Did You Know…

- The Extracorporeal Life Support Program at Nemours/Alfred I. duPont Hospital for Children has received the Award for Excellence in Life Support by the international Extracorporeal Life Support Organization (ELSO) in 2013. This award signifies to families a commitment to exceptional patient care and demonstrates to the health care community the highest quality standards, equipment and protocols, and advanced education of all staff members.

- As a recipient of the Leapfrog Award, duPont Hospital for Children is 1 of 12 children's hospitals in the country to be honored for outstanding quality and safety.

- The duPont Hospital for Children has also achieved Magnet status, the nation’s highest credential for nursing excellence.

- Our family-centered model of care ensures that caregivers and parents are part of the same team, working together to develop a personalized plan that best meets the needs of the child.

Nemours/Alfred I. duPont Hospital for Children is ranked by U.S. News & World Report as one of the best children’s hospitals in the nation in cancer, cardiology & heart surgery, diabetes & endocrinology, gastroenterology, neurology & neurosurgery, nephrology, orthopedics and pulmonology.

ECMO: A Parent’s Guide to ExtraCorporeal Membrane Oxygenation Treatment
# Understanding ECMO

ExtraCorporeal Membrane Oxygenation, or ECMO for short, is a treatment for serious problems of the heart or lungs (or both). It is used when the heart or lungs are too sick to work like they should and all other treatments to help them work better have been tried. ECMO can give the lungs and heart time to rest and heal.

**ExtraCorporeal** means treatment that takes place outside the body.  
**Membrane** means a type of artificial lung.  
**Oxygenation** means supplying oxygen to the blood.

# Why Does My Child Need ECMO?

The most common conditions that lead to ECMO treatment include:
- heart problems
- pneumonia (swelling of the lungs)
- persistent pulmonary hypertension (high blood pressure in the arteries that feed the lungs)
- congenital diaphragmatic hernia (part of the stomach bulges through an important breathing muscle called the diaphragm)

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How Does ECMO Work?

A pump inside the ECMO machine moves blood from a patient to the machine and back to the patient through sterile plastic tubes. The ECMO “lung” adds oxygen to the blood and removes carbon dioxide, the waste product of breathing.

What Does the ECMO Machine Look Like?

Because it has a big job to do, the ECMO machine is large. You may hear people call it “the circuit.” This is because it pumps blood to and from the patient and the machine in a circle. Photos of an ECMO machine appear above. Keep in mind that an actual ECMO machine will probably be larger than you expected.

Two Kinds of ECMO for Two Different Needs

Your child’s condition may call for one of two different ECMO treatment options. Your care team will explain the details before treatment begins.

Option 1: VV ECMO. Used when the heart is working but the lungs need time to rest and heal. The VV stands for “venovenous.”

Option 2: VA ECMO. Used when both the heart and the lungs need time to rest and heal. The VA stands for “venoarterial.”

What Will My Child Look Like On ECMO?

To provide a direct line to the heart, one or more plastic tubes called cannulas are surgically placed into large blood vessels of your child’s body, most often in the neck, leg or chest.

The tubes drain blood from the heart into the ECMO circuit. As the blood is pumped through the circuit, oxygen is added and then the blood flows into your child’s body. With so much help, the lungs and/or heart have a chance to rest and heal.

Even though the ECMO machine is doing most of the work for the lungs, your child will also use a breathing machine called a ventilator. The ventilator works through a tube in the nose or mouth that sends just the right amount of air pressure in and out of the lungs. This helps the lungs stay slightly expanded.

What Kind of Swelling Will Occur?

Many children become very swollen during their first few days on ECMO. The swelling, also known as edema, can get worse before it gets better. You may be upset to see your child like this, but caregivers know to expect this side effect. We will be carefully watching all swelling. Usually, much of it disappears by the end of ECMO treatment.

Will My Child Be In Pain?

In most cases, your child is sedated (asleep) while on ECMO. Children who are awake are protected from pain or discomfort with pain medication given through an IV (a small tube inserted in a vein) or directly into the ECMO machine. Extra doses of pain medication can be given if your child seems uncomfortable.
Who Will Take Care of My Child On ECMO?

A team of physicians, nurses, respiratory therapists and other specialists will care for your child. A surgeon performs the operation to insert the tubing at the start of ECMO and remove it when treatment is finished. Both operations require your consent. A care team member will review possible risks with you first. Members of the team will visit you in your child's room each morning to decide on a plan of care for that day. They may include:

**Attending Physician/Surgeon:** The doctor in charge of your child’s care.

**ECMO Physician:** A doctor who specializes in ECMO treatment.

**ECMO Coordinator:** The manager of the ECMO department, who acts as an extra resource for the care team.

**Fellow:** A doctor who supervises care under the guidance of the attending physician/surgeon.

**Resident:** A doctor who supervises care under the guidance of the fellow.

**Nurse Practitioner:** A nurse with advanced training and education who provides care under the guidance of the fellow and/or the attending physician/surgeon.

**Nurse:** A pediatric nurse who cares for your child in the hospital bed.

**ECMO Specialist:** A nurse, respiratory therapist or perfusionist (see definition below) who is specially trained to monitor the ECMO circuit while your child is on it.

**Respiratory Therapist:** A specialist in ventilators (breathing machines) and lung care.

**Perfusionist:** A specialist with advanced training in both heart-lung machines and ECMO.

**Social Worker:** A professional who helps families deal with the experience of having a child in the hospital. Social workers listen and help in many important ways.

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How Does the Care Team Track My Child’s Condition?

- **Blood tests.** ECMO requires frequent tests to make sure your child’s blood is in healthy condition. We draw blood from tubes already in place, so your child will not experience needles or pain. Sometimes a test shows that the blood is running low on platelets, red blood cells or plasma. This is a normal side effect that can be solved with blood transfusions. A blood transfusion means that your child receives new, donated blood to replace unhealthy blood. Donated (donor) blood is carefully tested before it is used for transfusions.

- **Daily X-rays.** Your child may even need more than one X-ray per day.

- **Other tests.** The care team may recommend extra tests to see what’s happening inside your child’s body. For example, they may take “pictures” using ultrasound or CT scans. They may check on brain activity with an EEG (electroencephalogram), or use an EKG (electrocardiogram) to check the heart. See ECMO Terms on page eight for more information.

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When Will My Child Be Ready to Come Off ECMO?

The care team will take your child off the ECMO machine when the heart and/or lungs are healthy enough to work without it. This can take several days up to several weeks, depending on your child's condition.

As daily test results begin to show progress, the care team may slowly lower the ECMO settings to allow your child’s body to gradually function on its own. The team may also try to “challenge” your child off the machine. During challenges, the ECMO circuit is clamped off (but not disconnected) for a few seconds or minutes to see how the heart and/or lungs work on their own. Challenges like this may be done many times before the team decides it is time to stop ECMO treatment.
What Happens After ECMO?

After the tubing comes out and the machine goes off, your child will remain on a ventilator to make sure that blood oxygen levels are steady. At first, medications may be needed to ensure normal heart function. Over time, the goal is to decrease the need for a ventilator and heart function medication. As your child adjusts to breathing without help, we will continue pain medication. The care team will also continue to watch vital signs carefully, just as we did when your child was on the ECMO machine.

How Long Will It Take for My Child To Recover?

All children are different, but a recovery that takes weeks is not unusual.

Advice for Families of Children on ECMO

If your child is on ECMO, you will likely experience a roller coaster of emotions. The experience can have many ups and downs: Your child may do well one day, while the next may bring a setback. It helps to know that all of this is common and natural with ECMO. Below, families who have been in your shoes offer some helpful tips:

1. Be part of your child’s care. Most parents have no medical training, so it can be hard to understand medical terms. This is expected. Ask questions that help you understand and make decisions. If an answer doesn’t make sense, ask again. You have the right to know all of the information about your child’s condition.

2. Talk to and touch your child, even when sedated. It is hard to know for certain, but we believe that children, including infants, can hear and recognize the sound of their parents’ voices while they are sedated. Your child (and you) may find it comforting if you talk to them, touch them, read to them, sing their favorite songs, etc.

3. Build a support system. During your child’s treatment, you will need to think about meals, where to stay, getting back and forth to the hospital, child care for siblings, and other basic needs. If friends and family offer to help, let them. If they don’t, ask them. If you do not have a support system in the area, please ask a member of your care team to connect you to a social worker who can help make your life easier.

4. Respect the ECMO equipment. The ECMO machine is very delicate. Please do not touch any part of the machine, for any reason. Keep a safe distance so you don’t accidentally bump into it. If you have any questions about the equipment, ask a specialist.

5. Let the doctors watch the monitors. Changes in numbers are normal and expected. Parents who can’t take their eyes off the monitors can get very worried for no reason. Please trust that the medical team knows what the numbers mean. We will tell you if there is a change you should know about.

6. Breastfeeding. Even if your infant is on ECMO, you can still pump milk and freeze it to use afterwards. Please ask your nurse for more information about pumping and saving milk. If you need an electric breast pump, ask your social worker about rentals. Your social worker can also find a lactation (breastfeeding) expert to advise you.

7. Take care of yourself. You are a very important part of your child’s care team. Be sure to eat, sleep and rest so that you will be ready to help make decisions.
**ECMO TERMS**

**Arterial blood gas (ABG):** A test that measures the amount of oxygen and carbon dioxide in the blood

**Cannulas:** Special tubes that drain and return blood to and from the ECMO machine

**Circuit:** The ECMO machine and tubing

**CT scan:** (Also known as a CAT scan) This test combines X-rays taken from many different angles to create a cross-sectional image of the bones and soft tissues inside the body

**Diuretics:** Medicines used to help increase urine output

**Echocardiogram (ECHO):** Ultrasound imaging of the heart

**Edema:** Swelling

**Electroencephalogram (EEG):** A test used to monitor brain activity

**Endotracheal tube (ET tube):** A breathing tube in the nose or mouth that connects the lungs to the breathing machine

**Head ultrasound:** A test that uses sound waves to take pictures of the brain to look for bleeding and other problems

**Heparin:** A medication used to keep the blood from forming clots during ECMO

**Oxygenator:** The artificial lung in the ECMO machine

**Pump flow:** How fast the ECMO pump is spinning

**Sweep flow:** How fast air is blowing through the artificial lung

**Ventilator:** A breathing machine that connects to a breathing tube