RWJBarnabas HEALTH

Children's Specialized Hospital

200 Somerset Street
New Brunswick, NJ 08901

rwjbh.org/csh
1-888-CHILDREN (244-5373)

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Children's Specialized Hospital:

Chronic Pain Management Team

About the Program:

Children's Specialized Hospital's Chronic Pain & Functional Neurological Disorders (FND) Center of Excellence (COE) encourages functional activity of children and adolescents by teaching strategies to manage pain and associated symptoms to engage in school, home, vacation, and community life.

Children served:

The Center focuses on treating conditions such as, but not limited to: Complex Regional Pain Syndrome (CRPS), Fibromyalgia, Amplified Musculoskeletal Pain Syndrome (AMPS), Chronic Headaches/Migraines, Chronic Abdominal Pain, Postural Orthostatic Tachycardia Syndrome (POTS), Functional Neurological Disorder (FND), and Functional Seizures. The typical age of children served is 10- 21 years.

Services provided:

Outpatient Program: This service line includes an initial Enhanced Evaluation (with physiatry and a mental health clinician) and follow-up (typically every 3-6 months), ongoing mental health (CBT) support, Physical Therapy and/or Occupational Therapy evaluation and treatment. Other related outpatient services that may be recommended include: Psychiatry, Nutrition, and/or Developmental Pediatrics.

Inpatient program: This program is typically for children, adolescents, and young adults with amplified chronic pain and/or functional symptoms who present with ongoing dysfunction despite participation in OP therapies, including but not limited to physical therapy, occupational therapy, and mental health services. This intensive interdisciplinary treatment is evidence-based focusing on regaining function through patient education on symptoms/diagnosis and development of adaptive coping skills. Therapy sessions focus on exercise, routine building, school re-entry, and age-appropriate daily activities. Length of stay is individualized and typically ranges from two to four weeks.

Treatment philosophy: to improve a patient's daily function through pain/symptom education, improving self-awareness, and promoting use of adaptive coping strategies. The goal of the program is to promote function by providing each patient with the necessary tools and information to manage potential stressors.

Arranging Services:

- Patients with an amplified pain disorder or functional neurological disorder seeking an evaluation to develop a treatment plan and determine needs may call **732-258-7150** or email **SpecialtyPrograms@childrens-specialized.org**.

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- An enhanced evaluation is completed by the team physiatrist and a mental health professional. Together, this team will evaluate the patient's physical, emotional, mental, and psychological status. They will then make recommendations for ongoing treatment; this may include ongoing outpatient services, referral for medical follow-up by another specialist, referral for mental health services, and/or admission to the Inpatient Chronic Pain and FND Program at Children's Specialized Hospital (CSH) in New Brunswick.
- Families seeking outpatient **Physical Therapy or Occupational Therapy** evaluation and treatment may contact our **Scheduling Department** at **888-CHILDREN, option #2.** Please mention if the child has recently had a PT or OT evaluation and is now seeking PT or OT treatment
- Families seeking outpatient Mental Health services may call our **Mental Health Access Coordinator** at **888-CHILDREN, x 5851** or **5131.**

Details of Inpatient Center of Excellence for Chronic Pain and FND:

- **Rationale for inpatient approach to treatment of chronic pain:** Inpatient treatment in a medically-based facility is often preferred for its intensity of Physical Therapy, Occupational Therapy, and integrated exposure to mental health intervention that might be limited on an outpatient basis.
- **Program goal:** to increase function, cope with pain/functional symptoms, and promote the use of adaptive coping skills for return to home, school, community, and leisure.
- **At admission,** a full evaluation will be completed by the Physical Therapist, Occupational Therapist, Psychologist, Child Life Specialist, Recreational Therapist, and Physician/Advanced Practice Nurse. At the evaluation, the team develops initial treatment goals with the patient/family and establishes a plan of care including frequency of therapies.
  - *Physical and Occupational Therapy*: Individualized services focus on promoting the use of the effected area(s) of the body, safely reducing and discontinuing the use of adaptive equipment or mobility aides, reducing allodynia (increased sensitivity to non-painful stimuli), increasing generalized strength, balance, and endurance, increasing body awareness, promoting time management skills, and increasing overall exercise knowledge. All therapies focus on the patient's knowledge and skills to promote independence in management upon discharge.

  - *Aquatic therapy*: facilitated by PT, OT, or RT with an emphasis on endurance training, generalized strengthening, and gross motor activity in a group or individual setting.
  - *Group Therapies*: may include meditation, yoga, gross motor activity, exercise, and diagnosis-related education.
  - *Psychology*: The psychologist provides education and counseling on the mind-body connection, identification of contributing stressors and coping strategies for management of chronic pain and functional symptoms. The psychologist also works with community schools to develop a plan for reintegration and support after program completion.
  - *Family education*: provides education and support regarding chronic pain and strategies for families to use to support functionality; this is a weekly requirement.
  - *Educational Instruction*: tutoring may be provided as needed when the patient is not in therapy. The amount of school is dependent on the individual school district. Upon admission, our educational liaison will attempt to gain a tutoring contract between our school district and the sending school district.

Recreational Therapy: Individual and group services. Individual leisure education sessions promote a patient's awareness of leisure, its benefits, and community-based resources. Group services promote socialization, community re-integration, and appropriate peer interactions. Outside of individual and group sessions, patients are encouraged to participate in our daily recreational programming held in the rec room.

Child Life: Child Life supports are available throughout a patient's inpatient stay as needed. Child Life services promote self-expression, use of coping skills, positive social engagement, and offer diversional activities to supplement their overall program. Patients are encouraged to attend recreation programming throughout their stay.

Social Work: Assists with discharge planning including coordination of school services.

At Discharge: During the last phase of the program, patients work with their primary therapists to develop a home exercise/activity program. Their participation in development of the program assists in the carryover and transition to independent management. Each program is individualized to the patient's needs, goals, and interests. The goal upon discharge is for the child to return to all normal activities, including school and extracurricular involvements, with modifications as appropriate. Ongoing services are recommended as needed for each patient, primarily including mental health and occasionally including physical or occupational therapy.

Program outcomes:

- Decrease in median patient reported pain level from 7 at admission to 4 at discharge on an 11 point scale.
- Improvement in median lower extremity functional activity (LEFS)* from admission (36 of 80) to discharge (69 of 80).
- Decrease in median child report of functional disability (FDI-C)* from 29 of 60 at admission to 6 of 60 at discharge. A lower score indicates better function.
- Increase in BOT-2* from admission (39) to discharge (50).
- Improved school attendance: At admission, 5.8% reported no school absences due to pain. At 3 months follow-up, 94.4% of patients reported no absences due to pain.
- Decrease in pain medication: 32% of patients were on pain medication at admission compared to 5% at discharge from the program. At 3 months follow-up, 12.2% of patients reached at follow up reported use of pain medication in the previous 2 weeks.
- At 3 months follow-up, 100% of parents reported no missed days from work due to their child's pain in the previous 2 weeks.
- 77.7% of patients who were reached at follow up reported following a home exercise program 3 months after discharge.

* LEFS— used to evaluate the impairment of a patient with lower extremity musculoskeletal condition or disorders. Scoring scale 0-80. All 20 items are scored with a maximum score of 4 for each item.

* FDI— assesses difficulty completing daily activities at home, school, recreational, and social domains. Items are rated in terms of difficulty the child or adolescent has completing each activity. Scoring Scale 0-60 with a higher score indicating more functional impairment.

* BOT-2— used to evaluate a wide variety of fine and gross motor skills for children, teenagers, and young adults 4-21 years of age.