

PEDIATRIC CRITICAL CARE: *Communication is Critical*

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A LETTER FROM JOHN SCHREIBER, MD

Dear Colleague,

At Floating Hospital for Children, we talk a lot about being there for you — the referring physician — and your patients in ways that are most beneficial to you. When making plans or improving our services, our specialists are often heard saying that the answer does not lie in what we need, but rather what community physicians and parents need. The announcement of our recent partnership with **MetroWest Medical Center** makes these comments far more than words — they truly are the mission and practice of Floating Hospital for Children.

Our relationship with MetroWest expands on the type of work we have been doing in the Lowell region for several years. The heart of these partnerships is bringing Floating specialty care to the community. Whenever possible, we don't ask people to come to us, instead we go to them. Outside of Boston we have **Pediatric Specialty Centers in North Chelmsford and Woburn**. We have neonatologists at **Brockton Hospital, Lowell General, Lawrence General, Melrose-Wakefield** and **Jordan Hospital** in Plymouth, and we have hospitalists caring for pediatric patients right on the halls of LGH. Be on the lookout soon for news of our seamless transport system to downtown Boston when a child needs complex specialty support and intensive care at Floating.

Now through our partnership with MetroWest's Framingham Union Hospital, families west of the city can experience the convenience and comfort that comes from Floating partnering with local pediatricians and family physicians. Pediatric specialists in gastroenterology, neurology, developmental-behavioral, genetics, nephrology and hematology/oncology will begin seeing patients in Framingham this year; some as early as May. In addition, our neonatologists and professional hospitalists will staff Framingham Union's NICU and Pediatric floor. This allows parents and children to stay safely in the community for both ambulatory and inpatient care of common pediatric conditions at their own, trusted community hospital. We are extremely excited to be working with the excellent pediatricians and family physicians in the MetroWest region and have greatly enjoyed the collaboration with MetroWest's physician and administrative leadership.

It is partnerships like this that remind us that we have a very special and important mission in the state. I hope that we can partner with you in an innovative way in the future. I am always open to ideas on how we can make pediatric specialty care more convenient and accessible for you and your patients. If you have ideas on how we can better serve you, call or email me — jschreiber@tuftsmedicalcenter.org, **617-636-8031**. I look forward to hearing from you.

All the best,

A handwritten signature in black ink that reads "John Schreiber, MD".

John Schreiber, MD
Pediatrician-in-Chief, Chief Administrative Officer
jschreiber@tuftsmedicalcenter.org
617 636-8031

Pediatric Otolaryngology



A multidisciplinary service that believes collaboration not only enhances the patient experience but improves patient outcomes.

Floating Hospital for Children is pleased to welcome aboard a new Chief of Pediatric Otolaryngology who not only expands the hospital's offerings in specialized ENT services for children, but also shares a commitment to working as a multidisciplinary team to provide the best results for his patients.

This past September, Mark Vecchiotti, MD joined Floating and is leading four areas of specialization: The Cleft Lip and Palate Program, Voice Program, Cochlear Implant Program, and Neonatal and Pediatric Airway Disorders. Each of these subprograms are collaborative in nature.

Vecchiotti says, "I really believe in the collaboration model. We are a pediatric otolaryngology department that is truly multidisciplinary."

Vecchiotti noted that he often works along side plastic surgeons for cleft lip and palate surgery. "Together we provide the greatest expertise in problems that are associated with cleft lip such as hearing loss, speech issues, and swallowing/airway disorders," he says.

Alex Flores, MD, Chief of Pediatric Gastroenterology, and Michele Palella, MD, PhD in Pediatric Pulmonary Services also collaborate often with Vecchiotti. Vecchiotti cites the example of a patient with gastroesophageal reflux disease.

"A patient with gastroesophageal reflux disease could also have a chronic cough and voice changes, as well as more frequent exacerbations of reactive airway disease. Dr. Flores

would provide input on how to optimize control of reflux, Dr. Palella would manage the lower airway disease, and I would treat the cough and voice changes."

Vecchiotti continues, "In this way, the best approach to treating a patient with upper aerodigestive complaints is by working together. This team approach allows for collaboration of different ideas and perspectives and avoids confusing or even conflicting recommendations."

Vecchiotti feels that collaboration with other pediatric services not only enhances the care provided and the outcomes achieved, but it also enhances the patient experience, especially since all of the pediatric services are located under one roof.

The addition of Vecchiotti has greatly expanded the capabilities of the Floating Department of Otolaryngology. The department handles a diverse and large scope of patients easily at Floating.

John Schreiber, MD, MPH, Pediatrician-in-Chief and Chief Administrative Officer of Floating Hospital for Children states, "Floating Hospital for Children is extremely fortunate to have Dr. Vecchiotti as our pediatric otolaryngologist. Mark brings outstanding training, great clinical experience and real warmth and enthusiasm to the Floating." □

MARK A. VECCHIOTTI, MD

Chief, Pediatric Otolaryngology

Medical School

Weill Medical College of Cornell University, 2001

Postgraduate Training

Case Western Reserve University Hospital; Children's Hospital, Boston

Board Certification

Otolaryngology — Head and Neck Surgery

DOCTOR'S NOTES

To refer a patient to the Division of Pediatric Otolaryngology at Floating Hospital for Children at Tufts Medical Center, call 617-636-2820.



PEDIATRIC CRITICAL CARE: *Communication is Critical*

When showing off a pediatric intensive care unit, most chiefs would focus on the state-of-the-art equipment, the constant monitoring technologies, and the 24/7 operations. But not Rashed Durgham, MD, Chief of the PICU at Floating Hospital for Children at Tufts Medical Center.

While Durgham and his staff have the most advanced technologies to care for their patients, Durgham says the tool that matters most is that of communication — communication with the patient’s family and communication with referring physicians.

“Interaction with the family of the patient is very important. They know their child is very sick, and they want to be informed and involved with the treatment of their child,” says Durgham, a 13-year veteran of intensive care medicine.

In fact, at Floating’s PICU, it is not uncommon to see parents take an active role in rounds every day. “We actively discuss the child’s treatment plan with the parents and, we, along with our subspecialists, are always accessible for consult. Academic medical centers can often seem like big, impersonal places, but at Floating, we make sure the parent doesn’t feel that way during their child’s time with us. We have a very close relationship with the family. This is a major distinction of our program,” says Durgham.

This attention to personal needs and communication is also evident in the Floating PICU team’s interaction with referring physicians.

“We are a tertiary care hospital but we certainly have a very close relationship with the family. This is a big distinction that I have to emphasize.”

— PICU Chief,
Dr. Rashed Durgham

“We emphasize continued communication with the referring physician. Once the patient has been transported to our PICU, we immediately inform the referring physician that their patient has been admitted,” says Durgham. “We provide the physician an update on the patient’s status and let them know we are available at any time to answer any questions.”

Durgham says his team of physicians, which include Mehrdad Mehr, MD;

Jason Cook, MD; and Carlos Duran, MD pride themselves on being available when referring physicians need them.

“We answer the phone right away,” says Durgham. “And if a second opinion is needed, it is readily available.”

Floating’s PICU is a 10-bed unit and fully equipped with private and spacious isolation rooms. Children receiving treatment are fully monitored, and each room has the capability of accommodating the sickest of patients.

In addition to the four physician-trained PICU intensivists who care for surgical and non-surgical patients, the unit also has a team of very experienced nurses. Four to five nurses are on the PICU at any given time. They are assisted by respiratory therapists, physical therapists, nutritionists and pharmacists when special services are needed.

Durgham says that patients entering the PICU have complex and complicated conditions.

“We work very closely with our surgeons to care for children after complex surgeries. Our multidisciplinary PICU provides exceptional care for high acuity patients coming from surgeries or dealing with other medical conditions that require constant monitoring. We have a full service PICU,” says Durgham.

The PICU staff also works closely with the Floating’s hospitalists who handle much of the referral process. There is a single toll-free phone number in place for a referring physician to call to have their patient transferred to Floating’s PICU (877-KIDS-FHC). A Floating hospitalist takes the call concerning the referral and helps triage that patient which may involve placement into the PICU. The hospitalists also work



RASHED DURGHAM, MD

Chief, Pediatric Critical Care/PICU

Medical School

Aleppo University School of Medicine, Syria, 1987

Postgraduate Training

Rainbow Babies and Children’s Hospital, Cleveland, Ohio; Henry Ford Hospital, Detroit, Michigan

Board Certification

Pediatrics, Pediatric Critical Care, Diplomat (FLEX)

DOCTOR’S NOTES

To refer a patient to the Pediatric Intensive Care Unit at Floating Hospital for Children at Tufts Medical Center, call the Floating hospitalists at 877-KIDS-FHC (877-543-7342).

diligently to secure all arrangements for transport — either by ground or by flight.

Durgham says that referring physicians have told him how much they value access to the hospitalists and intensivists and that the single phone number makes the referral process, as well as following up on the patient, simple and efficient.

“The referring physicians know that at Floating, the care team is only a phone call away and remains accessible 24 hours a day, 7 days a week,” says Durgham. □

MEET OUR New Physicians

Floating Hospital for Children at Tufts Medical Center is proud to announce the addition of **31 new pediatric clinicians** during the past year. To schedule an appointment with any of these expert physicians, call **617-636-8100**.

CENTER FOR CHILDREN WITH SPECIAL NEEDS



ROULA N. CHOUERI, MD

Neurodevelopmental Pediatrician

Board Certification:

Pediatrics, Neurodevelopmental Disabilities

Specialties:

Neurodevelopmental neurode disabilities, autism and autism spectrum disorders (ASD), early diagnosis of ASD

Foreign Languages:

French, Arabic



CATHERINE DAVIS, MD

Developmental-Behavioral Pediatrician

Board Certification:

Pediatrics

CRITICAL CARE



RASHED DURGHAM, MD

Chief, Pediatric Critical Care/PICU

Board Certification:

Pediatrics, Pediatric Critical Care, Diplomat (FLEX)

Specialties:

Sepsis, mechanical ventilation, head injury

Foreign Languages:

Arabic



JASON COOK, MD

Critical Care Pediatrician

Board Certification:

Pediatrics, PALS certification, NRP Certification

Specialties:

Management of intracranial hypertension and respiratory failure



MEHRDAD MEHR, MD

Critical Care Pediatrician

Board Certification:

Pediatrics, Pediatric Critical Care, Advanced Trauma Life Support

Specialties:

Traumatic brain injury, transport medicine

Foreign Languages:

Farsi, French

GENERAL PEDIATRICS AND ADOLESCENT MEDICINE



MARY E. BROWN, MD

Pediatrician

Board Certification:

Pediatrics, National Board of Medical Examiners

Specialties:

Chronically ill pediatric patients



ARVIN GARG, MD

Pediatrician

Board Certification:

Pediatrics

Specialties:

Pediatrics, clinical research



THERESA A. WILLETT, MD, PHD

Pediatrician

Board Certification:

Pediatrics Board Eligible

Specialties:

Primary care and adolescent medicine



HOSPITALISTS

PRIYA S. GARG, MD

Pediatrician, Hospitalist

Board Certification:

Pediatrics

Specialties:

Pediatrics, resident and medical education

COMMUNITY HOSPITALISTS

LISA CAPRA, MD

Director, Hospitalist Program, MetroWest Medical Center

Board Certification:

Pediatrics

Specialties:

Pediatric pain management, newborn care

JANA LEARY, MD

Hospitalist, MetroWest Medical Center

Board Certification:

Board Eligible, Pediatrics

LINDSAY MILLER, MD

Hospitalist, MetroWest Medical Center

Board Certification:

Board Eligible, Pediatrics

GENETICS AND METABOLISM

REENA JETHVA, MD, MBA

Pediatric Geneticist

Board Certification:

Pediatrics

HEMATOLOGY/ONCOLOGY

MICHAEL KELLEY, MD

Pediatric Hematologist/Oncologist

Board Certification:

Pediatrics

NEUROLOGY



ELIZABETH O'MAHONY, MD, BCH, BAO

Pediatric Neurologist

Board Certification:

Board Eligible

Specialties:

Pediatric neurophysiology (epilepsy)

SONYA G. WANG, MD

Pediatric Neurologist

Board Certification:

Pediatrics

Specialties:

Epilepsy/clinical neurophysiology

NEWBORN MEDICINE



SHADI MALAEB, MD

Neonatologist

Board Certification:

Board Eligible

Specialties:

Perinatal brain injury and development

Foreign Languages:

Arabic

SARBATTAMA SEN, MD

Neonatologist

Board Certification:

Pediatrics



MICHELLE WEISSMAN, MD

Neonatologist

Board Certification:

Pediatrics

ORTHOPAEDICS



STUART V. BRAUN, MD

*Chief, Pediatric Orthopaedics; Director,
Pediatric Orthopaedic Clinic*

Board Certification:

Orthopaedic Surgery

Specialties:

Orthopaedics, pediatric orthopaedics



PURU GHOLVE, MD, MBMS, MRCS

Pediatric Orthopaedic Surgeon

Board Certification:

Board Eligible, Orthopaedic Surgery

Specialties:

Pediatric hip and scoliosis, young adult and adolescent hip preservation, cerebral palsy and pediatric foot

OTOLARYNGOLOGY



MARK A. VECCHIOTTI, MD

Chief, Pediatric Otolaryngology

Board Certification:

Otolaryngology–Head and Neck Surgery

Specialties:

Pediatric otolaryngology

RHEUMATOLOGY

MARC D. NATTER, MD

Pediatric Rheumatologist

Board Certification:

Pediatrics

CHILD AND ADOLESCENT PSYCHIATRY



ANELA BOLFEK, MD

Child and Adolescent Psychiatrist

Board Certification:

Child and Adolescent Psychiatry, Psychiatry

Specialties:

Child and adolescent psychiatry



SMITA SIRVASTAVA, MD

Child and Adolescent Psychiatrist

Board Certification:

Child and Adolescent Psychiatry, Psychiatry

Specialties:

Child and adolescent psychiatry

PHYSICAL MEDICINE AND REHABILITATION



PATRICK J. BRENNAN, MD

Pediatric Service Physiatrist

Board Certification:

Board Eligible, Physical Medicine & Rehabilitation

Clinical Specialties:

Pediatric and adolescent rehabilitation, cerebral palsy and spasticity management, gait disorders, spinal cord injuries, head injuries, physiatry

PEDIATRIC SURGERY AND TRAUMA



CARL-CHRISTIAN A. JACKSON, MD

Pediatric Surgeon

Board Certification:

Surgery

Clinical Specialties:

Pediatric surgery □

WORKING TOGETHER

Real experiences from our referring physicians

Kumble Rajesh, MD

Kumble Rajesh, MD, Chief Medical Officer of Lowell Community Health Center and Chair of the Department of Pediatrics at Lowell General Hospital, has been referring his patients to Floating Hospital for Children at Tufts Medical Center for more than 10 years.

Both he and his patients are extremely satisfied with the level of care and professionalism the Floating has to offer. Rajesh is especially pleased with the pediatric partnership developed between Lowell General and Floating that brings Floating specialists right into the Lowell community.

"Floating Hospital for Children has an excellent group of referral physicians," says Rajesh. "Each is willing to spend time to discuss difficult patient cases. I have used the specialists not only for my patients but also for my own education about common medical topics."

Rajesh continues, "Almost all the specialists are willing to discuss current care standards that are useful for my own practice here. One specialist that definitely needs special mention is Dr. Milner, in Nephrology, who is an outstanding physician with the most courteous manner. He is always available and willing to help you with patients."

For more than three years, Floating and LGH have worked together to ensure that families in the Lowell area have ready access to top pediatric specialists. Floating specialists see outpatients in a convenient North Chelmsford location and Floating hospitalists and neonatologists care for young children and infants right at LGH. When a child's condition is extremely serious, the child is transferred to Floating's downtown Boston campus.

Rajesh constantly hears excellent feedback from his patients who have received both outpatient as well as inpatient referrals to Floating. Many of his families have had long standing relationships with the specialists, and Rajesh notes that his families would not consider going anywhere else but Floating. "Patients have been extremely satisfied with the level of care they receive at the Floating," he states.

The patient experience is very important for a physician when choosing what specialist to refer their patient to. But as Rajesh also points out, "The most important aspect of a referral is the appropriate communication between the specialist and the referring physician. In almost all instances at Floating, the communication is great, especially with urgent issues that need co-management between the primary care office and the specialist. Furthermore, the written communication is very good and details the visit as well as the plan."

Rajesh says it is really quite simple, "I will continue to refer my families to the Floating. The partnership with Lowell General Hospital has been a great boon to our patient population." □



To refer your patients to Floating Hospital for Children at Tufts Medical Center, call 877-KIDS-FHC (877-543-7342).

For the Pediatric Specialty Center/North Chelmsford, call 978-937-6362.

Have a Story for Us?

At Floating Hospital for Children, we value our referring physician partners and are committed to doing all we can to make it easy for you to refer your patients here. It is our mission to ensure that they, and you, have a positive experience during the entire referral process. If you have a story to tell about your experience with Floating Hospital, please contact us at heathyfutures@tuftsmedicalcenter.org. We would love to include it in a future Working Together column.

Whole Body

THERAPEUTIC HYPOTHERMIA

Floating's NICU— A leader in bringing research and technology to the bedside



IN THE PAST THERE WAS LITTLE HELP FOR NEWBORNS who needed prolonged resuscitation at birth followed by an abnormal neurologic status, but technology and research at Floating Hospital for Children are improving the odds for these most vulnerable infants.

The key to these improvements: therapeutic hypothermia.

Known less formally as “cooling,” therapeutic hypothermia involves placing a newborn admitted into the NICU on a “cooling blanket.” The blanket utilizes the circulation of cool water to lower the newborn’s core temperature from a normal 37 to 33 degrees centigrade, and maintain the child at this temperature for 72 hours. After 72 hours, the newborn’s core temperature is gradually rewarmed ($\frac{1}{2}$ degree centigrade per hour), which takes about six hours.

The first large scale human clinical trial of therapeutic hypothermia for newborns who required both prolonged resuscitation at birth and had an abnormal neurological exam and mental status was published in 2005. This year, the Floating NICU professionals will further investigate the subject, hoping to expand on the benefits discovered in the first trial.

The 2005 study, organized by the National Institute of Child Health and Human Development (NICHD) Neonatal Research Network, tested therapeutic hypothermia in certain newborns to prevent complications that follow neonatal encephalopathy. Encephalopathy can be followed by complications such as brain damage or moderate-to-severe disabilities, or in the worst case, death. A half-century ago, babies in this situation were treated utilizing various support respirations and cardiac output, but there was no therapy specifically directed at the brain.

Prior clinical trials were limited to animal subjects, but in 2005 the NICHD published the results of a classical randomized control trial where babies meeting certain criteria were either assigned to standard care (control group) or to standard care and therapeutic hypothermia.

According to John Fiascone, MD, Floating’s NICU Medical Director, the 2005 trial resulted in modest but significant advantages for the newborns who received therapeutic hypothermia treatment. Of the 205 infants participating in the trial, death or moderate-to-severe disability occurred in 45 of 105 infants (44 percent) in the hypothermia group and 64 of 103 infants (62 percent) in the control group. The conclusion of the study indicated that whole-body hypothermia reduces the risk of death or disability in

infants with moderate to severe encephalopathy. It was concluded that newborns who received the cooling treatment were approximately 29 percent less likely to result in moderate-to-severe disability or death. Despite these findings, too many of the infants with encephalopathy still had a negative outcome even with therapeutic hypothermia. This is where new research seeks to find answers.

Fiascone and his NICU team will once again be involved with the NICHD Neonatal Research Network’s research on the subject. The new research is headed by Floating Neonatologist, Ivan D. Frantz III, MD, who directs NICHD Neonatal Research efforts in the Floating’s NICU. The goal of this follow up clinical trial is to determine if a longer period of hypothermia or a lower core temperature will improve results.

Fiascone says, “There is a time-window here.... We know that there is a benefit to therapeutic hypothermia if it is started within six hours of birth. What we don’t know is if it can work for infants seven, eight or nine hours old.” According to Fiascone, the research is ongoing. “Does lowering the core body temperature lower than 33 degrees centigrade matter? Does the duration of the cooling process matter? There are many variables to work with here,” he says.

Frantz, Fiascone and the team hope to find the answers to these questions that will ultimately save more lives. □

“There is a time-window here.... We know that there is a benefit to therapeutic hypothermia if it is started within six hours of age. What we don’t know is if it can work for infants seven, eight, or nine hours old.... There are many variables to work with here.”

— Dr. John Fiascone,
Floating’s NICU Medical Director

ON CALL

A regular feature introducing the specialists at the Floating Hospital for Children at Tufts Medical Center

PEDIATRIC NEUROLOGY

The Division of Pediatric Neurology at Floating Hospital for Children at Tufts Medical Center cares for children of all ages with a full spectrum of neurological disorders, including conditions affecting development, movement, and learning as well as headaches, neurometabolic disorders and epilepsy. The division offers ready access to outpatient consultations.

The Division of Pediatric Neurology consists of four staff neurologists and one neuropsychologist, working in close collaboration with various pediatric services including Neurosurgery and the Center for Children with Special Needs. Current areas of specialized expertise include neonatal neurology, neuromuscular disease, cerebral palsy, headache, acute care neurology and epilepsy.

The newest member of the division, Elizabeth O'Mahony, MD, BCh, BAO, is fellowship trained in epilepsy and seizure disorders. Linda Specht, MD, PhD, Chief of Pediatric Neurology, states, "We are very excited to have Dr. O'Mahoney on our team. Her experience in the area of pediatric epilepsy is quite impressive and represents a tremendous benefit for our patients." Since her arrival, the division has established a Pediatric Epilepsy Unit with state-of-the-art equipment. Patients now have access to a dedicated pediatric center for EEG testing, including long-term monitoring and ambulatory studies. Sonya G. Wang, MD, a fellowship-trained epilepsy specialist, will be joining the division in October. □

Floating Hospital for Children offers a wealth of expert specialists to assist you in the care of your patients. During the past several years, we have added new physicians in many specialties to better serve you. This feature highlights several of our newest physicians, your newest referral resources. **To learn more about our new specialists, visit floatinghospital.org and click on "find a physician."** Or call 617 636-6432 to request a copy of Floating Hospital's Physicians Referral Guide.



LINDA SPECHT, MD, PHD
 Chief, Pediatric Neurology
Medical School
 Cornell University Medical College

Fellowships and Postgraduate Training
 Floating Hospital for Children at Tufts Medical Center;
 Massachusetts General Hospital

Board Certified
 Pediatric Neurology

Specialties
 Neuromuscular



REBECA ALVAREZ-ALTALEF, MD
 Pediatric Neurologist
Medical School
 Universidad de San Carlos
 de Guatemala

Fellowships and Postgraduate Training
 Beth Israel Medical Center, NY; Long Island College
 Hospital; Children's Hospital, Boston

Board Certified
 Pediatrics

Specialties
 Acute care neurology

Foreign Languages
 Portuguese, Spanish



PAMELA FOLLETT, MD, MPH
 Pediatric Neurologist
Medical School
 New Jersey Medical School

Fellowships and Postgraduate Training
 University of Massachusetts Medical Center; Children's Hos-
 pital, Boston; Harvard School of Public Health

Board Certified
 Child Neurology

Specialties
 Neonatal neurology, neuroepidemiology



ELIZABETH O'MAHONY, MD, BCH, BAO
 Pediatric Neurologist
Medical School
 University College Dublin

Fellowships and Postgraduate Training
 Floating Hospital for Children at Tufts Medical Center;
 Children's Hospital, Boston

Board Certified
 Board Eligible, Pediatric Neurology

Specialties
 Pediatric neurophysiology (epilepsy)

SONYA G. WANG, MD
 Pediatric Neurologist

Medical School
 Vanderbilt University School of Medicine

Fellowships and Postgraduate Training
 Floating Hospital for Children at Tufts Medical Center;
 Children's Hospital, Boston; Massachusetts General Hospital

Board Certified
 Pediatrics

Specialties
 Epilepsy/clinical neurophysiology

*To refer your patients to the Division of Pediatric Neurology at Floating Hospital
 for Children at Tufts Medical Center, call 617-636-8100*



Health Sheet

ROULA N. CHOUERI, MD

Neurodevelopmental Pediatrician
Assistant Professor Pediatrics,
Tufts University School of
Medicine

Medical School

St. Joseph University School of
Medicine, Lebanon

Post Graduate Training

American University of Beirut,
Lebanon; Children's
Hospital, Boston; Massachusetts
General Hospital

Board Certification

Pediatrics; Neurodevelopmental
Disabilities

Clinical Interests

Autism Spectrum Disorders
and early diagnosis of Autism
Spectrum Disorders

DOCTOR'S NOTES

To refer a patient to the Center for
Children with Special Needs (CCSN):

Main Campus, Boston

Little Kids Clinic: Children younger
than 3 years: 617-636-8009;

All other children 3+ years:
617- 636-7242

Pediatric Specialty Center/North Chelmsford

Little Kids Clinic: Children younger
than 3 years: 978-937-6362;

All other children 3+ years:
978-937-6362

AUTISM Q&A

with Roula N. Choueiri, MD neurodevelopmental pediatrician

ACCORDING TO THE NATIONAL INSTITUTES OF HEALTH, three to six children out of every 1,000 will have an autism spectrum disorder (ASD), and males are four times more likely to be affected than females. Scientists aren't certain what causes ASD, but it is likely that both genetics and environmental factors play a role.

Roula N. Choueiri, MD, Neurodevelopmental Pediatrician in the Division of Developmental-Behavioral Pediatrics at Floating Hospital for Children at Tufts Medical Center, answers some basic questions about this condition.

What is autism?

Autism was first described in 1943, by Leo Kanner, an Austrian psychiatrist. He described children with aloofness, indifference to others, who reacted differently to their environment and had speech delays. Autism: derives from the Greek autos: self.

As we know it today: Autism is part of the Pervasive Developmental Disorders (PDD) which include deficits in three core areas: social skills, language and communication, and repetitive behaviors and/or restricted interests. Onset is seen in the first three years of life.

Under the umbrella of PDD are:

- ▶ Autistic Disorder
- ▶ Asperger Syndrome
- ▶ Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)
- ▶ Childhood Disintegrative Disorder
- ▶ Rett Syndrome

Autism, Asperger Syndrome and PDD-NOS are grouped into the Autism Spectrum Disorders (ASD). Sometimes autism and ASD are used interchangeably.

Does Autism have grades of severity?

Yes — The "spectrum" in ASD means that there is a wide range of intensity, symptoms and behaviors. Children with Autism Spectrum Disorders may be non-verbal with significant social delays, as in the case of many with "classic" autism, or Autistic Disorder. Or, they can present with delays in their social skills and play, but with normal to superior cognitive skills and normal language development, such as seen in children with Asperger or high-functioning PDD-NOS. All ASDs have delays in the three core areas of: social interaction, communication and repetitive behaviors/restricted interests.

How early can autism be diagnosed?

Autism is usually diagnosed by the age of three years, although it can be recognized and diagnosed by the age of 18 months. Children with Asperger Syndrome and some children with high-functioning PDD-NOS might be diagnosed later, typically by the time they enter kindergarten or first grade.

Previous studies have shown that parents start being concerned between the ages of 12–24 months because of delays in language, play, difficulties with eye contact, but also with repetitive behaviors such as lining up toys or spinning objects or themselves. Other concerns that parents may have at this age: uncontrollable temper tantrums, extreme resistance to change, over- or under-sensitivity to sights and sounds and/or a regression in language and/or play skills.

Can a child be screened for autism?

The American Academy of Pediatrics (AAP) is recommending regular screening for Autism Spectrum Disorders at ages 18 months and 24 months if there are no other risk factors or concerns. This would be part of a well-child visit. However, screening is recommended at any age if there are risk factors and concerns. The AAP has a well detailed algorithm that can be accessed at: <http://www.medicalhomeinfo.org/health/Autism%20downloads/AutismAlarm.pdf>. Several screening tools are validated for ages older than 18 months and there is active research to identify screening tools for children younger than 18 months.

If the child fails the screening test, then he/she needs a referral for early intervention services and at the same time, a referral to a subspecialist for a final diagnosis. Sometimes the pediatrician can give the diagnosis. The earlier the child starts receiving the appropriate intensive services, the better the prognosis.

What causes autism?

We still don't know a lot about the causes of ASDs. We are able to find a cause up to 10 percent of the time. We know that there is a strong genetic basis from family studies. Parents who have a child with an ASD have a 2–8 percent chance of having a second child who is also affected. This genetic basis seems very complex and research is extremely active in this area. ASDs are frequently associated with: Fragile X, tuberous sclerosis, congenital rubella syndrome, and untreated Phenylketonuria (PKU). There are several reported associations with different chromosomal anomalies.

What treatments are available currently?

There are several treatment options currently available but they can be grouped into four categories, with the behavioral and educational interventions being the most proven, researched and the one that addresses treatment of the core features of autism spectrum disorders.

Treatments include:

- ▶ Applied Behavior Analysis (ABA): remains the foundation of most comprehensive programs; it is based on positive reinforcers and breaking down directions and tasks to simple tasks which leads to learning through repetition.
- ▶ Floortime: which is less structured but emphasizes the role of parents and family members; the child leads and the therapist supports the child's social development and play.
- ▶ Treatment and Education of Autistic and Communication-related Handicapped children (TEAACH): This program uses visuals and structure for learning.
- ▶ Relationship Development Intervention (RDI): is a parent-based treatment that focuses on social and emotional development.

Other clinical therapies that are essential in therapeutic programs are speech therapy, occupational therapy, and social skills group teaching.

Alternative treatments such as Chelation, megavitamin doses supplementation, and dietary changes such as the gluten/casein-free diet, are not proven and some can have side-effects. There is an ongoing study looking at environmental factors and heavy metals. The last category is the use of medications to help with associated disorders such as attention, hyperactivity, sleep issues, anxiety, depression, seizures or treating aggressive behaviors.

What advice can one give to parents who have a child with an ASD?

Parenting a child with an ASD can be emotionally and physically exhausting. Keeping up with new research, theories and treatments can be extremely stressful. Parents should be sure to:

- ▶ Take care of yourselves: rest and schedule times for yourselves.
- ▶ Talk to other parents and families and learn what worked and what did not work for them; join support groups, online list serves.
- ▶ Go to seminars and conferences organized by academic centers, scientific and knowledgeable groups to learn more about ASDs and the scientific basis of treatments.

Your child is unique in his/her differences. Learn to appreciate him/her, and be ready to be surprised by his/her progress and don't forget to still enjoy the ride! □

RESOURCES

Recommended web sites for more information: www.firstsigns.org
www.cdc.gov/ncbddd/autism/
www.aap.org/healthtopics/autism.cfm

Floating Hospital for Children

at **Tufts** Medical
Center

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Working Together for Healthy Futures is for pediatricians who are interested in learning more about referring patients to Floating Hospital for Children at Tufts Medical Center. We value your partnership with us and want your patients, their families and you to have a positive experience. Our physicians at Floating Hospital recognize that children and families must be cared for as individuals, and their overall physical and emotional health, not just their illness, is essential. It is our mission to treat each of your patients as if he or she was our own child.

Schedule a Clinic Visit

To refer a patient to one of our specialty clinics in Boston, **call 617 636-8100.**

For our Chelmsford Specialty Center, **call 978 937-6362.**

For our Woburn Specialty Center, **call 781 897-0240.**

For our Framingham Specialty Center, **call 866 618-5518.**

Admit a Patient

For inpatient admission, **call our Hospitalists at 877-KIDS-FHC (877-543-7342).**

Have Our Physicians Visit You

Interested in hearing directly from our physicians? If you would like to schedule a meeting with any of our physicians or have them to your hospital for grand rounds or other educational sessions, **please contact our Physician Liaison Erin Flaherty at 617 636-3252 or eflaherty@tuftsmedicalcenter.org**

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Please contact us at 617 636-0200 or healthyfutures@tuftsmedicalcenter.org

Floating Hospital for Children at Tufts Medical Center is the principal pediatric teaching hospital for Tufts University School of Medicine
www.floatinghospital.org

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