



VOLUME 4 – ISSUE 10: TRANSCRIPT

Featured Cases: Behavioral Treatment to Improve Dietary Adherence and Weight Gain in Children with Cystic Fibrosis

Our guest is Dr. Lori Stark, from University of Cincinnati College of Medicine.

After participating in this activity, the participant will demonstrate the ability to:

- Describe how to use “shaping” to encourage a child to eat a nonpreferred food
- Explain the role of “attention” in maintaining behaviors incompatible with eating
- Discuss the use of caloric goal-setting and dietary tracking applications to monitor treatment progress

This discussion, offered as a downloadable audio file and companion transcript, covers the important issues related to behavioral treatment to improve dietary adherence and weight gain in children with cystic fibrosis in the format of case-study scenarios for the clinical practice. This program is a follow up to Volume 4, Issue 9 *eCysticFibrosis Review Newsletter* – Behavioral treatment to improve dietary adherence and weight gain in children with cystic fibrosis.

The Johns Hopkins University School of Medicine takes responsibility for the content, quality, and scientific integrity of this CME activity.

MEET THE AUTHOR



Lori Stark, PhD, ABPP

Professor of Pediatrics
Director, Division of Behavioral
Medicine and Clinical Psychology
Cincinnati Children’s Hospital
Medical Center
University of Cincinnati College of
Medicine
Cincinnati, Ohio

Guest Faculty Disclosure

Dr. Stark has indicated that she does not have any relevant financial interests or relationships with any commercial entities.

Unlabeled/Unapproved Uses

Dr. Stark indicated that her discussion will not refer to unlabeled or unapproved uses of drugs or products.

Release Date

February 11, 2014

Expiration Date

February 10, 2016

Next Month’s Topic

What does CFTR tell us about Lung Disease?

PROGRAM DIRECTORS

Michael P. Boyle, MD, FCCP
Associate Professor of Medicine
Director, Adult Cystic Fibrosis
Program
The Johns Hopkins University
Baltimore, MD

Peter J. Mogayzel, Jr., MD, PhD
Professor of Pediatrics
Director, Cystic Fibrosis Center
The Johns Hopkins University
Baltimore, MD

Donna W. Peeler, RN, BSN
Clinical Coordinator
Cystic Fibrosis Center
The Johns Hopkins University
Baltimore, MD

Meghan Ramsay, MS, CRNP
Clinical Coordinator
Cystic Fibrosis Center
The Johns Hopkins University
Baltimore, MD

ACCREDITATION STATEMENTS

This activity has been planned and implemented in accordance with the Essential Areas and Policies of the Accreditation Council for Continuing Medical Education through the joint sponsorship of the Johns Hopkins University School of Medicine and the Institute for Johns Hopkins Nursing. The Johns Hopkins University School of Medicine is accredited by the ACCME to provide continuing medical education for physicians.

The Institute for Johns Hopkins Nursing is accredited as a provider of continuing nursing education by the American Nurses Credentialing Center's Commission on Accreditation.

The Institute for Johns Hopkins Nursing and the American Nurses Credentialing Center do not endorse the use of any commercial products discussed or displayed in conjunction with this educational activity.

CREDIT DESIGNATIONS**Physicians**

Podcast: The Johns Hopkins University School of Medicine designates this enduring material for a maximum of 0.5 *AMA PRA Category 1 Credit(s)*[™]. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

Nurses

Podcast: This 0.5 contact hour Educational Activity is provided by the Institute for Johns Hopkins Nursing.

Respiratory Therapists

For United States: [Visit this page](#) to confirm that your state will accept the CE Credits gained through this program.

For Canada: [Visit this page](#) to confirm that your province will accept the CE Credits gained through this program.

LAUNCH DATE

This program launched on February 28, 2013, and is published monthly; activities expire two years from the date of publication.

INTENDED AUDIENCE

This activity has been developed for pulmonologists, pediatric pulmonologists, gastroenterologists, pediatricians, infectious disease specialists, respiratory therapists, dietitians, nutritionists, nurses, and physical therapists.

STATEMENT OF NEED

Based on a review of the current literature, including national and regional measures, detailed conversations with expert educators at Johns Hopkins, and a survey of potential program participants, this program will address the following core patient care gaps:

Disease-Modifying Therapies

- Clinicians may be unfamiliar with recently introduced disease-modifying therapies and how they are altering the therapeutic landscape for patients with cystic fibrosis.
- Clinicians may be uncertain how to integrate genotyping into therapeutic decisions and how to communicate with patients and families about the relationship between genotype and therapy

Nutrition

- Many clinicians lack strategies to persuade patients to adhere to CF nutritional requirements, resulting in low body weight and nutritional failure in patients with cystic fibrosis.
- Many clinicians remain uncertain how to optimize pancreatic function in patients with cystic fibrosis.

Treating CF Patients with Inhaled Antibiotics

- Clinicians lack knowledge about the use of existing and emerging inhaled ABX to treat chronic pulmonary infections.
- Clinicians need more information to make informed decisions about the use of inhaled ABX in combination.
- Clinicians lack information about best practices for scheduling ABX therapy to suppress chronic airway infections.
- Common clinician assumptions about treating pulmonary exacerbations lack supporting evidence.
- CF clinicians are not aware of and/or are not actively advocating inhaled ABX patient-adherence strategies.

SUCCESSFUL COMPLETION

To take the post-test for eCysticFibrosis Review you will need to visit the [Johns Hopkins University School of Medicine's CME website](#) and the [Institute for Johns Hopkins Nursing](#). If you have already registered for other Hopkins CE programs at these sites, simply enter the requested information when prompted. Otherwise, complete the registration form to begin the testing process. A passing grade of 70% or higher on the post-test/evaluation is required to receive CE credit.

There are no fees or prerequisites for this activity.

Estimated time to complete activity: 30 minutes.

DISCLOSURE POLICY

As a provider approved by the Accreditation Council for Continuing Medical Education (ACCME), it is the policy of the Johns Hopkins University School of Medicine Office of Continuing Medical Education (OCME) to require signed disclosure of the existence of financial relationships with industry from any individual in a position to control the content of a CME activity sponsored by OCME. Members of the Planning Committee are required to disclose all relationships regardless of their relevance to the content of the activity. Faculty are required to disclose only those relationships that are relevant to their specific presentation. The following relationships have been reported for this activity:

- **Michael P. Boyle, MD, FCCPD** discloses that he has received grant/research support from Vertex Pharmaceuticals, Inc., and is a consultant to Gilead Sciences, Inc., Novartis, Pharmaxis, Inc., Genentech, Inc., Savara, and Vertex Pharmaceuticals, Inc.

No other planners have indicated that they have any financial interests or relationships with a commercial entity.

[Guest Author Disclosures](#)**STATEMENT OF RESPONSIBILITY**

The Johns Hopkins University School of Medicine takes responsibility for the content, quality and scientific integrity of this CME activity.

CONFIDENTIALITY DISCLAIMER FOR CME CONFERENCE ATTENDEES

I certify that I am attending a Johns Hopkins University School of Medicine CME activity for accredited training and/or educational purposes.

I understand that while I am attending in this capacity, I may be exposed to "protected health information," as that term is defined and used in Hopkins policies and in the federal HIPAA privacy regulations (the "Privacy Regulations"). Protected health information is information about a person's health or treatment that identifies the person.

I pledge and agree to use and disclose any of this protected health information only for the training and/or educational purposes of my visit and to keep the information confidential.

I understand that I may direct to the Johns Hopkins Privacy Officer any questions I have about my obligations under this Confidentiality Pledge or under any of the Hopkins policies and procedures and applicable laws and regulations related to confidentiality. The contact information is: Johns Hopkins Privacy Officer, telephone: 410-735-6509, e-mail: HIPAA@jhmi.edu.

"The Office of Continuing Medical Education at the Johns Hopkins University School of Medicine, as provider of this activity, has relayed information with the CME attendees/participants and certifies that the visitor is attending for training, education and/or observation purposes only."

For CME Questions, please contact the CME Office at (410) 955-2959 or e-mail cmenet@jhmi.edu. For CME Certificates, please call (410) 502-9634.

Johns Hopkins University School of Medicine
Office of Continuing Medical Education
Turner 20/720 Rutland Avenue
Baltimore, Maryland 21205-2195

Reviewed & Approved by:
General Counsel, Johns Hopkins Medicine (4/1/03)
Updated 4/09

INTERNET CME POLICY

The Office of Continuing Medical Education (CME) at the Johns Hopkins University School of Medicine is committed to protecting the privacy of its members and customers. The Johns Hopkins University SOM CME maintains its Internet site as an information resource and service for physicians, other health professionals and the public.

Continuing Medical Education at the Johns Hopkins University School of Medicine will keep your personal and credit information confidential when you participate in a CME Internet-based program. Your information will never be given to anyone outside the Johns Hopkins University School of Medicine's CME program. CME collects only the information necessary to provide you with the services that you request.

DISCLAIMER STATEMENT

The opinions and recommendations expressed by faculty and other experts whose input is included in this program are their own. This enduring material is produced for educational purposes only. Use of Johns Hopkins University School of Medicine name implies review of educational format design and approach. Please review the complete prescribing information of specific drugs or combination of drugs, including indications, contraindications, warnings and adverse effects before administering pharmacologic therapy to patients.

HARDWARE & SOFTWARE REQUIREMENTS

PC: Internet Explorer (v6 or greater), or Firefox
MAC: Safari

MR. BOB BUSKER: Welcome to this eCysticFibrosis Review podcast.

eCysticFibrosis Review is presented by The Johns Hopkins University School of Medicine and The Institute for Johns Hopkins Nursing. This program is supported by educational grants from Aptalis Pharma, Inc; Gilead Sciences Inc., and Vertex Pharmaceuticals.

Today's program is a companion piece to our eCysticFibrosis Review newsletter issue: *Behavioral treatment to improve dietary adherence and weight gain in children with cystic fibrosis*.

Our guest today is that issue's author, Dr. Lori Stark, from University of Cincinnati College of Medicine.

This activity has been developed for pulmonologists, pediatric pulmonologists, gastroenterologists, pediatricians, infectious disease specialists, respiratory therapists, dietitians, nutritionists, pharmacists, nurses and nurse practitioners, physical therapists, and others involved in the care of patients with cystic fibrosis. There are no fees or prerequisites for this activity.

The Accreditation and Credit Designation Statements can be found at the end of this podcast. For additional information about accreditation, Hopkins policies and expiration dates, and to take the posttest to receive credit online, please go to our website newsletter archive: www.eCysticFibrosisReview.org, and click the Volume 4, Issue 10 podcast link.

Learning objectives for this audio program are that after participating in this activity, participant will demonstrate the ability to:

- Describe how to use "shaping" to encourage a child to eat a nonpreferred food
- Explain the role of "attention" in maintaining behaviors incompatible with eating
- Discuss the use of caloric goal-setting and dietary tracking applications to monitor treatment progress

I'm Bob Busker, Managing Editor of eCysticFibrosis Review. On the line we have with us Dr. Lori Stark, Professor of Pediatrics and Director of the Division of Behavioral Medicine and Clinical Psychology at Cincinnati Children's Hospital Medical Center and the University of Cincinnati College of Medicine.

Dr. Stark has indicated that she does not have any relevant financial interests or relationships with any commercial entities, and has also indicated that her discussion today will not refer to unlabeled or unapproved uses of drugs or products.

Dr. Stark, welcome to this eCysticFibrosis Review Podcast.

DR. STARK: Thank you, it's nice to be here.

MR. BUSKER: The behavioral, nutritional, and educational interventions you discussed in your newsletter issue lead me to start out by asking you a very general question, and that's why it is so difficult to achieve the CF dietary recommendations with children?

DR. STARK: Well, Bob, I'm glad you asked that, because when I began working with families of children with CF 24 years ago now, that was a surprise to us. We knew that they had trouble gaining weight and meeting the CF dietary recommendations, and so we initially designed a treatment that if you think about it would be the reverse of obesity treatment. We'd have them increase their calories, do it a little at a time, and when we met with the families of our first treatment group they described mealtimes as a battleground.

They told us their kids took a long time to eat, that they often dawdled or talked a lot instead of eating, that they were very picky about what they ate. The parents also described that they were at their wits' end about how to encourage their children. They knew it was important that they gain weight. In fact, they described that their whole worth as a parent sometimes depended on whether the child had gained weight when that child stepped on the scale at clinic. So they said that they would make a second meal, they would try to encourage their child by eating by coaxing them, even loading their fork, and sometimes resorting to feeding them.

MR. BUSKER: You and your group researched an intervention to address this problem. You described that in your newsletter issue, and please review that for us briefly.

DR. STARK: Sure, our intervention used child behavior management training to focus on changing

these mealtime dynamics between parents and children with cystic fibrosis that I just described. So after that first treatment group, one of the things we wanted to understand is how widespread these problems were at mealtimes for families with children with CF, so we did an observational study where we filmed families who had children with CF and families with children who did not have CF during three dinner meals, and we coded that interaction.

These observational studies indicated that most of the families of a child with CF were dealing with these types of behavior problems.

MR. BUSKER: In these recordings of family mealtimes — children with CF and children without — what did you find?

DR. STARK: On the positive side, we found that children with CF ate as much as children who did not have CF. So while parents of the children with CF felt their child hardly ate anything, we found that was inaccurate; they were eating as much as children without CF. The problem is, they are not meeting the CF dietary recommendations of 120% to 150% of the recommended daily intake for energy each day.

Another surprising aspect that we found was, instead of these mealtime behaviors being abnormal or completely different from our families of children without CF, they were similar but they were occurring at a higher rate. For example, we found that children both with and without CF in the second half of the meal, their appetite decreased, so they took fewer bites, they refused food more often, they left the table and they didn't comply with parents' instructions to eat as much as in the first half of the meal.

The difference was the children with CF did this at about twice the frequency than children without. We also found that as the children were showing less interest in food, parents upped their efforts to get their children to eat. Again, parents of children with CF and parents of children without used similar behaviors, except the parents of children with CF used them twice as much.

These behaviors included coaxing, saying things like, ooh, daddy likes this chicken, you know, you should try it. Loading their child's fork, moving the plate closer to the child, and even as I mentioned before, feeding their child. One of the things that these parent behaviors have in common is, their attention. This is

the parent giving that child undivided attention and it's happening when the child is engaging in behaviors the parent doesn't particularly want to see — not eating.

These parent responses are not effective for any child, but they're especially not effective for children with CF who have to eat more. We realized that trying to meet the CF dietary recommendations is hard work.

MR. BUSKER: So you're talking about child behavioral management. Give us a working definition, if you would, please.

DR. STARK: According to behavioral principles, a behavior will increase or occur more if it's followed by something desirable, and a behavior will decrease or occur less if it's followed by something undesirable.

MR. BUSKER: Okay, that's simple and straightforward. Apply it to a mealtime situation.

DR. STARK: If we look at this principle in the mealtime interaction, parents are giving their attention, which is highly desirable for any child. That's why when you're on the phone, your kids want your attention, because they don't have it. Kids will do almost anything to get parental attention. In these mealtimes parents are giving their attention to behaviors they don't like, like dawdling, chewing slowly, and talking a lot, so they are inadvertently rewarding these behaviors, the very behaviors the don't want to see.

This happens because these behaviors are very annoying. These are not what you want. Anything that annoys us as human beings, we pay attention to and try to get it to stop. And also sometimes parents are afraid when kids are eating well that if they draw attention to it they'll stop. So they tend to ignore the behaviors they like, which is just the opposite of what we want.

We believe that because children have to eat more than children without CF, this often means going beyond that feeling of satiety and it's extra work. To get your child to eat more, we think we have to equip parents of children with CF with extra skills to overcome these behaviors.

In behavioral treatment we reverse this interaction pattern. We teach parents to use their attention to their advantage and to maximum effectiveness. We

take advantage of the fact that children with CF do eat and typically eat well at the beginning of the meal and have parents capitalize on that and build momentum by praising the eating behavior, especially anything they find that's desirable or a weakness for their child.

For example, if a child is usually sort of slow to come to the table or start eating, they might praise them right away, oh, I like the way you're sitting at the table, you got started right away. Children who are slow eaters, you can even say nice job taking one bite after another.

You can even integrate these praise statements into regular dinnertime conversation. So you can make sharing your day contingent upon your child eating. Saying things like, well, since you're eating your dinner so well, let me tell you about what happened to me today.

MR. BUSKER: What about the other side of that — withholding attention?

DR. STARK: The hardest part about the behavioral intervention is teaching parents to withhold their attention for behaviors incompatible with eating, such as the child is talking a lot and not taking bites or complaining about a food, or if a child sometimes is just sitting at the dinner table doing nothing. The typical parent response to these types of behaviors is to issue a command, something like, okay, stop just sitting there and start eating. It's very hard for parents to say nothing because these behaviors are annoying and because parents often feel uncomfortable ignoring them.

Sometimes they can feel it's rude, especially if the child's talking for a long time, to just turn away, it feels like oh, that's rude, and it feels more comfortable to say stop talking and eat. But if they do that, that's attention. So we teach the parents to just turn away, wait for the child to take a bite, and then praise that behavior, and then listen to what the child is saying. That's the tricky part for parents to learn.

MR. BUSKER: Very understandable. Talk to us about how goal setting fits into the picture.

DR. STARK: While praising and describing, along with ignoring — we call this differential attention — are the basic foundations of an effective behavioral intervention, and that's because it keeps the child

engaged in the moment. It's also very useful to teach the parent and the child to have explicit, shared goals that the child can understand and see the benefit of achieving.

After we've taught parents to use differential attention, we often introduce external reward and goal setting. We think of this as a way to teach the child to associate that good things come from taking care of themselves.

We will encourage parents and children to make a list of rewards that the child would like to earn and the parent is willing to give, and from that they can choose that when they meet a goal they achieve one of these rewards. We encourage them to be simple, like even spending time, 15 minutes playing a board game, or things that parents don't mind if their child does not earn. I've never seen a parent who says, oh, my child doesn't get enough video games. So those are always a good reward to use, something the parent doesn't care if the child earns or not but is very meaningful to the child.

By setting up these expectations and rewards, when you finish the food on your plate you can play Xbox is a good reward, and it helps the parent and the child be on the same page, and it can also take the struggle out of the meals. So the parent doesn't have to nag because they know that the child is highly motivated because of the reward.

MR. BUSKER: Let me ask you to illustrate what we've been discussing by applying it to a typical patient.

DR. STARK: Let's take a common occurrence, Emily, she's a 3 year old with cystic fibrosis, which was diagnosed at age 6 months. After the diagnosis she responded well to enzyme replacement therapy and gained weight. However, at around 18 months, when kids get a little bit more independent about what they will and will not eat, she began to fail to gain adequate weight.

When we interviewed her mother, she reported that Emily prefers juice over milk and that she's given in to that. So she tells us that she often serves her apple juice with breakfast and dinner and then serves her Sprite with lunch. When we queried her about what happens when she serves milk, she said that any time she tried that Emily throws a tantrum. And as anyone who has a 3 year old or experience with a 3 year old

knows, tantrums can be quite trying. Emily would cry, she would even pound the table, she wouldn't drink the milk, she would just sit there.

Mom said she tried a variety of strategies, first, trying to rationalize with Emily, explaining why milk might be good for her and help her to grow strong. She even said that she sometimes resorts to scolding, but that eventually she gives in because Emily just cries harder and it's just not worth it in the mother's opinion. So even though the mother feels guilty about giving Emily soda at lunch, she still does it because of Emily's tantrums.

MR. BUSKER: Specifically with this child: define for us the problem behavior, and why it's a problem.

DR. STARK: I think there are two things. One, certainly Emily's refusal to drink milk, because milk is much higher in calories and nutrients than either juice or soda, but second, it's also that Emily, as a 3 year old, is now in charge of her foods as opposed to her mother. So I think that Emily is learning that her tantrums are a way to get what she wants, because her mother gives in to it. She's learning that tantrums work. On the other hand, it's reinforcing for the mother, because when she gives her that juice or soda, Emily's tantrum stops, so that's very rewarding to the mother. So we're in this bad cycle.

MR. BUSKER: What would you advise the mother to do?

DR. STARK: I think that breaking the cycle can be difficult for a parent to do on their own. We'd want to support Emily's mom, and we'd want to do it slowly. By that I mean that we'd want to break it down into small steps.

In this case, we could set the first step as perhaps Emily taking one sip of milk and in return for drinking that one sip of milk, she can earn her juice or her soda. In that way, it might not be worth a full tantrum if you just have to do one sip in order to get the reward that you want, in this case using the juice as a reward for the behavior that mom wants, which is drinking the milk.

Mom would have to ignore Emily if she has a tantrum and wait until she took a drink of milk. So when Emily does this, her mother would have to jump on it and immediately praise Emily, saying things like, oh, good job, you took a drink of milk, now you can have your

juice. And because this is such an engrained behavior, we probably don't want mom to do this during mealtimes because it could ruin the whole meal. So we would probably set up small practice times of where Emily can earn a small amount of juice for taking a sip of milk.

Once we've taught Emily that she earns the juice by drinking her milk, we can then increase the amount of milk we require her to drink. So it starts out as a sip, after she's doing that without a tantrum, we can increase it to two sips, three sips, until then we are having her drink one and then two ounces of milk. Once she routinely will do what her mother asks, then you can serve it at meals.

MR. BUSKER: And we'll return, with Dr. Lori Stark from the University of Cincinnati College of Medicine, in just a moment.

MS. MEGAN RAMSEY: Hello, my name is Meghan Ramsay, Nurse Practitioner and Adult Clinical Coordinator for the Johns Hopkins Cystic Fibrosis Program at The Johns Hopkins University School of Medicine.

I am one of the Program Directors of eCysticFibrosis Review. These podcast programs will be provided on a regular basis to enable you to receive additional current, concise, peer-reviewed information through podcasting, a medium that is gaining wide acceptance throughout the medical community. In fact, today there are over 5,000 medical podcasts.

To receive credit for this educational activity and to review Hopkins policies please go to our website at www.ecysticfibrosisreview.org. This podcast is part of eCysticFibrosis Review a bi-monthly email-delivered program available by subscribing. Each issue reviews a current literature on focus topics important to clinicians caring for patients with Cystic Fibrosis.

Continuing education credit for each newsletter and each podcast is provided by The Johns Hopkins University School of Medicine for physicians and by The Institute for Johns Hopkins Nursing for nurses. Subscription to eCysticFibrosis Review is provided without charge, and nearly a thousand of our colleagues have already become subscribers. The topic-focused literature reviews help keep them up to date on issues critical to maintaining the quality of care for their patients.

For more information to register to receive eCysticFibrosis Review without charge and to access back issues please go to www.ecysticfibrosisreview.org.

MR. BUSKER: Welcome back to this eCysticFibrosis Review podcast. I'm Bob Busker, managing editor of the program. Our guest is Dr. Lori Stark, from the University of Cincinnati College of Medicine. And our topic is: Behavioral treatment to improve dietary adherence and weight gain in children with cystic fibrosis.

We've been talking about how to apply child behavioral management techniques to specific mealtime problems. So to continue our discussion, please bring us another mealtime situation.

DR. STARK: Let's talk about a child who's a little bit older. Jane is 10 years old, and her CF was diagnosed at age 2 years. She's always been small for age and is currently at the 10th percentile weight for age. Her mother describes Jane as a very picky eater who is never hungry for breakfast on school days and only eats a limited variety of foods. Her mother also reports that she used to force Jane to eat breakfast, giving her two or three choices, making a second meal.

She tells us that Jane prefers to watch TV before school instead of eating and they also have some problems at dinner. At dinner her mother reports that she only makes Jane's favorite foods, but Jane is still slow, spends a lot of time talking, and Jane and her father get into an argument about every bite.

The family, incidentally, has a rule that no one can leave the dinner table until everyone is done, and the mother reports that some meals can last an hour while everyone is sitting there waiting for Jane to finish.

MR. BUSKER: You've mentioned behavioral reinforcers. Would you identify for us the possible reinforcers in this particular scenario?

DR. STARK: If you look at the family rule that everyone has to stay at the table until everyone in the family is done, that puts Jane in complete control of the family mealtime. It gives her a lot of attention; no one can leave, they all have to sit there waiting for Jane. Her father, in trying to encourage her to eat, gives Jane a lot of attention when she's not eating. So that's another form of his attention. And finally, the mother making only Jane's favorite foods is giving

her a lot of control and power over the family meal and, hence, is also very reinforcing.

MR. BUSKER: Let's look at Jane not eating breakfast or insisting on watching TV instead of eating breakfast — what behavioral strategy might be best to address that problem?

DR. STARK: Well again, as we talked about with Emily, we'd want to start slow. This is called shaping, and it allows us to take small steps toward achieving a larger goal. In this case we want to condition Jane to eat breakfast.

The first step would probably be having her mother enforce Jane's just sitting at the table and not requiring that she eat anything, but that she has to sit at the table for, say, five or ten minutes, and then she can watch TV. Then she can use TV as a reinforcer, since Jane prefers that over eating.

As Jane cooperates with sitting at the table, that creates a family habit of sitting down at the table and carving out time for breakfast, then slowly, and we can start with Jane's favorite foods at breakfast, requiring Jane to eat a little bit of food in order to earn TV time, and gradually building that up. If she successfully eats one bite, allow her to then watch TV, and then increase that. Because Jane's 10, we can probably make increased demands more than one bite, but it depends on how much the child is going to push back. You start small and gradually build up. So then we'd continue to increase the amount of food Jane's required to eat to earn TV.

MR. BUSKER: Now this family's dinner rule, about no one getting up until everyone is finished. From a behavioral standpoint, what changes would you recommend?

DR. STARK: We'd recommend that family members can leave when they're finished eating, because that allows the family not to be held captive by Jane. It would also encourage her to eat faster so she can leave the dinner table. We would probably want to provide incentives for Jane to eat a little faster and at least get a minimum amount of calories in. So we could add a reward such as being able to view TV or being able to spend time doing something fun with her father, as opposed to having to sit at the table and be scolded, and we'd want to set a limit on the time spent at dinner.

We typically advise families to set a limit of 20 to 25 minutes. For most people, whether they have CF or not, your stomach sends a signal to your brain that you're full after 20 minutes, no matter how much you've eaten. So having a child sit there for too much longer after the 20 minutes is not going to get more calories in.

We encourage families to set a 20-minute rule, and to offer a meaningful reward, often some one-to-one time doing something fun with a parent if they meet their calorie goal within the 20 minutes. In this way, Jane's dad can back off from nagging her because he knows he has the ultimate reward and motivation for her. And then by giving attention to her for eating in the form of praise, they can also build up their relationship and make it more positive and make the family meal more positive.

MR. BUSKER: Thank you for sharing those insights. We've got time for one more scenario.

DR. STARK: Let's talk about Susan. She's five years old and lives with both her parents and has two older brothers. She's classified in the at-risk category for nutritional status according to the CF Nutrition Consensus Guidelines.

Her father is concerned about her welfare. He has a lot of concerns about CF and Susan dying early, and therefore he is not comfortable punishing her in the same way that he is her brothers for just basic behavioral infractions. Susan's mother is concerned about her growth and mentions in clinic that she'd like ways to increase her calorie intake, but she doesn't have any concern about Susan's behaviors at mealtime, she's just worried about her weight.

MR. BUSKER: Okay, this is a very different case, isn't it? Here the family's not reporting any mealtime behavioral problems. But the mother is asking for ways to increase her daughter's calorie intake. How would you advise her?

DR. STARK: I think a good first step would be to work with the mother to get a baseline of how much Susan eats in a day, so we'd ask Susan's mom to keep a seven-day diet diary.

In the past, families would have to record food intake on paper, look up calories, do the math — you know, how many calories did this amount of food take —

but now there are lots of applications out for smartphones, like My Fitness Pal or Lose It, that can make this process much easier for families.

For example, some applications, like My Fitness Pal, can even scan the UPC barcodes and put it right in the application. That makes it very easy to track, and if they share their password with the dietitian at the CF team, the dietitian can see what foods and how many calories Susan has eaten, and use that information to set a reasonable calorie goal that would allow Susan to gain weight. They can bump it up 25% or see what that 120% or 150% intake would be for Susan's age and then work with the family to set that calorie goal, divide the total by three meals and a couple of snacks, and work on identifying what's the easiest meal.

In our treatment studies that were reviewed in the newsletter, we always start with snack, because most families don't take advantage of that, they're not thinking about snacks, they're focused on the meal. There are lots of opportunities to spread it across the day, but for some families it's easier to start at breakfast or at lunch. You can let the family identify what meal they'd like to start with, and just start increasing the calories at that meal a little bit.

MR. BUSKER: Based on that, what specific ideas might work for this patient?

DR. STARK: Once you've identified which meal you're going to work on, the dietitian can go into the diet diary and personalize the information. For example, if Susan already drinks whole milk, the dietitian could suggest adding two tablespoons of a flavored syrup, like chocolate or strawberry, to increase the calories of milk. When you're starting with snack it is always a good idea to identify at least two occasions, such as after school and before bed, so you're not giving too much food at any one meal.

Also, while more calories seems like it's always better, we'd also advise Susan's mother not to exceed the calories that we set for meals. We don't want to overwhelm either Susan or her mother; we want to start slowly and just pace it.

About a week after you've focused on whatever meal is the family has selected, snack or breakfast, you can proceed to another meal. We typically start with snack, then breakfast. After that we usually

wait an extra week before we proceed to lunch and then to dinner. That way the child has a chance to adjust to the increase in calories without being too overwhelmed, and the family doesn't have to change everything at once.

We would also advise the mother to continue posting the calorie count to the food diary on whatever tracking system they use, so we can see the change and make sure that they are achieving it.

MR. BUSKER: My final question on this patient: Is there a chance that making these changes might create mealtime behavioral problems?

DR. STARK: It depends on the child. Problems may not develop at all because the child is a good eater and just is not being given enough calories or the mother isn't thinking about how to get those hidden calories in. On the other hand, if the parents have never had an expectation or tried to increase the calories, the child could become a little resistant. In that case, we would just go back to some of the other things that we've described before, such as providing a reward for eating a particular meal or for meeting the calories throughout the day. Again, those rewards can be simple, such as earning video time, earning time with a parent, being able to pick out an activity the family does, those types of things.

MR. BUSKER: Dr. Stark, thank you for bringing us these scenarios and for today's discussion. Let me ask you to look into the future for us and talk about the next steps in improving dietary adherence.

DR. STARK: One challenge that has plagued us is how can we make these behavioral treatments available to patients with CF across the country? Many of our CF centers do not have a behavioral pediatric psychologist such as myself readily available, so it's been difficult for CF centers to provide this level of care or intervention.

The CF foundation has given us funding to create a web-based version of our behavioral intervention. We've just been testing it and it looks like it has some promise, and we're excited about that. It has a dietary tracking app that interfaces with the web intervention so families can see what progress they're making. It allows them to identify foods that they'd like to try with their child, gives them tips on how to increase calorie intake, and it also introduces these behavioral

concepts and gives videos and shows cartoons to get these behavioral strategies into the hands of families who need them.

We're hoping we can partner with the CF Foundation once we've tested it and determined it's effective, and have it available to families all across the country in CF centers.

MR. BUSKER: Thank you. To wrap things up, let's review the key points of today's podcast in light of our learning objectives. So to begin: using "shaping" to encourage a child to eat a nonpreferred food.

DR. STARK: An example of shaping was in our case studies when we talked about breaking a bigger calorie goal into smaller steps, dividing it across three meals and snack, and only working on one of those meals at a time. Instead of saying, let's increase you by 500 or 1,000 calories a day, we say let's just increase 200 calories at breakfast.

MR. BUSKER: And our second objective: the role of "attention" in maintaining behaviors incompatible with eating?

DR. STARK: As we discussed, children will do almost anything for their parents' attention. In behavioral intervention we use this to our advantage by teaching parents to use their attention to reward their children for eating, and to withhold their attention to motivate their child to eat when they're not eating.

MR. BUSKER: And finally: the use of caloric goal-setting and dietary tracking applications to monitor treatment progress.

DR. STARK: It's important for parents of children with CF to have a stopping point. One of the things we see over and over, and the reason the parents do these behaviors like continuing to sit at the table for an hour, is that more food feels like a better goal than less food. But if you say this is how many calories you need and you can stop here, then the parents can end the meal feeling successful.

We think it's important that you have a calorie goal for the day, divide it by the number of meals and snacks, so the parents can stop. The only way you know if you're successful is by tracking that. We'd advise parents to track that when they're trying to increase the calories that their children consume.

This also teaches them what foods are high in calories and which ones would be good and get the most calories per bite.

MR. BUSKER: Dr. Lori Stark from the Cincinnati Children's Hospital Medical Center and the University of Cincinnati College of Medicine, thank you for participating in this eCystic Fibrosis Review Podcast.

DR. STARK: Bob, it has been a pleasure, thank you so much for having me.

MR. BUSKER: This podcast is presented in conjunction with eCysticFibrosis Review, a peer-reviewed CME and CNE-accredited literature review emailed monthly to clinicians treating patients with cystic fibrosis. This activity has been planned and implemented in accordance with the Essential Areas and policies of the Accreditation Council for Continuing Medical Education through the joint sponsorship of The Johns Hopkins University School of Medicine and The Institute for Johns Hopkins Nursing.

The Johns Hopkins University School of Medicine is accredited by the Accreditation Council for Continuing Medical Education to provide continuing medical education to physicians

For physicians, The Johns Hopkins University School of Medicine designates this educational activity for a maximum of 0.5 *AMA PRA Category 1 Credit*[™]. Physicians should only claim credit commensurate with the extent of their participation in the activity.

For nurses, this 0.5 contact hour educational activity is provided by The Institute for Johns Hopkins Nursing. Each podcast carries a maximum of 0.5 contact hours.

This educational resource is provided without charge, but registration is required. To register to receive eCysticFibrosis Review via e-mail, please go to our website, www.ecysticfibrosisreview.org. The opinions and recommendations expressed by faculty and other experts whose input is included in this program are their own. This enduring material is produced for educational purposes only.

Use of The Johns Hopkins University School of Medicine and The Institute for Johns Hopkins Nursing names implies review of educational format, design, and approach. Please review the complete

prescribing information of specific drugs, combination of drugs, or use of medical equipment – including indications, contraindications, warnings and adverse effects – before administering therapy to patients.

Thank you for listening.

eCysticFibrosis Review is supported by an educational grant from Aptalis Pharma, Inc, Gilead Sciences Inc., and Vertex Pharmaceuticals.

This program is copyrighted, with All Rights Reserved by The Johns Hopkins University School of Medicine.