

Information on the anomaly scan

The 20-week ultrasound

August 2014



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Zwanger!

Informatie en adviezen van verloskundigen,
huisartsen en gynaecologen



Informatie over de screening op downsyndroom

Prenatale screening

januari 2015



1 What can I find in this brochure?

Many expectant parents wonder whether their child will be healthy. That is understandable. Fortunately, the vast majority of children are born healthy. This brochure gives you (and your partner) information about the 20-week ultrasound scan. The 20-week ultrasound scan checks for spina bifida and anencephaly. The ultrasound operator also checks to see how the foetus's organs are developing. This examination is part of prenatal screening.

If you are considering a 20-week ultrasound, you will meet with your midwife, family doctor or obstetrician in advance for an in-depth consultation. The information in this brochure can help you prepare for this consultation. You can also reread all of this information at your convenience after the consultation.

Prenatal screening can help set your mind at ease about your child's health. However, it can also be a source of uncertainty and force you to face some difficult decisions. You are free to choose whether or not you want to undergo testing and whether you want follow-up testing if the results are unfavourable. You can decide to break off testing at any time.

There is a separate brochure on prenatal screening for Down's syndrome. Both brochures can be found at www.rivm.nl/downscreening and www.rivm.nl/zowekenecho. You can also ask your midwife, family doctor or obstetrician about this. There is also a leaflet entitled "Zwanger!" (Pregnant!). This leaflet contains general information about pregnancy, and about blood tests during pregnancy.



2 Screening for physical defects

What is the 20-week ultrasound?

The 20-week ultrasound is also known as the anomaly scan. The main objective of the ultrasound is to establish whether the child has spina bifida or anencephaly. The ultrasound also examines the development of the child's internal organs. This may reveal other physical defects (see examples). Finally, the ultrasound will establish whether the child is growing normally and whether there is sufficient amniotic fluid.

Some examples of the defects that can be revealed by a 20-week ultrasound include: spina bifida, anencephaly, hydrocephalus, heart defects, a hole or rift in the diaphragm, a hole or rift in the abdominal wall, missing or malformed kidneys, missing or malformed bones, malformed arms and legs.

The result of the 20-week ultrasound cannot guarantee that the child will be healthy. Some defects will not show up on the ultrasound.

Are there any risks involved?

The procedure does not pose any risk to the mother or child.

This ultrasound scan is not 'just for fun'

The 20-week ultrasound scan is a medical examination. The aim of this ultrasound scan is not to check the foetus's gender. If the ultrasound operator happens to notice the gender, he/she will only provide the details at your request.

If you are expecting a multiple birth, each child will be examined separately. When making an appointment for the 20-week ultrasound scan, you should indicate that you are expecting a multiple birth.

3 Abnormal test results

If the 20-week ultrasound reveals any abnormalities, the consequences for your child may not yet be clear. In most cases, you will be offered the option of follow-up testing. You will then be provided with extensive information on the follow-up test in a consultation with your ultrasound operator, midwife, family doctor or obstetrician, who can also provide support and answer any questions you may have.

You are free to determine whether or not you want testing and what steps to take on the basis of the results.

Follow-up testing

Follow-up testing consists of an extensive ultrasound scan at a specialised hospital. Any defect(s) revealed during the original test will then be examined in further depth. Your child will then have a more detailed examination. In some cases, you may also be offered the option of undergoing an amniocentesis procedure. Amniocentesis involves a slight risk of miscarriage.



Follow-up testing: what happens next?

Follow-up testing may show that there is nothing wrong with your child.

Follow-up testing may reveal that you are expecting a child with a disorder. A result of this kind is always followed by a discussion with one or more medical specialists. They will discuss the test results with you, in detail.

In the case of some abnormalities, it is better for the child if it is born in a specialised hospital. This ensures that the child will get the correct care immediately after birth.

Some abnormalities will have a major impact on the child, on you and on your partner. You are then faced with the difficult choice of continuing the pregnancy or of having it terminated. Discuss this matter with your partner, and with your midwife, family doctor or obstetrician. If you opt for early termination, this procedure can be carried out up until the 24th week of your pregnancy.

Some abnormalities are so severe that the child may die during birth, if not before.

4 Making a conscious decision

You are free to decide whether or not you want to take the 20-week ultrasound. If the test reveals any abnormalities, you can also decide whether or not you wish to undergo follow-up testing.

What should I base my decision on?

- How much do you want to know about your child before it is born?
- If the 20-week ultrasound reveals that your child may have a physical defect, would you have follow-up testing carried out?
- Follow-up testing may reveal that your child has a physical defect. How will you prepare for this outcome?
- How do you feel about ending the pregnancy prematurely if your child has a severe physical defect?

Help in making a decision

If you need help in deciding whether or not to take a 20-week ultrasound, you can discuss this with your midwife, family doctor or obstetrician.



5 What else do I need to know?

If you are considering a 20-week ultrasound, you will meet with your midwife, family doctor or obstetrician in advance for an in-depth a consultation. They will then provide you with:

- information about the examination
- an explanation of of the examination procedure
- an explanation of the various possible results
- information on physical defects, such as spina bifida

If you have any questions, make sure to take this opportunity to ask them.

When can I expect the results?

In most cases, you will hear the results of the 20-week ultrasound immediately after examination.

20-week ultrasound scan: costs and insurance coverage

The in-depth consultation about the 20-week ultrasound scan (with your obstetrician, GP or gynaecologist) and the costs of the ultrasound scan itself are covered by your basic health insurance. The costs will only be reimbursed if the individual conducting the screening has an agreement with a regional centre for prenatal screening. We recommend that you ask your midwife, family doctor or obstetrician about this in advance. At www.rivm.nl/zowekenecho, under 'frequently asked questions', there is a list of affiliated midwife, family doctor or obstetricians in your region. We also recommend that you check whether your health insurance company has a contract with the person conducting the screening. Ask your health insurance company for further details.

Insurance coverage for follow-up testing

If the 20-week ultrasound reveals any abnormalities, you can opt to take a follow-up test. The costs of this test will be covered by your health insurer.

6 Further information

Internet

The information in this brochure is also available online, at www.rivm.nl/zowekenecho and www.prenatalescreening.nl. These sites also feature a decision aid. You will also find more background information on prenatal screening, follow-up testing and birth defects.

Other websites featuring information on prenatal screening:

www.zwangerwijzer.nl

www.nvog.nl

www.knov.nl

Leaflets and brochures

If you would like to know more about the tests and defects discussed in this brochure, ask your midwife, family doctor or obstetrician for information leaflets. Information leaflets are available on the following subjects:

- Down's syndrome (trisomie 21)
- Trisomy 18 (Edwards' syndrome)
- Trisomy 13 (Patau's syndrome)
- Spina bifida and anencephaly

You can also download these information leaflets at

www.rivm.nl/downsyndroom and www.rivm.nl/zowekenecho

You may want more information on other tests administered during and after pregnancy, such as the standard blood test for pregnant women in order to determine blood type and detect infectious diseases. If so, ask your midwife, family doctor or obstetrician for the Pregnant! brochure, or visit

www.rivm.nl/bloedonderzoekzwangeren.

Organisations and addresses

The Erfo Centre

The Erfo Centre (Erfocentrum) is the national knowledge and information centre for heredity, pregnancy and genetic or congenital defects.

www.erfocentrum.nl, www.erfelijkheid.nl, www.zwangerwijzer.nl

E-mail Erfo helpline: erfolijn@erfocentrum.nl

Erfo-helpline: +31 (0)33 - 303 2110.

BOSK

BOSK is an association for people with impaired motor skills and their parents. BOSK provides information and advice, puts fellow patients in touch with one another and protects the interests of people with impaired motor skills. One of BOSK's main areas of focus is spina bifida, both in children and adults.

www.bosk.nl

E-mail: info@bosk.nl

Telephone: 030 - 245 90 90.

RIVM

The RIVM (Dutch National Institute for Public Health and the Environment) coordinates screening programmes for Down's syndrome and physical defects at the request of the Ministry of Health, Welfare and Sport and in cooperation with the various medical professional associations. For more information, visit:

www.rivm.nl/downscreening and www.rivm.nl/zowekenecho

Regional centres

The eight regional centres are all licensed to organise the screenings described above. They maintain contractual agreements with the screeners and are responsible for regional quality assurance. For more information on these regional centres, visit:

www.rivm.nl/zowekenecho > 'Frequently Asked Questions'

7 Test results and privacy

If you decide to take part in the screening, your data will be recorded. Without this data, it would not be possible to make an accurate diagnosis, to offer effective treatment, or to safeguard the quality of care. This data is recorded in your own medical dossier, and in the Peridos database. Peridos is used by all health care providers involved in Dutch prenatal screening. However, only those care providers involved in your screening can see your details. The system is thoroughly secured against any invasion of your privacy.

If necessary, the regional centre can also access the data held in Peridos. The regional prenatal diagnostic centre is licensed by the Ministry of Health, Welfare and Sport to coordinate the screening programme and to monitor the quality of the work carried out by all of the healthcare providers involved. Screening has to meet national quality standards, and the regional prenatal diagnostic centre uses the Peridos data to help monitor this quality. Care providers also monitor their own work quality, and sometimes need to compare data with each other. Your care provider can give you more information about the protection of your data. If you wish, your personal details can be removed from the Peridos database after the screening has taken place. If you would like this to be done, tell your obstetric care worker.

Scientific research

Aside from your healthcare providers and the regional centre, no-one can access your personal information. Information that is used for statistical purposes (to find out how many pregnant women make use of prenatal screening, for example) is entirely anonymous. This means that there is no way in which this information could be traced back to you – not even by those who produce the statistics in question.

The same applies to scientific research. Prenatal screening must be continually improved, so scientific research is needed. Scientific research always involves the use of anonymous information. If your data are nevertheless required for the purpose of scientific research, those involved will always ask for your permission.

Whatever your decision, this will not affect the way you are treated before, during, or after the screening.

Publishing details

The contents of this brochure were developed by a working group. This working group includes the organisations representing general practitioners (NHG), midwives (KNOV), gynaecologists (NVOG), ultrasound operators (BEN), paediatricians (NVK), clinical geneticists (VKGN), the Erfocentrum, the Dutch Genetic Alliance (VSOP), regional screening organisations and the National Institute for Public Health and the Environment (RIVM).

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This brochure outlines the current situation, based on the most recent available information. The parties responsible for drawing up this brochure accept no liability for any errors or inaccuracies. For a personal consultation, please contact your midwife, family doctor or obstetrician.

This brochure on the 20-week ultrasound is also available at www.rivm.nl/zowekenecho.

Layout and design: Vijfkeerbouw - RIVM, August 2014



Rijksinstituut voor Volksgezondheid
en Milieu
Ministerie van Volksgezondheid,
Welzijn en Sport

