

## RIVM vindt algemene invoering NIPT per 2023 haalbaar

Het RIVM Rijksinstituut voor Volksgezondheid en Milieu concludeert in haar [uitvoeringstoets](#) dat het haalbaar is om per april 2023 de niet-invasieve prenatale test (NIPT niet-invasieve prenatale test) in het landelijke screeningsprogramma in te voeren. Voortvarende voorbereiding door de betrokken partijen is een voorwaarde voor de implementatie in april 2023.

Zwangere vrouwen kunnen laten onderzoeken of hun ongeboren kind down-, edwards- of patausyndroom heeft. Lange tijd werd dit gedaan met de combinatietest. Sinds 2017 kunnen zwangere vrouwen ook voor een ander onderzoek kiezen: de NIPT. De voorwaarde is nu nog dat de vrouwen meedoen aan een wetenschappelijk onderzoek naar deze test (TRIDENT-studies). De NIPT is een betere test; de uitslag klopt vaker dan bij de combinatietest.

In de uitvoeringstoets geeft het RIVM duidelijkheid over de haalbaarheid en randvoorwaarden van de invoering van de NIPT in het reguliere screeningsprogramma. Het is ingewikkeld maar haalbaar om de NIPT in te voeren. Er is hiervoor voldoende draagvlak bij de beroepsgroepen en andere betrokken partijen. Het blijkt niet wenselijk om ook de combinatietest te blijven aanbieden. Nog maar weinig zwangere vrouwen kiezen voor deze test en het is daarom niet houdbaar om een goed landelijk aanbod beschikbaar te blijven stellen.

Het RIVM heeft deze uitvoeringstoets in opdracht van het ministerie van VWS Ministerie van Volksgezondheid, Welzijn en Sport verricht. De minister van VWS zal de uitvoeringstoets aanbieden aan de Tweede Kamer. Rond de zomer zal de minister van VWS zijn beleidsreactie op deze uitvoeringstoets geven.

*Commentaar KSME: NIPT is een vorm van prenatale diagnostiek en wordt derhalve wanneer er een afwijking aan het ongeboren kind wordt vastgesteld gevogd door een abortus provocatus. Lees het artikel over [foetale therapie en prenatale diagnostiek van kardinaal dr. W.J. Eijk](#) op deze website.*

---

## Paus over ongeboren leven: 'Abortus is nooit het antwoord'

*Katholiek Nieuwsblad,  
28 mei 2019*

"Abortus is nooit het antwoord"  
dat stellen moeten krijgen van wie een ongeboren kind een ernstige ziekte of beperking blijkt te hebben.

Dat zei paus Franciscus afgelopen zaterdag. "Het menselijk leven is heilig en onschendbaar en het gebruik van prenatale diagnostiek voor selectieve doelen moet sterk worden ontmoedigd omdat het een uitdrukking is van een inhumane eugenetische mentaliteit, die families de mogelijkheid ontnemt om hun zwakste kinderen te verwelkomen, omhelzen en liefhebben."

### Abortusstandpunt Kerk

Franciscus sprak deelnemers toe aan een Vaticaanse bijeenkomst over medische zorg voor "extreem kwetsbare" baby's en de pastorale zorg voor hun

ouders. De totale afwijzing van abortus door de katholieke Kerk is niet primair een religieuze positie, maar een menselijke, aldus de paus.

### **‘Elimineer nooit een menselijk leven’**

“Slechts twee zinnen, twee vragen, kunnen ons helpen dit te begrijpen.

Eerste vraag: is het toegestaan een menselijk leven te elimineren om een probleem op te lossen? Tweede vraag: is het toegestaan een huurmoordenaar in te huren om een probleem op te lossen?”

“Nee”, vervolgde Franciscus, “het is niet toegestaan. Elimineer nooit een menselijk leven, noch huur een huurmoordenaar in om een probleem op te lossen.”

Bij een prenatale diagnose van een ernstige ziekte of beperking, hebben de ouders het nodig dat medisch personeel en werkers in het pastoraat hun nabij zijn en steunen, aldus de paus.

### **Ieder kind is een gave**

Hoewel sommigen de situatie van de baby als “onverenigbaar met het leven” kunnen omschrijven, betekent volgens Franciscus het feit dat er beweging is en dat de moeder weet dat zij zwanger is, dat er leven is. De ervaring daarvan van de moeder moet gerespecteerd worden.

Ieder kind dat in de schoot van een moeder ontvangen wordt “is een gave die het verhaal van een familie, een moeder en vader, grootouders en broers en zussen zal veranderen. En deze baby moet worden verwelkomd, liefgehad en verzorgd.”

*Overgenomen met toestemming van [Katholiek Nieuwsblad](#).*

---

## **Over het ongeboren leven: geen mens is ongeschikt voor het leven**

### **Address of His Holiness Pope Francis to participants in the conference “Yes to Life! - taking care of the precious gift of life in its frailty” organized by the Dicastery for Laity, Family and Life**

Pope Francis

25 May 2019

Your Eminences, Dear Brother Bishops and Priests, Dear Brothers and Sisters,

Good morning and welcome. I greet Cardinal Farrell and I thank him for his words of introduction. My greeting also goes to all taking part in this international Conference, “Yes to Life! Taking Care of the Precious Gift of Life in its Frailty”, organized by the Dicastery for Laity, Family and Life, and by the Foundation Il Cuore in una Goccia, one of the groups that work daily in our world to welcome children born in conditions of extreme frailty. These are children that the throw-away culture sometimes describes as being “unfit for life”, and thus condemned to death.

No human being can ever be unfit for life, whether due to age, state of health or quality of existence. Every child

who appears in a woman's womb is a gift that changes a family's history, the life of fathers and mothers, grandparents and of brothers and sisters. That child needs to be welcomed, loved and nurtured. Always! Even when they are crying, like that baby over there... (applause). Some people might think: "But, the baby is crying... they should leave". No, this is music that all of us need to hear. (I think the baby heard that applause and thought it was for him!) We need to hear the sound always, even when the baby is a little annoying: Also in church: let children cry in church! They are praising God. Never, never chase a child out because he or she is crying. Thank you for your witness.

When a woman discovers that she is expecting a child, she immediately feels within her a deep sense of mystery. A woman who becomes a mother knows this. She is aware of a presence growing within her, one that pervades her whole being. Now she is not only a woman but also a mother. From the very beginning, an intense, interactive dialogue takes place between her and the child. Scientists call this "cross-talk". It is a real and intense relationship between two human beings communicating with one another from the very first moments of conception, and it leads to a mutual adjustment as the child grows and develops. This ability to communicate is not only on the part of the woman; even more, the child, as an individual, finds ways to communicate his or her presence and needs to the mother. Thus, this new human being immediately becomes a son or daughter, and this moves the woman to connect with her child with all her being.

Nowadays, from the very first weeks, modern prenatal diagnosis techniques can detect the presence of malformations and illness that may at times seriously endanger the life of the child and the mother's peace of mind. Even the suspicion of an illness, and especially the certainty of a disease, changes the experience of pregnancy and causes deep distress to women and couples. A sense of isolation, helplessness and concern about the eventual suffering of the child and the whole family, all this is like a silent cry, a call for help in the darkness, when faced with an illness whose outcome cannot be foreseen with certainty. Every illness takes its own course, nor can physicians can always know how it will affect each individual.

Yet, there is one thing that medicine knows well, and that is that unborn children with pathological conditions are little patients who can often be treated with sophisticated pharmacological, surgical and support interventions. It is now possible to reduce the frightening gap between diagnoses and therapeutic options. For years, that has been one of the reasons for elective abortion and abandonment of care at the birth of many children with serious medical conditions. Foetal therapies on the one hand, and perinatal hospices on the other, achieve surprising results in terms of clinical care, and they provide essential support to families who embrace the birth of a sick child.

These possibilities and information need to be made available to all, in order to expand a scientific and pastoral approach of competent care. For this reason, it is essential that doctors have a clear understanding not only of the aim of healing, but also of the sacredness of human life, the protection of which remains the ultimate goal of medical practice. The medical profession is a mission, a vocation to life, and it is important that doctors be aware that they themselves are a gift to the families entrusted to them. We need doctors who can establish a rapport with others, assume responsibility for other people's lives, be proactive in dealing with pain, capable of providing reassurance, and always committed to finding solutions respectful of the dignity of each human life.

In this sense, perinatal comfort care is an approach to care that humanizes medicine, for it entails a responsible relationship to the sick child, who is accompanied by the staff and his or her family in an integrated care process. The child is never abandoned, but is surrounded by human warmth and love.

This is particularly necessary in the case of those children who, in our current state of scientific knowledge, are destined to die immediately after birth or shortly afterwards. In these cases, treatment may seem an

unnecessary use of resources and a source of further suffering for the parents. However, if we look at the situation more closely, we can perceive the real meaning behind this effort, which seeks to bring the love of a family to fulfilment. Indeed, caring for these children helps parents to process their mourning and to understand it not only as loss, but also as a stage in a journey travelled together. They will have had the opportunity to love their child, and that child will remain in their memory forever. Many times, those few hours in which a mother can cradle her child in her arms leave an unforgettable trace in her heart. And she feels, if I may use the word, realized. She feels herself a mother.

Unfortunately, the dominant culture today does not promote this approach. On a social level, fear and hostility towards disability often lead to the choice of abortion, presenting it as a form of “prevention”. However, the Church’s teaching on this point is clear: human life is sacred and inviolable, and the use of prenatal diagnosis for selective purposes must be strongly discouraged. It is an expression of an inhumane eugenic mentality that deprives families of the chance to accept, embrace and love the weakest of their children.

Sometimes we hear people say, “You Catholics do not accept abortion; it’s a problem with your faith”. No, the problem is pre-religious. Faith has nothing to do with it. It comes afterwards, but it has nothing to do with it. The problem is a human problem. It is pre-religious. Let’s not blame faith for something that from the beginning has nothing to do with it. The problem is a human problem. Just two questions will help us understand this clearly. Two questions. First: is it licit to eliminate a human life to solve a problem? Second: is it licit to hire a killer to resolve a problem? I leave the answer to you. This is the point. Don’t blame religion for a human issue. It is not licit. Never, never eliminate a human life or hire a killer to solve a problem.

Abortion is never the answer that women and families are looking for. Rather, it is fear of illness and isolation that makes parents waver. The practical, human and spiritual difficulties are undeniable, but it is precisely for this reason that a more incisive pastoral action is urgently needed to support those families who accept sick children. There is a need to create spaces, places and “networks of love” to which couples can turn, and to spend time assisting these families.

I think of a story that I heard of in my other Diocese. A fifteen-year-old girl with Down syndrome became pregnant and her parents went to the judge to get authorization for an abortion. The judge, a very upright man, studied the case and said “I would like to question the girl”. [The parents answered:] “But she has Down syndrome she doesn’t understand”. [The judge replied:] “No, have her come”. The young girl sat down and began to speak with the judge. He said to her: “Do you know what happened to you”. [She replied:] “Yes, I’m sick”. [The judge then asked:] “And what is your sickness?” [She answered:] “They told me that I have an animal inside me that is eating my stomach, and that is why I have to have an operation”. [The judge told her:] “No, you don’t have a worm that’s eating your stomach. You know what you have? It’s a baby”. The young girl with Down syndrome said: “Oh, how beautiful!” That’s what happened. So the judge did not authorize the abortion. The mother wanted it. The years passed; the baby was born, she went to school, she grew up and she became a lawyer. From the time that she knew her story, because they told it to her, every day on her birthday she called the judge to thank him for the gift of being born. The things that happen in life... The judge is now dead and she has become a public prosecutor. See what a beautiful thing happened! Abortion is never the response that women and families are looking for.

Thank you, then, to you who are working for all this. Thank you, in particular, families, mothers and fathers, who have welcomed life that is frail – and I emphasize that word “frail” – for mothers, and women, are specialists in situations of frailty: welcoming frail life. And now, all of you are supporting and helping other families. Your witness of love is a gift to the world. I bless you and keep you in my prayer. And I ask you, please, to pray for me.

# Vaticaanse diplomaat keurt doden van ongeboren kinderen met Down syndroom af

## Social Protections For Women, Girls And All Those With Down Syndrome

*Statement* by H.E. Archbishop Bernardito Auza, Apostolic Nuncio, Permanent Observer of the Holy See  
At the Side Event entitled “*Social Protections for Women, Girls and All Those with Down Syndrome*” United Nations, New York, 21 March 2019

Your Excellencies, Distinguished Panelists, Dear Friends,

I am very happy to welcome you to this morning’s event on social protections for women, girls and all those with Down Syndrome, which the Holy See is pleased to be sponsoring, on this International Down Syndrome Awareness Day, with the Center for Family and Human Rights.

During the 63rd Session of the Commission on the Status of Women that has been taking place over the last ten days, we have been focused on the theme of social protections, access to public services and sustainable infrastructure to achieve gender equality and the empowerment of women and girls. We have considered the gaps in these protections and the various vulnerabilities to which women and girls are exposed. We have examined the situation of access in places across the globe to services like education, work, health care, and infrastructure like housing, energy, water and sanitation, and have looked at the discrimination that is often at the root of why people are deprived of them.

But what is a situation of concern for all women across the globe is particularly acute for women and girls with Down Syndrome, as well as parents of Down Syndrome children. And if there is one area in which there does not seem to be much of a variance between girls and boys it is with regard to what happens when parents receive a diagnosis of Down Syndrome. In many countries that diagnosis is sadly tantamount to a death sentence. Despite the assurances of the 2006 Convention on the Rights of Persons with Disabilities to “promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities,” including “those who have long-term physical, mental, intellectual or sensory impairments,” and to “promote respect for their inherent dignity,” there are really no social protections for those diagnosed in the womb with a third 21st chromosome. For children born with Down Syndrome, in many places access to public services — to education, work, adequate health care — is inadequate or non-existent. And in places with lagging infrastructure, the difficulties for those with Down Syndrome and their families can be exacerbated. Their special needs are often largely overlooked, including by an international community that is committed to leaving no one behind and ensuring the full and equal enjoyment of all human rights of persons with disabilities.

Back in 2011, the UN General Assembly made a commitment to ensure that those with Down Syndrome would not be left behind. With Resolution 66/149, it declared March 21 as World Down Syndrome Day and invited all Member States, relevant organizations of the United Nations system, other international organizations, and civil society to observe it annually in order to raise public awareness throughout society, including at the family level, regarding persons with Down Syndrome. March 21 (or in numerals 3-21 for Trisomy-21) had previously been marked from 2006 as World Down Syndrome Day by advocacy and research groups.

On the first observance of World Down Syndrome Day at the United Nations seven years ago today, then Secretary-General Ban Ki-Moon said, “Let us reaffirm that persons with Down syndrome are entitled to the full

and effective enjoyment of all human rights and fundamental freedoms. Let us each do our part to enable children and persons with Down Syndrome to participate fully in the development and life of their societies on an equal basis with others. Let us build an inclusive society for all.”

But it’s a struggle to build that inclusive society. In 2017, a major US television network reported that one country was on the verge of eliminating Down Syndrome, but what it really meant was that it was eliminating those with Down Syndrome, because practically 100 percent of parents of babies who receive a prenatal diagnosis of Down Syndrome were choosing to end the life of their son or daughter. Several other countries have similar statistics, to such a degree that many defenders of the rights of those with Down Syndrome, and other objective observers, call what is happening to children diagnosed with Trisomy 21 in the womb a “genocide.”

Even some within the UN System, despite the Convention on the Rights of Persons with Disabilities, despite the stated commitment of the UN General Assembly, are abetting that genocide. In November 2017, one of the members of the United Nations Human Rights Committee, based in Geneva, stated during an official meeting, “If you tell a woman, ‘Your child has ... Down Syndrome ... or that he may have a handicap forever, for the rest of his life,’ ... it should be possible for her to resort to abortion to avoid the handicap as a preventive measure.” Defending those with disabilities, he said, “does not mean that we have to accept to let a disabled fetus live.” Such a position is baldly inconsistent with the UN’s concern to leave no one behind and to defend the rights of those with disabilities. As Dr. Jerome Lejeune, who discovered the cause of Down Syndrome in 1958, once said, after what he had discovered was being against rather than in favor of those with Down Syndrome, “Medicine becomes mad science when it attacks the patient instead of fighting the disease.” He underlined, rather, that “we must always be on the patient’s side,” and that the practice of medicine must always be to “hate the disease [and] love the patient.”

Pope Francis said in 2017 that the response to the eugenic trend of ending the lives of the unborn who show some form of imperfection is, in short, love. “The answer,” he said, “is love: not that false, saccharine and sanctimonious love, but that which is true, concrete and respectful. To the extent that one is accepted and loved, included in the community and supported in looking to the future with confidence, the true path of life evolves and one experiences enduring happiness.”

And the happiness of those with Down Syndrome, and the happiness they bring to others, cannot be denied. A 2011 Study published in the American Journal of Medical Genetics by Harvard University Researchers associated with Boston Children’s Hospital showed that 99 percent of those with Down Syndrome say they are happy with their lives, 97 percent like who they are, 96 percent like how they look, 99 percent of them love their families, 97 percent like their siblings and 86 percent said they make friends easily. It also showed that 99 percent of their parents said they love their child with Down Syndrome, and 79 percent said that their outlook on life is more positive because of their child. And among siblings 12 and older, the survey indicated that 94 percent said they are proud to have a brother or sister with Down Syndrome, and 88 percent said they are better people because of him or her.

I cannot think of any other situation that would show such high numbers among children with a particular condition or no condition at all, and among their parents, and siblings. We could even say that Down Children and their families are simply among the happiest groups of people alive — and the world is happier because of them.

We’ll have a chance today to hear from our panel — Karen Gaffney, Michelle Sie Whitten, Deanna Smith and Rick Smith — where this infectious happiness comes from.



I thank you for your attendance today and for your interest in providing social protections and access to public services — indeed full and effective enjoyment of all human rights and fundamental freedoms — for all those with Down Syndrome, and for working not only to build a society that includes them, but cherishes them, and benefits from their presence and many gifts.