

*The Center for Pediatric
Feeding and Swallowing
Disorders
Day Treatment Program*

*What Every Parent
Should Know*



I. Levels of Service

The Center for Pediatric Feeding and Swallowing Disorders provides three levels of service. These include **Outpatient Services, Day Treatment, and Inpatient Consultation.**

Outpatient Services are offered for evaluations and follow-up. An initial outpatient evaluation consists of a multidisciplinary assessment of your child including a comprehensive history, physical examination, oral motor exam, motor exam and feeding observation. Outpatient follow-up services are typically provided for 45 minutes every three to four weeks. During outpatient visits, treatment strategies will be discussed and may include medication changes, tube-feeding changes, motor exercises, oral-motor techniques and/or procedures to optimize mealtime structure. These procedures will be demonstrated to you and you will be able to practice the techniques before implementing them at home. Based on your report of how your child has progressed at home, recommendations will be adjusted as needed.

The **Day Treatment Program** is designed for children who require more intensive therapy to achieve their goals. See below for additional information regarding the Day Treatment Program.

Members of the interdisciplinary team are available for **Inpatient Consultations** at St. Joseph's Children's Hospital as needed.

II. Why Our Program Works!

The Center for Pediatric Feeding and Swallowing Disorders uses a team approach to evaluate and treat your child's feeding difficulties. The philosophy of the Center is based on the concept that feeding issues are complex and usually many factors contribute to a child's feeding difficulties. Therefore, the expertise of many disciplines is necessary to help children improve their eating. The integration of expert members of this multidisciplinary team makes the program at St. Joseph's unique and effective.

Team Members

| | | |
|--------------------------------|---|--|
| Medical Director | - | Peggy Eicher, M.D. |
| Clinical Director | - | William J. Roche, M.S., CCC BRS-S |
| Pediatric Nurse Practitioner | - | Louise Vitello, M.S.N., APNC |
| Speech Pathologist | - | JoAnn Petronchak, M.S., CCC |
| Behavior Analyst | - | Merrill Berkowitz, Ph.D., BCBA |
| Physical Therapist | - | Jeannie Rojas, PT, DPT |
| Occupational Therapist | - | Jessica Donato, OTR/L |
| Family Counselor | - | Pamela Martorana, M.A., LPC |
| efeed™ coordinator | - | Annmarie Marando, B.A. |
| Feeding Specialists | - | Brittney Chambers, B.S. Sarah Mokray, B.A. Ashley Marchese, B.A. |
| Child Care Aides | - | Miriam Ramos Regina DeLeon |
| Medical Secretary/Receptionist | - | Helen Stockstill |
| Financial Representative | - | Maria Mercedes |

III. Description of Disciplines

Many of the children referred to St. Joseph's Center for Pediatric Feeding and Swallowing Disorders have complicated medical, developmental, and/or feeding histories. In order for a child to consume adequate amounts of a variety of foods across all food groups at age appropriate textures, a number of factors must be in place. The following are brief descriptions of each of the disciplines involved in your child's care.

Medical Interventions for Pediatric Feeding Difficulties

The neurodevelopmental pediatrician and pediatric nurse practitioner are the specialists who manage each child's medical issues. Feeding is especially vulnerable to medical problems involving the primary organ systems that influence eating: the respiratory tract, gastrointestinal tract, and brain. Any medical problem that causes even temporary interruption or disruption to the function of one of these systems can result in a feeding problem. Therefore, the team will identify and minimize the effect of each of the child's medical issues and feeding problems to maximize their body's ability to tolerate food. Recommended interventions may include medications, changes in formula or other liquids, or changes in feeding volume or schedule.

Occupational and Physical Therapy and Pediatric Feeding

Postural support, rib cage/spinal mobility, trunk weakness, muscle imbalance and respiratory issues are typical reasons for treatment. Positioning needs will also be addressed. Treatment often includes rib cage and spinal mobilization, muscle stretching, therapeutic exercises, and taping techniques. Parents may participate in some motor sessions and are often provided with recommendations, which can be practiced at home. Training of community therapists is also encouraged for continued care. Motor therapy will primarily focus on issues affecting **feeding and swallowing**, and **may not address fine motor or developmental issues**, which should be addressed outside of the center.

Oral-Motor Therapy and Pediatric Feeding Difficulties

The speech pathologist works to provide therapy and suggestions to maximize the child's oral-motor skills. Independent of the feeding sessions, the speech pathologist works, as needed, on facilitating oral-motor movements and skills to facilitate improved feeding skills. The goals in these sessions always focus on oral motor skills for advancement in feeding. **Speech/language therapy is not provided at the Feeding Center.**

Applying Behavior Analysis to Pediatric Feeding Problems

For children with feeding problems, practicing those skills necessary to eat new or higher textured foods is often difficult. Applying the principles of learning, techniques have been developed to help children with feeding difficulties learn and master the skills/behaviors necessary to consume new and/or more food, advance texture, and self-feed. Behavior analysis also aids in the assessment of feeding problems by identifying possible learned patterns, the development of treatment procedures, and in the evaluation of treatments by measuring specific behaviors related to feeding.

Family Therapy, Support Groups and Pediatric Feeding Issues

Feeding issues affect every member of the family, not just the identified patient. The family therapist meets with families from the initial goal setting to the final discharge planning meetings while the child is enrolled in the day treatment program. The family sessions focus on the child's feeding issues and how they affect the family. A family member is expected to attend the support group on Monday morning and Friday afternoon. The support group is co-facilitated by the family therapist. In

the group setting, families will have an opportunity to meet one another and share concerns, fears, frustrations and successes they have had at the Center and at home. Individual treatment is available as necessary.

The Feeding Specialist's Contribution to the Team

During day treatment, each child is assigned a feeding specialist, who is responsible for providing your child's meals throughout the day. Each feeder is in charge of preparing meals, initiating oral feedings and/or drinking sessions, training parents/caregivers in meal procedures, and recording your child's progress during meals through data collection. The feeding specialists are available to his/her assigned child throughout the day during meals and in the playroom. Parents/caregivers are encouraged to communicate any questions or concerns to their child's feeder, as this person also works as the liaison between parents/caregivers and the team.

The Child Care Aides Contribution to the Center

The childcare workers maintain the playroom where your child will be when not in a feeding session or receiving motor or oral motor therapy. They help in the transition process when children must be separated from their parents at the beginning of the day. They attend to the needs of the children and organize play/creative activities. Their responsibilities also include maintaining the general hygiene of the children, which consists of diaper changing, washing their hands, and cleaning spills. They also supervise the children during naptime, give bottle feedings, or help them to drink from a cup. **The Child Care Aides only work with children who are admitted to the Day Treatment Program. Children who are not admitted to the Day Treatment Program are not allowed in the playroom.**

Parents' Rights Regarding Treatment

We encourage parents to assist in determining their children's menus. Typically, one of the goals we set for our patients is to consume an adequate portion of at least 16 different foods across all food groups (3 to 4 foods per meal). If your child has dietary restrictions (e.g. multiple food allergies, family keeps Kosher, etc.), we would ask you to provide all foods.

Because, you, the parent, will be implementing the treatment procedures while at home, we encourage you to help make decisions regarding interventions. If you do not think you can implement a specific intervention or find an intervention unacceptable, it is unlikely that you will implement the intervention at home. Therefore, it is important that you express any concerns that you have regarding any of the proposed treatment options.

If a treatment procedure has been shown to be ineffective in producing the desired change in your child's mealtime behaviors, oral-motor skills, or medical condition, all available options will be provided and their typical outcomes and any potential risks will be discussed.

Parents are encouraged to observe their child's feeding sessions from our observation room. The observation room allows for the team members to observe several children at the same time. Because of this arrangement, parents can also observe children other than their own. Please do not observe meals other than your own child's unless the parent of that child has given permission.

Over the course of a child's admission here at the Center for Pediatric Feeding and Swallowing Disorders, parents may also find themselves **inadvertently** exposed to information concerning other outpatient or day treatment patients in our program and outpatients. In situations such as these, **we ask caregivers to keep this information confidential**. If you have any questions relating to confidentiality, please speak to either your feeding specialist or to a senior staff member.

IV. Day Treatment

Prior to Day Treatment

Before your child is admitted to the day treatment program, a few things need to be completed. First, approval from your insurance company should be obtained. You should contact your insurance company to inquire about authorization/pre-certification for the admission. Our staff will provide you with the necessary information (CPT codes and tax ID numbers).

Second, if you are working during your child's admission, you should arrange with your employer time off to bring and pick up your child from the Center each day and be present for training.

Third, the week before your child's admission date, you should complete the pre-admission checklist and family assessment and return it to Pamela Martorana, family counselor.

What to Bring on Your First Day

Before you bring your child to Day Treatment, there are a few things you should bring with you (if applicable):

1. Most importantly, bring **food or formula** for your child's non-therapeutic feedings. We will provide food for the therapeutic feeding sessions **ONLY**.
2. If your child is on any **medications**, please bring them, with a dosage schedule and method of delivery. They must be in their original containers, with your child's name on them. We cannot give medicine that is not in the pharmacy labeled bottle. **We do not provide any medications as we are considered an outpatient center.**
3. Also, if your child needs **special equipment** (e.g., customized seating, nebulizer, suction machine or feeding pump), please make an effort to bring them; if this is not feasible, please inform us ahead of time, so that we may make arrangements.
4. You must provide a list of **emergency contact numbers**, as well as a list of people with driver's license numbers who may be picking up your child. If that person's name is not on the list or their identity cannot be confirmed by a license photo ID, your child will remain with staff until you or your confirmed representative can be contacted.
5. **At least one change of clothes** for your child.
6. **Diapers**, wipes, and cream for diaper rash, etc., if your child needs them.
7. Anything special that your child needs for comfort (e.g., a favorite toy, book, or blanket) will definitely help, especially during nap/quiet time.
8. Please **label** all your child's belongings. We cannot be responsible for lost or misplaced items.

What to Expect On Your First Day

If the first day of your child's day treatment admission is your first visit to the Center, an evaluation will be conducted in which information will be obtained regarding your child's medical and feeding histories, in addition to a family assessment. Several evaluations designed to allow us to better understand your child's feeding problem will then take place. These include physical and motor examinations, an oral-motor evaluation and a meal observation. **It is therefore necessary that you are available during the first day of your child's admission** in order to provide detailed information to the team and conduct a meal as you would at home. **Please bring the food and utensils that you use to feed your child.**

Your child's feeding specialist will also obtain information regarding your child's favorite toys and activities, their napping schedule (if appropriate), toileting skills and any pertinent information related to outside of meal preferences or potential problematic behaviors. After the evaluations have been

completed, your child will be able to play in the Center's playroom. **Unless requested by the Center's medical staff or childcare aides, parents are not allowed in the playroom.**

Based on the information obtained from the multiple evaluations, the team will determine the best course of action. These may include modifications to your child's medication regimen, tube feeding schedule or formula (if appropriate). Every day during your child's day treatment admission, the team will meet to discuss your child's progress and determine the next steps to take. An assessment of your child's mealtime behaviors and oral-motor skills will begin during the first day of admission. Typically, your child will be presented with a variety and amount of food at a texture that he/she is capable of consuming. This texture may be lower than what your child is normally accustomed to if it is found that your child's oral-motor skills are not adequate for higher textures. Mealtime structure will be added during the first treatment meals. Most often these procedures consist of presenting bites at fixed intervals and allowing your child to play with some of his or her favorite toys throughout the meal. Although you will be able to observe many of your child's feeding sessions in our observation areas, most often you will not have any contact with him or her until the end of the day. During the first week of your child's admission, a goal setting meeting will be scheduled and your attendance is mandatory. This meeting will be an opportunity for you to ask questions, voice any initial concerns and discuss your expectations of the admission. The team will attempt to answer all of your questions and address any of your concerns. More concrete goals of the admission will also be set. A discharge meeting will also be scheduled during the last week of the admission. Informal meetings with any discipline may occur throughout the admission. **Parents are always welcome to request additional formal conferences with the team during your child's stay.**

Daily Journal

In order to help maintain open and complete communication between you and our staff, we require that parents complete their children's Day Treatment Daily Journal each day. Knowing what your child is doing at home regarding his/her meals, outside of meal behaviors, stooling, medications, etc. will better help us make any necessary changes in your child's care.

Typical Daily Schedule

A typical day, including meals, therapies, and other activities, may look something like this:

| | |
|--------------|--|
| 9:00 | Arrive, check in with nurse or feeding therapist **Please arrive promptly!** |
| 9:15 | Meal |
| 9:45 – 11:00 | Other Therapy / Playroom |
| 11:00 | Meal |
| 11:30 – 1:30 | Other Therapy / Playroom / Naptime |
| 1:30 | Meal |
| 2:00 – 3:30 | Other Therapy / Playroom |
| 3:30 | Meal |
| 4:00 – 4:30 | Leave to go home |

It is important to remember that each child's schedule is determined by health, medical, and feeding needs. Schedules will vary according to the needs of each individual child.

Things to Remember

1. Please be **on time** for both drop-off and pickup, as per your child's daily schedule. Treatment starts at 9:00 AM. Remember: we have your child's whole day planned.
2. Remember that Mondays, Wednesdays and Fridays are the days that your child gets his/her weight taken.

3. Bring **food for your child's breakfast on the first day**; we would like to watch you feed, as you would typically do at home. We may request that you bring in your child's preferred foods so that they can be presented to your child either in therapeutic feeding sessions or in between meals.
4. **After we observe you feeding your child and obtain information, we will escort you and your child to our playroom. After a few minutes, you will be separated from your child.** You may observe your child during meal sessions through the one-way mirrors. Separation may initially be distressing for you or your child, but this allows the therapeutic meals to progress faster when your child is not constantly dealing with separation anxiety.
5. **In-between feeding sessions your child will primarily be in the Center's playroom and will be supervised.** We encourage parents to spend this down time either in a family lounge located in Apartment 912 above the Center or outside of the Center (at home, doing errands etc.). If you wish to spend time in the family lounge, you will be allowed to borrow a set of keys to the family lounge. In order so that these keys do not get lost, we require that you leave your car keys with us until you return the family lounge keys.
6. Typically on the first Thursday and Friday of your child's admission to the day treatment program, you will be asked to join the feeding sessions, first to observe and then to participate in the meal. We will be in contact with you daily so you know what progress has been made. If you do not stay at the Center, please make arrangements with work or school, so that you will be able to attend the meals and participate in parent training and feeding procedures.
7. We are all working hard to help, and **we expect a commitment from you for the benefit of your child.**

What to Expect Regarding Parent/Caregiver Training

Parent/caregiver training is an essential part of the day treatment admission. It is important for you and any other caregivers who will be feeding your child to participate in the training process. After the feeding specialist working with your child explains the current treatment procedures you will be gradually introduced into meals. This usually occurs on Thursday and Friday but may occur other days depending on your availability. On Fridays we will provide specific instructions for what to do during the weekends. Practicing the procedures over the weekends allows us to evaluate how the child responds outside of the center. We may also ask you to record how well your son/daughter ate during each meal. **Please make arrangements with your workplace for time off and/or arrangements for day care for your other children during the training sessions.** As your child progresses through the admission, the treatment procedures may change. You will have many opportunities to feed your child during the admission while receiving feedback and support from the staff.

When Not to Bring Your Child to Day Treatment

Due to the fragile nature of some of the children in our program, please do not bring your child in if he/she shows any evidence of illness. This may include: cough, runny nose, diarrhea, or fever (above 100.7°F). **A child must be fever-free for 24 hours before returning to the program.** If illness occurs during the day, the sick child will be isolated with staff to limit germs, and you will be called to pick your child up.

Follow-up after discharge

At the time of your child's discharge from day treatment, you will receive a written protocol describing all of the provided recommendations. A videotape containing a few of the final meals conducted at the Center may also be sent home with you. It is very important that you consistently follow all of the recommendations provided to you during the admission after your child is discharged from the day treatment program. It is common for children to have more difficulty at meals during the first week or two after discharge. They are typically just adjusting to the rules practiced at the Center in their own, familiar environment. If you live close to the Center, follow-

up services are typically provided 1 or 2 times a week for the first 2 weeks post discharge. As your child continues to make progress, follow-up visits will occur less frequently. During each follow-up visit bring a complete meal and the utensils you use during meals.

VI. efeed™

For families who do not live close to the Center, we offer the efeed™ Program. efeed™ is a unique telehealth program offered by the Center for Pediatric Feeding and Swallowing. An efeed™ session is facilitated by 2-way interactive video-conferencing software. The session allows us to interact and make real-time changes to your child's treatment with you in the comfort of your own home.

The efeed™ Program is an extension of the outpatient and the Day Treatment programs, designed for those patients who do not require or who have completed the on-site day treatment program. efeed™ appointments can be scheduled to:

- Initial Screening: Children identified as having possible feeding and swallowing problems can be screened from home and admission to the Day Treatment Program can be recommended.
- Once a child has graduated from the Day Treatment Program, follow-up appointments can be made via efeed™. You can use these appointments to work on maintaining or advancing skills. These sessions can also be used to train other caregivers in the techniques implemented at the Center.

VII. Miscellaneous

When You Have Concerns

Whenever you have any concerns that you feel are not being addressed at the Center, please direct your questions to William Roche, Clinical Director, Center for Pediatric Feeding and Swallowing Disorders at (973) 754-2924 or rocheb@sjhmc.org.

Concerns regarding medical care, nursing care, or other therapies should be addressed directly with the doctor or specialist assigned to your child.

Contact Information For The Center

The Center for Pediatric Feeding and Swallowing Disorders
St. Joseph's Regional Medical Center
11 Getty Ave.
Paterson, NJ 07503
Phone: 973-754-4300
Fax: 973-754-4330
Website: www.feedingcenter.org

Other Important Telephone Numbers

The Center's Clinical Director – William J. Roche

(973) 754-2924 Office
(973) 516-1537 Pager

| | |
|-------------------------------------|----------------|
| St. Joseph's Maintenance Department | (973) 754-3475 |
| St. Joseph's Information Desk | (973) 754-7904 |
| St. Joseph's Security Department | (973) 754-3496 |
| Taxi Service: | |
| Yellow Cab Company | (973) 523-7500 |
| D&V Cab Company | (973) 279-5555 |
| Veterans Cab Company | (973) 278-1212 |
| Jiggets Cab Company | (973) 345-4800 |

Housing Opportunities

The Center provides limited housing for those families residing more than 50 miles from St. Joseph's Regional Medical Center. First is **Apartment 102 @ 200 Hospital Plaza**, which is a fully equipped apartment, only available for families of our patients. There is an eat-in-kitchen, comprised of a full size refrigerator, stove, and microwave. The kitchen is supplied with dishes, cups and utensils. Linens and towels are also provided. A washer and dryer are available in the basement of the complex, and are operated by quarters. There is a crib and a day crib provided. There is a hospital telephone in the apartment that allows calls to hospital extensions, including the feeding center, and toll-free numbers that can be used with a credit or calling card. There is no internet service provided. A complete list of apartment items is provided below.

The apartment fee is NOT covered by insurance and is an out-of-pocket expense. The apartment is typically booked months in advance and is not guaranteed to be available for every child's admission. **You should call 973-754-4302 for Pamela Martorana to find out the next available reservation date. There is a \$400.00 deposit required** for reserving the apartment. Deposit refunds are provided only if changes or cancellations are made **in writing** with more than 60 days notice. Deposit checks should be made out to "Swallowing Center Fund #26316000."

The fee is \$57.00 a day, or \$1,710.00 per 30-day reservation. After the deposit of \$400.00 is received, the balance of \$1,310.00 for the 30-day stay is required upon the first day of admission. If additional days are required they will be charged at a rate of \$57.00 per day. Any refunds for a stay shorter than 30 days will be made within two weeks upon written request for a refund. A \$100 deposit in the form of a check will be required for the key, which will be returned to the parent when the key is returned at departure. Keys can be picked up at the center Monday through Friday between 8am and 4:30pm, unless special arrangements are made in advance.

Families have also stayed at hotels close to the Center. Hotels recommended by parents include:

Residence Inn By Marriott
30 Nevins Rd.
Wayne, NJ 07470
Contact: Juliet Lopez
973-872-7100

www.marriott.com/EWRWY

**Make sure you mention St. Joseph's

Prime Hotel and Suites in Fairfield
690 Rt. 46E, Fairfield, NJ 07004
phone: 973-227-9200
fax: 973-227-1127

website: www.primehotelsandresorts.com

Hampton Inn & Suites
118-124 Rt. 46 East, Fairfield, NJ, 07004
phone: 973-575-5777

Holiday Inn Totowa
1 Rt. 46 West, Totowa, NJ, 07512
phone: 973-785-9000
fax: 973-785-3031

Best Western Hotel
216-234 Rt. 46 East, Fairfield, NJ 07004

phone: 973-575-7700

Howard Johnson Hotel
680 Rt. 3 West, Clifton, NJ, 07014
phone: 973-471-3800

Wellesley Inn Fairfield
38 Two Bridges Road, Fairfield, NJ 07004
Phone: 973-778-6500

Mahwah Homewood Suites
375 Corporate Drive
Mahwah, NJ 07430
phone: 201-760-9994

Churchill Corporate Services
phone: 1-800-832-8918
website: www.furnishedhousing.com

Oakwood Corporate Housing
phone: 1-800-259-6914
website: www.oakwood.com