Rijksinstituut voor Volksgezondheid
en Milieu
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Information about screening for Down's, Edwards' and Patau's syndromes

Prenatal screening
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1 What you can be tested for

You are pregnant. You can have tests to see if the baby you are expecting has a disorder. Or a physical abnormality. We call this prenatal screening. There are two types of screening:

1. Prenatal screening for Down's, Edwards' and Patau's syndromes.
2. The 20-week ultrasound examination. This is an examination for physical abnormalities.

It is entirely your decision whether or not you have these tests.

This leaflet contains information about tests for Down's, Edwards' and Patau's syndromes. There is also a leaflet about the 20-week ultrasound examination.

Opting to be screened for Down's, Edwards' and Patau's syndromes

You can be tested for Down's, Edwards' and Patau's syndromes early in your pregnancy. Are you pregnant? Then you will be seeing an obstetric care provider (the person looking after you during your pregnancy). At your first visit you will be asked if you would like to know more about this test. There are then two possibilities:

3. You may not wish to know about it. Then you will not have a test for Down's, Edwards' and Patau's syndromes.
4. You do want to know more about it. You will then have an in-depth discussion about this test and about the 20-week ultrasound test. After this discussion you are free to choose if you want to have the test or not.

Have you decided to have the discussion about the screening test?

Tip: before the discussion about the test, take a look at this site www.pns.nl where you can read about the screening test in advance. On this site you will also find a short film explaining about the test. If you have any questions, please feel free to ask them during the discussion.

The obstetric care provider will often be a midwife. It may also be another health care provider, such as a gynaecologist, sonographer or nurse.

2 The disorders

Down's syndrome

What is Down's syndrome?
Down's syndrome is a disorder that a baby is born with. It does not go away. People with Down's syndrome have an intellectual disability. They often look different. You don't know beforehand how severe the handicap will be.

How does a child with Down's syndrome develop?
Children with Down's syndrome develop more slowly and to a more limited extent than the average child. But this varies from child to child. It is difficult to predict how a child will develop. It is good to stimulate a child with Down's syndrome right from the time of birth. Parents can get support to help their child to develop well.

Young children grow up in the family. Usually they are able to go to a normal children's day care. Very occasionally a special day care group may be necessary. Most children with Down's syndrome go to a normal primary school. A small group go to a special education school. On average, those children who go to a normal primary school learn to talk and to read better.

After primary school most children go to a school for special secondary education. A few children go to a day centre. Some adolescent children with Down's syndrome will realise that they cannot keep up with their peers. This may make them shy, insecure and withdrawn. As a result, they may sometimes respond differently than expected.

A quarter of adults with Down's syndrome are still living at home at the age of 30. The rest live independently in supported accommodation. They usually live in residential projects for small groups.

The average life expectancy for people with Down's syndrome is 60 years. They need guidance and support from their parents and families throughout their lives.

What do parents and siblings say?
Almost all parents say that they love their Down's syndrome son or daughter very much. They are also proud of their child. Eight out of ten parents feel that their child has given them a more positive outlook on life. The same goes for most siblings. They say that they want to stay involved in their brother or sister's life when they have all grown up. However, some families do encounter problems. They find it difficult to cope with these problems.
To read more about this, go to www.downsyndroom.nl/home/levensloop/kwaliteit-van-leven

Health problems in people with Down's syndrome
The risk that a baby with Down's syndrome will die before birth is higher than average. In addition, a child with Down's syndrome may suffer from the following health problems:

- Almost half of them are born with a heart defect. In half of all cases it will disappear naturally. The other half will have surgery, after which they will usually have no more problems.
- One in ten children with Down's syndrome may also have an abnormality of the stomach or intestines. This can also be treated by surgery.
- Children with Down's syndrome are more at risk of having problems with their breathing, hearing, sight and speech. They are also more prone to getting infections. If these problems occur, how serious they are varies from person to person.
- Adults with Down's syndrome tend to develop dementia more often and at a younger age than average.

What sort of support is available for children with Down's syndrome and their parents?
A paediatrician, Down's syndrome outpatient clinic or Down's syndrome team can support children or young people and their parents. A Down's syndrome team may include the following people:
- A paediatrician
- A speech therapist. This is someone who helps with speech.
- A physiotherapist
- A social worker.

Adults with Down's syndrome can get help from their GP, a doctor specialised in caring for people with intellectual handicaps (AVG), a Down's syndrome clinic or Down's syndrome team.

Who pays for the care and support?
Health insurance companies cover the cost of medical care for children with Down's syndrome.
And of other resources, if they are needed. There are various other financial aid arrangements available to parents to cover costs.

Edwards' syndrome

What is Edwards' syndrome?
Edwards' syndrome is a very serious congenital disorder. It is much less common than Down's syndrome. The majority of babies with Edwards' syndrome will die either before or shortly after birth. Often they do not grow as well as they should before birth. Their health is very fragile, and they usually die during the first year of life.

Children with Edwards' syndrome have serious health problems. But exactly what problems they have, and how severe they are, varies from child to child. The following problems can occur:
- A very severe intellectual disability. This occurs in all children.
- Nine out of ten of these children will have a serious congenital heart defect.
- Some children have problems with other organs, such as the kidneys and intestines. This is not very common.
- An open abdominal wall and oesophageal atresia (a condition where the gullet is not connected to the stomach). This is not very common.
- A small face with a large skull. This is not very common.

Patau's syndrome

What is Patau's syndrome?
Patau's syndrome is a very serious congenital disorder. It is much less common than Down's syndrome. The majority of babies with Patau's syndrome will either die before birth or shortly after birth. Often they do not grow as well as they should before birth. Their health is very fragile, and they usually die during the first year of their life.

Children with Patau's syndrome have serious health problems. However, exactly what problems they have, and how severe they are, varies from child to child. The following problems can occur:

- A very severe intellectual disability. This occurs in all children.
- Most children have problems with their brain and heart.
- Some of the children have problems with their kidneys and abnormalities of their stomach and intestines. This is not very common.
- Extra fingers or toes. This is not very common.
- A hare-lip, jaw and palate (schisis). This is not very common.

An extra chromosome
All the cells in our body contain chromosomes. Chromosomes are made up of DNA. DNA determines what our body looks like and how everything in our body works. Every cell contains 23 pairs of chromosomes. Someone with Down's syndrome, Edwards' syndrome or Patau's syndrome has an extra chromosome in every cell.

- A child with Down's syndrome has three number 21 chromosomes instead of two. Another name for Patau's syndrome is trisomy 21.
- A child with Edwards' syndrome has three number 18 chromosomes instead of two. Another name for Edwards' syndrome is trisomy 18.
- A child with Patau's syndrome has three number 13 chromosomes instead of two. Another name for Patau's syndrome is trisomy 13.
  Do you want to know what the chances are of Down's, Edwards' or Patau's syndrome? Take a look at www.pns.nl.

3 Whether or not to have the screening test: it's up to you

You don’t have to have the test for Down’s, Edwards’ and Patau’s syndromes. It is entirely up to you. You also decide how far you want to go with the screening test. You can withdraw from the screening test at any time.

Help with choosing

This may help you to choose what you want to do:

- Fill in the questionnaire on www.pns.nl/dep/hulp-bij-het-kiezen. This questionnaire will give you insight into your thoughts and feelings.
- Talk about it with your partner or with other people.
- Ask your questions during the discussion with your obstetric care provider.

It is possible that you have a higher chance. If you have previously had a child with Down’s, Edwards’ or Patau’s syndrome, for example. You may then visit a Centre for Prenatal Screening, which is a department in a hospital. There you will be given in-depth information about the possibilities.

These questions can help you to decide whether you do or do not want a test:
Do you want to know whether it has Down’s, Edwards’ or Patau’s syndrome before your baby is born? Or would you rather wait and see?

- How much do you want to know about your baby before it is born?
- Suppose that the result is that your baby possibly has a disorder. In that case, would you want to have follow-up diagnostic testing or not? So that you can be sure. Both are possible, it is up to you.
- Follow-up diagnostic testing is chorionic villus sampling or an amniocentesis. This involves a small chance of a miscarriage. How do you feel about this?
- How would you feel about life with a child that has Down’s, Edwards’ or Patau’s syndrome?
- How would you feel about the possibility of terminating the pregnancy if your baby has one of these disorders?
- If you heard that your child had Down’s, Edwards’ or Patau’s syndrome, what would you want to do?

What could the test results mean to you?
These three situations are possible after the test results:

1. *You will be reassured.* The screening test found no indications of any disorders. Or it found a disorder that will not pose a lot of problems in your child’s everyday life. Please note: your baby could still have a disorder, even if the test results are good. Because the test cannot detect all types of disorder.

2. *You become worried*. Suppose that the result is that your baby possibly has a disorder. Follow-up diagnostic testing is needed, just to be sure. You can choose whether or not to have this follow-up test.

3. *You need to make another choice.* If the follow-up test shows that your baby has Down's, Edwards' or Patau's syndrome, or another abnormality. Then you have to think about what you are going to do.

4 A discussion about deciding to have screening or not: counselling

At the first visit to your obstetric care provider, did you say that you would like to know more about the screening test? If so, you will have an in-depth discussion about this with your obstetric care provider. You will also be able to ask questions. This type of discussion is also known as counselling. The person you will be talking to is called a counsellor.

Take someone with you

Two people hear more than one. So take someone with you to the counselling session. This could be your partner, a friend or one of your parents. Avoid bringing children with you, so that you can talk without being interrupted.

It is up to you

After the counselling session, you can decide if you do or don't want a test. Are you still in doubt? If so, you can discuss it again with your obstetric care provider. This may help to make things clearer for you. After the counselling session you can decide whether or not you want your baby to be screened for Down's, Edwards' and Patau's syndromes.

5 Screening: a choice of two tests

Have you decided that you want the test for Down's, Edwards' and Patau's syndromes?
If so, you can make the following choice. You can choose from two tests:

- The NIPT. If you have this you will also be asked if you want to be informed about any other abnormalities in the chromosomes - known as secondary findings.
- The combined test.
  Below we will explain what each test involves.

What is the NIPT?

The NIPT is a test in which a blood sample is taken from the pregnant woman. The blood is examined in a laboratory. If the blood test shows that the child may have Down's, Edwards' and Patau's syndromes then a follow-up test is necessary to be sure if the child has the disorder or not.
The NIPT can be done from the 11th week of pregnancy.

Extra choice on NIPT
Have you decided to have the NIPT? If so, you need to make another choice. Namely, do you want to be informed about any other abnormalities in the chromosomes? We call these secondary findings.
The laboratory can only find very serious abnormalities in the chromosomes, so any minor abnormalities will not show up. To be clear: an abnormality of the chromosomes usually has serious consequences. This is also true of the minor abnormalities that the laboratory does not find in the NIPT.

Has the laboratory detected a secondary finding? Then you can choose to have a follow-up test. This will tell you what the secondary finding will mean for you and your child. About 4 in every 1,000 women who opt for NIPT are told that there is a secondary finding.

More information about the NIPT

For more information about the NIPT and secondary findings, go to www.pns.nl/nipt

In the Netherlands, you can only choose to have the NIPT if you take part in a scientific study (TRIDENT-2). This means that researchers may use your data. To take part you will need to sign an informed consent form. Do you want more information about the study? And about what happens to your data? Take a look at www.meerovernipt.nl.

What is the combined test?

The combined test is a combination of the following two screening tests:

1. A blood test for the pregnant woman. This test is done from weeks 9 to 14 of pregnancy.

2. A nuchal fold (neck fold) test of the baby taken during an ultrasound scan. All babies have a thin layer of moisture under the skin of the neck, which is known as the 'nuchal fold'. The thicker this nuchal fold is, the higher the chance that the baby has Down's, Edwards' or Patau's syndrome. This test is done from weeks 11 to 14 of pregnancy.

What are the differences between these two tests?

Have you decided to have a test for Down's, Edwards' and Patau's syndromes? Are you finding it difficult to choose between the tests? If so, try using the Table on page 13.
You can then compare the tests. These differences are the clearest:

- The NIPT detects more babies with Down's, Edwards' and Patau's syndromes than the combined test.
- The results of the NIPT are often more accurate than the results of the combined test.

Screening in twins
Are you expecting twins or other multiple birth? If so, you can choose either the combined test or the NIPT. Take a look at www.pns.nl/dep/tweeling.

Does your age matter?
Older women have a higher chance of having a child with Down's syndrome than younger women. Out of 10,000 pregnant women aged 30, an average of 19 will be having a child with Down's syndrome. Out of 10,000 pregnant women aged 40, an average of 155 will be having a child with Down's syndrome. The chance of having a child with Edwards' or Patau's syndrome is also higher in older women.

A comparison of the combination test and the NIPT

	Combination test	**NIPT**
What does the test involve?	• Blood test for the pregnant woman. • Neck fold test of the baby with an ultrasound examination.	• Blood test for the pregnant woman.
Is the test part of a scientific study?	No. This test has been used in the Netherlands for quite some time.	Yes, this is a new test in the Netherlands. You must give permission for your data to be used for this scientific study. See **www.meerovernipt.nl**
When can I have the test?	Blood test between 9 and 14 weeks. Neck fold test between 11 and 14 weeks of pregnancy.	From 11 weeks of pregnancy.

How long will I have to wait for the results?	This varies from one sonography centre to another. If the blood sample is taken one or two weeks before the ultrasound scan, you will usually be given the result on the day you have the ultrasound scan.	Within 10 working days.
Can I choose whether or not to be told about the secondary findings?	If there are secondary findings, then you will always be told about them.	You can choose whether or not to be told about secondary findings.
What does the test cost?	Around € 177	€ 175

6 The result does not provide certainty

The results of the NIPT and the combined test do not provide absolute certainty. However, the results are usually reassuring: if the result is not abnormal then the chance of an abnormality is very small. In that case, you will not have any follow-up diagnostic testing.

Have you had an abnormal result? Then you can opt to have follow-up testing. This will give you certainty. Would you like to know more about the reliability of the result? Take a look at www.pns.nl/dep/uitslag.

Who will tell you about the results?

Your obstetric care provider will give you the results. He or she will explain what the results mean to you. Did you decide to have the NIPT? And did you want to be told about any secondary findings? You may be called about these results by an expert from a Centre for Prenatal Screening, or by a clinical genetics outpatient clinic of a university hospital.

When will you get the results?

Before you have the combined test or the NIPT, your obstetric care provider will tell you when you will get the results.

7 The NIPT results

What are the possible results of the NIPT?

These are the possible results:

A. The result is not abnormal.
This result is almost always correct. The chance that you are carrying a baby with Down's, Edwards' or Patau's syndrome is very small. Fewer than 1 in 1,000 pregnant women who get this result turn out to be carrying a baby with one of these disorders. No follow-up testing is necessary.

B. The result is abnormal.
There is a chance that you are carrying a baby with Down's, Edwards' or Patau's syndrome. The result will indicate which of the three abnormalities your baby may have. You can have follow-up diagnostic testing. Then you will know for sure if you are carrying a baby with Down's, Edwards' or Patau's syndrome.

- About 90 out of every 100 women who get this result are actually carrying a baby with Down's syndrome.
- About 90 out of every 100 women who get this result are actually carrying a baby with Edwards' syndrome.
- About 50 out of every 100 women who get this result are actually carrying a baby with Patau's syndrome.
  Are you thinking of terminating the pregnancy? In that case you must first have follow-up tests. Just to make sure that your baby has this abnormality.

Did you also want information about secondary findings? Then you will be informed about these results.

The following results are possible:

A. A secondary finding has been reported.
Someone will call you and explain what has been found and what this may mean for you or your child. You will receive an invitation for a counselling session at a university medical centre's clinical genetics outpatient clinic where you will be given more information about the abnormality that has been found. Follow-up diagnostic testing is always necessary, just to be sure.

B. No secondary findings were reported.
You will get a letter stating that no secondary findings have been reported. No follow-up diagnostic testing will be needed. But please note: NIPT does not detect every possible type of chromosomal abnormality. There is still a small chance that your baby may have a disorder.

8 The results of the combined test

What do the results of the combined test mean?

The combined test calculates the chance that your baby has Down's, Edwards' or Patau's syndrome. So this does not provide absolute certainty.

What are the possible results of the combined test?

The following results are possible:

A. You do not have an increased chance that you are carrying a baby with Down's, Edwards' or Patau's syndrome.
This means that the chance of a baby with Down's, Edwards' or Patau's syndrome is less than 1 in 200 (e.g. 1 in 100). You will not have any follow-up diagnostic testing. The result of the combined test shows how big the chance is, but does not give you absolute certainty. There is still a small chance that your baby has Down's, Edwards' or Patau's syndrome.

B. You have an increased chance of a baby with Down's, Edwards' or Patau's syndrome.
This means that the chance of having a baby with Down's, Edwards' or Patau's syndrome is more than 1 in 200 or higher than 1 in 50, for example. You can opt to have follow-up diagnostic testing, just to be sure.

C. There are indications of another abnormality or disorder.
Is the neck fold 3.5 millimetres or more? Then you can opt for an extra ultrasound examination. A thickened neck fold can also indicate that there are other chromosomal abnormalities. And physical disorders such as a heart defect. Sometimes no cause can be found for the thickened neck fold, and the baby is born healthy, with no disorders.

When performing an ultrasound scan, the sonographer sometimes sees other abnormalities in the baby. This could involve serious abnormalities, for instance the arms or brain of the baby might be missing. If this happens you will always be told about it.

9 Deciding whether or not to have follow-up diagnostic testing

Are there indications that your baby has Down's, Edwards' or Patau's syndrome? If so, talk to your obstetric care provider who will be able to offer you support. You have the following choices:

- You can do nothing. You can carry on with your pregnancy, have no more follow-up tests and give birth to your baby.
- You can have follow-up testing. Then you will know for sure if you are carrying a baby with Down's, Edwards' or Patau's syndrome. Are you considering terminating the pregnancy? In that case you must first have follow-up tests.

It is entirely up to you

If you want more information about follow-up diagnostic testing, you can visit a Centre for Prenatal Screening for a counselling session. After the session, you can decide what you want to do. You may also decide that you don't want to have any follow-up diagnostic testing.

Have you decided to have follow-up testing?

The first test you had determines what sort of follow-up test you will have.
A. If the first test was the NIPT
Your NIPT result was abnormal. The follow-up test will be one of the following two tests:

- Chorionic villus sampling. The doctor will take a tiny sample of the placenta and examine it. This test can be done from 11 weeks of pregnancy.
- An amniocentesis. The doctor will take a some of the fluid surrounding the baby and examine it. This test can be done from 15 weeks of pregnancy.
- Then you will know for sure if your baby has Down's, Edwards' or Patau's syndrome. The disadvantage is that there is a small risk that the test may cause a miscarriage. This happens in 2 out of 1,000 women.

B. If the first test was the combined test
If the combined test showed you have an increased chance of a baby with Down's, Edwards' or Patau's syndrome. You can choose from three possible tests:

- The NIPT
    - Are the NIPT results abnormal? If so, you can then choose to have chorionic villus sampling or an amniocentesis.
    - If the NIPT results are not abnormal then you will not have chorionic villus sampling or an amniocentesis.
- Chorionic villus sampling
- An amniocentesis.

The results of the follow-up test

The doctor will give you the results of the follow-up test. The result could be that there is nothing wrong. But there is also a chance that the test will indicate that you are carrying a baby with Down's, Edwards' or Patau's syndrome. This news could make you feel anxious or sad. You would probably have a lot of questions. This

means that soon after you will have counselling sessions with one or more medical specialists, such as a gynaecologist, a clinical geneticist, or a paediatrician. Exactly which specialists are involved will depend on the abnormality or disorder that has been found.

Extensive support

During the session one or more doctors will be there to help you and give you more information. The following things will be discussed with you at this session:

- What life with your child could be like.
- The consequences the abnormality will have for you and your child.
- If the abnormality that your child has can be treated.
- Where you can find more information about the abnormality. More details about the most important organisations and websites can be found on page 21 of this folder.

You and your partner can, of course, ask any questions you wish during the session.

Help in deciding what to do about the results

The next step is usually a difficult one – you have to decide what you want to do about the results. It goes without saying that the experts at the Centre for Prenatal Screening will help you with this.

- You can continue with the pregnancy and give birth to the baby. You can prepare for the arrival of the baby with a disorder or an abnormality. You can also organise extra care for your pregnancy and the birth.
- With some abnormalities the baby may die before or during birth, or shortly after. Your obstetric care provider will give you careful guidance on this.
- You may also choose to terminate the pregnancy. Then the baby will die. Talk about this with your midwife, gynaecologist, paediatrician or clinical geneticist, and put your questions to them. You may also want to talk to other experts, a social worker for example. If you choose to terminate the pregnancy, this can be done up to 24 weeks of pregnancy.

10 Costs and reimbursements

What does the screening test cost? Does the healthcare insurance reimburse these costs?

Costs of counselling
Your healthcare insurer will pay the costs for counselling. Counselling is an in-depth discussion about the possibilities for tests for Down's, Edwards' and Patau's syndromes. You do not pay anything yourself. It will not be taken off your obligatory deductible excess.

Costs of the test
You have to pay for the test yourself. You cannot claim the money back from your healthcare insurer.
The NIPT costs around € 175.
The combined test costs around €177 for one child.

Costs of the test if you have an increased chance of a baby with Down's, Edwards' or Patau's syndrome
If you have an increased chance because you have previously had a child with Down's, Edwards' or Patau's syndrome, then your healthcare insurer will pay for the test. However, you will usually have to pay an amount from your obligatory deductible excess. Ask your healthcare insurer about this.

Costs and reimbursements for follow-up testing
Did you receive an abnormal result from the combined test or the NIPT? If so, you can opt to have follow-up testing. Your healthcare insurer will pay for this. The costs of this care are covered by your basic health insurance package. However, you will usually first have to pay an amount from your obligatory deductible excess. Ask your healthcare insurer about this. An expert from a Centre for Prenatal Screening will be able to give you more information.

Please note: the costs and reimbursements described above may change. For up-to-date information on the costs see www.pns.nl/dep/kosten.

The terms and conditions of your healthcare insurance provider may also affect your reimbursements.

11 More information about diagnostic screening

Internet

You will find more information on this subject on www.pns.nl. There is also a questionnaire. If you are finding it difficult to decide whether or not you want your baby to be screened for Down's, Edwards' and Patau's syndromes, then maybe the questionnaire will help you. The questionnaire also contains tips on how to discuss this topic with other people.

You will find more information on prenatal screening on the following websites:
www.meerovernipt.nl
www.erfelijkheid.nl
www.deverloskundige.nl
www.thuisarts.nl
www.degynaecoloog.nl

Leaflets

You can read more about it in these leaflets:

- The 20-week ultrasound examination. This leaflet can be found on www.pns.nl/20-wekenecho/folders.
- Pregnant! This is a general leaflet about pregnancy. It also gives details about the blood test you will have when you are 12 weeks pregnant. This is a test to determine your blood group, and it also examines whether you have any infectious diseases. You can find this leaflet at www.pns.nl/documenten/folder-zwanger.

Your midwife, general practitioner and gynaecologist also have these leaflets. Ask for them!

Books, organisations and addresses

There are a number of organisations and websites where you can get more information about your pregnancy, as well as various abnormalities and disorders.

The Dutch Down's Syndrome Foundation
This is an organisation for parents who have a child with Down's syndrome. The organisation strives to promote the interests of people with Down's syndrome, and their parents.

The foundation offers the following help:

- They support women who are carrying a baby with Down's syndrome. If they want to decide for themselves whether they can handle life with a child with Down's syndrome, the foundation will provide information about living with Down's syndrome, allowing the parents to make a decision that is right for them.
- They also support women who have a new-born baby with Down's syndrome.
- The website of the Dutch Down's Syndrome foundation is www.downsyndroom.nl.

In the book ‘Down’s syndrome – Alle medische problemen op een rij’ (Down’s syndrome - A summary of all the medical problems involved; 2010) by Artsen voor Kinderen (Doctors for children), there is an overview of the medical problems that commonly affect people with Down’s syndrome, from birth up to and including the teenage years.
You can also download this book as an app, which is called ‘Down’s syndroom – Medisch op weg’ (Down’s syndrome - Medical route map).

The Cyberpoli (Cyber outpatient clinic)
This is a website with a lot of information for children and young people with a chronic disorder or disability. You will find a lot of information and people's stories, and you can ask questions. The website is www.cyberpoli.nl/downsyndroom.

The Dutch Patient Alliance for Rare and Genetic Diseases (VSOP)
The VSOP is an association in which 81 parent- and patient organisations work together. These organisations focus on people with certain rare or hereditary disorders. The VSOP promotes the interests of everyone with rare and hereditary disorders. They influence policy, stimulate research and make doctors and others aware of rare conditions. The website is www.vsop.nl.

The Erfocentrum
The Erfocentrum provides information about hereditary conditions. See the websites www.erfelijkheid.nl and www.zwangerwijzer.nl

Vereniging VG-netwerken
This association is for people with an intellectual disability or learning difficulties due to a very rare syndrome, and for their parents. Their website is www.vgnetwerken.nl.

Platform ZON
Platform ZON is an organisation for the parents of children who have a very rare or unknown disorder, such as Edwards’ or Patau’s syndrome. Their website is www.ziekteonbekend.nl.

BOSK
Association/s for people with a physical handicap and their parents.
Their website is www.bosk.nl.

The Dutch Heart Foundation
You can find more information about congenital heart abnormalities on www.hartstichting.nl.

Fetusned
On www.fetusned.nl there is information about abnormalities of the bones, arms and legs. As well as information about possible treatment.

RIVM
RIVM coordinates everything concerning the organisation of prenatal screening. For example, Information and research. RIVM does this on behalf of the Ministry of Health, Welfare and Sport. For more information see www.pns.nl/down-edwards-patau-en-seo/professionals, under the heading ‘Organisatie’.

Regional Centres for Prenatal Screening
The Regional Centres for Prenatal Screening are responsible for good quality prenatal screening in your region. For more information see www.pns.nl/down-edwards-patau-en-seo/professionals, under the heading 'Organisatie'.

12 How we use your data

Where do your healthcare providers store your data?

Have you decided to have prenatal screening? Then your healthcare providers will store your data in a healthcare file. Some of these data will go into a national databank (Peridos). This is necessary to ensure that the screening tests run smoothly. Only healthcare providers can access this databank. For example the midwife, gynaecologist, laboratory technician, nurse and sonographer.

What will your data be used for?

Your data will be used for two different things:

1. Checking that the screening tests run smoothly and ensuring that the healthcare providers do their jobs properly. This quality control is carried out by a Regional Centre. This centre is responsible for good quality prenatal screening in your region. The centre is licensed to do this work by the Ministry of Health, Welfare and Sports. A member of staff at the Regional Centre is able to look at the data to check if the screening test is going well. The system is well safeguarded.
2. To further improve screening tests. To do this, the figures about the tests and about the effects of the tests are used. For example, these could be figures showing how many pregnant women opt to have prenatal screening, and what the results of the various tests are. From the data, the researchers cannot tell the identity of the people the data belongs to. However, it is sometimes necessary for researchers to know this, when investigating new methods for example. What if we want to use your data for this? Then we will first ask your permission.

What if you do not want us to use your data?

What if you don't want us to use your data for quality control and scientific research? If this is the case, tell your obstetric care provider. Your obstetric care provider can then make sure that your data are removed from the databank. This will happen after the date on which your obstetric care provider expects that you will give birth (due date). All that will be left in the databank is an anonymous report that you have had prenatal screening, so you will be included in the statistics, but no-one can see your personal data.

Want to know more?

Do you want to know more about how we protect your data? Your obstetric care provider can tell you more about it. Or go to www.peridos.nl. There is more information on www.pns.nl/screening-op-down-edwards-en-patausyndroom/juridische-informatie.

Studies TRIDENT-1 and TRIDENT-2

Have you decided to have the NIPT? Then you will be taking part in a scientific study. We need your personal data for this. For more information about this see www.meerovernipt.nl.

Colophon

Who has compiled this leaflet?
This folder has been compiled by a working group. This working group includes a number of organisations:

- The organisation of general practitioners (NHG)
- The organisation of midwives (KNOV)
- The organisation of gynaecologists (NVOG)
- The Regional Centres for Prenatal Screening
- The organisation of sonographers (BEN)
- The organisation of paediatricians (NVK)
- The organisation of clinical geneticists (VKGN)
- The Erfocentrum
- The Dutch Patient Alliance for Rare and Genetic Diseases (VSOP)
- The National Institute for Public Health and the Environment (RIVM)

The information in this leaflet is based on our current knowledge. The people and organisations responsible for compiling this leaflet accept no liability for any errors or inaccuracies. You can get personal advice from your midwife, general practitioner or gynaecologist.

This leaflet is also available on www.pns.nl/down-edwards-patau-en-seo/folders.

Are you an obstetric care provider? If so, you can obtain extra leaflets from the webshop on www.pns.nl/down-edwards-patau-en-seo/professionals.

RIVM, June 2020