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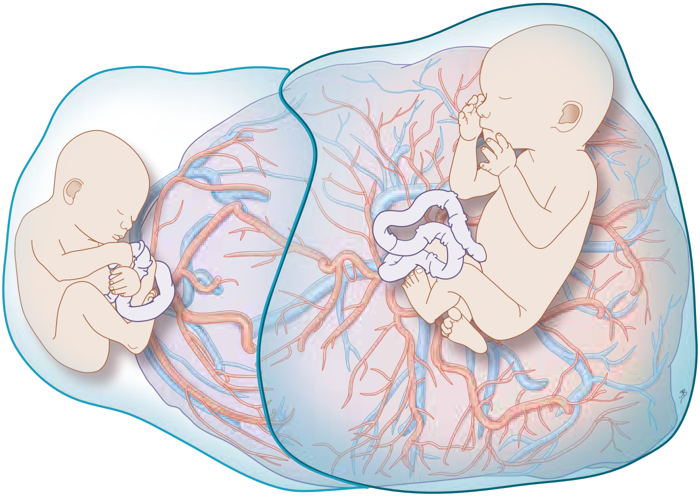


Selective foetal growth restriction (sFGR)

patient information

WHAT IS SELECTIVE FOETAL GROWTH RESTRICTION (SFGR)?

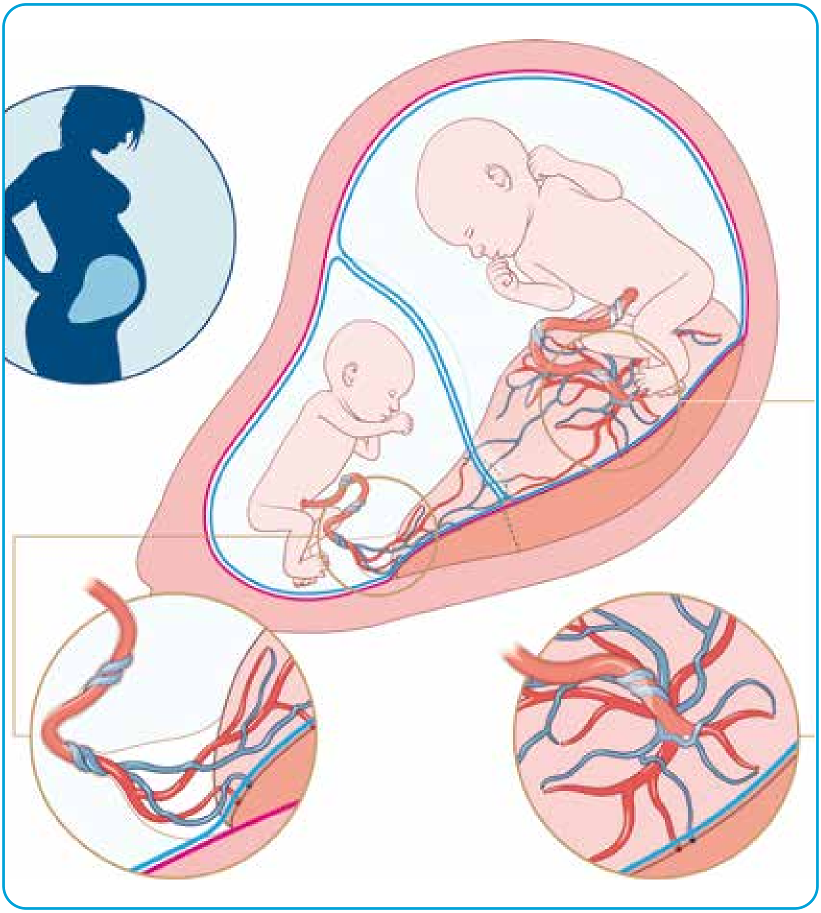
Selective foetal growth restriction (sFGR) in monochorionic twins is when there's a big difference in growth between the two babies. Monochorionic twins share the same genes which means they should normally grow at the same rate.

Monochorionic twins share a placenta. Blood vessel connections on the placental surface connect the circulatory systems of both babies. The main cause of sFGR in monochorionic twins is unequal placental sharing. The smallest baby often has the smallest portion of the placenta, which means it has less access to nutrients and oxygen and therefore cannot grow properly. Sometimes the smallest baby receives additional nutrients through the blood vessel connections of the twin sibling.

The severity of sFGR depends on how unequally the placenta is shared and the presence and size of the blood vessel connections and thus the blood exchange between the twins. The operation of the placenta is also thought to play a key role in the severity of sFGR.

It's important to note that sFGR does not involve an imbalance in blood exchange between twins, which is the case with twin-to-twin transfusion syndrome (TTTS) and twin anaemia polycythemia sequence (TAPS). However, sometimes a combination of these syndromes occurs – often requiring a different treatment/follow-up.

SFGR can affect the well-being of both babies. The growth and health of both babies will therefore be closely monitored during pregnancy.



Unequal placental sharing with visible blood vessel connections between the twins. The smallest baby's umbilical cord is usually located at the edge of the placenta, while the largest baby's umbilical cord is inserted in the middle. (Illustration: Amanda Gautier)

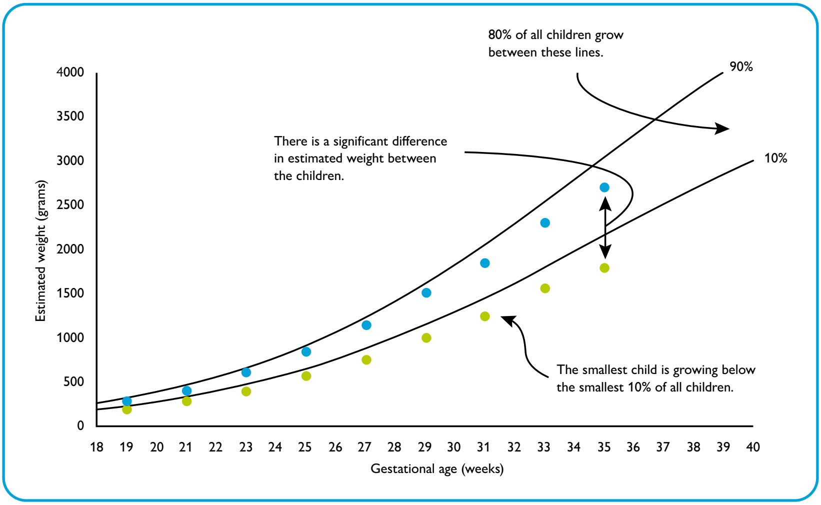
HOW OFTEN DOES SFGR OCCUR?

Selective growth restriction occurs in one or two out of ten monochorionic twin pregnancies.

HOW IS SFGR DETERMINED?

You won't experience any symptoms of sFGR if you're pregnant. The diagnosis is made by ultrasound. Various definitions are used to determine sFGR. UZ Leuven uses a difference in estimated weight of 20% or more between babies. The difference in estimated weight is shown in the figure below.

The difference in growth between the babies is even more apparent when you look at the difference in abdominal circumference. The abdominal circumference is one of the measurements taken during an ultrasound to estimate the weight.

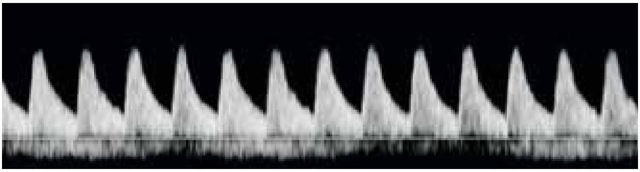


THREE TYPES OF SFGR

sFGR is divided into three types, based on the blood flow pattern in the smallest baby's umbilical cord. This pattern is examined by ultrasound (Doppler echo) and provides a picture of the severity of sFGR.

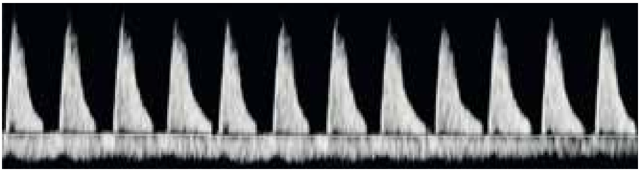
TYPE 1 – NORMAL FORWARD BLOOD FLOW

The Doppler examination shows a forward blood flow in the smallest baby's umbilical cord. This is the normal blood flow pattern for a growing baby.



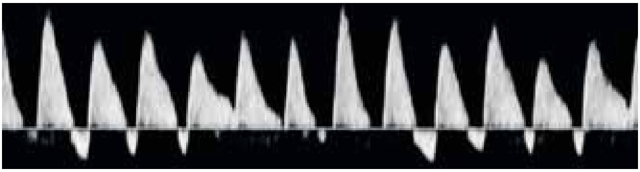
TYPE 2 – PERSISTENT ABSENT OR REVERSE BLOOD FLOW

Doppler examination shows persistent absent or reverse blood flow in the smallest baby's umbilical cord during the heart relaxation phase. This blood flow is abnormal and indicates a reduced blood flow in the smallest baby.



TYPE 3 – ALTERNATING PATTERN (ALTERNATING FORWARD - ABSENT OR REVERSE BLOOD FLOW)

The Doppler examination shows an alternating pattern of forward and absent or reverse blood flow in the smallest baby's umbilical cord artery. This pattern is often seen in unequal placental sharing with large blood vessel connections between the twins (read more about this in the next chapter).



OUTCOME

PREGNANCY OUTCOMES PER TYPE

The outcome for the baby depend on the severity and type of selective growth restriction. Early-onset sFGR (diagnosed early in pregnancy before 28 weeks) tends to be more severe than late-onset sFGR (after 28 weeks).

Other ultrasound findings that affect the outcome include:

- the degree of growth difference between babies
- stunted growth of the smallest baby
- abnormal blood flow in other blood vessels
- too little amniotic fluid around the smallest baby

The team following you up will pay attention to all of these factors during your pregnancy.

Type 1

In the majority of sFGR pregnancies, the smallest baby has a forward blood flow in the umbilical cord (type 1). Most type 1 sFGR twins do well. Pregnancy outcomes are similar to, or possibly slightly less favourable than monochorionic twin pregnancies without growth problems. The recommended gestational age for delivery is slightly earlier, usually between 34 and 36 weeks.

Type 2

A persistent absent or reverse blood flow in the umbilical cord of the smallest baby (type 2) is not common. It is thought that in type 2, in addition to unequal placental sharing, the placental portion of the smallest baby isn't working properly and there's very little blood exchange between the babies. In twins with type 2-sFGR, the outcome is uncertain, especially when the abnormal blood flow occurs early in pregnancy. The health of the smallest baby with type 2-sFGR usually deteriorates as the pregnancy progresses. Survival rates of these twins are lower than for types 1 and 3, i.e. at around 70%. These twins are delivered on average around 32 weeks or earlier, if the health of the smallest baby deteriorates.

Type 3

An alternating forward and absent or reverse blood flow in the smallest baby's umbilical cord (type 3) is caused by blood flowing back and forth in a large arterial connection between the two babies. In twin pregnancies with type 3-sFGR, the largest baby with the largest placental portion provides extra oxygen and nutrients to the smallest baby with the smallest placental portion. This allows the smallest baby to continue growing. Most twins with type 3-sFGR do well, and survival rates are between 80 and 85%.

But the large arterial connection also comes with risks. In one in ten twin pregnancies with type 3-sFGR, sudden changes in blood exchange between the two babies may occur, and a baby may suddenly lose a lot of blood through the large arterial connection.

In the worst case, this can lead to loss of the smallest baby or both babies. Twins with type 3-sFGR are usually born between 32 and 34 weeks.

Strong together or vulnerable together

As monochorionic twins have a shared blood circulation, the health of the one baby affects the health of his or her twin sibling. The twins can help each other grow through the shared blood vessel connections, but it may also cause problems. In the unfortunate event that the smallest baby dies in the womb, there's a 50% chance that the largest baby will also die, because a lot of blood can flow from the largest baby to the deceased baby. And if the largest baby survives, there's roughly a 30% chance of brain damage.

Twins with type 2- and type 3-sFGR are more likely to have problems after birth than twins with type 1-sFGR because twins with type 2 and 3 are usually born much earlier and are smaller than twins with type 1-sFGR. Often the largest baby is more likely to need breathing support immediately after birth than the smaller twin sibling.

LONG-TERM OUTCOMES

The risks of long-term health problems depend on the severity of sFGR and gestational age at birth. If it's safe to let babies grow longer in the womb, they'll be heavier at birth and the risk of long-term health problems is reduced.

Twins with type 2 and type 3-sFGR are born earlier and are smaller. This makes them more vulnerable to developmental problems. To date, very few studies have examined the development of children with selective growth restriction.

Most children develop normally. The smallest child is slightly more likely to have mild developmental problems than the largest child (35 compared to 10%). Both the smallest and largest child have a 5% chance of developing severe developmental problems.

Because of the potential health problems with severe premature birth, your twins will have regular checkups to detect developmental problems as early as possible if delivery is before 32 weeks or if the baby weighs less than 1,500 grams. This follow-up is performed by a specialised team consisting of a paediatrician, developmental psychologist, physiotherapist, general educationalist and speech therapist.

FOLLOW-UP DURING PREGNANCY

ULTRASOUND CHECKUPS

The twins will have regular ultrasound checkups.

Ultrasound allows us to monitor the babies' growth, blood flows and amniotic fluid. If we find indications that the babies' health is deteriorating, we'll discuss the next steps with you.

The frequency of the ultrasound checks depends on the severity of the sFGR and the gestational age. This may increase from once every two weeks to twice a week. Sometimes hospitalisation is recommended to monitor the twins' health (see “Hospitalisation and birth”).

TREATMENT

To date, there is no treatment to cure sFGR. Ultrasounds allow us to monitor the twins closely and determine whether treatment or planned delivery is necessary.

Selective reduction

Selective reduction can be considered in twins with type 2- or type 3- sFGR, if there's a suspicion it's severe and life-threatening for one or both babies. Selective reduction is a procedure that cuts off the blood flow to the umbilical cord of the smallest baby. The smallest baby dies as a result. The aim of selective reduction is to improve the outcome and chances of survival of the largest baby. The chances of survival of the largest baby after selective reduction are good (between 80 and 90%). On average, these babies are born at 35 to 37 weeks.

Your gynaecologist will discuss this procedure in detail with you when and if necessary. The risks of the procedure will be weighed against the severity of the sFGR and the risks of possible death and harm without treatment. We also take into account what you want of course.

Laser treatment

Laser treatment of the blood vessel connections on the placental surface can cure TTTS and TAPS. However, laser treatment cannot change the position of the placenta. In other words, unequal placental sharing – the main cause of sFGR – cannot be resolved with laser treatment. Also, blood vessel connections that allow the smallest baby to receive extra nutrients and oxygen from the largest baby are closed with laser treatment. This can lead to a reduced survival rate of 30 to 40% for the smallest baby and 70% for the largest baby. Laser treatment is therefore only recommended in monochorionic twins with selective growth restriction and TTTS or TAPS.

HOSPITALISATION AND BIRTH

The best time of delivery will be estimated based on the babies' health and the ultrasound findings.

There's no hard evidence on the best time to give birth. Usually, twins with type 1-sFGR are born between 34 and 36 weeks. Twins with type 2-sFGR are born around 32 weeks on average, or earlier if the health of the smallest baby deteriorates. Twins with type 3-sFGR are usually born between 32 and 34 weeks.

Sometimes you need to be hospitalised to monitor the twins even more closely with a cardiotocography or CTG (a continuous recording of the foetal heart rate). A planned hospitalisation is usually only necessary for twins with type 2- or type 3-sFGR and begins around 28 weeks or later. The gynaecologist will discuss this with you.

When twins are born before 32 to 34 weeks, admission to the neonatal intensive care unit is often necessary. The same applies to very small babies at birth (< 2,500 grams). Our neonatologists will explain more about this before the planned delivery.

PARENTAL GUIDANCE

An sFGR diagnosis can have a major impact on the lives of (expectant) parents. To guide and support parents during this intensive and sometimes uncertain pregnancy, we offer parental guidance by a psychologist and/or social worker who will assist you during exciting, sad and beautiful moments. They also offer support with practical questions (such as questions about insurance, leave, options for support through the municipality). They remain involved even after the birth when the babies are in the neonatal intensive care unit.

CONTRAST STUDY

For a better prediction of the outcomes of twins with selective growth restriction over time, we launched an international study, referred to as the CONTRAST study. UZ Leuven, LUMC (Leiden), Karolinska University Hospital (Stockholm), BCNatal (Barcelona), Mount Sinai Hospital (Toronto) and Boston Children's Hospital (Boston) are working together to improve the care of twin pregnancies with selective growth restriction.

If you'd like to participate in this study, some additional ultrasound measurements will be taken during your scheduled ultrasounds to find out whether they allow us to make better predictions of the babies' health. We'll also examine the placentas of twins with selective growth restriction. For more information, contact the doctors of the twin team.

Because we're trying to improve the outcome of sFGR twins, you're free to take part in research projects (such as the CONTRAST study).More information is available from the doctors of the UZ Leuven twin team or in the flyers of the gynaecology and obstetrics ultrasound centre.

SUMMARY

✔ sFGR concerns a large growth difference between twins. This is usually caused by unequal placental sharing.

✔ sFGR is broken down into three types based on the blood flow profile in the smallest baby's umbilical cord.

✔ Ultrasounds allow us to closely monitor the development of sFGR twins.

Selective foetal growth restriction:

20% of monochorionic twins **≥ 20%** difference in weight **Unequal** placental sharing	**Ultrasound checkup** Findings predict **outcome** and **treatment**.	Long-term outcomes depend on **different** factors. **Developmental Problems** occur more often.

WHAT'S IMPORTANT FOR YOU?

You can use this section to write down topics that are important to you. You may have specific questions about these (or other) topics. Write them down and discuss the questions with your doctor at your next appointment.

STORY OF LARS AND FLORIS

WHAT A ROLLERCOASTER!

On hearing the news that I was pregnant with identical twins, we were both surprised and overwhelmed. We were happy, but worried at the same time. We were referred to UZ Leuven, because it was a high-risk pregnancy that had to be closely monitored.

I went to the hospital for a checkup every two weeks. These visits were always tense and made me feel anxious. It soon became clear that the placenta was not being shared equally. The smallest baby's umbilical cord was on the edge of the placenta, while the largest baby's umbilical cord was nicely in the middle. Blood flow in the small baby was far from optimal. It could still go either way.

> “I didn't always fully grasp that the situation was very serious at certain moments”

The strange thing was that I actually felt fine and suffered few pregnancy ailments. The reassuring and motivating words during the consultations were great and meant we didn't worry all the time and were able to enjoy the pregnancy. Looking back, I sometimes think I didn't fully grasp that the situation was very serious at certain moments.

I'd known for a long time that I'd be hospitalised at 28 weeks so that everything could be monitored closely. Three times a day I was hooked up to the monitor and ultrasounds were twice a week. It was tense at times, because the heartbeats of our babies were hard to detect. The idea was to stretch the pregnancy to 32 weeks. But Lars and Floris were born at 31 weeks and 2 days. Lars didn't feel

like exploring the world yet, but the risk for Floris had become too great.

Floris weighed 915 grams and Lars 1.536 kg. The babies were taken away immediately and examined by the pediatricians. They took Lars out of the incubator for a short time so I could hold his hand. Floris was too small and had to be taken to the neonatal unit immediately. Fortunately I was able to visit the boys the same day.

> “He's drinking like a baby weighing 2 kg”

Their stay at the neonatal unit was a tense period. Every time they made a leap forward, we were very happy: less or no more breathing support, wearing a romper the first time, the first time in the bathtub, together in a twin room, kangarooing with both of them together the first time, the top coming off the incubator, no more alarms, breast-feeding, no stomach tube, sleeping in a normal bed, etc.

And we felt really heartened when they said things like “he's drinking 8 times 25 ml already”, “he's really good, he's drinking the same amount as a baby weighing 2 kg”, “he's drinking like a big boy, then he can go in the bath”, “what a strong kid, he's turned around in his incubator”, “they're really strong, they keep moving around when I'm changing their nappy, you better be warned”, etc. We loved the positivity: “Great, our boys are doing really well!”

Sometimes it was a step backwards, only to then move forward again. For example, Floris had to go under the “blue lamp” several times. At one point, their skin looked a bit “florid”, leading the doctors to believe they had a virus and needed a blood transfusion. A small part in Lars' brain lit up, which they didn't expect to be a major problem, but which needed further follow-up. Things like that meant it was a rollercoaster of emotions: from being scared, feeling sad, trying to grasp things properly to putting things into perspective and being positive again. The care teams were a great help. It helped us to share our concerns and listen to sound advice.

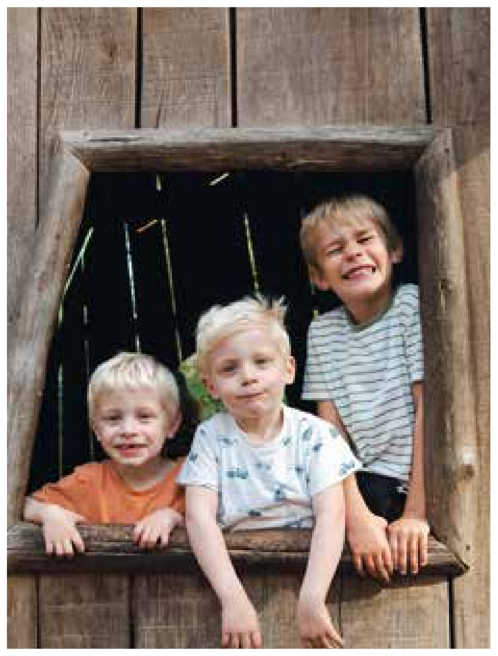
“All the boys at home!”

After seven weeks, on 15 October, we were allowed to take Lars home. Hurrah! His big brother Vince proudly came with us to pick up his brother. Because Floris was still too small, he had to stay in hospital. It was a busy period, and it wasn't easy dividing our attention between our three boys. Every day I took Lars to the hospital to be with Floris. But when I went home with Lars in the evening, I had to leave Floris at the hospital. Even though I knew he was getting the best care from a great team, it felt strange taking my one son home and leaving the other one. But a month later, on 14 November, we were allowed to take Floris home as well. Finally! All the boys at home!

And then things got even crazier. We had to get used to not being at the hospital anymore and the safety and familiarity this gave us: no more monitors, no-one to ask questions to, etc. We had to trust our intuition and ability. An encouraging word that we were doing a great job did wonders. And it was so nice to really get to know our boys! We still had to be very careful the first winter because Floris and Lars were still quite poorly, but after that things got better and better.

After about a year we had to go to a physiotherapist, because Lars was experiencing some problems transitioning from lying to sitting and crawling. He was a real 'bottom scooter'. Thanks to the physiotherapist's exercises and encouraging words, Lars made great progress. After an appointment at the paediatric neurology unit, we learned that Lars had cerebral palsy (CP). Even though we knew several weeks after the birth there might be a problem, we hadn't given it much thought, partly because we were so busy.

We just went from day to day in that period. When people ask us now how we coped, I don't know how to answer. We just carried on. Sometimes we were very aware of what has going on and at other times things seem to have passed us by practically unnoticed. We had to divide our attention between Lars and Floris and of course we also had big



“His perseverance and courage are huge”

brother Vince who wanted attention. The arrival of two little brothers who demanded a lot of attention and care took some getting used to for him.

Floris and Lars are four now. They are two energetic little guys who love to play outside and climb on everything. Every day they ask: “Are we going to do something fun outside?” Together with their big brother Vince (who is seven) there's never a dull moment. They're doing really well. They have a lot of fun together, are always joking around and getting up to all kinds of mischief. They started playing football and practising judo to get rid of some of that excess energy. There's still a difference in growth which is actually quite handy, because if they had the same build, it would be very hard to tell them apart. Lars often likes to say he's bigger than Floris and makes comments like “I can do that, I'm a big boy. Floris can't do that, he's still too small.” He'll be surprised when he realises that although he's a little bigger, he's actually the youngest.”

Soon Lars will have to wear splints on his legs for the first time. That'll be quite confronting for a while. Despite the fact that he's doing great, of course we'd have preferred to spare him all this. We realise that Lars is doing very well and that it could have been much worse. But on the other hand, everything could have been fine of course. In those difficult moments we soldier on, hoping, but also knowing that he'll get there. His perseverance and courage are huge.

And when we look at how small Lars and Floris were at birth and where they are now, we can only be grateful and incredibly proud. And when we're feeling sorry for ourselves because it's so busy with three energetic, temperamental, argumentative boys, that phrase from neonatology comes up again and again: “We're sure they'll be two fiery characters, but it's because they're so strong they made it.” And when I think of this I can only be proud and happy with our wonderful boys!

SUPPORT US

More information on donations is available on www.uzleuven.be/steun.

MORE INFORMATION?

Information on giving birth:
https://www.uzleuven.be/en/gynaecology-and-obstetrics/obstetrics/giving-birth

Information on the neonatal unit:
https://www.uzleuven.be/en/neonatology

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