

Information on the anomaly scan

The 20-week ultrasound

2011 version



English

This brochure is designed to inform you (and your partner) about the 20-week ultrasound. The English brochure text is available on www.rivm.nl/zwangerschapsscreening.

Deutsch

Diese Broschüre bietet Ihnen (und Ihrem Partner) Informationen über die Ultraschalluntersuchung in der 20. Schwangerschaftswoche. Sie finden den deutschen Text der Broschüre auf der Internetseite www.rivm.nl/zwangerschapsscreening.

Français

Dans cette brochure, vous (et votre conjoint ou compagnon) trouverez des informations sur l'échographie de la 20ème semaine. Vous trouverez la version française de cette brochure sur www.rivm.nl/zwangerschapsscreening.

Español

Este folleto le ofrece información (también a su pareja) sobre la ecografía de las 20 semanas. El texto español de este folleto lo encontrará en www.rivm.nl/zwangerschapsscreening.

Português

Este folheto proporciona a si (e ao seu parceiro) informação sobre a ecografia de 20 semanas. O texto deste folheto em português encontra-se em www.rivm.nl/zwangerschapsscreening.

Papiamentu

Den e foyeto aki bo (i bo partner) ta haña informashon tokante e ekografia di 20 siman (20-weken echo). Bo ta haña e kontenido di e foyeto aki na Papiamentu na www.rivm.nl/zwangerschapsscreening

Türkçe

Bu broşür, gebeliğin 20. haftasından itibaren uygulanan ultrason hakkında size (ve eşinize) bilgi verme amacıyla hazırlanmıştır. Türkçe metne şu adresten ulaşabilirsiniz: www.rivm.nl/zwangerschapsscreening.

عربي

تم إعداد هذا الكتيب لتعريفك (وتعريف شريكك) على برنامج العشرين أسبوعاً. يمكن العثور على نص هذا الكتيب باللغة العربية على الموقع التالي www.rivm.nl/zwangerschapsscreening.

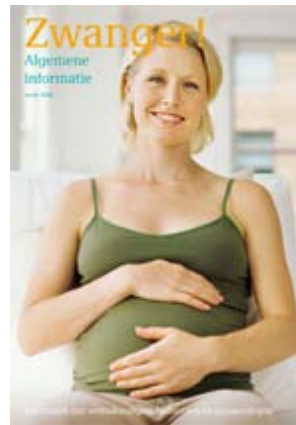
中文

本小手冊的・容是要告訴您 (和您的伴侶) 關於第 20 週的超音波圖譜。您可以在下面網站取得本小手冊的中文版，網址：
www.rivm.nl/zwangerschapsscreening.

Contents

1. What can I find in this brochure?	5
2. Screening for physical defects	7
3. Abnormal test results	8
4. Making a conscious decision	12
Help in making a decision	
5. What else do I need to know?	13
When can I expect the results?	
Prenatal screening: costs and insurance coverage	
6. Further information	16
Internet	
Leaflets and brochures	
Organisations and addresses	
7. Test results and privacy	14

1 What can I find in this brochure?



Understandably, many expecting parents wonder whether their child will be healthy. Thankfully, most children are born without any complications. This brochure provides you and your partner with information on the 20-week ultrasound. The 20-week ultrasound determines your child's growth and development. The ultrasound can also reveal serious physical defects. This test is known as 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 the 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.

We also offer a separate brochure on prenatal screening for Down's syndrome. This brochure is available at www.rivm.nl/zwangerschapsscreening. You can also ask your midwife, family doctor or obstetrician for a copy. In addition, we offer the 'Pregnant!' brochure which contains general information on pregnancy and the pregnancy blood test.

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 extensively 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.

Examples of physical 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 20-week ultrasound is no guarantee of a healthy child. Some defects will not show up on the ultrasound. The procedure does not pose any risk to the mother or child.

No 'snapshot'

The 20-week ultrasound is not intended to provide you with 'snapshots' of your unborn child. The ultrasound is also not intended to determine your child's gender.

If the ultrasound operator can distinguish your child's gender from the ultrasound, he or she will only tell you at your request.

If you are expecting a multiple birth, each child will be tested individually.

3 Abnormal test results

If the 20-week ultrasound reveals any abnormalities, the consequences to 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. In some cases, you may also be offered the option of undergoing an amniocentesis procedure. Amniocentesis involves a slight risk of miscarriage.

What happens after follow-up testing?

Follow-up testing may show that your child is healthy. The results will then be discussed with you extensively, after which your mind will hopefully be set at ease.

However, follow-up testing may also reveal that your unborn child has a serious physical defect. If this is the case, you will always be provided with a consultation with or one more medical specialists.

Abnormal test results may force you to face some difficult questions. Certain defects are so serious that your child could die before or during birth. In other cases, it may be better for the child if you give birth in a specialised hospital, where your baby can immediately receive the appropriate care.

Certain serious birth defects will have great consequences for both the child, you and your partner. You will then be faced with the difficult decision of whether to keep the pregnancy or have it terminated. Discuss this with your partner and your midwife, family doctor or obstetrician. If you do decide to terminate the pregnancy prematurely, you may do so until the 24th week of pregnancy.



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 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 consultation. They will then provide you with:

- information on the test
- an explanation of the testing 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 testing.

Prenatal screening: costs and insurance coverage

The in-depth consultation on the 20-week ultrasound with your family doctor, midwife or obstetrician and the ultrasound itself are covered by your basic health care insurance. You can visit www.rivm.nl/zwangerschapsscreening and click on '20-week ultrasound' and 'kosten' (costs) for an overview of the affiliated midwives, family doctors and obstetricians in your region. We also recommend that you check whether your health insurer has a contract with the person conducting the screening. Ask your health insurer for more information.

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/zwangerschapsscreening and www.prenatalescreening.nl. These sites also feature a help centre to help you make a balanced decision. You will also find more background information on prenatal screening, follow-up testing and birth defects.

Other websites featuring information on prenatal screening:

www.zwangernu.nl
www.zwangerwijzer.nl
www.kiesbeter.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:

- 20-week ultrasound
- Down syndrome
- Spina bifida and anencephaly

You can also download these information leaflets at

www.rivm.nl/zwangerschapsscreening and www.prenatalescreening.nl

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/zwangerschapsscreening

Organisations and addresses

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.prenatalescreening.nl, www.erfelijkheid.nl,
www.zwangernu.nl, www.zwangerwijzer.nl

E-mail Erfo-helpline: erfolijn@erfocentrum.nl

Erfo-helpline: 0900 – 66 555 66. The Erfo-helpline is open Mondays and Thursdays, from 8.30 to 11.30 (€ 0.25 a minute)

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

Phone number: 030 - 245 90 90.

RIVM

The RIVM (Dutch National Institute for Public Health and the Environment) coordinates screening programmes for Down 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/zwangerschapsscreening

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/down-seo/organisatie

7 Test results and privacy

If you decide to take part in the test, this means that your test results will be used to form a diagnosis and possibly also to offer treatment, in order to provide the highest quality of prenatal health care.

Your test results are kept in a general database system called Peridos. 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.

The regional prenatal diagnostic centre also has access to Peridos data. 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 those 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 test results. 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

Apart from your care providers and the regional prenatal diagnostic centre, no-one can see your personal details. When the data is used to produce statistics (for example, the percentage of pregnant women who opt for screening), the data is fully anonymized. This means that it is absolutely impossible for anyone, including the people doing the statistics, to trace the data back to you in person.

The same applies to the scientific research that is needed to ensure that prenatal testing continues to improve. This research almost always uses anonymized data, and every care is taken to ensure that it is impossible to trace this data back to you or your child. However, there are exceptional circumstances in which scientific research does need traceable data. If you would prefer that your data is not used in this research, tell your care provider.

Naturally, your privacy decisions will have no effect at all on how you are treated before, during or after the screening.

Colophon

The contents of this brochure were developed by a working group. This working group includes the association of family doctors (NHG), midwives (KNOV), obstetricians (NVOG), ultrasound operators (BEN), the Erfo-centre, the Dutch Association of Parent and Patient Organisations (VSOP) and the RIVM.

© Central body, RIVM

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/zwangerschapsscreening

Midwives, obstetricians, family doctors, ultrasound operators and other obstetrical care providers can order additional copies of this brochure through the website www.rivm.nl/pns/folders-bestellen

Layout and design: Uitgeverij RIVM, December 2010



National Institute for Public Health
and the Environment
Ministry of Health, Welfare and Sport



NEDERLANDSE VERENIGING VOOR
OBSTETRIE & GYNAECOLOGIE



Beroepsvereniging
Echoscopisten
Nederland
voor verloskunde & gynaecologie



ISLN 41113:ETIE WJOP ERFE.L.04E035VF4W6S*U:3REW