



# ECMO Parent Handbook

*Dedicated to the parents of all our precious ECMO patients.*

**KAPI'OLANI  
MEDICAL CENTER  
FOR WOMEN & CHILDREN**



*An affiliate of Hawaii Pacific Health*

The Hanuola ECMO Program of Hawai'i is dedicated to "TJ" and his family. Their trust in us has opened the door for many infants and children to receive this life saving technology.

Dear Parents,

Having a very ill keiki (child) and being treated in a strange and overwhelming environment of an Intensive Care Unit can be an extremely stressful situation. A group of critical care providers has written this booklet to provide you with information. This booklet will answer some important questions you may have and help you deal with this difficult time.

The hospital staff will do their very best to take care of your keiki's medical needs. You and your ohana are essential to the care of your precious keiki. Your familiar face, voice and touch are very important. We will encourage you to be involved at the bedside.

Feel free to ask questions and express your concerns. There are many people here to help you, including your keiki's bedside nurse, the ECMO doctor, the perfusionist and the ECMO coordinators. We encourage you to ask questions all throughout your keiki's care.

ECMO Team

## WHAT IS MAKING MY CHILD SO SICK?

Your child is very sick with severe lung disease or respiratory failure. When the lungs and heart are not working well together, blood that goes through the lungs does not pick up enough good air (oxygen) or get rid of enough bad air (the unwanted carbon dioxide).

Other children may have a sick heart. Perhaps, your child has an infection and the heart is unable to properly pump blood to the lungs and the rest of the body.

The usual ways to help these problems are:

- ◆ Oxygen delivery
- ◆ A breathing machine, called a ventilator
- ◆ Several medications that relax the blood vessels between the heart and lungs, including special inhaled gases through the ventilator
- ◆ Medications to support the heart and blood pressure

Sometimes the lungs and heart of the child are too sick to respond to these treatments. Your child is one of those few who are not helped by our usual therapies and medical care.

A therapy called, **E**xtra**C**orporeal **M**embrane **O**xygenation, ECMO for short, uses an artificial lung and heart to help children whose lungs and heart can not work well enough to support the rest of the body. Your child's doctor will give you more details about your child's specific illness.

## WHAT IS ECMO?



ECMO uses a heart-lung machine similar to the machine used in open-heart surgery. There are two types of ECMO. Venoarterial (VA) ECMO uses an artery and a vein. Venovenous (VV) ECMO uses one or two veins. The doctor will decide which one your child needs. When a child goes on ECMO, the following things happen:

1. The child is given medications to prevent pain and movement during the placement of the catheters. This procedure will happen in the Intensive Care Unit.
2. A surgeon will place the catheters, or cannulas, into large veins and/or arteries located on the right side of the neck or the groin. The number of cannulas used depends on the type of ECMO your child needs. Your child may have one special cannula placed into the vein of the neck, depending upon how big your child is. This cannula will do the job of two cannulas.
3. The ECMO machine is made up of several parts: a pump, an artificial lung, a blood warmer and monitoring device. The ECMO machine takes the blue blood (without oxygen) out of the body and pumps it through the artificial lung (oxygenator). The blood is now red (with oxygen). This blood is also warmed before returning to the child.

The ECMO machine does the work for your child's lungs (VV ECMO) and heart (VA ECMO), which allows them time to rest and heal. During the time your child is on ECMO, he/she will still be connected to the breathing machine, also known as the ventilator. The ventilator is used to prevent the lungs from collapsing.

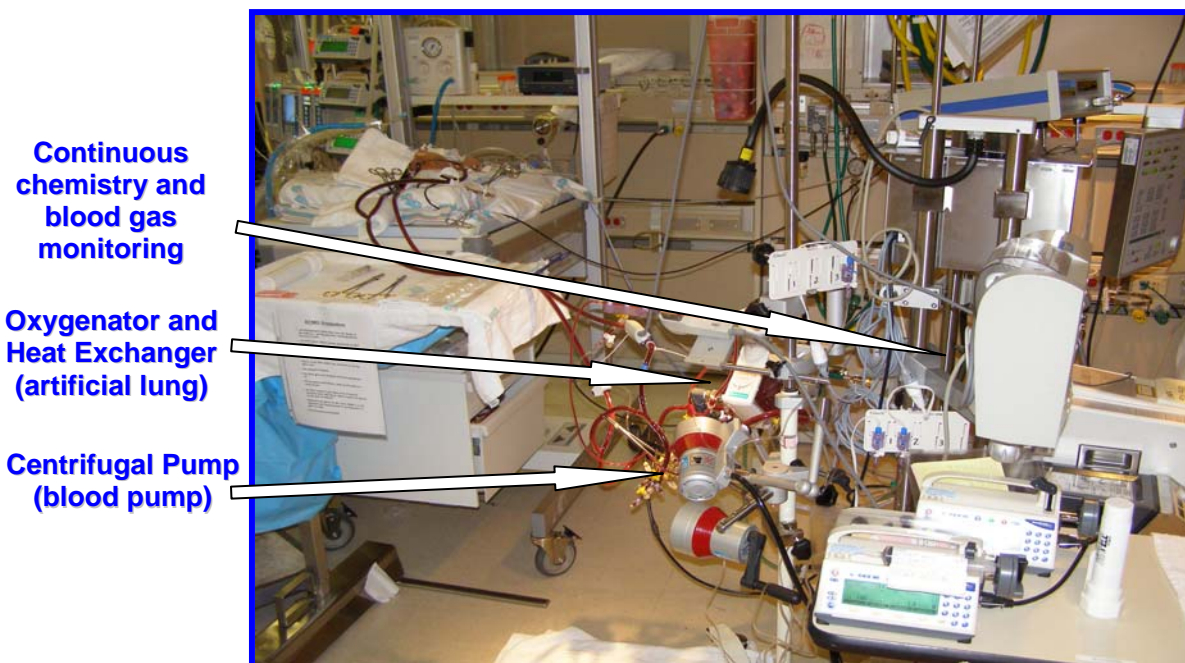
At the beginning of ECMO, the ECMO machine does most of the work for their lungs (VV ECMO) and heart (VA ECMO). Even though your child will seem to be much better, it is important to remember that the ECMO machine is doing the work the lungs and/or heart cannot do.

To see how they are doing, a small amount of blood will be drawn from your child's special IV, called an arterial line. This test (a blood gas) will check to see how much oxygen is present in the blood. As your child's lungs begin to heal, the oxygen level in the blood will begin to improve. This allows us to slowly turn down the ECMO machine, or reduce the amount of oxygen going to the artificial lung and wean off ECMO. The lung and/or heart support, provided by the machine is turned down until it is doing only a small amount of the work. At this time we may try to take him/her off ECMO and measure the level of oxygen and carbon dioxide in the blood to see if the lungs are ready to work on their own.

While your child is on ECMO he/she will receive a medicine called heparin. Heparin will keep your child's blood from clotting in the ECMO circuit. Heparin may cause your child to bleed while on ECMO. Special blood tests (ACT's) will be done to check how fast the blood is clotting. When your child is weaned off of ECMO, the heparin will be stopped and the time that it takes for your child's blood to clot, will return to normal within a few hours.

Babies are on ECMO for an average of 5 to 7 days. The older child and some infants may be on ECMO for weeks. The doctor and ECMO team will determine how long it should take for your child to get better, but the time needed for possible recovery is not pre-set.

## THE ECMO CIRCUIT



## WHO IS ON THE ECMO TEAM?

The ECMO Team caring for your child is made up of an ECMO doctor, a Neonatologist or a Pediatric ICU Intensivist, a surgeon, an ECMO perfusionist, ICU nurses and respiratory therapists, and a social worker.

1. **The ECMO Doctor:** A consultant doctor to the Intensive Care Unit where your child is to receive ECMO therapy. These doctors have received special training in the management of the ECMO machine and children who are in need of this medical therapy. This doctor will be responsible for overseeing the ECMO needs your child, from start to finish.
2. **The Neonatologist or Pediatric Intensivist:** A pediatrician who specializes in the care of very sick babies or children. This doctor will be the primary doctor for your child.
3. **The Pediatric Surgeon:** A doctor who specializes in performing surgery on children. This doctor will place and remove the cannulas needed for ECMO. The surgery will take place in the intensive care unit.
4. **The ECMO Perfusionist:** A certified perfusionist is educated and trained in the management and operation of the ECMO machine. The perfusionist will prepare the machine and tubing to help the surgeon and ECMO doctor place your child on ECMO. In the event there are problems while your child is on ECMO, the perfusionist will work to correct the problem. They will always be at the bedside taking care of your child.
5. **The ICU Nurse and Respiratory Therapist:** These members of the ICU team are specially educated to care for very sick babies and children. They will be at the bedside providing care to your child.
6. **The Social Worker:** The social worker is educated to help families cope with the feelings and experiences of having a child in the hospital. They can assist you with any arrangements you may need.

# COMPLICATIONS OF ECMO

ECMO is an extreme, life-saving procedure. Your child was placed on ECMO because of the seriousness of their disease. However, ECMO is not without risks. The ECMO doctor discussed the risks and/or complications with you when you gave permission to place your child on ECMO. Here is a review of the possible complications. If you have any other questions, or are unclear about anything, please ask your child's doctor.

1. The most common complication is bleeding. This is often due to the heparin that is given to prevent clotting of the blood. Sometimes this can lead to internal bleeding. The most serious place in which bleeding may occur is in the brain. Bleeding in the brain may lead to brain damage. If bleeding of any kind occurs, the problem will be discussed with you in detail.
2. The surgical procedure used to place the cannulas into the neck or groin requires clamping of veins (internal jugular or femoral vein) or an artery (right carotid artery or femoral artery). The right carotid artery is one of the four arteries that supply the major blood flow to the brain. When one of the arteries is used for ECMO, the other three arteries take over and carry plenty of blood to the brain. After ECMO, the vein will be tied and closed; however, the artery may be repaired.
3. Your child will be receiving transfusions of blood and other blood products. This may slightly increase the risk of infection from hepatitis and HIV (the virus that causes AIDS). All blood products are screened carefully before use, but purity cannot be absolutely guaranteed. Your child will be monitored for any signs of infection from blood transfusions.
4. The ECMO machine that your child is on may fail or malfunction and we may not be able to restart the therapy. The ECMO perfusionist, the doctor, the bedside nurse and the respiratory therapist are trained to take care of any problems that may happen. Your child may have to be off ECMO while the problem is being corrected. During this time, your child will receive the required support needed. In most cases, but not all, the ECMO machine should be repaired or replaced and ECMO support restarted.
5. Whenever a cannula is inserted in a blood vessel, there is an increased risk of infection. Your child may receive antibiotics as a precaution or may have them added if an infection happens. We will watch very carefully for signs of infections.
6. Your child may gain considerable weight while on ECMO. This is due, in part, to the fact that your child does not move much while critically ill. This allows fluid to settle in the tissues and make him/her look "puffy." This is called edema. This will go away a few days after he/she is off ECMO and moves around. If the extra fluid is causing difficulty in weaning from ECMO, we can give medications (lasix, bumex) or use an artificial kidney (hemofiltration) to remove the fluids quickly.
7. Small blood clots or air bubbles can get into the blood stream of the ECMO circuit. There

is a safety device that should catch most clots and air bubbles, but there is a chance that clots or bubbles may reach your child.

8. There is a chance that a complication may happen that makes it impossible to keep your child on ECMO. If it is too early in your child's recovery, he/she may not survive off of ECMO.
9. Your child and the ECMO machine are monitored by an ECMO doctor, an Intensive Care doctor, an ECMO perfusionist and an ICU nurse. We take every possible precaution to decrease the risks of ECMO. If a problem of any type occurs, we will discuss the issue with you and consider what plan is best for your child.

## **THE PARENT'S ROLE IN ECMO**

Parents and the ohana are encouraged to visit their keiki while he/she is on ECMO. Visiting hours are unrestricted for parents. Others may visit if they come with one of the parents. No more than two people may visit at the same time. Brothers and sisters are allowed to visit after checking with your child's nurse. Child life services (play therapist) are available to help your child's brothers and/or sisters to cope with this. For more information about individual unit policies, please check with the bedside nurse. The following paragraphs provide some suggestions to assist you in making the most of your visits with your child.

Some children may need to get medicine to help them sleep, or may just feel too sick while on ECMO. On the other hand, some children will be alert and responsive during awake periods. In either case, it is important for you, as parents and ohana members, to let your keiki know you are there. You can give your child what we can't, because this keiki is yours and will respond uniquely to you. Always check with your child's nurse to see if it is all right to talk or touch them. Some children do not do well with stimulation when they are very sick. Yet, most children can tolerate simple visits.

The simplest forms of interaction are probably the most important for you and your child. Talking to your child can be very satisfying. All children, whether newborn or older, know the voices of their loved ones. You may wish to read a story or sing a lullaby. Touching your keiki and holding his/her hand will provide much needed comfort. If your child is too sleepy or unable to open his/her eyes, it is still important for you to interact with your child. Your child may move at the sound of your voice or from your gentle touch and let you know that they recognize you.

Although your child cannot be held while on ECMO, you can help with other parts of their



care. You may cleanse your child's lips with a moist swab or apply cream to the skin. We encourage you to bring pictures of family members for the bedside as well as music boxes or recordings of your voice. Reading stories or just holding hands can be very rewarding.

For the moms who wish to breast-feed, we encourage you to pump and save the milk by freezing it. It can be stored this way for later use after your infant is off ECMO. Please ask your nurse for more information about pumping and saving the milk. Your social worker may also be able to help you locate an electric breast pump for rental and arrange a referral to a lactation consultant.

Most ohana members feel more comfortable when they are able to "do something" for the keiki. We encourage you to do whatever you feel comfortable with and at the same time, keep in mind that your child also needs quiet time to rest and heal. If you are unsure of what to do for your child, please ask. Please feel free to ask the nurse or perfusionist any questions you may have about your child. Part of our job is to help you. There are no questions too small.

## **COMING OFF OF ECMO**

When your child needs very little help from the ECMO machine, a "trial-off" of the machine will be attempted. The cannulas will remain connected to the child until we are sure that he/she is able to do all the work with his/her heart and lungs. When your child is ready, the cannulas will be removed from the neck or groin by the surgeon. This requires an operation, during which your child will receive pain medication and medicine to keep him/her from moving during the surgery. The surgery will be done in the ICU. The surgeon will remove the cannulas and tie the vein and/or artery so that no blood will leak through them. Once the cannulas are taken out, your child may be able to wake up. He/she will remain on the same kind of bed and breathing machine. This breathing machine will still be used to give support to the lungs even after ECMO. However, the amount of support will not be as much as your child needed before ECMO.

The arterial line will also stay in place, so small amounts of blood can be drawn to see how your child is doing.

A dressing may be placed over the incision. The stitches will stay in place for about 5 days and will then be removed. A scar about several inches long will remain on your child's neck or groin, but this will fade and shrink as your child grows.

As your child's lungs heal, the oxygen level in the blood will get better and better. This will let us decrease the amount of work the ventilator is doing. Little by little your child will do all the work on his/her own and we will be able to take him/her off of the ventilator. Your child may require some extra oxygen after the ventilator is removed. This will also decrease until potentially no extra oxygen is needed at all.

## **GOING HOME!**

To go home, your keiki needs to be medically stable, gaining weight (if your child is a newborn) and on established feedings. Many children have difficulty swallowing after ECMO. We are uncertain why this occurs; the muscles may be sore after the tube was removed from the throat, or the child may be feeling weak after having been so ill. Whatever the cause, these feeding problems are usually temporary and will most likely go away over the next few months. If your child is swallowing poorly and unable to take enough food, a tiny plastic tube, will be placed through your child's nose or mouth into the stomach. This allows the child to get the food and the calories they need to grow. Speech and occupational therapists will help you in learning the correct way to feed your child. Keep in mind that the feeding problems do eventually go away with time and patience.

While you have hoped for the day when we would say that your child might go home, it is often accompanied by mixed feelings. Besides your feelings of happiness and relief there may be feelings of anxiety, loneliness and uncertainty. A period of adjustment is normal. Be patient with yourself and your keiki.

## **ECMO FOLLOW-UP CLINIC**

In addition to your routine pediatric care we highly recommend that your child be seen in the Kapi'olani NICU follow-up program for the NICU baby graduates. All PICU graduates will be followed through the ECMO clinical coordinator. The NICU follow-up program will coordinate or provide the special medical care your child may need, identify any special needs that your child may have, help you understand your child's growth and development, and assist in finding any necessary services for your child as soon as possible. All babies are offered this program. Older children are followed by the ECMO clinical coordinator and their pediatricians who will monitor your child for medical, developmental, visual, speech or hearing needs.

For newborns, we will want to see them at 4 and 8 months after discharge and again at 1 year and 2 years old, if necessary. Extra visits may be scheduled depending on your child's individual needs. They will have a physical exam at every visit and a neurodevelopmental exam. This is done to check the child's progress with sitting, walking, and using his/her arms and legs equally. This will also help us see how well he/she is learning about the world around them. The doctor discharging your child will schedule an appointment for the first clinic visit. The clinic will send a reminder several weeks before the appointment. You may also receive a call to confirm the appointment.

A summary of each follow-up visit is sent to your doctor and others involved in your child's care. Remember this program is not to take the place of the care your child would normally receive from your doctor. Well child care, shots, and sick visits should still be scheduled regularly with your pediatrician.

We would like to keep your current address and phone number in our records, so if you move, please let us know.

## **CARING FOR YOUR CHILD AT HOME**

Any parent who has experienced the threat of the loss of their beloved child may react by wanting to prevent anything bad from ever happening to that little one again. Those feelings are normal and expected. Hopefully, they will lessen over time as life returns to usual and as you and your child recover physically and emotionally. If you experience a continuing high level of fear about your little one's life and well being we suggest that you speak with your child's doctor (pediatrician), a counselor, or a person in the community who you can talk to.

It is our goal to provide you with information about your child's health so that you can best provide for their physical and emotional growth. Knowingly, children are helped by parents who encourage and praise their accomplishments and recognize and seek assistance for their special needs.

It is important for you to realize that long term follow-up results are just becoming available. Neonatal ECMO has only been in widespread use since 1980, and pediatric ECMO since 1989. Until all of these children reach later adulthood, we do not have any knowledge about the long term outcome of ECMO patients. This is why it is very important for you to keep in touch with your child's doctor and the NICU Neurodevelopmental Follow-up Clinic or the ECMO clinical coordinator.

Finally, the most important thing your keiki needs is parents and ohana members who enjoy and adore them. Come back and see us. We love seeing you and your child doing well. We care about you and wish you a long and happy life together as an ohana.

## COMMON ECMO TERMS AND DEFINITIONS

**ACT:** Activated Clotting Time: a test to determine how long it takes blood to form a clot. The bedside perfusionist will be performing this test, at least every hour.

**Antibiotic:** A drug that kills bacteria or germs. Used to prevent or cure an infection.

**Aorta:** The large artery that carries oxygenated (red) blood from the heart to the body.

**ABG: Arterial Blood Gas:** A small amount of blood that is drawn from the artery and tested to determine the amount of oxygen and carbon dioxide in the blood.

**Artery:** This is the type of blood vessel that pumps red (oxygen rich) blood to the body's organs.

**Cannula:** A large tube that allows the drainage of blood from, or return to, the body. Also known as a catheter.

**Cannulate:** To insert a cannula into a part of the body, in this case, an artery or vein.

**Carbon dioxide (CO<sub>2</sub>):** This gas is one of the body's waste products that is expelled through exhaling or breathing out.

**Cardiac:** Refers to the heart.

**Cardiologist:** A physician specializing in the diseases of the heart.

**Carotid artery:** The large artery in the neck that carries blood from the heart to the brain.

**Centrifugal Pump:** This device circulates the blood through the ECMO circuit and then returns it back to the patient.

**Chest tube:** A tube that is placed through the chest wall into the space between the lung and chest wall to drain air or fluid. Used to treat a collapsed lung (pneumothorax) or to drain fluid.

**Chest X-ray:** An X-ray performed to look at the lungs and heart.

**Congenital Diaphragmatic Hernia (CDH):** An opening in the diaphragm on either the right or left side that allows the abdominal organs (liver, intestines, etc.) to escape into the chest. Prevents proper growth and development of the lung on the affected side because of the pressure on it and because of the decreased space.

**Decannulate:** To remove a cannula.

**ECHO: Echocardiogram,** 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.

**ECMO: ExtraCoporeal Membrane Oxygenation:** Is the process by which blood is pulled from the body, carbon dioxide is removed, oxygen is supplied, the blood rewarmed and circulated back to the body. This is to take the place of the heart and lung function.

**EEG: Electroencephalogram,** A tracing of the electrical activity of the brain. Electrodes (wires)

are placed on the scalp in several locations.

**Head Ultrasound:** A painless procedure that uses sound waves to look at brain tissue. Gel is placed on the top of the head and a special wand is passed slowly over the soft spot on top of the head. This test cannot be done once the soft spot closes.

**Heat Exchanger:** This warms the blood to body temperature before returning it to the patient.

**Heparin:** A drug used to prevent the blood from clotting.

**Hemofiltration:** An artificial kidney that may be used to remove extra fluid that the child's own kidneys can't remove. It is inserted into the ECMO circuit.

**Incision:** A surgical cut.

**Keiki:** Hawaiian name for child.

**Intracranial or Intraventricular Hemorrhage:** Abnormal bleeding in the brain or head. Seen on Ultrasound or on a CT Scan.

**Meconium:** The first stool of the newborn. May be present in the amniotic fluid at birth. It is dark green and thick.

**Meconium Aspiration:** Small particles of meconium become lodged in the lungs when the child breathes in the womb. This causes a chemical reaction and prevents oxygen from reaching some areas of the lung.

**MRI: Magnetic Resonance Imaging,** A test that uses a magnetic field to obtain pictures of the brain or body. Sedation is required, as movement will interfere with the test.

**Neuro:** Relating to the brain.

**Neurologist:** A doctor who specializes in disorders of the brain and nervous system.

**Ohana:** Hawaiian name for family.

**Oxygenate:** To combine or supply with oxygen. When oxygen enters the blood, as in the lungs, it becomes oxygenated. This is known as arterial blood.

**Oxygenator:** A device that is part of the ECMO circuit which removes carbon dioxide and supplies oxygen to the blood stream.

**Pau:** The Hawaiian word for finished or all done.

**Persistent Pulmonary Hypertension of the Newborn (PPHN):** In the womb, the child is supplied with oxygen by the mother through the umbilical cord. The lungs do not oxygenate the blood until the child is born. At this time, the circulation must change from fetal to newborn circulation, allowing the blood to pass through the lungs to be oxygenated. If this fails to occur, the blood continues to circulate as it did in the fetal state, and the child's body does not get enough oxygen.

**Platelets:** Small particles in the blood that help in the clotting ability of our body.

**Pneumothorax:** Escape of air from the lung into the space between the lung and chest wall.

**Radiologist:** A doctor who specializes in the interpretation of x-rays and sonograms.

**Respiratory Distress:** At birth or shortly after, the child may encounter difficulty breathing. This may be caused by immature lungs or foreign material present in the lungs.

**Sepsis:** An infection in the blood.

**Surfactant:** A soap-like substance normally found in the lungs of full-term babies, children and adults. Presence of this substance keeps the lungs from collapsing. Premature babies may not have enough of this to keep their lungs from collapsing.

**Trial Off:** Removing the child from ECMO to see if the lungs are well enough to support the child.

**Vein:** This is the type of blood vessel that pumps blue (without oxygen) blood back to the heart from the organs.

**Unxygenated blood:** Blood that has delivered most of its oxygen to the tissues of the body and is lower in oxygen. Also called venous (blue) blood.

**Venoarterial bypass (VA):** A type of ECMO where the blood is drained from the right side of the heart and returned to the left side of the heart through the carotid artery.

**Venovenous bypass (VV):** A type of ECMO where the blood is drained from the vein and returned in the same cannulae in the right side of the heart. Also called, "single catheter-double lumen ECMO".

**Ventilator:** A breathing machine that delivers oxygen, pressure and a rate of breathing to the child by a breathing tube. Also known as a respirator.

**Weaning:** ECMO blood flow rate being decreased gradually as the child improves.

# Acknowledgements

1. Mahalo nui loa, Senator Daniel Inouye, for your unwavering support of Hawai'i's keikis.
2. The Hanuola ECMO Team.
3. Kapi'olani Medical Center for Women and Children and all the personnel that make this happen for children to receive ECMO therapy services.
4. Kaiser Permanente Moanalua Medical Center, Neonatal Intensive Care Unit. Without these pioneering people, ECMO would not be present in Hawaii.
5. Excerpts taken from the ECMO Parent Handbook at Egleston, Children's Healthcare of Atlanta.
6. Excerpts taken from the Family Guide at the University of Michigan's ECMO Program.
7. Excerpts taken from the ECMO Parent Manual at Rady Children's Hospital, San Diego Regional ECMO Program.

The Hanuola ECMO Program of Hawai'i is a collaborative effort of:



# ECMO Parent Handbook

Neonatal Intensive Care Unit (NICU)

808-983-8673

Your NICU Doctor is: \_\_\_\_\_

Your ECMO Doctor is: \_\_\_\_\_

Your Primary Nurse is: \_\_\_\_\_

*ECMO Medical Director:*

*Mark Ogino, MD*

*ECMO Perfusion Coordinator:*

*Kristen Costales, CCP*

*ECMO Clinical Coordinator:*

*Melody Kilcommons, RNC*

Pediatric Intensive Care Unit (PICU)

808-983-8681

Your PICU Doctor is: \_\_\_\_\_

Your ECMO Doctor is: \_\_\_\_\_

Your Primary Nurse is: \_\_\_\_\_