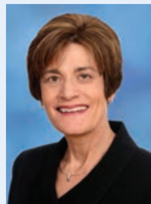
Inova L.J. Murphy Children's Hospital

Fetal Care Center UPDATES

Winter 2022

A Note from the Medical Director


Margot Ahronovich, MD

Dear Colleagues,

We have officially opened the doors to our new fetal care center! It is complete with offices, an exam room and a state-of-the-art conference room ready for in-person or video conferencing. Please feel free to come by and visit; we are just behind Panera on the ground floor and can be accessed through the antenatal testing center. Our door is open for you, as is our phone line. Please feel free to call us with any referrals, for follow-up information or just for a conversation.

We will be working closely with our obstetric and pediatric subspecialists as well as with radiology to organize a clinic-style arrangement to meet with families at our center. We welcome your referrals for patients who may be expecting a medically complex baby or a definite neonatal intensive care unit (NICU) stay (known cases requiring delivery before 35 weeks, etc).

We are continuing to safely pivot our patient care coordination in 2022 to meet our community's needs while COVID-19 and its variants remain a public health concern.

On behalf of the fetal care team, I wish you all a happy, healthy 2022.

Sincerely,

Margot Ahronovich, MD
Medical Director

Craniofacial and Pediatric Plastic Surgery

Jenny Chen, MD

Jenny Chen, MD

The breadth of craniofacial and pediatric plastic surgery includes management of cleft lip and palate, lymphatic and venous malformations, craniosynostosis, Pierre Robin sequence, and other craniofacial anomalies.

Patient after surgical repair

Pierre Robin sequence is a triad of micrognathia (small jaw), glossoptosis or retropositioning of the tongue, and airway obstruction. Pierre Robin sequence can be an incredibly emotional diagnosis, and the initial hospitalization can be extremely stressful for families. However, with multidisciplinary care, our goal is for every child with Pierre Robin sequence to do well and live as normal a life as possible.

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Learn more about Inova L.J. Murphy Children's Hospital Fetal Care Center

inovachildrens.org/fetalcare

Refer a patient:
Phone: 703.776.6371
Fax: 703.776.6591
Email: fetalcare@inova.org
Epic message: Melissa Eatherly and Erin Caulfield

Inova L.J. Murphy Children's Hospital
3300 Gallows Rd.
Falls Church, VA 22042
inovachildrens.org

INOVA® L.J. Murphy Children's Hospital

The small jaw and tongue placement can lead to airway obstruction and respiratory distress. This can require intervention ranging from positioning changes or supplemental oxygen to urgent intubation to maintain an airway. Micrognathia can be difficult to identify on prenatal ultrasound (Figure 1), but when possible, it may identify infants who require advanced care and respiratory support. Approximately 50 percent of these patients may have a cleft palate. The incidence of Pierre Robin sequence is 1:8500 with a 1:1 male-to-female ratio.

▲ Found on fetal ultrasound

Figure 1

▲ Preoperative photo with micrognathia

Figure 2

In the setting of airway obstruction and respiratory distress, increased oxygen and metabolic demands are seen. Maintaining a stable airway and adequate enteral nutrition can be a challenge (Figure 2). A multidisciplinary approach with the maternal-fetal medicine specialists, neonatologists and pediatric anesthesiologists at Inova L.J. Murphy Children's Hospital allows for streamlined care in this challenging patient population.

> ***With multidisciplinary care at Inova Children's, our goal is for patients to thrive.***

▲ Postoperative photo after completed distraction

Figure 3

For patients who fail conservative management with positioning and temporary use of supplemental feeding, the only effective long-term solution previously was tracheostomy. In 1992, James McCarthy, MD, a plastic surgeon at New York University, described mandibular distraction, or surgical lengthening of the mandible. A cut is made in the mandible, and it is slowly lengthened. This results in an increase in airway size with an expectation of improvement in the airway and feeding potential.

For the patient with Pierre Robin sequence who has failed conservative management, coordination between the neonatologists, pediatric anesthesiologists, pediatric otolaryngologists and the craniofacial surgeon at Inova L.J. Murphy Children's Hospital allows for superior outcomes and a decrease in average length of NICU stay. Immediate extubation is achievable in the setting of jaw expansion intraoperatively, using multimodal pain control and multidisciplinary care, allowing us to avoid the short- and long-term sequelae of prolonged intubation. This is a capability available at only a handful of institutions throughout the country. Mandibular distraction, or jaw lengthening, is performed in the NICU, and then the metal pins (Figure 3) can be removed at the bedside. Discharge from the NICU is dependent on the infant's ability to feed independently and breathe without supplementary support. Six weeks after the distraction process has been completed, the mandible has ossified and the plates can be removed in an outpatient appointment.

For patients with Pierre Robin sequence and an accompanying cleft palate, the cleft palate is repaired at 10 months. A cleft palate can affect a child's ability to both eat and speak, and the goal for all patients is normal speech. For patients who are born with both a cleft lip and palate, the lip is typically repaired at 3 months, prior to the palate repair. Optimizing their growth and development is enhanced with close follow-up care at Inova's cleft and craniofacial program.

Patients with Pierre Robin sequence can be complex, particularly during the initial hospitalization. However, with multidisciplinary care at Inova Children's, our goal is for them to thrive.

Inova Children's Craniofacial Program

Lora Hindenburg, RN, MSN

Our goal is to restore form and function and optimize aesthetic outcomes to improve a child's quality of life and promote overall well-being.

◄ *At 4.5 months, Paxton (left) with twin Owen approximately one month before Paxton's surgery.*

▲ *Paxton (right) and Owen at 2.5 years.*

Lora Hindenburg, RN, MSN

The craniofacial program at Inova L.J. Murphy Children's Hospital provides comprehensive, family-centered care to children with craniofacial differences throughout the Northern Virginia and Washington, DC, region including distant regions of Maryland, Virginia and West Virginia. The program is recognized as a Cleft and Craniofacial Team by the American Cleft Palate-Craniofacial Association's Commission on Approval of Teams and meets the association's clinical and organizational team care standards. The craniofacial team provides a multidisciplinary team approach to care for children with a range of conditions involving the head and face such as cleft lip, cleft palate, Pierre Robin sequence, craniosynostosis, hemifacial microsomia and many other diagnoses. The team is comprised of pediatric specialists in the fields of plastic and reconstructive surgery, neurosurgery, otolaryngology, psychology, speech-language pathology, genetics, audiology, dentistry, orthodontics, and nursing. Team members are experts in their respective fields with many years of education and experience. Our goal is to restore form and function and optimize aesthetic outcomes to improve a child's quality of life and promote overall well-being.

The fetal care team works in partnership with the craniofacial team to care for the needs of couples who are expecting an infant with a facial difference. The craniofacial surgeon and patient navigator meet with expectant couples to provide information about the suspected diagnosis, what to expect after delivery and the plan of care after discharge. The goal of prenatal consultation is to prepare the couple for their infant's birth by providing the education they need to feel confident in their ability to make informed decisions about their baby's care. During the visit, we reassure them that they are not alone; they have the guidance and support of our team of specialists throughout the course of treatment.

The team navigator is available to meet with the family at the birth hospital to offer guidance and support and arrange inpatient consultations as needed. The optimal time for a newborn's first team evaluation is within the first few days of life. This enables the team to determine whether an infant is a candidate for any presurgical interventions and to address feeding needs in a timely fashion.

Patients will also be seen at an outpatient clinic held twice a month, where the family will meet with individual team members who perform an overall assessment, answer questions and discuss treatment needs. A team conference is held after each clinic to discuss the child's current status, identify and sequence interventions, and coordinate care with other treating specialists. A team report is written and shared with parents and community providers. Children are scheduled to see the team at regular intervals. Longitudinal follow up is recommended to monitor each child's progress and to address any new concerns in timely manner.

The patient navigator can be reached at **703.776.6920**.

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L.J. Murphy
Children's Hospital

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The New Fetal Care Center at Inova L.J. Murphy Children's Hospital

Featuring:

- A designated examination room equipped for fetal echocardiograms
- Fetal specialist and subspecialist office spaces for patient consultations
- Private, comfortable meeting room space for multidisciplinary patient meetings
- Conference room with IT capability for telehealth visits, staff education, and fetal care conferences or rounds
- An administrative assistant welcome desk
- Fetal care patient navigator office space
- Onsite genetic counselors