

A PARENT'S GUIDE TO CRANIOFACIAL SURGERY



The Weill Cornell Medicine
Pediatric Brain and Spine Center

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Cover photo of Kennedy McConnell courtesy of Heather McConnell

We Are Here for You

We understand that a child’s surgery is a significant event for you, and our team wants to help your family through the process. In this guide, you will find information about what to expect before, during, and after your child’s procedure. While your child is under the care of the craniofacial team at the Komansky Children’s Hospital, the doctors, nurses, and staff will be here to support you before, during, and after your child’s procedure. Please ask us questions at any time.

Your Craniofacial Surgical Team



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NewYork-Presbyterian
Columbia University



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Craniofacial Clinical Coordinator
Weill Cornell Medicine and NewYork-Presbyterian

Our Offices

MANHATTAN

1305 York Avenue, New York, NY 10021
161 Fort Washington Ave, New York, NY 10032
428 E. 72nd Street, Suite 100, New York, NY 10021
(multidisciplinary clinic)

BROOKLYN

263 Seventh Avenue, Brooklyn, NY 11358

QUEENS

198-15 Horace Harding Expressway
Fresh Meadows, NY 11365

WESTCHESTER

1 Pondfield Road, Bronxville, NY 10708

LONG ISLAND

1510 Jericho Turnpike, New Hyde Park, NY 11040

How to Reach Us

Office Phone: 212-746-2363
Office Fax: 646-962-0118
Surgical Paperwork Fax: 646-962-0117

For questions related to insurance approval and authorization, please contact the surgical coordinator at 646-962-3774.

Surgery for Craniosynostosis

Surgery is the only effective treatment for craniosynostosis, as fused sutures must be opened to allow the brain to expand. This is not something that will happen naturally, and a child cannot “outgrow” craniosynostosis. A skilled surgeon must create new openings in the skull to allow for the rapid brain growth that takes place in the first year of life.

There are several surgical options for treating craniosynostosis. It is usually best to perform surgery at just a few weeks to a few months of age, since the skull bones are the softest and most malleable at this time. The craniofacial team that evaluates a child will recommend the best surgery based on which suture closed prematurely, the degree of deformity, and the age of the patient.

Endoscopic Surgery

In the simplest forms of single suture synostosis in a young infant, minimally invasive endoscopic surgery may be an option. An endoscope is a long tube that fits through tiny incisions. An attached light and camera allow a surgeon to see under the skin without having to make a large incision.

Although the results are excellent with either corrective form of surgical treatment (traditional cranial vault vs. endoscopic repair), there are many advantages to the minimally invasive approach:

- Shorter surgical time, including less time under anesthesia
- Smaller incision
- Reduced risk of infection
- Lower risk of blood loss and transfusion
- Shorter hospital stay

The minimally invasive approach is best for younger infants (typically less than 4 months of age), since the extremely rapid brain growth of early infancy helps reposition the cranial bones after surgery. The soft, malleable skull of a very young baby also makes it easier for a surgeon to open the sutures using only small incisions. After five months, a baby’s skull starts to become thicker and less malleable, making endoscopic visualization and manipulation more difficult.

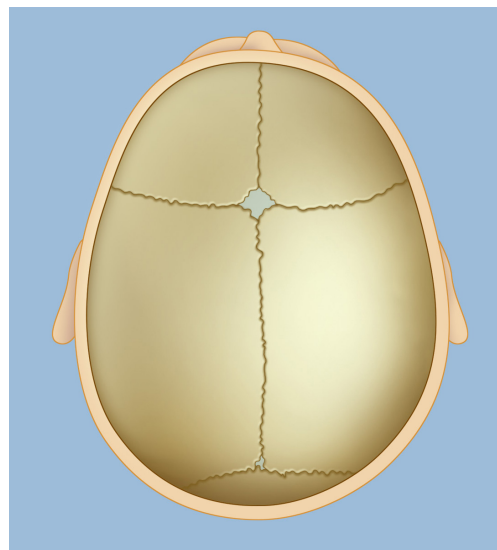
Although all patients are evaluated on a case-by-case basis, younger babies are generally considered better candidates for endoscopic surgery and older babies usually undergo the cranial vault approach.

Helmet therapy after endoscopic surgery helps reshape the baby’s head—see page 15 for more information about helmets.

Open Surgical Procedure

Traditional open surgical procedures are described as cranial vault remodeling and vertex craniectomy; they are extremely safe and produce excellent results. In this surgery, a neurosurgeon removes the affected or closed suture and then “remodels” the skull. This type of surgery is offered to children older than 4 months of age or who have multiple suture craniosynostosis, where more than one suture has closed too early. The surgery usually takes between four and six hours and requires three to five days in the hospital, depending on the age of the child and which suture is involved. Some children need blood transfusions during the surgery.

No helmet therapy is needed after open cranial vault remodeling or vertex craniectomy.



Surgery for Multi-Suture Craniosynostosis and Craniosynostosis Syndromes

Our team provides comprehensive care for patients affected by multi-suture craniosynostosis and craniosynostosis associated with craniofacial syndromes. We participate in the multidisciplinary craniofacial team at Weill Cornell Medicine to ensure that surgical options are individualized and appropriate for these unique patients. Our team provides a full panel of procedures, both staged and definitive. These procedures include but are not limited to suture release; anterior and posterior distraction; occipital decompression; fronto-orbital advancement; midface monobloc; Lefort I, II, and III; box osteotomies; and distractions. Our team is leading the field of craniofacial surgery in outcomes, volume, and the use of technology in surgery. The team will review the surgical recommendations with you, along with a cutting edge virtual surgical plan to prepare the patient and the family for the procedure both verbally and visually.

Diagnoses treated:

- Single-suture craniosynostosis
- Multi-suture craniosynostosis
- FGFR-2 related syndromes (Apert syndrome, Jackson Weiss syndrome, Crouzon syndrome, Meunke’s syndrome, Saethre Chotzen)
- Skeletal dysplasia
- Fronto-nasal dysplasia
- Chromosomal microdeletion syndrome
- Trisomy syndromes

Our multidisciplinary team has specialty centers for:

- FGFR-2 related syndromes (Apert syndrome, Jackson Weiss syndrome, Crouzon syndrome, Meunke’s syndrome, Saethre Chotzen)
- Kabuki syndrome
- Trisomy-related disorders
- Skeletal dysplasia
- Van der Woude syndrome
- 22 q 11 deletions
- Goldenhar syndrome
- Pierre Robin sequence
- Trisomy-related syndromes
- CHARGE syndrome
- VACTERL/ VATER syndrome
- Cornelia de Lange syndrome

As part of the multidisciplinary craniofacial team at Weill Cornell Medicine, we have immediate access to disciplines focused on craniofacial care:

Pediatric otolaryngology (ENT)

Oral maxillofacial surgery

Dentistry

Pediatric genetics

Orthodontics

Prosthodontics

Pediatric pulmonology/sleep medicine

Pediatric speech therapy

Pediatric swallow therapy

Child life

Neuropsychology

Educational advocacy

Before the Surgery

Prior to surgery you will have a surgical planning visit with the craniofacial team to go over the details of your child's procedure, review the consent forms for research and surgery, and schedule your child's lab work if needed.

Pre-operative forms are emailed to you prior to the procedure. Handouts include health history and anesthesia PPST. You will receive a call the night before surgery for arrival time and feeding.

- A Health History and Physical Examination form—this will be completed by your child's pediatrician and sent back to the surgical coordinator (fax: 646-964-0117).
- An Anesthesia Questionnaire—this form is also emailed and completed by the parent and faxed.

About Blood Tests

Blood work is done on a case-by-case basis and will be discussed with you prior to ordering blood work or lab work. If necessary, appointments will be scheduled in advance for your child's blood draw at the pre-operative services unit at:

NewYork-Presbyterian
David H. Koch Center (DHK)
1283 York Avenue, 9th floor
New York, NY 10065

The building is accessible from York Avenue and driveways on East 68th and 69th Street.



There will be a Patient Ambassador to greet you at DHK and guide you through the building. Your Ambassador will provide you with a personalized identification "smartband." You will not be able to move through the building without this band. You may also register at the self-serve kiosks in the lobby. Please visit nyp.org/locations/david-h-koch-center to learn more about the building.

Pre-Operative Ophthalmologic Evaluation

We may refer your child to an ophthalmologist to obtain a baseline exam around the surgery date. Some children with craniosynostosis are at risk for increased brain pressure, which can be screened for with a dilated eye exam.

Skin and Hair Preparation

Your child's hair will be shaved where the surgical procedure will take place. To help lower the risk of infection, please wash your child's hair with Aveeno Unscented Baby Shampoo the night before surgery. Do not add any lotion, oil, or creams to your child's hair.

Additional Instructions

We may provide additional instructions about how to prepare for surgery, based on the type of procedure being performed. Your child may need to wear a helmet after surgery. See "About the Helmet" on page 15.

Your Responsibilities

- A letter for the upcoming surgery is included in your surgical forms packet sent via email.
- Insurance is pre-authorized by the office. All FMLA forms will be processed after the first post operative appointment if needed as per policy.

Blood Donation

Some children may need a blood transfusion during surgery. Blood comes directly from the New York Blood Center, one of the largest independent, community-based, nonprofit blood centers in the world. The NYBC provides blood products to nearly 200 hospitals in New York, New Jersey, and surrounding states.

Families may choose to have blood donated directly to their child from a parent or close family member. It is important to know that parents are not necessarily a match for their child and the blood may not be able to be used during surgery. The process of direct donation must be started approximately four weeks before surgery. This requires multiple visits to the hospital location where the surgery is scheduled.

If you choose to pursue direct blood donation, please inform the craniofacial team as well as the NewYork-Presbyterian Blood Bank at 212-746-4440 (ask for Gail or Novolette). The parent/donor must undergo a blood screening test for a virus and antibodies that can be found in blood, as well as for blood type. You must know your child's blood type and your child may need an additional blood draw. Once screening has occurred, the donor will go to a blood donation center to donate, at least one week in advance of surgery. If the blood is not used during surgery, it will be discarded. Please inquire early if you wish to explore this option.

Pre-Operative Phone Call

The business day before the surgery, you will receive a pre-operative phone call confirming your arrival time and location. You will be given instructions about when to stop feeding your child prior to surgery.

What to Bring to the Hospital: Checklist

- ✓ Reading materials
- ✓ Phone charger
- ✓ Photo ID
- ✓ Insurance card

- ✓ Your child will be in a hospital gown for the majority of the hospital stay. Bring a pair of comfortable pajamas that zip/snap up the front for when your child is discharged and the first few days after surgery. You will want to avoid stretching clothing over your child's head.

You do not need to bring medications to the hospital unless they are highly specialized. If you are unsure, please contact the craniofacial team.

The hospital is breastfeeding friendly. They can provide a pump and appropriate storage during your stay.

Do NOT Bring:

- ✗ Valuables

- ✗ Electrical devices (such as hairdryers and heating pads)

- ✗ Linens. There is a pull-out couch at the bedside of each bed in the Pediatric Intensive Care Unit (PICU), and parents can remain with their child for the duration of their hospitalization. Linens are provided.

Note that parents can stay in the PICU 24 hours a day during their child's hospital stay. Young siblings or other young family members should not visit the PICU. Other friends and family members should be limited to two visitors at the bedside. Some families reserve a nearby hotel room for the duration of their child's hospitalization. For a list of nearby hotels, see page 18.

Arriving and Checking In

You must arrive at NewYork-Presbyterian/Weill Cornell Medical Center approximately 90 minutes prior to your child’s scheduled surgery. During your pre-operative phone call, you will receive your arrival time. The entrance is at 525 East 68th Street (east of York Avenue), New York, NY 10065. (For information about parking, see page 18.)

Please note: The surgery time is approximate. If your surgery is delayed, you will be informed.

When you reach the hospital, please enter through the main entrance on East 68th Street, where you will go through security screening. After the screening, walk toward the information desk and make a right, then follow **GREEN SIGNS** toward the Greenberg Pavilion. Take the elevator to the third floor and follow signs to the pre-operative services area.



Please do not update your child’s name on the day of surgery by adding a middle name, initial, or suffix/prefix. It will delay your child’s procedure. Please check your child’s name and date of birth in advance on the chart and wristband for accuracy.

Check in on the third floor of the Greenberg Pavilion, 3 West.

After You Check In

When you arrive in the pre-operative area, the peri-anesthesia staff will greet you. Your child will be weighed and have his or her temperature taken, then will be changed into a hospital gown.

At this time, a Child Life specialist can offer toys, crafts, or movies to help children scheduled for surgery feel more at ease.



Medical Consent

A parent or legal guardian must be available on the day of surgery to discuss the surgical consent. You will be asked to sign the surgical consent form when you arrive. If you need a translator, please ask. Read it carefully. Make sure everything on the form is correct. It should include:

- The patient’s name
- The type of surgery being performed

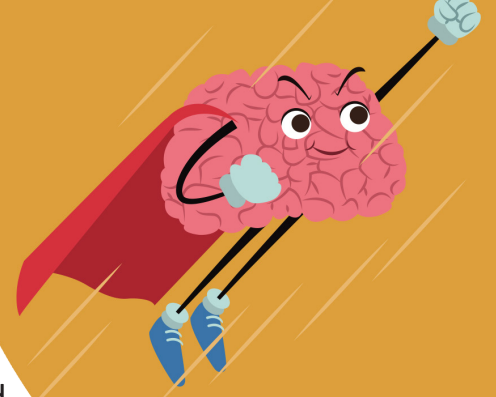
The form also verifies that you have:

- Talked to the team about the risks and benefits of surgery, and have had your questions answered
- Agreed to the surgery
- Agreed to the possibility of a blood transfusion when medically necessary

If you don’t understand something on the form, or if you have questions about the surgery, ask to speak with a health care provider before you sign the forms. You have the right to an interpreter at all times if necessary.

Welcome to Child Life

The Komansky Children's Hospital has dedicated Child Life therapists, pet therapists, and social workers who can offer additional support during your child's surgical experience. Please inform the team if you feel your child—either the patient or a sibling of the patient—would benefit from meeting with a Child Life therapist in advance of surgery. Pre-operative tours are also offered. To arrange an in-person pre-operative tour, please call (212) 746-9970.



For a helpful video about Child Life and preparing your child for surgery, visit nyp.org/komansky/families-and-visitors

Advice From Child Life

A hospital experience can be challenging and stressful for children and their families. What children imagine about their upcoming surgery is often more frightening than reality. You can reduce your child's fears and your own anxieties by being properly prepared for surgery.

What Does Your Neurosurgery Child Life Specialist Do?

- Prepare children and family members for scheduled procedures, including pre-admission tours
- Accompany a patient during clinical procedures to provide alternative focus
- Teach pain management methods
- Educate children and family members about a new diagnosis, illness, injury, or recovery
- Address concerns following surgery and during rehabilitation
- Assist in reintegration back into school
- Offer children and adolescents age-appropriate coping skills
- Address the needs of siblings affected by illness/hospitalization
- Provide emotional support for patients and families facing a critical condition

How to Explain Surgery to a Child

Be open and honest. Use simple and accurate explanations connecting back to the presenting symptoms, e.g. “the doctor has to fix something inside of your body that is giving you headaches.”

Keep it age appropriate. Children under age 6 may think they did something wrong to cause the procedure. Reassure them that it is not their fault and it is not contagious.

Be mindful of your emotions. Children can sense stress from their surroundings.

What to Expect on the Day of Surgery From Your Child Life Team

Before the procedure you will meet with the surgeon and anesthesiologist. They will review the medical plan for the day and give you a chance to ask questions.

Two parents may walk their child to the operating room. You will be asked to wear protective clothing and a mask. Your child may bring his/her favorite stuffed animal or blanket into the operating room.

The anesthesia team will place stickers on your child’s body which allow them to monitor your child throughout the procedure.

Anesthesia medicine is given either through a mask or an IV. This will be discussed with you on the day of surgery.

Reassure your child that he/she will be asleep for the entire surgery and will not hear, see, or feel anything in the operating room.

You may stay until the medical team escorts you out of the operating room and to the family lounge.

During surgery, you will wait in the family lounge. This is where the surgeon will come speak to you once the surgery is finished.

The Surgery

When the procedure is ready to begin, you will accompany your child to the operating room. The anesthesiologist will put your child to sleep using inhaled anesthesia, and then an IV line will be placed. After the patient is asleep, family members go to the surgery waiting area down the hall from the operating room. Shortly after that, your child will have a breathing tube placed. Throughout the surgery, we monitor the patient's anesthesia along with breathing rates and other vital signs.

During the procedure, your child will receive anesthesia, fluids, pain medication, and possibly blood products.

The Waiting Room

Once the surgery begins, family members and caregivers may wait in our surgery waiting room on the third floor. At least one adult **MUST** remain in the surgery waiting area or close by throughout the surgery in case we need to communicate with you during the procedure. You will receive updates during surgery when necessary.

After the Surgery

Shortly after surgery is complete, your doctor will meet with family members and caregivers to discuss the procedure and how your child is doing.

Your child will be moved from the operating room to the Pediatric Intensive Care Unit (PICU), where any post-operative needs are addressed by a dedicated and specialized team.

In the PICU

After the surgery, expect to see your child connected to a machine that monitors breathing, pulse, and blood pressure. Your child will have an IV tube and a head dressing in place. The IV is used during and after surgery to administer fluids and medications. Once the child is drinking well after surgery and taking pain medications by mouth, the IV is removed.

Vital Signs

After surgery, we closely monitor your child's blood pressure, pulse, temperature, and breathing. A nurse will be in the room to check your child and respond to any changes in vital signs.

Parents can stay in the PICU 24 hours a day during their child's hospital stay. Other visitors should be limited to two visitors at a time. No children under 6 years old may visit the PICU.

If your child is in pain, is hungry, or needs anything after surgery, please ask your bedside nurse. Your bedside nurse and the PICU team are available to assist you and your child with your needs.



Your Child's Recovery

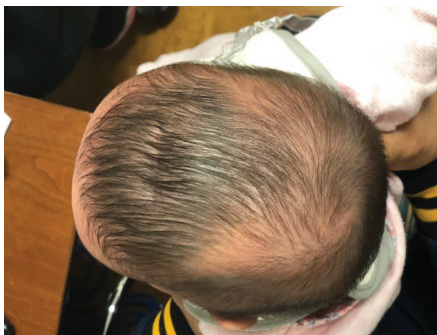
Your child's recovery begins immediately after surgery is complete and continues over the days that follow.

Stitches, Dressings, and Bandages

Whenever appropriate, we will use dissolvable sutures to close the incision. We will inform you if there are sutures that need to be removed. A head wrap will be in place over the incision to help with swelling after surgery. The head wrap will be removed a day after surgery, or right before discharge.

The Incision

The appearance of the incision depends on the type of surgery your child had.



Endoscopic: Your child will have a 3 to 4 cm incision (about an inch and a half) over their affected suture. Incisions are closed during surgery with dissolvable stitches.



Cranial Vault Reconstruction: Your child will have a zig-zag incision from ear to ear. Incisions are closed during surgery with dissolvable stitches. The incision is designed to blend in once your child's hair grows back over the incision line.



Swelling

Swelling is a normal part of surgery. Your child may have significant swelling of the face and over the eyes after surgery. Your child's eyes may swell shut temporarily. Swelling is usually worst on the second day after surgery. Sitting upright, walking around (if appropriate), and time will help swelling improve. Mild swelling may persist for weeks after the surgery and is part of the expected post-operative recovery.



Before



After

Photos courtesy of Kate Fullerton

Diet and Digestion

Starting to Eat: After surgery, children can resume their regular diet once they are awake and showing signs of hunger. Patients may start with water, ice chips, or Pedialyte to make sure they can tolerate eating after their procedure. Most children can breastfeed once they show signs of hunger. If you plan to bring or pump breast milk at the time of your hospital stay, ask your bedside nurse about proper labeling and storage.

Bladder and Bowel Activity: Bladder and bowel needs depend on the type of surgery performed. For surgeries lasting more than two or three hours, a foley catheter (a tube inserted into the bladder) may be placed to help your child drain urine during surgery. The use of some pain medicines and/or the low levels of physical activity after surgery can cause some constipation. If constipation becomes a problem, your medical team will be available to respond to and treat these needs appropriately.

About Pain

Patients experience pain after surgery. Pain is how someone's body responds to surgery or injury.

- Pain can range from mild to severe.
- Pain medications will be used after surgery and it is important that the nurses offer medications for pain before the pain becomes too severe.
- Taking medicine regularly (including at night) is important to prevent severe pain.
- Controlling pain helps a patient recover more quickly.

Tylenol is often used after surgery, and after your child is discharged, to prevent pain. You can give your child Tylenol every four to six hours, no more than five times per day. Talk to your medical team about what dose to give your child. Ibuprofen may also be used. Instructions for use will be given to you, if appropriate, upon discharge.

Some children require stronger pain medication after surgery, and a medication such as oxycodone may be prescribed. Oxycodone in a liquid form can be difficult to obtain, so please be sure to pick up your prescription from the hospital pharmacy prior to going home. If you feel your child's pain is not well controlled, please speak to your health care team.

Discharge From the Hospital

The length of a hospital stay after surgery depends on the type of procedure performed and how quickly your child recovers. Once your child is eating, drinking, voiding normally, and on oral pain medication, he or she will be discharged from the hospital. Before you leave the hospital, we will give you instructions about recovering at home and scheduling your follow-up appointments.

At Home

Expect your child's schedule to be "off" for a few days. He or she may require a couple of days to return to a normal sleep schedule and may eat more or less than usual. Your child should have at least three wet diapers daily and be producing stool daily. You may give your child a dose of Tylenol every four to six hours if needed. Tylenol is often required in the evenings and mornings for a week after surgery for some children after a cranial vault reconstruction.

Shampoo

Please wash your child's hair when instructed to after the post-operative appointment. Do not wash directly on the incision or scrub the incision line. Allow the soapy water to run over the incision and pat dry. Please call the office at 212-746-2363 if you have questions or concerns about your child's incision or if your child has redness, drainage, or swelling at the incision line, or fever after surgery.

Following Up

Patients should expect to see the nurse practitioner within one week of surgery to make sure the incision is healing well. You will also have a follow-up with the plastic surgeon and neurosurgeon. Expect to come to the office for regular follow-ups until one year after surgery.

Pre-Operative Helmet Evaluation

Children who have endoscopic surgery will wear a helmet after the procedure. Before the surgery your child will have a helmet evaluation by a trained orthotist close to your home. The orthotics company will obtain insurance authorization for your child's helmet in advance of surgery.

About three days after surgery, your child will be scanned for the helmet, which is usually delivered and applied within seven to ten days. Over the next week you will gradually increase the time your child wears it (see typical schedule below, but discuss your child's schedule with your orthotist). You should monitor your child's incision and skin every day while in the helmet and immediately report any concerns about redness, or problems with contact points of the helmet.

A helmet should not be uncomfortable after a few days of wearing it. If your child seems to be uncomfortable in the helmet, it may need to be re-fit, which is common with the first helmet.

Helmet Introduction

Sample Schedule (Many parents use meal times as the break.)

Day 1: Wear 1 to 2 hours, remove for 3 hours, repeat until bedtime

Day 2: Wear 2 to 3 hours, remove for 2 hours, repeat 4 to 5 times until bedtime

Day 3: Wear 3 hours, remove for 1 hour, repeat 3 to 4 times

Day 4: Wear 4 hours on, 1 hour off, repeating until bedtime, then wear to bed overnight

Day 5: Take off helmet in morning, wipe clean, check for redness, leave off 1 hour, wear 4 hours. Take another one-hour break, then wear another 4 hours, and repeat. Take a one-hour break before bed, then wear to bed overnight.

Day 6: Wear full time, 21 to 23 hours a day. Remember to take the helmet off in the morning to wipe it clean and take a break, and then remove it again for an hour for bathing and cleaning the helmet.

The helmet needs to be worn for 21 to 23 hours a day until the child reaches 9 to 12 months of age. (Although the baby's head shape is corrected within the first three or four months after surgery, the skull shape can regress if helmet therapy is discontinued too early.) Your child will have no special precautions or significant limitations on activities during this time.

The orthotist and craniofacial team will work together to determine when helmet therapy should be stopped.

Decorating the Helmet

Parents often ask about decorating their child's helmet. Please do not decorate your child's helmet until the incision is healed, because a clear helmet allows the team to monitor your child's incision during the healing process.

After the first few weeks, it may be fun to decorate your child's helmet. Below are a few companies our patients have used to decorate their child's helmet.

Etsy.com: Search "cranial band decals"

Babbleworthy: itsbabbleworthy.com

Bling Your Band: blingyourband.com

Paula Strawn (custom painted helmets): paula@lazardo.com



Photo courtesy of Sara Finne

One for the “Win” Column

Photos courtesy of Mimi Melvin

At 9 months old, John “Win” Melvin loved the ocean and pools, dropping things into buckets, and bathtime! Lovingly referred to as Win (short for his middle name, Winifred, a family name), the little boy kept his parents, Rory and Mimi, busy—and they wouldn’t have had it any other way. They were completely unprepared for a diagnosis of craniosynostosis at nine months, but thanks to Dr. Caitlin Hoffman, they soon had their happy baby back—better than ever.

Craniosynostosis, which occurs in one out of 2,000 live births, is caused when the individual bones of the skull fuse too early. An infant’s skull is made up of five separate plates, joined by flexible bands called sutures that allow the skull to expand to accommodate rapid brain growth. When the brain reaches its full size, the sutures harden and the plates fuse. If one or more of those sutures hardens too early, the brain cannot expand normally in all directions. This results in a misshapen skull as the brain grows and expands, and in severe cases it can hinder cognitive development.

Win showed no visible symptoms, but at his nine-month well-baby visit, the pediatrician noted that Win’s fontanel (the “soft spot” at the top of an infant’s head where the unfused plates are most obvious) was hard, and he had a ridge on his skull. The sagittal suture, the suture that separates the right and left sides of the skull, had fused early, causing an abnormal skull shape. Suspecting sagittal synostosis, the pediatrician recommended that Roy and Mimi take Win to see Dr. Caitlin Hoffman at Weill Cornell Medicine and NewYork-Presbyterian—immediately.

Mimi and Rory were concerned, of course, but they thought they would check in with Dr. Hoffman at the hospital and quickly return to their regularly scheduled lives. “We thought he would be fine,” Mimi remembers. But the resident who saw Win first at the emergency room seemed concerned, which worried them. “We could tell that he knew something,” Mimi said of the resident, “but we weren’t really sure.” Once Dr. Hoffman came in, she confirmed the diagnosis and told the couple that their baby needed surgery. Due to Win’s age, Dr. Hoffman recommended that he have the surgery soon.

At 9 months, Win was too old for the endoscopic option. Dr. Hoffman told his parents he would need the traditional open surgery, called cranial vault remodeling.

The Melvins, still trying to reorient themselves given this sudden turn of events, next met with Dr. Thomas Imahiyerobo—or Dr. I, as patients call him—the plastic surgeon who would work with Dr. Hoffman reshaping Win’s head during the operation. “He was super helpful,” Mimi remembers, noting that she and Rory walked away still in shock, but confident that Dr. Hoffman and Dr. I would take great care of their son. “Here at Cornell you don’t need to go anywhere else,” Mimi recalls. “We felt like we didn’t have to get a second opinion anywhere else.”

Dr. Hoffman ordered a CT scan to confirm her suspicion of sagittal synostosis. Win did a great job of staying asleep during the scan, and his parents were grateful to the radiology technologist who patiently waited for him to be ready. The CT scan confirmed Dr. Hoffman’s diagnosis and the surgery was scheduled for the following Monday.



continued

On the day of surgery, the Melvins walked the short distance from their home to NewYork-Presbyterian/Weill Cornell Medical Center. After Win was admitted and prepped for the procedure, Dr. Hoffman and Dr. I walked the family to the operating room, where Mimi and Rory lovingly held Win as he was administered the anesthesia. Then it was back to the waiting room for the six long hours of surgery.



The surgery went well, and Win was admitted to the pediatric intensive care unit to begin his recovery. Rory and Mimi were surprised to see him: his head was swollen and he couldn't open his eyes. "It was scary," Mimi remembers, "but by the third day he turned the corner and his eyes started to open up again." Win started looking and acting more like himself as the swelling went down and he no longer needed pain medicine. It was then that his parents' concerns started to melt away and they knew he was going to be fine. They took him home on Friday, just four days after surgery. By Sunday night—less than a week since the surgery—Win was totally back to himself.

It was a whirlwind week and a half for the Melvins, and they were so thankful for the support they received. "For a bad situation, we had the best experience we could have had with Dr. I and Dr. Hoffman," says Mimi. "I would walk through fire for the two of them...we owe Dr. Hoffman and Dr. I everything!"

For other parents going through the same thing, Rory and Mimi have one thing to say: "It's really scary, but it's going to be a bad week and then it's over." As for baby Win, he's growing up fast and not letting his head surgery get in the way. Mimi says, "He's trying to scale our bookcases now—we'll have to take him back to Dr. Hoffman if he keeps at it!"

Friends of the Weill Cornell Medicine Craniofacial Team

We know how stressful this entire experience can be, and we know how much it can help to talk to others who have walked in your shoes. The families listed below have agreed to talk to other parents to share their experience and help you through this.

Endoscopic Families

Diana Estevez 646-221-5498
de4128@gmail.com

Heather McConnell 631-513-1381
heatherlynnemcconnell@gmail.com

Christine Batillo 914-844-1161
cbattiloro@gmail.com

Cranial Vault Families

Mimi Pitney 610-574-9342
margaret.pitney@gmail.com

Nathaniel Towolawi 646-327-7572
yajorel@gmail.com

Sandra Olaya 646-643-3632
sandra_p_olaya@me.com

Kimberly Liao 626-382-8700
kcl9@georgetown.edu

Advances in Science

Research is an integral part of academic medicine. Research helps us to evaluate new technologies, surgical techniques, and plans for follow-up. Our team is dedicated to evaluating the advances of medicine and contributing to the body of clinical research and what is known about craniosynostosis. You may be invited to participate in multiple clinical research trials, and we would welcome your participation.

Hotels and Temporary Housing

Parents can stay at the bedside during their child’s hospital stay. Some parents also like to use hotel accommodations during their child’s stay, or before and/or after the procedure. Here are a few nearby hotels convenient to the hospital.

Helmsley Medical Tower
1320 York Avenue (btwn 70th and 71st)
Phone: 212-472-8400

Be sure to mention that your child is a patient at NewYork-Presbyterian Weill Cornell
Rates can range from \$200’s-300’s depending on the time of the year and day of week

Fitzpatrick Manhattan Hotel
687 Lexington Avenue (btwn 56th and 57th)
Phone: 800-367-7701
Their guest rates for Weill Cornell range from \$300’s-400’s depending on weekend/weekday

Affinia Gardens Hotel
215 East 64th Street
Phone: 866-233-4642
Their guest rates can range from \$300’s-400’s depending on weekend/weekday and time of year

Courtyard Marriott Hotel
(Two locations)
410 East 92nd Street
866 3rd Avenue
Phone: 800-321-2211
Weill Cornell guest rates can vary between \$200’s-600’s depending on weekend/weekday

Ronald McDonald House
405 East 73rd Street
New York, NY 10021
\$35 deposit, \$35 per night per room (rates are subject to change)
You will need a social worker from Weill Cornell Medicine to help coordinate your stay, so please contact your craniofacial team if you’d like to request a room. For additional information about housing and requirements, please visit rmh-newyork.org/guest-services/guest-experience

Parking

The Greenberg Pavilion Garage
525 East 68th Street
212-746-2015

Laurence G. Payson House Garage
426 East 71st Street
212-746-1977

Helmsley Medical Tower Garage
507 East 70th Street
212-746-1974

The Phipps House Garage
1285 York Avenue
212-746-1979

Places to Eat at NYP

The Garden Café
212-746-6368
Monday through Friday, 6 am to 8 pm
Saturday and Sunday, 7 am to 8 pm
“B” Level of the main hospital building

Au Bon Pain
Main Lobby: 24 hours a day/7 days a week
Starr Pavilion Lobby: M-F, 7 am to 3 pm
Perelman Heart Center Atrium, 4th Floor Greenberg:
M-F, 7 am to 7 pm



**525 East 68th Street, Box 99
New York, NY 10065**

212-746-2363

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