The Seattle Children's Hospital ECMO (Extra-Corporeal Membrane Oxygenation) team has created this handbook to help you understand ECMO, also known as ECLS (Extracorporeal Life Support). The handbook explains what ECMO is, some of the risks and benefits of ECMO and how the equipment works. It also tells you about the people caring for your child while on ECMO and the support services available to you.

This handbook is meant to provide you with additional information so that discussions you have with your child's healthcare team are more meaningful. We urge you to ask questions and share your concerns at any time.
What is ECMO/ECLS?

ECMO/ECLS is a heart and lung life support. It allows the lungs and heart to rest and heal while doctors treat a child’s underlying illness that is causing heart and lung failure. For example, sometimes children have severe breathing problems that need more support than what a breathing machine (respirator or ventilator) can provide. ECMO serves as an artificial lung to assist in breathing. ECMO can also support the heart (cardiac) when a child has low blood pressures or when the heart is not working as well as it should. Many kinds of lung disease or heart problems may get better over time with ECMO and many children on ECMO fully recover.

Who needs ECMO?

ECMO is used for children who have reversible (not permanent) lung or heart problems that have not improved with other treatments. For example, some children have severe lung or heart problems that do not get better even after using a breathing machine (ventilator) with high settings and a large amount of heart medicine.

In some cases, long-term use of the breathing machine at high settings can damage your child’s lungs. ECMO allows the lungs and heart to rest and heal by lowering your child’s breathing machine settings and the amount of heart medicine they may be on.

Children who need ECMO usually have one or more of these problems:

- Meconium Aspiration Syndrome
- Sepsis
- Respiratory Distress Syndrome
- Persistent Pulmonary Hypertension
- Pneumonia
- Congenital Diaphragmatic Hernia
- A life-threatening heart condition

Your child’s doctor will explain your child’s specific problems.

What are the different types of ECMO?

There are two types of ECMO, VA (veno-arterial) and VV (veno-venous). The pictures on the next page show the two types of ECMO.

**VA ECMO** supports the heart and lungs. One plastic tube, or cannula, is placed in a large vein and another cannula is placed in a large artery.

**VV ECMO** supports the lungs, but can sometimes help the heart as well. Generally, only one cannula is placed in a large vein but sometimes two cannulae are needed.
Blood vessels, other than those described above, may need to be used in some special cases and with older children. Your child's doctor will explain this to you. Some children who start with VV ECMO will need to be changed over to VA ECMO.

**How is my child placed on ECMO?**

Your child will have a surgery to insert the ECMO cannula (s). This is usually done at your child's bedside by a surgeon and the surgical team. Sometimes the surgery must take place in the operating room if your child has a hard time separating from the support used during surgery. Before the ECMO surgery begins, your child will be given medicine through an IV to prevent any pain. They also get medicine to make them sleep during the surgery and a medicine to keep them from moving during the surgery. Your doctor or nurse may refer to this medicine as “paralysis” or a “muscle relaxant.” This medicine will wear off within an hour or so after it is given.

The area of the neck or groin where the ECMO cannula(s) are placed will be numbed with a medicine called Lidocaine. Then the cannulae are inserted into the blood vessels, and directed towards the heart. The cannulae are then connected to the ECMO circuit. An x-ray will be taken afterwards to make sure the cannulae are in the right place. Your child will stay on the breathing machine while they are on ECMO. This helps get rid of mucus (secretions) in your child's lungs and will help keep the lungs inflated.

**How Does the ECMO circuit work?**

Blood leaves the body through a cannula and moves through the ECMO tubing to a blood pump. The blood is pushed through an artificial lung (called an oxygenator) by the pump. The pump is adjusted based on your child's needs. The artificial lung puts oxygen into the blood and gets rids of carbon dioxide. After passing through the artificial lung, the blood will return to the body through the same cannula (VV ECMO) or another cannula (VA ECMO).
Is ECMO painful?

We partner with you and your child to prevent and relieve pain as completely as possible. Your child may feel pain from their disease and treatments. However, once the cannulae are in place, ECMO is not painful. Your child will get continuous sedation to keep them comfortable, and to prevent restlessness. Your child will also be given pain medicine and sedation when the ECMO cannulae are being placed and taken out. We encourage you to take an active part in your child’s care by talking with your healthcare team about options for your child. No matter the level of their pain, we join you to assess and respond right away.

What will my child look like on ECMO?

The cannulae in the neck and the large amount of tubing in the ECMO circuit may be upsetting to look at. You will notice a breathing tube (endotracheal tube or ET tube) going into your child’s mouth or nose. This will be attached to a breathing machine, which helps keep the lungs inflated. Your child will be attached to other routine monitoring equipment, like a heart machine. Your child’s bed will be like others in the ICU.

Your child’s head and body may look puffy. The puffiness (edema) is often seen in the eyelids and may limit how much your child can open their eyes. The puffiness (edema) is generally caused by lung disease or the therapies needed to support your child. It usually gets better after the first few days.

ECMO may make your child look much better after a short time, but this may not mean that your child has reached a healthy state.
How will my child be cared for while on ECMO?

Here are several unique things about your child’s care while they are on ECMO:

- Your child will get an anti-clotting medicine, called heparin, to keep the blood from becoming too thick (clotting) in the ECMO circuit.
- A blood test called the Activated Clotting Time (ACT) will be done at the bedside to make sure your child is getting the right amount of heparin. Too much heparin can cause bleeding. Samples of blood will be taken from the ECMO circuit for this test.
- Every Monday, Wednesday and Friday your child will have an ultrasound of their head to look for signs of bleeding in the brain (intracranial hemorrhage or ICH). This test will not cause any discomfort to your child.
- Your child will get extra blood and platelets when needed. Blood that is removed for lab tests must be replaced. Platelets are cells in the blood that are needed to stop bleeding. They are damaged and used up by parts of the ECMO circuit and need to be replaced.
- Your child will have a chest X-ray taken each day. This is looked at for signs that your child’s lungs are getting better and to make sure the cannulae are in the right place.
- Your child will have a cardiac ECHO (echocardiogram), or cardiac ultra-sound, to see how well the heart is pumping. This is usually done soon after admission and every few days.

Routine ICU procedures will be part of your child’s care while on ECMO. These may include:

- Suctioning of the breathing tube
- Chest physiotherapy
- Wound and skin care
- Urinary catheter care
- IV (intravenous) therapies
**Who will be taking care of my child?**

A nurse will provide the bedside care for your child. The nurse will check your child's vital signs (temperature, breathing and heart rate and blood pressure), give medicines and provide daily care. An ECMO specialist, a specially trained ICU nurse or respiratory therapist, will take care of the ECMO circuit and pump system. Your child's ECMO care will be supervised by doctors who are trained in ECMO therapy. The ICU attending doctor or surgeon will also be a part of the daily care of your child while on ECMO.

Each day your child's healthcare team will come to the bedside to talk with you about how your child is doing and your child's plan of care. These sessions are called “rounds.” We encourage you to take part in rounds by sharing your insights, questions and concerns. We expect you to have questions about your child's care, and want to hear them.

**Your Child’s ECMO team**

These are the main people who will care for your child and help your family.

**ECMO attending doctor** – intensive care pediatrician trained in ECMO therapy.

**ECMO Surgeon** – surgeon trained in the surgical management of ECMO patients.

**ECMO specialist** – intensive care nurse or respiratory therapist trained in using the ECMO circuit.

**ICU bedside nurse** – intensive care nurse who provides and coordinates most of your child's daily care and education. They are your main contact with other members of the healthcare team.

**ICU attending doctor** – an intensive care pediatrician (or neonatologist) who directs your child’s care and supervises the residents and fellows caring for your child. This doctor will work closely with the ECMO attending doctor.

**Fellow** – licensed doctor who has finished residency training and is now training in critical care or neonatology.

**Resident** – licensed doctor who is training in critical care. They will have the most contact with you and your child. They give daily orders for care and update the attending doctor about your child's progress.

**Respiratory therapist** – evaluates your child’s breathing. They may treat breathing problems with oxygen, medicines, techniques to clear the airway or a breathing machine.

**Cardiologist** – doctor who specializes in treating heart conditions.

**Neurodevelopmental doctor** – pediatrician who specializes in neurobehavioral and developmental issues.

**Perfusionist** – specialist training in cardiopulmonary bypass (heart and lung machine) and ECMO.

**Social worker** – skilled counselor who works with families to provide emotional support and get the resources they need.

**PACT team** – offers consultation about the care of children with potentially life-limiting conditions. Our team includes a doctor, nurse, and social worker who consult with the child's care team and parents.
What are the risks for my child on ECMO?

Some children who need ECMO may develop problems that put them at risk of brain injury or death. As parents, you are a part of the care team and will be involved in the decisions about how ECMO is used to treat your child. Below you will find examples of some of the risks for a child while they are on ECMO.

Bleeding in the brain

There are not any tests to find out if a child has brain injury from the low levels of oxygen before being placed on ECMO. In some cases, an injured area in the brain may bleed when a child is given heparin (blood thinner) during ECMO. We will closely monitor the amount of heparin your child needs and will take steps to reduce any bleeding that takes place. If the bleeding becomes too great, ECMO therapy may need to be stopped.

Stroke

The carotid artery is one of the blood vessels that delivers blood to the brain. During the ECMO surgery the carotid artery may be tied off. In general, this does not cause any problems because other blood vessels take over and carry blood to the brain. Because the long-term risks of ECMO are not known, children on ECMO may have a greater chance of having a stroke as they become adults.

Infection

When a catheter is inserted into a blood vessel, there is a chance of infection. Your child will be given antibiotics to lower the chance of getting an infection and will be watched carefully for signs of infection.

Blood reaction

Your child will need frequent blood transfusions while on ECMO. This blood is carefully tested for viruses. As with any blood transfusion, there is always a chance of a blood reaction. Your child will be watched closely for any signs of a reaction.

ECMO circuit failure

Although every safety measure is taken, the ECMO circuit can malfunction or fail. If this happens, steps will be taken to keep your child stable. For example, your child may be placed on full support from the ventilator at this time. Your child will be placed back on ECMO as soon as possible. A back-up ECMO circuit is available at all times.

Blood clots

Small blood clots or air bubbles can get into the bloodstream from the ECMO circuit. This can be fatal in some instances. Every safety measure will be taken to prevent this from happening.

What can I do for my child while on ECMO?

One of the most important things you can do during this difficult time is to be in the room with your child as much as possible. Your child will be sleeping most of the time but hearing your voice and knowing that you are there can be very soothing. Your child will need rest but there may be times when reading a story, playing music or just talking to your child may be comforting.
Although you won't be able to hold your child while on ECMO, we encourage you to hold your child's hand. Talk to your child's nurse about other ways you can help, such as:

- Providing special toys or comfort items.
- Helping with baths and diaper changes.
- Touching your child. A reassuring touch and your voice are important and comforting. Healing happens faster in a child who is touched. If you are afraid to touch your child, ask the nurse or ECMO specialist for guidance.
- Tape yourself reading stories or singing songs and bring them in so your child may listen. When you are away, your child's nurse will play this tape on a tape recorder kept near the bed.
- If your child has siblings, have them draw pictures that can be placed at your child's bedside. It is important to include siblings in the care and recovery of their brother or sister. Ask your child's nurse for more information about visitation.
- Keeping a journal of your questions and your child's progress may help when speaking with your child's doctors.
- Take care of yourself. Eat properly and get plenty of rest. Although you may want to be at your child’s bedside all of the time, it is important that you keep up your strength.
- Please remember that you may call at anytime to check on your child when you are away from the bedside.

**How will my child get the nutrition they need?**

All the nutrition needed for energy and growth will be given to your child by IV therapy while they are on ECMO.

If you are breastfeeding or are planning to breastfeed your baby you can pump your breasts and store your milk. Often, breastfeeding can be started after a baby comes off of ECMO. Ask your baby's nurse for information about pumping and storing breast milk. A lactation specialist is on-site to help you.

**When may I visit my child during ECMO?**

We welcome you to stay with your child in the ICU. You are the caregiver and nurturer of your child. In general, parents may be with their child any time of the day or night, and for as long as they choose, except when special procedures are being done.

Your child's siblings, other relatives and friends may visit between 8 a.m. and 8 p.m. The number of family and others who can be at the bedside at one time is limited to 3. This may vary based on your child's needs, the space available in the room and your child's condition. Your child's nurse will work with you to meet your needs while assuring safe care for your child. All sibling visits need to be planned with your child's nurse and Child Life because seeing a sibling on ECMO can be frightening. Child Life specialists work with your family to help ease the fears and anxiety of your other children and to help them adjust to being in the hospital. Children under the age of 12 who are not siblings may not visit patients in the ICU.

If you or any member of the family have a cold or flu, please do not visit the ICU. If you are unsure about being with your child or having other visitors come to see your child, please check with your child's nurse.
What kind of special follow-up care will my child need?

In addition to routine pediatric care, your child will be seen by a team of doctors and nurses who specialize in child development. These doctors will examine your child from time to time to see if they are progressing normally. If there are any problems, these doctors will make suggestions for evaluation and care.

Where can I get more information?

If you have questions or would like to learn more about ECMO, your child's condition or the support services available to you:

- Ask a member of your child's healthcare team
- Visit these Web sites:
  - www.seattlechildrens.org
  - www.cherubs-cdh.org

If you would like to speak with other parents whose children have been on ECMO, please ask the ECMO specialist or your child's nurse for information on support groups.

Glossary

Here is a list of words and phrases you may hear from the team caring for your child. Please be sure to ask questions about words you hear that are unfamiliar.

**ACT (Activated Clotting Time)** - A test that measures how long it takes for blood to form a clot.

**Antibiotic** - A medicine that destroys or slows the growth of bacteria or germs. Used to prevent or get rid of an infection.

**Arterial blood gas (ABG) test** - A small amount of blood that is drawn from an artery and tested to find out the amount of oxygen and carbon dioxide it contains.

**Cannula** - A plastic tube used for the drainage and return of blood to the body.

**Cannulate** - To insert a cannula into a part of the body such as a vein or artery.

**Carotid artery** - A larger artery in the neck that carries blood from the heart to the brain.

**Chest tube** - A tube placed into the space between the lung and chest wall that removes air or fluid. It is used to treat a collapsed lung (pneumothorax) or to remove fluid around the lung (pleural effusion).

**Clamped off** - A trial period when your child is taken off ECMO before the cannulae are removed (de-cannulation).

**Congenital diaphragmatic hernia** - A condition in which the diaphragm (the muscle that separates the chest cavity from the stomach area) is missing on one side. Organs, such as the stomach or intestine, move into the chest and take up space needed for the lungs to grow normally. This prevents the lungs from being able to fully develop on that side.

**Decannulate** - To remove a cannula.

**EEG (Electroencephalogram)** - Recording of the electrical activity of the brain.
ET (Endotracheal tube) - A tube placed in the child’s windpipe which is connected to a ventilator to help a child breathe.

Heparin - A drug used to prevent blood from clotting.

Head ultrasound - An ultrasound study of the brain. Ultrasound can be used to look at structures inside of other parts of the body as well.

Infection - An attack on the body or part of the body by a bacteria or virus.

Idling flow – A lowered ECMO flow for a period of time to make sure that the lungs are working well before stopping ECMO.

Intracranial hemorrhage (ICH) - Abnormal bleeding in the brain.

Meconium - The first stool of a newborn infant.

Meconium aspiration - Small particles of meconium get stuck in the lungs before or during birth. This causes a chemical reaction that prevents the lungs from working properly. Depending on the amount of meconium, this can cause mild to severe trouble breathing (respiratory distress).

Nasogastric (NG) tube - A feeding tube that is passed through the nose and into the stomach.

Oxygenator - The artificial lung part of an ECMO circuit that provides oxygen and gets rid of carbon dioxide from the blood.

Platelets – Cells in the blood that help stop bleeding by helping to form clots. Platelets are damaged and used up by the ECMO circuit. They are regularly monitored and replaced.

Pulmonary hypertension of the newborn (PPHN) – A condition in which the blood vessels in the lung constrict (narrow) causing high blood pressure and low blood flow to the lung. This may cause the blood to receive too little oxygen from the lungs to supply the rest of the body.

Pump - This device passes the blood through the ECMO circuit and returns it to the patient.

Pump flow - The amount of blood being pumped through the ECMO circuit.

Respiratory distress syndrome (RDS) - At birth or shortly after, the baby may have trouble breathing. This may be caused by immature lungs or abnormal material in the lungs. A baby may need oxygen and help with breathing from a breathing machine (ventilator).

Surfactant - A lubricant normally found in the lungs of full-term babies, children and adults. This substance keeps the lungs from collapsing. Sometimes surfactant is given as a medicine down the endotracheal tube to help the lungs work better.

Trial off - A period of time where your child is connected to the ECMO circuit but the amount of support is reduced or stopped for a period of time to find out if your child can safely be taken off the machine.

Ventilator - Breathing machine used to deliver oxygen to the lungs through a tube in the windpipe.

Weaning - The process of slowly lowering your child’s therapy as their health improves. This may include support from ECMO, a ventilator, or medicines.
Notes

Important Phone Numbers and Information

- Seattle Children's Hospital (main number) 206-987-2000
- Pediatric Intensive Care Unit (PICU) 206-987-2040
- Neonatal Intensive Care Unit (NICU) 206-987-2041
- Cardiac Intensive Care Unit (CICU) 206-987-2040
- ECMO Program Office 206-987-4001
Free Interpreter Services

- In the hospital, ask your child’s nurse.

- From outside the hospital, call the toll-free Family Interpreting Line 1-866-583-1527. Tell the interpreter the name or extension you need.