

DEPARTMENT OF HEALTH AND HUMAN SERVICES  
OFFICE OF DIRECTOR

ACTION REFERRAL

TO	DATE
<i>Boring</i>	<i>7-11-06</i>

<b>DIRECTOR'S USE ONLY</b>		<b>ACTION REQUESTED</b>	
1. LOG NUMBER	000047	<input type="checkbox"/> Prepare reply for the Director's signature DATE DUE _____	
2. DATE SIGNED BY DIRECTOR	<i>Cleared 8/3/06, letter attached</i>	<input checked="" type="checkbox"/> Prepare reply for appropriate signature DATE DUE <i>7-20-06</i> <input type="checkbox"/> FOIA DATE DUE _____ <input type="checkbox"/> Necessary Action	

APPROVALS (Only when prepared for director's signature)	APPROVE	* DISAPPROVE (Note reason for disapproval and return to preparer.)	COMMENT
1.			
2.			
3.			
4.			

June 27, 2006

South Carolina Medicaid  
Attention: Robert Kerr  
P.O. Box 8206  
Columbia, S.C. 29202

Regarding: Faith Hudson  
Date of Birth: 1/7/04  
Recipient Number: 1780249432

To Whom It May Concern:

Enclosed is information in support of Faith Hudson's referral to the Marcus Institute Feeding Program in Atlanta. We are requesting review of her medical history as well as a request from her primary care physician to allow treatment and payment by S.C. Medicaid to the Marcus Institute. The Marcus Institute has accepted Faith for an evaluation on July 26, 2006 pending Medicaid approval. We are enclosing the following pertinent information:

- Packet introducing Marcus Institute Feeding Program including: Program Outline, Outcome Summary, Feeding Disorder description information, FAQ sheet, Biography of Director, Affiliations and Contact List for Marcus Institute
- Referral Letter from primary care physician, Dr. Frank Stewart
- Reference Letter from Ocone Co. C.R.S. Nutritionist, Elaine Prock
- ~~Reference Letter from Developmental Pediatrician, Dr. Mark Clayton~~ will be sent at a later time
- O.T. Feeding Summery, Occupational Therapist, Diane Nix
- O.T. Re-evaluation Summary Of Progress, Diane Nix
- S.T. Summery Of Progress, Speech Therapist, Karen Shoemaker
- Contact List of Physicians and Therapists involved in Faith's care

We thank you in advance for your time reviewing this urgent matter. Please feel free to contact us with any questions. Also, please contact us at the phone number below for confirmation that you received this packet.

Sincerely,

*Candace Hudson*

Candace and Carl Hudson  
231 Elaine Dr.  
Salem, S.C. 29676  
864-944-8954

**RECEIVED**

JUL 10 2006

Department of Health & Human Services  
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*Jos. Bowling*  
*U. Group - Secy.*

## **THE MARCUS INSTITUTE**

*Turning Disabilities into Possibilities*

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### **Introduction**

**The Marcus Institute recognizes the need for a place where children learn skills and caregivers receive support –**

#### **A PLACE THAT PROVIDES HOPE**



HOPE can be found in all the little things that help children reach their potential. Finding effective services for children with disabilities and learning problems can create a constant struggle for their caregivers. The Marcus Institute reduces the stress of that search by offering the most comprehensive diagnosis, therapy and care management possible for a wide range of disabilities and learning problems.

All of our experts are under one roof. The Marcus Institute's staff of health care professionals is the largest team dedicated to child development in one facility in Georgia. In addition, our affiliation with Emory University and Kennedy Krieger Institute affords us access to a wealth of academic and medical resources.

Our facility offers a unique environment. The Marcus Institute serves as a resource for continuous research, training, and education that allows us to share our knowledge and expertise with caregivers, school and social services personnel and the medical community.

The Marcus Institute can help your child. We're the comprehensive resource for children and adolescents with: · Developmental Delay · Autism Spectrum Disorder · Cerebral Palsy · Feeding Disorders · Learning Disabilities · Neurological Disorders · Severe Behavior Disorders · Fetal Alcohol Syndrome

Our programs are designed to give children and their caregivers support, opportunity, encouragement, pride, commitment, and determination.

*These are the building blocks of HOPE*

[Letter from the President](#) | [History/Mission](#)  
[Important Institute Information](#) | [Board of Directors](#) | [Faculty](#)

[http://www.marcus.org/kki\\_print\\_intro.jsp?pid=1](http://www.marcus.org/kki_print_intro.jsp?pid=1)

6/20/2006

## **Pediatric Feeding Disorders Program**

**Director:**

David L. Jaquess, Ph.D.

**Description of Program:**

A feeding disorder is characterized by difficulties with eating or drinking that affect weight or nutrition. This problem may include food or fluid refusal or selectivity. Some children may be dependent on tube feedings to grow. A feeding disorder may be accompanied by behavior problems during mealtime (e.g., tantrums). Some children also may have skill deficits such as an inability to chew or swallow foods. Finally, medical problems such as vomiting also may play a role in the feeding disorder.

Children may have feeding difficulties as a result of a complex interaction between a number of factors. For example, medical problems such as reflux may cause eating to be painful. Early experiences with pain during eating cause the child to stop eating and develop behavior problems (e.g., crying), which make it difficult if not impossible for the parent to feed the child. If the child frequently avoids eating, he or she may fail to develop the appropriate oral motor skills (e.g., chewing and swallowing) to be a successful eater. Other children may have peculiar feeding patterns (e.g., only eating a limited number of foods), which could compromise their health or socialization.

**Pediatric Feeding Disorders Program at the Marcus Institute:**

Our program is one of the first to combine medical expertise and behavioral psychology to provide a continuum of services for children and their families. Pediatric feeding disorders may present themselves in various ways. Common feeding problems may include a dependency on tube feedings, the inability to chew or swallow foods, poor oral intake, and/or behavior problems during mealtimes which make it difficult to feed your child. These problems may arise at any time during childhood. They affect a child's ability to function properly at home, school or other social settings and create patterns that can potentially last a lifetime.

By determining the factors that contribute to and maintain your child's feeding difficulties and by recommending the scope of treatment, and providing long-term follow-up, we help you and your child to overcome these obstacles. The components of the program include:

**Feeding Clinic** – The feeding clinic determines whether a child is appropriate for the day treatment or outpatient program. The evaluation team obtains a medical history, observes the child and family interactions during mealtime, assesses the child's oral motor skills, and determines the family's ability to participate in the program.

**Intensive Day Treatment Program** – The intensive day treatment program

is designed for children who need daily intensive therapy for their feeding difficulties. The child attends the program Monday through Friday 8:30 a.m. to 5 p.m. The program involves intensive feeding sessions of three to five meals a day, medical oversight, nutritional monitoring, and caregiver training and support. The program lasts approximately eight weeks.

**Outpatient Follow-up Program** – The outpatient program serves children who graduate from the intensive day treatment program or children who could be treated less intensively (e.g., once a week). As part of the program, the caregiver reports on the child's progress and practices the recommended feeding methods at home and other environments.

The Pediatric Feeding Disorders Program at the Marcus Institute has achieved a high degree of success— 86% of patients' feeding difficulties have been resolved or significantly improved by the time of discharge.

- The Pediatric Feeding Disorders Program list of frequently asked questions
- The Pediatric Feeding Disorders Program suggested reading list

**Getting started in the Pediatric Feeding Disorders Program:**

If you are interested in having your child evaluated by our team, you must obtain a physician referral and/or complete the intake form below. Please fax the physician referral and/or intake form to our Intake Specialist at 404-419-4016 or email to [Behavior\\_Center@marcus.org](mailto:Behavior_Center@marcus.org). Once the referral and/or intake form is received by the Marcus Institute, we will then contact you to conduct an intake interview and if appropriate, schedule your child for an evaluation.

The physician referral must include the following information:

- Child's Name
- Child's Date of Birth
- Child's Diagnosis
- Reasons for Referral
- Primary Caregiver's Name (i.e. parent or legal guardian) and Contact Information
- Referring Physician's Name and Contact Information

Download the Pediatric Feeding Disorders Program Intake Form, Microsoft Word format

Download the Pediatric Feeding Disorders Program Intake Form, Adobe PDF format

**Contacts:**

For general questions regarding our program or if you would like to receive an informational packet from the Marcus Institute Behavior Center that explains the Pediatric Feeding Disorders Program in detail, please e-mail your name and mailing address to [Behavior\\_Center@marcus.org](mailto:Behavior_Center@marcus.org) or call (404) 419-5000.

**Additional Resources:**

[http://www.marcus.org/ki\\_print\\_inside.jsp?pid=2446](http://www.marcus.org/ki_print_inside.jsp?pid=2446)



Marcus Institute  
Dedicated to Caring for Children with Disabilities

## Pediatric Feeding Disorder Day Treatment Program Outcome Measure Summary

The Pediatric Feeding Disorders Program at the Marcus Institute has a 90% success rate. In other words, 90% of all goals that are set upon admission are met upon discharge from the intensive program. These outcomes are based on the seventy-three patients seen at The Marcus Institute Pediatric Feeding Disorders day treatment program from October 1999 through September 2003. We measure patient success in a variety of domains (e.g., total increase in oral consumption, decrease in tube feedings, decrease in inappropriate mealtime behaviors, caregiver training). The feeding team and the family develop specific individualized goals for each child's admission. Goals are established for both the clinic and for the home/community environment. The average number of goals set for each child's admission is 7.

The Marcus Institute Pediatric Feeding Disorders Program is equally successful with children with a variety of medical and developmental concerns. Success rates for children with a history of developmental disorder (90%) are similar to those for children with typical development (89%). Of children with typical development, 68% were diagnosed with gastroesophageal reflux and another medical condition (e.g. tube dependency, failure to thrive), while 21% of children with typical development had a diagnosis of gastroesophageal reflux with no other medical condition. Children with no history of gastrointestinal complications are also treated in our program (14% of typically developing children/ 30% of children with developmental disorder).

For those patients who had a total oral consumption increase goal, 75% of them meet the goal by the end of their admission and 91% of all patients had some increase in their total oral consumption during their day treatment. The Marcus Institute Pediatric Feeding Disorders Program is also 89% successful at meeting the goal of increasing liquid oral consumption. For those patients who had a weight increase goal, 80% of them met this goal by the end of their admission. Overall, 97% of all patients admitted to the program had some increase in weight during their treatment.

The Marcus Institute Pediatric Feeding Disorders Program also has a high success rate for avoiding permanent gastrostomy tube placement and dependency. The program has demonstrated the need for permanent gastrostomy tube placement in 88% of all patients with ~~gastroesophageal reflux~~ or nasogastric tube feedings) had a decrease in their tube dependency upon discharge. Dependency on tube feedings was reduced by a mean of 46%.

We also have been successful in decreasing inappropriate mealtime behaviors (59% of patients meet the goal) and training caregivers to implement the final treatment protocol with high retention (90% of patients meet the goal). Treatment outcomes are also successfully transformed

- ✓ Session-by-session data are graphed, reviewed, and analyzed during each session by therapists and the interdisciplinary team.
- ✓ Data are used systematically to guide assessment and evaluate and refine treatment development.
- ✓ Treatment components are evaluated systematically using single-case designs; ineffective components are refined or replaced until discharge goals are achieved.
- ✓ Assessments and treatments for each patient receive regular peer review by multiple senior behavior analysts and staff.
- ✓ A specialized physical plant is used to allow safe evaluation of feeding behaviors (e.g. treatment rooms with one-way observation).
- ✓ All therapists receive intensive, specialized training in behavior analysis and management of feeding disorders.
- ✓ Caregivers are trained to criteria to implement the procedures that are designed during the admission.
- ✓ A physician examines the child and evaluates the impact of increases in oral intake on the child's medical status. Thus, any medical problems that arise as a result of increased oral intake (e.g. increased emesis) can be assessed and treated.
- ✓ A nurse monitors the child's growth pattern twice a week.
- ✓ A nutritionist monitors the child's nutritional status (e.g. conduct calorie counts) on a daily basis to insure that the child is receiving sufficient calories for growth.
- ✓ A nurse and nutritionist monitor the child's hydration status daily to insure that the child receives sufficient fluids to maintain hydration.
- ✓ The nurse conducts daily physical assessments to monitor the child's health status and delivers medication as needed.
- ✓ The nutritionist provides nutritional education and counseling to the family.
- ✓ An occupational therapist consults with the feeding team to improve the child's oral motor skills and to monitor the child's safety for oral feeding.
- ✓ A social worker meets with the family at least once a week to address any issues that might impact the child's food refusal or the family's ability to carry out the treatment plan.
- ✓ The professionals work together as a team via daily rounds, steering conferences, and planning meetings to insure coordinated care and to address all of the issues that impact the child's food refusal.

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## Feeding Disorders

A pediatric feeding disorder is diagnosed when children fail to consume an adequate quantity or quality of solids or liquids to sustain growth. Feeding disorders are fairly common in infants and toddlers, with approximately 25 percent to 40 percent of these children experiencing some difficulties with feeding. The incidence of severe feeding problems has been reported to be even greater—as high as 80 percent—in children with severe to profound mental retardation. In fact, the number of children affected by feeding disorders is growing because medical advances have reduced the mortality rate of children born prematurely, a population especially at risk.

Feeding disorders typically develop for several reasons, including medical conditions (food allergies), anatomical or structural abnormalities (defects of the palate), and behavioral mismanagement (e.g., early or delayed introduction of solid foods, excessive parental anxiety during meals or delivery of inappropriate consequences for food refusal). In most cases, no single factor accounts for a child's feeding difficulties. Rather, several factors interact to produce them.

Awareness of risk factors and clinical presentations of feeding disorders, combined with appropriate referrals at an early age, will produce the best outcomes for children and their families.

### Examples, Subsets and Synonyms for Feeding Disorders

- Oral Motor Dysfunction (dysfunctional swallow, dysphagia, oral motor dysphagia)
- Food Refusal/Selectivity
- Failure to Thrive
- Short Gut Syndrome
- Gastrointestinal disorders

### Related Marcus Institute Clinical Programs

#### Pediatric Feeding Disorders Program

#### Related Marcus Faculty:

• David L. Jaquess, Ph.D.

#### Additional Resources:

#### Penn State Children's Hospital

(<http://www.hmc.psu.edu/childrens/healthinfo/f/feeding.htm>)

#### Speech Sense

(<http://www.speechsense.com/probs/feedDisorder.htm>)

#### University of South Alabama

(<http://www.southalabama.edu/speechandhearing/parents.html>)

#### Dysphagia Resource Center

([www.dysphagia.com](http://www.dysphagia.com))

[http://www.marcus.org/ki\\_print\\_inside.jsp?pid=2510](http://www.marcus.org/ki_print_inside.jsp?pid=2510)

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The Food and Nutrition Information Center  
[\(www.nal.usda.gov/fnic/\)](http://www.nal.usda.gov/fnic/)

The Food Allergy & Anaphylaxis Network (FAAN)  
 [\(www.foodallergy.org\)](http://www.foodallergy.org)

American Dietetic Association  
 [\(www.eatright.org\)](http://www.eatright.org)

Centers for Disease Control  
 [\(www.cdc.gov\)](http://www.cdc.gov)

Nutrition.gov  
 [\(www.nutrition.gov\)](http://www.nutrition.gov)

Healthfinder: Your Guide to Reliable Health Information  
 [\(www.healthfinder.gov\)](http://www.healthfinder.gov)

Mayo Health Clinic  
 [\(www.mayohhealth.org\)](http://www.mayohhealth.org)

Tufts  
 [\(www.navigator.tufts.edu\)](http://www.navigator.tufts.edu)

Consumer Lab.com  
 [\(www.consumerlab.com\)](http://www.consumerlab.com)

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## Feeding and Swallowing Disorders in Infants and Children

Children with feeding and swallowing difficulties (also called dysphagia) are at risk for malnutrition, dehydration, and respiratory problems. Infants and children with feeding and swallowing problems are a diverse group, ranging from premature babies to teenagers. Parents are often the first to notice a feeding problem.

### Causes of feeding and swallowing problems

- Prematurity
- Cerebral palsy
- Autism
- Head and neck abnormalities
- Muscle weakness in the face and neck
- Gastroesophageal reflux
- Multiple medical problems
- Respiratory difficulties
- Medications that may cause lethargy or decreased appetite
- Problems with parent-child interactions at mealtime

### Symptoms

Children with feeding and swallowing problems present with a wide variety of symptoms, depending on the nature and cause of their disorder. Typical symptoms include:

- Poor feeding
- Difficulty chewing
- Difficulty drinking from a bottle or cup
- Difficulty breast feeding
- Refusing food or liquid
- Coughing or choking while eating or drinking
- Excessive drooling and food spilling from the mouth
- Liquid leaking out the nose
- Gagging
- Vomiting during meals
- Increased congestion during meals
- Increased fussiness or crying during meals
- Accepting only certain types of food (only pureed foods or only crunchy foods)
- Poor weight gain

- Frequent respiratory infections or pneumonia (may occur when food or liquid is aspirated into the airway, rather than swallowed effectively)

### **Evaluation and Diagnosis of Feeding and Swallowing Disorders**

If you suspect that your child is having difficulty eating, contact your pediatrician right away. Your physician will examine your child and address any medical reasons for the feeding difficulties, including the presence of reflux or metabolic disorders. The pediatrician may refer you and your child to a feeding team or speech-language pathologist who specializes in treating children with feeding and swallowing disorders.

The SLP will discuss your concerns and observe your child while they eat. The SLP may also conduct an instrumental assessment of your child's swallowing ability. This involves having your child eat and drink foods and liquids mixed with barium while watching them on an x-ray. This procedure is typically called a **modified barium swallow** and is conducted in a radiology office. Sometimes a different instrumental assessment will be completed, which involves having a lighted scope inserted through the nose so your child's swallow can be observed.

If a feeding team is involved, which may include the SLP, an occupational therapist, a physical therapist, a physician or nurse, and a dietitian, your child's posture, self-feeding abilities, medical status, and nutritional intake will also be examined. The team will then make recommendations on how to improve your child's feeding and swallowing.

### **Treatment**

Based on the results of the feeding evaluation, the SLP or feeding team may recommend any of the following:

- Medical intervention, as needed
- Direct feeding therapy designed to meet your child's individual needs
- Nutritional changes
- Postural or positioning changes (different seating, etc.)
- Behavior management techniques
- Desensitization to new foods or textures
- Food temperature and texture changes
- Referral to other disciplines, such as psychology or a dentist

If feeding therapy with an SLP is recommended, the focus of intervention may include:

- Strengthening the muscles of the mouth
- Increasing tongue movement
- Improving chewing patterns
- Increasing tolerance of different foods or liquids
- Improving sucking /drinking ability
- Coordinating the suck-swallow-breathe pattern (for infants)
- Altering food textures and liquid viscosity to ensure safe swallowing
- Other interventions depending on your child's specific needs

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Adapted from text developed in 2001 by Lisa Newman, SCD, CCC-SLP

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## Pediatric Feeding Disorders Program Frequently Asked Questions

### Frequently Asked Questions:

#### **1. What can I expect to happen during an evaluation in the Pediatric Feeding Disorder Clinic?**

The interdisciplinary feeding team: medicine, behavioral psychology, occupational/speech therapy, nutrition, social work and nursing will interview you regarding current feeding practices and your child's feeding history. Additionally, the team will observe your child eating a typical meal. The team will then provide recommendations as to whether your child is a candidate for our intensive day treatment program or outpatient program.

#### **2. What should I expect a typical day to be like in the intensive day treatment program?**

The intensive day treatment program is a Monday through Friday all day program. Therapy is scheduled between 8:30 AM and 5:00 PM. A typical schedule includes five meal/session times including snacks. Between meal times your child will have scheduled free times and a nap/quiet time. It is important to remember that each child's schedule is determined by his/her health, medical, and feeding needs. Schedules will vary according to the needs of each individual child.

#### **3. What should I expect a typical visit to be like in the outpatient program?**

This program consists of regularly scheduled weekly, bi-monthly, or monthly one-hour visits. We will observe you and your child during a typical meal using the treatment protocol developed by the team. Additionally, the team will then provide further recommendations to continue to make progress in feeding and/or in other areas.

#### **4. What does your facility offer for my child to do when he/she is not receiving treatment?**

Free time can include individual playtime, structured group playtime, and schoolwork. Our facility offers an indoor playground, an outdoor playground, and a Kaboom@ playground. Free time may also include occupational, speech, physical, or other outside therapy. However, it is important to remember that each child's schedule is determined by his/her health, medical, and feeding needs. Schedules will vary according to the needs of each individual child. We may suggest a short hiatus in outside therapies for the length of the day treatment program in order to provide a more consistent focus for your child on feeding.

#### **5. What does your facility offer for me to do when my child is not receiving treatment?**

Our facility offers a parent lounge, adjacent to the individual nap suites equipped with monitoring devices so caregivers can monitor their child from the parent lounge. If you are traveling from out of state, you may be interested in the many shops and dining areas near the Marcus Institute. Both Lenox Mall and Phipps Plaza are large shopping plazas nearby with movie theaters. We have a weekly meeting for parents of children in the feeding program to share their experiences with other parents facing similar problems. These meetings provide an

opportunity for parents to support each other, share successes and maintain perspective about their children's progress in treatment. Parent meetings are held weekly and are open to parents of children currently in day treatment as well as parents of children who have completed treatment.

**6. Do I supply the food for my child to eat while receiving treatment?**

We will supply food and beverages for all of your child's meals while at the Institute for the day treatment program. However, the family is required to supply food and beverages for the evaluation and outpatient visits. Our program is equipped with a limited food service facility. The foods we are able to provide include, but are not limited to, jarred baby foods, canned fruits and vegetables, canned and frozen meats, dairy products, "convenience" foods, condiments, beverages (both high and low calorie), and frozen foods. We are unable to have fresh fruits, fresh vegetables, raw meats, or raw eggs. If you would like for these food items to be presented to your child, please speak with the nutritionist. These food items can sometimes be brought from home. Near the end of your child's admission, we may ask you to bring food items similar to what your family eats at home.

**7. If my child is tube dependent, how will his/her needs be met while receiving treatment?**

The nutritionist and medical team will evaluate your child's oral consumption, daily, throughout the admission. As your child's oral consumption increases, they will adjust your child's tube feeding schedule accordingly.

**8. During my child's admission, when or how often do I need to be present?**

The intensive day treatment program requires that you are available for a number of things at the center. Upon admission, we conduct a number of assessments, which require the presence of the caregiver(s) during the first week. Additionally, it is important that you are available for a goal meeting, which will be held one to two weeks after admission. The purpose of this meeting is to establish specific goals for your child's stay in the day treatment program. This goal meeting also will be an opportunity for you to voice any questions and concerns you have pertaining to your child and the treatment he/she will receive during his/her admission, as well as to have input in finalizing your child's treatment goals.

Throughout the admission, you will be involved in our caregiver-training program, which typically takes place over the last few weeks of treatment. Caregiver training is a very important part of our program because we need to prepare you to successfully implement your child's treatment protocols in the home environment. Before discharge we try to have your child feeding in an environment similar to the home environment. This may include bringing your other children and caregivers into the session. If possible, we will conduct meals in the home or school prior to discharge.

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[Frequently Asked Questions](#) | [Success Stories](#) | [Reading List](#)

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**THE MARCUS INSTITUTE**

Turning Disabilities into Possibilities

[Close](#) | [Print](#)**David L. Jaquess, Ph.D.***Acting Director of the Feeding Disorders Program*

In 1993 Dr. Jaquess received a Ph.D. in Clinical Psychology from Virginia Tech under the tutelage of Jack Finney; he also worked on research there with Thomas Ollendick and Richard Winnet. He completed a predoctoral internship at the Medical University of South Carolina and a postdoctoral fellowship at the Kennedy Krieger Institute and Johns Hopkins University School of Medicine. Dr. Jaquess has taught at various levels in higher education from undergraduates in a comprehensive liberal arts college to postdoctoral fellows. Currently he is the Acting Director of the Feeding Disorders program at the Marcus Institute.

**Biographical Sketch:**

Dr. Jaquess has been licensed in the states of Georgia, Maryland, Virginia and Indiana. He is a clinical supervisor for the Outpatient and Day Treatment Programs in the Pediatric Feeding Disorders program. Current areas of research interest include empirical support of using behavior analytic techniques for pediatric feeding disorders, factors predictive of developing feeding problems in high risk children, and family and behavioral impacts on children in families that include a person with HIV/AIDS. In addition, he is investigating the effectiveness of workplace stress management interventions. He has served as ad hoc reviewer for Journal of Applied Behavior Analysis and Journal of Pediatric Psychology.

**Recent Publications/Presentations:**

Ninness, H. A. C., Richman, G., **Jaquess, D.**, Vittemberga, G. (1995). Facilitating objective-setting in behavioral therapy through social mediation. *Behavior and Social Issues*, 5, 13-20.

**Jaquess, D. L.**, & Finney, J. W. (1994). Previous injuries and behavior problems predict children's injuries. *Pediatric Psychology*, 19, 78-89.

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### The Marcus Institute Partnering with the Kennedy Krieger Institute brings services to underserved children.

Grounded in more than 65 years' experience serving children and adolescents with neurological disabilities, Baltimore-based Kennedy Krieger Institute (KKI) is renowned for its expertise—not only in providing care but also in research, professional training and education related to childhood disabilities. Through its commitment to sharing its acquired wealth of knowledge in the field of disabilities, KKI has enjoyed an informal affiliation with the Atlanta-based Marcus Institute since its inception in 1992. A generous donation from Bernard Marcus—the entrepreneur behind Home Depot who is also a philanthropist and co-founder (with his wife Billie) of the Institute—enabled a formal partnership in 1998.

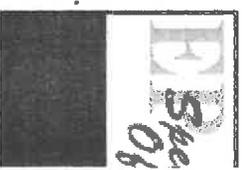
As a result of this merger, the Marcus Institute has become the cornerstone of a long-range plan envisioned by KKI to establish a national network of developmental behavioral services for children with neurological disorders and to heighten awareness regarding disabilities within communities and legislative systems governing them. Says Marcus, "We want to take the very best of what's happened in Baltimore and move it to Atlanta, then to other cities."

Prior to the establishment of the Marcus Institute, children with developmental disabilities living in the Southeast region of the US were diagnosed and treated somewhat inconsistently. Moreover, coordination of services among providers, critical when managing complex disabilities requiring various specialists and services, was often disjointed. The Marcus Institute fills an important void by offering coordinated and appropriate services for children whose needs were not previously met.

Highly specialized programs offered at the Marcus Institute require equally specialized medical professionals. Some of these programs, such as the Behavior Center and the Pediatric Feeding Disorders Program, utilize techniques that have been proven effective through years of application and refinement at Kennedy Krieger Institute.

#### **Addressing severe behavioral disorders**

For the children who live with this problem—approximately 10-15 percent of individuals with mental retardation, autism, or severe developmental disabilities—not a lot of options exist. Families may



turn to pharmacological therapies, which have produced mixed results at best. From sheer desperation, families sometimes consider placing such children in institutions. Out of this dire need grew Kennedy Krieger Institute's neurobehavioral inpatient and outpatient programs in Baltimore and now, an affiliated program at the Marcus Institute in Atlanta.

The goal of these programs is to provide advanced and comprehensive treatment services, promote widespread dissemination of effective treatment technologies through highly specialized training and consultation, and facilitate the development and refinement of effective treatments through systematic evaluation of clinical innovations.

Positive results are evidence of behavioral theories that can work as well in practice as they read in text books, when applied with meticulous detail and consistency. Not only have the behavior analysis techniques honed by the NBU staff proven effective in treating the most difficult behavioral problems—the staff achieves a 90 percent decrease in aggressive behavior among three quarters of its inpatients and a recidivism rate below 5 percent—they have set the standard for the entire country.

#### **Keeping families together**

Scott Fendlay was born with his umbilical cord wrapped around his neck. Despite the pessimistic predictions of medical professionals who told the Fendlays that Scott would never walk, he learned to walk, ride a bike, and roller-skate. But as Scott got older, his behavior began to present a major challenge to his family. "Scott's behavior worsened to where he was a threat to our safety," says Scott's mother Carol. He was a big adolescent strong enough to heave the microwave oven out the window and cause injuries to his parents. "At that point, life was just...impossible," says Carol.

Then Carol learned about Kennedy Krieger's Neurobehavioral Unit (NBU) and eventually, Scott was admitted to the NBU as an inpatient, where he stayed for two months.

From the beginning, the Fendlays let Dr. Wayne Fisher, who was then the director of the NBU in Baltimore and now heads its sister program in Atlanta, know that their main priority was to get Scott's behaviors manageable enough to where he could return home. Dr. Fisher not only respected their wishes, he exceeded them. "I have called him [Dr. Fisher] many times and he's even come to my house when things were really, really bad with Scott, and we've reasoned with him," Carol notes.

Scott is now 32 years old. Every weekday, he chooses to dress in a tie and pressed shirt before boarding a bus that takes him to an adult day care center. In his free time he enjoys bowling in a recreational league and listening to music on his walkman.

Keeping Scott's behaviors in check remains an issue. A "token" system, developed jointly by Carol and Dr. Fisher while Scott was on the NBU, helps to make this challenge manageable. "I find that you have to use the protocol every day. Not just Monday, or Friday," says Carol.

Scott's progress can be attributed largely to his family's decision to

treat him like a healthy, contributing member of the family. "Overall, he's given us much more back than we've ever had to give out," remarks Carol. Explains Wayne Fisher, Ph.D., "Bernie Marcus gave us his donation because he realized how important these behavior problems are, how devastating they are to families, and how little attention and financial resources have been devoted to them." And it is these specific challenges that are driving the continued evolution of the Kennedy Krieger and Marcus behavioral programs.

#### **When children won't eat**

Another service that sets Kennedy Krieger and Marcus Institutes apart is the Pediatric Feeding Disorders program. Designed to help children who are failing to consume the appropriate amount of nourishment to survive because of medical or behavioral dysfunction, this program combines the medical expertise of pediatric gastroenterology and the precise therapeutic interventions of behavioral psychology to evaluate and treat children with feeding impairments.

The program is unique because of its intensity and interdisciplinary nature, and this is the reason that families travel from all over the country, and sometimes the world, to enroll their children. Most of the children who are seen in this program have been through many other attempts to get them to eat, including—when nothing else works—inserting a feeding tube via the nasal passage or gastrointestinal tract.

The practice of meticulously analyzing data and recording observations has made professionals in Kennedy Krieger and Marcus' Feeding Disorders Program experts in behavior analysis. It has also contributed to the staff's numerous published studies proving the benefits of this methodology.

Before admission to the feeding program, Leslie Muldrow constantly worried about her daughter's weight. After Aylea's enrollment in the program, she ate a variety of foods that, before, she never would have even swallowed. But Aylea's follow-up visit after discharge was to be the true test for her mother. Then she would know how effectively she had assisted Aylea with maintaining the progress she made while in the program. The fateful day came two months after Aylea's discharge. When Aylea hopped on the scale, it read two pounds more than what she weighed at discharge.

"Follow-up is such an important part of the long term outcomes for our patients," explains Dr. Cathleen Piazza, behavior psychologist and director of the Pediatric Feeding Disorders Program at Kennedy Krieger and Marcus Institutes. This continued involvement with patients and their families has helped keep the program's recidivism rate below 5 percent, and was in part the impetus for piloting a telemedicine component within the program.

Currently, Kennedy Krieger and Marcus' feeding experts consult via teleconferencing between program locations in Baltimore and Atlanta, allowing staff to collaborate on individual cases. And, in homes in both markets, patients and their families have been connected to the Institutes' experts through teleconferencing capabilities, working virtually with therapists during feeding sessions and follow-up consultations.

"The demand for these services is so great, we needed a way to

expand our Feeding Disorders Program capabilities and to reach families who were unable to travel to Atlanta or Baltimore,” explains Cathleen Piazza Ph.D. “This new approach enables us to help more children and their families, right in their home environment.”

#### **An educational and research focus**

Kennedy Krieger Institute shares an educational and research affiliation with The Johns Hopkins University School of Medicine in Baltimore, and Marcus Institute shares a similar relationship with Emory University School of Medicine in Atlanta.

Faculty at both facilities conduct professional training and research to discover preventions and novel therapies for disorders of the brain that begin in childhood. Together with families, support groups, government agencies and foundations, the Institutes advocate at the local, state and national levels for fuller integration of individuals with developmental disabilities into school and community life, better access for families to appropriate clinical and educational services, and enhanced funding for research and training in this field.

While the tools and techniques used to treat children with disabilities have changed and improved significantly over the past 60 years, the guiding focus on comprehensive, interdisciplinary and individualized care remains at the core of these two Institute’s philosophy.

“Ultimately, in everything we do—whether it be a new therapy to help children with lead poisoning learn better, microarray research to uncover the genetic cause of autism, or training with a new group of pediatric neurologists—we strive for one common goal, to improve the lives of children with disabilities and to help them participate as fully as possible at home, school and in their community,” summarizes Gary W. Goldstein, president and CEO of Kennedy Krieger Institute.

To learn more, please visit Kennedy Krieger Institute’s Web site at <http://www.kennedykrieger.org> or Marcus Institute’s Web site at <http://www.marcus.org>, or call 1-888-554-2080.

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**THE MARCUS INSTITUTE**

Turning Disabilities into Possibilities

[Close](#) | [Print](#)**Affiliate Programs**

The Marcus Institute is committed to expanding the services and programs available to children with developmental disabilities and their families. By combining our expertise and strengthening partnerships with service providers, we are able to meet this need by improving access to appropriate clinical and educational services.

**Kennedy Krieger Institute**

In October 1998, The Marcus Institute merged with Baltimore-based Kennedy Krieger Institute creating the cornerstone of a plan to establish a national network of developmental services. Together, we strive for fuller integration of individuals with developmental disabilities into school and community life, better access for families to appropriate clinical and educational services, and enhanced funding for research and training.

For more information about Kennedy Krieger Institute, please visit their website at [www.kennedykrieger.org](http://www.kennedykrieger.org)

**Emory University Department of Pediatrics**

The Marcus Institute began as the Marcus Developmental Resource Center at Emory University in 1991 as a result of a generous donation to the Children's Research Center at Emory. Today, many of our professionals hold faculty appointments through the Emory Department of Pediatrics. In addition, we are an approved site for the Emory Pediatric Residency Program. Our affiliation with Emory affords us access to a wealth of academic and medical resources.

For more information about Emory University Department of Pediatrics, please visit their website at [med.emory.edu/pediatrics](http://med.emory.edu/pediatrics)

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**THE MARCUS INSTITUTE**

Turning Disabilities into Possibilities

**Contact Information / Phone Numbers**

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Telephone Numbers by Department

Department	Phone	Fax
General Information	404-419-4000	404-419-4505
Marcus Behavior Center-Behavior Therapy-School-Feeding Program	404-419-5000	404-419-5005
Marcus Evaluation Project	404-419-4070	404-419-4065
Corporate Relations	404-419-4082	404-419-4085
Fetal Alcohol Syndrome Clinic	404-419-4260	404-419-4265
President's Office	404-419-4062	404-419-4505
Pediatric Neurodevelopmental Center	404-419-5300	404-419-5410

Directions to The Marcus Institute  
 1920 Briarcliff Road Atlanta, GA 30329

For detailed driving directions and a map to The Marcus Institute from surrounding areas, please click here.

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 Indicates a link to the web site of our affiliate, Kennedy Krieger Institute.  
**Contact Us:** [webfeedback@marcus.org](mailto:webfeedback@marcus.org) © 2005 The Marcus Institute

Oconee Pediatrics  
210 North Pine Street Seneca, SC 29678  
William H. Lee, MD      Frank A. Stewart, DO      Thomas J. Alber, MD  
Susan McGilvra, NNP      Catherine Wilson, NNP

June 23, 2006

South Carolina Medicaid  
Attention: Robert Kerr  
P. O. Box 8206  
Columbia, SC 29202

Regarding: Faith Hudson  
Date of Birth: 1/7/04  
Recipient Number: 1780249432

**To Whom It May Concern:**

This letter is in support of a referral to the Marcus Institute for Faith Hudson. Faith has microcephaly, severe developmental delays, cerebral palsy, and severe feeding problems requiring a G-tube. Faith has continued to make slow progress with the assistance of PT, OT, and speech but not adequate as she still has profound feeding problems. Her condition is well beyond the abilities of the available services and any resources available in the state of South Carolina. The Marcus Institute in Atlanta, Georgia is affiliated with Emory University and is a comprehensive resource for children with developmental delay, cerebral palsy, neurological disorders and feeding disorders, such as Faith. Finding comprehensive services for children with disabilities is a constant struggle for parents and caregivers, and the Marcus Institute offers the most comprehensive diagnosis, therapy and care management possible for children with special needs like Faith, which are not able to be met locally. While Faith has made slow steady progress she has not met expected and needed goals with the limited services available in South Carolina and continues to have severe deficits. Early and prompt interventions are crucial to optimize her potential improvement, therefore please give this matter prompt attention. Faith has been accepted for an evaluation pending South Carolina Medicaid approval.

Please feel free to contact me with any questions or further information needed, and thank you for your consideration of this referral.

Sincerely,



Dr. Frank A. Stewart, D.O.



South Carolina Department of Health  
and Environmental Control

APPALACHIA I PUBLIC HEALTH DISTRICT  
Seneca Clinic  
P. O. Box 488  
609 North Townville Street  
Seneca, SC 29679  
864-882-2245 Fax 864-885-9659

June 30, 2006

To: Whom It May Concern

From: Elaine Prock, MS, RD

*E.P.*

Re: Feeding therapy for Faith Hudson

Faith Hudson would benefit from an in house feeding therapy program as she has issues related to textures and swallowing. There is no in house program in Oconee County or surrounding area. I have worked with one child who was in our Children's Rehabilitative Program who benefited greatly from this kind of program offered by Kennedy Krieger Institute, Johns Hopkins Hospital in Baltimore, Maryland. I hope you will consider this as necessary medical care for this child.

## Occupational Therapy Feeding Summary

Client: Faith Hudson

Date: 6/12/06

DOB: 1/7/04

Initial Date of Therapy Onset: 6/15/04

### Feeding Summary

Frequency: 2x/week

**History:** Faith has a history of feeding difficulties since birth. She was receiving services through Spartanburg Regional Hospital for feeding difficulties when therapy was initiated through Pediatric Therapy Works (PTW.) She has attended other specialty feeding clinics and/or therapies since but not intensely.

**Oral Motor Skills:** Initially, Faith would not voluntarily take anything to mouth. She initially demonstrated significant oral apraxia. She had no idea how to work any food items orally when presented. She demonstrated significant oral hypersensitivity. Gag reflex was strong. Faith has begun to voluntarily play with foods and/or toys orally. She enjoys taking vibrating toys to mouth. She will allow foods to be placed into her mouth and will allow the spoon to depress mid-blade tongue. Gag reflex is improving. She has minimal tolerance of cold food items. She has recently learned to bite on toys and/or foods. She will at times bite off small pieces of food items and allow them to dissolve in her mouth. She is noted to swallow minimal amounts of foods. She uses lip pursing to thrust most foods out of her mouth. She has recently begun to reject many foods when presented by turning her head and clinching her jaws. She enjoys interacting with unlidded cups. She allows mom to put some fluids into her mouth from cups. She does not, however, retain the majority of the fluid. She does not suck fluids via a straw nor blow bubbles or any blow toys at this time. She is able to click her tongue. She enjoys the use of a Z-Vibe during therapy and parents have subsequently purchased one for home use. No food item, flavor or texture has been identified as being favored by Faith.



Diane Nix, OTR/L  
*Pediatric Therapy Works*



HUDSON, FAITH A  
 Allied Health  
 OT Pediatric Therapy Works  
 14040-04111th 1434 TC: 08/19/05 14 04  
 ROOM - ADM: 04/03/08 02:34  
 AGE 27 SEX F INACTIVE LEONARD, S  
 DOB 01/07/2004 ID 5382056 MR 458032  
 RESCHEDULED-04/19/04 14 04 (S)21  
 OPT/OUT

Feeding

Faith has a PEG tube through which she receives most of her nutrition. She takes foods to mouth and has recently begun to bite on them. At times she will keep foods in mouth until they dissolve but purposefully spits out of mouth.  
 Dependent  
 Feeding is a critical concern at this time.  
 Concerned and knowledgeable parents

Sensory skills

Assess based on clinical observation  
 parent question

Tactile DN3  
 Displays some sensitivity to certain textures however this has improved markedly.  
 Takes many toys to mouth. Loves vibration. Demonstrates moderate to severe oral tactile sensitivity.  
 Responds appropriately to name  
 Wears glasses  
 Enjoys swinging and vestibular input. Unable to spin due to seizure tendency

Oral sensory DN3  
 Demonstrates moderate dyspraxia

Auditory DN3  
 Visual DN3  
 Vestibular DN3  
 Praxia DN3  
 Areas of concern DN3  
 Strengths DN3  
 Regulate indicate delay DN3

PE/CC Input POC

Strengths DN3  
 Areas of concern DN3

Assessment

Plan of care is discussed regularly with mom  
 Knowledgeable parents; motivated; cooperative; enjoys interaction  
 Feeding: fine motor; visual motor/perception; tone; strength; mobility; sensory processing  
 Faith continues to benefit from therapy 2X/week to address both feeding and neuromuscular, fine motor and sensory processing delays.

Plan DN3  
 The recommended clinic based DN3  
 Individual OT 2x week DN3  
 Copy eval to BabyNet DN3  
 referring MD

Prescription Screen

Ther-feeding diff DN3  
 Therapy provided DN3  
 Diag affect nutr DN3  
 Current medd DN3  
 Appetite DN3  
 Nutr supplement DN3  
 Curr PEG/G tube DN3  
 (1) OT  
 (0) office  
 (2) develop delay  
 (1) reflux  
 (2) poor  
 (3) pediatruce  
 (5) yes

HUDSON, FAITH A  
 ROOM: .

MR: 458032 ID: 5382056 CONTINUED  
 DOB: 01/07/2004 - OT Pediatric Therapy Works



See nutritionist  
Serv-health dept

Total Score  
Refer nutrition  
Summ of progress  
Attendance  
Time seen

(0) yes  
(0) CR5  
(0) baby net  
14  
no

- Goal #1
- Goal #2
- Goal #3
- Goal #4
- Goal #5
- Goal #6

Prog toward goal mastered  
 Prog toward goal slow progress  
 Prog toward goal slow progress  
 Prog toward goal mastered  
 Prog toward goal mastered  
 Prog toward goal mastered

other

Cont treatment

2x week

STG 7: Slow progress; STG 8:  
 Slow progress; STG 9: Slow  
 progress; STG 10: Ongoing

Excellent: seen 2x/week  
45 minutes

Plan  
 It denies pain  
 Education  
 Parent educated  
 Child education  
 Parent understanding

Yes  
 mother  
 observed session  
 verb understanding

HUDSON, PATRICK A  
 Pediatric Therapist  
 OT Pediatric Therapy Works  
 FROM 08/11/08 14:04 TO 08/12/08 14:04  
 ROOM: ADM 040808A 0754  
 AGE: 4Y SEX: F INACTIVE LEONARDA E  
 DOB: 01/07/2004 ID: 5362058 MR: 456932  
 SPECIALTY: OT  
 08/11/08 14:04 (SVT)  
 REQUIRING SIGNATURE  
 OPT OUT

Page 3

DN3  
 DN3

INTERIM



HUDSON, FAITH A	OPT OUT
Infant/Neon	
ST Pediatric Therapy Works	
PHONE: 04/1/02 11:03 TO 04/12/08 11:03	
ROOM - ADM: 060006 00:00	
AGE: 2Y SEX: F RAC/ETH: LEONARDA S	
DOB: 01/07/2004 TO 5:00:00 AM, 458832	
REGISTRATION: 04/12/08 11:03 (K516)	

Goal #4  
 container; raise arm for I DO.  
 Pt. will expand her phonetic inventory to 5 or more consonant sounds as observed in therapy and reported by her parents.  
 KSI-5

Goal #4 status  
 goal met: produces the sounds b, d, h, f, l, m, k, and occasionally v  
 Patch will take turns up to 4 times during play activities with the clinician to improve her precommunication skills needed for further speech and language development.  
 KSI-5

Goal #5 status  
 Progress has been reviewed with parent; mother participates in each weekly session.  
 KSI-5

Pt/CG education  
 cont. therapy  
 cont home prog

Recommendations  
 cont. home prog

Goals include  
 Goal #1  
 KSI-5

Goal #2  
 KSI-5

Goal #3  
 KSI-5

Goal #4  
 KSI-5

Goal #5  
 KSI-5

Goals from  
 oral motor act  
 sound declm act  
 expressive lang  
 play based act  
 receptive lang

Interventions  
 Goal #5  
 KSI-5

Goal #4  
 KSI-5

Goal #3  
 KSI-5

Goal #2  
 KSI-5

Goal #1  
 KSI-5

Copies to  
 (KSI15) KAREN SHUMAKER, ST  
 Parents; Babyinet (Oconee County); Dr. Stewart  
 KSI-5



**Physician and Therapist List**

**Oconee Pediatrics**

Pediatrician- Dr. Frank Stewart  
210 N. Pine St.  
Seneca, S.C. 29678  
864-882-7800 office  
864-882-5908 fax

**Pediatric Nutrition and Special Needs**

Feeding Pediatrician- Dr. Caroline Dy-Go  
3941 Hwy 9  
Boiling Springs, S.C. 29316  
864-585-2765 office  
864-560-9450 fax

**Developmental-Behavioral Pediatrics**

Developmental Pediatrician- Dr. Mark Clayton  
200 Patewood Dr.  
Greenville, S.C. 29615  
864-4545115 office  
864-454-5151 fax

**Pediatric Neurology**

Neurologist- Dr. Randal Blouin  
205 Enterprise Blvd.  
Greenville, S.C. 29615  
864-454-5110 office  
864-454-5141 fax

**Pediatric Surgery**

PEG Surgeon- Dr. Randal Abrams  
890 W. Farris Rd.  
Greenville, S.C. 29605  
864-455-5070 office

**Pediatric Therapy Works**

Occupational Therapist- Diane Nix  
Physical Therapist- Ashley Coleman  
Speech Therapist- Karen Shoemaker  
218 E. Calhoun St.  
Anderson, S. C. 29621  
1-800-825-6688 ext. 1198- Anderson office  
864-886-1012- Oconee office  
864-885-6073- Oconee fax

**BabyNet Early Intervention**

Early Interventionist- Kristi Freeman  
116 South Cove Rd.  
Seneca, S. C. 29672  
864-885-6048 office  
864-885-6073 fax



*State of South Carolina*  
*Department of Health and Human Services*

Mark Sanford  
Governor

Robert M. Kerr  
Director

August 3, 2006

Mr. and Mrs. Carl Hudson  
231 Elaine Drive  
Salem, South Carolina 29676

Dear Ms. Hudson:

Thank you for your letter requesting approval for Medicaid coverage for your daughter to receive services from the Marcus Institute Feeding Program in Atlanta, Georgia.

Pursuant to South Carolina Medicaid policy, out-of-state services cannot be approved until it has been verified that medically necessary services are unavailable in the state. The Medical Director for the South Carolina Department of Health and Human Services, Dr. Marion Burton, has reviewed your daughter's records and has indicated that we need to determine if your daughter can be treated by the Evelyn Trammell Institute for Voice and Swallowing at the Medical University of South Carolina (MUSC) in Charleston.

It is my understanding that program staff in the Division of Hospital Services has been in contact with you regarding the status of your request. We appreciate your cooperation as we thoroughly evaluate your daughter's medical needs.

If you have any additional questions or need assistance, please contact Ms. Zenovia Vaughn, Director, Division of Hospital Services, at (803) 898-2665.

Sincerely,

*Susan B. Bowling*  
Susan B. Bowling  
Deputy Director

SBB/gvb

Log #47

