

Your Child on ECMO

This book is intended to help you understand the process of Extra-Corporeal Membrane Oxygenation (ECMO). It will explain what ECMO is, and the function of the many pieces of equipment you will see around your child. It identifies the various people who will be caring for your child while on ECMO, and the support services available to you.



Some information about the risks and benefits of ECMO is also provided.

This book is not intended to take the place of discussions you will have with the medical staff. We encourage you to ask any questions at any time.

What is ECMO ?

Extra-Corporeal Membrane Oxygenation (ECMO) is a special procedure that is used when your child has a condition which prevents the lungs or heart from working properly. It involves a machine that will take over the work of the heart and lungs until your child is able to get better and do this work on his or her own.

Conditions For Which A Child Might Be Placed On ECMO

ECMO is used only when all other less invasive therapies fail or stop working. Patients who benefit from ECMO have a reversible condition.

Types of patients commonly seen on ECMO include:

- Meconium Aspiration
- Congenital Diaphragmatic Hernia
- Persistent Pulmonary Hypertension
- Respiratory Distress Syndrome
- Sepsis
- Aspiration
- Pneumonia
- Myocarditis
- Electrolyte disturbances
- Congenital Heart Disease (before or after cardiac surgery)

Your physician team will explain what condition your child has and why he or she is in need of ECMO. Please be sure to ask questions about these issues in order to better understand the need for ECMO in the care of your child.

ECMO Team

There will be many people involved in the care of your child while on ECMO. Caring for a child on ECMO requires the involvement of specialists from many different areas. Each one plays an important role in the care of your child.

Attending Physician: the doctor who is in charge of the entire Pediatric Intensive Care Unit (PICU) and who leads the team taking care of your child.

Fellow and Resident: the doctors who monitor your child's care and work very closely with the Attending doctor.

ECMO Specialist: the person who monitors your child and runs the ECMO equipment. An ECMO specialist is at your child's bedside at all times.

Registered Nurse (RN): the RN is responsible for your child's general bedside care.

Respiratory Therapist (RT): the RT is responsible for the respiratory needs of your child including the respirator. Many of the RT's are also ECMO Specialists.

Pediatric Surgeon: the surgeon who places the tubes in your child that connect to the ECMO pump. The surgeon will also remove them once the ECMO procedure is completed.

Other people who may be involved in the care of your child include:

- Pediatric Pharmacists
- Nutrition Specialists
- Echocardiology / Ultrasound Technicians
- Physical Therapists / Occupational Therapists
- Social Workers
- Case Worker
- X-Ray Technicians
- Child Life Specialist
- Special physicians consulted for their specific expertise
- Pastoral Care professionals are available for support

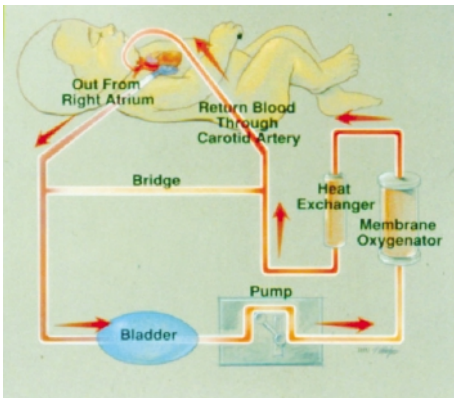


Starting ECMO

A pediatric surgeon will place two tubes (cannula) in your child which will carry blood from your child, through the ECMO machine and back into your child again.

The ECMO team will be monitoring your child very closely to make sure your child is stable and comfortable during the procedure.

The pediatric surgeon will place the first cannula through a large vein in the right side of the neck. This will carry blood low in oxygen and high in carbon dioxide into the ECMO circuit. You may notice that this blood is very dark.



Blood is carried out of a tube which the surgeon has placed and drained by gravity from your child to a plastic pouch, or bladder.

The blood is then moved through the circuit by the ECMO pump. The ECMO pump will be adjusted according to how quickly your child needs the blood pumped through his or her body.

The blood is then pumped through an artificial lung called a membrane oxygenator. This artificial lung, puts oxygen into the blood and removes carbon dioxide.

After going through the artificial lung, the blood will pass through a heat exchanger that warms the blood to body temperature.

Finally, the blood re-enters the body through another large tube which the surgeon has also placed.

Your Child While On ECMO

While on ECMO, your child will receive many types of medication and blood products. Some of these medications will keep your child comfortable. Other medication will provide nutrition. A certain medication (Heparin) is also added to help prevent the blood from clotting and help it flow through the circuit.

While your child is on ECMO, he or she will be watched very closely by an ECMO Specialist. The ECMO Specialist is a highly trained individual, who is either a respiratory therapist, nurse, or perfusionist.

You will notice that the ECMO Specialist watches the pump and your child very closely to ensure that the machine is functioning properly. They will instruct you and others who are around the bedside about the machine, and make sure people stay at a safe distance away from important parts of the ECMO machine. The machine and your child are checked frequently by the ECMO Specialist who is at the bedside at all times.

The ECMO Specialist will take blood samples frequently from your child and the ECMO machine. Adjustments will be made based on the results of these blood tests such as blood counts and oxygen levels. All blood taken from your child, as well as all medication given to your child, are strictly prepared, checked and recorded.

In addition to the ECMO machine, there will be many other types of equipment at your child's bedside. All this equipment is necessary for the care of your child. This equipment may include a monitor to show your child's heart rate and rhythm, as well as the many different blood pressures we monitor in your child. Also at the bedside, will be the ventilator which will be connected to a tube placed in your child's mouth that goes into his or her lungs. The ventilator will help breath for your child. There will also be many intravenous (IV) lines connected to your child. These IV's provide needed medication and nutrition for your child.

Finally, if you intend to breastfeed your infant, the nurse can arrange a breast pump until your baby is able to eat.

Your Child Coming Off ECMO

ECMO is usually intended for use from 5 to 28 days. This depends on the severity of your child's condition. The decision to discontinue ECMO is made when careful evaluation of your child's lung and heart function has been made.

Potential Benefits Of ECMO

Some children have severe medical or surgical (lungs or heart) problems which do not improve in spite of the use of a breathing machine with high settings and/or a large amount of heart medication. Long term use of the breathing machine at high settings can damage your child's lungs. ECMO allows the lungs to rest and heal by letting us lower your child's breathing machine settings and the large amounts of heart medications that your child may require.



Many kinds of lung disease or heart problems may improve over time with ECMO, which will allow your child to recover and survive.

Complications that Might Occur With ECMO

Bleeding is the most common complication of ECMO. This problem is associated with the use of Heparin, which is an anti-clotting medication. Heparin must be used in order to allow blood to flow freely through the ECMO machine. Although bleeding can occur in any part of the body, it is most serious when it occurs in the brain as this can cause brain damage or death.

Mechanical failure is another potential complication. The ECMO circuit is composed of many parts, all connected into a closed, smoothly flowing, system. If any of the parts malfunction, there is the risk of blood loss or the introduction of air into the system. Either of these could cause death or damage to any of the organs, including the brain. There may also be complications that have not yet been recognized, as ECMO is a relatively new treatment. An ECMO Specialist will be at the bedside at all times. This person has been trained to deal with all emergency situations, but cannot prevent all potential complications.

Important Phone Numbers and Information

Pediatric Intensive Care Unit (PICU)	410-955-5260
Neonatal Intensive Care Unit (NICU)	410-955-5255
The Johns Hopkins Hospital (main number)	410-955-5000
ECMO Program Office number	410-614-4591

ECMO Program Staff

Ivor Berkowitz, M.D. Program Director
Gary Oldenburg, R.R.T. Program Coordinator

Support Groups

Should you need to speak with other parents whose children have been on ECMO, please ask the ECMO Specialist or Nurse for information.

Web Sites for Additional Information

www.hopkinschildrens.org
www.else.med.umich.edu
www.geocities.com/athens/4069/
www.cherubs-cdh.org

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This book is prepared by the ECMO Services Division of the Respiratory Care Department
at The Johns Hopkins Hospital.