and the study medication as they come to mind.
- With your permission, we will audio record today's interview to make sure we do not miss any important information and to help us create a transcript of the interview. All information you provide to us will be kept confidential. While they will be provided to the study sponsor, all names and any other identifying information will first be removed from the transcripts of the interviews.
- Please keep in mind that there are no wrong answers to our questions. We appreciate the opportunity to learn from your experiences and are truly grateful for your time.
- Before we begin, do you have any questions?
- Okay, I'm going to go ahead and turn on my recorder.

START RECORDING

I am now audio recording. Do I have your permission to continue with the audio-recorded interview?

- Yes → **CONTINUE**
- No → **STOP INTERVIEW**

II. Experiences Before Clinical Trial

We'd first like to hear about your observations before your son/daughter started the (first) clinical trial of setmelanotide in which he/she participated.

- About how long ago did your son/daughter start that (first) trial?
- As best you can, please tell us about your son's/daughter's hunger or appetite before that first trial.
- Please tell me about a typical day with your son/daughter in relation to his/her hunger.
 - What did you notice about your son's/daughter's hunger in terms of what they were saying and doing throughout the day?
 - How often did he/she wake up feeling hungry during the night?
 - Did you observe variations in the severity/intensity of your son/daughters' hunger throughout the day/night (for example, were there times when he/she seemed to be more or less hungry)?
- How did your son/daughter try to obtain food when he/she was very hungry and food was not easily accessible (i.e., it wasn't time for a normal meal or snack)?
 - What else did he/she do to obtain food? *[Try to obtain as much information about food-seeking behaviors before asking more specific probes below.]*
 - Did he/she try to bargain with you for more food?
 - Did he/she sneak food during the day? What about during the night?
 - Did he/she try to get other people to give him/her food?
 - Did he/she ever take food off others' plates? Out of the trash?
- How did your son/daughter react if he/she was very hungry and unable to obtain food?
 - Did he/she get upset? Cry? Throw temper tantrums?
 - How difficult was it for you to redirect him/her to thinking about something other than food?

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- Were there times your son/daughter didn't seem to feel hungry at all?
 - **[If yes]** How much of the time, during a typical day, did he/she not seem hungry at all?
 - Under what circumstances would he/she not feel hungry?
 - **[If no]** How would you describe the lowest level of hunger your son/daughter experienced before the (first) clinical trial?
 - Under what circumstances would you notice this lowest level of hunger?
 - Before the (first) clinical trial, how do you think your son/daughter felt after eating a meal?
 - Did he/she ever seem to feel full or satisfied?
 - [If yes]** How could you tell he/she felt full or satisfied?
 - Did your son/daughter ask for specific types of foods before the (first) clinical trial?
 - **[If yes]** What kind of foods did he/she ask for most frequently?
 - Did your son/daughter ever eat things that others would find inedible or distasteful to satisfy his/her hunger? Please tell us about that. **[If needed: for example, condiments, food that others have left on their plates, food from the trash]**
 - How often did he/she typically eat throughout the day?
 - To what extent did he/she have control over how much he/she ate before the (first) clinical trial?
 - Before starting the (first) clinical trial, how did your son's/daughter's hyperphagia affect his/her life?
 - Did your son's/daughter's hyperphagia affect his/her mood or emotions? How?
 - Do you think your son's/daughter's hyperphagia ever made him/her feel anxious or depressed? Please tell us more about that.
 - Did your son's/daughter's hyperphagia affect his/her sleep? How?
 - To the best of your knowledge, did your son's/daughter's hyperphagia affect him/her at work/school? How?
 - Do you think he/she had difficulty getting things done because he/she was hungry?
 - Did he/she have trouble concentrating when he/she was hungry?
 - Did your son's/daughter's hyperphagia affect his/her social life? How?

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- Did your son's/daughter's hyperphagia affect his/her interactions or relationships with you/ your family? How?
 - How did your son's/daughter's hyperphagia affect **your** life?
 - Did your son's/daughter's hyperphagia affect your mood or emotions? How?
 - Did your son's/daughter's hyperphagia affect your sleep? How?
 - Did your son's/daughter's hyperphagia affect your productivity? How?
 - Did you miss time at work? How often?
 - Did you have difficulty getting things done? Why?
 - Did your son's/daughter's hyperphagia affect your social life? How?
 - Did your son's/daughter's hyperphagia affect your relationships with other family or friends? How?
 - What bothered you most about your son's/daughter's hyperphagia before starting the (first) clinical trial?
 - What types of strategies did you try to cope or deal with your son's/daughter's hyperphagia before starting the (first) clinical trial?

III. Experiences During and After Clinical Trial

Next, we'd like to hear about your observations since your son/daughter started treatment with setmelanotide.

- How has your son's/daughter's hunger changed, if at all, since he/she started the (first) clinical trial of setmelanotide?
 - Does he/she seem to feel more or less hungry during the day? What about at night? Please tell me more about that.
 - Does he/she seem to feel *really* hungry more or less of the time? Please tell me more about that.
 - Are there times he/she doesn't seem to feel hungry at all?
 - **[If yes]** How much of the time, during a typical day, does he/she not seem hungry at all?
 - How can you tell when he/she isn't hungry?
 - Under what circumstances does he/she not feel hungry?
 - **[If no]** How would you describe the lowest level of hunger your son/daughter experiences now?
 - How can you tell when he/she isn't very hungry?
 - Under what circumstances do you notice this lowest level of hunger?

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- How do you think your son/daughter feels now after eating a meal?
 - Does he/she ever feel full or satisfied?
 - *[If yes]* How can you tell he/she feels full or satisfied?
 - How often does he/she seem to feel full or satisfied after eating?
 - Does it take less food for him/her to feel full or satisfied? Please tell us more about that.
 - How meaningful or important do you think these changes in your son's/daughter's hunger are to him/her? Why?
 - How meaningful or important are these changes in your son's/daughter's hunger to **you**? Why?
 - How have the changes in your son's/daughter's hunger affected **how much** he/she eats?
 - Do you allow him/her more freedom when it comes to choosing and accessing food? Please tell us more about that.
 - To what extent can he/she control how much he/she eats now? Please tell us more about that.
 - How have the changes in your son's/daughter's hunger affected **what** he/she eats?
 - Have you changed what you provide in terms of meals and snacks? How?
 - Does he/she ask for different types of foods now? Please tell us more about that.
 - *[Only probe if a problem before the trial]* Does he/she ever eat things that others would find inedible or distasteful to satisfy his/her hunger now? *[If yes]* Please tell us about that.
 - Did he/she lose weight since he/she started the (first) clinical trial?
 - *[If yes]* Approximately how much weight has he/she lost?
 - If you remember, when did you first start to notice he/she was losing weight?
 - Has he/she gotten taller since starting the (first) clinical trial? How much has he/she grown?
 - How have the changes in your son's/daughter's hunger affected the way he/she behaves?
 - Do you think he/she spends more or less time thinking about food?
 - *[If yes]* How can you tell he/she is thinking about food less often?

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- Does he/she spend more or less time working to obtain food? Please tell me more about that.
 - How does your son/daughter react now if he/she is denied food?
 - How have the changes in your son's/daughter's hunger affected his/her life?
 - Have the changes in your son's/daughter's hunger affected his/her mood or emotions? How?
 - Do you think your son/daughter feels more or less anxious or depressed now? Please tell us more about that.
 - Have the changes in your son's/daughter's hunger affected his/her sleep? How?
 - Do you think it's easier for him/her to get things done at work/school? What makes it easier?
 - Have the changes in your son's/daughter's hunger affected his/her social life? How?
 - Have the changes in your son's/daughter's hunger affected his/her interactions or relationships with you/your family (parents, siblings)? How?
 - How have the changes in your son's/daughter's hunger affected *your* life?
 - Have the changes in your son's/daughter's hunger affected your mood or emotions?
 - Have the changes in your son's/daughter's hunger affected your sleep? How?
 - Have the changes in your son's/daughter's hunger affected your productivity? How?
 - Have the changes in your son's/daughter's hunger affected your social life? How?
 - Have the changes in your son's/daughter's hunger affected your relationships with other family or friends? How?
 - What are the most important changes in your son's/daughter's life that you associate with the changes in his/her hunger?
 - What are the most important changes in your life that you associate with the changes in your son's/daughter's hunger?
 - I know it's been a while, but how quickly did you start to notice the changes in your son's/daughter's hunger?
 - What did you notice first? How did you know there was a change?

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- What did you notice after that? Did the changes become more noticeable, or did your son's/daughter's hunger sort of stay the same after that?

IV. Treatment Satisfaction and Overall Impact

- Overall, how satisfied are you with the effect of the study medication (setmelanotide) on your son's/daughter's hunger? Not at all satisfied, a little satisfied, or very satisfied? What makes you say you're *[participant's answer]*?
- *[If not very satisfied]* In what other way would you like a medication to change your son's/daughter's hunger? Why is this important to you?
- Has treatment with setmelanotide changed the way your son's/daughter's BBS is managed? How?
- How would you feel about it if you were told that your son/daughter had to stop taking setmelanotide? Why?

V. Closing

Is there anything else about your son's/daughter's experiences or any feedback related to the studies he/she has been participating in that you would like to share with us?

The sponsor of the study asked us to thank you, on their behalf, for sharing your valuable thoughts and experiences with us. Thank you so much!