

A Research Paper
from
No Less Human
Questions
and
Answers
on
Pre-natal testing

N.B. This booklet is for general readers only, and is not aimed at giving specific advice to expectant mothers. Those who have personal questions on issues of pre-natal testing may wish to contact SPUC for recommended sources of advice.

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A GROUP WITHIN THE SOCIETY FOR THE PROTECTION OF UNBORN CHILDREN
FOR FURTHER INFORMATION PLEASE CONTACT:

Alison Davis
No Less Human
Society for the Protection of Unborn Children
5-6 St Matthew Street
London SW1P 2JT
Tel: 020 7222 5845

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1. What is pre-natal testing?

Pre-natal testing is one way of finding out whether the unborn baby has a disabling condition.

It may be done by:

- imaging the baby (i.e. producing a picture, which may be still or moving);
- by testing some of the tissues and fluid which surround the baby;
- by examining a sample of the mother's blood.

2. What is the purpose of pre-natal testing?

A. POSITIVE PURPOSE.

An ultrasound scan at 12 weeks of pregnancy is offered routinely to all pregnant women, in order to determine the baby's age, so that a delivery date can be planned.

At around the same stage a range of tests will be arranged.

This may be for a good purpose:

- i) If the mother's blood is found to be of a rare type called rhesus negative, and the father is rhesus positive she may need monitoring to avoid problems with future pregnancies. If the father is also rhesus negative, then, there will be no problem at this time or in the future.
- ii) If protein levels in the blood are high, it could be a sign of a condition known as pre-eclampsia, which causes raised blood pressure in pregnant women and can stop the placenta working properly. This is dangerous to both the mother and the baby.
- iii) If diabetes is detected because of high blood sugar levels in the mother's urine, then she can be referred to a specialist who can arrange the best possible care for both mother and baby. Failure to do this could cause harm to the baby.
- iv) If it is discovered from blood tests that the mother does not have immunity to rubella (German measles), she will be counselled that she should exercise caution so that she does not come into contact with anyone who has this virus, as it can cause disability in the unborn; unfortunately, most of the harm to the unborn child will have already occurred before the twelfth week of pregnancy. (see P.4 iii)

B. NEGATIVE PURPOSE

It is a sad fact that most pre-natal tests are done to find out whether the baby has a disabling condition so that s/he can be aborted.

i) Specialised ultrasound scans can be used to indicate conditions such as Down's syndrome, heart conditions or spina bifida and hydrocephalus.

ii) Specialised maternal blood tests can also indicate these conditions (Down's syndrome, heart conditions or spina bifida and hydrocephalus).

iii) If it is discovered from blood tests that the mother does not have immunity to rubella (German measles), the baby may have already been exposed to rubella and have suffered harm such as deafness, eye disorders, heart problems, bone problems, learning disability and cerebral palsy as a result of such exposure. If this proves to be the case, the mother will be offered an abortion and may come under pressure to abort her baby.

Virtually the sole aim of the two main diagnostic tests:

- a) Amniocentesis
- b) Chorionic Villus Sampling is to detect disability.

Although much is made of “*informed choice*” for women, in fact, it is frequently assumed that a woman whose baby has been found to have a disability will want to have an abortion.

Later, on pages 13 & 16 there are examples of undue pressure from doctors on women to choose abortion.

Indeed pre-natal tests are funded by the Government on the basis that they are “*worth*” the cost because they “*prevent the birth of*” disabled babies, who cost society a lot of money to support.^{1 2}

It is offensive to suggest that killing disabled babies “*prevents disability*”; it just kills disabled people and it is insulting to say that disabled people may be legally killed to save money. If people are disposable and have to justify their right to life by their productivity or cost, none of us is safe.

¹ **Reducing the Risk: Safer Pregnancy and Childbirth** HMSO, London 1978. This DHSS document states “... because caring for the handicapped can impose great burdens on our society the prevention of handicaps ... in addition to its other benefits may save money. The costs of providing amniocentesis for all expectant mothers over the age of 40 years, and maternal serum AFP screening for all pregnant women, would be more than offset by the economic benefits in terms of savings of expenditure on children and adults with Down’s syndrome and spina bifida.”

² “Costs were overestimated” by Prof. T.M. Reynolds. *British Medical Journal* 18 November 1995. Prof. Reynolds estimated the cost of detecting a baby with Down’s syndrome was £40,000. He said “£40,000 to prevent the birth of a baby with Down’s syndrome to a woman under 30 may be perceived as expensive but is low compared with the costs of caring for someone with the syndrome.”

3. What sort of tests are available?

There are two categories of tests, both of which may be offered to a pregnant woman:

A. SCREENING TESTS

Almost all pregnant women now have ultrasound scans and blood tests to measure the amounts of several proteins in the mother's blood which derive not from the mother but from the unborn baby. The information from these two screening tests does not give a definitive diagnosis of disability, but it is used to estimate the chance of the baby having a disability.

If it is found that the chance the baby has a disability is *more* than 1 in 250, this is defined as “*screen positive*.” One pregnant woman in 20 will fall into this category, but only one in 50 of this group will *actually* be carrying a baby with a disabling condition.³

These tests are safe for the baby, but are not as precise as diagnostic tests.

B. DIAGNOSTIC TESTS

If the tests reveal a “*screen positive*” result, the mother, particularly if she is in the “*older*” age range⁴, will be offered diagnostic tests such as:

- amniocentesis or
- chorionic villus sampling, which usually give a more accurate idea of whether or not the baby has a disability.

Both these tests are invasive (meaning that they involve taking a sample from inside the womb) and therefore carry a risk of causing miscarriage (see separate section on individual tests for details, pages 11 - 12)

³ “Down’s testing can be a lottery” by Nicki Daniels. *The Times* 5 June 2002

⁴ The chance of having a baby with Down’s syndrome rises steeply with the mother’s age. At age 20, the chance is one in 1,527. This increases to one in 30 when the mother is aged 44. “Good Birth Guide: Part Two: antenatal tests.” *The Times* 16 July 2002

4. What is meant by 'false positive' and 'false negative'?

The terms '*false positive*' and '*false negative*' always refer to the results of tests taken. This means that of those babies diagnosed after the tests as either having or not having the disability, a certain percentage will be wrongly diagnosed.

False positive means that a baby will be *said* to have a disabling condition but, in fact, it will be found later that s/he will not have that condition.

False negative means that a baby will be *said* not to have a particular disabling condition but, in fact, it will be found later that s/he will have that condition.

Certainly, different studies report different percentages and different tests report different percentages but the point that must be noted is that ALL tests report both '*false positives*' and '*false negatives*'. i.e. their results are not absolutely reliable.

Built in to the national pre-natal testing programme is the AIM of discovering disabled babies and aborting them and the ACCEPTANCE that this will inevitably mean that a certain number of non-disabled babies will be aborted in error and others will also die as a result of the test causing miscarriage.

5. What specific tests might pregnant women be offered?

A. ROUTINE TESTS

i) "Dating scan"

This is offered to all pregnant women at 12 weeks to check the age of the baby. A hand held instrument called a transducer is used to produce a moving picture of the baby on a video screen, using high-frequency sound waves.

Ultrasound scans are generally thought to be safe for the baby. However, according to an article in *The Lancet*, studies in Sweden and Norway have shown that unborn children exposed to only one or two ultrasound scans while unborn are more likely than usual to be left-handed or ambidextrous (i.e. able to use both hands equally well.) This is particularly scans are causing subtle changes in the baby's brain.⁵

⁵ Paneth, N, Dept of Epidemiology, College of Human Medicine, Michigan State University, East Lansing, MI 48824, USA. "Prenatal sonography – safe or sinister?" *The Lancet* 4 July 1998

ii) Blood tests

These are offered to all pregnant women at around 12 weeks when a small amount of blood is taken from the woman's arm. They are done to check the mother's blood group, particularly the rhesus factor (see "*What is the purpose of pre-natal testing – positive purpose*" Page 2).

Blood tests are believed to be very safe, with no significant risks for either mother or baby. They can be used to predict complications at an early stage, enabling treatment to be initiated before any problems arise.

iii) Urine tests

These tests, offered to all pregnant women, can reveal signs of pre-eclampsia, a dangerous condition for both mother and baby which can be treated if discovered early. They can also detect signs of diabetes in the mother, which could harm the baby if treatment is not initiated.

There are no disadvantages of urine tests for either mother or baby.

B. "ABNORMALITY" TESTS

As their name suggests, these tests are done solely to discover whether the unborn baby has a disability.

They may be divided into invasive and non-invasive.

1. NON-INVASIVE TESTS

i) Ultrasound

The "*abnormality scan*" is offered to most (90%) pregnant women at 18-20 weeks. It is similar to the "*dating scan*" except that the aim is to detect signs which might indicate that the baby has:

- Down's syndrome
- spina bifida
- other disabilities.

An "*abnormality*" ultrasound scan, on average, identifies 50% of "*significant*" (*i.e.* "*serious*") conditions.

When ultrasound is combined with a consideration of the mother's age, (Down's syndrome is very much more prevalent in the babies of older mothers), an estimation can be made of the chance that the baby has a disability.

Mothers whose unborn babies have a disabling condition detected or *suspected* will then be offered invasive diagnostic tests.

A recent refinement of ultrasound is hi-tech 3D scans which provide moving pictures in minute detail of every feature of the baby.

These can detect several disabilities including

- spina bifida
- fetal tumours
- cleft palate.

It is possible that this could lead to pre-natal treatment, but it is very much more likely that it would facilitate abortion of the baby.⁶

Another recent development is the observation that unborn babies with Down's syndrome often have no nose bone. Looking for the absence of this bone could mean that 85% of babies with Down's syndrome would be detected, with a "*false positive*" rate of about 1%,⁷ which means that for every 100 . babies detected as having Down's syndrome one will not actually have it.

ii) Maternal blood tests

Blood tests are one of the most widely used screening tests, offered to 70-80% of pregnant women.

They can be used to calculate the chance of the baby having:

- Down's syndrome
- spina bifida,
- other more rare disabling conditions.

These tests measure levels of different substances ("*markers*") which are usually either increased or decreased if the baby has Down's syndrome or spina bifida.

There is recent evidence that some "*markers*" for disabling conditions (i.e. signs which lead doctors to believe that the baby has a disability) are not as reliable as previously had been thought.

⁶ "Womb view boost for expectant parents" *BBC News*. 6 July 2001

⁷ Nicholaides, K. et al "Absence of nasal bone in fetuses with trisomy 21 at 11-14 weeks of gestation: an observational study." *The Lancet* 17 November 2001

An American study found that although 10-14% of pregnant women have several markers for Down's syndrome, fewer than 1% of their babies actually have Down's syndrome.⁸

When the mother's age is also taken into account, the levels of these substances can provide an assessment of the chance that the baby has a disability.

The markers most frequently measured are:

- a) Alpha-fetoprotein (AFP). A low level of AFP indicates Down's syndrome. A very high level indicates spina bifida or a related disability.
- b) Human chorionic gonadotropin (hCG). Very high levels indicate Down's syndrome.
- c) Unconjugated estriol (uE3). Low levels indicate Down's syndrome.
- d) Inhibin – A. Very high levels indicate Down's syndrome.
- e) Pregnancy associated plasma protein (PAPP) which is often found in low levels when the baby has Down's syndrome.

A “*quadruple*” blood test can also be done which measures four different markers during the second trimester.

If the chance of having a disabled baby is assessed as less than one in 250 for a particular woman, it is described as “*screen negative*” and above this level is “*screen positive*.”

Women in the “*screen positive*” group are then offered invasive diagnostic tests. (P 6 and pages 11 -12)

Blood tests plus taking account of the mother's age detect correctly around 60% of babies with Down's syndrome.

However, the maternal blood tests, with no other factor taken into account, are reported to have a “*false positive*” rate of 8%, meaning that: 8 times out of 100 positive tests, the baby will not have the disability which is indicated by the test.⁹

iii) Combined tests

a) Nuchal Translucency scan (NT)

This test is done at 11-14 weeks. It is offered to only 10-15% of pregnant women.

⁸ “Study questions usefulness of ultrasound in detecting Down syndrome” by Lindsey Tanner. *Fox News* 28 February 2001

⁹ “The cost of knowledge” by Anne Marie Owens. *National Post* 19 March 2001

It uses a high-resolution ultrasound scan to measure the width of a thin layer of fluid between two folds of skin at the back of the baby's head.

Babies with some genetic conditions, including Down's syndrome, have a thicker layer of this fluid.

The baby's heart rate is also measured (babies with Down's syndrome tend to have a faster heartbeat than others) and the mother's age is considered.

All this information is then combined to provide an assessment of the chance that the baby has a disability.

It is claimed that this test will detect 78% of babies with chromosomal disorders.¹⁰

b) Integrated screening

However, a very new combination of Nuchal Translucency (NT) and maternal blood tests may give more accurate results.

NT can be combined during the first three months of pregnancy with a blood test called PAPP ("*pregnancy associated plasma protein*") which is often found in low levels when the baby has Down's syndrome (See p. 9).

In addition a "*quadruple*" blood test is also done which measures four different markers during the second trimester.

When combined with a consideration of the mother's age, early reports suggest that this may detect 90% of babies with Down's syndrome.

However, there is a "*false positive*" rate of 1-2%. This means that of the babies diagnosed positively as having Down's syndrome 1-2% (up to 2 out of 100) actually will not have the disability.¹¹

This is known as integrated testing also called "OSCAR"- *the* "One Stop Clinic for Assessment of Risk."

c) Three-Step or Ultrascreen testing

¹⁰ "A matter of birth and death". Interview with Prof. Kypros Nicolaides by Rebecca Tyrrel. *Sunday Telegraph Magazine* 8 April 2002

¹¹ *The Times* Good Birth Guide Pt II Ante natal Tests 16th July 2002

This is a series of tests offered between 11- 16 weeks and involves Nuchal Translucency screening plus a “triple” blood test (i.e. testing for three different markers.) It identifies the 5% of women who have the highest chance of having a baby with Down’s syndrome.

It has been reported that this test has a false positive rate of 5%¹². (5 out of 100 babies diagnosed by this test as having Down’s Syndrome, will not have the disability)

2. INVASIVE TESTS

iv) Diagnostic Tests

a) Chorionic Villus Sampling.

In this test a small sample of cells from the placenta is taken at 11-13 weeks and analysed in the laboratory. As the baby and the placenta originate from the same cells it is usually possible to detect whether the baby has Down’s syndrome and other disabling conditions (though *not* spina bifida.)

This test can cause the baby to miscarry. The miscarriage rate is between 1 - 3%.¹³

This means that up to 2 in every 100 babies subjected to CVS screening will die as a direct result of the test.

However, the main tragedy of this test is that its *aim* is to facilitate the deaths by abortion of those babies found to have a disability; if the aim were not present, no babies would die- it is the AIM which causes the deaths of both non-disabled and disabled babies. In addition, there is also some evidence that CVS may occasionally cause damage to the unborn child’s limbs.^{14 15}

b) Amniocentesis.

This test is usually done at around 18 weeks, though it can be done as early as 13 weeks.

It involves a needle being inserted into the womb under ultrasound guidance. A sample of the amniotic fluid (the fluid that surrounds and protects the baby, and which contains cells shed by the baby) is removed and analysed in the laboratory.

It can usually detect:

Down’s syndrome

¹² “Test identifies Down syndrome in First Trimester” *Daily University Science News* 22 August 2000. “Down’s screening is more effective” by Mark Henderson. *The Times* 23 August 2000. Both reports cover an article in *Obstetrics & Gynaecology*. August 2000

¹³ “Prenatal Genetic Testing” Published by the Department of Health. February 2000

¹⁴ “Limb abnormalities and chorion villus sampling” Letter by H.V. Firth et al. Dept of Medical Genetics, Churchill Hospital, Oxford. *The Lancet* 6 July 1991

¹⁵ “Babies need folic acid” by Dr. Thomas Stuttaford. *The Times* 15 January 1998

- ☒ spina bifida
- ☒ many other disabling conditions.

Amniocentesis causes the baby to miscarry in 0.5 - 1% of cases.¹⁶ Up to 1 baby out of every 100 will die as a result of undergoing amniocentesis.

It is reported that about 400 babies die each year as a direct result of this test, and 100 are found to have Down's syndrome, most of whom will subsequently be aborted.¹⁷

This means that for every **ONE** baby found to have Down's Syndrome, **FOUR** babies not diagnosed with any disability will die as a result of the test

Occasionally babies are injured permanently or even fatally as a direct result of being stabbed by an amniocentesis needle.^{18, 19}

In the pursuit of ensuring that no disabled babies are born, the pre-natal testing programme actually causes some previously non-disabled babies to become disabled or to die.

Mothers can also be injured by this test, and one woman died as a result of an infection caused by the amniocentesis needle.²⁰

v) additional Techniques

Recently two additional techniques for detection of fetal cells in the mother's blood have been applied to pre-natal testing :

a) **PCR** ("*polymerase chain reaction*") testing uses a chemical reaction to detect whether the baby has an extra chromosome (as in Down's syndrome).

b) **"FISH" screening** ("*Fluorescence in-situ Hybridisation*") also detects an extra chromosome.

It is said that these tests could ultimately be as accurate as amniocentesis.²¹

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¹⁶ "Prenatal Genetic Testing" Published by the Department of Health. February 2000

¹⁷ "Down's test kills more babies than it detects" by Jonathan Leake and Emily Milich. *Sunday Times* 1 April 2001 (reporting research carried out by Prof. Rebecca Smith-Bindman at St. Bartholomew's)

¹⁸ "£75,000 paid over fatal Down's test" by Paul Wilkinson. *The Times* 10 March 1999

¹⁹ "£2.4m paid to child for womb error" *The Times* 27 February 2001

²⁰ "Pregnant woman killed by Down's test blunder" *The Times* 20 March 2001

²¹ "Prenatal detection of fetal Down's syndrome from maternal plasma" by Leo L.M. Poon et al. Departments of Chemical Pathology and Obstetrics and Gynaecology, Chinese University of Hong Kong. *The Lancet* 25 November 2000

²² "Good Birth Guide Part Two: Antenatal tests." *The Times* 16 July 2002

6. What happens if a disability is detected?

The assumption is frequently made that if a disability is detected, abortion is the logical response.

A study in the British Medical Journal found that parents whose unborn child was diagnosed as having a chromosomal disability were sometimes given “grossly inadequate or frankly misleading information” leading many to abort their babies.²³

Chris Rudge found out during an ultrasound scan at 8 months of pregnancy that her baby had had a brain haemorrhage and could be brain damaged.

The doctor said it was *“a disaster. There’s really no hope”* and asked if she would abort.

She refused but he asked again, *“Are you sure you won’t consider a termination?”* (This means an abortion)

He asked this question *five times*, and each time Chris Rudge refused.

The doctor also said, *“You do realise your baby will not look like other children? Its head will be badly disfigured.”*

The baby, Katie, is now five years old and her parents are justly very proud of all she has achieved, none of which would have been possible had they succumbed to the pressure put upon them by the doctor.²⁴

It is sadly not unusual for parents to experience pressure to be screened, and to abort if a disability is found.^{25 26 27}

It is reported that abortions are carried out on:

- ☒ 92% of babies found to have Down’s syndrome²⁸
- ☒ 90% of babies with spina bifida.²⁹

²³ “Editorial: Prenatal diagnoses of sex chromosome conditions” by Barbara Biesecker. *British Medical Journal*. 24 February 2001

²⁴ “Thanks for letting me live, Mummy” by Chris Rudge. *Take-a-Break* 2 August 2001

²⁵ “Why I refused genetic testing” by Deborah Dooley. *The Times* 6 April 2000

²⁶ “Your Baby: Facts for Families”. Support Organisation for Trisomy 13/18 and related disorders. 1999

²⁷ “Battle for my baby” Letter by Mary Teale. *Sunday Telegraph* 20/12/98

²⁸ “Trends in prenatal screening for and diagnosis of Down’s syndrome: England and Wales, 1989-97. *British Medical Journal*. 3 October 1998

²⁹ “Long road to fortification – we’re up for it” *LINK* (Association for Spina Bifida and Hydrocephalus) September – October 2002

7. Are pre-natal tests reliable?

No pre-natal test is 100% accurate.

In every test there is a possibility of:

- ♦ “false positive” results (when a baby is reported to have a disability that s/he does not have)
- ♦ “false negative” results (when a disability a baby does have is not detected.). Each test has a different rate.

For instance Nuchal Translucency screening for Down's syndrome detects 82.2% of babies with the syndrome, but the false positive rate is 8.3%.

This means that of every 100 babies diagnosed by this test as having Down's Syndrome, between 8 and 9 will *not* have the condition. This error rate results in some non-disabled babies being aborted by mistake.³⁰

Although the exact figures are by no means clear, one doctor has suggested that:

“..studies show that detecting and eliminating two babies with Down's syndrome by screening programmes costs one 'normal' baby who succumbs as a result of the programme. The loss of one 'normal' baby is thought to be a price worth paying.”³¹

It is important to note that, while the abortion, in error, of non-disabled babies is utterly tragic, the abortion, on purpose, of disabled babies is equally tragic.

The assumption that it is acceptable to kill on the grounds that a baby has a disability leads to the deaths of both disabled and non-disabled babies.

It has been found that mothers who received a “false negative” pre-natal test result (i.e. the baby had a disability not detected by tests) have higher levels

³⁰ Senior, K. “More reliable prenatal screening for Down's syndrome proposed” *The Lancet* 21 August 1999

³¹ Venn-Treloar, J. “Nuchal Translucency – screening without consent” *British Medical Journal* 12 September 1998

of parenting stress, and also more negative attitudes towards their disabled children than those who either have not had tests or have been given an accurate diagnosis.

These effects persist even up to six years after the birth of the disabled child. Such women may feel anger “stemming from a mistaken belief that screening tests are highly sensitive.”³²

8. What are the risks and benefits of pre-natal testing?

For the risks of individual tests, see under the relevant test. (Look up names of individual tests in the index)

Generally non-invasive tests (Ultrasound and blood tests) have no direct dangers to either mother or baby. (See pages 7-11).

Invasive tests (Chorionic Villus Sampling and Amniocentesis) can cause the baby to miscarry.

- ♦ 40,000 unborn babies are examined by amniocentesis each year.
- ♦ 100 will be found to have Down's syndrome.
- ♦ 400 non-disabled babies will miscarry as a direct result of the test.³³
- ♦ Occasionally babies are injured permanently or even fatally as a direct result of being stabbed by an amniocentesis needle.³⁴
- ♦ Mothers can also be damaged by amniocentesis, and one woman died as a result of an infection caused by the amniocentesis needle.³⁵
- ♦ Very occasionally, it is possible to help the baby because of information gained in a pre-natal test.

³² Hall, S., Bobrow, M. & Marteau, T.M. “Psychological consequences for parents of false negative results on prenatal screening for Down's syndrome: retrospective interview study.” *British Medical Journal*. 12 February 2000

³³ “Down's test kills more babies than it detects” by Jonathan Leake and Emily Milich. *The Sunday Times* 1 April 2001. (reporting a study by Prof. Rebecca Smith- Bindman at St. bartholomew's)

³⁴ “£75,000 paid over fatal Down's test” by Paul Wilkinson. *The Times* 10 March 1999; “£2.4m paid to child for womb error” *The Times* 27 February 2001

³⁵ “Pregnant woman killed by Down's test blunder” *The Times* 20 March 2001

In the vast majority of cases there is no benefit to the baby, and the tests are done solely to detect disability so that the baby can be aborted.

9. Is pre-natal testing compulsory?

Pre-natal testing in pregnancy is supposed to be entirely optional.

The Department of Health Report on Prenatal Genetic Testing (2000) stated that: All women capable of giving consent can accept or refuse any or all of the (pre-natal) tests offered ... Consent should be freely given, without pressure from third parties."³⁶

However, disabled women³⁷ and parents who already have one or more disabled children may experience great pressure to have the tests. Caroline Armstrong-Jones, whose daughter India has Down's syndrome, says that during her second pregnancy:

"One doctor even admitted he thought I was irresponsible in refusing tests that would determine if my second child had Down's syndrome. When I continued to resist, there were the raised eyebrows, the exasperation, the curt, intrusive questioning... with (one) exception ... the medical profession displayed a callously casual attitude to life..."³⁸

Women who are pro-life and *do not want* these tests also often experience pressure to have them.³⁹ Even those who are very knowledgeable medically may be screened without their consent.

Dr. Josephine Treloar who is a G.P. has described her anger at finding that nuchal translucency testing had been done without her consent. The test was described to her simply as "*the first trimester scan*" with no hint that the key purpose was to detect if the baby had Down's syndrome.^{40 41}

³⁶ "Prenatal Genetic Testing" Published by Department of Health February 2000

³⁷ "How tragedy has made our love stronger" by Angela Seitler. *Daily Express* 7 February 2002

³⁸ "India enriches the lives of those around her" by Olga Craig. *The Sunday Telegraph* 5 March 2000

³⁹ "Doctor, leave them kids alone" by Jo Knowsley. *The Sunday Telegraph* 9 February 1997

⁴⁰ Venn-Treloar, J. "Nuchal translucency – screening without consent" *British Medical Journal* 12 September 1998.

⁴¹ "Voluntary HIV tests. The Association for Improvements in Maternity Services." *Independent (Monday Review)* 16 August 1999

10. Is the Government involved in Pre-natal Testing?

It has been reported that the Government aims to test every pregnant woman for Down's syndrome by 2004.⁴²

Current Government advice on serum testing for Down's syndrome is based on the 1998 Health Technology Assessment report, which concluded that it is "*effective*" and should be offered to all pregnant women. There are now plans to introduce a national programme of pre-natal testing for Down's syndrome.

A Department of Health spokesperson said, "We welcome any studies which could lead to improved ways of detecting Down's syndrome."

Economic arguments are sometimes presented to women, to justify pre-natal detection of disability.

These claim that as disabled people "*cost society a lot of money*" it is preferable to detect disabled babies in the womb. They can then be aborted and save the country the money it would have spent in caring for them.^{43 44 45}

This sort of calculation is highly offensive to born disabled people, and implies not only that their lives have *NO* value, but that they actually have a *NEGATIVE* value.

11. Is it ethical to test unborn babies for disabilities?

Whether or not pre-natal testing is ethical depends on the purpose for which it is done.

If it is done to help the baby - for instance to diagnose a condition which could be treated in the womb, it may be ethical.

However, the vast majority of pre-natal tests aim to detect disabled babies with the aim of aborting them.

Pre-natal tests are sometimes said to be done to "*reassure*" the mother. However, this begs the question of what will be done if a disability is discovered.

⁴² "Down's testing can be a lottery" by Nicki Daniels. *The Times* 5 June 2001

⁴³ "Hidden cost of testing for Down's" by Dr. Kieran Sweeney. *The Times* 5 April 1994

⁴⁴ White Page, C. "Screening for Fragile X is cost effective and accurate." *British Medical Journal* 26 July 1997

⁴⁵ "Reducing the Risk: Safer Pregnancy and Childbirth. HMSO. London. 1977

There is ample evidence of pressure on women whose unborn babies have been found to have a disability.⁴⁶

Every human being has the right to life from the moment of conception to the moment of natural death. No Less Human campaigns to protect the most vulnerable of human beings from harm.

Pre-natal testing sends out a strong message to adult disabled people that society would very much rather that they did not exist.

It is clear that disabled unborn children are particularly vulnerable. Most screening and diagnostic tests aim to detect disabled babies with the aim of aborting them.

This can never be ethical, because it involves denying to disabled babies their infinite human worth, and their absolute right to life.

⁴⁶ “Your Baby: Facts for families” by *SOFT* 1999 Ibid.

On this page and the next is the true story of one of the members of No Less Human which shows that disabled people can enjoy life and are equally valuable members of society. The policy of seeking out before birth and destroying unborn children suspected of having a disability is a form of fatal discrimination to the individual, and deprives society of a chance to learn the truth about the value of every life.

Evangeline - an infinitely precious person.

Evangeline Edwards, was born with a very rare condition called Thrombocytopenia Absent Radius (TAR) Syndrome in December 1994. Less than fifty children in the UK are thought to have this condition.

People with TAR syndrome have a blood clotting deficiency, because they have a reduced number of platelets in the blood. Often blood transfusions are needed, and in the early years, minor injuries may cause major bleeding. In addition the arms are shortened, and the legs are often bowed.

Evangeline's parents, Sue and Evan, found out that she had a disability during a routine scan at 20 weeks into the pregnancy. They were given several different diagnoses, including being told that her chest was so small she would not be able to breathe when born, before tests in London gave more hope.

They were strongly encouraged to consider abortion, which they refused. Sue and Evan did not know for sure what Evangeline's disability was, and whether or not she would survive, until she was actually born.

Evangeline had many hospital stays during her first few years because minor illnesses such as stomach upsets were much more serious for her.

Evangeline is now doing very well in a mainstream school. She walks short distances with callipers, and uses a wheelchair when she feels she needs it.

Life is not always easy for her, but she has a lot of friends and enjoys many activities, including horse riding and attending her local "Out and About" group for disabled and non-disabled young people.

Evangeline is a very bright child, who has had an inquisitive and determined nature since she was born - and even before that! She has a wonderful ability to deal with strangers who ask too many questions, and also has a knack of finding her own ways to do things she wants to do - like playing the piano with her feet!

Evangeline has achieved so much, especially for someone whom doctors, at one point, thought would never breathe alone. Her mother, Sue, says:

“Words will never describe how much we love her. She has brought so much joy to our family.”

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