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Veenendaal, April 30th, 2019

Subject: Response by the Dutch Patient Association (Nederlandse Patiënten Vereniging, or NPV) to your request with regard to the evaluation process of the Pregnancy Termination Act (Evaluatie Wet afbreking Zwangerschap, WAFZ).

Dear Dr. Ploem, Ms. Floor,

In response to your letter of March 4th, we would like to inform you that we will gladly participate in the evaluation of the WAFZ. Your question is strictly juridical; our response will possibly extend beyond its scope. In our opinion, however, the information provided is important and can be included in recommendations and follow-up research. Before we respond to your questions, we will provide a brief introduction to the NPV.

The NPV

The NPV is a Christian organization which champions life; it is also the largest patient organization in the Netherlands. With a bureau of paid staff, over 55,000 members and 70 local departments with over 7,000 volunteers, the NPV is active in the areas of public policy, consultation, and voluntary home assistance. The NPV maintains a large network within and outside the Christian community in the Netherlands on themes and projects related to medical ethics, with an emphasis on the beginning and end of life (including prenatal screening, termination of pregnancy, palliative care, euthanasia and the current debate surrounding "fulfilled life"). The NPV also carries out annual surveys amongst its members regarding knowledge, attitudes, and experiences on topical medical ethical issues.

■ *What is your view regarding the functioning of the current law? Are the objectives that the legislator envisioned (balance between the legal protection of unborn human life and the provision of care to women seeking help with an unwanted pregnancy) sufficiently achieved?*

Lack of balance in basic values

The WAFZ is based on two principles: women facing an emergency because of an unwanted pregnancy must be able to get help, but at the same time, protection must be afforded to unborn

human life. The balance of these basic values of the law, the interests of the mother[1] and that of the unborn child, should be reflected in decision-making in a situation of emergency. The WAFZ evaluation process of 2005 indicated "finances" and "no desire for children" as the most mentioned reasons. Because the concept of "emergency" was left insufficiently defined by the legislator, the question has arisen as to whether in practice, the termination of pregnancies in all reasonableness may be considered to be the result of inescapable emergency situations. This, in our opinion, is an important sign of practice that has lost its way and illustrates that practice does not reflect the careful consideration that the law requires.

Normalizing and inviting effect

The current law dates from 1981 and came into effect in 1984. That is now 35 years ago. Since then, there has been an increase in abortion, both absolute and relative.[2] This raises the question as to whether the presence of abortion legislation in itself has a normalizing or even an inviting effect. Viewed against more restrictive legislation in neighboring countries, the current Dutch abortion time restriction of 24 weeks may also have an inviting effect on women from abroad.[3]

Insufficient transparency

The Health and Youth Care Inspectorate (Inspectie Gezondheidszorg en Jeugd, or IGJ) reports on pregnancies terminated up to 24 weeks by means of WAFZ annual reports. In part because of the heightened supervision of the CASA clinics,[4] the NPV queried the IGJ concerning the law regulating agreements for medical treatment (Wet op de geneeskundige behandelingsovereenkomst, or WGBO), the law on quality, complaints and litigation regarding medical treatment (Wet kwaliteit, klachten en geschillen zorg, or WKKGZ), the WAFZ, and the law regulating fetal tissue. With regard to CASA, abuse occurred in seven clinics. Nevertheless, as is usual for healthcare institutions under supervision, the Inspectorate does not publish any background information (telephone reports, e-mails, etc.) about its investigation, but restricts this to summary information in a "letter report." On the basis of the Transparency of Public Administration Act (Wet openbaarheid van bestuur, WOB), the NPV has submitted a WOB request on CASA, requesting additional information.[5] Despite this, reports of incidents or unsafe-for-patient situations remain secret. Minister Bruins refuses to disclose the information, in part because of fears of reduced willingness to report.[6]

The perspective of the woman with an unwanted pregnancy

A crucial condition to see if the current law is functioning as intended is research among women with unwanted pregnancies, their treatment outlook, their considerations, their decision-making process. Without this knowledge, only limited statements can be made. These come from the perspective of

[1] When we speak of the mother or the woman, we also mean the partner, even though his role is not always known in women's decision-making process.

[2] WAFZ Annual Report 2017, p. 14.

[3] WAFZ Annual Report 2017, p. 6.

[4] http://www.igj.nl/actueel/nieuws/2017/10/20/verscherpt-toezicht-voor-casa-klinieken. Consulted on April 26th.

[5] http://www.npvzorg.nl/nieuws/npv-vraagt-inspectie-op-treden-casa-affaire/. Consulted on April 26th.

[6] http://www.rd.nl/vandaag/binnenland/inspectie-dwong-veiligheidsmaatregelen-af-bij-curator-abortuskoepel-1.1511987. Consulted on April 26th.

employees of abortion clinics, other aid workers and the perspective of the IGJ. However, we know from research that the patient's perspective is substantially different from the perspective of professionals. It is important to invest in efficient and effective methodologies to gain the perspective of the woman with an unwanted pregnancy. This is an important prerequisite for drawing balanced conclusions regarding the functioning of the law.

Threshold of viability

It chafes that the prescribed limit for terminating a pregnancy is related to the viability threshold of the fetus. Viability is understood to be the possibility of surviving outside the uterus. When the law was passed, the absolute limit for this was set at 24 weeks "according to the then prevailing state of medical science." This limit is arbitrary, since the child's viability outside the uterus depends on factors such as the state and availability of technical devices. Medical developments in neonatology now allow extremely premature babies to be treated from 24 weeks onward. In individual cases, this limit may be reduced by a few days.[7] At the time the WAFZ came into force, the treatment limit for premature babies was 26 weeks. Now that this treatment limit has been reduced to 24 weeks, it would be in line with expectations to reduce the current abortion limit – in accordance with the considerations of the early 1980s – likewise by two weeks, to 22 weeks. It is desirable that current practice be brought into line with the current medical state of affairs. In the light of these medical developments, the NPV considers the current abortion limit of 24 weeks to be unacceptable.

■ *What in your opinion constitute bottlenecks?*

Right to life versus self-determination

The right to life is a basic human right.[8] Although self-determination is an important underlying principle in jurisprudence, the right to individual self-determination is not recognized as a human right in any treaty.[9] Although the term self-determination is frequently used in publicity about abortion, neither in the law nor in the explanatory memorandum is this term used. The explanatory memorandum speaks of a woman's right to help with an unwanted pregnancy. But this is not the same thing as the right to an abortion. It being a matter of strict interpretation, slogans such as a right to self-determination and freedom of choice in the case of unintended pregnancy are therefore misleading,[10] certainly if the right to life is omitted from the discussion. For some parties, women's right of self-determination has priority. We believe, however, that the fundamental right to life and the protection that the government should provide this life has priority.

[7] "Moet ieder vroeggeboren kind geholpen worden," *Trouw*, December 3rd, 2018.

[8] The right to life is anchored in Article 2 of the European Convention on Human Rights, Article 6 of the International Covenant on Civil and Political Rights, and Article 2 of the Charter of Fundamental Rights of the European Union.

[9] Buijsen, M.A.J.M. "Theorie en politiek in het gezondheidsrecht" [Theory and Politics in Health Care Legislation], *Pro Vita Humana,* volume 18 (2011), no. 1, pp. 2–5.

[10] https://fiom.nl/producten-en-diensten/campagnes/praat-over-abortus/recht-zelfbeschikking-en-keuzevrijheid-onbedoelde. Consulted April 18th.

Self-determination versus underlying problems

The emphasis on self-determination can give the impression of assertive decision-making by self-conscious women. But this can lead to a false impression. Pressure, coercion, honor killings, or sexual violence can be underlying factors which in this manner are kept out of view. Thus, abortionist Gabie Raven suspects that 10 to 20 percent of all women who wish to have an abortion are having to deal with sexual violence in one form or another. Because of this, she advocates more scientific undergirding for her profession.[11] Women who are considering abortion are under pressure and suffering from existential doubt. This comes partly to expression in the number of appointments that are not kept. For example, the no-show percentage (women not keeping appointments) remains significantly higher (6.5% in 2015) than with other care institutions.[12] Abortion (care) is increasingly provided in terms of "sexual and reproductive health and rights." In our view, however, social and health policies intended to reduce the abortion rate should come first. WAFZ registration shows that in 2017 nearly a quarter of treated women had already undergone a pregnancy termination, while twelve percent had experienced two or more. Abortion (care) for women with unwanted pregnancies in fact only deals with symptoms while leaving underlying problems untouched. This is why we advocate counselling that takes into account the woman's overall situation. Sexuality demands mutual respect and responsibility both of the woman and her partner.

Insufficient monitoring of quality of care

We advocate an informed decision-making process which allows for an independent party to discuss unambiguous information with the woman. With this informed consent, motives and the related emergency situation should be brought up, alternatives should be laid out, and a complete range of care providers offered. This entails providing adequate information on possible positive and negative post-abortion reactions, as well as information about the proposed treatment that is comprehensible and as complete as possible. By treatment we mean all medical operations associated with an abortion, including investigation and aftercare. The current review process is marginal. We believe that there is a need for better registration and review respecting the independence of the (hospital or clinic) admission, the severity of the emergency situation and reasons for an abortion, the proposal of alternatives, insight into whether the choice was voluntary and informed. This is necessary to be able to draw a conclusion as to the carefulness or lack thereof of abortion practice. The current data in the annual reports are only available at an aggregate level, not by hospital or clinic. The current financing structure incentivizes clinics to conduct abortions, necessitating independent control and inspection.

Absence of research on the psychological consequences of abortion

In addition, the NPV advocates further research into the physical risks and psychological problems women have after having an abortion. Research into possible consequences of abortion is characterized by methodological problems. The most common positive reaction immediately after an abortion can be relief. Negative reactions such as depression, guilt, anxiety, sadness, and regrets are also noted. It is very important that care workers be aware of the symptoms of negative/problematic reactions and of risk factors. Only then can adequate help be provided to women requesting an

[11] http://www.medischcontact.nl/nieuws/laatste-nieuws/artikel/er-is-leven-na-abortus.htm. Consulted April 18th.
[12] CASA Netherlands Annual Report 2015, p. 7.

abortion or experiencing emotional problems after an abortion. Research by Van Ditzhuijzen[13] on the basis of the DSM-IV investigated problems among women with a recent abortion experience (2.5 to 3 years after). Nevertheless, guilt and shame, even in the longer term, are beyond the scope of this research. The NPV favors paying attention to abortion as a trigger for later problems. Abortion is a stressful life event. It is to be expected that women who have had an abortion experience run into problems in other stressful experiences (a subsequent pregnancy, relationship problems, childlessness, or the "empty-nest syndrome"). Care workers therefore should as a matter of course ask about previous pregnancies, including a terminated pregnancy or miscarriage.

Absence of research on physical effects of abortion

Researchers at the Amsterdam Medical Center have discovered that stretching the uterine mouth and curettage lead to increased risk of premature birth in a subsequent pregnancy.[14] In the next pregnancy, the risk of the child being born before the full pregnancy period of 37 weeks is increased by no less than one-third. And the probability of coming into the world prior to 32 weeks is increased by no less than 70%. A child born so prematurely runs a high risk of all kinds of complications, making a hospital stay necessary. In its research program of pregnancy and birth investigating the detection and treatment of the top four disorders including premature birth, the Organization for Health Care Research and Innovation(Nederlandse organisatie voor gezondheidsonderzoek en zorginnovatie, or ZonMw) does not inquire as to whether the mother has had an abortion.[15]
Worldwide, there is a broad range of research available that shows the impact of abortion on women's later mental and physical health.[16] Dutch research in these fields is almost entirely lacking.

Attention for the position of vulnerable groups such as minors and refugees

The request for an abortion can be a symptom of deeper problems for which other care is desirable. Recently, the Second Chamber voted in favor of a revised law allowing doctors to retain fetal tissue after miscarriage or abortion if there are suspicions of a serious sexual crime. The DNA obtained from a fetus can serve as evidence in rape cases. Over a period of ten years there have been 55 criminal cases in which fetal tissue has played a role.[17] Minors who undergo an abortion may also be the victims of trafficking of women or of sexual exploitation by family or acquaintances. Sometimes the sexual contact that led to the pregnancy was forcibly imposed by a stranger. Fear of parents or of gangs keeps any report from being made to the police. The law is aware that denials by victims are very common in matters relating to trafficking of women, precisely because of women's fear of their attackers.[18] We advocate an interdisciplinary review commission for minors which looks into the

[13] http://www.doi.org/10.1016/j.jpsychires.2018.04.001. Consulted April 26th.

[14] http://www.academic.oup.com/humrep/article/31/1/34/2380037. Consulted April 26th.

[15] http://www.zorgkennis.net/downloads/kennisbank/ZK-kennisbank-Onderzoeksagenda-2016-Zwangerschap-en-Geboorte-4281.pdf. Consulted April 26th.

[16] https://www.deveber.org/womens-health-after-abortion/. Consulted April 26th.

[17] http://www.volkskrant.nl/nieuws-achtergrond/foetaal-weefsel-mag-na-abortus-bewaard-worden-om-verkrachting-te-bewijzen~bd8da017/. Consulted April 26th.

[18] Dutch physician Nizaar Makdoembaks analyzed data from his general practice in the Bijlmer borough of Amsterdam in the period 1993–2004 regarding the causes and backgrounds of child abortion and high rate of embryo death among Surinamese and Antilleans in Amsterdam. http://www.perssupport.nl/persbericht/19723/geheime-abortus-maskeert-kindermisbruik. Consulted April 26th.

request for aid and attends to these young girls and women. Teenage pregnancies are also relatively common among asylum seekers. In addition, women who become pregnant shortly after arriving in the Netherlands are more likely than other women in the Netherlands to ask for an abortion.[19] We advocate targeted guidance, taking into consideration the culture and religious context of these women.

■ *What developments are expected to affect the extent to which the law is "future-proof"?*

Workload of general practitioners

Two-thirds of GPs in the Netherlands find the workload to be too heavy, which according to the National General Practitioners' Association (Landelijke Huisartsen Vereniging, or LHV) is pressuring the quality of care they provide.[20] However, the GP is also an important gatekeeper in proper care for women with an unwanted pregnancy. Fifty-five percent of women requesting an abortion are referred to a clinic by the GP.[21] Research into knowledge of the problem-set and into the expertise needed to help women along are important, for example by ascertaining whether the guideline developed by, among others, the Federation of Institutions for the Unmarried Mother and Her Child (Federatie van Instellingen voor de Ongehuwde Moeder en haar kind, or FIOM) is known and used.[22] The impact of decentralization on the provision of care to pregnant women should also be investigated. It is advisable to consider whether consultation teams such as those which also act in palliative care (in which GPs can fall back on external expertise) merit a place in abortion care as a whole.

The debate surrounding the abortion pill

The debate surrounding the abortion pill regularly reappears, with proponents advocating prescription by the GP. The debate lacks clarity on why a GP should be able to terminate a pregnancy. Providing the abortion pill requires expertise, guidance, and aftercare of its own. The abortion pill can lead to serious complications. According to the Food and Drug Administration (FDA), at least 22 women have been killed by abortion pills and thousands of women have had to deal with complications.[23] If the abortion pill – without the obligation to register in terms of the WAFZ – becomes available through the GP, this means that current oversight of abortion practice will be lost. The same applies to online availability of the abortion pill.

Impact of prenatal diagnostics

Changes in medical technology and in society affect the functioning of the law in practice. Prenatal research can turn a desired pregnancy into an unwanted pregnancy. Investigations like the 20-week echo and the Non-Invasive Prenatal Test (Niet Invasieve Prenatale Test, or NIPT) are offered to all

[19] Goosen, S. *A safe and healthy future? Epidemiological studies on the health of asylum seekers and refugees in the Netherlands.* Amsterdam, 2014.

[20] http://www.medischcontact.nl/nieuws/laatste-nieuws/artikel/huisarts-kan-hoge-werkdruk-amper-aan.htm. Consulted April 26th.

[21] WAFZ Annual Report 2017, p. 21.

[22] http://www.fiom.nl/sites/default/files/files/Leidraad-huisartsen.pdf. Consulted April 26th.

[23] http://www.fda.gov/Drugs/DrugSafety/PostmarketDrugSafetyInformationforPatientsandProviders/ucm492705.htm. Consulted April 26th.

pregnant women. Balanced and expert counseling is crucial when an abnormality is discovered. We have gotten signals that this is not always the case. It occurs regularly that counseling is biased, for example when an abortion is characterized as the first option and alternatives are identified only in the second instance, when the abortion option is rejected. These include intensive assistance, (sometimes) intervention in the uterus, and hospital childbirth. In 2017, 1,152 women opted for abortion because their child had an abnormality. In 2016, that number was 1,011. Certainly now that this number is on the increase, it is vital that abortions on account of abnormalities be registered. Counselling and assistance can be improved using this information. We advocate the inclusion of diagnoses in prenatal diagnostics in WAFZ registration.

Children born alive after terminated pregnancy

British research shows that one out of thirty babies who are aborted due to disability come into the world alive.[24] They survive an average of one and a half hours, but some remain alive for more than six hours. Between 2000 and 2009, Canadian doctors left 491 babies born alive after a failed abortion to die.[25] In the Netherlands as well, children are born alive after an abortion.[26] Here, the question is whether this is an abortion as intended by the WAFZ or whether it is a matter of an act to terminate life to which another legal framework applies.

Use of embryonic and fetal tissue

Abortion clinics cooperate with academic hospitals in Leyden, The Hague, Maastricht, and Rotterdam in the framework of scientific research with fetal material.[27] For the practical implementation of the Fetal Tissue Act, article 6 stipulates that any institution in which fetal tissue becomes available must draw up an institutional regulation in accordance with the model provided by the Dutch Association for Obstetrics and Gynecology (Nederlandse Vereniging voor Obstetrie en Gynaecologie, orNVOG),[28] describing how the law is applied in the institution.

This regulation should give consideration to the way in which the choice is obtained from women from whom permission for the use of fetal tissue is sought; the manner in which information is given and permission is requested; and the conditions under which fetal tissue is supplied to the user. There is an increasing demand from scientists for embryonic and fetal tissue to use as research material. For example, there are those who advocate the cultivation of embryos, because the condition of residual embryos after IVF and fetal tissue do not answer the questions scientists have in their research. In the context of privacy and respect for the mother and her aborted fetus, the supervision of the provision of information and the consent of the mother are essential. The use of tissue without the knowledge of the mother is unacceptable. This is particularly true in research

[24] http://www.digibron.nl/search/detail/012dbfe0baa13837aca24d3d/een-op-de-dertig-babys-levend-na-late-abortus. Consulted April 26th.

[25] "Artsen lieten 491 baby's sterven na mislukte abortus." *Katholiek Nieuwsblad*, November 29th, 2012.

[26] http://www.volkskrant.nl/wetenschap/late-abortus-om-sociale-reden-niet-van-deze-tijd~b28e0481/. Consulted April 26th.

[27] CASA Annual Report 2015, p. 12.

[28] http://www.nvog-documenten.nl/uploaded/docs/modelreglement%20terbeschikkingstelling%20foeaal%20weefsel.pdf. Consulted April 26th.

[29] http://www.ncbi.nlm.nih.gov/pubmed/24440997. Consulted April 26th.

involving the gonads of a fetus for the development of fertility techniques for infertile couples. Research conducted at the Leyden University Medical Center by Dr. Susana M. Chuva de Sousa Lopes invites further investigation as to whether this falls within the boundaries of the law.

Abortive effect of the morning-after pill

In this context, we also refer to the morning-after pill EllaOne (freely available over the counter). Recent research shows that an abortive effect from its use cannot be ruled out. The leaflet included with EllaOne claims that the active ingredient, ulipristal acetate, works by modifying the action by the natural hormone progesterone needed to allow ovulation to occur, resulting in delayed ovulation. However, a scientific article by Mozzanega et al. published in 2014[29] in the American journal Reproductive Sciences shows that the operation of ulipristal acetate is explicable only in small part by the postponement of ovulation, and largely by preventing implantation of a fertilized ovum. According to this article, EllaOne does indeed have a "post-fertilization effect." EllaOne's possible abortive action is not mentioned in the leaflet. An exchange of letters between the NPV and the Medicines Evaluation Board (College ter beoordeling van geneesmiddelen, or CBG) did not lead to a conclusive answer, with the CBG appealing to European legislation. New scientific insights require the actualization of current standards.

Increasing friction in the legal position of the unborn child

An unborn baby is a legal figure without clear status in national and international law. Article 1 of the Civil Code says that "The unborn fruit is considered to be already born as often as its interest requires this." For example, an unborn child has a position in the law of succession, while in countries where the death penalty is applicable, a pregnant woman may not be put to death. In health legislation, an embryo is given an increasing amount of protection, as in the discussion surrounding the placement under supervision of unborn babies. In addition, there are several international sources with varying principles: the United Nations Convention on the Rights of the Child, the European Convention on Human Rights, the Universal Declaration of Human Rights, and the International Covenant on Civil and Political Rights. The recent ability to incorporate stillborn children into citizen registration brings the societal debate to a new phase. Registration has now also become a practice for aborted children. By this registration the child is also recognized by the government as a person with an existence. This challenges the government to clearly formulate when it is that one is human, what rights one has, and when those rights are to be recognized by the government.

■ *In the light of the foregoing, in what respects, in your judgement, should the law be amended?*

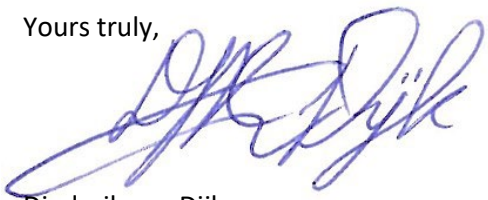
Abortion is an accepted and legitimated practice in our country. The emergence of legislation regarding abortion was one of the main reasons for the establishment of the NPV. We became united in one voice for life, from the deep conviction that a human life should not be terminated by another human being, and also because vulnerable human life asks for protection. The government should be able to guarantee the unconditional protection of unborn life. The fundamental rethinking of the earliest beginning of a human life is desirable, especially now that, in legislation regarding the registration of stillborn children, society so broadly recognizes the value of life before birth.

From this perspective we advocate:

1. The recognition of the intrinsic value of the unborn child;
2. The clarification of the juridical status of the unborn child;
3. The clarification of the juridical status of children who are born alive after a failed abortion;
4. The bringing out into the open of the emergency situation of the woman, whereby independent counselling and testing is crucial with regard to specific target groups;
5. The reduction of the time limit for abortion to 22 weeks;
6. Registration of abnormalities and motives in the case of terminated pregnancies after prenatal diagnostics.

It is possible that we were not exhaustive in this letter. We look forward to meeting with you as investigators on May 6th, at which time we will be able to elucidate the above-mentioned points.

Yours truly,



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