A Family’s Guide to ECMO
Extracorporeal Membrane Oxygenation
Dear Parents, Family, & Friends

If you are reading this booklet, your child is being considered to receive a potentially life-saving support we call ECMO. While we are busy taking care of your child in a very critical time, there are a few things that are important for you to know:

- Your child and your family are very important to us.
- Our experienced critical care family is doing everything medicine can offer to save your child’s life as well as support your family.
- We will be communicating with you and we want you to talk to us. Any questions or concerns you may have about your child or his or her treatment are a priority. We will make every effort to keep you informed and communicate with you every step of the way.

When you look at your child receiving the support of the heart-lung machine, called ECMO (also known as Extracorporeal Life Support, or ECLS), you may feel overwhelmed. We want to remind you that we are experienced and highly trained professionals whose number one priority right now is your child’s care.

Our team of specialists in intensive care, surgery, cardiology, neonatology, perfusion, nursing, respiratory, social work, child life, and clergy all collaborate to provide the best support for your child and you during this time.

We place great emphasis on your role and perspective as parents. We value your input and our goal is to have good communication and a trusting relationship with you. Your child is a precious and valuable treasure.

ECMO: so that Every Child May Overcome.

Sincerely,

The ECLS Team at
Medical City Children’s Hospital
It is important to remember that ECMO does not heal the heart or lungs. ECMO will buy time for the heart and lungs to heal but does not guarantee that they will recover.
First things First

We are a family centered hospital, so we realize your priorities for your child include pain treatment, comfort, and quality of care. When you are at your child’s bedside, we will talk with you more about your child’s needs for that specific moment and day. However, we have learned that there are a few things that parents want to know at the beginning of ECMO so we made a list of Frequently Asked Questions and Answers for you.

FAQs

How long do we have to wait before we can visit our child?
The process of placing a child on ECMO (Extracorporeal Membrane Oxygenation, also known as Extracorporeal Life Support or ECLS) does not take long but other parts of the process may take some time. Like any other surgical procedure, there must be time to set up the room as well as gather the necessary people and supplies. A member of our team, usually the ECLS Coordinator or the Charge Nurse, will make every effort to keep you updated throughout the process. As soon as your child is safely on the ECMO machine and stable, we will bring you back to the room to be with your child.

What is ECMO?
ECMO stands for extracorporeal membrane oxygenation.
Extracorporeal: Outside the body
Membrane: A type of artificial lung
Oxygenation: The process of getting the oxygen to the blood.

ECMO is a treatment for life threatening heart and/or lung disease. As the doctors have explained to you, your child has a life threatening illness. The main problem is that your child’s heart and/or lungs are not able to perform their usual jobs well, and the doctors caring for your child believe that ECMO is necessary to try to save your child’s life.

The ECMO machine is similar to a heart lung bypass machine used in the operating room during open heart surgery. It is a machine that does the work of the heart and lungs. It helps move the blood in and out of the body while the machine adds oxygen and removes carbon dioxide. Basically, the machine does the work of the heart and lungs giving your child’s heart and/or lungs an opportunity to recover.
What will my child look like on ECMO?

While on ECMO your child will continue to need the tubes, lines and other machines that he/she needed before ECMO. These may include an orogastric tube (called an OGT) placed through the mouth into the stomach to deliver nutrition or medications, a breathing tube (called an endotracheal or ET tube), and the intravenous (IV) lines that provide fluids, medications, and nutrition. Your child will also have a catheter in the bladder (called a Foley) to drain urine.

Children who are put on the ECMO machine will often become swollen. This is an expected reaction to the stress that their body is under. The swelling can be severe and your child’s appearance may change. As your child’s body begins to recover, the swelling gradually resolves.

ECMO requires your child to be on a blood thinner called heparin. Due to this blood thinner you may see blood seeping from your child’s mouth, nose, IVs, cannulas, or chest tube sites. This is common for ECMO patients and your child’s doctor, ECMO specialist, and bedside nurse are always monitoring these developments and doing everything possible to minimize their effects.

Where do the tubes (called cannulas) connect on my child’s body?

When your child is placed on ECMO he/she will have two or more plastic tubes called cannulas that are surgically inserted into large blood vessels. These cannulas are most often placed in the vessel of the neck but can be inserted into the leg or directly into the heart itself. These cannulas are then connected to the ECMO circuit and used to remove and return blood from your child to the machine.

Will my child be awake? asleep? in pain?

When your child is put on ECMO (a process called Cannulation), the surgeon and the ICU doctors and nurses work quickly to give your child medications for three things: pain, stress, and movement - in that order. During the cannulation process your child will effectively be deep asleep like general anesthesia.
Does ECMO hurt? (going on, during, coming off)

ECMO does not hurt. When the surgeon is placing the cannulas in your child, your child will receive medicine for the following medicines:

1. Pain (called Narcotics)
2. Stress (called Sedatives)-The combination of these two medications will result in your child being in a deep sleep during the process of cannulation.
3. Movement (called Muscle Relaxers) - Your child will be given a muscle relaxant that is a short-acting medicine to stop any movement while the surgeon inserts the cannulas. While this medicine wears off quickly, sometimes it is necessary to continue this medication until your child becomes more stable.

Is it only my child’s blood in the machine?

No. The blood we need to support your child includes ordering blood to fill the pump circuit (called Priming) as well as needing to give various blood components while your child is on the machine. We use the smallest amount of blood necessary to support your child while on ECMO.

Is the blood drained from my child’s body into the machine? Do you empty the blood from my child when you circle the blood through the pump (called Circulation)?

The blood stays in a constant balance so that your child always has a normal amount of blood in the body at all times. The circuit provides a loop for the blood to circulate into your child’s body and then return to the machine to get rid of carbon dioxide and pick up fresh oxygen.

If my child is breastfeeding, can I breastfeed my child while he/she is on ECMO?

When your child is on ECMO, all nutrition will be provided through an IV. Once ECMO has been discontinued and the doctors begin to allow your child to receive breast milk or formula again, we will use the breast milk that you have pumped and stored to begin feeding your child through a temporary feeding tube. Ask your nurse how you can pump while visiting your child.

Can I touch my child while he or she is on ECMO?

We want you to touch your child in a way that is comforting to him/her; if you do not know how to do this or are afraid or uncomfortable, tell us. We can help you know when and how to touch your child and also spend time comforting your child with therapeutic touch.
What can I do to help with caring for my child?

First, take care of yourself. There will be many opportunities for you to assist with your child’s care but you must be healthy in order to help. Second, talk with the nurses. Ask them if your child is stable enough for you to help with diaper changes and comforting touch. If you are not comfortable with these things, you can always ask a nurse to help you or you can stand nearby and talk to your child while the nurse is working. Bring photos, cards, or drawings from siblings to decorate the room.

How can I let my child know I am there with him/her?

Your child recognizes your presence, scent, and voice. We will give your child medicines that help him/her relax so they may not open their eyes to look at you when you talk. They will nonetheless hear you, smell you, and know your voice.

You can also leave voice recordings and items in the room that you have worn close to your body (such as a teddy bear or infant eye shield that the nurse can give you) so that your scent is nearby.

Can I bring in my other children to visit their sibling?

Yes, although the visitation rules of Medical City Children’s Hospital and the individual units may change depending on community-related health care issues that may be going on during your child’s stay. Please check with your child’s nurse about the sibling ages and visitation hours.

Can I have family come with me?

We want you to have the best possible support system during this stressful time, but also need to maintain a safe, uncongested environment for your child’s complex care. The intensive care unit’s rules allow two (2) visitors to be in the room at one time. We follow this rule as strictly as possible. ECMO is a high risk procedure and to minimize risk of infection and to maximize patient safety due to the extensive equipment necessary to treat your child, visitors must be in good physical, emotional, and mental health.
Can my church group or spiritual advisor come pray with me for my child?

While only you and one other visitor may be at the bedside, we allow clergy to pray with you and your spouse/significant other at the bedside. Church groups are welcome to wait/pray for you in the waiting area. We do ask all large groups (e.g., extended family, religious/church groups, or friends) to be considerate of the other family members and their needs while sharing the waiting area.

Who will be taking care of my child?

Once the decision has been made to place your child on ECMO, the surgeons and the ICU doctors will be in charge of your child’s care. There may also be other consulting specialist doctors who will be asked to be involved in your child’s care. These physicians may include a neurologist (a brain doctor), radiologist (x-ray doctor), cardiologist (heart doctor), pulmonologist (lung doctor), or nephrologist (kidney doctor).

Everyday your child will also have a team of specially trained nurse practitioners, perfusionists, ECLS specialists, bedside nurses, and respiratory therapists, all of whom provide care under the guidance of the physician. The Nurse Practitioner is a nurse with advanced education and training in nursing. The perfusionist or the ECLS specialist monitors the ECMO machine, maintaining a constant presence at your child’s bedside. The bedside nurse has received special training to provide the best possible care for your child while on ECMO. The respiratory therapist monitors the breathing machine and gives breathing treatments to your child.

For more information or for any questions, please contact Leslie Lewis ECMO Coordinator at 214-783-2954.
**Important ECMO Words**

These words or phrases you may hear us say as we talk about your child and ECMO. The meanings of these things are explained below to help you know more about your child’s care.

**ECMO:**
Extracorporeal Membrane Oxygenation. We often use this term to refer to the ECMO machine and the name of the treatment your child is receiving. ECMO means Extracorporeal (outside the body), Membrane Oxygenation (how oxygen is delivered to the body). So ECMO is the delivery of oxygen to your child’s body from a source outside the body: the ECMO circuit.

**ECLS:**
Extracorporeal Life Support. Our program also uses this term in addition to the term ‘ECMO.’ The two words can be used in place of one another.

**The ECMO Team:**
Consists of perfusionists, nurses, and respiratory therapists that are specially trained to manage the ECMO pump and provide care for your child while on ECMO. There are also specially trained bedside nurses and respiratory therapists assigned to your child while they are on ECMO.

**Cannulas:**
The tubes we place into your child’s body, either through an artery or vein. These are what you see coming from your child to connect to the ECMO circuit.

**Cannulation:**
The time and process by which the cannulas are placed in your child’s body. This is done by a surgeon. Your child will receive medicine for pain and rest during this time so that he/she feels nothing but rest.

**De-Cannulation:**
The time and process by which the cannulas are removed from your child’s body. This is done by a surgeon. Your child will receive medicine for pain and rest during this time so that he/she feels nothing but rest.

**Membrane:**
A type of artificial lung that promotes oxygenation and removal of carbon dioxide.

**Oxygenation:**
The process of getting the oxygen to the blood.
**Oxygenerator:**
The oxygenator gives oxygen to the blood and takes away carbon dioxide from the blood. The oxygenator is the artificial lung that we use to do the work of your child’s lungs while he/she rests.

**Heater:**
Heat exchanger that assists with controlling your child’s temperature while on ECMO.

**ECMO Flow:**
ECMO flow is the amount of blood that is being moved through the circuit and oxygenator per minute. It is usually measured in mL/kg/min.

**ECMO Pump:**
The ECMO pump controls how much support is being given to your child. The pump acts like an artificial heart.

**Venoarterial (VA) ECMO:**
Is a type of ECMO providing both heart and lung support. It required two cannulas, one in the jugular vein and one in the carotid artery.

**Venovenous (VV) ECMO:**
Is a type of ECMO providing lung support only. It usually requires only one cannula placed in the jugular vein.

**Trial off:**
Is a period of time where the ECMO circuit is weaned or clamped allowing tests to be completed to determine if your child is ready to successfully come off ECMO.

**Head Ultrasound:**
A painless procedure that uses sound waves to look at brain tissue, we use this to monitor your child for complications of head bleeds while on ECMO. Can only be performed if the fontanel is still open.

**ECHO:**
A procedure similar to the head ultrasound, uses sound waves to look at the heart to see its structures and how well the heart is functioning and measure the pressures in the heart.

**ACT:**
Activated clotting time is a bedside test that measures how long it takes blood to clot, we monitor this at least once an hour.

**Hemofiltration:**
A filter placed in the ECMO circuit that functions as an artificial kidney to assist with the removal of extra fluid your child’s own kidneys cannot remove.
How we offer you HOPE

HOPE is our favorite word. We like what it means and what it represents. The acronym HOPE tells families WHAT we do, WHY we do it, and HOW we prioritize decisions for the care of our patients, your child.

H: Healing
We always strive to promote health and healing in every way possible. Healing is our purpose.

O: Options
We offer you options in your child’s treatment and opportunity for input.

P: Permission
We do not provide care that is not in the scope of your permission and seek to work with you to decide what is best for your child. We communicate with you daily and as often as you need to ensure we have understood one another well.

E: ECMO
We are one of a few centers that offer the advanced life-saving service of ECMO, a heart-lung machine. This intervention distinguishes our center from others but what we distinguish is your understanding of any intervention we may offer regarding your child’s care, including ECMO. Before we implemented this technology for your child, you know we have first followed all steps in the HOPE acronym.

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