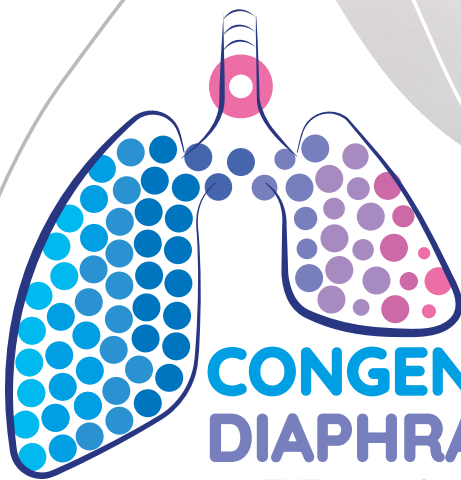
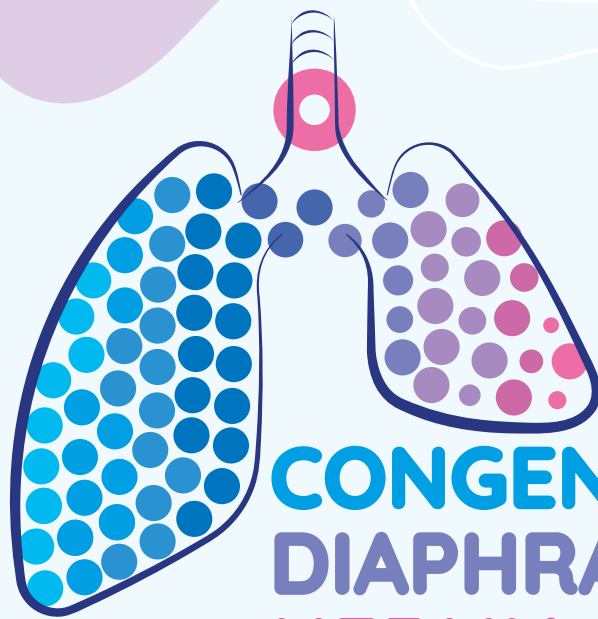


# CDH Parent Reference Guide



**CONGENITAL  
DIAPHRAGMATIC  
HERNIA**

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# CONGENITAL DIAPHRAGMATIC HERNIA



# CDH Parent Reference Guide

**Whenever prospective parents learn their child has a physical defect, it is a hard blow. Congenital diaphragmatic hernia (CDH) is a rare birth defect associated with a very serious prognosis. This guide has been designed to assist parents who are seeking more information or support. We know how important it is to have access to a reliable source of advice and guidance, and we believe this handbook will be helpful to you. The information has been gathered with support from parents of children born with CDH and physicians specializing in the management of CDH.**



## 1. What is CDH?

Congenital diaphragmatic hernia (CDH) is a birth defect that occurs when a baby's diaphragm – a thin sheet of muscle that separates the abdomen from the chest – fails to close during prenatal development. The diaphragm normally develops by around the 10<sup>th</sup> week of pregnancy. CDH occurs when the diaphragm fails to form correctly, allowing the abdominal contents to move into the chest cavity through a hole in the diaphragm. Depending on the severity of CDH, this occurs earlier or later during an unborn baby's development.

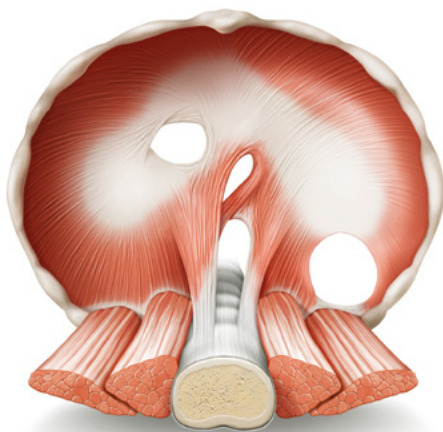


Fig. 1. Types of CDH: left-sided defect

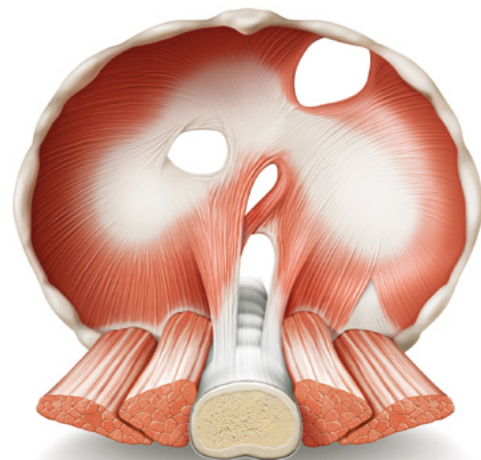


Fig. 2. Types of CDH: right-sided defect

Usually the stomach, liver fragment, spleen, intestine and sometimes the kidney enter the chest.



Fig. 3. Left-sided hernia

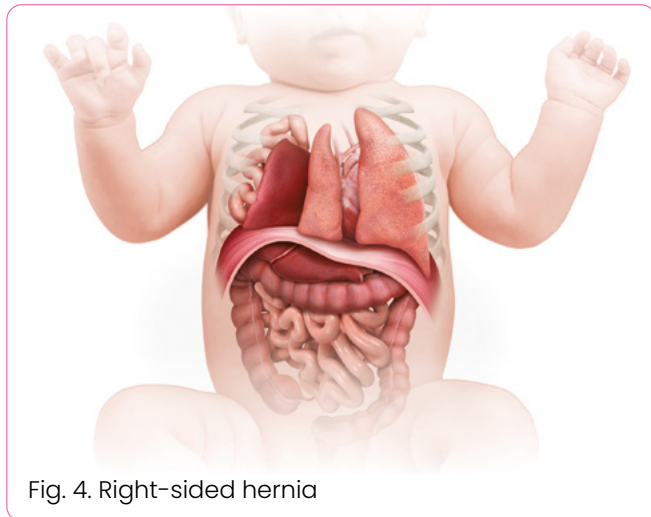


Fig. 4. Right-sided hernia

CDH occurs in approximately 1 in 4,000 live births. The vast majority of babies with CDH have a posterolateral defect on the left side of the diaphragm.

## 2. What is FETO? What are the selection criteria for the procedure?

The FETO procedure can double the chances of survival of a newborn with severe CDH. In 2021, results of a randomized clinical trial were published, which evidenced the effectiveness of the procedure. FETO is now an internationally recognized in-utero treatment option for CDH.

**The study results evidencing the effectiveness of the FETO procedure were published in the prestigious New England Journal of Medicine** (<https://www.nejm.org/doi/full/10.1056/NEJMoa2027030>).

The procedure is performed to increase the chances of survival of a newborn with CDH.

CDH is one of the most serious congenital structural malformations diagnosed in unborn babies, associated with a very high mortality rate. The procedure is offered only to patients with the most severe prognosis and involves placing a balloon in the fetal trachea, which is filled with about 1 ml of saline. This results in a tight occlusion of the airways. This builds up the pressure of the fluid below the balloon, which helps the lungs to grow and expand, and increase their volume. As a result, your baby will have a better chance of survival.

## 3. How does the surgeon perform the FETO procedure?

FETO is a high-precision fetal therapy procedure. It should be performed in a specialized health-care center, with experienced pediatric surgeons and facilities that allow taking proper care of a newborn in case of preterm delivery or any other FETO-related complications. The most suitable center is a highest-level (tertiary) referral hospital for CDH patients, which offers prenatal diagnosis, in-utero (FETO) and neonatal procedures,

and has a delivery department and an intensive care unit for children with CDH, all in one building (e.g. the Children's Teaching Hospital in Warsaw, located at ul. Żwirki i Wigury 63A).

The FETO procedure is performed in an operating theatre setting. Mother receives epidural (commonly given for pain relief in childbirth) or local anesthesia. Next, an injection is made through the skin on the pregnant woman's abdomen to

anesthetize and immobilize the fetus. In the following step, a thin 3-mm tube is inserted into the uterus and a special instrument (fetoscope)

is placed inside the tube to visualize the baby. The fetoscope is guided through the baby's mouth into the windpipe, where a balloon is placed.

## Practical information

### 4. Before your baby is born

#### Contact details to arrange a consultation/ appointment:

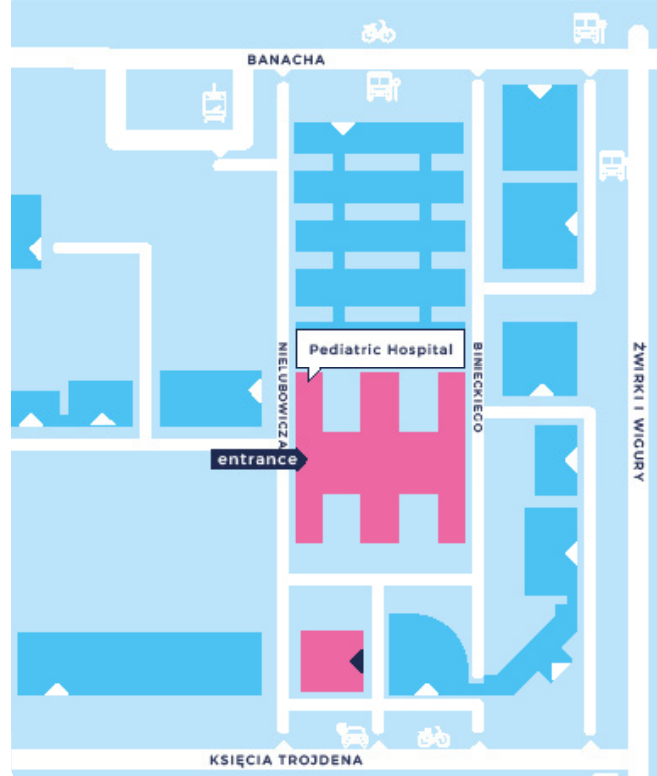
poloznictwo.dsk@uckwum.pl  
[kontakt@przepuklinaprzeponowa.pl](mailto:kontakt@przepuklinaprzeponowa.pl)

#### Responsible person:

dr hab. n med. Przemysław Kosiński  
Specialist in Obstetrics and Gynecology,  
Maternal Fetal Medicine Specialist  
(Fetal Management Unit, Clinical Department  
of Obstetrics, Maternal Fetal Medicine and Gynecology,  
Medical University of Warsaw)

#### Address:

Department: Oddział Kliniczny Położnictwa,  
Perinatologii i Ginekologii Warszawskiego  
Uniwersytetu Medycznego. The hospital  
is situated at ul. Żwirki i Wigury 63A  
in Warsaw. The entrance is located at  
ul. Banacha.



#### 4.1. Consultation

Once you have booked an appointment, you will be most likely referred for a consultation at the Fetal Medicine Clinic in the hospital. The Fetal Defects Outpatient Clinic is located on the second floor (section D). Before your appointment, you will be asked to go to the reception of the Children's Teaching Hospital. During your first consultation you will not have to stay in hospital.

A doctor will perform an ultrasound scan and examine your results from previous tests. You should bring with you all your medical records and results of tests ordered during pregnancy.

Parents can ask questions and, together with the medical team, plan the next steps.

If you are considered eligible for the FETO procedure, you will be scheduled for admission to hospital (usually at 26-28 weeks of pregnancy).

#### 4.2. Admission procedure

When you arrive on the day of your appointment, the first thing to do is to go to the reception of the Obstetrics Department (to the left of the hospital's main entrance, near the ambulance entrance). Once you complete appropriate consents and other forms, you will be directed to the Perinatal Pathology Department, where you will remain under the care of a team of doctors and midwives.

### 4.3. Frequently asked questions

#### Why WUM? Why this hospital?

The Children's Teaching Hospital in Warsaw is a tertiary (highest level) reference center, designed to provide specialist services for children with complex medical conditions, such as CDH. ALL procedures: consultations, FETO, delivery and postnatal treatment are delivered within one building. There is no need to transfer the baby to other facilities. You should keep in mind that transferring a newborn with CDH to another facility will always affect the baby's condition (the transfer ambulance has no specialized equipment and medication). Following the consultation and FETO procedure, a medical case conference is conducted, during which a team of obstetricians, neonatologists and surgeons develops a treatment plan. Proper planning is extremely important to improve the prognosis of a child with CDH. It is therefore best to have all the procedures performed within the same building. A team of specialists is prepared to provide care to a particular baby and the baby's mother.

#### What documents should I bring with me?

Bring all your medical records and test results with you. If necessary, doctors at the Children's Teaching Hospital in Warsaw will order additional tests.

#### What medical services are offered by the hospital?

The medical team of the Department of Obstetrics, Perinatology and Gynecology at the Children's Teaching Hospital has the most experience in the management of children with CDH. The hospital offers a wide range of examinations, procedures and surgeries for children with CDH, from prenatal consultations and FETO procedure, to delivery and CDH repair surgery after your baby is born. Your hospital stay may also include psychological care.

#### What is FETO?

FETO procedure (Fetoscopic Endotracheal Occlusion) involves the placement of a balloon (about 2 cm in size) into an unborn baby's airway. The balloon blocks the baby's airway, which allows the lungs to grow. The available medical references and research studies show that FETO can help to double the chances of survival of a newborn (e.g. from 15% to 30%). For more information, visit our website:

[www.przepuklinaprzeponowa.pl](http://www.przepuklinaprzeponowa.pl)



Fig. 5. FETO procedure

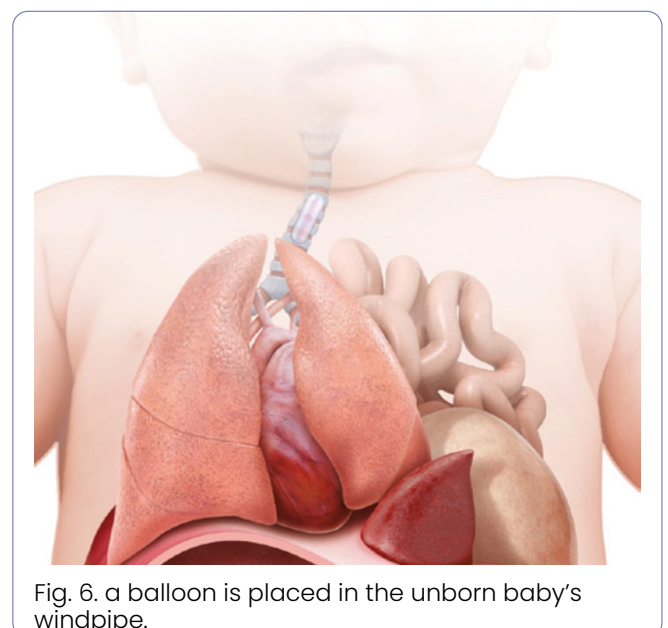


Fig. 6. a balloon is placed in the unborn baby's windpipe.

### ● **When is FETO performed?**

FETO procedure (the placement of a balloon into an unborn baby's airway) is usually performed at 26–28 weeks of pregnancy. The next step is to puncture and remove the balloon, which is carried out at 33–34 weeks of pregnancy.

### ● **Is FETO a dangerous procedure?**

FETO procedure is safe for both the mother and the baby, and the risk of complications is minimal. The most common complications are uterine contractions, discharge from the birth canal and drainage of amniotic fluid.

### ● **Will my baby feel pain during the FETO procedure?**

No, your baby will not feel pain. During the FETO procedure there is no need to make any incisions in the baby's skin. Before the procedure, the baby receives anesthesia so that it stops moving (falls asleep), following which the procedure can be performed.

### ● **Will I feel pain during the procedure?**

No, mother receives anesthesia (usually similar to that for childbirth). She is conscious, but feels no pain. You may experience slight discomfort during the procedure.

### ● **What are the selection criteria for the FETO procedure?**

The eligibility for the FETO procedure is determined based on results of an ultrasound scan performed by an experienced doctor. The LHR and o/e LHR parameters are used for assessing the severity of CDH. Babies with the most severe types of CDH are considered eligible for the FETO procedure.

### ● **Do I have to undergo FETO?**

NO! The procedure is offered to mothers whose unborn baby has been diagnosed with severe

CDH. It has been demonstrated that the placement of a balloon into an unborn baby's airway increases the baby's chances of survival. A patient can choose not to have this procedure – like any other surgery or medical procedure. Before the procedure you will be asked to sign an informed consent. Attending a consultation does not mean necessarily that you are eligible for the procedure.

### ● **How long is the recovery period after the FETO procedure?**

Typically, the FETO procedure is well-tolerated by the mother who needs less than 24 hours to fully recover. Monitoring of mother and baby usually involves a several-day stay at the Perinatal Pathology Unit.

### ● **Does the placement of a balloon into my baby's windpipe will cause polyhydramnios?**

No! The balloon is placed into your baby's windpipe and not into the esophagus. Babies with CDH are usually surrounded by excessive amniotic fluid because the digestive tract is partially located within the chest. The placement of the balloon in your baby's windpipe will not affect the amount of amniotic fluid.

### ● **Is there one lung in my baby's chest, not two? Why is there only one lung seen on ultrasound scan?**

CDH is the displacement of abdominal organs into an unborn baby's chest. The displaced organs compress the lung which cannot be seen on an ultrasound scan. Therefore, before your baby is born, only the lung – on the opposite side of the hernia, is usually visible on an ultrasound scan (the left lung in right-sided CDH, the right lung in left-sided CDH). The other lung, however, is located in the chest. It can only start to grow after a surgical operation following the birth of the baby.

## What is the prognosis after the FETO procedure?

Published studies show that FETO can double the chances of survival of a baby. Babies diagnosed with CDH can also survive without FETO, however, their chances of survival are lower.

## What causes CDH? Is CDH a genetically inherited disease?

It is most often an isolated (single) defect that occurs spontaneously, with no connection to genes. It is attributable to genetic factors in about 15–20% of cases. Once CDH is diagnosed, it is recommended carrying out amniocentesis to check if CDH is caused by a genetic defect.

## Can a patient who lives far away from the hospital return home and her attending physician after surgery?

No, because if you start having uterine contractions and your baby is born prematurely, it will be necessary to remove the balloon to allow the baby to breathe on their own. You will need to stay with your relatives or friends, in a hotel or rented apartment with your family for a period of about 6 weeks. Thanks to the Ronald McDonald Foundation, it is also possible for our patients and babies hospitalized at the Children's Teaching Hospital to stay at the Ronald McDonald House which forms part of the hospital.

## What should I do to be able to stay in the Ronald McDonald House?

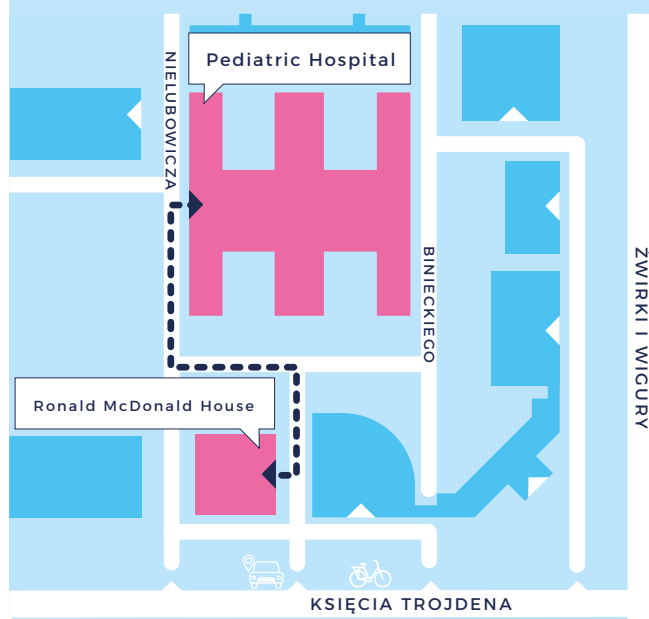
If you wish to stay at the Ronald McDonald House, you need tell this to medical staff before the FETO procedure, and the medical staff will complete all formalities.

## How much does it cost to stay at the Ronald McDonald House?

The stay at the Ronald McDonald House for patients of our Hospital is free of charge. All the costs are paid by the Ronald McDonald Foundation.

## What are the selection criteria for staying at the Ronald McDonald House?

Patients who had FETO procedure during their hospitalization at the Department of Obstetrics, Perinatology and Gynecology of the Children's Teaching Hospital in Warsaw can stay at the Ronald McDonald House immediately after discharge from the hospital. The Ronald McDonald's Home is situated 200 meters from the Children's Teaching Hospital.



## What should I bring with me to the Ronald McDonald House?

Normally, you should bring with you the same things that are necessary during a hospital stay. You will not have to bring bed linen with you. If you decide to stay at the Ronald McDonald House, you will need to comply with the Internal House Regulations. For more information, you can visit the website:

[https://frm.org.pl/co-robimy/  
dom-ronalda-mcdonald-w-warszawie/](https://frm.org.pl/co-robimy/dom-ronalda-mcdonald-w-warszawie/)

or contact the staff of  
the Ronald McDonald House:

tel. 22 633 04 94



## 5. What to expect after birth

### What will happen to my baby after birth?

The baby will remain in the Neonatal Intensive Care Unit, which – like the Clinical Department of Obstetrics, Perinatology and Gynecology – is located on the second floor of the hospital. A team of experienced neonatologists (newborn baby doctors) will be caring for your baby.

### Can CDH be repaired laparoscopically?

Yes, it is possible. The selection for surgery is always done by surgeon according to the health status of the baby, the week of pregnancy and many other parameters.

### How long will it take for my baby's condition to become stable before the surgery?

The surgery can be performed after the delivery, when the circulatory and respiratory systems become stable. Usually, the procedure is performed within up to 7 days after delivery. However, the surgery will be scheduled according to your baby's condition. You will receive detailed information from the team of surgeons and neonatologists of the Children's Teaching Hospital in Warsaw.

### How long is the baby's recovery period after the surgery?

As each case is different, each case warrants its own outlook. You should keep in mind that your baby may need long-term rehabilitation.

### How should I take care of my baby at home? What is the chance of reherniation? If CDH recurs, what are the symptoms?

Caring at home for a baby after diaphragmatic hernia repair surgery is usually not much different from caring for any other newborn. Follow the recommendations you received at the time of discharge from hospital.

**The signs that this may have happened are as follows:**

- The skin around the wound is red.
- Does your baby has fever / high temperature?
- Does the baby choke and gag during feeding?
- Your baby is drooling excessively.

**If your child has any of the symptoms listed above or you are concerned about your child's behavior, consult your doctor urgently! If you think your child's condition requires additional help, call an emergency ambulance.**

In cases of severe CDH, it is usually necessary to repair the diaphragm by sewing in synthetic material. As the child grows, the diaphragm also grows, unlike the sewn-in patch. As a result, reherniation can occur. If reherniation occurs, an additional hernia repair surgery will be necessary to stitch in a synthetic mesh.

For more information, please visit our website:

[www.przepuklinaprzeponowa.pl](http://www.przepuklinaprzeponowa.pl)



**The partner of this publication is Association of Parents of Children with Congenital Diaphragmatic Hernia "ZUZIK" – find us on Facebook.**

